

**Palliative Care as Progressive Journey: The Interplay of
Hope and Social Death in Nurse–Patient Encounters
across Three Care Settings**

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ABSTRACT

Palliative Care as Progressive Journey: The Interplay of Hope and Social Death in Nurse–Patient Encounters across Three Care Settings

In this study I examine the care trajectory of terminally ill patients across three different sites in the hospice setting: home care, day therapy unit and in-patient unit. I will focus on the patients' journey and the nurses' ways of working in each setting as the continuum of care progresses towards the end of life. Much of this work is accomplished through talk, so by focusing the analysis on nurse–patient encounters, this study aims to fill a gap in this sensitive area of health and social care.

The study is rooted in the prevailing philosophy of palliative care which aims to address 'total pain', that is, social, emotional, and spiritual, as well as physically occurring phenomena. Upon diagnosis of terminal illness, it will be argued, the patient undergoes a shift in the conceptualisation of 'self'. The focus of my analyses will therefore be the interlocking themes of social death and hope *vis-à-vis* the biological event. I will argue that the concept of social death mediates the interactional trajectories, while hope and 'healing', in the palliative sense, may be seen as counterpoints to the inevitability of the end-of-life journey.

The process of social death can be viewed as a continuum as patients experience physical losses and deterioration that will in most cases lead to the institutional setting of the in-patient unit. Palliative care nurses and patients have the opportunity to intersect the continuum with interactional strategies that have the potential to promote hope in order to deflect from the suffering of total pain. The main findings can be captured in terms of the contextual differences across the three care settings as the care process occurs at different stages of the patient's terminal journey. For the purposes of demonstrating the complex interplay of these experiential domains, I adopt a theme-oriented discourse analysis.

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Chapter 1: Introduction

This dissertation examines communication between patients suffering from terminal cancer and nurses in three different sites of care in the palliative setting: home care, day therapy unit and in-patient unit. This study aims to make a contribution to the current research base of nurse–patient communication in the palliative site whilst offering a cross-site contextual analysis for the first time.

In comparison to many primary and acute care contexts, the need for effective communication is of significant importance within palliative care, due to the emphasis on psychosocial as well as clinical issues (National Institute for Clinical Excellence 2004). Despite the orientation towards caring through talk within this context, few communication studies have been undertaken that use qualitative methodology with empirical data (but see ethnographic studies by Lawton 2000; Thé 2002 and narrative interviewing by Armstrong-Coster 2004) and fewer still have used a discourse analytic approach.

This introductory chapter will provide an overview of the status of communication in palliative care and introduce the research sites and the thematic foci of the present study by articulating the research questions that form the basis of my enquiry.

1.1 Palliative care and communication

The overall effectiveness of palliative care as a discipline has been systematically reviewed and shown to have positive outcomes (Hearne and Higginson 1998). However,

it has also been subject to accusations of increasing medicalisation (Clark 2002, taken up in detail in Chapter 2.6), which is perceived as being detrimental to the palliative care philosophy. The ideal that nurses are able to just talk and 'be' with patients is seen as being under threat as clinical interventions take priority, despite the fact that talk with patients is an essential component of the work undertaken by palliative care professionals. The philosophy of palliative care calls for the total care of patients and their families, not only in respect to clinical issues but also in regard to psychosocial and spiritual issues (World Health Organization 2006a). For this reason, the nurse/patient ratio in palliative care is twice that of nursing care in general settings. During a morning shift, for example, the recommended ratio of nurse/patient is 1:4 to allow for higher dependency levels (Royal College of Nursing 2006: 34). Unlike the majority of other primary care settings, where much of the caring will be task-based or clinically oriented, much of the work of terminal care in this setting consists of psychosocial assessment and intervention, thus making communication a vital ingredient of effective care.

Increasingly, the need for adequate communication skills is given high professional priority but the quality of interaction between health care professionals and patients is frequently judged to be poor (NICE 2004). A key publication in the domain of palliative care, the NICE Guidance for Supportive and Palliative Care Research Manual, offers systematic reviews of all aspects of palliative care. One chapter is dedicated to the topic of face-to-face communication and outlines the importance of effective interactional skills as follows:

Good communication skills are therefore key to the delivery of effective supportive and palliative care services, but patients and carers frequently report that the communication skills of health and social care professionals are poor. (2004: 8)

The NICE manual emphasises that supportive care in the form of patient information, communication, and psychological support should be given equal priority alongside treatment. The report also calls for accredited training courses in communication skills for all health and social care professionals working with patients and carers. Training programmes to enhance communicative skills have been devised but these often rely on role-play or simulated interactions and seldom use empirical data such as naturally occurring conversation. Research into the effectiveness of communication training tends to use content coding and dialogue tagging software in the analysis of data and pays insufficient attention to the interactional analysis that may provide an alternative resource (Ong, Visser, Kruijver, Bensing and van den Brink-Muinen 1998; Ford, Hall, Ratcliffe and Fallowfield 2000).

1.2 Research setting and focus

This work will focus on the palliative care setting, taking data from three different sites of care: home care, day therapy unit and in-patient hospice care. Data will consist of transcriptions of tape-recorded interactions between patients and nurses during the usual practices of care. There are a total of 30 nurse–patient encounters, each ranging from 5-10 minutes to over an hour in length, depending on the setting. For instance, interactions in the home care setting are considerably longer than in the in-patient unit. The thematic foci across all settings will be on social death and on hope and healing.

Few research studies have used empirical data from nurse–patient interactions generally (exceptions are Fisher 1991; Crawford, Brown and Nolan 1998 and Candlin 2000), and fewer still from the palliative care setting. Most discourse analytic research in the field of health care tends to be preoccupied with the doctor-patient interaction. Candlin

(2003), one of the few researchers in the field of nurse–patient encounters, accounts for this inclination by posing that researchers aspire towards more prestige research subjects in order that they may feel ‘they have a joint base in the academy’ (2000: 231). Candlin (2000) also signals the differences in the amount of time allocated to patients by nurses and doctors during medical consultation. In the palliative care setting, I would suggest that nurses spend a great deal more time with patients than other members of the multidisciplinary team and consequently are most likely to address end-of-life issues with patients. It is for this reason that I focus on nurse–patient interactions in this study.

Relational alignment between nurse and patient is essential to effective communication concerning sensitive topics such as death and dying, or the management of distressing symptoms. Contextual differences ranging across the three sites will be considered in the light of the thematic analysis. I will use a thematic framework with the twin foci of social death and hope and healing, viewed from a discourse analytic perspective. These two themes can be linked as the concept of social death mediates the interactional trajectories, while hope and healing may be seen as counterpoints to the negative effects and the inevitability of the end-of-life’s journey. The research questions are as follows:

1. To what extent can the process of social death be evidenced in nurse–patient encounters as they present at each of these care settings: home care, day therapy unit and in-patient unit? (Chapter 5)
2. How do nurses and patients counter social death within interaction? (Chapter 6)
3. What communicative resources do nurses and patients draw upon to capture the differences associated with the terminal journey? (Chapters 7 and 8)

4. How do nurses manage the contrasting styles of adjustment used by patients?
(Chapters 9 and 10)

1.2.1 Social death and the diminished self

Patients enter palliative care with the knowledge that they have a terminal illness which will already have affected their normal social role relationships, abilities, and self-identity. I will take up these issues using the theme of social death (Chapter 5). This can be briefly defined here as the notion that terminal patients may be affected by both the physical and the psychological processes of their disease, causing them to experience a diminishment of self. They are at risk of suffering a social death before dying in a biological sense. By examination of interactional practices, my primary aim is to consider the effect of a terminal illness on interactions between patients and nurses, and how changes in identity and sense of 'self' threaten to cause further distress in a context that is already, physically and psychologically, hard to bear. I discuss this concept in depth in Chapter 5, but I bring forward here what I see as a primary definition of social death:

During the course of their illness and bodily deterioration, patients may lose various aspects of their selfhood and identity which qualify them for the status of a 'person'. In other words, it is possible for a patient to die socially—that is to enter the realms of non-personhood prior to his or her physical cessation. (Lawton 2000: 2)

The skills of the specialist palliative care nurse are paramount here in tactically reducing concerns, wherever possible, and in promoting understanding and acceptance of the terminal journey. I will show that individual patients have different ways of adjustment, depending on a range of factors, in the context of their disease progression. There is a

need for nurses to accommodate to individual patients using a repertoire of communicative trajectories, as I shall discuss in Chapter 10.

1.2.2 Hope and healing

As I have noted, psychosocial and spiritual issues are major elements of the philosophy of palliative care. Definitions of spirituality are often associated with purely religious concepts. Whereas religion may be part of the process, in a non-secular sense spirituality is concerned with issues of coping in illness by finding hope, value and meaning in life. The most apt definition of spirituality in the palliative care context derives from Addington-Hall and Higginson (2004) who view spirituality as:

The search for existential or ultimate meaning within a life experience, such as illness. (This belief usually refers to a power other than the self, which people may or may not describe as God, higher power, or forces within nature, and with which they communicate. The power helps the person to transcend the here and now, re-establish hope and the ability to cope). (2004: 123)

In this study I will examine discursive constructions of spirituality in the palliative care setting following this definition. I will focus on hope and healing (Chapter 6), which may be seen as useful in mitigating the effects of the process of social death. The trajectory of hope in palliative care differs from curative hope. Patients are not hoping that they will get better but that better days or moments may come (Charmaz 1991; Benzein, Norberg and Saveman 2001). Healing is associated with relieving suffering and psychological distress, rather than curative intervention. Cassell (1991) maintains that suffering is not contained bodily but extends to the person and all their individual experiences. Each person's suffering bears little relation to the somatic realisation of their disease but relates to the effect upon their personhood. In the best case scenarios, patients will be helped to find meaning in their situation which can, in turn, facilitate a

final stage of personal growth and bring a positive experience to the relentlessly inevitable physical outcome.

1.3 Structure of thesis

The thesis can be seen as consisting of three distinct but interrelated parts. Chapters 1-4 establish the background for the study and provide methodological and procedural information. The following four chapters (5-8) are the core analytic chapters, the first pair, 5 and 6, examining the overarching themes of social death and hope with data analyses to support the discussion; and the second, 7 and 8, using the specific rhetorical devices of humour and metaphor in the analysis of the twin themes of social death and hope. The third part, chapters 9 and 10, consists of two case studies as a way of drawing the analytic findings together. I will finally revisit the main threads of the discussion in light of the research questions in the concluding chapter (11).

1.3.1 Chapter summaries

Part One

Chapter 2: Palliative care: Context and setting

Within this chapter I firstly provide background information about palliative care in the U.K. to place this research in context. I provide information and statistics that draw attention to the increasing need for adequate provision of palliative care. I also pay specific attention to the incidence of cancer in old age to underline the fact that the vast majority of patients receiving palliative care are elderly, a statistic that will inevitably affect practice. I continue to consider issues relating to old age in sub-sections throughout the remainder of this study.

I provide a definition of palliative care and details of its philosophical aims, including an overview of the concept of ‘total pain’, a largely psychological process, which draws attention to the therapeutic role of communication within the discipline. I discuss the role of the palliative care nurse and the multiple dimensions of care that are intrinsic to this role.

I also explore the notion that in contemporary society, dying and palliative care itself have become increasingly medicalised (Clark 2002), leading to de-skilled communication that will have an adverse effect on patients who are routinely made aware that they are dying. Finally, I look at the provision of palliative care and the fact that patients who may prefer to die at home are often denied the chance to be cared for in the setting of their choice or to be cared for in a palliative care setting at all. These facts assume a particular relevance following the contextual analysis across the three care settings.

Chapter 3: Methodology: Research processes

Within this chapter I provide details of the research setting which consists of three different care sites selected in order to capture the progressive journey towards the end of life. I describe the three care sites: home care (HC), day therapy unit (DTU) and the in-patient unit (IPU) linked to the hospice, together with the data collection processes and issues raised per site. This includes a description of the ease (or not) of gaining access and the recruitment of participants to the study. I also provide details here of the gaining of ethical approval, the equipment used for data collection, statistical information regarding the transcripts, and a key to the transcription conventions used. I

also discuss the fact that, as a researcher, I found that I had to adopt a different approach in each case according to the level of engagement needed in the different care contexts.

Chapter 4: Methodology: Analytic framework

Chapter 4 links to the previous chapter and gives an account of the thematic approach to this study and its analytic framework. I begin with a brief discussion of discourse analysis generally before specifying the particular approach that I use in this study, i.e. theme-oriented discourse analysis. I briefly describe the focal themes of social death and hope that underpin the study, before taking them up in greater detail in the following two chapters in order to provide a firm base for the remainder of the thesis. I provide a glossary of the discourse analytic constructs underpinning the analytic framework, including humour and metaphor, which will be taken up in chapters 7 and 8 respectively.

Part Two

Chapter 5: Trajectories of social death in terminal illness

As one of the focal themes of this work, I discuss the concept of social death by examining social constructions of dying and consequent effects on individual identity. I focus on patient and professional perspectives in the palliative care setting, and consider patients' styles of adjustment to a terminal diagnosis, including the notion of anticipatory grief.

I also show how the three settings, HC, DTU and IPU, can be seen to raise a range of issues that are often particular to each and are relative to the stages of disease and adjustment that the patient is experiencing at the time of engagement with the nurse.

In the home care setting, the focus on one young female patient reveals her difficulties in accepting the physical and relational effects of her diminishing health, possibly more acutely than older patients in the same position. The focus on just one young female patient will be balanced by the case studies in chapters 9 and 10 where both participants are elderly, one male and one female, and receiving home care visits.

In the DTU setting I explore collusion and protectionism by and against family members, as well as instances of peer support which are evident from the data.

The in-patient unit carries a different set of issues relevant to the theme of social death. The threat to individual identity is compounded here by both the institutional context and the amount of personal care that patients receive. There is far less therapeutic talk in this setting as much of the nursing contact is task-based. Very little talk is socially situated, and as I will show, when social talk does occur it can be overshadowed by the clinical and institutional mode.

Chapter 6: Trajectories of hope in the context of palliative care

Despite the inclination towards social death in terminal illness, the nurse–patient encounters reveal coping mechanisms adopted by both participants. In this chapter I discuss the role of hope in the context of palliative care, focusing on its effect on the patient and the role of the nurse. I consider barriers to hope and hope-fostering strategies that health care professionals may encourage. I also consider the process of adjustment by patients to a terminal diagnosis and the need to find meaning in illness in order to promote healing and reduce suffering. Due to the age-related demographic bias of the

participant population, I again give consideration to the particular implications that adjustment in old age may have.

The analyses of the three care settings focus on living environments, especially in the case of home care patients, and the difficulties that some patients face in adjusting to a changed identity. Analyses of the DTU setting reveal its function as a locus for peer contact between patients, emphasising their membership of a social group, as individuals can assess and make self-comparisons to the group norms. Family relations are also addressed here as nurses attempt to facilitate open talk, rather than collusion, between family members. The in-patient unit setting has an overarching institutional presence and here I examine the potential for loss of dignity due to the patients' need for intimate care or discussion of sensitive topics and how nurses manage to counter this with positivity in interaction.

Chapter 7: Laughter and humorous lightheartedness in palliative care

Within this chapter I concentrate on the functions of laughter as they appear across the care settings. In the previous chapter I discussed the link between lightheartedness and hope, and I build on this here, but I also demonstrate that laughter is not always a response to humour and can fulfill a range of functions. By coding the data on the basis of occurrences of laughter I explore the ways in which laughter is used across the three care settings, i.e. as a stress relieving mechanism or as a mitigation strategy during difficult talk.

Chapter 8: Metaphor and metaphoric idiom in the palliative care setting

Parallel to my discussion of the role of laughter, I again draw on relevant literature to argue that in the context of palliative care metaphor is an important communicative resource when talking of taboo subjects such as death and dying. Within this chapter I look at how metaphors can be used to facilitate communication about complex and sensitive topics. In the palliative care setting in particular it can be seen as an aid to assist difficult talk about death and dying, although care must be taken that mutual understanding is achieved in order to avoid further damage to patients' already fragile identities. The potential for misunderstanding metaphors is also highlighted.

Part Three

Chapter 9: Contrastive styles of engagement with end-of-life: A closer look at two cases

Within this chapter and the next I focus on just one care setting, home care, using two case studies to draw together the discussion to this point. The advantage of using a case study approach is the ability to use cross-individual comparisons for a fuller understanding of the preceding discussions. It is useful to look at two cases which are demographically similar and include the participation of the same nurse to examine variations in coping styles and expectations and their communicative manifestation.

This chapter demonstrates that the two patients are at differing stages of acceptance and rehabilitation or healing in the context of living with a terminal illness. This then forms the basis for the following chapter, which is linked but viewed from the nurse's perspective.

Chapter 10: Repertoires of communicative trajectories: The professional perspective

Following the discussion of the case studies in the previous chapter it becomes clear that individual patients are very different and that a homogeneous approach to care may not be sufficient. I explore the repertoire of communicative strategies used by the nurse in interaction with two patients. Within this chapter I discuss how the nurse discursively manages these home care patients at different stages of adjustment to their terminal disease.

I consider the fact that patients' attitudes to previous interactions with health care professionals may impact on the quality of the interaction, leaving aside any personal factors as discussed in the previous chapter. I show how one well-adjusted patient is able to talk at length in a social mode about topics unrelated to her clinical status. I also show that the nurse has clinical outcomes in mind when she allows the patient to do this, but that despite this purposive reasoning it would appear that the patient is able to exercise her own agency to take control of the interaction. I suggest that she is able to do this from the safety of a well-aligned relationship with the nurse and open communication.

I then consider how the nurse has to employ a different set of communicative strategies as she works with a more challenging patient and how it is necessary for her to prove her worth before she is eventually successful in engaging with the patient and earning his trust.

Chapter 11: Conclusion

In the concluding chapter I draw the threads of the study together. I revisit the research questions and discuss the patterns of discourse across the three settings that have been identified in the analyses. I conclude by addressing limitations to this research and suggesting recommendations for further study.

Chapter 2: Palliative care context and setting

2.1 Chapter overview

In order to place this study in the particular context of care that palliative patients are experiencing, this chapter will present an overview of palliative care, starting with an illustration of the demographics of cancer incidences (2.2), and a definition of and philosophical approach to the discipline (2.3.1). This will be followed by a brief history of this relatively young specialty, with particular regard to one of its founders, Cicely Saunders, exploring her concept of ‘total pain’ and how it is particularly relevant to the philosophy of palliative care today. I will discuss the arguments concerning societal attitudes to death and dying and concerns about the medicalisation of both death and palliative care (2.4, 2.6). Consideration will then be given to palliative care provision in relation to the acute hospital setting, quality of care, and patient choice, in order to place the growing size and scope of patient need in context. Furthermore, I will discuss the role of the palliative care nurse (2.7.1) I will then move towards a more political perspective on the nature and provision of palliative care in the U.K. at the present time (2.8), and acknowledge previous studies that have been conducted in the area of palliative nurse and patient communication (2.9).

2.2 The need for palliative care: Incidences of cancer

According to statistics provided by the World Health Organization, more than 11 million people worldwide are diagnosed with cancer every year. It is estimated that there will be 16 million new cases every year by 2020. Cancer causes seven million deaths every year, or 12.5 percent of deaths worldwide (World Health Organization 2006b).

In Wales, the site of this study, statistics collated by the Welsh Cancer Intelligence and Surveillance Unit show that over the period 1993-2002, the average total number of new registrations of a cancer diagnosis annually was just under 15,000. According to this survey, the mean age at diagnosis for males was 69.1 years and slightly lower in females at 67.5 years (Wales NHS 2006: 145). The incidence of the most common cancers – lung, prostate, breast and colon – has generally been on a downward trend in recent years but for most other cancers this is not the case. These figures reflect worldwide progress in public health information, earlier detection, and prevention measures for the high profile cancer types listed above. Public health information promoting decrease in smoking and improved diet together with extensive screening programmes have all made a contribution to public attitudes and the subsequent reduction in figures (cf. Babb and Quinn 2000). Nevertheless, at the present time, 1 in 3 people will develop cancer during their lifetime and one in four people will die from cancer (National Statistics 2006).

A systematic review of the effectiveness and cost effectiveness of palliative care teams commissioned by the Welsh Assembly Government (2003: 6) found that there is evidence to show positive benefit of palliative care services on patient and carer outcomes, with possible advantages of specialist palliative care services over services from non-specialist or uni-professional teams (see also Hearne and Higginson (1998) for a systematic review of the literature noting positive effect). Palliative care is usually seen as a model of excellence in the care of the dying and there is growing debate that palliative care services should be available for all terminal conditions, for example, heart failure (NHS 2005).

2.2.1 Cancer in old age

Cancer is primarily a disease of the elderly (National Statistics 2006). More than 50 percent of cases in Wales between 1992-2001 occurred in those aged 65 or over (Wales NHS 2006). I will discuss how this predominantly high age range raises two concerns. Firstly, there is the matter of equal access for the elderly population in a social context that sees old age and dying as interlinked. The risk here is that people dying of 'old age' with an associated range of illnesses and already complex health issues will be overlooked as far as specialist palliative care needs are concerned when a diagnosis of terminal cancer is included in the portfolio of illnesses. Seymour, Clark and Philp from the Sheffield palliative care studies group note that:

Older people are systematically disadvantaged in accessing specialist palliative care services and that many older people's experiences of old age and dying are characterised by unacceptable levels of suffering. (2001: 270)

The group calls for a greater integration between the fields of gerontology and palliative care as the focus on the social context of ageing and issues of spirituality in gerontology can be seen to have relevance across all disciplines.

Secondly, with regard to elderly people in palliative care it must also be noted that the trajectories of the dying process may be different in old age. Kafetz (2002: 536) suggests that for this age group, 'death in old age is often a protracted affair, rather than a clear cut process that can allow patients and those bereaved to go through the classic stages'. Death from cancer, or any other disease or event, is more likely to occur alongside a trajectory of long term disability and other self-care deficits (Lynn 2001). Functional decline in the elderly can contribute to the process of social death that may have started before a terminal prognosis. In some sense then, an older patient group may have been

enabled to adjust to the disabling effects of a terminal illness and social death more readily than their younger peers. The majority of patients in the hospice setting, and in the data collected, are elderly and, therefore, I will draw attention to specific issues relevant to old age throughout this work.

2.3 Definition of palliative care

The word ‘palliative’ derives from the Latin word ‘pallium’ meaning a cloak or cover. In simple terms it refers to the active care of patients with non-curative disease. The most widely accepted definition of palliative care is that put forward by the World Health Organization (WHO):

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organization 2006a online)¹

I follow this definition throughout this study, focusing on the relevance to psychosocial suffering. In particular, this definition forms the basis of the palliative care philosophy that is discussed in the following section.

2.3.1 Philosophy of palliative care

Palliative care is based on the philosophy that death is a natural process within life. In the hospice setting the aim is to care for the whole person, to meet all needs, physical, emotional, social and spiritual. Palliative care professionals take a holistic approach,

¹ ‘online’ indicates that there is no page number available as an internet reference.

encompassing whole family care, based on individual need and personal choice. The

WHO notes that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (2006b online)

Many of these core values would be expected to be manifest in communicative practices and will be explored throughout this study. The basis of the palliative care philosophy can be attributed to the work of one woman, Dame Cicely Saunders, as I will discuss in the following section.

2.3.2 The work of Cicely Saunders and the concept of ‘total pain’

In an autobiographical account of her life (Saunders 1996), Dame Cicely Saunders describes the motivation for her approach to care of the terminally ill. She was born in 1918 and studied Philosophy, Politics and Economics at Oxford before changing course to train as a nurse. She was forced to leave nursing due to a back injury and in 1947 she

trained as a medical social worker before qualifying as a doctor in 1957. It was through her work at St Joseph's Hospice in Hackney, East London, that a modern philosophy of terminal care began to emerge. By attending to and listening to patients' stories of illness, disease and suffering she developed the concept of 'total pain'. It became clear to her that:

Each death was as individual as the life that preceded it and that the whole experience of that life was reflected in a patient's dying. This led to the concept of "total pain," (*sic*) which was presented as a complex of physical, emotional, social, and spiritual elements. (Saunders 1996: 1600)

Saunders encouraged new approaches to the alleviation of chronic or complex pain by educating health care professionals. In the context of the dying patient she viewed pain as 'meaningless as well as endless, it can bring a sense of isolation and despair' (Clark 1999: 487). This concept of pain directly contrasts with the pain of acute or general disease, which is often seen as clinically relevant, for example in diagnoses as an indicator of problems, or postoperatively, where, inevitably, pain will lessen as recovery progresses. Saunders was a pioneer in her prescription of pain control drugs in that she advocated constant and high doses of painkillers when appropriate. The continuation of unrelieved pain, she argued, could prevent patients from achieving their wishes in the last year of life (Saunders 1978).

Saunders was also sensitive to the treatment of non-physical aspects of pain, and the importance of communication in the process of care. She emphasised the value of listening and communication in patient care. In her work, the terminal pain of the patient is given equal priority alongside the physical symptoms, and the experiences of family members. She comments that:

The whole experience for a patient includes anxiety, depression, and fear; concern for the family who will become bereaved; and often a need to find some meaning in the situation, some deeper reality in which to trust. (Saunders 1996: 1600)

This experience can be likened to grieving in advance of death. A terminal prognosis allows time to dwell on what is to come. This process, first recognised by Lindemann (1944) is referred to as ‘anticipatory grief’ and will be taken up in section 5.7.1.

In Saunders’ writings (for an overview see Clark 1998; 1999) the emphasis on pain as consisting of emotional and physical suffering, is underpinned by her overt Christian beliefs. Clark and Seymour (1999) argue that the spiritual component of her thesis should not be interpreted as an expression of a definitive Christian morality that must form the foundation of palliative care. Palliative care teams are multidisciplinary which allows for each discipline to apply its skills appropriately and it could be argued that the spiritual care of the patient, in the religious sense at least, should be undertaken by the chaplaincy.

The role of the palliative care nurse, therefore, will not necessarily constitute alignment with a Christian ethos. Not all nurses are Christians and neither are all patients. A specific religious standpoint may withhold the equity of provision to non-denominational patients. However, palliative care nurses are educated to take account of the concept of total pain and are encouraged by the palliative care philosophy to attend to psychosocial and spiritual needs of patients (RCN 2002). There is a clear need here for effective communication and many nurses working in this area will have undertaken communication skills training via palliative care diploma or degree, in order to deal with

this in practice. The nurse role will be discussed further in section 2.7.1, but in what follows I first discuss the broader issues and attitudes that any professional may be affected by when dealing with death and dying, in particular the social context of dying and talk about death, historically and in the present time.

2.4 The medicalisation of dying and the denial of death thesis

Medicalisation is defined as ‘a process of increased medical intervention into areas that hitherto would be outside the medical domain’ (Bilton, Bonnett, Jones, Skinner, Stanworth, and Webster 1996: 422). Natural life events such as pregnancy, childbirth, unhappiness, ageing and death have been brought within the medical remit (Taylor and Field 1997) and therefore are increasingly viewed under the principles of the medical model.

Medicine and health care have changed a great deal in recent years. New specialties and treatments have increased in number and there is now a greater focus on cure and rehabilitation. Over time, hospitals and institutions have become the usual place of death. In 2003, U.K. figures show that of all cancer deaths, 21,949 occurred in a hospice whilst 69,994 took place within hospitals (National Statistics 2005). Historically, the deathbed scene has often included prayers for the departing soul read by the priest at the bedside. In modern times this is a rare occurrence. The medical presence has replaced religious representation at the deathbed (Walter 1999). This shift from the model of family and community involvement in death has resulted in terminally ill patients being physically and perhaps emotionally removed from their families. By moving away from community care of the dying, the dying process has become increasingly medicalised and removed from the wider social view. Illich (1976) proposes that as a society we

have lost the capacity to accept death and suffering as meaningful aspects of life and that there is a sense of being at war against death at any stage. Because of these perspectives, Illich feels that there has been a devaluation of traditional death and dying rituals as well as a detrimental effect on personal and family care. Once a natural event, death is now seen as a failure of medical practice, technology and science, 'something that ought not to have happened and which people find more difficult to accept and come to terms with' (Taylor and Field 1997: 56). It is seen as the end of an individual life rather than, as in traditional societies, a process of renewal of the generations (Giddens 1991).

Alternatively, Parsons and Lidz (1967) argue that the medical profession does not deny death, that there is an overall acceptance of the scientific reality of death and a sensible attempt to control it through scientific means. Furthermore, the 'differentiation between the adventitious and inevitable aspects of death has rendered the latter still more irreducible something that must be faced more squarely than before' (Parsons and Lidz 1967: 140). Aspects of societal treatments of death in 1960s U.S. society equate with a certain level of acceptance and a 'practical, realistic, activist culture' (Walter 1994: 188). The practice of embalming the body to deny the physical reality of death can be seen to promote the value of a natural death, where the body is unmarred. Blood and organ donation uphold a positive aspect enabling the deceased to be viewed as 'a giver of gifts' (Parsons and Lidz 1967: 394) and the provision of life assurance can be viewed as an 'act of control' and as 'an acknowledgement rather than a denial of death' (Seale 1998: 85).

Illich (1976) advocates a resistance to the medical dominance over all areas of life and encourages people to take responsibility for their own health care. He promotes the importance of viewing death as a natural process rather than a pathological condition, in order to avoid the 'social death' that results in the alienation and ostracism of the terminally ill (Taylor and Field 1997). According to Illich, the medical profession has made patients dependent, and has undermined their ability 'to face their reality, to express their own values, and to accept inevitable and often irremediable pain and impairment, decline and death' (1976: 133).

Writing in 1995, Illich's views, based on his earlier writings relating to death as a natural process, appear to gain momentum (and increase his concern) as he sees the increase in technology impacting in more disturbing ways. Medicalisation is replaced by system management as medical care is broken down into component parts with a global style of management:

Medicalisation spelled dependence, not disembodiment.
Disembodied people are those who now think of themselves as lives
in managed states like the RAM drive on their personal computer.
Lives do not die they break down.
(Illich 1995: 1653)

The process of medicalisation has resulted in a change in the way death is perceived. Aries (1981) and Illich (1976) consider that the fear and medicalisation of death has led to a death-denying society. However, Kellehear (1984: 713-723) systematically reviews the sociological arguments and then lists the major components of his thesis under the five themes of:

- i) denial
- ii) fear of death
- iii) medicalisation of death
- iv) individualism
- v) examples of death denying practices

Kellehear (1984) concludes categorically that, as a society at least, we are not death denying. His chief criticism of the mainstream standpoint is that group behaviours are taken as explanations of individual attitudes. This reductionist view, he says, obscures the individual death denial, which is apparent, in favour of the group behaviours and organisation of death practices that take priority. Zimmerman and Rodin (2004: 121-128) have modified and restructured Kellehear's (1984) categories into what they consider to be the five major clinically relevant components of the sociological evidence. These are:

- i) the taboo on conversation about death
- ii) the medicalisation of death
- iii) the segregation of the dying
- iv) the decline of mourning rituals
- v) death denying funeral practices

Zimmerman and Rodin (2004) conclude that the notion that we are a death denying society is simplistic, although on an individual level this may be the case. They argue that technology and advancements in practice may lead to the 'idealistic conclusion that *all* diseases may be cured and *all* lives prolonged' (Zimmerman and Rodin 2004: 127

original emphasis). At the same time, longer illness trajectories may have a beneficial effect by promoting ethical discussions about the appropriateness of life prolonging techniques, thereby opening up discussions about death between medics, patients and families. I will explore the notion that death is a taboo topic of talk in the following section but will first discuss the segregation of the dying.

The concept of social death can be viewed from an individual perspective but also as a sociological construction. Segregation of death is an inherent component of the denial of death thesis. Death and dying are no longer community concerns as aging people, or those who are chronically ill, are isolated from the larger social group to be cared for in institutions rather than at home. Armstrong-Coster notes that this change in how individuals die has been further affected due to significant advances in medication:

Death is more inclined to occur after a prolonged period of chronic, rather than, acute illness and, as a result, dying became colonised by the medics (Zola, 1972; Illich, 1976). Consequently, individuals who were dying were subjected to ‘shutting away’ (Ariès, 1974, 1981), ‘cutting off’ (Illich, 1976) and ‘exiling’ (Elias, 1985) from mainstream society.² (2004: 9)

However, Lawton (2000: 123) argues against the commonly accepted argument that in contemporary western societies, death and dying is sequestered away from society. Her argument is that it is a ‘specific kind of demise’ that now becomes sequestered, i.e. patients with difficult to manage and socially unacceptable symptoms such as disfigurement and malodorous conditions. Care providers may view this perspective differently. It could be argued that patients with this severity of symptoms would be

² The frequency of metaphor, as seen in the above quotation, is not unexpected when talking about death and dying and will be explored further in Chapter 8.

prioritised for beds, in any case, even though palliative care provision is at a premium and cannot accommodate every dying patient, as I will discuss in section 2.8.2.

Illich's (1995) image of the dying process as connected to component failure of the whole can be related to the discussion of old age in section 2.2.1. As I have noted, in old age patients may have already lost key components of their previous functioning and may, therefore, be further along the road to acceptance of disease than their younger counterparts. However, most patients will face a dying trajectory consisting of repeated and exponential losses of function, not necessarily directly related to technological advances as Illich might envisage.

2.5 Death as a taboo topic of talk?

Before the development of new technologies for improving prognosis and delaying death, physicians considered the care of the dying to be one of their major roles. Now, however, it is seen as a failure when modern medicine cannot prevent death, and talk of death becomes increasingly taboo. Gorer (1965) wrote about the pornography of death, drawing a parallel between death and sexuality, with death becoming more taboo and treated as a forbidden subject in the same manner as sex was in earlier times. However, clinicians and researchers working directly with patients are well aware that patients often want and need to talk about death (cf. Feifel 1959; Glaser and Strauss 1965; Kübler-Ross 1970). Death is also discussed widely within the media and in academia, but usually in the abstract. As pointed out by Zimmerman and Rodin (2004: 123), Kellehear (1984) acknowledges that at an interpersonal level the topic of death is avoided for the sake of conversational propriety and protection of emotions. Walter (1994: 2) states that death is talked about more and more, and that we are a society

obsessed by it as the new 'radical chic', in the context of media representations. On an interpersonal level, however, such open dialogue about death may not be so evident. A survey recently undertaken (Yougov 2004) involving 2543 U.K. respondents, found that 79 percent of respondents agree that death is a taboo subject for the majority of people living in Britain, although on an annual basis there are over half a million deaths in the U.K.

In many health care settings, the inability to talk openly about issues surrounding death can be further compounded by aggressive medical procedures to delay death, thereby keeping the focus on curative issues, rather than allowing patients to come to terms with the end of their life. Efforts to resuscitate or sustain life with artificial feeding and hydration can be made inappropriately, when curative treatment is no longer possible and death is inevitable (cf. Frederich 2002). Therefore, patients are often denied a dignified death and the opportunity to receive specialist palliative care. Within the hospice setting and other areas of palliative care, however, there exists an opportunity to participate in 'revivalist discourses on death' (Seale 1998: 5). This provides an alternative to the notion of death as taboo, underpinned by the theories of grief and loss that are prevalent in the palliative care philosophy:

The revivalist alternative proposes an elevation of the (supposedly) private experiences of dying and bereavement, so that these are brought into the field of public discussion, as they are in psychological knowledge. (Seale 1998: 4)

Palliative care aims to foster an open awareness, with communication viewed as a fundamental component of care (NICE 2004). In the analytic chapters to follow, I will explore talk of death and dying across the three sites of study.

Having discussed medicalisation in the broader perspective, I now locate the discussion of medicalisation within the context of this research setting and palliative care.

2.6 The medicalisation of palliative care

Clark (2002) reviews the rise of palliative care and notes how, in the 1950s, concerns about improving care at the end of life began to emerge. In the U.K. attention focused on the medical neglect of the dying, whereas in the United States a reaction to the medicalisation of death began to emerge. Clark (2002) notes that these two concerns originated in systematic observation of the care of the dying and subsequent published articles in medical journals. This raised debate which, together with a new perspective of dying, encouraged medics not only to inform patients of their prognoses but also to find ways to care for the bereaved.

James and Field (1994) examine the development of the hospice movement during its period of expansion (1965–91) and suggest that a number of factors have led to the routinisation of hospice care. Following Weber's (1968) model of charismatic authority, they argue that the influence of leaders such as Cicely Saunders is in direct opposition to the existing hierarchical, medically dominated model of care. They propose that new recruits to the cause produce a dilution of the original leader's vision and affect the individualistic outlook, especially when combined with the increasing bureaucracy of health care systems. This includes sponsorship and development at local level, as well as pressures towards bureaucratisation and the need for professionalism, especially in the context of fundraising. They suggest that some of the founding ideals may have been lost in this process.

The hospice movement, led by charismatic individuals such as Saunders in the U.K. and Kübler-Ross in the U.S., was eventually made mainstream by the medical profession when it was declared a specialty by the Royal College of Physicians in 1987 (RCP 2006). Walter (1994: 165) comments that, 'no sooner did doctors see a sphere of influence springing up outside their control than they colonized it, and indeed many hospice nurses welcomed the better informed medical advice that the colonizers offered'. Walter provides no evidence of nurses' opinion here to warrant this claim.

However, although in present-day western society care of the dying has long been removed from the home, and therefore is no longer seen as a societal responsibility, it is still the case that death and illness are constituent parts of our humanity. The move towards a different medical perspective has done little to emphasise the social context of dying and could, instead, be seen to have created a new and improved, but still institutional and medical, means of sequestration within palliative care.

The palliative care specialty is not without its critics; it has also been subject to claims of increasing medicalisation. In response to Ellershaw, Ward and Neuberger's (2003) study of the last days of life, Curtis (2003) voices some important concerns:

Now termed Palliative Care, it is a distinct and growing medical specialty in the U.K. legitimised firstly by The Royal College of Physicians in 1987 and latterly in academic institutions with appropriate accredited programmes and so forth. This was followed in time by a change in the organisational routine of (some) hospices whereby the 'haven of peace' metamorphosed into a 'hive of activity'. In these hospices staff rush about checking intrathecal, blood and pamidronite infusions, resuscitation equipment and so forth – sorry, no time to talk – no time to sit and just 'be' with a patient – important things to do, time is of the essence!! (Curtis 2003: 324)

Notice here the alleged shift from psychosocial interventions and communication to the priority of clinical activity. Certainly, the usual policy of short admissions and early discharge planning disallows the type of long-term care that many people assume a hospice provides. The facts are that upon first admission an average of two thirds of patients will be discharged in less than two weeks (Hospice Information 2005), with the likelihood of future admission when further symptom control is needed. The focus of care is symptom control and assisting patients and families with unmet needs as well as future planning. In my own experience of working in a hospice³, although intravenous fluids and bloods may sometimes be used, as well as equipment for pain relief, the ‘hive of activity’ is not quite as medically chaotic as the above extract describes, especially with regard to resuscitation equipment, which, according to the usual policy, will not be used. The question of just ‘sitting and being’ or in fact talking with a patient will be taken up later and is what this study will explore in depth. It appears that accusations of medicalisation bear a strong relation to the perceived lack of time for communication, which should be an integral facet of palliative care.

However, the notion that palliative care is becoming medicalised is by no means universal and seems to depend upon the professional roles of the palliative team; nurses and doctors, for example, may put forward very different viewpoints. Jefferson and Cooper (2003), speaking from within the medical and nursing disciplines respectively, offer a mutually shared perspective. They argue against accusations of the medicalisation of palliative care by viewing the types of care offered as a social response rather than the actions of a hierarchical institution. They note that it is society

³ Discussed in more detail in chapter 3.

that is responsible for the segregation of all aspects of death and dying, with institutional care responding accordingly. They therefore see medicine as following society rather than the reverse. They also point out that clinical palliative interventions can work in favour of the patients and their expectations, as they allow palliative care patients to temporarily cheat death by buying time.

The art of palliative care then could be seen to be the ability to gauge the effectiveness of medical interventions according to a holistic assessment of patient needs and preferences. Leaving aside the current debate about end-of-life decision making with regard to ending life via euthanasia, i.e. assisted dying or palliation that may result in death (Seale 2006), I consider decision making in terms of patient care and goals. This responsibility will often be a whole team decision with recommendations for the care of the patient, with the views of the patient and relatives being given priority:

Patients, families and other carers should play the central role in making decisions about the care they receive. They may need support from health and social care professionals to help them to make decisions, to plan and evaluate their care, and to explore whether earlier decisions might need to be changed. (NICE 2004: 21)

Shared decision making relies on effective communication between each member of the team so that decision making reflects the patient's complete medical condition and goals of care. The nurse, as a key member of the team, using her particular knowledge of the patient, will inform any decisions to be made. I consider the palliative care team and the nurse role in greater detail in the following sections.

2.7 Palliative care and the multidisciplinary team

Palliative care nurses function as part of a multidisciplinary team. As Nigel Sykes (1998 online), Head of Medicine at St Christopher's Hospice, London, comments, '[p]alliative care is not a matter for the individualist: it is a playing of an orchestra'. The team, as a whole, offers the quality and depth of care that is not possible to achieve by non-collaborative palliative care services or by independent practitioners. In the context of palliative care, Lickiss, Pollack and Turner observe:

A team is a strategy to achieve a goal, a means to an end. Team efforts centred on facilitating human flourishing in the face of eventually fatal illness, and especially in the face of approaching death, need clearly articulated goals, reformulated as often as necessary, in the light of changing circumstances and ethical dimensions. (2004: 42)

With this shared approach, emphasis is placed on the contribution of the multidisciplinary team to meet the present and anticipated needs of patients and their families. By taking a team approach, patient priorities are recognised, with families also being fully included in the decision making process. Another outcome of team working is, hopefully, that no one individual is overwhelmed by the responsibility of working in this sensitive and potentially distressing environment. I acknowledge here the impact of team working on the nurse role but cannot demonstrate team working in the course of this study as my focus and data is on the interaction between nurse and patient alone.

2.7.1 The role of the palliative care nurse

Nursing is widely acknowledged to be an art and a science. The 'art' component occurs across all settings. According to Freshwater and Stickley:

The art of nursing is the intentional creative use of oneself, based upon skill and expertise, to transmit emotion and meaning to another. It is a process

that is subjective and requires interpretation, sensitivity, imagination, and active participation. (2004: 93)

The notion that nursing constitutes an emotional and sensitive interpretation of patient relationships draws attention to the need for particular communicative skills. 'Effective communication has been described as the essence of effective care' (Lugton and Kindlen 1999: 53). Heaven and Maguire (1996: 283) comment that 'good communication is one of the most important aspects of care, since it pervades every part of the nurse-patient relationship, from before diagnosis to death or cure'. I would suggest that these skills need to be refined appropriately according to the context of care.

Styles of nursing care differ across a large number of settings and it would be difficult to capture all that the profession demands, in a clinical sense, with one definition. One criterion for staff recruitment of qualified nurses to work in palliative care is the requirement for further qualifications relating to the care of the dying (RCN 2002). Palliative nursing, as a term, was introduced by a sub-group of the Royal College of Nursing (RCN) in 1989 and is now recognised as a distinct nursing category with educational provision to degree level (Johnston 1999). The specialty is usually associated with the care of cancer patients but, in practice, the palliative nurse's skills can be used for the care of all patients at the end-of-life stage (ibid).

Talk of death and dying, as discussed above (2.5), can be difficult and although open communication is encouraged and advocated in palliative care, nurses need to be confident of their communicative skills in order to achieve this. The use of blocking tactics, such as topic shifting, ignoring patient cues and taking a lighthearted attitude to

serious talk have been noted by Menzies (1960) and Wilkinson (1991) and will be discussed in more detail later (5.5).

Davies and Oberle (1990) explored the role of the nurse in palliative care using interview data. They list six dimensions of the supportive role of the nurse in palliative care:

1. valuing or having respect for the patient's individual worth
2. connecting or being able to relate to the patient's subjective experience
3. empowering by allowing the patient and family autonomy wherever possible
4. 'doing for' to focus on the physical care of the patient
5. finding meaning to make sense of the situation
6. preserving own integrity and functioning abilities by taking care of the nurse's own self esteem and self worth

Davies and Oberle (1990: 90)

These dimensions reflect the interpersonal and holistic nature of nursing. They imply that the nurse as a professional cannot be separated from the nurse as a person if a therapeutic nurse-patient relationship is to be achieved. Although they are described separately, often these dimensions are connected and occur simultaneously. I will be paying particular attention to numbers 1, 2 and 5 as I explore these categories in greater depth in later chapters.

Having given a definition of and provided insight into the philosophy of palliative care, I will follow this up in the remaining sections of this chapter with a discussion of the

broader context of care. In particular I will focus on service provision and access to palliative care at the current time.

2.8 Provision and funding of adult palliative care. 2005 Statistics

According to the Hospice Information service, collated data statistics for 2005 indicate the following:

In-patient care

Total number of adult in-patient units: 220 (about 29 percent are NHS managed)

Total beds: 3,156

Beds per million population: 52

Estimated number of admissions per year for in-patient units: 58,000

Estimated number of new admissions per year for in-patient units: 41,000

Mean length of stay in a hospice: 13 days

Estimated number of deaths in palliative care units: 30,000

Estimated percentage of cancer deaths occurring in palliative care units: 18 percent

Community palliative care services

Number of different palliative care nursing services: 361 of which over a third are based at hospice in-patient units

Estimated number of patients seen annually: 155,000

Estimated new patients per year seen by home care nurses: 110,000

Estimated percentage of cancer deaths cared for by home care teams :70 percent.

Estimated number of deaths at home: 38,000.

Day care

Number of palliative day care units: 263

Average number of places per service per day: 15

Estimated number of attendances per week: 8,600 (excluding Scotland)

Estimated number of patients cared for annually: 32,000 (excluding Scotland)

Patient profile (in-patient)

Diagnosis 95 percent cancer

Ethnicity 96 percent white

Age 32 percent < 65

9 percent > 84

Source: Hospice information. Hospice and Palliative Care Facts and Figures 2005. (Data derives from 2003-2004 figures).

Drawing on the above statistics, there were approximately 58,000 new patients per year admitted to a hospice in-patient unit in the U.K. in 2003-4, of which 95 percent were

suffering from cancer. About 30,000 deaths in 2003-2004 were in a hospice or hospital palliative care unit, which means that almost half of the admissions result in discharge. About 155,000 patients were seen annually by home care teams, out of which home care nurses saw 110,000. Home care teams cared for an estimated 70 percent of terminal cancer patients. The average length of stay as an in-patient is 13 days. Hospice care and specialist palliative care is provided by a combination of charitable and NHS services.

Two thirds of provision is in the voluntary sector. Service providers include:

- Voluntary/Independent hospice (including Marie Curie Centres or Sue Ryder Palliative Care Centre)
- NHS Hospice or Palliative Care Unit
- Macmillan nurses
- Marie Curie nurses
- Hospital Palliative Care Team (or Support or Symptom Control Team)
- Macmillan Cancer Care Unit

Source: Department of Health (2003a)

2.8.1 Service provision

‘Hospice or palliative care is free of charge to patients and their families. The cost is funded by a combination of public donations, legacies, fundraising activities and through contracts between Strategic Health Authorities and providers of hospice and specialist care’ (Department of Health 2003a: 2). According to Welsh Assembly Government (2003) strategy, the key principles of provision in Wales are as follows:

- Every person with life-limiting conditions, irrespective of age, should be able to receive palliative care, appropriate for their assessed clinical, cultural, social and psychological needs.
- Every health care professional should incorporate basic palliative care in their approach to clinical practice, knowing when to call in specialist palliative care colleagues to improve the quality of life for patients.
- Health care commissioning bodies should ensure that there is a clear strategy for the delivery of palliative care services to their defined population, that the resources (both facilities and trained staff) are available to meet the plan and that

providers of care meet agreed standards of delivery both in volume and quality terms.

- Health care commissioners should ensure that NHS and voluntary sector providers work together in developing palliative care strategy and delivery of services.
- Every commissioner and provider of palliative care should ensure that patients and families are consulted on the quality and nature of the services.
- The three cancer service networks in Wales must ensure that specialist palliative care services are incorporated into all aspects of service provision, and are equitably available to the population served by the network.
- The cancer services networks should promote and facilitate research, education and training in palliative care as well as in oncology.
(Welsh Assembly Government 2003: 6-7)

However, the principles as described above are still an ideal. Government funding is inadequate in Wales, and the rest of the U.K. Where initiatives to provide supplementary funding have been announced, for example via the much heralded NHS cancer plan, it has proved difficult to access and slow to acquire (Department of Health 2003b). Therefore, access to a palliative care service is not guaranteed and will depend upon a range of factors. This will be considered in the following section.

2.8.2 Gaining access to palliative care services

Financial restraints and public and professional perception of palliative care have raised several issues, as identified here by the Sheffield Palliative Care Study Group's work in progress (2006 online). Problems include:

- heterogeneity in what palliative care services in different localities offer (a form of 'postcode lottery');
- lack of understanding amongst professionals about whom to refer, and when;
- resistance by some professionals to share with or hand over patients to palliative care services, even when it would be in the patients' interest;

- reluctance by many patients and family carers to be referred for palliative care, because of misunderstandings of what it offers, or fear of its association with dying;
- perception that palliative care is only for cancer patients; and
- missed opportunities resulting from cultural background or being in institutional care.

These difficulties, they note, have resulted in the double disadvantage of disease and distress and exclusion from the most appropriate care. Equity of access is also affected by age, where there is a negative association for older patients attempting to access services. This finding is reinforced by studies in recent publications (Grande 2003; WHO 2005). Equity of access and palliative care in old age are the key requirements advocated by the World Health Organization in their latest guidance documents addressing international palliative care issues (WHO 2005). Social class is also an issue, as found by Kessler, Peters, Lee and Parr (2005) using qualitative interviewing of 18 U.K. carers. They found that patients of the lowest social class were less likely to die in the hospice setting, mainly due to less active information seeking and a reluctance to request a place when wanted. The double jeopardy of being old and having a lower social status may, therefore, impact significantly on patients' ability to access palliative services. Catt, Blanchard, Addington-Hall, Zis, Blizard and King (2005) sought to examine the age related differential of use of services via questionnaire interviewing of 256 patients divided into two age groups, 55-74 years and 75+ years. Interestingly, they found:

Despite believing that it is easier to die in old age, respondents did not agree that hospice and specialist care services should give priority to younger patients nor that younger people deserved more consideration than older people when dying. Thus, from the perspective of people aged over 55, the potentially greater psychological and spiritual needs of younger patients do not justify their greater use of hospice services.
(Catt *et al* 2005: 407)

In spite of the fact that older patients acknowledged that they did not have as many concerns as younger patients when facing death and dying, they nevertheless felt that they should be allowed equal access to services. The perspective of older people on death and dying, seen here to differ from other age groups, will be explored later in this study (5.8.1, 6.5.1), especially in the case study chapters (9 and 10), which focus on two elderly patients.

Lack of access to specialist palliative care can be seen as a disadvantage because specialist professionals are trained in the philosophy of total care, many having undertaken special training to enhance their communicative skills at end-of-life care. If patients are unable to access specialist palliative care services, the quality of care offered to them by other health care professionals will be less tailored to their needs. The National Council for Palliative Care (NCPC 2005 online) highlights the distinction between those providing palliative care and specialist palliative care providers:

Palliative care is provided by two distinct categories of health and social care professionals:

- those providing the day-to-day care to patients and carers in their homes and in hospitals
- those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example)

Those providing day-to-day care should be able to:

- assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs
- meet those needs within the limits of their knowledge, skills, competence in palliative care
- know when to seek advice from or refer to specialist palliative care services

If patients are unable to access specialist palliative care it is important to assess the quality of the alternative option, as I discuss in the following section.

2.8.3 Quality of care in alternative settings

General Practitioners (GPs) and district nurses or medical and nursing staff in hospitals, may provide alternative palliative care services (Department of Health 2003a). They may, subject to local provision, draw on the extra resource of a hospice-based specialist palliative care team via a 24 hour helpline, as in the setting of this research project. The team will usually be available to advise on symptom control and pain relief but will have nil or reduced contact with the patient, thereby disallowing access to direct specialist care that is known to be the better treatment and care.

Hospital based palliative care teams are on site and cover various wards within the general setting. The NCPC (2005: 26) estimates that 125,000 patients are seen by a hospital specialist palliative care team during admission to non-specialist in-patient units. The efficacy of such teams is well established (Ellershaw, Peat and Boys 1995; McQuillan, Finlay, Roberts, Branch, Forbes and Spencer 1996; Edmonds, Stutterford, Penny, Lynch and Chamberlain 1998). Ellershaw *et al* (1995) developed an assessment tool (PACA - Palliative Care Assessment) that was used in their study to assess specialist palliative input, including the insights of patients into their disease diagnosis and prognosis following intervention by a specialist palliative team. They found that communication with palliative care team members significantly changed the insights of both patients and relatives. Jack, Hillier, Williams and Oldham (2004) further developed the study by using the PACA tool on 50 patients receiving specialist input and 50 patients in a control group, who were not accessing the service. There were limitations

to this study, as discussed by the authors, including the ethical concerns of non-access to the service from the control group. The study does not explain the mechanics of participant selection but it is possible that the palliative team at the site of study was a limited resource and in the usual course of events did not see all patients. Jack *et al* (2004: 51) found that the non-control group had a greater insight and noted that the specialist input offered ‘knowledge that is coupled with specific skills to communicate comfortably and effectively with dying patients’. Communication is an essential component of specialist palliative care and in this study I aim to draw attention to it as a resource in palliative care settings.

Research shows that half of all patient deaths occur in the acute hospital setting where there is evidence to show that the care of the dying is of poor quality and results in an undignified death for the patient and relatives (Hockley, Dunlop and Davies 1988; McWhan 1991; Seale and Kelly 1997; Copp 1999; Edmonds and Rogers 2003). One of the major shortcomings in a hospital environment is the lack of open communication and actual diagnosis of dying (Rogers, Karlsen, Addington-Hall 2000; Costello 2001). The evidence for effective symptom control is conflicting. Parkes and Parkes (1984), using the surviving spouses’ perspective to evaluate hospice care versus hospital care, claim that pain and distress are not a problem in either setting. However, other larger scale studies show that the majority of hospital in-patients with palliative care needs are less likely to have their needs met compared to hospice patients (Hockley 1989; Mills, Davies and Macrae 1994). Environmental circumstances also affect the quality of care, for example, when the busy atmosphere of a large public institution disallows for quiet and the preservation of personal dignity (Magnusson 1996; Seale and Kelly 1997). Hospital care may also differ from hospice care in the approach taken towards the

disclosure of a terminal prognosis. Leaving aside for the moment the arguments regarding open or closed awareness of dying (Glaser and Strauss 1965), in some institutions operational strategies of non-disclosure are the norm (Costello 2001). Whether or not staff agree with the justification of this paternalistic approach makes little difference. Finlay (2003) notes that within acute hospital in-patient settings:

Dying with dignity has a long way to go. The hospitals in which patients find themselves as they approach their last days or hours are sometimes overcrowded, with shared wards without facilities for relatives to stay overnight, to have food and drinks, and to walk around away from the bedside for a short break, without leaving the hospital. The pressure on beds is such that no sooner has someone died than the bed is needed for another patient ... Thus it is only the hard-pressed consultant who can provide some sort of long-term continuity of care for the most vulnerable of all patients – those approaching death. (2003: 102-3)

It is clear that in the interests of best care, access to effective palliative care services should be available to all who require it. In what follows I discuss patient preferences towards sites of care and whether they are actually achieved.

2.8.4 Patients' choice of care setting

It would seem that patients are very unlikely to receive the care they deserve in the acute hospital setting or to be able to access the care setting of their choice. There is firm evidence to show that the majority of people would prefer to die at home (Higginson and Sen-Gupta 2000). A survey commissioned by Marie Curie Cancer Care (Yougov 2004, n=2543) found that just 4 percent of the sample group preferred to die in hospital. The overwhelming preference was to die at home (64 percent) or in a hospice (23 percent). In reality, however, as Taylor and Carter (2003) point out, this merely represents the ideal scenario. As the disease advances, many patients' circumstances and opinions change due to unmanageable symptoms or carer distress, resulting in just 60

percent of patients with an original preference to die at home actually achieving this aim (Thomas, Morris and Gatrell 2003).

Some community palliative care teams provide an extended home nursing service, often known as Hospice at Home (Hospice Information 2006). This is a community-based hospice, which provides palliative care services for terminally ill patients in their own homes. Charitable organisations also operate nursing services that may be available, subject to referral by the primary care team. Care may be provided to prevent inappropriate admission to an in-patient unit, or for respite or crisis management. There are many different models of Hospice at Home, varying from rapid response teams offering a high level of specialist support, to those providing less intensive on-going support. Unfortunately, few teams are able to offer 24-hour access to care for more than a few days, which causes difficulties in achieving the aim of a home death if there is inadequate family or carer support.

Where continuing care cannot be guaranteed, patients will routinely be admitted to a hospice unit, if a bed is available, or to the acute hospital setting. 47 percent of all cancer deaths occur in an NHS hospital setting (Higginson, Astin and Dolan 1998). The majority of these deaths will be in the emergency department, possibly the worst scenario for a terminally ill patient, where last minute admissions can cause severe distress (Higginson *et al.* 1998).

The current status of the care of cancer patients is reported in a Department of Health document:

Too many patients still experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from healthcare professionals during the final stages of an illness. This can have a lasting effect on carers and those close to the patient, who often carry the burden of care. The care of all dying patients must improve to the level of the best. (National Health Service 2000: 66)

It is clear that communication, here specifically mentioned as a mode of patient support, is key to many of these issues and that further research in this field is needed with practice development in mind.

Whilst outlining the statistics and issues involved in the need for and provision of palliative care, I have drawn attention to the need for effective communication in terminal care. In the next section I will briefly review the existing research that has been undertaken in the area of palliative nurse–patient communication in the U.K.

2.9 Nurse–patient communication studies in palliative care (U.K.)

Effective communication has been described as a core element of palliative care (Wallace 2001). However, there is a paucity of studies conducted in the area of nurse–patient communication, often due to the problems involved in gaining access to sensitive sites, as I shall discuss in Chapter 3.3, and the apparent bias of researchers towards studying the doctor–patient encounter (Candlin 2000). There are few studies to date that use tape recordings of nurse–patient encounters in palliative care. Of these, several have focused on nurse ‘performance’, rather than the dynamic interaction between nurse and patient, and are oriented to communication skills training and evaluation. These studies do, however, bring valuable insights into communication in this area. In one of the first studies of communication in palliative care, Wilkinson (1991) tape recorded nurse–patient interactions and demonstrated through her analysis

that nurses commonly use 'blocking' devices such as not taking up patient cues, ignoring comments, or using distancing or avoidance strategies. Heaven and Macguire (1997), studying nurse training, found that patients' concerns remained, overall, undisclosed. Nurses' skills in eliciting and identifying concerns were under-developed, resulting in 60 percent of patients being left with unmet needs. Other research has shown that nurses are thought to give priority to physical needs rather than paying attention to perhaps more challenging psychosocial issues (Hockley 1989; Wilkinson 1991; Heaven and Macguire 1997).

Wilkinson, Bailey, Aldridge and Roberts (1999) note the beneficial effect of a communication skills training programme that was devised with a sample of nurses post-training (n=33). They conclude that all of the nurses had shown improvement in the psychosocial care of patients. The results were based on appraisals carried out by Wilkinson *et al* (1999) using tape-recorded data of nurses' talk during the patient assessment interview. This was, therefore, a quantitative approach based on a specific nursing process undertaken at the admission stage, where there had been little opportunity for building the nurse-patient relationship.

The improvements that are noted, based on nurses' psychological assessment performance, were measured 'in terms of the nurses' ability to pick up on cues and explore in depth how the patient's illness has affected their life and psychological well-being' (Wilkinson *et al* 1999: 344). I have deliberately chosen to exclude the assessment interview from my own data collection and will instead focus on more established relationships where nurses' psychosocial work has possibly become further integrated in the dialogue with individual patients. The initial assessment interview is a discrete

interactional event that occurs at the beginning of the nurse–patient relationship; it can also be relatively formal in style as a range of questions is asked in order to complete an admissions page within the medical notes. I would suggest that this event does not reflect the communicative content of a more established relationship. Although the nursing assessment is an important component of care, the analysis for this study will focus on naturally occurring talk during routine nursing care.

As I have mentioned before, the study of communication using naturally occurring tape-recorded data as the basis for analysing the palliative nurse–patient relationship has received little attention to date. However, a notable contribution was made by Hunt (1991), whose data consists of 54 recordings of naturally occurring conversations between Symptom Control Team Nurses and patients in their own homes. Her aim was to explain the means by which nurses were able to uphold the often taken for granted ‘friendly and informal’ relationship as an aspect of practice, and how this was achieved by talk. She describes the distinction between ‘being friendly’ and ‘friendship’ as follows:

While being friendly can be displayed through ways individuals present themselves to others e.g. smiling, a particular tone of voice, use of ‘social’ talk etc., these characteristics are superficial in contrast to those attributed to ‘friendship.’ Friendliness and informality, however, appear to have similar features. (Hunt 1991: 932)

Hunt uses an extended case study approach, applying ethnographic theories of common sense context related meanings in the interpretation of her data. Within the role format of ‘friendly, informal’, she is able to identify various aspects of talk and behaviour that contribute to the informal feel of the interactions (1991: 930). These are:

- The explicit information given by the nurses concerning use of Christian names, lack of uniform and the relaxed nature of their interactions
- Social pre-activity talk to ease into the main agenda and as a boundary between being received and waiting for the appropriate time to engage with the patient
- Use of small talk between 'formal' activities, assessments, histories, record taking
- Closing sequences consisting of pre-closure and terminal sequences, for instance between taking leave of the patient and then taking leave again from the relatives
- Non-urgent departures and generosity with time
- Self-disclosures from nurse to patient for relational alignment

Hunt (1991: 936) acknowledges the impetus to create 'partnerships' in order to enable freedom of expression, but argues against the reality of this due to the inequity of the relationship and the lack of characteristics relevant to 'friendship'. She advocates that the idealised aim of an unlikely relationship, based on friendship, would be better replaced by a reversion to 'formal' means of communication not commonly forming part of mundane 'informal' conversations', in order to achieve the professional agenda (Hunt 1991: 937). Her research has relevance to this study based on both the site of data collection and the participants involved. However, her study is confined to home care only and it will be interesting to see whether these relational tactics are evident in my own home care data and the two other sites of care that are used in this research.

More recently, the concept of friendliness, or 'niceness', has been explored by Li (2004; 2005). She explores the concept of 'symbiotic niceness' and poses that:

The niceness of nurses simultaneously requires, feeds on and grows from the niceness of nurses and patients. It is a symbiotic existence which is mutually benefiting and sustaining. (Li 2005: 1949)

In contrast to my own study, where I consider the dynamic aspect of nurse–patient interactions, Li notes that ‘patients, relatives and other professionals were ‘incidental’ as her primary focus was on nurses’ talk’ (Li 2004: 2575). Tape-recorded data was collected from nurse handovers whilst an ethnographic approach ensured that observational data was gathered whilst shadowing nurses. Li’s published studies use data derived from two hospices and one hospital, and aim to examine how psychosocial care is mediated by the collaborative practice of niceness between nurses and patients in daily activities. Niceness, she comments, is:

Not just about presenting a good professional front, it also concerns the wider implications of social interaction. It may be regarded as a mechanism for constituting moral identities and for maintaining social order. (Li 2004: 2573)

Li’s use of the term ‘front’ here gives an indication of the superficial nature of professional niceness, which she also relates to Hochschild’s (1983) study of flight attendants’ work and the personas that are adopted in order to perform other service work of this type. She also notes the views of Aranda (2001) who claims that ‘this veneer of niceness could hamper effective peer appraisal which could make it difficult for nurses to resolve conflict or ease tension in interaction’ (Li 2004: 2574). Niceness as a means of maintaining social order could be said to serve to get things done, to facilitate nurse or patient agendas. I will consider this notion, where relevant, in the chapters to follow.

Li’s data revealed that ‘symbiotic niceness’ was achieved via paying compliments, self-compliments, use of first names (see also Hunt 1991), and the use of humour, in conjunction with the sequential arrangement of talk and the creation of personal and

team *curricula vitae* in an overt acknowledgement of their 'marketable assets'. In the case of individual palliative nurses, these assets included warmth, a smiling face, maintaining composure, patience, kindness, competence, sympathy and empathy, as well as physical assets such as attractiveness and age. As a symbiotic relationship, the patients' assets were also under examination and were found to be courteousness, having a sense of humour, joking, showing appreciation, pleasantness, politeness and having an appearance of physical well-being. Li suggests that in practice 'healthcare professionals learn how to 'do' niceness better' (Li 2004: 2582).

Li's recognition of the use of humour in palliative care relationships is significant to this research and humour has also been noted in previous studies as a way of enhancing the nurse-patient relationship (Dean 1997; Langley-Evans and Payne 1997). I will consider the use of humour and laughter across the three care settings in Chapter 7. This study will take forward Li's findings but will depart from her methodology by using tape recordings of each nurse-patient encounter with the focus of analysis on the dynamics of interaction between nurse and patient rather than on the nurses' contributions alone.

2.10 Chapter summary

Within this chapter I have provided information and statistics that draw attention to the increasing need for adequate provision of palliative care. I have paid specific attention to the incidence of cancer in old age to underline the fact that the vast majority of patients receiving palliative care are elderly, a statistic that will inevitably affect access to care, practice and patient attitudes to death and dying. I will continue to consider issues relating to old age in sections 5.8.1, 6.5.1, and in the case study chapters 9 and 10.

I have given a definition of palliative care and its philosophical aims, including an overview of the concept of total pain and drawn attention to the role of communication within the specialty. I have explored the notions that both the treatment of the dying and palliative care itself have become increasingly medicalised in contemporary society, leading to de-skilled communication that will have an adverse effect on patients who are routinely made aware that they are dying. I have discussed the role of the palliative care nurse and the multiple dimensions of care that are intrinsic to this role. Again, the majority of these require effective communication for their delivery.

I have looked at the provision of palliative care and the fact that patients who may prefer to die at home are often denied the chance to be cared for in the setting of their choice, or are unable to access the palliative care setting at all. These facts may assume a particular relevance following a contextual analysis across the three care settings.

Finally, I have discussed the existing research in the area of palliative nurse–patient communication, noting its relevance to this study. Hunt’s (1991) study population and design matches one of the three sites of my own study. She uses an ethnographic analytic framework that provides useful categories that will inform my analysis. Li’s (2004; 2005) research gives an insight into the nurse–patient relationship within three in-patient settings. As with Hunt (1991), I would expect the study findings to relate to my own data from the in-patient unit. My study departs from these previous studies mainly regarding the nature of the analyses, which will be carried out using a discourse analytic framework and also by the use of an extended analysis across three different sites of care.

Having established the background for the study, I will continue in the following two chapters to focus on the methodological processes and procedures and the analytic framework for the study.

Chapter 3: Methodology: Research processes and procedures

3.1 Chapter overview

Within this chapter I will focus on the procedures of the research process. I will describe the three care sites linked to the hospice, and the different data collection processes and issues raised by each of them (3.2). I will also discuss the ease or difficulty of access to each setting (3.3) and the consent and recruitment of participants to the study. I consider the ethics of conducting research with dying people (3.4) and the process of gaining informed consent. I will then consider some of the unexpected issues that arose in relation to the researcher role during data collection, as well as the issues surrounding presentations of self as researcher and the effect of my 'insider' role (3.5). Finally, I will provide details of the equipment used, brief demographics concerning the participants in the data collected, and a discussion of the transcription conventions used (3.6).

3.2 The research setting

The site of this study is a large hospice in Wales, operated by a charitable organisation. There are 17 in-patient hospice units in Wales at the present time (Welsh Consumer Council 2005: 14), the majority of which are small hospital based units. The average number of beds per unit is 15. The hospice that is the setting for this research comprises a 30-bedded in-patient unit and an annexed day therapy unit (DTU). 500 in-patients each year are cared for here,⁴ in addition to patients who regularly use the DTU. Specialist care is also provided to patients in their homes by nurses based at the hospice. The

⁴ These statistics were kindly provided by the hospice management team (2003).

hospice's running costs total around £2.2 million a year two thirds of which is funded by charitable donations. The data for this study has been collected from three different areas of the palliative care setting, home care (HC), day therapy unit (DTU) and the in-patient unit (IPU). A brief description of the physical characteristics of each setting follows. I will discuss the settings in more detail in sections 3.5.2, 3.5.3 and 3.5.4 when I consider the researcher role in each.

3.2.1 Home care

This setting provides specialist palliative care in the patients' own homes. The nurses operating from the hospice are distinct from the other palliative care teams that also work in the community. Teams such as the district nurses or Marie Curie Nursing Service can provide all aspects of care including 'hands on' care. The hospice-based home care teams, however, are specialist nurses that work as part of the primary health care team alongside the patient's own General Practitioner and district nurses. Their role is to provide expertise in assessing and treating symptoms, and to act as psychological and social support for the patient and their family, if required (Skilbeck and Payne 2003).

3.2.2 Day Therapy Unit (DTU)

The DTU is annexed to the main hospice site and has a capacity for 13 patients. It consists of a suite of rooms including a main lounge/dining area, gardens and balcony, treatment rooms and a sensory/relaxation room. Volunteers also work with the patients, chatting, serving teas and lunch and giving manicures etc. There are also two coordinators who perform administrative duties, greet patients, and generally ensure that

events run smoothly. Patients have access to the multi-disciplinary team, a range of complementary therapies and other provisions such as a hairdresser and music or craft sessions.

The specialist home care nurses also run this unit, which usually offers patients a six week package of care, or visits on an *ad hoc* basis. Patients are often referred by the home care nurses, sometimes whilst receiving home care visits as well.

3.2.3 The in-patient unit

There are 30 beds divided between two virtually identical wards, one situated on the ground floor and the other on the first floor. There are usually five nurses per shift with a higher ratio of qualified to unqualified nurses. Both groups were considered eligible for taping. Medical and ancillary staff are also present during working hours and on call when necessary. Patients are referred by their General Practitioners or other health care agencies for symptom control, respite care or terminal care and can usually expect an admission of approximately two weeks' duration.

3.3 Access to the site

Professional data sites and especially medical sites are notoriously difficult to access. Medical professionals, acting as advocates of their often vulnerable client group, are keen to respect the latter's rights to privacy and peace at difficult times. This is especially the case when dealing with 'outsider' researchers, non-medical professionals or even medical professionals unknown to the site of care. As Sarangi (2002: 100) discusses, researchers may be seen to be driven by their own agenda or are otherwise

viewed with suspicion. Moreover, researchers may have to coordinate with others seeking to conduct research in the same site.

For example, during the course of data collection for this study, several other studies were being undertaken by researchers that were linked to the hospice in some way, either through medical education or as multi-centre researchers for the organisation. Most studies focused on the in-patient unit. In fact, as I was nearing the completion of data collection from the in-patient unit, a study to assess the perceptions of patients agreeing to participate in research was just beginning. This choice of topic highlights the real concerns of exploiting patients for research purposes. In practice, researchers had to liaise with each other to avoid exploiting the patients or overwhelming them with more than one study at a time.

Gaining access to nurses as participants was challenging, as the usual research preference is for doctor-patient interactions. As noted by S. Candlin (1997) and Candlin and Candlin (2003), the majority of discourse studies in health care settings have been concerned with the more favoured doctor-patient relationship. S. Candlin rightly points out that:

Whether this is related to the prestige and power which the profession holds, or the autonomy which medical practitioners are thought to enjoy, are moot points. (2003: 388)

A request for access to the nursing discipline was perhaps less usual and there were specific concerns relating to this data site. S. Candlin (2003) discusses how the quality of the typical doctor-patient interaction differs from that of the nurse-patient relationship in that the former interactions are more likely to be of limited duration and

concerning discrete events, as opposed to nursing contact with patients, which is an activity that is ongoing and cumulative. For this study, data collection would have to follow the same working pattern. Discourse studies may gather data from indirect patient care as evident from meta-discursive events such as multi-disciplinary team meetings, which are several stages removed from patient care and are unlikely to fully reflect nurse work as practiced in context. Access to nursing interactions, then, needed to be gained despite the extra difficulties of these occurring at random times and often during task-based care. My interest was in the nurse–patient interactions across three care settings which was to prove difficult as I needed to access three different groups of staff, showing varying levels of cooperation.

I was able to access the site as a whole with management permission by virtue of my experience as an employee of ten years standing. During this time I had worked as an auxiliary nurse whilst studying for my first degree. I was very fortunate to have the encouragement and backing of the Centre Director and the Medical Director who were both very interested in communication issues, especially when approached from a new direction and who each took a personal interest in my own self-development.⁵

When I approached the Medical and Centre Directors with a proposal for this PhD study there was no hesitation in allowing access as both of them saw it as important and prestigious for the Centre and palliative care education, in general. I have no doubt that an ‘outsider’ would not have been allowed access so readily, if at all. Any medical site,

⁵ After I had graduated, a position as Research Officer was offered to me in order that my skills could be used most effectively. I then worked as a Clinical Auditor on a freelance basis in order to comply with ESRC scholarship requirements.

as discussed earlier, is difficult to access but a hospice site has particular moral and ethical implications that render it significantly more complex.

3.4 The ethics of research with people who are dying

There is a sensitivity associated with conducting research with terminally ill patients.

Patients who are receiving palliative care are perceived as vulnerable and at risk, physically and psychologically (Aranda 1995; Polit and Hungler 1999). Patients may be experiencing complex symptoms including physical and mental fatigue and cognitive deterioration. Their psychological vulnerability, whilst they are dealing with issues surrounding death and dying, places them at risk of distress when sensitive topics are touched upon during the research process (Aranda 1995). Consideration of the use of patients' time is also a factor as it is in limited supply and perhaps, therefore, more valuable when used for family and friends.

At the same time, it is known that there is a dearth of rigorous, evidence-based quality of life research (Salisbury, Bosanquet, Wilkinson, Franks, Kite, Lorentzon and Naysmith 1999), with the majority of studies in the topic area relying on proxy attitudes and opinions, rather than on the direct patient contact which is thought to provide a more rigorous outcome measure (Cartwright and Seale 1990; Higginson, Priest and McCarthy 1994; MacMillan and Mahon 1994; Yip, Wilber, Myrtle and Grazman 2001; Snow, Cook, Lin, Morgan and Magaziner 2005).

The inclusion of patients rather than proxies within the research design is therefore beneficial to future development of palliative care and, generally, the case for direct involvement is strong. Aranda (1995) comments that an immediate patient benefit may

be experienced with the possibility that a therapeutic value may arise out of the research process. This study is concerned with the progressive experience of palliative care across three settings as evidenced by the real life interactions between nurses and patients. As such, direct participant involvement is an inevitable and valuable part of the research design.

The recruitment of both patients and nurses differed according to the site, depending on the willingness of nurses to be involved in the process. Providing information in order that patients and nurses can give informed consent is an important aspect of the research process and especially in what could be seen as a 'vulnerable' group. Before the process of gaining formal ethical approval I first had to decide the length to which I was personally and morally willing to go without feeling that I was exploiting this patient group. I was not willing to undertake any research with patients who were thought to be days or weeks from death. My view is that this time is precious and special. Moreover, this patient group generally does not have enough energy to deal with impositions on their time. However, I also feel strongly that terminally ill patients have as much right as anybody to voice their own opinions and make their own judgments. As I will show in chapter 5 (5.9.1.2 and 5.9.2.1), during the analysis and discussion of the concepts of 'secrecy' and 'collusion', these patients are routinely 'protected' from information, especially by family and friends and so denied the full autonomy of a competent adult, a process which has the potential to cause psychological damage.

These issues and other ethical issues that I will discuss next, were dealt with instinctively by myself. I relied on my personal moral stance but was aware that because the study was subject to formal ethical approval this would, in turn, be validated by

others. I was able to access the advice of the Centre Director, herself a past member of the local ethics committee. I had, at first, considered that should patients become fatigued, distressed or ill during the recording that the nurse or myself would call a halt to the taping. This did occur on two occasions, once when I was not present (taping occurred during intimate care on the ward), and once during a long interaction with a distressed patient. I have since decided to include this data in the study as my intention was to collect empirical, real-life data and that the fatigue or distress was in no way connected with the research process. To steer away from patients' distress (on the condition that the research process is not adding towards it) undermines the reality of what actually occurs at the hospice on a day-to-day basis and could be said to give an overly optimistic perspective, thus biasing the research. However, in respect of patients' autonomy and because of the potentially sensitive nature of the nurse-patient interactions, it was particularly important to gain ongoing informed consent as I will discuss next.

3.4.1 The consent process

I will discuss the consent procedures for each setting separately in sections 3.5.2, 3.5.3 and 3.5.4, as they differed per site of care. Overall, I managed the consent procedures *in situ* and with the supervision of the Local Research Ethics Committee. However, work since undertaken by Wiles, Heath and Crow (ongoing 2006), an ESRC (Economic and Social Research Council) group based at the University of Southampton, retrospectively provides a formal framework to the processes that had been adopted somewhat instinctively by myself.

The framework consists of three elements: giving appropriate information, voluntariness, and competence/autonomy. Some of the challenges Wiles *et al* describe are familiar to my own experience. Attempting to give information, written or verbally, for example, was sometimes met with an overly trusting attitude from patients who were happy to sign without reading the information sheet or without wanting to hear in detail a verbal description. In these instances, I gave a verbal summary of the research aims as informally as possible. In the instances described below, where the nurses acted on my behalf, I was confident of their ability to fully understand both the research aims and the processes. In the case of informed consent, due to the professional emphasis on consent issues, their understanding very likely surpassed my own.

The second element, voluntariness, includes the issues of allowing time to consider decisions and the right to withdraw. The criteria for this research allowed one week between the giving of information and the signing of consent, excepting the in-patient unit where this timescale was reduced due to the limited length of admission. Several patients declined to consent immediately and one declined after having had time to consider. During the course of actual taping, patients were reassured that we could stop at any time. One patient exercised this option because he wanted to discuss a particular topic involving litigation. In another case, during home care, the nurse asked that taping be stopped, as she was about to perform an intimate examination, although patients and nurses continued to be taped during the same process in the ward setting.

The competence and autonomy of patients giving consent also needs to be considered. The nurses and I jointly established a set of criteria that would need to be met before

considering a patient's inclusion in the study. In the home care setting, for example, this was that patients were:

- relatively well or stable in their condition at the time of taping
- able to talk and hear to a functional level
- previously known to the nurse
- engaging in a usual visit as opposed to a 'crisis' visit

3.4.2 Ethical approval

Formal ethical approval was a requirement for this study as the research involved human subjects. The first submission to the Local Research Ethics Committee (LREC) Cardiff involved the home care site only, as a pilot study, but this was unfortunately rejected. A second application (ref no 00/3606) for the home care site was successful in May 2000 and data collection began immediately. The DTU and IPU application was passed in February 2002 (ref. no: 01/4346). The awarding committee was the Bro Taf Research Ethics Committee.

3.5 Reflexivity and the effect of 'insider' status on the researcher

The ethnographic elements of the research design of this study, i.e. non-participant observation (in the home and DTU settings) and the recording of real life data, placed myself, as researcher, within the sphere of the participants' experience. As such, consideration must be given to the effect of the researcher role, particularly regarding the potential for conflict caused by my 'insider' status and roles both as a researcher and as a former auxiliary nurse and current employee at the hospice.

Allen (2004) reviews insider-outsider roles with consideration to reflexivity and the need for a systematic approach in the context of the increasing frequency of research

using nursing ethnographies. Her evaluation acknowledges the perspectives of insider researchers as the only researchers that 'can ensure an authentic account' (Allen 2004: 15), as opposed to outsider research, that may be seen as 'a preferable stance as it is free from the potential for bias that arises from too close an affiliation with the research subjects' (ibid). As Allen notes, Burgess (1984) discusses how many studies in health care use the researcher's insider status as the basis for the research and that 'the debates about familiarity and strangeness have become polarized in the literature. Situations are neither totally familiar nor totally strange' (Burgess 1984, cited in Allen 2004: 15). This viewpoint, Allen comments, is echoed by Hammersley and Atkinson when they put forward that 'we are part of the world that we study' (Hammersley and Atkinson 1983, cited in Allen 2004: 15). Allen draws on her own research experience to reinforce the notion of a more accommodating stance: 'I have taken a dual approach, which combines my own expectations, feelings and emotional responses to the field with an analysis of the social practices that gave rise to them' (Allen 2004: 22).

The notion of the insider-outsider status as a continuum rather than two discrete points seems to be a more feasible perspective. Within the context of this study, for example, it is unlikely that any outsider researcher could appear within a health care organisation without some knowledge or preconceptions of the people and issues within it. Any consideration of hospice care and terminally ill patients would inevitably invoke a range of associations and responses, depending on individual life experiences and knowledge. The idea that any similar research can be conducted from a 'clean' outsider starting point is unlikely to be viable.

I would suggest that outsider research in particular carries the potential for powerful descriptive accounts. Lawton (2000), a social anthropologist, conducted research in a U.K. hospice, a setting that was new to her experience and that proved to be challenging to her in many ways. Lawton's study, in contrast to my study, is undertaken by a researcher with an 'outsider' perspective and has added value because of that. The taken-for-granted elements of my own professional familiarity with the in-patient setting are brought to the fore and vividly described. Lawton admits, for example, to being extremely shocked at the sights and odours that she experienced, and that may be seen in any hospice. Many of the patients she observed, as an inexperienced non-medic, were admitted because of problems such as incontinence, fungating wounds, or fistulae. An insider, such as myself, is unlikely to capture such scenes as it requires the fresh perspective of the outsider.

However, it could also be said that in health care settings there may be a lack of awareness by 'outsiders' as to what may constitute an issue of concern, or what normal practice should entail. To understand professional acronyms or jargon requires experience and knowledge, as noted by Sarangi (2002) when, in his own research, the multiple uses of the 'DNA' acronym were a source of confusion. The average patient will be far more versed in medical terminology specific to their condition, than a novice researcher could hope to be. For an outsider researcher with less contextual knowledge it becomes more difficult to locate or identify discursive structures that comply with or deviate from the norm in order to see variance in behaviours and/or pertinent issues.

Full knowledge of the systems and practices of the professional site can complement the analysis but equally, the professional role can sometimes obscure the researcher role. An

insider researcher may possess a pre-understanding of relevant issues due to his/her cultural and situational proximity to the field of study but is unlikely to know all, as is evident in this research where I had little prior experience within the home care or DTU settings. It is the acknowledgement of these factors, together with the application of this understanding within the analyses, which will reduce the potential for bias. The methodological and analytical implications of the dual role also need to be explicated beforehand. Denzin (1989: 12) comments that 'interpretive research begins and ends with the biography and self of the researcher'. As I have stated, my previous experience within this research setting is as an auxiliary nurse and as a result I have worked with many of the ward nurses. All of the nurses from the other settings are also known to me as colleagues in a less direct way. I do not wear a nurse's uniform in my present role and was introduced to patients as a researcher based at the hospice. The presentation of myself as a researcher to patients and colleagues was, I found, a process of negotiation and turned out to be more challenging than expected.

3.5.1 Presentations of the researcher self

Presentations of self are evolving and dynamic in any situation and identity is a socially mediated process. Goffman (1959; 1974) has described how people negotiate and validate identities in face-to-face encounters and how people establish 'frames' within which to evaluate the meaning of encounters. Sarangi's metaphorical use of the comparison of marijuana smoking gives an interesting insight towards the socialisation of professionals into the field of discourse studies:

If discourse is a form of marijuana, then professionals also need to inhale discourse slowly and steadily in order to become competent practitioners of discourse. (2002: 117)

I was in the fortunate position of working with people that I knew and more importantly, knew me as an informed colleague. To continue the metaphor, I was already a fully-fledged marijuana smoker. They were able to trust that I was working for their benefit as much as my own and they committed to the research enthusiastically. The positioning of myself as researcher/practitioner was not, however, totally positive and did have a negative impact at times as I shall explain later.

The researcher role proved to be contextually sensitive and required several different presentations of 'self' as well as different strategies employed to gain consent from nurses and patients and to collect the data. As a novice researcher, I soon found that ideals of observing interactions in these settings as a non-participant were impossible. Indeed, it soon became clear that the opposite is true – in sensitive settings a compassionate researcher *must* engage where appropriate. To do anything less is to diminish the patient, causing the research process to be unethical and morally wrong. To be allowed access to these settings was a privilege not to be abused. Gaining consent was sometimes difficult even as an insider, and as an insider and a researcher I felt doubly responsible to act in the patients' best interests, for the sake of the hospice and for my academic department. I will now discuss each setting individually with regard to these issues.

3.5.2 Home care setting: consent and researcher participation

The nurses that were to be involved in the study were invited to a meeting during which we jointly decided on the method of approaching the patients to ask for their consent to be included in the study. The nurses thought that it would be best for them to make the initial approach to the patient so as to allow time and an opportunity for a refusal

without embarrassment if necessary. They chose the patients according to a set of criteria (3.4.1) that we jointly discussed regarding the patient's condition. The seven patients that were approached all consented to be taped. The home care tapes varied in length between twenty minutes and an hour. I used a small analogue dictaphone for the home care visits. The quality of the tapes was good if there was not too much background noise. The demographic details are as follows⁶:

Approximate length of consultation	Transcript number	Patient gender/pseudonym	Patient age	Nurse gender	Nurse age
20 mins + 20 mins untaped	TRAHC1	Male/John	70+	Female	50+
60 mins	TRAHC 2	Female/Sarah	20+	Female	50+
50 mins	TRAHC 3	Female/Mary	50+	Female	50+
60 mins	TRAHC 4	Female/Amy	80+	Female	50+
20 mins	TRAHC 5	Female/Olive	70+	Female	50+
20 mins	TRAHC 6	Female/Irene	70+	Male	30+
Not transcribed – poor sound	TRAHC 7	Male	40+	Male	30+

Whilst collecting the data from the home care setting I accompanied a nurse who would ideally have had a one-to-one session with her patient. Instead, as was more usually the case, the nurses' time was often shared with students of several specialties, nursing, medicine, physiotherapy etc. As a result they were well used to being observed in their practice and were not particularly concerned about this. The nurses did not wear a uniform, apart from an identity badge. In this setting, the nurses treated me as an equal

⁶ Patients' names have been anonymised.

and although I had said that I would not become involved in the conversation, I found from the first consultation that this was not going to be possible.

I had planned that after the introductions had been made I would sit apart if I could and avoid eye contact by taking notes. However, I immediately felt uncomfortable and more of an intrusion than if I had been included in the interaction. The problem here was the context of the interaction; although it was a medical consultation it was taking place in a non-institutional setting, the patient's home, which for him was primarily his social space. In the context of a medical or institutional setting it may not be unusual for a health care professional to work with an observer, but in the intimate setting of the patient's home this did not conform to normal social expectations and behaviour. Ultimately, in the first consultation, the patient himself drew me into the interaction by showing me his artwork.⁷

Extract 1 (HCTRA1) John 80+

P=Patient

N= Nurse

R=Researcher

Patient leaves room, coughs. Returns and shows polystyrene mould to researcher

- 151 P: I made it (*unclear*) a house in France you know being rich (.) and um (.)
all this is to feed the metal
- 152 N: yes
- 153 P: you stick it in sand (.) it's a technique of my own (.) dry sand (.) which
just pours where I've made all these hole (*shows to researcher*)
- 154 R: mmm
- 155 P: so the sand goes through so it'll have a core (.) I hate the thing but they
say it's alright so why bother and then
- 156 N: and this is going to go in a well
- 157 P: there's their well (*shows photos to Nurse*)(.) this is p'raps a bit better
- 158 N: oh I think it'll look lovely is that going to be in bronze?
- 159 P: say?
- 160 N: in bronze

⁷ For transcription conventions see section 3.6 and appendix 1.

161 P: aluminium
 162 N: aluminium
 163 P: mmm
 164 R: oh right
 165 N: a nymph
 166 P: (*unclear*) so who is the wretched man? (.) doesn't matter (.) take him out
 of sight
 (*Leaves room*)
 167 R: he's carrying a fish we should know that (*nurse*) (.) it's not Pan is it
 168 N: is it (.) who is it
 (*Re-enters*)
 169 R: who is it then?
 170 P: who's the lady?
 171 N: who's the man? who's the sprite
 172 P: Bacchus oh [no no no it's not no (.) Pan
 173 N: [Bacchus
 174 R: Pan

My first reaction, as researcher, was to make minimal responses such as 'mm' and 'oh right' (154 and 164), but as the patient was so clearly depressed about his work and was using highly emotive vocabulary, I felt that I had to offer some encouragement rather than allow the patient to think that I was completely disinterested, as evident in turn 169 ('who is it then?'). At this point, having responded to the patient I felt that I was now included in the patient's social space and was able to act in response, if required. Although I had not intended to participate, my presence nevertheless made it a triadic interaction. As Caplow states:

Social interaction is essentially triangular rather than linear ... Social interaction, the basic social process whereby persons and groups modify each other's behaviour, is triangular-or triadic-because it is always influenced by an audience, present or nearby. (1968: preface)

In this and the other home care consultations, discursive relational alignment was cooperatively constructed by other participants in the interaction, i.e. the patient and the nurse, to include myself to a greater or lesser degree. I feel that in these situations with respect to the patients' distress and humanity there is no place for observation alone, it is

just not possible to remain passive and inanimate during sensitive talk in the patient's own home. I would argue that to do so could cause the patient to feel undervalued as a social individual, which would totally contradict the aims of this study. Attempting to be unobtrusive can also be paradoxical. Clarke (2003: 380-381), with his experience both as a researcher and as a subject of research, presents the view that an 'ideal' observer would engage with subjects by eye contact, smiles and warmth in order to be least obtrusive. The 'fly on the wall' approach, in his opinion, is more obtrusive than an appropriate level of backseat interaction. Following this first consultation I found myself to be included in the interactions by the interventions of both patients and nurses.

Further examples of researcher inclusion

Extract 2. Acknowledgement of a humorous comment (HCTRA3) Mary 50+

- 159 P: yes and I've got um (.) barley lemon barley water (.) I've been drinking a lot anyway (.) yes that was that was lovely (.) I don't know what I don't know whether there was an infection or it was to do with that stuff you know the new one (.) but um (.) it's been ok this time (.) thank God
- 160 N: yeah (.) what about tumble dryer?
- 161 P: well (.) um (.) Sue came and [(N turns to researcher)
- 162 N: [waterworks it follows did you get that
- 163 P: (laughs)
- 164 R: yeah very good (laughs)

Extract 3. Asking researcher's opinion (HCTRA3) Mary 50+

- 317 N: was there anything else?
- 318 P: no don't think so
- 319 N: anything else? (to researcher)
- 320 R: no
- 321 N: no? [think that's it

Extract 4. Recognising mutual contacts (HCTRA5) Olive 70+

- 271 N: was (.) done by um (.) L R (wife of HCTRA1)
- 272 R: oh right
- 273 N: F R's [wife

274 R: [yes
 275 P: [the top one here
 276 P: the top construction that was one of L's
 277 R: you knew each other did you?
 278 P: pardon?
 279 R: did you know each other
 280 P: oh very well
 281 R: oh I see

Extract 5. Patient initiatives: (HCTRA4) Amy 80+

468 N: I thought that um (.) [that was best
 469 P: [(unclear) can I talk to her (*refers to researcher*)
 now?
 470 N: you can certainly talk to her
 471 P: is it alright to [talk?
 472 R: [feel free yes

Extract 6. Addressing the audience during personal narratives (HCTRA 3) Mary 50+

243 N: how's the family?
 244 P: fine (.) yeah (.) yeah T was up early but I sent him back to bed I said wait
 (.) till you've been and gone (*laugh voice*) and then I'm going to call you
 (.) cause he gets himself all (.) uptight you know my husband he's got a
 nervous complaint had it since my children were little (.) since I've been
 ill he's sort of got himself so (.) het up and he's given up smoking which
 he used to smoke no end (.) you know
 245 R: yeah
 246 P: cor I said to him the other day I'd rather you go back on the cigarettes
 than he's so [um (.) like a time bomb
 247 N: [*laughs*)
 248 R: [*laughs*)
 249 R: [how long's he given up for
 250 P: about four months now
 251 R: very good

During one consultation the husband of the patient was also present. This, therefore, including myself, was a quadratic interaction and the coalition structure was dynamic throughout the interaction. Talk occasionally split into two pairs as the husband talked to me whilst the wife talked to the nurse. In the home care setting, overall, it was necessary to maintain an involved approach. I would participate in the interactions when

appropriate but would not initiate talk that would detract from the nursing agenda or the nurse–patient relationship.

3.5.3 Day Therapy Unit (DTU): Consent and researcher participation

The DTU is a nurse-led operation. It is managed by the same set of nurses that attend patients at home. Each nurse has one day per week where a different set of patients will attend, many of them already known to the nurse through home visits. All of the nurses had already consented to the study during the home care tapings and this time we decided that a joint approach to obtain patients' consent would be tried. The nurses would ask patients that were suitable as and when they saw them and I was also free to visit the DTU over a period of about two months and talk to patients myself. All of the patients were given a week's notice and were free to change their minds before they signed the consent forms. On receipt of the signed consent form they were taped. Demographic details follow:

Transcript number/patient pseudonym	Length	Nurse	Patient
DTU1/Colin	50:14	Male 30+	Male 70+
DTU2/Bill/George/ Phil	23:20	Female 30+	Males x 3 70+
DTU3/Alan	7:56	Male 30+	Male 40+
DTU4/Bernard	07:20	Female 30+	Male 70+
DTU5/Catherine	06:48	Female 50+	Female 50+
DTU6/David	08:37	Female 50+	Male 40+
DTU7/Steve	07:56	Male 30+	Male 40+
DTU8/Pat	06:29	Female 50+	Female 50+
DTU9 (not transcribed due to researcher involvement in clinical care)	50:31	Male 30+	Male 70+
Researcher interview	08:12	Male 30+	

There were a number of different scenarios where taping occurred. The patients mainly occupied a communal area where the nurses circulated, speaking to them in small groups or on a one-to-one basis. There were also outdoor areas, such as the balcony or the garden where a more private casual talk could occur, or there was an office if full privacy was needed or preferred. The nurses carried the tape recorder around with them and taped the patients wherever they were. I was often present in the communal room but distanced from the interaction through talking to other patients, or taking field notes. I was present for the private consultations, which were all conducted by a single nurse, seemingly as a preferred way of working.

In the private consultations it was again a triadic interaction but my participant status here was markedly different to the home care setting. As a more formal, institutional

encounter, with the nurse sitting at a desk and the patient to one side of it, it was far more typical of a doctor-patient consultation. The nurse wore a suit and the office in use was the one used by the doctors when they saw DTU patients. These consultations were also the longest of the DTU tapings. I was able to remain distant during these consultations with one exception, where the participant was a male in his thirties and in the late stages of terminal disease. He was attending with his mother and a small child. He would not allow the child to be looked after by staff and so they all attended the consultation held in a small room. I became involved, initially, by entertaining the child as they talked about child care for her in the future, but also professionally when the family asked my advice when the nurse had left the room. I was aware that there was other help available from the Centre for the family members who were struggling with child care, and advised them accordingly. In this instance I had to put the researcher role to one side in order to ensure that the patient had best care. This tape has not been transcribed.

In this setting, many of the interactions were very short and consisted of brief social exchanges. I have not included these tapes. I supplied the DTU nurses with a digital recorder that could be tucked in their pocket like a pen. The data was then downloaded onto my computer and transcribed from a sound file. The quality of the recordings was often very poor and I decided not to use this device for the ward setting.

3.5.4 In-patient unit: Access, consent and non-participation

In this setting it was extremely difficult to access and gain consent. Initially, the main problem was ward closures due to shortages of nursing staff. This was eventually resolved by a recruitment drive in the Philippines, which resulted in an influx of new

staff. In fact, approximately half of the trained staff were new in post and were undertaking an extensive adaptation programme. The ward was unsettled during this period and was not available for research purposes.

When I gained access I was met with resistance from several nurses who refused to consent to the study. Their reasons were very much related to my other role in the Centre, at the time, as a Clinical Auditor. The 'inspection' element of my role caused suspicions that their practice would be under scrutiny and that any shortcomings would be made known to management. In relation to my earlier discussion about the benefits of insider status, here was an example that inevitably showed that there will also be a negative bias to the role. Clarke (2003: 376) in a commentary about the negotiation of roles within institutions notes that attitudes to audit in health care settings range from 'sullen resentment' of an unhelpful institutional imposition, to positive responses in favour of the potential of improving service. The nurses were also mindful of performing for the tape and worried that it would restrict their normal interactions. I spoke to each nurse on a one-to-one basis to give each a realistic explanation of the research process and to separate myself from my institutional role. I eventually obtained consent from enough nurses for the amount of data required. Here again, the nurses decided that they would recruit the patients and as I would not be able to be present at most of the interactions, due to the task-based and often personal nursing care taking place at the same time, I made several tape recorders available to them.

The next difficulty was recruiting patients. I had decided on a certain number of criteria that patients would have to meet in order to take part in the study. These were that I did not want to impose extra stress on patients that were close to death, in pain or fatigued,

new to the hospice, or confused or embarrassed by speech or hearing difficulties. This set of strict criteria was added to by the nurses' perceptions of their patients' conditions, As I had left it to their discretion I was confident that the nurses would ensure that the consent would be informed and that they would have no interest in coercing patients to the study.

Due to all these restrictions, data collection was extremely slow and took several months to complete. There are a total of 14 nurse-patient interactions. The majority of them take place during intimate care procedures lasting a maximum of 15-20 minutes and unobserved by myself. For the wards, because the nurses were going to be operating the recording equipment themselves, I provided equipment that they were familiar with and after testing the taping quality I used the standard dictaphones that were already available at the hospice. All of the patients were elderly with the exception of IPU13, a female aged 40+. Demographic details follow:

Transcript number/patient pseudonym	Patient	Nurse(s)	Activity
IPU1/Bill	Male 70+	2 Qualified Females	Bed bath
IPU2/Alice	Female 70+	1 Qualified female	Introduction and planned wash
IPU3/Louise	Female 70+	1 Qualified female	Introduction and planned mobilisation to toilet
IPU4/Beryl	Female 70+	2 Auxiliary nurses	Bed bath
IPU5/Nancy	Female 70+	2 Qualified Females	Bed bath
IPU6/Sally	Female 70+	1 Qualified Male	Bed bath/massage
IPU7/Jean	Female 70+	1 Auxiliary nurse	Assisted bath
IPU8/Ian	Male 70+	2 Qualified females	Oral care/ reposition
IPU9/Elizabeth	Female 70+	2 Qualified females	Assisted shower/ skin assessment
IPU10/Margaret	Female 70+	2 Qualified females (Physio?)	Mobilisation assessment stairs
IPU11/Elin	Female 70+	2 Auxiliary nurses	Assisted wash
IPU12/Rose	Female 70+	2 Auxiliary nurses	Assisted wash
IPU13/Lorna	Female 40+	1 Qualified female	Death and dying talk
IPU14/Arthur	Male 70+	2 Qualified females 1 Sister	Chair to bed reposition

3.6 Transcription conventions

Lemke, in referring to Ochs (1979), notes that:

This is a classic paper which discusses the sense in which transcription conventions, for both verbal and nonverbal (*sic*) data, represent choices which have important theoretical implications. Because transcription is always selective and can never display all aspects of the information from a sound or video recording, we

need to consider what should be represented and how. (Lemke 2006 online)

Lemke's summary suggests that consideration should be given to which aspects of talk need to be included within the transcription, in direct relevance to the research aims. As Ochs notes, '*transcription is a selective process reflecting theoretical goals and definitions*' (1979: 44) (original emphasis). Ochs (ibid) also argues that a transcript should not be too detailed or contain an excess of information.

In the case of a methodology such as Conversation Analysis (CA), very detailed transcripts are used in a style of analysis that is based only on recordings of what is seen and heard at the time of interaction. The focus of analysis is exclusively on the structure and sounds of the speech and therefore every aspect, such as pronunciation, breath sounds and pauses, is transcribed in fine detail to examine features of the way talk is produced. The analytic methodology for this study is Discourse Analysis (DA), which will be explained fully within the following chapter. This approach, unlike CA, goes beyond the data to explore interpretation against a theory, or in this case, a set of themes. Consequently, the transcripts are notated to include only that which is relevant to the analysis (Ochs 1979; Psathas and Anderson 1990). I have used simple transcription conventions as this study will use a theme-oriented approach focusing mainly on rhetorical devices as found in the content of talk in general. Devices such as contrast, reported speech and personal narrative, for example, will not be highlighted by transcription conventions. Instead, I concentrate on other aspects such as speakers' turn management. The co-construction of talk will be significant in signalling relational alignment, and so I include indications of turn taking including overlaps, approximately timed pauses and latching. The use of questions will be of interest in the analysis and so

I use question marks in the event of high rising tone and/or lexical content indicating an enquiry.

The transcription conventions used in this study are as follows:

N:	Nurse
AN:	Auxiliary nurse
P:	Patient
R:	Researcher
(.)	Short untimed pause (less than 0.5 of a second)
(...)	Longer pause. One dot represents 0.5 of a second
=	Equal signs for 'latching,' that is, two utterances that follow one another without any perceptible pause.
[A square parentheses between turns indicates the point at which overlap by another speaker starts.
{Guess}	Words between curved parentheses in the transcripts represent a guess at talk which was difficult to hear.
<i>(Laughing)</i>	Material between brackets in italics provides extralinguistic information.
/	Forward slash indicates cut off speech or interruption by other speaker
?	Question indicated by high rising tone and syntax
—	Underlined words indicate stressed intonation

For ease of use the transcription conventions are reproduced and located in this study preceding the data transcripts in Appendix 1.

3.7 Chapter summary

In this chapter I have described the three care sites linked to the hospice as well as the data collection processes and issues raised for each of them, including ease (or not) of access and recruitment of participants to the study. I have also discussed the fact that, as a researcher, I found that I had to adopt a different approach in each case depending on the level of engagement needed in each context. I have discussed the methodological implications of my dual role and of the need for self-awareness of possibly conflicting points of view during the analytic process to follow. I have also provided details of the gaining of ethical approval, the equipment that I used, brief demographics of the participants in the data and a key to the transcription conventions used.

In the following chapter I will discuss my rationale for the analytic framework for this study. I will then discuss how this is put into practice and I will provide details of the discourse analytic constructs used throughout the study.

Chapter 4: Methodology: Analytic framework

4.1 Chapter overview

In this chapter I intend to provide a rationale and details for the analytic approach that I will use for this study. I will give an overview of discourse analysis in general (4.2) before proceeding to describe the method that I will be following here, i.e. theme-oriented discourse analysis, and reasons for its choice (4.3). I will discuss and summarise the focal themes that will be explored by this analytic framework (4.4) as well as the analytic themes (4.5). Chapters 7 and 8 focus on the particular discourse events of humour and metaphor. I will therefore discuss these separately here (4.5.1) and in greater detail in the dedicated chapters. I will follow with an overview of other key analytic devices used in the study (4.5.2).

4.2 The methodology of discourse analysis

There are varying approaches to discourse analysis; it is a multi-disciplinary interpretative approach with a range of theories and methods. Some of these strands include discursive psychology, critical discourse analysis, conversation analysis, pragmatics and sociolinguistics, amongst others.⁸ What each of these approaches has in common is their aim of providing a systematic analysis of empirical data representing language in real life situations.

⁸ For a representative overview see Jaworski and Coupland (1999), Schiffrin, Tannen and Hamilton (2001)

In order to determine the most appropriate methodology for this study, I draw upon the existing body of discourse analytic knowledge to select a robust and appropriate framework that will shape and position the research outcomes. There are methodological choices to be made when faced with a body of data to be analysed, depending on the research focus. In this case, much of the focus of this study is on the construction of attitudes and social roles in terminal illness within the context of palliative care nurse–patient encounters. Such encounters require multiple levels of professional/social involvement in order to simultaneously manage the professional agenda whilst addressing relational needs. I therefore incline towards studies rooted in interactional models of discourse analysis.

Cheepen (1988) maintains that there are two styles of talk, interactional and transactional. Interactional talk establishes relationships and promotes rapport whilst transactional encounters focus on achieving task-based agendas. The notion of two separately discrete styles is arguable. Tracy and Coupland (1990: 2) note that interlocutors typically have multiple goals in conversation that should be ‘conceived of as intertwined concepts’. The transactional and interactional elements will therefore occur simultaneously. The three settings within structured palliative care, i.e. home care, day therapy unit and in-patient unit, bring relational and institutional differences that may also coincide and impact on the interactions observed. The three settings are likely to differ from each other in terms of transactional aims, from the talk-based work in the home setting through to the clinical task-led agenda in the IPU. However, these categories are not discrete. The macro level of transactional achievement, particularly during task-based nurse work, is likely to be intersected by the micro-interactional use

of phatic, or more socially styled talk (Malinowski 1923; Schneider 1988; Coupland 2000).

In clinical task-oriented nurse–patient encounters speakers have several interpersonal goals, such as developing a relationship and establishing rapport. Nurses need to earn trust, establish expertise, or persuade patients to take some particular course of action. Interactionally oriented small talk is likely to be used in conjunction with transactional agenda based talk to achieve multiple goals. However, to what extent such talk can be considered as interactional, in the social sense, is compounded by the professional role of the nurse and the experiential role of the patient. This was evident in Li’s (2004) study, which points to tensions at an interactional level. She found that both nurse and patient participants appeared to be establishing a pseudo-social relationship in order to fulfil their role and task demands.

A superficial relationship such as this is likely to contain small talk, which can be viewed as sociable conversation about everyday topics. However, interactional work still occurs as speakers continue to maintain multiple goals related to conversation initiation, regulation and maintenance (Ragan 1990; 2000, Cegala and Waldron 1992). These include managing ‘face threats’ (Goffman 1967), being polite (Brown and Levinson 1987) and being cooperative (Grice 1989). Goffman (1974) furthermore describes how people negotiate and validate identities in face-to-face encounters by the establishment of frames within which to evaluate the meaning of encounters. Goffman (1959) uses a dramaturgical metaphor to explain how social meaning is constructed by individuals in ordinary everyday interaction with the notion of an on-stage and off-stage persona playing to various audiences. In the context of my data settings, the institutional

frame of the hospice may be seen to cause a tension in individuals between conforming to usual social roles whilst at the same time playing the part of a patient or nurse.

It is these differences that I aim to make explicit in order to explore the varying constructions of patient and nurse roles in the progression through palliative care. However, I also want to look at elements of interaction with a thematic orientation in order to focus on particular concerns that will be relevant to patients and professionals alike. I will specify the approach that I will be using for this study in the following section. I have chosen to use a theme oriented discourse analysis, which draws upon a range of discourse analysis constructs and analytical tools.

4.3 Theme-oriented discourse analysis (TODA)

The analytic framework I adopt is 'Theme-oriented discourse analysis'. It is based on a specific strand of discourse analysis and is a methodology recently outlined by Roberts and Sarangi (2005). Their approach draws on other traditions in a collaborative sense, with both discourse analysts and health professionals aiming towards a joint understanding of what occurs within the health care setting. Roberts and Sarangi (2005: 639) note that a theme-oriented discourse analysis 'encourages a free-range DA, drawing inspiration from many approaches' whilst remaining 'an ethnographically grounded study of language in action'. Analytically, this research is based on a discourse view of language and communication. That is to say that it differentiates from the linguistically based notion of language as composed of invariant structures of units and rules of usage and the overarching tendency to analyse texts with the focus on patterns or choices. The social orientation draws on the notion that every discourse takes place

within a more or less mutual understanding, or ‘lifeworld’ in Mishler’s (1984: 14) terms, that cannot be fully or explicitly formulated.

A theme-oriented discourse analysis is particularly appropriate for the analysis of talk in the institutional setting of health care as it links to ‘wider issues of professional practice with a critical stance’ (Roberts and Sarangi 2005: 633). In their study, they distinguish between two kinds of focal themes relevant to the professional domain in their data: risk and understanding. These two themes are then explored using a range of analytic themes including, face and facework, contextualisation cues and inferences and rhetorical devices.

In my study, I will concentrate on the two focal themes of social death and hope, which will be discussed in more detail below. This approach examines the interactions in their entirety, combining a macro-level focus on the themes of professional interest with a micro-level discussion of how talk is constructed with regard to these themes. The analysis of interactions is based on a broader view, both in terms of the size of extracts under analysis and the extended focus of analysis that will be applied. The focal themes overlap within the interactions but will be discussed separately in two analytic chapters (5 and 6). The analytic themes will be used in further exploration of the data and reinforcement of the focal themes.

The extracts to be analysed will consist either of specific events within the interactions, looking at the focal themes as they occur across all data, or of entire interactions when used as case studies. The use of case studies, following the core analytic chapters, will provide an extended real-life context of a complete interaction. Thus it will be possible

to see the intersection between the focal and analytic themes and to draw the study together. It will aim to underline the social identities of the patient participants and the contextual background and the discursive processes and events that contribute to their social status. A resource for the analysis, as discussed in Chapter 3, will inevitably be my own 'insider' knowledge of the practices, ways of working and culture of the research settings. I aim to make this explicit where it influences the analyses.

4.4 Focal themes (social death, hope and healing)

Social death and hope and healing are the two focal themes for the study in its entirety and relate to the topical content of the interactions. The selection of these two themes is informed by the philosophy of palliative care (Chapter 2.3.1) and its intention to holistically care for patients during the process of dying. Patients are encouraged to live as actively as possible despite the difficulties that they have and will face along the course of their disease. The concept of social death encompasses many of these issues whilst strategies to aid hope and healing, in the palliative sense, may be seen as its counterpoint. Data is extracted following repeated readings informed by the sociological and cultural concepts of palliative care and the focal themes. A theme-oriented discourse analysis is then applied to selected extracts.

Within this framework I will use the three settings, HC, DTU and IPU, to explore the notion that the effects of social death and hope will differ in accordance with the course of terminal disease and that, in general, there are likely to be issues that are pertinent to each care setting. I will also consider the notion that with the effective use of communication there is the potential for professional help in dealing with many of these

issues, in order to attach new meaning to the illness experience and thus counter many of the negative effects of social death.

The notion of hope, in the context of palliative care, is not concerned with cure but rather with the process of building belief that symptoms will be managed and that inner peace will bring a sense of meaning to a terminal diagnosis. Healing, in this setting, focuses on the relief of psychological suffering rather than curative clinical intervention. By using strategies of hope-fostering and healing in the palliative sense, nurses and patients can construct new outlooks in order to make sense of and accept the terminal journey.

Nurses may also need to adapt to the differing needs of patients at varying stages of psychological adjustment, using a repertoire of rhetorical strategies to promote positive acceptance of the experience of terminal disease. For this reason I will use the thematic foci to examine working practices, especially in chapters 9 and 10, which will use a case study approach of two encounters in their entirety. I will show that there will be contextual sensitivity, even within the same care environment with patients sharing similar demographic characteristics, and with the same nurse attending.

In chapters 5 and 6 I will discuss the focal themes in detail with a review of the literature and an overview of these concepts, whilst using analyses of nurse–patient talk across the three settings to enhance the discussion. These chapters will serve as a basis for discussion of issues and factors that contribute to social death or hope and healing in the context of terminal illness. Chapters 7 and 8 will consider the multifunctional use of humour and metaphor, which proved particularly salient in the data. In what follows, I

provide a brief overview of the remaining analytic themes that are used throughout all of the core chapters.

4.5 Analytic themes

I have chosen to use a range of analytic themes within the analysis to highlight the relational aspects of the interactions. As I have discussed, nurse–patient interactions can have intersecting aims, e.g., to accomplish a professional care agenda whilst simultaneously maintaining and developing relationships. The management and negotiation of what is ultimately an asymmetric (nurse–patient) relationship can be seen as a delicate process requiring a wide range of rhetorical skills. The analytic themes which will form the basis of my interpretation of data are listed below.

4.5.1 Laughter and metaphor

In relation to the theme of social death, the function of laughter and lightheartedness in maintaining social cohesion and relational alignment allows for the diminishment of isolation and social withdrawal that may otherwise be felt. In relation to the concepts of hope and healing, as I shall discuss in Chapter 6, humour and lightheartedness may be used as mechanisms to foster hope, especially in conjunction with the relational alignment between nurse and patient. However, these statements suggest that laughter is used with positive effect and this is not always the case. Humour or laughter cannot be considered as universally positive because its effect depends on the circumstance of its application and the function that it serves. I will discuss, in Chapter 6 the different functions of laughter and explore its use within nurse–patient interactions across the three settings.

The use of metaphor is allied to laughter in the sense that both rely on mutual understanding and appreciation. Metaphors are used to explain the unfamiliar or to see the world from a new perspective, thus allowing alternative meanings to develop. Likewise, the use of laughter can be used to shift meaning and provide new perspectives. Metaphoric expressions can use a word or a phrase to accomplish the communication of complex issues whilst at the same time providing a mental cue to the listener to direct his/her thinking. In the palliative settings, where there is a need for talk about taboo or sensitive topics, it is likely that metaphoric expression will facilitate communication.

The two analytic devices of laughter and metaphor are interesting within the hospice setting. The use of laughter, particularly, is perhaps unexpected within the 'sombre' confines of a hospice. The reason for the discussion of these specific devices in discrete chapters (7 and 8) is both due to their frequency within the data and because of their potential for multifunctional use. In conjunction with the focal themes, both devices have the potential to be used for a variety of means, and this merits further examination. Full discussions and literature reviews of laughter and metaphor are contained within the dedicated chapters. In addition to laughter and metaphor, I will draw on a number of other devices, which will inform my data analysis throughout the remainder of the study.

4.5.2 Other analytic devices

Reported speech

Reported speech is the quoting of another person's, or one's own, prior words. This may take the form of direct quotation by quoting the actual words of the original speaker, or

indirect quotation, i.e. a summary of what was said in the words of the teller (Holt 1996). Reported speech can be characterised as a 'doublevoiced discourse' reflecting both the original speaker and the present speaker (Bakhtin 1981). There is, therefore, an opportunity for speakers to creatively reorganise the speech of others to align with or reinforce their own perspective. However, Tannen (1989) argues that it is not possible to report speech accurately as either the quoted words were never uttered, or the reported words (and original meaning) have ceased to belong to the original speaker when appropriated by someone else. Furthermore, she argues that the use of reported speech in conversation is a creative act in the same way as writing dialogue for fiction. Tannen comments:

Dialogue--the representation of voices (what has been called, erroneously I argue, "reported speech")--creates rhythm and musical cadence as well as setting up a drama-like scene in which characters interact with each other and engage in culturally recognizable activities. Details provide seeds from which listeners sprout characters, emotions, and meanings. (1998: 632)

I will be referring to self-reported speech and reporting of inner thoughts which can be seen as a resource with which speakers can position their own internal viewpoints. In the context of the focal theme of social death with its inherent notion of damage caused to previous identities, versions of reported speech may be used as a tool for patients to restate and justify their personal traits and opinions.

Reformulation

Reformulations are the means by which speakers adapt their own or their interlocutor's speech to change or modify their words, thus producing a new (reworded) version that is offered as a more satisfactory one (Gülich and Kotschi 1995). Gülich (2003) found that chronically ill heart patients in face-to-face interaction showed a marked preference for



conversational strategies that related abstract medical information to everyday life and experience. This style of talk is equally applicable in the palliative care setting where reformulation may be used in the same way to explain clinical information but also as a means of providing a more positive orientation for topics that may cause distress. Similar to reported speech, as far as potential function is concerned, reformulation offers an opportunity to create a change of viewpoint and/or emphasis.

Contrast

Contrast, or antithesis as it is also termed, can be defined as opposite (or contrasting) words, phrases, or ideas expressed in discourse. Antithesis establishes a contrasting relationship between two ideas and is useful for making relatively fine distinctions, or for drawing attention to differences that might otherwise be overlooked by the listener. It is, therefore, another means for the speaker to impose his/her perspective and ideals in reinforcement of opinions. Drawing on Smith (1978), Sarangi and Clarke (2002) focus on how contrast is used in the context of childhood genetic counselling to differentiate between normal and abnormal states and to create a perspective or stance from which to make decisions about outcomes. The idea of differentiation between normal and abnormal will draw attention to the differences felt by terminal patients experiencing social death as opposed to a normal, healthy social individual. It will also be used to position patients in contrast to each other, as comparison is needed in the construction of changed identity.

Personal narrative

Reissman (2000 online), in the context of her early research, notes that personal narratives may appear as 'large sections of talk and interview exchanges--extended

accounts of lives that develop over the course of interviews'. She describes how at first these accounts were treated as distractions from the main purpose of the research agenda before their value was realised. In the same way, personal narratives will appear in medical consultations, but only if allowed to do so. Reissman (2002 online) building on Mishler's (1984) theory about the different voices in a medical consultation also refers to Hyden's (1997: 49) observation that 'patients' narratives give voice to suffering in a way that lies outside the domain of the biomedical voice'. In the context of my study, the occurrence of narratives suggests that patients feel enabled to talk freely and do not feel constrained by the medical agenda. They are therefore able to talk more easily about their lifeworld issues.

Questions

I will examine the function of nurse questions at various stages during this study and particularly in Chapter 10. In the health care setting, Mishler (1984) and Treichler, Frankel, Kramarae, Zoppi and Beckman (1984) are concerned with how the type of questions physicians ask their patients may or may not elicit from the patients sufficient background information on the progression of the illness and its impact on their lives. Treichler *et al.* (1984: 73-76) reported on the differences between a medical student's interview with the patient, in comparison with the physician's. They found that the physician gathers extensive detail on the medical history of the patient, but the medical student picks up on the indirect meaning conveyed by the patient by responding to non-clinical cues from the patient about his 'sadness'. As a result, the student is able to gather information relating to the patient's psychological status that may have been missed by the doctor. I will also consider the strategic use of questioning by the nurse

where it will be seen that often the clinical and psychological care of the patient is achieved simultaneously.

Hedging and mitigation devices

I have included hedging and mitigation devices in order to explore talk of sensitive topics within nurse–patient encounters. Biber provides the following definition:

Hedges are informal, less specific markers of probability or uncertainty. Downtoners give some indication of the degree of uncertainty; hedges simply mark a proposition as uncertain. (1988: 240)

Biber (ibid) finds hedges ‘co-occurring with interactive features such as first and second person pronouns and questions, and with other features marking reduced or generalized lexical content, for example, general emphatics, pronoun *it*, and contractions’. In the context of this study, hedging is often used when discussing sensitive topics that may be more difficult to approach directly in the health care setting (cf. Prince, Frader and Bosk 1982; Hopper, Ward, Thomason and Sias 1995). For the purposes of identifying hedging within my data, I draw on the categories as described by Chimombo and Roseberry:

Hedges are commonly constructed with modal verbs (may, might, could), modal lexical verbs (think, imagine, feel, suppose), modal adjectives and adverbs (possible, likely, maybe, perhaps), tag questions (. . . isn't it? . . . aren't there?), and phrases and clauses that serve a modal function (in my estimation, it seems to me). (1998: 163)

Mitigation uses many of the same devices and may be used to soften the effect of a directive to lessen the imposition of requests that may be made in nurse–patient encounters.

4.6 Chapter summary

In this chapter I have given details of the analytic framework which will form the basis of data analysis. I began with a brief discussion of discourse analysis generally before specifying the particular approach that I will use in this study, that is, theme-oriented discourse analysis. I have discussed the two focal themes that will form the basis for the study, social death and hope, and these are to be taken up in greater detail in the following two chapters. I have also provided a glossary of the analytic devices underpinning the analytic framework, e.g., reported speech, contrast and reformulation, and I have given a rationale for the selection of the analytic devices of laughter and metaphor. Having described the research processes and procedures and given an account of the analytic framework for the study, I now proceed to the first of four analytic chapters with a discussion and analysis of the concept of social death.

Chapter 5: Trajectories of social death in terminal illness

5.1 Chapter overview

The purpose of this chapter is to focus on the identity status of patients and the way that this is constructed by nurses and patients in interaction, and to relate this to the possible psychological impact that their terminal diagnosis may already have caused. I intend to look at the patient as a social individual to explore how the diagnosis of a terminal illness has affected them and their sense of identity as presented in the different settings of care.

I begin with an overview of the existing literature on disability and dying with a social perspective (5.2, 5.3, 5.5) before moving on to current theories on social identity and the complex changes experienced by individuals with the joint burdens of a terminal diagnosis and various disabilities (5.4, 5.6). I will discuss styles of adjustment to death and dying (5.7, 5.8) followed by data analyses to evidence the issues of significance in each of the three settings (5.9). These include difficulties with physical decline, altered body image, loss of relationships and secrecy in the home care setting, collusion and denial in the DTU setting, and the institutional effect in the in-patient unit.

The illustration of a range of issues already affecting patients will give an indication of the factors that nurses will have to take into account when undertaking the care of patients' psychosocial needs. I will firstly look at how death has been viewed by scholars as a socially situated event up to the present time and the effects on 'self' and 'identity' of a terminal illness.

5.2 The terminal journey: Care beyond cure

Within the majority of health care settings there is an increasing interest in the concept of (non-terminal) patient experiences as a metaphorical journey, from care to cure. Case studies of patient journeys are used in evidence-based practice as a process-mapping tool to highlight deficits in the care/cure process and as an aid to improve shortcomings (NHS Modernisation Agency 2006). In the curative context, the focus is on rationalising treatment to make the journey easier and less stressful for the patient, while also efficiently streamlining the use of clinical staff and resources.

For patients receiving palliative care the agenda is different. The care to cure journey must be replaced by a different trajectory, care beyond cure, where the journey is an internal one consisting of a search for validation and meaning in the life that patients have left behind. As Saunders notes of many patients receiving palliative care:

Feelings of fear and guilt may seem inconsolable, but many of us have sensed that an inner journey has taken place and that a person nearing the end of life has found peace. Important relationships may be developed or reconciled at this time and a new sense of self worth develops. (2003: foreword)

The inner journey towards finding meaning, peace and self worth can create an opportunity for personal growth in counterpoint to the negative aspects of social death. This concept will be discussed in depth in the following chapter but for the time being it is the detrimental effect of a terminal diagnosis that is my focus of attention.

Cassell (1991) has suggested that suffering can be understood in terms of the extent to which one's sense of personhood is threatened or undermined. This study aims, in part, to explore the palliative patients' perspectives across the journey through progressive

care settings. By progressive, I refer to the physical and psychological route that patients will take from home care to DTU and on to the in-patient unit. Each of these settings will offer increasing levels of care to the patient, in the sequential order above. It is important to point out, however, that although this may be seen as a typical progression during the disease process, this is not always the case. Patients may 'bounce' between settings according to their needs. For example a patient may have been receiving home care or attending the DTU and then be admitted for a blood transfusion or paracentesis (drainage of excess fluid) before returning to the previous care setting. However, for the purposes of the analysis, I follow the general concept of a patient's typical journey through hospice care.

5.3 Socially situated dying

In 1965 sociologists Glaser and Strauss published findings from their extensive qualitative study of how death was managed in the acute care setting, with a focus on the social interaction of dying people and their relatives in different hospital departments. One of their aims was, 'to ask whether people can die socially before they die biologically, and what this means for human relationships' (Glaser and Strauss 1965: x). Sudnow (1967), at around the same time, was engaged in an ethnographic study of the hospital setting. His focus was on the routine procedures of care and the manner in which the treatment of patients was reflected by their perceived health status. Sudnow (1967), for example, describes how bodies of still living, but comatose or sedated, patients would be partially prepared for the morgue, or would be removed to spatially separate areas away from the main wards. He describes a case where the wife of a 'dying' man stopped visiting her relative, removed all of his belongings from their home and started a relationship with another man. In the event, however, the male

patient recovered enough to return to his home where he suffered a fatal heart attack upon discovering his wife's actions. This could be viewed as an extreme case, perhaps, but in my own experience some relatives do indeed discontinue visiting patients before biological death occurs, explaining that they feel their relative has already 'passed on' in the social sense. As discussed by Seymour, Sudnow argued that:

dying places a 'frame of interpretation' around people resulting in 'social death' practices that serve to isolate them ... the studies are rooted in symbolic interactionist theory and recognise that, death was not a moment that could be recognized irrefutably, but rather that death, the process of dying, and the meanings with which it was associated were a product of social interaction. (Seymour 2001: 14)

Therefore a social death could be seen as the point at which an individual was treated as if biological death had already occurred, a point at which the person is perceived to be treated as less than a social individual.

These ideas are related to those developed by Goffman (1961; 1968). In Goffman's analysis of the interactional formation of identity in institutions he introduces a concept he terms 'mortification of the self' (Goffman 1961: 21). This notion, he says, occurs in institutions, due to loss of possessions, prevalence of uniforms, imposed routines and loss of privacy. In combination, these effects lead to a loss of human status or reduced sense of self. The combination of physical dying and institutional admission to the in-patient unit is likely therefore to create a double jeopardy, which increases the potential for negative experience in terminal illness.

A review of the literature concerning the concept of social death from the 1990s onwards reveals a broader perspective than the 1960s model. The later model widens the

concept to include non-institutionally based patients and patients at a pre-terminal stage. Recent studies have also considered Alzheimer's disease, old age or any other area where identity becomes an issue. Young, Bury and Elston (1999) interviewed 40 terminally ill women to explore friendship dyads of women dying at home, their attitudes to their situation, and their management of changing social relationships:

Three modes for social dying were identified from the data: integration, segregation and transformation. The reflexive nature of friendship dyads was illustrated, as either the dying woman or her friend's mode of social dying could change, or end, the friendship. In some cases new friends, friends for death, so to speak, emerged. (1999: 269)

The potential loss of social relationships is a factor of social death as the management of terminal disease takes on the form of a social pressure. The notion of 'friends for death' is convincing as social relationships are built on shared outlooks and goals. The related topic of peer support will be explored in the DTU setting, as the only setting in this study where patients are located in a communal area (see sections 6.7, 7.8, 8.7).

Sweeting and Gilhooley (1997) interviewed caregivers of persons with Alzheimer's disease. Carers were rated according to the degree they appeared to believe their dependent was socially, or 'as good as', dead. They also observed behaviours that might suggest that they had discounted the sufferer in social terms. In over one third of care giving relatives there was evidence of both beliefs and behaviours suggesting that a degree of social death had occurred before the sufferer's biological death. Almost all those categorised as behaving towards a sufferer as if they were socially dead expressed beliefs indicating that this was how the sufferer was perceived. The researchers also

found that *perceiving* a sufferer in ways which could be characterised as socially dead was not necessarily combined with *behaving* as though they were.

Such clear-cut attitudes are less likely to emerge from real-life encounters, as opposed to interview accounts, and I would like to take this notion further and view it from the patients' perspectives. In an illness or ageing context, the concept of mind/body dualism is extended to include bodily autonomy (or loss of) during illness; it is related to an individual's sense of self and how they see and are seen by the wider social world. The matter of patients' 'self' is a key concern throughout this study and I follow here with a discussion of identity in relation to suffering.

5.4 Identity, 'self' and suffering in the palliative care context

Goffman (1959) proposes that the formation of identity relies on the performance of a social front, according to the context of the setting and situation. For terminally ill patients, the ongoing continuum of disease and effect mean that they are unable to contain their identities within a stable role and must continually adjust as new scenarios occur. Foucault (1973) notes that people do not have a fixed identity within themselves and the notion of identity is simply a way of talking about the self, a discourse. As it is a variable, the temporary construction of new identities may be influenced by external effects. It is these changing identities that I will explore in the palliative care patients.

Giddens (1991) has argued that an individual human being consists of two components, the person that they are inside, the interior 'essence' of the individual, and the external factors that relate to the wider social group, i.e. their identity. He comments:

A person's identity is not to be found in behaviour, nor – important though this is – in the reactions of others, but in the capacity *to keep a particular narrative going*. The individual's biography, if she is to maintain regular interaction with others in the day-to-day world, cannot be wholly fictive. It must continually integrate events which occur in the external world, and sort them into the ongoing 'story' about the self. (Giddens 1991: 54) (original emphasis).

Note here the reliance on an anticipated future and regular contact in the day-to-day world. From this perspective, terminally ill patients will have less chance of retaining a stable self-identity than they may have had before their illness. Cassell (1991) notes that suffering can be understood in terms of the extent to which one's sense of personhood is compromised. When illness affects the integrity of functions, roles, or 'a loss of a part of a person' (ibid: 44) it causes suffering to the individual. Suffering can be viewed both in a physical sense in relation to terminal disease outcomes and in a psychological sense, in relation to social death.

A recent ethnographic study has raised controversial views of individual identity in relation to the palliative care setting. Lawton (2000) comments that the premise of her own view of self and personhood in modern Western society is as follows:

Certain specific bodily capacities and attributes must be possessed: the most important being a bounded, physically sealed, enclosed body, ... and also the bodily ability to act as the agent of one's embodied actions and intentions. (2000: 7)

Her study of a modern day hospice raises the argument that it is the 'unbounded body' (Lawton 2000: 142) that is unacceptable in contemporary England, the site of her study. She observed that the patients are often perceived, by themselves and their carers, to have somehow lost their personhood, to have died a social death before their biological death. She develops her argument by claiming that hospices could be seen as places of

sequestration, to admit the patients that in society's view are no longer truly people. This leads on to the theory that constructions of the 'self' are determined by the ability to control one's body and not simply by the ability to maintain social relationships. This is indeed the case, as I will show in section 5.9.1.1. I will discuss how the inability to contain the body can furthermore affect social relationships due to socially taboo symptoms, regardless of damage to self (see Chapter 9 section 9.3).

Dying patients may be reduced to the status of 'a body'⁹ where all other aspects of identity are obliterated. Without the attributes and functions of an undamaged body, according to Lawton, a loss of personhood in their own and others' eyes will result. She describes a 'significant theoretical advance on social studies of embodiment' (Lawton 2000: 8) in acknowledging the connection between bodies and social relationships. Although Goffman (1959; 1967) is credited with describing the ways that the presentation of the body affects social interactions, Lawton (2000: 84) notes that Goffman's analysis concentrates on the body intact or 'the presence of a healthy, autonomously functioning body; that is, of a body which can actually be 'controlled' and 'fashioned' by the self'. We may question, therefore, whether Goffman's observations will hold for all individuals. In an illness context, the statements do not hold when bodily autonomy is overtaken by the effects of disease. I agree with Lawton's view that bodily status in illness is an important aspect of self and therefore agree with the

⁹ Lawton's perception of the situation experienced by dying patients may, unfortunately, have some basis in fact; a recent audit that I conducted for the hospice where I work revealed that one of the major reasons for choosing hospital admission instead of home care by specialist nurses was because relatives just could not cope with the patient at home, no matter how much help was received. Apart from the emotional and physical burnout caused by caring for a very sick loved one, carers expressed the desire not to have to face the sights, sounds and odours of death in their own homes. They expressed the view that this would leave a lasting memory that they would prefer not to have. In these cases hospice or hospital admission was the only option whether this met with the patient's desires or not.

following declaration in which she gives a defining account of social death in the context of palliative care:

During the course of their illness and bodily deterioration, patients may lose various aspects of their selfhood and identity which qualify them for the status of a 'person'. In other words, it is possible for a patient to die socially – that is to enter the realms of non-personhood prior to his or her physical cessation. (Lawton 2000: 2)

Having thus established what I take as my working definition for social death, I will move from theoretical considerations to discuss the sociological position of death as a taboo topic, followed by the experiential effect on individuals.

5.5 Death as a taboo subject

Aries (1981: 560) comments that 'except for the death of statesmen, society has banished death'. Whereas previously death was a public and community event, changes in the western world have reduced its impact on the community. Society has 'reduced death to the insignificance of an ordinary event that is mentioned with feigned indifference' (Aries 1981: 614). In modern society, few people will have any close experience of death until they lose a close relative.

Seale (1998: 3) argues against the view that we are a death denying society, saying that socially death is now treated with an open awareness. Routine medical policy now allows that, on an individual basis and often with an assessment of the patient's ability to cope, doctors disclose true prognoses to terminal patients. However, Seale differentiates between the psychological stance that is realistic and death accepting, and the sociological position, which denies death by hiding it away by sequestration. Psychological discourse, he notes, can help people 'restructure narratives of self-identity

and transform the event of death into a positive experience' (Seale 1998: 1). I will explore this notion as it occurs throughout Chapter 6, especially. I will also show that some of the patients in this study have found it very difficult to talk about their death with their loved ones¹⁰, which potentially leads to secrecy and collusion.

Elias (1985) notes that people have lost the ability to be emotionally close to each other during old age and death, which thus becomes a lonely experience and places the onus on health care professionals to take the role previously fulfilled by family and friends. The notion of the medicalisation of the dying, discussed in chapters 1 and 2, is an ongoing argument that suggests palliative care is becoming increasingly technologised with a shift in emphasis from the original concept of the treatment of total pain towards the main focus on physical symptoms. The medicalisation of the specialty could also lead to 'de-skilled' communicators, especially regarding the sensitive and taboo topic of death (2.5). The following is a response from a doctor to Clark's (2002) paper concerning the medicalisation of death, previously cited:

One of the main obstacles to the care of dying patients is the taboo against speaking or writing about impending death. A few simple tests to see how you or your colleagues are doing. Try reading a selection of charts of deceased patients. Patients do 'poorly,' 'fail to respond,' or are 'palliative,' but I would wager that you will find very few patients described as 'dying' or 'near death.' (Some dying patients even 'demand' futile treatment such as CPR in the event of a 'cardiopulmonary arrest,' when asked to 'consent' not to receive it.) You should also see how often and how vigorously you avoid talking about death when speaking to a patient likely to die. I am always surprised at how difficult I find it to talk openly about death and dying, even when it clearly is necessary and appropriate and I have carefully thought out what I am going to say. If compassionate care of dying patients is to occur physicians need a structured and consistent approach to talking with patients about death and dying. (Workman 2003. BMJ online rapid response)

¹⁰ See Chapter 5.9.1.2, 5.9.2.1 and chapter 6.7 (extract 9).

However, these opinions relate to the experience of doctors only. The discourse of doctors and nurses is known to be different, with nurses inclined towards the ‘discourse of the social’ (Fisher 1991) and informal narrative engagement with patients (Hunt 1991). I will show that nurses from all settings are willing and able to discuss death and dying in the context of palliative care (chapters 6.8.1, 8.7, 9.6).

5.6 The effect of social death on the individual

Illness affects the self because of the psychological meanings and physical and social consequences of the illness and the disease process. Adjustments to usual life and self have to be made according to the stage of illness. This patient group will also have to deal with additional issues such as disfigurement and the stigma of terminal disease. Dickenson and Johnson (1993) claim that since death is a taboo subject it causes extra suffering for those who are dying or grieving. There will also be the fact of burdening family members with not only the uptake of patients’ previous roles and duties but also the extra tasks involved in caring for an ill person. The ill person may have to reconstruct their sense of self (Bury 1991; Kelly 1992) and create a new social identity to accommodate the fundamental changes that have occurred, for example, as a person with a disability and all that this entails. The adjustments that need to be made are daunting and may contribute to an overall despair. Lavery, Boyle, Dickens, Maclean and Singer (2001) studied HIV patients whose ‘loss of self’ was an overwhelming factor in their desire for euthanasia or assisted suicide. Lavery *et al* conducted qualitative research using interview and grounded theory methodology on a sample of 32 HIV/AIDS sufferers. They concluded that ‘participants desired euthanasia or assisted suicide because of disintegration and loss of community, which combined to create a perception of loss of self’ (Lavery *et al* 2001: 362).

This is a strong statement to make and the notion of testability could be raised, given that all of the interviews were conducted by one member of the research team and might be said to be subjective. However, Lavery *et al's* definition of loss of community relates strongly to the concept of social death, which they describe as:

The progressive diminishment of desire and opportunities to initiate and maintain close personal relationships, owing to loss of mobility, exclusion and alienation by others, and self isolating actions by participants.
(Lavery *et al* 2001: 365)

In linking this process with the desire for suicide, it is possible to understand how damaging it can be and how devastating it must feel to be in this situation. Clearly, the importance of the ability to make a positive adjustment is crucial. In the next section I will discuss means of making this adjustment.

5.7 Styles of adaptation to a terminal illness

The diagnosis of terminal illness will provoke differing reactions. When all treatment options have failed, many patients will have to make the shift from viewing their condition as part of a curative trajectory to realizing the inevitability of dying from their disease. Some patients will not have had this preparation and will hear the prognosis with no previous awareness of their cancer. Individual scenarios will impact differently on styles of adjustment.

Petticrew, Bell and Hunter (2002: 1068) have undertaken a systematic review of 26 studies exploring psychological coping styles of cancer patients. They noted recurring categories of styles of adjustment:

- 1) Fighting spirit
- 2) Helplessness/hopelessness
- 3) Denial or avoidance
- 4) Stoic acceptance or fatalism
- 5) Anxious coping/anxious preoccupation, depressive coping
- 6) Active or problem focused coping

These categories summarise the patterns of thoughts, feelings and behaviours that an individual may display, although not necessarily in the above order. I would suggest that each patient will find their own way according to their particular situation. However, following a cancer diagnosis with an as yet unknown or undisclosed prognosis, it follows that there must also be a period of extreme uncertainty, which must impact on the style of adjustment. For a patient who has received a terminal diagnosis, the uncertainty of whether they will live or die is replaced by the uncertainties of when and how. When there is no hope of cure, the adjustment style must take account of the hopelessness of survival whilst making the best of the time remaining and making sense of the life lived to this point. Following a terminal prognosis, the patient, and his/her family and friends experience reactions similar to the grieving process when a bereavement has occurred. This process of projected mourning has been termed ‘anticipatory grief’ (Lindemann 1944) and is a reaction to losses and limitations caused by the disease process and also the expected death of the patient.

5.7.1 Anticipatory grief

For the patient, the process of social death is strongly related to a gradual isolation from social networks. Social networks are likely to instigate withdrawal due to failure to cope

with the taboo nature of death. 'Anticipatory grief' (Lindemann 1944) becomes a part of this process as it occurs in anticipation of the death of a loved one. Bereavement grief follows when the act of death has occurred and become ritualised by the mourning process and other social signals. Anticipatory grief, however, is not socially sanctioned due to the taboo nature of death and unmarked by social rituals, unlike a physical bereavement. As Seale notes:

Rituals soon after a death serve initially to separate close mourners from normal social life; later rituals draw the mourning period to an end and reintegrate mourners, when fear of the malevolence of the dead is reduced. (1998: 1518)

Therefore, there is disinclination to talk about the anticipated death of a family member's or one's own eventual death, rendering death socially unacceptable when unbound by social customs. Patients living with a terminal diagnosis are not only mourning the physical fact of death. As a result of their situation there will be multiple losses throughout the trajectory of the illness, which Rando (1996), expanding on Lindemann's (1944) original concept, describes as follows:

The phenomenon of anticipatory grief is not composed exclusively of grief over losses that are being anticipated but in fact encompasses grief for losses that have already befallen or are currently being experienced. (1996: 13)

Rando's (1996) concept allows that the process of anticipatory grief is not confined to the family or carer, but also to the patient. I would suggest that it can be seen as the psychological effect of the social death process. This is true of the patient and his/her loved ones to different degrees. As well as anticipating the actual death of the patient there are also multiple losses experienced on the way such as loss of hope, loss of a future, loss of levels of functioning, and loss of security and invulnerability. With an

extended period of time to consider these series of losses it is as though a range of grieving episodes occurs over and over before the patient's physical death.

However, this period of early mourning can also be viewed in a positive light and used accordingly, as noted by Chochinov, a psychiatrist specialising in palliative medicine:

Patients and family members should be encouraged to use this period to reconcile differences, extend important final communications and reaffirm feelings and wishes. It is a vitally important time that can often set the tone for the subsequent bereavement. Anticipatory bereavement is a common experience, which allows patients, loved ones, and health care providers the opportunity to prepare mentally for the impending death. (2000: 143)

I will take the concept of making meaningful use of remaining time forward in chapter 6 as I consider the role that palliative care has in aiding a positive adjustment to terminal illness.

5.8 Trajectories of adjustment to death and dying

The trajectory towards a positive reformulation of dying is understandably not straightforward. The classical Kübler-Ross (1970) model of (phases of) death and dying consists of five stages:

- denial of death
- anger
- bargaining
- depression
- acceptance

The Kübler-Ross model for describing the grief process is widely cited, but has also been subjected to criticism. The more usual criticism is of the 'stages' structure of the model. Schneidman (1980) notes that 'stages' oversimplify the process as it is more likely that patients may revisit stages or indeed process them out of sequence, according

to their individual circumstances. The stages of dying often do not unfold in temporal order but are overlapping to different degrees over time. To follow a staged model suggests the process of dying as something to be graded, and can potentially put pressure on patients and medics to resolve each staged response and move toward a so-called 'good' death and the final stage of acceptance. As I will show in the case study chapter 9, two patients can have very different attitudes, depending on a range of external and internal influences characteristic of the social death process.

Chaban (1998) has claimed that many of the patients Kübler-Ross interviewed were unaware that they were dying, which would impact on the anger and denial stages. Their diagnoses were apparently obscured by hospital staff, including Kübler-Ross herself. The focus of Kübler-Ross's research sample was on middle-aged patients, rather than an older patient group that is both more representative of the cancer population and more likely to accept a terminal diagnosis with a less negative attitude. I agree that old age carries a high degree of relevance here but would also suggest that this factor alone is not an exclusive means of easing the journey, something I will explore further in the case studies. In what follows, I will consider the effect of old age combined with a diagnosis of terminal illness.

5.8.1 Terminal diagnosis in old age

In the typical temporal order of life, many elderly people have experienced a gradual reduction of health and abilities, which predates any knowledge of terminal illness. A terminal diagnosis may be accepted differently by the elderly both because of gradual infirmity and because approaching death is not viewed as the end result of a medical diagnosis but rather as an inevitable fact of life. For elderly patients perhaps the losses

are not as profound; they have long since retired from a work role and may have already lost their spouses. Adult children bring reduced parenting responsibilities and many will have long since come to terms with decreasing physical functioning. Due to the fact that elderly patients constitute the majority of the palliative care group that I studied, I will pay special attention to the implications of old age in relation to social death and the aims of palliative care throughout this study.

Theories of lifespan development take account of the differences and priorities within different age ranges. Notably, Erikson's (1963) notion of the eight stages of growth focuses on the psychosocial development and 'crises', or challenges, at each stage. Old age, demographically categorised as between 55-65 years of age to death, is a stage labelled as 'integrity versus despair' (Erikson 1963: 268-9). Erikson's perception is that much of life is preparing for the middle adulthood stage and the last stage is that of recovering from it. In old age, integrity derives from the ability to look back on life with happiness and a sense of fulfillment in order to feel that life has meaning, whilst also feeling that a contribution has been made. Wisdom is gained as death is accepted as the completion of life. Alternatively, some individuals may reach this stage and feel despair at their experiences and perceived failures. They may fear death as they struggle to find a purpose to their lives or take a narrow view that, whatever they have or have not achieved, their actions and behaviours were correct.

I will now consider the specific emotional and practical effects of a terminal diagnosis across a range of ages and in each care setting. At this point during the discussion, I will make explicit some of the psychological processes that are known to impact on patients' attitudes and behaviours, including models of adjustment styles, grieving processes, the

relevant effects of old age, and the losses and stigma typically suffered by this patient group. I will then proceed to data analyses, in order to highlight certain of the fundamental losses that patients have already suffered as they present at the three settings.

5.9 Indicators of the process of social death and contextual differences in care settings

In any of the care settings the patient is likely to have experienced various stages of adjustment and will have faced a range of secondary practical and physical losses and effects. As I initially read through my data, focusing on the focal themes, I found that changes in patients' social and physical status were often expressed in terms of losses. These losses are described as they occur in the content of talk during the nurse–patient encounters and include:

Social changes:

- Loss of family role
- Loss of job
- Loss of autonomy
- Loss of past life
- Loss of relationships
- Loss of community/peer group
- Secrecy/collusion/protectionism, i.e. loss of open communication

Physical changes:

- Loss of health
- Loss of stamina
- Loss of healthy body image
- Loss of certainty in continuing to live a long life
- Physical decline

Many of these losses have the potential to contribute to a loss of identity or personhood and cause psychological distress. I have given an overview of each care setting in Chapter 2. Clearly, each of the care settings is physically different and has more or less priority attached to different aspects of care, whether talk-based or task-based. An interaction that takes place during a one-to-one encounter in a patient's home and that consists purely of talk will clearly differ from an interaction taking place in the institutional setting of a ward during task-based care with the likelihood of over-hearers. In the DTU, much of the talk was likely to be overheard or taking place in a group. The topic content of patient talk varied accordingly. I will consider the issues that were apparent within the data from each setting, although many of them could be evidenced across settings.

As discussed in chapter 4, the thematically-oriented analysis for this chapter will use a range of rhetorical devices in order to draw out the relevant features of the interactions. For the purposes of this chapter the priority is a discussion of the focal theme of social death.

5.9.1 Home care: Indicators of social death

At the point of first contact with the patient, the home care nurses are meeting an individual who is aware of his/her terminal prognosis. In this setting, with a greater amount of talk occurring at length and on a one-to-one basis, most of the topics listed on the previous page were discussed. In contrast to the case study chapters, which will also consider indicators of social death in interactions with two elderly patients, I will focus here on data from the youngest patient in the study who, it could be argued, will be likely to suffer the consequences of her disease and the social death process more

acutely than a person who has come to the end of their natural life in the usual temporal order of events. The patient here is a 30 year old female, Sarah, sharing a house with friends of the same age. I will consider the effects of her physical decline and loss of body image, secrecy, and the loss of relationships. Talk about aspects of physical decline and secrecy occurs regularly in other consultations as well as I will show in the case study chapters 9 and 10 (see also HCTRA3 146-152 128-130, HCTRA4 6-9, HCTRA5 365-369, 520-531).

5.9.1.1 Physical decline and loss of body image

Extract 1 (HCTRA 2) Sarah 30 years. *She shares a house with other young females, referred to as 'E' and 'M'. Sarah uses crutches due to reduced mobility in her legs.*

- 253 N: yes (.) is there anything that (.) they do for you (.) at all?
254 P: no (.) E E is very thoughtful unless she's like having a new depression for whatever reason she still sees M umm (.) I I come down and the kettle's full of water and she's very very thoughtful for little things like that (.) and she used to do things like that all the time when I was first diagnosed and then we went through those months when really I was fine I could do everything and like this morning E was last up last night and I got down and the kettle was full of water whereas usually I get down and there's not a drop in it and I have to go around (.) which doesn't bother me but

This extract is an example of how Sarah uses contrast to express physical and relational changes over time. The comparisons between how things were and how things stand now indicate the deterioration in Sarah's physical condition as well as deterioration in the relationship with her housemate.

At the start of the extract (253) the nurse voices her concern about the patient's ability to cope at home. Her emphatic intonation places stress on her comment 'is there anything that (.) they do for you at all?' Her use of the evaluative tag, 'at all', contrastively

implies that Sarah's housemates are *in no way* considerate of her situation. By using what could be termed an extreme case formulation (in the sense of Pomerantz 1986), the nurse invites Sarah to elaborate on her home situation, thus achieving the dual aim of gaining information for herself as well as giving her patient the chance to reflect on the practical difficulties of every day living when faced with reduced mobility. The deterioration of Sarah's physical functioning is obvious by her use of crutches. Her awareness of this is also indicated in the structure of her talk, i.e. her use of contrast to express changes on a temporal basis. Thus, for example, she reflects retrospectively on her previous physical ability, 'we went through those months when really I was fine I could do everything' (254), and compares this with her present status. This emphasises her current difficulties with basic tasks such as filling a kettle whilst having to use crutches.

Changes within her relationships with her housemates are also expressed through contrast. She notes the thoughtfulness of one of her housemates in assisting with household tasks, 'she's very very thoughtful', but then qualifies this thoughtfulness as linked to differences in mood, 'having a depression', and to changes over time, 'she used to ... all the time', implying that this thoughtful act is much less frequent now. The simple act of filling a kettle is a major task for Sarah, as is keeping herself clean.

Extract 2 Sarah (HCTRA 2)

- 256 N: what about the bathroom?
257 (.)
258 P: no they've [it's it's a phewph
259 N: [no problem
260 P: yeah there is a problem with the bathroom (.) the problem with the bathroom is it's more difficult for me to get into the bath now cos of this leg it sort of hurts to get into the bath (.) so I've had hardly any baths at all I smell atrocious I don't feel clean

Again the nurse initiates a question on a topic she knows will be of concern. The nurse's awareness of the difficulties likely to be faced by her patients is a key factor in addressing many, often very sensitive, concerns that may have been left unsaid and undealt with otherwise. Sarah appears to struggle, at first, to answer the question. There is a hesitation, indicated by a short pause (257), a denial, and then a total loss of words, 'it's a phewph' (258) before she laboriously constructs an answer. The nurse appears to want to help complete Sarah's sentence, 'no problem' (259), but has anticipated the patient's answer incorrectly. Sarah has taken a circuitous route to explain what is likely to be her main concern 'I smell atrocious I don't feel clean' (260). This is a devastating admission from a young woman, particularly as her cancer has affected her pelvic area. Later on in the consultation she is embarrassed at the prospect of an examination by the nurse:

Extract 3 Sarah (HCTRA 2)

438 N: those lumps in your groin do you want me to have a look before I go or?
439 P: I'm very smelly today
440 N: I think I can cope with that
441 P: if you can cope with that you can have a look ok

Lawton's concept of the 'unbounded body' is relevant here, as she has noted the breakdown of the body's boundedness is 'often accompanied by the emission of smells' (2000: 135)¹¹. Sarah will suffer the indignity of having to subject her nurse to repellent odours that have become rare in the wider deodorised, sanitised culture. The nurse mitigates the potential embarrassment by an understatement, which implicitly refers to her professional experience, 'I think I can cope with that' (440). Sarah responds with a

¹¹ Lawton (2000: 22,77,126-8, 135-7, 164) comments frequently upon the effect of odours. Upon entering the hospice she herself was struck by the 'nauseating' smells that often permeated the wards and the devastating effect it could have on patients and their peers.

repetition of the nurse's words, a signal of 'sharedness' (Tannen 1989: 52) that contributes to conversational involvement and relational alignment.

5.9.1.2 *Secrecy*

In order to avoid being stigmatised by the social taboos of death and dying, some patients choose not to disclose their prognosis for as long as they can. When patients are attending DTU or the in-patient unit for any length of time it is unlikely that they would be able to hide the fact of their diagnosis, if they would choose to do so. Whilst receiving care at home, however, away from the public arena, this fact is easier to hide. The following extract exemplifies possible repercussions of this. Sarah has not told her housemates that she has terminal disease, simply that she is ill. Her comments give some indication about her anxiety of revealing the information to her housemates, although she is struggling to manage her share of chores within the house or even self care tasks.

Extract 4 Sarah (HCTRA 2) *A is a housemate.*

226 N: that's the other thing we have to talk [about really
227 P: [yeh even if (*unclear*) because I was
telling E about it because I thought I thought well I don't want it to be a
big secret cos somebody's going to leave a message one day saying have
you filled in your forms and sent them off or something so I said well
look (*unclear*) and so I said to A look I'm going to need a ground floor
bedroom at some point but she made it fairly clear that she's not going to
move from her bedroom

The patient uses combinations of reported speech in her reply, moving between direct reported speech, 'so I said well look', self reported inner speech, 'I thought well I don't want it to be a big secret', and the indirect reported speech of her flatmate's response, 'she made it fairly clear' (227). These devices allow her to set the stage for the nurse to

share her opinions as she positions the argument from her own perspective. The contrast between her comments about her wishes not to disclose and the favours she needs from her friends indicates her difficulty. Although she says that her secrecy is eventually bound to be uncovered and that she has discussed this, she has, in fact, not yet told her friends. As a result, her request for the ground floor bedroom that she needs has been refused. This situation would be unlikely to occur if her friends had a full understanding of her situation. However, the moment that she tells all is the moment where she will lose her current identity, albeit that she has already declared herself to be ill. A terminal diagnosis in a young woman will mark her apart with the tragic aspect of one who dies before their time and will subject her to the gaze of sadness and pity.

5.9.1.3 Loss of relationships

Collusion and denial are often effective coping mechanisms but can lead to alienation of loved ones and relationship difficulties. In the context of the home care setting relationships are affected more directly by the disease process in the form of stigmatisation due to socially unacceptable symptoms. I will discuss this further in the case studies in section 9.3. In the following extracts, Sarah talks at length about her difficulties with her mother, who is fully aware of her diagnosis and has quite naturally been moved to search for increased contact with her daughter via phone calls, visits and presents, all of which are rejected by the patient.

Extract 5 (HCTRA 2) Sarah *In an extended narrative response to an enquiry from the nurse about Sarah's parents. Previous comments have reported recent arguments with her mother.*

328 P: and then we got past that and then I said well how about a compromise because she's got this thing now that she's not allowed to speak on the phone (.) and I said you are allowed to speak on the phone Mum I'm only

329 N: stopping the phone calls when (.) you've been talking about the weather
obviously as a fill in (.) [cos there's nothing left to say=
[mmm

The patient uses reported speech again to position her perspective. The disparity here, according to Sarah, is that her mother believes she cannot call to talk and yet Sarah tells her she can, although this is conditional and dependent on her mother being able to find something newsworthy or useful to say. Ultimately Sarah has control over the amount of contact and will reject her mother's efforts if they become mundane. Sarah appears to be placing barriers between herself and her closest family and friends in denial of her diagnosis and symptoms. The entire interaction during the visit has significant stretches of personal narratives, put forward by the patient and uninterrupted by the nurse as she listens and allows Sarah to express her concerns:

Extract 6 (HCTRA 2) Sarah

349 P: I said Mum this isn't very nice you know receiving these presents just cause I'm dying of course you're not allowed to say that to Mum so um (.) (*unclear*) and um then I said well that's what it feels like I said I feel perfectly fine and then every second week I'm sent down poorly presents (.) a carrier bag full of tissues (.) I haven't got a cold (.) why do I need a carrier bag full of tissues for (*laughing*)

Contrast and reported speech are again used to highlight how others are reported to perceive Sarah and how she actually feels. It is true that even patients with a terminal diagnosis may feel comparatively well, according to their base line level of symptoms, although the patient herself will probably find it difficult to compare how she feels now, even when reasonably symptom free, to how she felt when she was free of disease. However, Sarah maintains that she is dying but feeling 'perfectly fine' (349). There is further contradiction here with the fact that her mother, as reported by Sarah, is not

comfortable with talk of dying, 'I'm dying of course you're not allowed to say that to Mum' but is giving extra attention via presents and unwanted phone calls (extract 5). Sarah's rejection of the continuous supply of presents possibly relates to their significance as tokenistic reminders of her own sick role. She ridicules the gifts, which could be seen as a further rejection of them and her sick role, or simply as amusement at what she may view as an overreaction on the part of her concerned mother. Later in the interaction her use of rejection extends to include others' treatment of her illness, as she appears to withdraw from her mother still further.

Extract 7 (HCTRA 2) Sarah

- 335 N: is she coming down this weekend? (*refers to mother*)
336 P: (.) yeah (.) oh yeah yes (.) I told her on that phone call that I'd rather she didn't come the weekend after you know I said I've only been given one weekend off these visits since I've been diagnosed and bearing in mind that we only used to see each other once or twice a year before that time (*unclear*) then it's really difficult you know for me to suddenly know or have to have one weekly visits

The contrast here, between what used to happen in the normal course of events and the increased contact now sought by her mother again highlights changes that have occurred due to the illness and are again rejected by Sarah. It appears that the usual relational dynamics with her mother have changed in intensity. Her mother is likely to be strongly affected by the impending death of her daughter, subjected to anticipatory grief and struggling to cope in her own way. From the patient's perspective, however, her mother's concern is perceived as having a task-based orientation with extra responsibilities which need to be endured. She likens it to a work role as she comments, 'I've only been given one week off these visits' (336). Her choice of passive formulation gives a sense that she has no active role here and that the visits are imposed

on her. Furthermore, a connotative linking between ‘time off’ for good behaviour and the reduction of an unpleasant activity such as work suggests that the visits have become a burden. Her consistent use of reported and self reported speech to position her actions throughout the above extracts may indicate a realisation that *she* is doing something socially unacceptable in rejecting her mother.

5.9.1.4 Summary of home care setting

In the home care setting, then, it is already clear that this patient is experiencing significant threats to the ‘self’ of her previous existence. Loss of roles and loss of physical capabilities ranging from maintaining previous skills to simple acts of self-care are increasingly difficult. Relationships are strained by secrecy, collusion and the rejection of her mother’s attempts to care for her sick daughter. Embarrassment about evident symptoms and consequences of illness are also affecting relationships at this stage, all of this steadily contributing to her increasing isolation and social withdrawal. It is clear that the young female patient featured in the extracts above will need skilled help to progress to any level of adjustment. However, for help to be effective she has to be prepared to receive it, as I shall discuss in chapter 6 (extract 5).

As I have discussed previously, the trajectory of the illness will have compounding problems as patients draw closer to death and I focus now on the patients attending the Day Therapy Unit, annexed to the hospice.

5.9.2 DTU: Indicators of social death

Sudnow’s (1967) concept of social death focuses on the treatment of imminently dying patients in hospital settings and so does not transfer sufficiently to other areas of care

such as home care or the Day Therapy Unit. In the DTU, patients have varying ranges of functioning, some may still be driving a car and looking after themselves at home whilst others are becoming dependent on help and possibly approaching the need for in-patient care. As I have noted, I will follow Lawton's (2000) definition of social death (5.4) throughout this study in order to view patient losses from a perspective of changing patient identities.

I have discussed the loss of community or social networks experienced by patients as part of the process of social death (5.9). Transfer to an illness setting such as the DTU enables patients to reposition themselves amongst peers. It is well recognised by most professionals that, 'while good symptom control and psychological support can be provided by professional carers in the community, there is often an urgent need for peer group support' (Fisher and McDaid 1996: 147), or possibly 'friends for death' (Young *et al* 1999: 280).

The DTU is an institutional setting albeit with all the social 'props' (Goffman 1959) of a home. The philosophy behind the provision of day care is that when patients' usual roles are compromised and they and their families are struggling with the situation, it can function as a continuing line of support whilst enabling patients to remain at home. It is a setting where patients can become part of a new social group as insiders with mutual attitudes and norms.

Outsiders to the group cannot understand what it means to be a member and talk of outsider attitudes occurs regularly within the DTU setting, especially regarding the issues of collusion, denial and protectionism. The ability to maintain previous

relationships between family members is affected by the secrecy and adds to the social isolation of patients. Collusion is also allied to denial, which is often used as a coping mechanism. Denial is reactive and dynamic and, in the patients whose conversations I taped, never total. The patients know that they are dying, biologically, it is the how and the when that is often blocked out. I examine collusion, denial and protectionism with analyses in the following section.

5.9.2.1 Collusion, denial and protectionism

I will use this setting to explore how patients use and are subject to further acts of collusion between their selves and their family members. At this point in the disease stage it is very unlikely that friends and family are unaware of the terminal diagnosis. Collusion and secrecy are now likely to take the form of withholding symptoms or avoiding distressing topics of talk. Protection often takes the form of withholding information that may cause pain. Withholding information can occur as an action of either patient or relative and may be difficult to maintain. The family and the patient may repress their own grief to present a controlled front. This causes severe tension, which can drive a wedge between loved ones.

Extract 8 (DTU 6) David 40+ *Talking about previous night's television programme, a documentary following three terminal cancer patients.*

- 10 P: I think er I think er (.) did you watch that programme on last night
'Death'
- 11 N: I recorded I [haven't seen it yet did you?
- 12 P: [on cancer
- 13 P: my wife came in she said what you watching that for
- 14 N: mm?
- 15 P: my wife came into the room (*unclear*) watch it (.) she come in and she
said why are you watching that (.) cause we all die you know
- 16 N: mmm

David uses direct reported speech to convey the accusation in his wife's tone of voice by stressed intonation, 'what you watching that for?' Reproducing his wife's utterances by using mimicry allows him to present her comments subjectively (Baynham and Slembrouck 1999; Holt 1999). Seemingly, she feels that it is distressing enough to be experiencing the disease without the need to watch it in a documentary programme. David's justification, 'cause we all die you know' (15) is that death comes to us all. He positions his self along with everybody else; his implicit wish is to remain a member of the wider social group despite his diagnosis.

Despite this, David also clearly feels the need to identify and position himself amongst a peer group, as we see in the following extract. He explains his need to learn about other sufferers despite his wife's apparent concern that he should be interested. The nurse responds to David's comments and enquires further:

Extract 9 (DTU 6) David

- 39 N: so was your wife upset that you'd watched it?
40 P: yes (.) she was I said what? you know (.) doesn't upset me I just want just
curious see how people cope different you know (.) disabilities they have
(.) but one had a patch over her eye same as me (.) balance
41 N: yes

As part of a peer group David is likely to make self-comparisons and judgements about others within the same group, such as the people portrayed in the television documentary. Later in the same conversation David talks disapprovingly about another patient who is very depressed in mood. David has a teenage son and talk about him reveals how David, as far as his family is concerned, is using denial as a coping mechanism notwithstanding the needs of his son:

Extract 10 (DTU6) David

- 69 P: I'm not saying he would have survived beyond that but it would help I mean (.) for him and (.) for other people for his family as well don't forget his family have seen that (.) he's going home and being (.) his kids would see it (.) makes them down as well
- 70 N: yes
- 71 P: goes through you doesn't it (.) as I always try (.) in front of my son (*unclear*) I always (.) have a laugh
- 72 N: but does your son never say anything David?
- 73 P: no (.) just get on with life (.) but at the time when I had it (.) like I said (.) he coped (.) he just went on /what was he then he's fifteen and a half he's twelve he went on the computer every day (.) every day (.) on brain tumours and cancer (*unclear*) he knows more about cancer than the doctors I think (.) treatments afterwards and different side effects (.) and that's the way I think that's the way he coped you know
- 74 N: mm
- 75 P: comes in from school and we do tea you know and get on with it (.) that's what you've got to do

The unspoken collusion here between father and son means that his disease is not openly acknowledged or discussed, despite his son's obvious need for information. The nurse's question (72) potentially signals a disagreement with David's strategy here but she continues with a minimal response, 'mm' (74), as he gives his account of how his son copes. She does not contradict the David's means of coping at this point.

The following extract features further discussion of the 'Death' documentary. It proved to be a popular topic of discussion as patients were able to identify and compare with the peer group of terminal patients featured in the programme.

Extract 11 (DTU5) Catherine 50+ *Talking with a nurse in the communal sitting area.*

- 52 P: yes (.) cause she was saying how lonely she was with nobody there/it it's a lovely programme
- 53 N: mm
- 54 P: but my daughter rang me she said now don't you go watching that programme tonight (*unclear*) I want to see how other people get on you know

55 N: mm
 56 P: it was good very good (.) I'll get that paper
 57 N: yes please cause I have I've taped it so I am going to watch it
 58 P: mm
 59 N: yes (.) I didn't watch it last night because my husband was there and he
 wasn't very keen on [watching it so
 60 N: [no
 61 P: no men don't like things like that do [they
 62 N: [although (*other patient*) watched it
 and he said his wife came in and was quite angry that he'd watched it
 63 (.)
 64 P: see it's like my [family
 65 N: [yes (.) hmm
 66 (.)
 67 P: they don't like it do they (.) cause they have (.) to face our mortality

All the family members that patients talked about disapproved of the patients viewing the 'Death' documentary. In this case, Catherine's daughter rang beforehand in an attempt to dissuade her mother from watching the programme. Direct reported speech again imitates the daughter's tone of voice, the use of the imperative reminiscent of scolding a child, 'now don't you go watching that programme tonight' (54). In this way, the daughter seems to have reversed roles with her mother as carer. The loss of family role in this manner is indicative of the social death process, as the autonomy of the patient is lost through well-meaning but possibly misplaced advice from others. The relational alignment between patient and nurse is indicated by the interactional collaboration between nurse and patient, for example, when the nurse's talk of 'my husband' (59) and 'men' (61) is echoed by the patient's comments on 'men' in general. Aside from the gender alignment there is an implication here that 'outsiders', i.e. not nurses and not patients, have problems facing up to imminent death, 'they don't like it do they (.) cause they have (.) to face our mortality' (67).

It appears that the collusion initiated by relatives and patients to avoid talking about the disease is extended when symptoms and prognoses are also masked by the patient. In my data, the palliative care nurses often introduce family members into the conversation in order to monitor communication between family members, as I shall discuss in the following chapter. The elderly male patient, Colin, in the following extract has not discussed his death yet with his wife.

Extract 13 (DTU 1) Colin 70+ Talking with a nurse in the doctor's office.

- 176 N: are you worried about having to go back into hospital?
177 P: er no no (.) no no (.) like I said to the doctor I'd like to die in hospital
178 [if that's possible
179 N: [right
180 P: I don't want my wife [to
181 N: [right right
182 P: (*unclear*)
183 N: have you talked to her about that
184 P: no (.) I don't think so (.) I should
185 N: well it might be an idea [for her to talk about that because she might have
different ideas to you
186 P: [yes

For Colin, his awareness of the avoidance of talking about sensitive issues with his wife is evident from the tag, 'I should' (184). He potentially risks damage to their relationship by his well-meaning deceit. His self-reported speech, 'I said to the doctor I'd like to die in hospital' (177), reinforces my earlier discussion about the taboo nature of death (5.5), and illustrates how the taboo effect of dying makes it easier for Colin to disclose his feelings to a relative stranger rather than to his wife. He seems to have difficulty in talking to his wife about his wishes and is choosing to die in hospital to protect his wife, 'I don't want my wife to' (180). The nurse's seeming concurrence, evident from her positive affirmation (179) and the overlap (181) apparently aligns with the patient's wishes, thus making the suggestion, 'have you talked to her about that'

(183) seem less confrontational. The nurse further mediates the proposal with modality to position it as a sensitively placed plan without imposition, ‘well it might be an idea for her ... because she might have different ideas’ (185). Note here as well how the nurse presents the wife’s point of view with interactive embodiment, *her* and *she*. To some degree, it appears that the nurse is colluding with the patient’s wife to manage Colin’s denial of his wife’s right to express her own wishes. Equally, the following extract reveals David’s apparent difficulties in hearing his own prognosis, notwithstanding the fact that he requested it himself.

Extract 14 (DTU 6) David 40+ years.

- 53 P: you know (.) like the doctor told me when (.) Dr H in (*local oncology hospital*) she told me the first one after the operation (.) I asked I said (.) how long (.) have I got (.) said five years (.) average (.) I might have ten then (*laughs*) (.) I didn’t like it didn’t like her attitude
- 54 N: yes
- 55 P: a very down person (*indistinct*) I came out I wanted to cut my throat (.) I haven’t seen her since thank God I don’t want to see her
- 56 N: yes
- 57 P: made me depressed and that’s not me see
- 58 N: mm
- 59 P: you know (.) sometimes I still think of that I think oh I’ve had two years I’ve got three years left sometimes it comes in my mind (.) I try and get it out of my mind then (.) you know I don’t think being positive all the time helps but it does help a bit
- 60 N: I’m sure it does yes

David’s account is noticeably rich in the use of reported speech devices (53, 59). He constructs the scene from his own perspective to reflect and address his concerns and priorities. He uses reported speech to project the voice of the doctor, as well as his own reply and internal thoughts. He has asked the question, ‘how long have I got’ (53). David persists in maintaining a positive stance, when the doctor says that he has five years left, as an average figure, as he counters with ‘I might have ten then’ (53), and

scorns the doctor's 'attitude', 'a very down person (*indistinct*) I came out I wanted to cut my throat (.) I haven't seen her since thank God I don't want to see her' (55). Nevertheless he has, in fact, absorbed the stated time scale, 'I've had two years I've got three years left' (59), countering the factual knowledge with avoidance and positivity.

5.9.2.2 Summary of DTU setting

In the DTU setting there is evidence of many of the factors contributing to social death (listed in section 5.9). My analyses in this setting have explored patients' losses of family roles, autonomy, relationships and healthy bodies. I have also considered occurrences of collusion and protectionism by patients and family members.

However, DTU has been described as a 'haven' (Fisher and McDaid 1996: 5). In this setting, patients can talk amongst themselves and with nurses about their families' reactions to their disease and their concerns and worries about their loved ones. It is a space where they can be themselves amongst their peers. The social network that they maintained previously, when they had a foreseeable future, is temporarily replaced by one consisting of others in the same position as themselves that they can identify with. This acts as a countermeasure to the gradual loosening of social bonds that they may have started experiencing as a result of illness progression. It is noticeable here that the nurses are finely tuned to the needs of the families and constantly and sensitively draw the topics of conversation towards addressing the needs of both families and patients. I follow this discussion with an account of the institutionally oriented setting of the in-patient unit.

5.9.3 In-patient unit: Indicators of social death

Having looked at the issues confronted by patients as they present to the home care and DTU settings, I now move on to the care setting that, by its very nature, is most threatening to the personality, identity or 'self' of the patients. The in-patient unit accepts referrals for patients that require a high input of specialist palliative care. Often patients are very ill and require a great deal of medical and personal care. The setting, despite comprising a homely day room furnished with plants, comfortable chairs and a television set, is undeniably clinical and cannot mask the institutional nature of the setting. Patients rarely display many personal effects in the small spaces that are available to them, with the exception of get well cards that highlight even more strongly their patient role. Their ability to be seen as social individuals is obscured by the institutional effect. In addition, as patients present to this setting they are often experiencing severe symptoms such as pain, diarrhoea and vomiting, constipation, or confusion, and many of them need total care. The varying degrees of loss of independence and the need to accept help are a major threat to the self of the patient as it was before the illness episode.

In this site, the care will be shared between teams of nurses, operating on a shift system with teams consisting of both qualified and unqualified nurses¹². The unqualified nurses will perform most personal care tasks while the qualified staff attend to all clinical events, administration and record keeping and the majority of liaising with other professionals and relatives. The nursing care is task-based, as opposed to the therapeutic interactional model of the previous two settings. Most conversations, as can be seen in

¹² I will, throughout the study, differentiate between trained and untrained nurses at the level of the transcript N = qualified nurse. AN = untrained auxiliary nurse.

the demographic table in Chapter 3.5.4, occur with patients during some form of care procedure, clinical or personal. As a result, many of the patient contributions during interaction are minimal and spaced around the nurses' constant commentaries on how they are about to approach the patient or what they are going to do next. As James (1992: 498) comments, 'With physical tasks dominant ... at times the 'total care' the staff were so anxious to give became expendable and had to be dropped to deal with what were seen as the more immediate, physical needs'.

As I shall demonstrate in this and the following chapters, the taped interactions from this setting generally consist of sequences of praise, encouragement, and banter or verbal play. There are few interactions in my data from this setting that contain the social talk with nurses as it occurs in home care and the day therapy unit. This, in itself, together with the contextual information provided above, offers some insight into the degree of social death that patients are likely to be suffering in this setting.

5.9.3.1 The institutional effect

Although socially situated talk occurs rarely in the data from the ward setting, some instances can be found, usually occurring around care tasks.

Extract 15 (IPU 4) Beryl 70+ *During a bed bath.*

- 64 AN: if you had your CDs or records what did you used to collect Beryl? (.)
anybody in particular (.) did you have favourites?
65 P: me?
66 AN: yes (.) who did you like to listen to
67 P: I don't know what I'd say

This extract and the following are temporally based. The nurse uses the past tense for both speaking turns, suggesting that not only is collecting records a discontinued activity but also that the pleasure of listening to them is a thing of the past. By doing this she has treated the patient as though she has already stopped living an active life.

Extract 16 (IPU 7) Jean 70+ *During an assisted bath.*

66 AN: how many children did you have Jean?
67 P: me? (.) two (.) two husbands and two girls

The choice of the past tense in the above extract would be unusual in a normal context; it would be more natural to ask ‘how many children *do* you have’. Again, the past tense suggests that the nurse’s perception is that something has ended, as though the patient has already dispensed with that role. Notice as well in both extracts 15 and 16 the response of the patient when asked a socially-oriented question. They both respond with ‘me?’ as though they are surprised and need to clarify that this type of question is directed at them. This could be seen as an indication that personal questions are infrequent in this situation where the patient role may supersede their social identity.

Clothing can function as an indicator of social identity and in the following extract, the nurse makes a comparison between patients’ nightwear:

Extract 17 (IPU 11) Elin 70+ *During an assisted wash.*

80 AN: I think you’ve got a similar nightie to Phyllis next door haven’t you
81 P: (*unclear*)
82 AN2: I think so (.) that’s the problem you know with Marksies they’re so nice that everybody ends up (.) I think at one time we washed a ladies ward like we are now and by the time we finished I think we had three ladies in the identical and colour nightdress and the other lady had the identical nightdress on but it was a different colour (.) all in the same room one morning

This chitchat that could be seen as socially situated could also have the opposite effect. Whereas the talk shows that the nurse notices Elin as an individual and makes positive comments about her clothing, she follows with chat about the similarity between patients' nightdresses. The patients have been positioned as jobs of work, 'we washed a ladies ward like we are now' (82). Each individual patient is referred to in the collective as a 'ward', and the description of the patients all washed and dressed in the same nightwear could give an image of institutionalisation and loss of identity. The in-patient unit is an institutional setting in which the majority of patients choose to wear night clothes, although they are equally allowed to wear day clothes if they so desire. However, in my experience, this option is rarely verbalised by nurses, and patients are unlikely to wish to deviate from the perceived norm. Clothing and appearance are a major part of an individual's personal expression and when this is reduced to the 'uniform' of a patient, perceptions of personal identity are likely to change. Nurses are also in uniform making the differentiation between carers and patients more extreme.

Extracts 15-17 are good examples of how social death can be evidenced in this setting. However, other considerations should be attended to here. There was little evidence of personal small talk in the IPU data and to consider the few extracts that were available in more detail must involve an exploration of the circumstances of the interactions. In each of these cases the nurses were talking at the same time as undertaking intimate care of the patients. Small talk, in these situations, can function as a means to gloss over the potential embarrassment to the patient, but the distraction of working at the same time may mean that nurses are paying less attention to the words that they are delivering, which, of course carries the potential for insensitive expression. N. James (1989) has noted, as has Waugh (1992), that older auxiliary nurses (as featured in the above

extracts) are likely to be particularly sensitive to the emotional needs of patients, due to skills gained through the life experience of raising families and dealing with personal trauma. From my data it is only possible to capture auxiliary nurses' interactions in the in-patient unit and extracts will be analysed in each of the following three chapters.

5.9.3.2 Summary of in-patient unit setting

The very real risk to patients' identities in a ward setting then is that they are one of many. Patients may be seen as a job of work for the nursing team, which, combined with their nightwear 'uniform' results in a loss of social signals. They are most likely to be recognised clinically, by their disease or symptoms and the 'gaze of the clinic' (Foucault 1973), rather than by any social or personality driven signals. As I have shown, as patients conform to the uniformity of their group, they themselves are sometimes surprised to receive nurses' questions regarding the personal or social domain.

5.10 Summary of Chapter

I have discussed the concept of social death by examining social constructions of dying and their effects on individual identity. I have focused on patient and professional perspectives in the palliative care setting and considered styles of adjustment to a terminal diagnosis, including the notion of anticipatory grief.

I have shown how, in the three different palliative care settings the patients featured in my study present a range of factors associated with social death and loss of personhood, and also how these issues may be context sensitive. The three settings can be seen to cover a range of issues that are often particular to each but at the same time are relative

to the stages of disease and adjustment that the patient is experiencing at that point of his/her life.

In the home care setting, the focus on just one young female patient revealed her difficulties in accepting the physical and relational effects of her diminishing health. She is at a stage where the process of rejection and withdrawal from social and family ties is gradually becoming evident. This reflects how she and others in the same position begin to split from the wider social group as a consequence of their disease and changing identities.

I have discussed that, upon attending DTU, patients are both using and subject to collusion and protectionism by and against family members. Much is left unsaid and open awareness about prognoses and symptoms is difficult to share with family members. A great deal of benefit may be gained in this setting from peer and professional support and the ability to talk openly without fear of hurting loved ones. At this point it appears that patients are keen to identify with individuals cognisant of their situations. A new identity is emerging specific to this group, with relatives and 'outsiders' kept distant from total knowledge of all that the disease entails.

The in-patient unit carries a different set of difficulties. The threat to individual identities is compounded here by both the institutional context and the amount of personal care that patients need. There is far less therapeutic talk in this setting as much of the nursing contact is task-based. Very little talk is socially situated and, as I have shown, when it does occur it can be overshadowed by the clinical and institutional

mode. This is also the setting where patients are most likely to experience the 'unbounded body' noted by Lawton and the subsequent threats to personhood.

Having reviewed the presentation of patients at the three settings I will now examine how hope and healing, the counterpoints to the detrimental effects of social death, are evidenced discursively across each setting.

Chapter 6: Trajectories of hope in the context of palliative care

6.1 Chapter overview

It is evident from Chapter 5 that as terminal disease progresses many patients suffer a gradual loss of function, roles and attributes that previously were an integral part of their social identities. As a result of both their own and their social contacts' joint construction of a different self, they may gradually disengage from the life they knew before and the social network that has supported them. Patients are therefore marginalised from mainstream society and unable to perform previous social roles and functions. Unlike the rest of society, they are unable to deny their mortality in an uncertain but optimistically viewed future and must be confronted by the certain fact that they will die within a temporally uncertain but predictive timescale. They have little or no future and subsequently are unable to use the resources of an unlimited futuristic hope in the way that the rest of society can. The ability to rediscover hope and new meanings in life can be seen as the antithesis to the social death process and loss of identity.

Patients with advance notice of a terminal diagnosis, as opposed to sudden death or death as the result of an acute illness, are in the dubiously privileged position of being able to prepare for death. Their time, expectations, and physical worlds are very much reduced, resulting in an intensity of focus on the issues and topics that remain open to them. This can have negative implications, as discussed in Chapter 5, or can alternatively lead to a positive adjustment when a different perspective is applied. In this chapter I will examine the concept of hope and what this can mean to the palliative

patient, as well as the different facets of hope and how they can be applied within the palliative care setting (6.2). Much research has been carried out into the range of coping strategies that patients use to manage the immense stress and significant threats to their previous identities during this time, and the importance of maintaining hope is fundamental to this adaptive process. Following this, I will give consideration to the nurse role in fostering hope and a brief discussion of listening skills (6.3)

I will also discuss the notion of healing in the context of palliative care, not in the curative sense, but as a means to reduce suffering (6.4). The negative effects of social death may be countered if patients are enabled to 'feel better'. If patients are able to find meaning in their lives and pleasure in the time they have remaining they will be able to adjust to their terminal diagnosis more easily and overcome many of the difficulties deriving from the process of social death, which were discussed in the previous chapter. The case study chapters 9 and 10 will further illustrate the factors involved, based on full-length interactions with two patients and the same nurse.

As I have previously discussed, the vast majority of palliative care patients are elderly, consequently there is a bias to the patient population. With this in mind, and also with regard to Erikson's (1963) life stages as discussed in the previous chapter (5.8.1), there are certain issues specific to this age range, the implications of which are discussed in section 6.5.1. I will examine how elements of rehabilitation are achieved discursively in the palliative care setting (6.6, 6.7, 6.8). In doing so, I will analyse extracts of interactive work between patients and nurses as nurses attempt to construct positive orientations using acknowledgement and praise and encouraging reformulations of difficult situations. As with the previous chapter, I will divide my attention across the three care

settings on the basis that although many of these issues will occur across settings there are those that will be especially relevant in the context of each setting.

6.2 Hope in the terminally ill patient

Hope is an important element in the psychological management of the dying process. Lin and Bauer-Wu (2003), using 43 primary research studies, undertook an integrative literature review of research on psycho-spiritual well-being in persons with advanced cancer. They concluded that prognostic awareness, family and social support, autonomy, hope, and meaning in life all contributed to positive psycho-spiritual well-being. Their review of the hope element of these studies suggested that changing one's outlook on life and the future and living with meaning through self-transcendence were significant factors. I will take these notions up within this chapter.

A conflicting view is expressed by Schofield, Ball, Smith, Borland, O'Brien, Davis, Olver, Ryan and Joseph (2004) who conducted a longitudinal study of non-small cell lung cancer patients to assess their approach to life and the effect this had on their disease progression. They found that an optimistic outlook had no effect on the temporal outcome of the disease, which typically has a short prognosis. In fact, they noted that the findings suggested that encouraging cancer patients to remain positive about their illness might be an extra psychological burden and make them feel reluctant to talk about any distress or anxiety. They did, however, note that a shift in focus to less aggressive forms of cancer may have produced different results. The publication of the article provoked a considerable response from cancer sufferers who believed that the researchers had taken away their hope (Chowka and Sawyer 2004).

Hope in palliative care is not concerned with cure but is built on the belief that better days or moments can come (Ballard, Green, Logston 1997; Flemming 1997; Benzein, Norberg, Saveman 2001). Herth's (1990a) study involved 30 terminally ill patients and found that the meaning of hope was revealed as 'an inner power that facilitates the transcendence of the present situation and movement toward new awareness and enrichment of being' (Herth 1990a: 1252). The study showed that the presence of aims such as specifically personal targets, including the relief of pain and the ability to manage daily living activities, or wider wishes that accounted for the needs of their families, enabled hope-fostering. When death was imminent, achieving inner peace and rest was what patients aspired towards.

Seymour discusses Peräkylä's (1991) study of interactional practices and identity as patients approach death in the hospital setting:

Peräkylä applied the concept of 'frame' to an analysis of the way in which, through interaction, hospital staff achieves a transformation of 'curative' hope to palliative hope within hospital wards. He showed how, as the hope that a patient will be cured diminishes, a skilful slanting in conversation achieves a different emphasis. The patient becomes someone who will 'feel better' even though they may not 'get better'. (Seymour 2001: 14)

Moreover, Peräkylä argues that 'all variants of hope work are linked to the maintenance of the legitimacy of medicine in relation to the death of the patients' (1991: 407). In this way, 'hope work', in his terms, reinforces the ability of doctors and nurses to improve the situations of patients facing difficult circumstances thereby sustaining hope. These actions are not only for the patients' benefit. Walter (1994) argues that 'hope work is done for everyone's sake' (1994: 135) noting a nurse's comment that, 'it's all about

sustaining the moral order. To live in a social world without hope, without a future, is difficult' (ibid).

However, in order for patients to be receptive to hope-fostering interventions there are other issues that need to be addressed to facilitate an effective delivery. Herth (1990a) has identified three obstacles to hope in terminally ill people:

- abandonment and isolation
- uncontrolled pain
- devaluation of personhood

Leaving aside the clinical aspect of pain control, it is clear from the previous chapter that isolation and devaluation of personhood are major characteristics of this patient group and the threat to maintaining hope is significant. In undertaking psychosocial care of patients, the use of hope-fostering strategies is an intrinsic part of the nurse's role.

6.3 The nurse's role in fostering and maintaining hope

Kinghorn and Gamlin (2001: 14) note that in the context of palliative nursing, 'the alleviation of distress is synonymous with achieving hope for a better quality of life'. The responses of nurses and medics then are essential in maintaining the delicate outlook of hope that is so necessary as a coping mechanism. Herth (1993) conducted a longitudinal study on carers of terminally ill people using interview and questionnaire instruments and applying a content analysis of hope-fostering and hope-hindering categories. She found that a common theme which hindered hope was the lack of a sense of 'presence', that is, an individual that can listen to and attend to the physical and psychosocial needs of the dying family member. She comments that 'hope as a resource

is dynamic, evidence of hope in one person supports, maintains and sustains hope in others' (ibid 1993: 560). The role of the nurse in fulfilling these needs is crucial. Byock and Corbeil note that:

Experienced nurses recognize that these developmental opportunities not only can be preserved, they can also be nurtured. People can be helped to identify the things that matter most to them now during this concluding phase of their life. Are there important things that they feel a need to say to another? Are there things that would be left undone if they were to die suddenly? (2003 online)

Nurses may be able to help patients address issues and regain control whilst searching for meaning in their illness. Therefore, although the physical course of disease is relentless, the experience of the illness may be altered. Rousseau (2000), a palliative care practitioner, has observed that hope-fostering interventions by health care professionals can include:

- a. Controlling symptoms
 - b. Providing assistance with practical goals
 - c. Fostering interpersonal connectedness
 - d. Affirming individual worth
 - e. Identifying personal attributes
 - f. Supporting spiritual beliefs
 - g. Encouraging humour and lightheartedness, when appropriate
 - h. Facilitating uplifting memories with life review
- (2000: 118)

Herth (1990a) identifies seven factors to foster hope:

1. Having meaningful relationships with others (or at least one other)
2. Having attainable aims
3. Having a spiritual base
4. Personal attributes

5. Lightheartedness
 6. Uplifting memories
 7. Affirmation of worth
- (1990a: 1254)¹³

These categories overlap significantly, both sets highlighting the practical and psycho-social needs of an emotionally compromised individual. For the purposes of this study I will not consider those categories that are mainly linked to the physical care of the patient, for example, by symptom control, but will take up those that are achieved discursively.

The categories of affirming worth (d. and 7) and life review (h. and 6) will be discussed later in this chapter and taken up for analysis in chapters 9 and 10. The importance of relational attachments (c. and 1) in fostering hope will be discussed in this chapter and throughout this study in respect of both the social networks and holistic care of the patient and the relational alignment between patient and nurse across the three care settings. Recognising personal attributes (e. and 4) is intrinsic to this alignment, as is the ability to properly see the patient for the person that they were and have become. The identity status of the patient is, of course, essentially linked to the focal theme of social death and I will pay particular attention to this throughout the remaining chapters.

Lightheartedness and laughter are important as hope fostering categories, as a coping strategy, as an indicator of identity, and for relational bonding. Herth's study of 14 terminally ill patients concludes that 'humour is essential, if not even more essential,

¹³ Herth's (1990a) American study has been replicated in the U.K. context in a study that supports the original findings (Buckley and Herth 2004).

during the terminal phase of an illness than at other times during illness and health' (1990b: 40). The author comments that more exploration of the nurse's role in supporting humour in palliative care needs to be undertaken. Due to the multifunctional nature of laughter and lightheartedness (g. and 5) in the context of palliative care I will dedicate a separate chapter (chapter 7) to its analysis.

6.3.1 Listening skills

I divert slightly here to reflect on a skill that is needed in order to facilitate all discussions at the end of life. Nurses need to be able to listen, to allow patients to talk and express their feelings. This section gives a brief overview of the listening skills that will enable patients to enter into dynamic communication with their nurses.

Listening skills are paramount as nurses process what patients are saying. Ryan, Schofield, Cockburn, Butow, Tattetsall, Turner, Girgis, Bandaranayake and Bowman (2005) review active listening as one aspect in their study of the recognition of psychological distress in cancer patients. They note that active listening takes account of verbal and non-verbal behaviours and aims to understand these behaviours in the context of the patient's life and circumstances. Non-verbal communication is also considered as a potential signal or cue of distress (cf. Cohen and Alpert 1981, Robbins *et al* 1994, cited by Ryan *et al* 2005). Active listening, they comment, involves 'using eye contact, having an attentive posture, and facilitating the patient's disclosure through behaviours such as nodding and making noises of agreement or encouragement' (Ryan *et al* 2005: 11). Active listening is a taught concept in palliative nursing practice with

prescriptive suggestions, as the following extract from an educational worksheet¹⁴ demonstrates:

Active listening

This is not just paying interest, but demonstrating that you are listening by:

Keeping eye contact

Feeding back eg. "So, tell me more about this pain."

Reflecting eg. "This seems to be making you anxious..."

Summarising eg. "Let me make sure I've understood, your main problems are...."

Open body language ie. not hunched over a desk with little eye contact.

One aim of this activity, as described above, is to check and clarify speakers' meanings. It is known that listeners do not process everything; they listen selectively, according to the purpose of the task. This, in turn, determines the type of listening required and the way in which listeners will approach a task. As I have noted (4.2), Cheepen (1988) defines talk as interactional or transactional. Much listening research is within the field of language teaching. Richards (1990), for example, expands Cheepen's notion in his discussion of the difference between an interactional and a transactional purpose for communication as a *dynamic* process, which takes account of how participants hear and receive talk. Interactional use of language is socially oriented, aimed at satisfying the social needs of the participants through small talk and casual conversations. Interactional listening is described as highly contextualised and dynamic, involving interaction with a speaker. A transactional use of language, however, is used primarily to communicate information in a one-way delivery and therefore requires accurate

¹⁴ Taken from an online worksheet (Help the Hospices 2006)

comprehension of a message with less opportunity for clarification with the speaker. Interactional listening can thus be likened to the active listening techniques employed by palliative care nurses.

Having discussed hope and the nurse's role in the context of this study I will now take the concept of hope a stage further as I discuss the notion of healing in the palliative sense.

6.4 Healing versus cure: Transcending suffering

With the advent of palliative care as a medical specialty there has been an increasing focus on the psychological care or rehabilitation of the terminal patient. The emphasis is on the alleviation of the patient's psychosocial distress and the relief of suffering rather than curative clinical interventions. Suffering can be seen as the basis for transcendence and also as a condition resulting from the social death process. Cassell (1991: 32) defines suffering as 'the state of severe distress that is associated with events that threaten the intactness of person'. His concept of personhood is inclusive of a number of dimensions that work together to form an individual's sense of self. The dimensions include the physical self, the mind, the past, family of origin, present family, culture, ethnicity, spiritual beliefs, political beliefs, family roles, roles at work and organisations, preferences, aversions and habits. It is the sum of these facets of one individual that need care and attention in order to lessen distress and the threat to identity. Nurses, as has been mentioned, need to be able to 'see' the person as a whole being and not simply as a patient. Cassell notes that:

Recovery from suffering often involves borrowing the strength of others as though persons who have lost parts of themselves can be sustained by the personhood of others. (1991: 44)

The notion of the 'other' can also be seen as a recompense for the loss of control of self. The role of the other, whether they are nurses, other patients, or members of the regular social group, gives terminal patients a resource that they may draw upon as a comparison to assess what is worth living for. In the following sections, nurses can be seen to facilitate the peer support element that will become clear in the DTU setting. Cassell offers two other aids to restore aspects of personhood, i.e. 'meaning' and 'transcendence' (Cassell 1991: 43). He likens 'meaning' to karma where suffering relates to past behaviours, and sees the need to contextualise the occurrence of disease as follows:

It is more tolerable to for a terrible thing to happen because of something one has done-and even suffer the guilt – than be it simply a stroke of fate; a random, chance event. (ibid: 45)

Maybe in this way, persons can assume some level of control over their illness rather than be overwhelmed and tormented by the unfairness of a chance occurrence. In the same vein, it is common for patients to query the trajectory of the curative treatment that they have received prior to a terminal diagnosis. Patients agonise whether every possible avenue towards a cure has been explored¹⁵ and nurses are well used to explaining the clinical reasons for the choices made.

Transcendence, according to Cassell (1991: 43), is about locating an individual in a 'larger landscape', not necessarily religious, in order to reduce feelings of isolation and to feel bonds with other people and the world we live in. These are valid points and well evidenced in my data corpus. In section 6.6 I will show the importance of physical surroundings, particularly to patients that are still managing at home, whilst in section

6.7 the need for patients to make self-comparisons with others is discussed. The importance of appreciating and seeing is, as Nelson (2000) eloquently comments:

A rare gift, and yet most of us, most of the time, look with a superficiality which robs all creation of its wonder. Dennis Potter described to Melvyn Bragg the sight of a plum tree in blossom outside his window. His seeing is made acute by the fact that he knows he will not live to see another spring. '...looking at it, instead of saying...oh, that's nice blossom...looking at it I see it is the whitest, frothiest, blossomest blossom that there ever could be, and I can see it.'(Potter 1994) This intense quality of seeing is a kind of seeing in depth, a kind of insight through which hidden truth comes to light. (2000: 37)

It is this kind of acute appreciation and intensity of seeing that patients and nurses alike need to employ to see past the disease and appreciate and share their own lived experiences.

Byock and Corbeil (2003) note:

A sense of meaning about who one is pervades a person's experience of self. A sense of meaning serves as a meshwork on and through which the process of personhood is woven. Damage to this crucial dimension of self inevitably causes suffering, as if personhood were unraveling. (2003: online)

As I have discussed in chapter 5, the care beyond cure trajectory consists of a search for meaning in the illness experience. To cite Byock and Corbeil once more:

People confronting the last phases of living report a new sense of wholeness and well-being despite progressive decline in function, the loss of roles and the loss of relationships. Herein lies the essence of the phrase '*healing versus curing*'. (2003 online) (original emphasis).

If we consider curative treatment as a biological, clinical event then healing, in this context, can be seen as its substitute. Healing can be seen as a way of learning to live with the terminal illness where acceptance will also bring peace of mind. The ability to

¹⁵ e.g. DTU1 346-355

take a positive view and appreciate the important things that are left in life also leads to the possibility of spiritual growth. As I will demonstrate, nurses are able to help patients find peace of mind by attending to family issues, encouraging patients to take a positive view of themselves and their situations, giving information to allay doubts and fears, and encouraging engagement with the world that is left available to patients. In the following section I will consider the process of rehabilitation that may be seen as the vehicle for initiating hope and healing.

6.5 Rehabilitation in the context of palliative care

The concept of rehabilitation in this setting may at first seem contradictory. However, as I have argued, this process is not related to curative measures but rather to achieving an improved quality of life. Hockley and Mowatt (1996) provide the following description of rehabilitation in palliative care:

The skilled help given to enable a person and their family to re-adjust to a situation that is unlikely to remain static for more than a few weeks at a time, because of progressive, far advanced disease. Such help involves not only the expert control of distressing physical symptoms, but the exploration of strengths/coping strategies in relation to the patient's emotional/psychological/spiritual health. The outcome of such assistance alongside specialist therapies is designed to affect positively the quality of life, making the time lived worthwhile. (1996: 14)

To achieve a level of peace of mind, patients need to undertake the adaptive process of rehabilitation. Not all patients are prepared or equipped to attempt to make changes and may prefer to resort to other coping strategies. The use of defence mechanisms such as denial, suppression and other negative devices by an individual who is pessimistic, passive, submissive or self-blaming will lead to a difficult experience and increased emotional distress (Weisman and Worden, 1976-77; Worden and Sobel 1978, cited in Livneh 2000). These are patients who are entrenched in the process of social death. In

order to help such patients, nurses need to give information and take action to reduce uncertainty. They also need to use active measures to promote stability and enhance the meaning of their patients' lives. A positively aligned relationship with the patient will be important for this aspect of care. Byock (2002) also notes the importance of what he terms 'bearing witness', or the encouragement of life review when caring for dying patients:

We have the capacity to bear witness, metaphorically saying to the other, "We will bear witness to your pain and your sorrows, your disappointments and your triumphs. We will listen to the stories of your life and will remember the story of your passing". (2002: 283)

Bearing witness, or listening to patient narratives, may not be an obligation in the same sense as other fundamental components of end-of-life care. However, it offers the potential for creating or strengthening the nurse-patient alignment whilst being of significant value to the patients involved. As I will show throughout the following chapters, the home care nurses are especially accommodating in this respect, largely due to their willingness to allow for and listen to patients' extended personal narratives alongside the medical agenda. McIntyre and Chaplin reinforce this perspective, which also reiterates the hope-fostering categories listed in section 6.3:

Affirming the patient's worth through facilitating life review, exploring perceptions and experiences, and exploring avenues of belief and spirituality promotes a sense of autonomy and self-respect. This will allow the individual to see that, despite their dying, their life has purpose, meaning and a sense of value. (2001: 132)

The use of life review seems particularly appropriate in elderly patients and in the following section I discuss how this strategy can also be seen as a usual function of ageing.

6.5.1 Life review and rehabilitation in the context of old age

It has been suggested that the process of hope differs in older patients. Duggleby and Wright (2005) undertook interviews and used a grounded theory approach to examine the ways in which older palliative patients live with hope. The participants defined their hope in the form of expectations such as not suffering any more and having a peaceful death. In order to live with hope they undertook the social process of the transformation of hope. The researchers defined this process as an acknowledgement of life the way it is, searching for meaning, and positive reappraisal. This view echoes the non age-related findings of Lin and Bauer-Wu (2003), previously discussed (6.2). However, although age was not a variable in the 43 primary research studies that were examined by Lin and Bauer-Wu, it is likely, as per national statistics, that many of the study participants were in the over 65 age bracket.

Life review can be seen as a form of personal evaluation when death is imminent and occurs in the normal temporal course of events during old age. Psychologists view the process as the final life crisis of persons reaching 65+ years. According to Butler (1963), as individuals realise that there is limited time remaining to them, they will examine the life they have lived to determine whether they feel their life was a success or a failure. Erikson (1959) proposes that the critical factor in accepting death is an individual's acceptance of their personal life experience. An acceptance of a life lived well is an important preparation for death which will reduce fear and, as Butler (1963) notes, may account for the wisdom and serenity that is often seen in old age and in my experience in terminal illness. I will explore this concept in more detail in the case studies to follow.

Old age was historically defined as post retirement age of 60-65, an age that the greater part of the population would never see (Thane 2000) and this categorisation remains, as is evident from the eligible age for drawing state pensions, although a raising of the age limit has recently been under consideration. Old age can be viewed alongside terminal cancer as a stage before death. The vast majority of palliative care patients are elderly and so in many cases may be better equipped to deal with a terminal diagnosis. With increased disease protection, treatment and medical technologies, thoughts of death are far removed from the majority of younger people's concerns. In old age, however, as Howarth notes, the acceptance of a terminal disease may be a simpler process:

For elderly people, however, because the modern 'good' death is thought to belong to old age, this final rite of passage becomes a scheduled rather than a nonscheduled one. That being the case, hospice care is largely viewed as superfluous to their needs as they slip into an awareness and acceptance of mortality. The fact that most people generally spend a lifetime avoiding thoughts of death and dying means that they do not know 'how to die'. In old age, and facing their own death and the loss of those they love, they are unlikely to be in a position to control the process of dying and to think of death in an 'accepting' and 'enlightened' fashion as the completion of the journey of life. (1998: 688)

However, for those individuals who assess their life to be a failure, the life review process is a difficult process which, according to Butler (1963), produces psychopathological manifestations in the form of guilt, depression, and anxiety. At its worst, Butler (1963: 269) notes, 'it may involve the obsessive preoccupation of the older person in his past and may proceed to a state approximating terror and result in suicide'. I will take up this concept again in chapters 9 and 10 but firstly I will consider various aspects of adjustment across the three settings.

6.6 Home care: Location and appreciating the here and now

When nurses visit patients at home, they are able to see them in the context of their own living environment, whether this is their own home or whether they have moved on to the supported care of a nursing home. Consequently, with patients' lives on display, as it were, talk of their environment occurs here that does not occur in the other settings to the same degree. Patients are more likely to feel a sense of control over their own environment and subsequently, as Bunston, Mings, Mackie, Jones (1995) conclude, they feel more able to hope to control their cancer.

The interaction in extract 1 occurs during a home care visit in a nursing home. The patient, Olive, has recently had to make the difficult decision to move to supported living as she was no longer able to manage independently at home. Her view of familiar landmarks is an important factor in her hugely reduced physical world, both aesthetically and as a connection to her previous life. The nurse is clearly well aware of the patient's needs and concerns as she explains to me at the start of the consultation:

Extract 1 (HCTRA 5) Olive 70+ Nursing home as permanent residence.
R=Researcher

- 23 N: and one of the things with Olive and um this tree because it's a really
nice nice view (.) but from Olive's flat=
24 R: mm
25 N: =in Penarth Olive could see Flatholm and [Steepholm
26 P: [and Steepholm [and er
27 R: [yes

The importance of the view is acknowledged by the nurse. As I have noted, the appreciation of location, whether physical or social, enables the ability to retain bonds with the world and is an important component of hope. The patient's conversational involvement and attunement to the topic is indicated by the overlapping talk (25, 26)

when patient and nurse jointly complete the sentence. The appreciation of the here and now can act as a diversion from what is to come. It can also extend to focus on the world around, giving the patient an opportunity to move out of self, to look beyond the now of terminal disease and move to the view from the window and ultimately the ongoing life cycle of nature. The following extract is from the same interaction. The patient had a very small room and few possessions but most of the interaction is concerned with what she could see in and around her room,

Extract 2 (HCTRA5) Olive 70+ *Nursing home as permanent residence.*

- 686 P: that tree's come out a lot since er I first came here [it has its little pointing boughs up to the
- 687 N: [it has
- 688 P: and then they came they came to sticky buds (.) and now they're actually coming into leaf [aren't they
- 689 N: [yes
- 690 R: can you see past these lower trees?
- 691 P: mm?
- 692 R: can you will you be able to see these when they [leaf?
- 693 P: [yes I can see that part of the sea has got Steepholme [but Flatholme is just behind the right hand side of the tree from here
- 694 R: [mm
- 695 P: er can't see that once the tree's um (.) in leaf (.) but of course when those leaves come off the tree I'll be able to see
- 696 N: there's also quite a lot of activity in this [(.) upon this headland which is rather nice
- 697 P: [oh yes yes there is
- 698 R: all the bottle banks and everything [are by there aren't they
- 699 P: [often there there's a children's playground down there [and you often get flying kites
- 700 N: [yes
- 701 N: yes
- 702 P: and you know
- 703 N: and in the summer people picnic across [on here don't they and play (.)
- 704 P: [mm mm
- 705 N: miniature golf and things
- 706 P: that's right
- 707 N: yes

In extract one the topic is initiated by the nurse, but later in the encounter, following talk about room decor and colours, the patient draws attention to the outside view, 'that tree's come out a lot since er I first came here' (686). In this exchange there are frequent indicators of conversational involvement via overlapping talk and affirmative feedback responses from patient and nurse as well as researcher. In this encounter the nurse had drawn me into the conversation at the beginning of the visit (extract 1: 23) and I was therefore legitimised to contribute when appropriate.

This extract shows how the patient is able to appreciate nature and to see acutely. Nelson (2000) has commented that this kind of 'seeing' is made possible by the fact that patients know that they may not live to see this seasonal change again. It is spring and the tree will gradually obscure the patient's wider view. She chooses to look ahead to winter when the leaves fall (695) although it's unlikely that she will live so long. The nurse deals with this expression of denial (696) by distracting attention, expanding on the topic to focus on the shorter term activities of summer and drawing attention to other sights (699, 703, 705) that will be visible to the patient and that may take her interest instead. The nurse's use of positive imagery here, i.e. children playing, flying kites, summer picnics and miniature golf paints an idyllic scene that the patient can look forward to enjoying, even if only as a non-participating onlooker outside of the larger social world. Despite the inability to join in with most social activities, the positive imageries can be seen to promote engagement with the wider world and have social value, with the potential to reduce the feelings of isolation that can lead to a gradual withdrawal from society and the social death that I have previously described.

Taking pleasure from one's surroundings may be heightened both by a physical reduction of a previous world and by a prognosis that limits the time left to live in their world as it is now. For several patients in this study talk of their environment is, on occasion, a priority ahead of physical symptoms or other major issues, and nurses appear to be aware of this perspective. In the following extract, the nurse initiates the first topic of the interaction:

Extract 3 (HCTRA6) Irene 70+ (patient). Frank (P2=Husband) 70+.

The couple have recently moved to a sheltered housing flat.

- 1 N: is there anything you need to go through before (.) [we start?
2 R: [no no
3 R: not really just that I'll give you a consent form afterwards to sign if that's
alright just to say that you've allowed me [to do the
4 P: [yes that's lovely
5 N: ok so the furniture's a big problem at the moment
6 P: yes
7 N: ok
8 P: I I it's er well it is you know I mean you can't (.) you can't this room
looks really untidy you know what I mean
9 P2: till you got the furniture and the pictures on the wall
10 P: (*unclear*) pictures on the wall (.) see?
11 N: ah ok (.) you can't do that till you've got your furniture in
12 P: well no you can't can you
13 N: no you can't
14 P: no you can't

Following the preliminary talk to manage the research procedure (1-4) the nurse directs the talk to the business of the patient, using the discourse markers 'ok' (5) to initiate a topic change and 'so' (5) to place emphasis on the change of direction. It appears that the nurse, based on earlier visits, is aware of the patient's concerns regarding her accommodation and this allows her to build continuity between visits. It also has the

interactional effect of continuing a prior conversation and the relational aligning effect of caring for the patient by remembering and paying attention to her concerns.

The patient has recently moved to more suitable accommodation and it appears to be important to her and her husband that, in order to feel settled, they make it into their ideal of a home as soon as possible. She describes the room as 'untidy', which it is not, but her husband's following comment 'till you got the furniture and pictures on the wall' (9), echoed by his wife (10), indicates that their feelings about how the room looks are linked to the need to have all their possessions in the right place in order to feel at home. The three-stage confirmation process (turns 12, 13, 14) sees the nurse using repetition to agree with their views, which is then reconfirmed by the patient. The ability to 'feel better', rather than 'get better', is enhanced by a sense of control and this can be enabled by at least being able to establish the feeling of being at home and creating a sense of security.

Patients remaining at home are more accessible to visitors. Once admitted to the in-patient unit it is likely that their status as a patient will determine that only their closest contacts will visit them. In extract 4, the patient is expressing appreciation of her family and social group as visitors whilst also demonstrating to the nurse her retained value as a social individual:

Extract 4 (HCTRA 5) Olive 70+ *Talking about Palm Sunday.*

- 611 P: all my visitors on Sunday I had seven visitors one after the other (.) I was
just never alone all day
612 N: all bringing palms
613 P: all bringing [palms and flowers and cacti and all sorts of lovely things
614 N: [(laughs)

615 (.)
616 N: it's rather nice though isn't it to know that you've got/
617 P: I'm so fortunate [to have so many good friends=
618 N: [yes
619 (.)
620 R: ok?
621 N: ok
622 P: =and they're all lovely

Olive emphasises her social popularity by drawing attention to the number of visitors she has received and the time that they spent with her (611). The nurse responds by noting that they also brought palms, a token of thoughtfulness and, as such, a signal of social popularity and a sign of membership of a (religious) community even when physically absent from church. An overlapping comment is made by the patient (613) who describes the other presents received. The nurse's affirmation of Olive's social status (616) is reinforced by the patient (617) and the nurse's confirmative overlap (618) then serves to enhance Olive's sense of self-worth. The use of repetition and overlap (612-613, 616-617) shows an alignment between nurse and patient, as they work together to construct a favourable impression of the patient as a socially desirable individual.

Following a pause that appears to signal the end of the topic (619), the nurse and researcher cross-check that each has finished their business (620, 621). Olive's apparent need for social approval is further revealed as, despite the pause in the conversation (619) and the topic shift, she makes a further qualifying statement to boost her social position, 'I'm so fortunate to have so many good friends =' (617) '= and they're all lovely' (622).

The presence of others from her social network brings signs of life and hope that she may draw upon. In the same way that this patient moves out of self to appreciate nature (extract 3), she also shows appreciation of her friends, ‘they’re all lovely’ (622).

However, when a patient’s environment is the in-patient unit there is less opportunity to be received as a social individual or assume control over the environment. Even when the nurse attempts interactional work to promote positivity or increase feelings of self-worth it is not always well received by the patient, as this next extract demonstrates. I have already noted that this narrative style of social talk rarely occurs within the in-patient data and so I draw here on an interaction that occurred during a home visit. Here Sarah talks, at home, presenting her reflections on being an in-patient¹⁶.

Extract 5 (HCTRA 2) Sarah 30 years. Talking during a home visit.

- 365 P: and I’d be a different person again on the ward cause I’d I’d probably wake up so this is where I got into my bad sleeping routine because I was in the room by myself and of course I could stay up all night watching films and things like that because I had nothing to get up for in the morning (.) now if I was on the ward everybody else would be up (.) and I’d still be in bed but I would at least be awake (*laughs*)
- 366 N: but you might be the fittest person there
- 367 P: well I might be but I can honestly say to you (*nurse*) the number of times I’ve been into (*oncology hospital*) and stayed on the ward I’ve always not been the fittest person there (*laughing*) cause that was a real eye opener you know when I was in a couple of weeks after being diagnosed I walked right the way the length of the ward and I’ll always remember I was looking at the people and (.) looking back were these sort of sickly group of people that they had in at the time and nearly everybody had sort of a cast with their leg in and everybody was a lot older than me and I remember walking up thinking I shouldn’t be in here you know I’m not this ill and (.) looking as ill it wasn’t half an hour before I was being sick into the sick hat and I really was very poorly at the time (.) and it was one of our little jokes that I was obviously the youngest much by far the youngest in our little corner and I was the one moved the most slowly (.)

¹⁶ This patient was very negative about her admission (see transcript from turn 359) she had felt ‘thoroughly miserable’ on the ward. I will discuss this in more detail in the concluding chapter as I focus on what the analyses have revealed about the contextual differences across settings.

can you get the chair out the way frequently so I can get to the bathroom
and (.) yeah (.) so I'm used to not being the fittest
368 N: mm
369 (.)
370 P: so that's what it did feel like (*unclear*)
371 N: mm
372 (.)

Previously in this interaction Sarah had talked of her bad experience of the in-patient unit. She felt that she had lost her autonomy as far as her diet was concerned and that the nurses were talking about her lack of cooperation. She had been in a single cubicle and felt that she had nothing to get up for, which had had a consequent effect on her sleeping routine when she had returned home. She comments that if she were to return as an in-patient it would be different next time, 'if I was on the ward everybody else would be up (.) and I'd still be in bed but I would at least be awake' (365). At home, at the time of this consultation, Sarah was mobile with the aid of crutches and so it is interesting that she sees herself as bed-bound within the context of the ward setting and less mobile than any other patient. In order to counter this negative self-portrayal, the nurse immediately reformulates to the positive with a reasonable alternative, 'but you might be the fittest person there' (366). This is followed by an extended response by Sarah as she constructs herself less as a social individual and more as a younger, less well, and therefore more tragic patient than any other, 'I really was very poorly at the time (.) and it was one of our little jokes that I was obviously the youngest much by far the youngest in our little corner and I was the one moved the most slowly' (367). Notice here the rhetorical use of the third person 'our', 'our little jokes' and 'our little corner' to indicate a group perspective. The emphasis markers 'obviously' and 'much by far', in conjunction with the positioning of a group perspective, is an attempt to justify her self-proclaimed status as she also presents the opinion of her peers.

This is the same young patient from the previous chapter who is perhaps feeling the effects of her terminal illness more acutely than an older person might. It seems that if, as she loses her previous self, Sarah is to find meaning or a particular identity for herself it is by rejecting relationships and by constructing herself as the sickest or the most tragic patient. The nurse's reaction is by minimal response and a pause (368, 369) causing Sarah to seek the nurse's confirmation of her justification by drawing attention to her feelings with a summing up, 'so that's what it did feel like' (370). The nurse, in the interests of promoting positivity whenever possible, is unwilling to affirm Sarah's negative attitude and again uses a minimal response and a pause to indicate that she will not confirm or elaborate on the topic (371, 372). Note, however, that by neither agreeing nor disagreeing, the nurse avoids influencing or dissuading this patient's style of coping.

6.6.1 Summary of home care setting

I have shown the importance of environment to patients who are still able to remain at home or in supported care. The knowledge that the ability to remain reasonably independent is not indefinite lends acuteness to patients' experience of their physical surroundings and therefore impacts on their topics of conversation. I have also discussed the negative implications that the transfer to a structured care setting may have on visits from patients' networks and the ways in which nurses can work with patients to enhance their self-worth by jointly constructing a picture of them as valuable social individuals. Wherever possible, nurses appear to reduce negativity and add positivity. I have also shown one patient rejecting the positive constructions offered by the nurse as she experienced difficulties in adjusting to her changing status in a differing care environment.

6.7 DTU: Locating oneself by comparison with peers

Unlike the home care setting, DTU is a group setting. Cassell (1991) has noted the importance of locating oneself amongst others in order to reduce suffering by feeling connected with others. The difficulty lies in the ability to feel connected with usual contacts when the previous self is dramatically altered by the illness experience. In the context of usual, curative illness, Sontag comments:

Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (1977: 1)

The return journey metaphor may be common to most illnesses but for patients undergoing palliative care the journey is one way and there is no passport to return. In this respect, the DTU has an important function as the only care setting where patients may socialise with each other whilst still living in the wider social world. Hope implies a sense of ongoing connection with the world and in the DTU patients are able to connect with and compare themselves to individuals who inhabit the same world as they do. Comparisons of self enable patients to locate themselves amongst their peers and this topic is particularly visible in this setting. At the time of taping, as I have mentioned in the previous chapter, a documentary about terminal cancer patients facing death had recently been broadcast. I have already discussed the effect that this programme had on the relatives of patients who were keen to protect them from distress. However, from the patients' perspective, the programme was interesting and useful as a tool for self-comparison, as was the ability to compare or make judgements about fellow patients through observation. Although many of the comparisons appeared to be critical of their peers this served the useful function of enabling the patients to use contrast to justify their own attitudes and therefore feel good about their selves and their coping styles.

Extract 6 (DTU 6) David 40+ Talking about the 'Death' documentary.

- 17 P: through ovarian cancer two had (.) and one had treatment after treatment in the end (.) I told my wife after six months and my quality of life was going down (.) and you can stop don't want no more (.) another one had (*unclear*) life she had a tumour on the head (.) she died I thought oh what (*whistles*) (.) you know
- 18 N: what did you feel about watching it then David and why did you watch it?
- 19 P: (.) oh (.) don't worry me (.) see how people cope
- 20 N: yes
- 21 P: I suppose (.) same type of you know
- 22 N: mm
- 23 P: and one one woman the older one I think she's so she's a kirk you know (*unclear*) a real Catholic or something
- 24 N: yes
- 25 P: she's the one who took all the treatment (.) went on and on and on and all this treatment (.) and I thought this faith like dying wasn't (.) you know it doesn't (*unclear*) at the end of the day we're all still human
- 26 N: yes
- 27 P: no matter what people think I've got a strong faith in this
- 28 N: yes

In this extract the nurse asks David to explain his reasons for choosing to view the programme (18), following a discussion about his wife's disapproval. His hedged and indirect response, '(.) oh (.) don't worry me (.) see how people cope' (19), uses pauses and the discourse marker 'oh' as a signal of his hesitation (cf. Schiffrin 1987). He specifies 'people' in the third person, so excludes himself, but follows with 'same type of you know' to imply people like him and diseases like his, i.e. cancer. So although David identifies with them he does not do so explicitly. This patient is critical of others both from the programme and from the DTU. He comments on one patient from the documentary, having already classified her as a religious type (23), 'she's the one who took all the treatment' (25), this is in contrast to his own wishes not to have extended treatment, previously stated, 'I told my wife after six months and my quality of life was going down (.) and you can stop don't want no more' (17).

In the following extract David criticises a fellow patient for his low mood but again he presents this criticism in contrast to his own coping style, thus using actions and the perspectives of others to justify and establish his own position and attitudes:

Extract 7 (DTU 6) David 40+

- 59 P: I don't think being positive all the time helps but it does help a bit
60 N: [I'm sure it does yes
61 P: [in some ways (.) I'm not saying you got being positive you're going to survive another thirty years but I think it helps in in yourself (.) has for me down (.) remember poor Frank (*anonymised*)(.) Frank remember?
62 N: yes
63 P: he was so down wasn't he
64 N: yes
65 P: most of the time after (*indistinct*)
66 N: sorry?
67 P: he was just down all the time
68 N: yes
69 P: I'm not saying he would have survived beyond that but it would help I mean (.) for him and (.) for other people for his family as well don't forget his family have seen that (.) he's going home and being (.) his kids would see it (.) makes them down as well
70 N: yes

Contrast is used as a rhetorical aid here as David constructs his position, i.e. being positive all the time may not help but for some of the time it does (59), and being positive won't gain more time but it will help you feel better (61, 69). For David, at least, his coping style is to use an optimistic approach, however superficial that may be, to help in adjusting to his terminal status. However, this response is not for his own sake, he is also acting in what he sees as the best interests of his family (69). It would appear that patients may use strategies to instil hope in others, to make them 'feel better'. David is in his 40s and has children at home, so his disease has different implications than it would have for an elderly patient whose children are adult. In his

case he feels he has to maintain a hopeful attitude for their sakes as well. However, it is not always helpful to deny his and his family's distress, as I have discussed previously.

As in the extract above, the data from the DTU site, especially, suggest that patients who appeared to lack hope were judged negatively by their peer group, as can be seen in extract 8:

Extract 8 (DTU5) Catherine 50+

- 92 P: (*indistinct*) I'm watching
93 (*indistinct few sentences about what's in room*)
94 P: she's having the children's bereavement counsellor go up I see
95 N: she was interested and I knew (*bereavement counsellor*) had been here
96 (..)
97 N: mm
98 (..)
99 P: she's quite convinced she's not going to make it
100 N: it's a shame really because (*very quiet*)=
101 P: awful shame (.) because you're wasting time
102 N: mm

Catherine, as many patients do in this setting, was observing the behaviours of her peers (92). The nurse does not discourage her observations but instead offers further information (95) before pausing as they both continue to watch the other patient. Catherine's judgement of her peer is not uncommon in this setting as patients measure and compare their values and opinions against each other. Her comments (99, 101) indicate her view that her peer is not making the best use of the time remaining, because she has lost hope and is suffering in the little time left to her. By contrast, the implicit alternative is to deny the prognosis, as this patient seems to be doing with the unspoken contrast to 'she's quite convinced she's not going to make it' (99), and make the most of her time.

Day care enables patients' usual carers to have some time away from their usual duties and the heavy demands placed upon them. However, as I have discussed, the palliative care philosophy takes a holistic, whole family perspective, and therefore the DTU care nurses are constantly making assessments about patients and their relationships with other family members, as in extract 9 below.

During the following interaction, Colin is distressed and worried about the provisions that he has made for his wife after his death. He has also been hiding symptoms and has not discussed his death in detail with his family. In the home care setting, partners or carers are often present at the time of the nurse visit in contrast to the DTU setting where talk with relatives is less accessible. By the end of this interaction the nurse had sought permission from the patient to call and make an appointment to see his wife.

Extract 9 (DTU 1) Colin 70+

- 128 N: you worry about your wife quite a lot [don't you
129 P: [I do it's good it's been marvellous
she's very house proud (.) house garden ground she's fantastic (.) no not I
say ideal but she's good
130 N: cause I've not seen your wife very much really have I I've only met her a
few [times
131 P: [once I think you did she's very good [she's simple really you know
she's not clever you know
132 N: [mm
133 P: (*unclear*) still working at Tesco's now brings in money you know she's
not supposed to
134 N: I just wondered if it would be useful if I saw your wife at some point
135 P: by all means
136 N: and then we can have a chat about what her concerns are [really
137 P: [that's right er
(.) today every Monday is her day off
138 N: yes
139 P: because I'm not there she rings a friend and goes into town
140 N: oh lovely
141 P: for lunch a little bit of shopping and by half past two she's back she's
back before me

142 N: yes she always make sure she's back before you
 143 P: yes I say what you doing here why don't you stay out? no no no no no
 144 (.)
 145 N: so I was just wondering whether it would be worth me ringing just to um
 make an appointment to see [her
 146 P: [by all means
 147 N: it may be she wants to see me on our own is that ok?
 148 P: no don't mind no
 149 N: it's just so we can have a chat about what her concerns are really and
 then it may be that we all get together at some point
 150 P: right [that's fine
 151 N: [to
 152 N: is that ok?
 153 P: that's fine yes yes (.) yes
 154 (*Patient breaks down crying*)
 155 N: it's not easy for you at the moment is it

Colin's construction of his wife in his narrative uses contrast to position her as a vulnerable individual, good at domestic duties but not intelligent, 'she's very house proud (.) house garden ground she's fantastic (.) no not I say ideal but she's good she's very good' (129) 'she's simple really you know she's not clever you know' (131). This implies that his role as a husband has involved looking after his wife and taking care of issues that he thinks she may not have the capacity to deal with. His distress at his own death is possibly heightened by the concern that he feels in leaving his wife to cope alone. The nurse role here includes the care of the patient's family to the extent of visiting the wife separately from any other appointment the patient would attend. Rehabilitation can also be seen as a process where adjustments can be facilitated, not only to the psychological status of patients but also to relationships. If some of Colin's wife's concerns could be managed it could possibly benefit the patient by reducing his concerns about his wife. The nurse will care for both the patient and his wife by opening up lines of communication in order that previously unspoken issues may be brought forward and dealt with openly. However, as the patient has been using denial and collusion as a coping style to this point, the nurse's objective must be relayed in a

sensitive manner to avoid the further distress of unbalancing the patient's adjustment style. The nurse's mitigated approach initially uses high levels of modality and a chained sequence of phrases with each phrase expanding on the previous,

I just wondered if it would be useful if I saw your wife at some point (134)
and then we can have a chat about what her concerns are really (136)
so I was just wondering whether it would be worth me ringing just to um make
an appointment to see her (145)
it may be she wants to see me on our own is that ok (147)
it's just so we can have a chat about what her concerns are really and then it may
be that we all get together at some point (149)
is that ok (152)

All of the nurse's comments are interspersed with the patient's agreements, which are indicators that allow the nurse to become more and more definite in his/her objectives as the interaction continues. Colin agrees to each comment but breaks down in distress, possibly in anticipation of having to deal with this difficult issue (154). The nurse acknowledges his distress but continues with the interaction.

6.7.1 Summary of DTU setting

I have discussed the fact that the DTU is the only place where patients can be among their peers on an informal basis. This allows them to form a group identity that does not rely on the wider social group from which they may have become increasingly isolated. To belong to a group means sharing similar traits that bond individuals to each other in connected relationships which promote hope and self-worth. As I have shown, patients make continuous assessments and judgements of themselves compared to their peers, as they gradually adjust to a new identity. Patients' coping styles, particularly regarding the theme of hope, are one of the topics used for self-comparison. As I discussed in the

previous chapter, talk of family networks occurs frequently as patients discuss both their own and their families' collusion or protectionism towards each other. In this respect, nurses are keen to open up lines of communication to reduce the isolating effect that this may cause.

6.8 In-patient unit: Keeping up appearances

By its institutional nature, the in-patient unit is the setting where patients' identities are most at risk. I have noted that devaluation of personhood is one of the main obstacles to maintaining hope. The potential indignity of receiving physical care will also impact on this although this can be lessened with a sensitive approach. Patients are generally closer to death and suffer from more severe physical symptoms in this setting. Many patients, due to the severe fatigue often suffered as a result of their condition, together with increased levels of medication, will have little ability to concentrate on pleasurable activities such as reading or watching television or anything that is not within their immediate physical domain. In order to help patients 'feel better' in this highly compromising setting, nurses skilfully use language to reformulate potentially stressful events.

The following episodes of talk occur during a task-based interaction as the two nurses wash and reposition the patient whilst he remains in bed. He has little mobility and has been incontinent of faeces, potentially a source of major embarrassment and loss of dignity.

Extract 10 (IPU 1) Bill 70+ During a bed bath.

- 29 N1: could you manage to roll over that side so that I can wash your back can you see me now (.) can I just protect your head in here oh you have had your bowels open but that's great
- 30 N2: yes you have it here
- 31 P: is it
- 32 N1: yea that's great
- 33 N2: I bet you have been waiting for it for probably some time
- 34 P: yea yes
- 35 N1: when you were able to feel it went
- 36 P: all of sudden
- 37 N1: we'll put your head back down on the bed so we can wash down here
- 38 N2: okay (.) you lie back now
- 39 N2: can you put the bed up a bit higher (*nurse*)
- 40 N1: well how do you feel now
- 41 P: tired I am now
- 42 N1: but a bit relieved now that you've opened your bowels
- 43 P: yea yea
- 44 N1: suppositories will help you (.) are you comfortable lying like that
- 45 P: yes I am
- 46 N1: it's about to finish now (.) right (.) I'll just put some cream there
- 47 N2: she will just put some cream
- 48 P: yea yea

Neither the nurse nor Bill is aware that he has opened his bowels until he has been turned to his side (29). The nurse's interjection of surprise 'oh' (29) is quickly modified with praise and repeated (32). Nurse 2 joins in (33) to position the patient's incontinence as an awaited achievement, which also has the effect of promoting it as a positive happening. The nurses' clinical interest in bowel functioning to prevent the alternative of constipation lessens the embarrassment to the patient of the need for the nurses to deal with his personal hygiene. Further interactional work by the nurses (40, 42) continues to gloss over the imposition to them and focuses on the positive effect on the patient. In this way, the nurses have reduced the loss of dignity and threat to the patient's self-worth as far as they possibly could.

The nurses on the ward, especially, take a great interest in helping patients with their personal appearance. A volunteer hairdresser is available to patients within the in-patient unit and at the DTU, but often it is the nurses who wash and style the female patients' hair. The nursing profession is well aware of the need to respect and consider issues patients may have with body image and quality of life. Kabel and Roberts (2003), using qualitative interview methodology, conclude that hospice staff use a range of strategies and methods of normalising distressing symptoms in order to improve quality of life in this group. These include managing physical symptoms, encouraging independence, respecting patients' decisions, provisions for hair styling and make up, flexibility in patient care and listening, and communicating with patients. However, the staff was interviewed specifically on the topic of personhood and was likely to answer according to their knowledge of best practice. An observational study may not see practice match theory in a real-life setting. In the next extract the nurse is more than willing to make the extra effort to help Jean to take care of her personal appearance:

Extract 11 (IPU 7) Jean 70+ *Following an assisted bath.*

- 145 AN: how's that (.) got a brush in your bag?
146 P: no love I think it's in my locker
147 AN: cos if it dries like that (.) just pop back up (.) if I sit on the bin it'll
collapse (.) you have a little fringe don't you
148 P: don't be too fussy I'm not going anywhere
149 AN: hey you're going to look gorgeous (.) doesn't matter you're not going
anywhere

The nurse shows that she has properly seen and noticed the Jean's usual hair style (147) and despite the protestations of the patient (148) she is determined to make her look her best. The nurse's comment, 'hey you're going to look gorgeous (.) doesn't matter you're not going anywhere' (149), gives validation to Jean as a valuable and cared for individual in a potentially compromising institutional setting.

In a similar vein, the following extract shows a different nurse dismissing the protestations of Elin who does not want to cause work for the nurses or take up their time. She has birthday cards on her bedside locker that would usually be displayed on a wall board behind the patient's bed.

Extract 12 (IPU 11) Elin 70+ *During an assisted wash.*

- 29 AN2: and we need to get those cards up (.) you're the only one that hasn't got a board I wonder why
30 P: (*unclear – don't worry?*)
31 AN2: no I'll certainly see if I can find you one
32 P: oh don't bother
33 AN2: well no it's important you've got birthday cards to go up (.) right (.) ummm
34 P: don't worry about it you've got other things far more important than cards
35 AN2: well there will be (.) well if I find a board it will give your daughter something to do won't it
36 P: yes
37 (*Laughter*)

Elin's comment, 'oh don't bother' (32), downplays her own worth and reflects negatively on her self-image. The nurse responds with reinforcement of the importance of displaying the cards, thus implicitly signalling the patient's social value. The patient deflects attention to 'other things' (34) that she perceives as more worthy of the nurse's attention than her cards. Following the three attempts to help (29, 31, 33), the nurse, instead, respects the patient's point of view and autonomy and does not impose her services further. Instead she playfully suggests family involvement (35) using humour and laughter (37) to realign with the patient.

The perception of nurses as busy can be detrimental as patients may withhold discussion if they sense time restrictions or interruptions to consultations with nurses. Walsh and

Ford (1989: 120) have observed nurses' obsession with 'getting all the work done by lunchtime', whilst Rasmussen and Sandman (1998: 827) note in an observational study that nursing care in the hospice setting was mainly related to 'doing' rather than 'being'. That is, when with patients, nurses most often had some task to accomplish. Their 36 observations of 21 different patients at ten-minute intervals, day and night, resulted in a total of 1252 recorded events. They present their findings for the category of 'being with nurses' as follows:

Hospice patients spent an average of 128 minutes during the day and 58 minutes at night with nurses. Most patients needed help with their daily activities. Thus two-thirds of the time patients and nurses spent together in the day (86 minutes) was related to patients getting help with their basic physical needs such as eating, elimination, mobility, rest and hygiene. During the night, 43% or 25 minutes were spent on these needs, whereas the remaining 57% or 33 minutes were spent on *psychosocial-spiritual care (10 minutes)*, medication, IV, dressings and monitoring. In the day, the latter activities took up 43 minutes including the *18 minutes nurses and patients spent together in relation to psycho-social-spiritual care such as small talk, consolation and dialogue about the patient's life and current situation*. One observation was coded for a patient and a nurse praying together, and another for listening to spiritual music together. *For 14 or 39% of patients no observation was coded for 'psycho-social-spiritual care'*.

(Rasmussen and Sandman 1998: 823) (emphasis added)

This Swedish study was conducted on a small scale and so findings cannot be generalised across the U.K. palliative care patient population. It also does not account for talk occurring *during* the task-based procedures or when, as I have shown above, nurses are using small talk and addressing psychological concerns. However, it does reveal the limited amount of time that nurses spend with each patient and that this time is, in the main, spent on physical care.

The task orientation contributes to the busy nurse syndrome, which may keep the nurse busy all the time and therefore prevent him/her from talking to the patient at anything more than a superficial level. The legitimacy of 'doing for' the patients may also enable nurses to distance themselves from aspects of psychosocial care through communication. In keeping up the appearances of the patients by prioritising ritualistic nursing practices like morning bathing, tidy lockers and fresh beds, nurses may be seen as busy and therefore less available. Despite the emphasis on making patients 'feel better' by attention to personal care and the possibility of small talk, these task-based actions create a barrier to strategies of hope and healing enabled via in-depth, attentive talk. However, in this study, psychosocial care in the form of talk about death or dying did occur separately to task-based care, as I will discuss in the following section.

6.8.1 Witnessing death: Seeing dying as a positive experience

As I have discussed in Chapter 5, death and dying may be the subject of open awareness on an individual basis but from a societal position it remains hidden from view. In the in-patient unit setting, it is very likely that patients will experience the deaths of other patients, which, for some, will be the first time that they have experienced the dying process at first hand. Dying patients are not routinely segregated to single cubicles unless there is a particular need to do so, for example, by the likelihood that other patients will be unduly disturbed by a confused or hallucinating patient. Most patients in my research setting are admitted to four-bedded wards and may, over the course of their admission, be aware of more than one death. Particular care is taken by the nurses to ensure that patients being moved to the morgue are not seen by others, but many patients quickly realise that closed curtains and doors are the signal that this is happening out of their sight. The potential stress of seeing others die is compounded by

the fact that patients themselves are close to death and are soon to be in the same situation. It is inevitable that the delicate balance of hope and optimism that may have been achieved by patients, with or without the facilitation work of nurses, will be affected detrimentally by this exposure to the certain fact of death.

As a result, nurses take particular notice of patients' reactions after a death. In the following extract the nurse is assessing the patient's state of mind with regard to the fact that she is aware that several patients sharing the same ward have died or are very ill. The nurse takes the lead with directed questioning to open a discussion on death and dying and to offer a break from the hospice if the patient so desires.

Extract 13 (IPU 13) Lorna 40+ *One-to-one talk with nurse at bedside.*

1. N: you've felt a bit distressed because there have been so many (.) you know so many of your colleagues
2. P: you know you get to know people (.) there was Tina (.) I was talking to her and then Marie and sort of thing (.) you get to know people and they go so soon (.) not that I know them
3. N: no but you know that things have progressed with them
4. P: yes
5. N: does that make you feel apprehensive?
6. P: I think about myself (.) I understand that this is (*unclear*) every family has to got through (.) I see how different families are coping with different things (.) it's silly really (.) it's as though I am an onlooker on these things (.) I don't know (.) I can't say it's done me any harm
7. N: right (.) okay
8. P: you know I think there's three people in here (.) I don't know what it is
9. N: do you feel there is an extra burden on your shoulders?
10. P: no I don't think it's an extra burden on my shoulders
11. N: does it make you think about what's happening with you?
12. P: yes it makes me think about what is happening with me (.) makes me think that will there be a time sometime in my life when the same thing will be happening for me (.) and I think this may be happening because different people cope with different things differently and I don't know (.) I just find it amazing (.) many just go out leave and get hit by a car (.) they don't know anything about it (.) and you know the relations are totally different do you understand what I'm saying
13. N: yes cos you've got time to think

14. P: yes I have time to think about it all
15. N: you've had a warning kind of thing haven't you
16. P: yes (.) no surprises
17. N: and we have seen this before as well (.) when somebody relatively well like yourself, who can potter about and look after yourself what have you (.) and when you're in for control of your pain (.) and seeing others around (.) we have seen this in the past and we know that it can be distressing (.) but others have turned round and said it's been a comfort because they know what is ahead of them
18. P: yes I would say that (.) I mean you all know your own emotions (.) you know (.) well I though (.) it's a bit like a privilege to be here sometimes

In the above extract, wherever possible, the nurse offers an alternative reformulation of the negative aspects of the patient's situation by promoting the benefits of a terminal diagnosis in psychological terms, using her own and the wider patient group's experience, 'you've got time to think' (13), 'you've had a warning' (15), 'others have turned round and said it's been a comfort because they know what is ahead of them' (17). Lorna works with the nurse here as they co-construct a positive perspective, 'I can't say it's done me any harm' (6), 'yes I have time to think about it all' (14) and 'it's a bit like a privilege to be here sometimes' (18). As the interaction continues, the nurse offers a period of respite from the hospice, which offers both a change from the institutional environment, and the autonomous choice of accepting it.

There is little empirical data that considers the impact of death on fellow patients. However, Payne, Hillier, Langley-Evans and Roberts (1996), using questionnaire and interview methodologies, assessed the views of 34 hospice patients that had witnessed a death. The results indicated that patients witnessing a death were significantly less depressed than those who did not. Awareness of dying was found to be both comforting and distressing, although, overall, patients reported more comforting than distressing

events. These researchers did not assess the contribution of nurses or how they might influence the outcomes of such events.

Extract 14 (IPU 13cont)

- 31 N: of course it does but if you said you wanted out we could get your prescription sorted out so if over the weekend (.) you feel things are getting a bit heavy and you feel you want to
- 32 P: I know what you mean
- 33 N: maybe just go out for the afternoon and if you have warm clothes and you want to go out for lunch (.) if you felt well enough for a couple of hours (.) just let us know where you are going
- 34 P: lovely okay (.) that would give me a break (.) good idea
- 35 N: yes a change of scenery but only do it if you feel ready (.) but it would definitely be a change of scenery

The nurse's talk (31, 33, 35) is laden with modifiers and shows a high level of modality, 'if you feel things are getting a bit heavy', 'if you feel you want to', just let us know' and 'but only if you feel ready', which all contribute to a sense that Lorna is being offered the opportunity to exercise choice and control in choosing to follow the nurse's advice or not.

6.8.2 Summary of in-patient setting

The focus in this highly compromising setting has been on the discursive reformulation of distressing events. I have shown how nurses attempt to alleviate some of the indignity of incontinence. I have also discussed how nurses can impact on patients' well-being by paying attention to concerns such as personal appearance and the birthday cards that will enhance the patients' surroundings and draw attention to them as special. Finally, I have shown that even during talk of death and dying nurses attempt to promote a perspective that can find a positive meaning to a terminal diagnosis.

6.9 Chapter summary

In this chapter I have discussed the role of hope in the context of palliative care. I have discussed this concept focusing on both the effect on the patient and the role of the nurse. I have considered barriers to hope, and hope-fostering strategies that health care professionals may encourage. I also considered the adaptive process of adjustment to a terminal diagnosis and the need to find meaning in illness in order to heal and alleviate suffering. Furthermore, I have given consideration to the particular implications that adjustment in old age may cause.

The analyses of the three care settings have focused on the living environment and the difficulties that some patients will face in adjusting to a changed identity. The DTU has been shown to be especially useful as a source of contact with patients' peers. This enables membership of a new social group in which individuals can assess and make self-comparisons to the group norms. Family relations are also addressed here as nurses attempt to facilitate open talk, rather than collusion, between family members. The in-patient unit, as I have noted, can most strongly affect the identity of patients because of the overarching institutional presence and the possibility of loss of dignity due to the patients' need for intimate care. Nurses here reformulated to a positive viewpoint whenever possible, even during talk of dying. However, the orientation towards task-based care and preserving the appearances of patients could potentially affect the quality and frequency of interaction and therefore reduce the use of hope and healing strategies.

In the following chapter I take forward aspects of hope, as discussed in this chapter (6.2). Verbal play, humour, banter and laughter are prevalent in the hospice settings but each can be seen as multifunctional and require further consideration in the context of

palliative care. I aim to capture aspects of these types of interactions under the category that I will term lightheartedness.

Chapter 7: Laughter and humorous lightheartedness in palliative care

7.1 Chapter overview

Humour and laughter are, perhaps surprisingly, commonplace in palliative care (Langley-Evans and Payne 1997; Dean, Kinsman and Gregory 2004; Dean and Gregory 2005). Laughter and what I shall term humorous lightheartedness are often connected but are not reliant on each other. Laughter often occurs as a response to humour, or as a signal from the teller that there is humorous intention, but it also functions in other ways. Humorous attempts intended to provoke laughter may not always be successful. In this chapter, I will focus on instances of laughter across the three care settings and analyse the events surrounding the occurrences of laughter in relation to the nurse–patient relationship. I will use broad categories of humour/lightheartedness and will refer to more concrete categories of humour such as banter and teasing where appropriate.

In relation to the theme of social death, laughter and humorous lightheartedness may serve to maintain social cohesion via relational alignment. Relational alignment between patient and nurse has the potential to diminish the effect of isolation and social withdrawal that may otherwise be felt. In relation to the theme of hope and healing, interpersonal connectedness and lightheartedness are hope-fostering strategies. I have already alluded to the role of lightheartedness in relation to hope-fostering strategies that may be employed by nurses (6.3).

I will begin with an overview of laughter as a social response (7.2), followed by a discussion of humorous lightheartedness and previous research in relation to my research focus (7.3). I will then provide my rationale for the selection of data extracts used in this chapter (7.4) before returning to the data to analyse occurrences of laughter across the three care settings (7.5).

7.2 Laughter

Smidl (2003) produces an intelligent review of laughter studies within her thesis, using narrative enquiry to explore laughter in the context of the classroom. She puts forward that:

In communication, there is a transfer or exchange of messages that occurs between the sender and receiver. Laughter can help to facilitate this exchange of interactions because whether or not it is intended as a communication transaction, it contains meaning and mood, which is usually positive. (2003: 13)

Smidl comments on the paucity of research into laughter saying that it 'is seen as a lightweight topic, and has always dangled at the threshold of scientific scrutiny' (ibid: 8). It could be argued that the difficulty in categorising laughter and humour may be a contributory factor in the dearth of such research. Referring to Apte's (1985) discussion of researchers' perspectives, Smidl notes that:

Most researchers will exasperatingly agree that it is very difficult to decipher between the semantic borders of laughter and humor, although they will undeniably concur that there is a very intimate and definite relationship between them. (2003: 22).

Regarding methodological considerations, Apte (1983: 200) explains that distinctions between humour and laughter need to be assessed before criteria can be established. He notes that, 'generally, extreme degrees of smiling or laughter may suggest humor

stimuli, but the ethnographer nevertheless needs to verify such an assumption'. Smidl acknowledges this differentiation, commenting that:

Though most researchers will concur that laughter is the response to humor, few of them have made attempts to richly describe it and its occurrence and even fewer have considered the case where laughter is a nonhumorous response. (2003:11)

Laughter, as Smidl notes, 'is engaged in almost exclusively during social encounters, and mirth responses are rated as funnier when they are shared with others'. (Smidl 2003: 12). This social perspective is well illustrated by Hertzler (1970) when she argues that:

Laughter answers to certain fundamental requirements of the common social life. It is questionable whether a human being would laugh at all if he lived in complete isolation from his fellows. (1970: 28)

Similarly, Provine (1996) has shown that people are about 30 times more likely to laugh when they are in a social situation than when they are alone. His study collected 1200 occurrences of laughter as he and his team eavesdropped on groups in public areas such as shopping malls. They took note of what was said before and after the laughter occurrences. Provine also comments that, 'most conversational laughter is not a response to structured attempts at humor, such as jokes or stories. Less than 20 percent of the laughter in our sample was a response to anything resembling a formal effort at humor' (Provine 1996: 39). As Smidl (2003: 13) comments, 'Laughter serves as a means of communicating and bringing people closer'. Based on her review of laughter studies, she finds that the social significance of laughter has been documented in studies that have focused on the, 'enhancement of interpersonal relationships, development of group cohesiveness, easing communication, and decreasing social distance' (Smidl 2003: 11), a statement for which she draws on earlier research. It is exactly these dimensions of laughter that are relevant to my research.

However, it should be noted that laughter is not always used for positive emotion, as acknowledged by Chapman:

Laughter can prosper when individuals are oppressed, impoverished, or in acute pain: those very circumstances may be manna for laughter. As far as we know laughter can erupt in association with any of the emotions; certainly it can be witnessed in fear, embarrassment, contempt, and grief, as well as in love and joy. (1983: 151-152)

Edwards (2005: 13) reinforces this multifunctional perspective, noting that ‘detailed studies of laughter in conversational interaction ... have revealed various kinds of ‘serious’ business being performed, including participant alignment and misalignment’. In the palliative care settings, it is very likely that laughter will occur across a range of interactions that may involve difficult emotional or relational circumstances.

Laughter may be either shared or ‘affiliative’. Schenkein (1972: 371) describes affiliative laughter as signalling ‘coincidence of thought, attitude, sense of humour and the like’. Alternatively, it may be unreciprocated. Jefferson (1984) has noted the withholding of affiliative laughter during sensitive topics of discussion or, in her terms, troubles-telling receipts:

A laughing troubles-teller is doing a recognizable sort of job. He is exhibiting that, although there is this trouble, it is not getting the better of him; he is managing; he is in good spirits and in a position to take the trouble lightly. He is exhibiting what we might call ‘troubles-resistance’. But this does not mean that ... a recipient is invited to join in the merriment, to also find the thing laughable ... In troubles-talk, it appears to be a recipient’s job to be taking the trouble seriously; to exhibit what we might call ‘trouble receptiveness’. (1984: 351)

In the context of my data sites, both of these types of laughter, affiliative and unreciprocated, appear in interaction and will be explored in terms of how this will impact on the relational alignment between nurse and patient.

7.3 Humorous lightheartedness

Humour is a multidisciplinary field of research which can include the disciplines of psychology, philosophy, sociology and literature, amongst others. Some discourse studies have examined the use of humour in interaction. Many of these studies categorise and make distinctions between types and functions of humour, such as joke telling or conversational humour (cf. Norrick 1993; Boxer and Cortes-Conde 1997 and Kotthoff 2000). However, in order to achieve a cohesive focus within this chapter, I do not seek to examine humour as a concept but to explore the *effect* of humorous lightheartedness and laughter in the particular context of my research themes and research settings. In what follows, I will, therefore, confine the discussion of the discourse and humour literature to studies undertaken within the health care setting.

7.4 Humour studies in health care settings

Health care professionals are aware of the potential benefits of humour on the psychological well-being of all patient groups. However, studies in this area are often conducted on the basis of interviews, questionnaires, and diaries, and rarely use naturally occurring instances of humour in interaction (cf. Blumenfield and Alpern 1986; Boyd and McGuire 1996; Astedt-Kurki and Isola 2001; Olsson, Backe, Soerensen, and Kock 2002). As such, reported humour is distanced from the actual event and therefore likely to be biased, as it is a recycled version of the event itself. Ragan (1990), Bottorff, Gogag, Engelberg-Lotzgar (1995) and Haakana (2001) are notable exceptions and I will restrict my focus to interactional studies such as these. As I have noted, humour in interaction is a dynamic process and will be better evidenced in real-life interactional data than in participants' later reconstructions of events. Within this chapter, therefore, I will focus on real life occurrences of laughter and humorous

lightheartedness and how it works within interaction to impact on the nurse–patient relationship.

The encouragement of humour can be seen as a defence mechanism to create a psychological distance, away from thoughts of death and dying. From a psychological perspective, Vilaythong, Arnau, Rosen and Mascaro (2003) have suggested that the experience of humour may significantly increase a person's level of hope by competitively replacing negative thoughts with positive ones, thereby fostering hope. Humour, they propose, can act as a stimulus towards positive emotions and thought processes and can potentially create a more optimistic response to stressful events, thus contributing to an enhanced sense of self-worth.

Bottorff *et al* (1995) videotaped nurse–patient interactions on a cancer treatment ward to explore how nurses provided comfort to their patients. They found that the use of gentle humour was associated with physical comfort measures, emotionally supportive statements, and connecting touch. Gentle humour, they commented, seemed to provide an important vehicle for nurses to interact with patients in a lighthearted manner in a wide variety of situations. Verbally, nurses used gentle humour, such as exaggeration, slang or colloquial expressions, gentle forms of teasing, or highlighted incongruities in amusing ways during comforting interactions. This style of humour was viewed as a deliberate attempt to help patients relax, to endure monotonous, painful and distressing situations, or to heighten their spirits. Hockey (1996) notes that patient and nurse joking increased their levels of involvement and Li (2004) explains how joking and laughter serve to bolster the co-enactment of niceness, in a symbiotic sense, which leads to the construction of a reciprocal nurse–patient relationship.

7.5 Humour studies in palliative care

Dean, Kinsman and Gregory (2004) have observed that humour and laughter are common in palliative care despite the seriousness of the care context. Dean and Gregory note that existing research tends to 'identify the importance of humor as a means of enabling communication, fostering relationships, easing tension and managing emotions' (2005: 293). They also comment that appreciation of humour is relevant to context and although crises, serious discussions and anxiety are commonplace in hospice settings, so too are humour and laughter. Their observational and interview based study, which claims to be unique in the palliative in-patient setting, found that humour was pervasive and significant in terms of 'conveying respect for human dignity and regard for the personhood of the other' (ibid: 299).

In the palliative day care setting, Langley-Evans and Payne (1997) observed that the environment enabled patients to engage in social interaction. Talk of death was maintained 'at a superficial or 'light-hearted' level, through the use of humour' which, the researchers noted, 'may serve as a psychological defence mechanism, affording some protection from the fear or threat of death' (ibid: 1096).

7.6 Humour studies focusing on nurses

From the nurse's perspective, Wooten, a nurse specialising in humour comments that, 'a sense of humor helps us to manage the stress of care giving. The 'detached perspective' that humor provides helps us to disengage from the suffering we witness and, yet, still remain sensitive' (Wooten 1993: 428). James (1986) has further noted that nurses' perceptions of patients are affected by their possession of what is considered to be the positive quality of humour. The use of humour, therefore, can be seen as beneficial to

nurses and patients alike, even within the 'serious' setting of palliative care. However, the appropriateness of its use is dependent on the form it takes and the way in which it is received.

In a ward setting, conversational humour potentially operates as a strategy to rapidly reduce social distance or to reduce embarrassment. As nurse researchers Pierlot and Warelow note:

The use of humour can help improve the nurse–patient relationship by initially breaking the ice between nurse and patient. This alternative mode of delivery can then be foundational to other areas of the nurse patient relationship such as self-disclosure, the enhancement of learning and relieving stress. (1999: 124)

Humour, they comment, 'is regarded by those who use it as a social lubricant acting as a positive in nurse patient relationships' (ibid: 126).

In the context of intimate nursing procedures there is a need to reduce social distance quickly and humour can serve to further this aim. Ragan (1990) explored verbal play during gynaecological examinations and found that although joking and teasing could be threatening to the patient, verbal play had an inclusive function and served to reduce social distance in this context. Grainger (2002 online), using the analytic framework of politeness theory, points out that the characterisation of joking as 'positive politeness' does not hold when taking into account the 'influence of the situation'. Even playful banter, she notes, has the potential to be controlling at the same time as promoting intimacy. Grainger's study site is the institutional setting of a hospital geriatric ward and she finds that humour in this context may be collaboratively used to construct 'an intimate relationship which wouldn't otherwise exist'. However, as well as acknowledging the construction of 'a sense of intimacy', achieved through verbal play,

she warns of the risk of creating tension and distance if verbal play is misjudged. As she notes:

It is not enough then, for the nursing literature to advocate the use of humour as a therapeutic tool, without understanding the relational dynamics in a particular situation. Therefore the use of verbal play is context dependent and multi-functional especially when accounting for the institutional, social or contextual content of interaction. (Grainger 2002 online)

However, as I have noted before, the use of humour is subjective and therefore needs to be viewed in the context of each individual interaction. The data for Grainger's (2002) study of verbal play on a geriatric ward consisted of twelve interactions. Of these, she said, four contained 'some kind of verbal play, and three of these had substantial and prolonged sequences of humorous 'banter''. Grainger does not, however, specify how the verbal play and humorous banter in these extracts were specifically categorised or coded, although it is noticeable that all of the extracts contain transcribed laughter.

Holmes (1998) signals the involvement of the analyst within data coding, noting that instances of humour may be missed or misinterpreted. She notes that instances of humour are categorised differently across a range of researchers. Some take into account the speaker's perspective, using paralinguistic clues, and others take the audience response or even both the speaker's intention and the listener's response into account when deciding that an instance of humour has occurred. I will take a different line and identify extracts from the data on the basis of occurrences of transcribed laughter. My rationale for this is that instances of laughter can occur during attempts to relieve stressful or embarrassing situations, which may not be overtly humorous in nature. It has been noted that laughter is often not simply a response to humour but also reflects states of mind, such as fear, grief, embarrassment and contempt amongst others (Chapman

1983: 151-152). Laughter, as a response to humour, can therefore, 'lead to either (heightened) interactional rapport or (aggravated) interactional awkwardness' (Bekkers 2003: 27) and thereby affect the nurse–patient relationship. As I have stated, laughter can either be the signal for an instance of humorous lightheartedness *or* the signal for interactional difficulty. I will explore within the analysis how each individual event impacts on the nurse–patient relationship.

Whereas researchers using the methodology of conversation analysis commonly transcribe laughter in fine detail (e.g., Jefferson 1985), I aim to isolate instances of laughter and analyse the discourse surrounding the event and its context, rather than the laughter in itself. I will therefore transcribe laughter as a paralinguistic occurrence, i.e. (*laughter*), giving further detail if required.

In summary of the discussion so far, humorous lightheartedness can have a beneficial effect on the nurse–patient relationship but alternatively, it can be used to hurt or to manage stress. In the nursing context it can reduce social distance and create a sense of intimacy in order to manage embarrassment in care-related talk or tasks. Laughter will be considered in relation to its effect on the interaction and on the relational alignment between nurse and patient. I will now move on to analyses in the three care settings focusing on relational alignment.

7.7 Home care: Stress, shared values and patient narratives

Much of the research on humour in the health care setting focuses on verbal play or humour used in a positive sense. It can be seen as having a therapeutic effect, acting to promote relational alignment, and as a hope fostering mechanism. In the context of the

hospice care settings, relational alignment is a major factor in facilitating talk about potentially distressing or embarrassing topics. The patient role involves a high degree of self-disclosure, which is more easily accomplished if there is trust and rapport in the patient's relationship with the nurse. Shared humour may be used to enhance relational alignment by bonding nurse and patient in mutual appreciation, or as co-partners as they face the issues of the disease process.

Extract 1 (HCTRA6) Irene 70+ (husband also present)

Previous talk has involved Irene's husband's physical problems, although he is not a patient, as well as her own. Between them, topics have included low blood pressure/heart condition, stomach trouble, hip pain, ear syringing and the mention that they are on '26 prescriptions between us' (124). The nurse is attempting to collate hospital and GP visits:

- 814 N: well (.) you need to (.) who are you seeing this afternoon?
815 P: er um (*coughs*) Miss (.) S
816 N: and she was your
817 P: yes for [the (.) tummy
818 N: [for your for your tummy wasn't she
819 P: yes
820 N: it might be worth mentioning to her that you know you are getting this
problem with your hip
821 P: yes
822 N: but you definitely need to talk to your GP about that cos he can refer you
back to the orthopaedic people
823 P: oh I see
824 N: ok
825 P: oh well I can mention [it
826 N: [yet more doctors to see I'm afraid
827 (*all laugh*)

Nurse and patient are collaborating here to establish the facts. The nurse's question (814) is followed by a direct answer (815) and then further clarification is achieved by a

jointly constructed answer (816, 817) with a repetition (818) to signal alignment. The nurse makes a mitigated suggestion, 'it might be worth mentioning to her' (820), which is followed up with a strong assertion, 'but you definitely need to' (822), to direct the patient to specialist help via the GP. An emphatic directive such as this could be seen to disturb the interactional alignment that has been achieved, but its impact is modified by the use of humour, which links to the context of the preceding talk, 'yet more doctors to see I'm afraid' (826). Affiliative laughter signals that the patient is in accord with the nurse's humorous contribution. The humour works because it draws attention to the ridiculous, that is, the exaggerated amount of health care input that these two people in old age are accessing due to declining systemic functioning.

The following extract occurs towards the end of a lengthy interaction. The young female patient, Sarah, has many difficulties that need the coordinating skills of the nurse.

Extract 2 (HCATRA2) Sarah 30 years

- 296 N: the one on your back has that changed at all? (*refers to lump*)
297 P: oh bigger yes (.) that changed as we were doing the tests
298 (*writing*)
299 N: so how [many things have we got now?
300 P: [(unclear) (*laughing*)
301 P: well the important one really is calcium I think=
302 N: yes

The nurse has decided to make a list and uses the inclusive pronoun 'we' (299) to signal joint working. The patient responds with laughter (300), which, as in the previous extract, can be seen to highlight the ridiculous and to relieve the stress of dealing with the increasing number of symptoms and the obvious progression of disease. The patient's response, 'well the important one really is calcium I think' (301), allows her to use emphasis by placing intonational stress on the topic marker 'well' and thus voice her

own priority. The assessment of calcium levels is important to Sarah due to the association of increased levels with confusion, a situation where she will lose control of her 'self' entirely. Sarah's laughter, in combination with the nurse's enablement of her viewpoint, is affiliative and has a relational bonding function in this context.

The following extract occurs after talk about Amy's loss of social support from her peers, i.e. her sister and friends that have since died. She is talking about a remaining friend, now a widower:

Extract 3 (HCTRA 4) Amy 80+

- 131 P: what can you expect at my age (.) I shouldn't be here (.) but he brought me this (*refers to footstool*) (.) you couldn't perhaps tell me (.) he thinks it's supposed to be that way but I thought it would I thought the legs were supposed to be up higher [but (*unclear*)
- 132 N: [no they shouldn't be too high
- 133 P: they should be on the (.) [the the
- 134 N: [yes
- 135 P: because the chair that I had them on was too (.) er high he said [so (*unclear*)
- 136 N: [yes they shouldn't be that high
- 137 P: well he brought me this one and er (.) and er
- 138 N: does it feel comfortable [like that?
- 139 P: [very comfortable indeed
- 140 N: yes
- 141 P: so um in fact he only brought it yesterday but he rings me up when he can he's he's another one of my friends (.) I've found these men are so good and so kind but they're unpredictable they will go their own way [I can't control them (*unclear*)
- 142 N: [(*laughs*)

Amy's poignant self-reflection, 'what can you expect at my age (.) I shouldn't be here' (131), is immediately followed, and perhaps softened, by recalling the kind act of a friend. This is a stretch of collaborative talk, indicated by overlap and agreement,

concerning how best to use the footstool (132-134). As Amy praises her friend (141) she also makes the overt observation that he is male and then says of men in general 'I've found these men so good and so kind but they're unpredictable they will go their own way' (141). The nurse and patient are both female and share what could be seen as in-group humour. The nurse responds with laughter at Amy's gendered construction of 'men'. They identify with each other in terms of gender and thus find a shared basis for humour. Shared values, expressed through humour, are a key component of relational alignment and in the following extract we see this expressed in relation to interior decor of Olive's new room in a nursing home.

Extract 4 (HCTRA 5) Olive 70+

- 38 P: and eventually I'm going to have it redecorated [so that I make it more
my own than it is now
- 39 N: [yes
- 40 P: cause er (*laughs*) that's not exactly my taste you know (.) anchors and
things
- 41 N: sort of rear admiral had this [*unclear*] before
- 42 P: [*laughing*]
- 43 N: um (.) seagoing man

The nurse and Olive's mutual laughter is at the expense of the previous occupant. Both unite through humour and use understatement, 'not exactly my taste' (40), and ridicule, 'sort of rear admiral' (41), to criticise the symbols of masculinity and therefore the previous occupant's taste in decor. The nurse and Olive's personal taste are aligned, promoting relational bonding while highlighting once again (see also chapter 6.6) the importance of controlling location to patients at the end of life.

The above extracts show a typical pattern of situated humour. It is a particular style of nurse and patient aligning with each other to display inclusion and mutual values. This has the effect of lessening the institutional presence of the nurse attending at the patient's home and helps to mask the interaction as something very much more akin to a social meeting.

I have discussed previously (6.2) the various means of fostering hope in palliative patients. The acknowledgement of an individual's personal attributes and an affirmation of their worth can give meaning to their existence and is often achieved through humour. I also earlier highlighted the value of personal narratives (5.9.1). In the home care setting, extended personal narratives by patients are common and often unrelated to symptoms or clinical features of their disease. It is clear that patients are enabled to present narratives by virtue of being in their own homes and engaging in a one-to-one interaction with a nurse who is prepared to spend up to an hour at a time with them. Hunt's (1991) discussion of home care nurses being friendly and informal explores how nurses signal to patients the non-urgency of visits. My data concurs with this finding and is evidenced, as in Hunt's study, by the occurrence of pre-closure exchanges, the length of the visits and the allowance of extended patient narratives, or story telling sequences in Hunt's terms. In this way, patients, as in the next extract, share personal anecdotes that enable them to show their personality through humorous expression:

Extract 5 (HCTRA3) Mary 50+ at home.

- 382 P: (T *husband*)'s in the back bedroom now you know why he's got um (.)
you wouldn't believe me yesterday (.) I turned the tap on and the radio
went on (.) and I turned it on and T was out the kitchen he was out the
toilet and I shouted to him he thinks I'm going mad anyway (*laughs*)
383 N: (*laughs*)

- 384 P: I said the wireless just come on and it's not switched in he said well don't be so stupid then it's got to be switched in I said and I'm looking at it and the plug is not swi/ the switch is not down and of course he panicked then because he said it must be live then (.) it just come on the wireless I've like something you see on the telly you know how they all disconnect everything to the wrong places and I turned the tap and the wireless came on (.) so I get my friend's an electrician so I phoned him straight away (*laughing*)
- 385 N: (*laughs*)
- 386 R: (*laughs*)
- 387 P: and I said J I just turned the tap on and the wireless came on he said what are you talking about
- 388 (*all laugh*)
- 389 P: anyway I came home last night well then he T we unplugged everything then (.) and when we when we came back in T plugged it in again and it came on again (.) not switched on it's just um going the plug's going (.) so um anyway one of my friends came over last night took it all out and he cut (.) all the wires or whatever and he blocked them all up so (.) you can't use it (.) but to get to have it done properly you got to go up in that room where the bathroom is
- 390 N: yes
- 391 P: because that's where the (.) whatever it is comes from you know where he's made the plug so what he's going to do now tonight J T going to take up all the carpet in there (.) and then they're going to bring new wires down through and then I'll have a new plug after (.) it was like (.) it was like something (.) I couldn't believe it I went like that (*facial expression*) you know
- 392 R: and N: (*laughs*)
- 393 P: and the one that came on (.) I mean lucky we knew I suppose really because the other the other one I got the toaster in although they're not on I got like a toaster in one and the wireless in the other one but um anyway my son's going to put that right (*unclear*) but it's all going I told you (.) my washing machine my tumble dryer the hoover (.) my kettle (.) sometimes it'll turn off and sometimes it won't that's temperamental as well and now (.) this went yesterday
- 394 N: yes
- 395 R: job [lot from Curry's
- 396 N: [*unclear*]
- 397 N: we'd better turn the tape recorder off before that goes
- 398 (*all laugh*)

This lengthy anecdote follows a classic Labovian (1972) narrative pattern, that is, the story line is based on a past event, made interesting to the nurse audience by its unpredictable content and uses a typical structure. It is uninterrupted by the nurse

despite the non-medical agenda. The nurse (and researcher) join in and enjoy the comedy of the ridiculous situation. The patient has an opportunity to entertain and demonstrate her sense of fun, quite distinct from her usual participant role in this context as a cancer sufferer. As she takes the emphasis away from issues relating to her illness and introduces talk about her domestic life she has, in effect, placed herself back in the wider world, dealing with household problems that anyone else could identify with. By these means she has temporarily created a distance between the self of her illness and the self of her past. This is partly made possible by the fact that she is still living at home and undertaking household chores as usual. Although there is a tension between her illness and normal household life, caused by a reduction in physical functioning, she can still draw on her previous identity as represented by her household possessions and her remaining role at home.

The above extracts have shown how affiliative laughter in the home care setting can help to progress the nurse–patient relationship. I will continue to examine data from this setting as I analyse instances of laughter that are not simply affiliative, and explore the reasons for their occurrence.

Nausea and vomiting, often the result of pain medication, are distressing and tiring symptoms to cope with in terminal illness. Olive, in extract 6, is having ongoing difficulties that are, as yet, uncontrolled. Complementary therapies, as the nurse discusses, can sometimes alleviate symptoms and are available at the hospice day therapy unit.

Extract 6 (HCTRA 5) Olive 70+

- 176 N: you know when I was here before we were talking about you possibly coming back to the day centre?
- 177 P: mm
- 178 N: to have some aromatherapy
- 179 P: mm
- 180 N: or reflexology
- 181 P: mm
- 182 N: what do you feel about that at the moment?
- 183 P: I'd love to I'd love to if we can get a day when I'm (.) well [(unclear)
- 184 N: [(unclear)
- 185 P: yes (.) um as I say after yesterday which was a (.) awful day you know I can't remember a day as bad when I was being sick for an hour or trying to be sick for an hour
- 186 N: yes
- 187 P: and not being able to and I was I was trembling you know I was sort of shaking with the (.) trying to relax you know and not oh dear we were in a real mess (*laughing*)
- 188 (.)
- 189 N: and when you went back to the flat
- 190 P: yes
- 191 N: did you go in a taxi or did V come and pick you up?
- 192 (.)
- 193 P: V came (.) and er I think that's where we went wrong (.) instead of staying two hours I stayed three
- 194 N: yes
- 195 P: and that was just too much
- 196 P: and I was I had to stop the lot on the prom because I felt as though I was going to be sick any minute you know
- 197 N: yeah
- 198 P: you know and I didn't want to be sick in the car
- 199 N: no
- 200 P: so I sort of (.) put my legs outside the car (.) I I wasn't actually sick I just [retched and retched
- 201 N: [it was that (.) sensation
- 202 P: yes that feeling of being wanting to be sick (.) anyway she got me back here and (.) I paid for it the next day in (.) you know (.) sort of one step back
- 203 N: yes
- 204 P: um (.) but then I thought well I mustn't do that again and I I mean they're willing to take me back again if I want to go
- 205 N: yes

The nurse uses a three-part question (176, 178, 180) to re-establish a previous conversation topic whilst the patient signals her recollection by minimal responses. The

nurse then places the past topic within the present time with a linked question, ‘how do you feel about that at the moment?’ (182), in order to offer Olive the option of accessing complementary therapies. Olive’s response, ‘I’d love to I’d love to if...’ (183), signals agreeable intention, using repetition for emphasis but also indicating a potential problem. She gives a vivid description of her experience of illness (185, 187), which is continued in (196, 198, 200, 202).

During the descriptive telling of her troubles she laughs, ‘oh dear we were in a real mess (*laughing*)’ (187). The nurse responds with a pause followed by a question but does not respond with laughter. This exchange follows Jefferson’s (1984) notion of troubles resistivity. Olive is putting on a ‘brave front’, thereby resisting her troubles and signalling her ability to manage whilst the nurse, although apparently invited to laugh, remains serious about receiving her troubles. The nurse’s response indicates that Olive can trust her to react appropriately thereby inspiring confidence as regards the telling of further troubles.

Humour, or at least laughter, is often used to reduce the impact of negative comments. In the palliative care settings it was used by patients and nurses to differing degrees. Nurses, despite aiming to create a relationship with the patient that is as congenial as possible, nevertheless are the coordinators of care and the gatekeepers of knowledge. As such, they must aim to advise and direct patients without tilting the already asymmetrical relationship too far. Nurses giving directives commonly use laughter in mitigation of the underlying message delivery, not always successfully. In the following extract the nurse is asking about contact details:

Extract 7 (HCTRA2) Sarah 30 years

- 50 N: did you say you'd got a mobile?
51 P: I have (.) would [you like its number?
52 N: [when do you turn it on?
53 P: I turn it on [about
54 N: [you don't you don't turn it on during [the day (*laughing tone*)
55 P: [I turn it on once a day to see if I've got any messages on [it
56 N: [oh
right
57 P: so [i/ if Big Brother's been on and I've been watching that I phone up
and see if my friends have texted me a message about it
58 N: so it would be worth
59 P: so (.) shall I go and get it and give you the number?
60 N: when you well we'll do it before [I go
61 P: [ok
62 N: leave my pen [out to remind me
63 P: [but yes I've got one (*unclear*)

The nurse has used a laughing tone (54) to limit the impact of her potentially aggressive contradiction of the patient, 'you don't you don't turn it on' (54). With her statement refuted by Sarah (55) the nurse backs down with, 'oh right' (56). The nurse would like Sarah to turn her phone on during the day but does not succeed with this mitigated directive approach.

Although nurses maintain a balance of power through the possession of professional knowledge, it remains the patient's choice whether to accept advice. The following extract sees Sarah using laughter to mitigate the effect of disregarding the nurse's advice in favour of her own psychological coping style:

Extract 8 (HCTRA 2) Sarah

- 405 N: how much Palfium are you taking a day?
406 P: um well I don't go every day and I've never had to take um two in a day
cause I didn't know whether I was allowed to
407 N: and they're five milligrams
408 P: they're five milligrams
409 N: you can take them

- 410 P: I had noticed that my pupils were um like pin pricks (.) about half an hour after taking a Palfium that was about one of the only times I took it (.) cause I know that is (.) sort of heroin in its working and I thought gosh this is very strong stuff
- 411 N: it's it's because it's absorbed quickly that you will get an immediate well not immediate about twenty minutes
- 412 P: oh I don't know I'm going to continue to fool myself into thinking that it's only about three minutes (.) from now on
- 413 N: well=
- 414 P: (*laughs*)
- 415 N: = if if you take it sub-lingually [that's the quickest way
- 416 P: [yeah

Sarah needs to believe that the pain medication will have an almost immediate effect (412) and laughs at the fact that she will consciously fool herself into believing that this is so, despite the medical information that the nurse has provided that contradicts her strategy (411). The nurse realises her anxiety and provides her with additional information in line (415) so that she may use the drug with best effect, without directly opposing her coping style.

In the home care setting I have noted the use of laughter for affiliative function and also as a device for managing the stress of troubles telling and for mitigation of directives. I now turn to the DTU setting where, on a patient and nurse one-to-one basis, many of these functions are still likely to still apply. However, the more limited time with nurses and the dynamics of communal socialising and interaction may highlight differences between the two settings.

7.8 DTU: Team work, troubles and teasing

In the DTU, patients are encouraged to take up different art and craft activities such as macrame or making greeting cards. It allows them an opportunity to work together and to see a useful output from their efforts. This, in some small way, may help in creating a

useful role for patients in compensation for all that they have lost in their illness. The cards are often sold as fundraisers for the hospice or, as often happens, patients make things for each other. In this way they can use a shared interest to show appreciation of each other as peers. A similar affirmation of group membership occurs when a patient aligns himself to the hospice by identifying the craftwork he has been working on as belonging to the institution. In the extract that follows, Bill is referring to another patient (A):

Extract 9 (DTU 2) Bill (P1), George (P2), Phil (P3) Males 70+ Communal talk

- 426 P1: of course the pull cords is my own (.) design like [you know
427 N: [oh the pullcords are
great
428 P1: you know
429 (...)
430 N: the pull cords are great
431 P1: and A wanted me to make half a dozen of them to send over to his
daughter to sell in America
432 N: yes oh ha export (*laughs*)
433 P1: Welsh export from (*hospice*)
434 N: you/ there you go (.) see (.) put us on the map

Bill takes great pride in his work and has taken it a stage further to create a new product (426). The nurse responds with praise twice (427, 430) when either the patient does not hear her initial comments or waits for the nurse to make further comments. The patient emphasises the worth of his product as he constructs the idea of mass production and international demand, ‘A wanted me to make half a dozen of them to send over to his daughter to sell in America’ (431). The nurse attunes to his need for praise and recognition and echoes his comments with exaggeration for humorous effect, ‘yes oh ha export’ (432) underlined by her affiliative laugh (432). The patient responds by taking up the exaggeration by positioning his work as being representative of Wales and the

hospice as an institution (433). The nurse responds by signalling her solidarity with her use of the inclusive pronoun 'us' (434) as she continues to exaggerate, 'put us on the map', which indicates geographical connotation as well as institutional affiliation.

In the following extract, David is the initiator of the humour at the expense of the researcher. This talk follows discussion of a planned operation on David's knee, unrelated to his cancer. Timing is obviously an issue as the pain is affecting his quality of life in the time he has left.

Extract 10 (DTU 6) David 40+

- 103 P: yes I I had the scan that's the main thing I had the scan done but no one asks like six maybe months years so by the time I've organized this to go in the (*hospital*) so looking at that I don't think it'll be years a few months I imagine the way he was talking (*unclear*) sort it out nothing I can do now can I (*unclear*) just wait (.) there we are (.) terrible pain with it (.) terrible (.) get more pain than I get with that you know walking sitting in the car oh (*unclear*) like an old man
- 104 N: mm
- 105 (.)
- 106 P: you haven't been taping me have you?
- 107 N: no
- 108 R: (*laughs*)

David talks seriously as he surmises what might happen and describes the pain he is in, 'get more pain than I get with that you know' (103), linking it implicitly to his cancer. Following his troubles telling, the nurse offers a minimal response and allows a pause. The patient then deflects from the seriousness of the topic with a comment that presumably is not to be taken seriously, 'you haven't been taping me have you?' (106). It is my laughter that follows the deadpan response from the nurse (107) because I am well aware, having carefully explained the study and the equipment and taken consent, that he is teasing me. He has used humour to distance himself from the potentially

distressing talk and, apparently in respect of his feelings, the nurse stopped the audio taping at that point.

As I have discussed in chapter 5, identity can be seen as outside of ‘self’ and represented or constructed by talk itself. Identity involves comparison with others and external viewpoints as the following extracts show. Laughter is used alongside reported speech to increase the impact of these self-reported comparisons.

Extract 11 (DTU 5) Catherine 50+ *Talking with nurse in communal area.*

- 7 P: I feel a little bit (.) well I’ve always had a a slightly pinker bit there for donkey’s years they thought I had lupus in my 30s (.) but yesterday and the day before absolutely blood red
- 8 N: it’s redder than it was last week [isn’t it yes
- 9 P: [yes I can’t touch it there it’s so sore
- 10 N: perhaps I’ll get (*doctor*) to have a [look at it for you today
- 11 P: [mm you know whether it’s chemo or
- 12 N: mm
- 13 P: but you know even my little grandson said to me on Sunday ‘your head’s gone bright red grandma’ (*laughs*) (.) and it has but it’s totally sore to touch (.) the bone feels sore to touch you know that feeling
- 14 N: yes

Catherine laughs at her grandson’s unguarded comment about her appearance. Her laughter is difficult to account for here as it could be taken as a sign of embarrassment, as mitigation of the perceived inappropriateness of such a direct remark, or simply as an indicator that she has taken enjoyment from the remark in a lighthearted way. Reporting the speech of a child (13), however, allows herself to be seen through a child’s eyes, and gives a vivid indication of how noticeably different the patient appears to others. Although laughter is used to lighten her comments, Catherine is potentially disturbed by her appearance and draws on the child’s viewpoint to express her concerns instead of

providing a direct troubles telling about what in the larger scheme of things could be seen as a trivial symptom.

In the DTU, as I have shown, the value of peer support is highly relevant as is the ability to make identity comparisons amongst peers. However, there is also the possibility that patients will compare physical concerns as well and this is not always valid or helpful.

The nurse role requires the co-construction of the patient-nurse relationship with the option of using humour for positive alignment. However, the role also involves giving advice or making requests that are a necessary feature of the professional role. Humour may be used as a means of mitigation in an attempt to reduce the asymmetry of the institutional nature of the relationship. It can also be used to lighten the stress of embarrassing or distressing talk or events. In the following extract, Colin has been concerned about his swollen legs and the nurse is assessing the problem:

Extract 12 (DTU1) Colin 70+ (D refers to other patient)

247 N: let's have a look
248 P: sorry (.) course I was looking at D's legs
249 N: mm
250 P: D's legs
251 N: oh right yes
252 P: they were red from down here to here
253 N: perhaps I need to look at his
254 P: yes (*laughs*)
255 N: (*laughs*)
256 P: no/ I don't know I I thought you know
257 N: unless he's been out in the sun of course
258 P: yes yes of course
259 (*laughter*)

Colin has noticed the condition of another patient's legs (248). Redness can be a sign of infection but whether Colin realises this is unclear. He places emphasis on the word 'red' to which the nurse responds, 'perhaps I need to look at his' (253). The incongruity of the situation, whereby the nurse is attending to a patient who seems to implicitly suggest that the nurse needs to look at *another* patient's legs in order to determine what is wrong with his own, gives an (ironic) edge to the nurse's comment. The patient realises that he is the cause of this teasing remark and his embarrassment shows in his hedged and hesitant withdrawal, 'no/I don't know I I thought you know' (256). The nurse is able to reduce the patient's embarrassment by transposing the medical symptoms to the mundane, i.e. the redness is due to too much sun (257). This observation propels the humour to the level of the absurd, considering the seriousness of the setting/situation, and thereby provides an opportunity for joint laughter which lessens the patient's embarrassment and leads to re-alignment of the nurse-patient relationship.

The main feature of the DTU, as it occurs throughout this study, is the element of peer support that is evident. Patients are able to be themselves amongst equals in this forum and enjoy socialising with like-minded individuals, unlike in the wider world where they are marked by the stigma of terminal illness. The following two extracts are an illustration of how this forum is guarded by the patients' rejection of nurses' attempts to talk about themselves, even when using self-deprecating humour.

Extract 13 (DTU2) Bill (P1), George (P2), Phil (P3) Males 70+ Communal talk

173 P3: I won't be coming [next week
 174 N: [oh right
 175 P3: because I'm on holiday

176 N: oh(.) fabulous where to?
 177 P3: south er (.) south Avon somewhere down there er
 178 P2: Somerset way?
 179 N: Somerset Somersat (*assumes rhotic accent*) Somersat excuse my accent
 it's dreadful
 180 P3: yes
 181 N: (*laughs*) well it makes a change me doing somebody else's accent than
 the other way round (*this nurse has a broad southern Irish accent*)
 182 P3: oh yeah aye (.) it's only for a week
 183 N: for a week (.) who you going with
 184 P3: with my wife
 185 N: oh right how you getting down there
 186 P3: bus
 187 N: oh you're getting the bus down oh that's [lovely

Phil resists the nurse's attempt at humour, i.e. with her lighthearted mimicking of a regional accent (179), in favour of his own concerns, that is, his wish to talk about his holiday. Phil agrees politely with the nurse's self-assessment that her accent is 'awful' but does not laugh (180). The nurse responds with a laugh, possibly due to her embarrassment that the humour was not taken up or perhaps at the directness of Phil's reply. She then tries to justify her humorous attempt (181). Phil ignores this completely by reverting to the previous topic, not acknowledging the nurse's contribution at all (182). He seems uninterested in her humorous attempts and seems to prefer to get on with his own agenda. The nurse's reaction is to continue with straightforward fact finding (183, 185) which leads to a positive appraisal of Phil's mode of transport (187). However, the nurse's questions are all met by minimal responses (184, 186). This further reveals Phil's lack of interest in the nurse's contributions. A similar incident occurs at the start of the interaction, in the following extract, involving Bill:

Extract 14 (DTU2) Bill (P1), George (P2), Phil (P3) Males 70+ Communal talk

- 6 P: is it switched on or (*refers to tape recorder*)
7 N: I am (.) see it's switched on (*laughs*) say hello to Annmarie (*laughs*)
[*laughs, more laughs*]
8 P: [stop/ (.) I'm/ yeah go on (*impatient tone*)
9 N: yeah/ no no it's just a talk to see how you are it's really just a normal
transaction
10 P: yeah yeah I'm not too bad but I've started to get a lot of indigestion very
bad again now

The nurse laughs loudly (7), and appears to be amused by using the tape recorder. Bill resists and sounds annoyed, 'stop/ (.) I'm/ yeah go on (*impatient tone*)'. He does not take up the nurse's suggestion to join in with the humour (8) and wants to get on with his own agenda. The nurse composes herself (9) and reassures him that all is normal, implying that the taping will not interfere with the normal business of the DTU, and she then allows him to carry on with his chosen topic. Although relational alignment is important within the nurse-patient relationship, The DTU is also undeniably an institutional context in which, ultimately, there is a job of work to be accomplished. In this instance it is the patient who wishes to report on his current status and he takes the lead to return to the medical agenda of business and his preferred topic, 'I've started to get a lot of indigestion' (10).

The two extracts above reinforce findings by Dean and Gregory (2005) who have noted that palliative nurses need to know when to use humour by observing cues such as timing, eye contact and markers of receptivity. Some nurses commented that they used humour to make fun of themselves to test for receptiveness. In both of the humorous attempts above the nurse instantly changes her interactional direction to more serious contributions.

Several functions of laughter in the DTU can be seen to match those of the home care setting. Troubles telling occurs in both sites of care, as does the need to manage the stress and embarrassment associated with disease. The communal aspect of the setting does, I suggest, impact on the occurrence of laughter within the interactions. Firstly, the notions of group belonging (extract 9) and the ability to make comparisons with other patients (extract 12) provided opportunities for humour that would not exist in the home care setting. Secondly, the limited availability of the nurse as a shared resource could have contributed to patients' apparent need to reject humour in favour of their own agenda (extracts 13, 14). Laughter as a result of humorous teasing was observed (extracts 10, 12) in the DTU and in what follows I examine similar occurrences in the in-patient unit.

7.9 In-patient unit: Banter and teasing

In the ward setting, often pairs of nurses work with a single patient to accomplish some form of physical care, as in the next extract which involves aiding a patient, Margaret, to walk up a flight of stairs. This is a form of discharge assessment that will enable Margaret to return home if she is able to complete the test of her mobility.

Extract 15 (IPU 10) Margaret 70+

- 71 N2: how many stairs you got at home Margaret?
72 P: 13
73 N2: fine
74 N3: so that counting 7 8 9 10 11 12 13 14
75 N2: that's more than full
76 N3: 13 (.) well every little extra helps
77 P: if I can do at least twice a week (.) once a day you know it would be good
(.) at least twice a day
78 N2: (*laughter*)
79 N3: it's easy done isn't it?
80 P: god (*unclear*)

81 N3: (*unclear*) walks what you are used to
82 P: that's right it all helps
83 N3: hmmm that's right (.) ok (.) good
84 P: excellent girls
85 N3: good (.) one more
86 N2: well done Margaret
87 P: thank you
88 N3: do you want a rest?
89 P: no
90 N3: you sure
91 P: no I'm fine (*unclear*)
92 N3: you sure?
93 P: absolutely (*unclear*)
94 N3: which side do you want me to go on
95 P: this side if that's ok
96 N3: that's alright (.) you alright?
97 N2: fine thanking you
98 All: (*laughter*)

It is hard work and a huge achievement to regain mobility when it has been compromised by illness and bedrest. Margaret's independence and sense of self relies on the ability to function as well as she possibly can. The nurses are working with Margaret with her best interests at heart and they are doing so using encouragement and praise (76, 83, 85, 86), with Margaret reciprocating in the same manner (82, 84). The use of laughter (78, 98) can be seen as a mitigating device when exaggeration or overstatement has been used. When Margaret comments, 'if I can do at least twice a week (.) once a day you know it would be good (.) at least twice a day' (77) Nurse 2 uses laughter in response whilst nurse three follows up with the comment, 'it's easy done isn't it' (79). Clearly it is not a task that is accomplished easily and the patient's expectations are too high. Nurse 2 does not voice her disagreement directly and relies on humour to deflect the awkwardness whilst Nurse 3 takes a more direct approach to verbalise with a comment that is not expected to be taken literally.

In the second half of the extract, both nurses have to negotiate their positions whilst also keeping Margaret fully informed of what is happening so that all movement can be synchronised comfortably and safely. In the process of extensive checking that is required before the movement they use an overly polite register (90, 92, 94, 96, 97). The exaggerated politeness is shared between all participants and thus becomes the joke. This is a typical example of the bantering style of teasing that can be observed in this setting as nurses and patients have to coordinate joint working. The affiliative laughter (98) signals that all parties are sharing the joke.

In the following extract, joint working is taken a stage further as the nurses (AN1 and AN2) tease each other about the division of work. The patient, Beryl, joins in to share the professional wisdom of the nurses in an alignment towards their domain:

Extract 16 (IPU 4) Beryl 70+ During a bed bath

- 30 AN2: is this one okay for me to move though just slightly
31 P: yea
32 AN1: that one's alright (.) I've got the good side then
33 AN2: you planned that didn't you (*laughter*)
34 AN1: I'm not daft (.) I think she's a little tinker at heart you know
35 AN2: I've been doing it for too long now B (*other nurse*) I know all the dodges
(.) I need to be a bit quicker off the mark
36 P: how long you been doing it now
37 AN2: oh (.) 17 (.) 18 years now sweetheart (.) a long time (.) so if I don't know
the dodges now
38 P: you never will will you

The reference to 'the good side' (32) is in relation to the unaffected body part, most likely an arm in this case. Good side or bad side are commonly used euphemisms for differentiating when assessing how to proceed with a move, as a different approach is required depending upon at which side each nurse is positioned. The bad side is

generally heavier to move and requires more care so as not to hurt the patient. The endearment 'sweetheart' (37) is typical of the ward setting, unlike home care and DTU where patients are usually addressed by their first names. When the nurses tease each other about the work aspect of the care that they are providing for this patient (33-35), Beryl takes an objective perspective and asks, 'How long you been doing it now?' (36). While this in effect diminishes Beryl's self yet further by removing her feelings from the care-task at hand, the nurses' openness and Beryl's inclusion in the talk relating to their world aligns her to them as a joint participant. Thus, by momentarily entering the others' domain the patient can distance herself from her own illness experience. In this extract, laughter signals the teasing aspect of talk which then enables interactional cohesion through alignment with the nursing community.

The following extract sees a patient, Arthur, taking the lead to tease the nurse with the suggestion of non-professional behaviour, i.e. swearing. The nurse responds with repetition and laughter thus validating the relational work initiated by the patient.

Extract 17 (IPU 14) Arthur 70+ *During a move from chair to bed.*

- 1 N1: you going to try some supper?
- 2 P: ohhh (.) what's that
- 3 N1: that's the tape
- 4 P: I know that's the tape
- 5 N1: that's ok with you isn't it?
- 6 P: yes (.) no swearing
- 7 N1: no swearing
- 8 P: no swearing
- 9 N1: (*laughter*) yes (.) as if (.) oh it's warm behind here isn't it
- 10 P: yes

Here the banter concerns unprofessional behaviour. The nurse has interpreted Arthur's comment (6) as referring to herself (although he could be referring to himself here). The nurse positions herself as not conforming to the institutional norms of professional behaviour. This may have the affiliative effect of lessening the institutional feel of the setting and provides less of a 'them and us' division between patients and staff. This bantering style of humour is typical of a ward setting and has also been observed by Sullivan and Deane (1988) and Grainger (2002). Astedt-Kurki and Liukkonen (1994: 185) have noted that, ' [t]easing created a cheerful and unaffected atmosphere on the ward, which helped the nurses to cope with the stress of their job', thus acting as a dynamic resource to create benefits for patients and nurses alike.

The potential or actual use of swear words can present the nurse as less professional and yet more humane. It allows the patients to see the individual behind the uniform and to know that the nurse is trusting them not to make a complaint about her 'naughty' behaviour, as in the following extract:

Extract 19 (IPU 7) Jean 70+ *During an assisted bath*

- 151 P: how old are you?
152 N: oh I'm forty this year (.) I should have lied and said I was 31 again (.)
let's have a look (.) bloody gorgeous
153 P: (*laughter*) no swearing
154 N: I've been very good
155 P: it needs a lot of work on it
156 N: it'll come
157 P: surprised when they told me it was a mini stroke
158 N: when did they tell you that
159 P yesterday
160 N: how long have you been here Jean
161 P just over a week I think
162 N: I've been off (.) did you have the mini stroke here?
163 P: woke up one morning couldn't move my legs or my arm
164 N: that's frightening isn't it (.) very scary isn't it

165 P: well I am 73
 166 N: well you don't look that kid (.) you don't look that at all (.) got lovely skin

Here Jean asks the nurse a personal question, 'how old are you?'(151). This request for self-disclosure from a patient is unusual within my data but is accepted and responded to by the nurse with playful banter. The nurse's self-disclosure, banter (152), and use of a swear word shows her willingness to engage with Jean and provokes affiliative laughter from the patient. Walter (1994: 97) comments that 'offering a listening ear while doing a practical task, especially if it involves physical contact such as rubbing a bottom or bathing a patient, is often hailed as the best form of holistic care'. This humorous exchange signals relational alignment and the patient is enabled to talk about a distressing experience (157-161). The nurse responds with empathetic comments and praise of the patient's appearance (166).

The style of humour in the in-patient unit was noticeably different to the other two settings. As I have noted above, the use of endearments and banter were fairly typical of this setting. I will discuss the use of over-accommodation in more detail in chapter 8, but I will pre-empt this slightly here with an example to show how ill-judged humour and over-accommodation, especially when occurring in conjunction, can cause offence to the patient and lead to an aggressive response.

Extract 20a (IPU 14) Arthur 70+ Moving from chair to bed. There are 4 nurses present including the ward sister (S).

69 N: right 1 2 3 (.) stand up (.) 4 up up (.) hang on (.) hang on (.) go back (.)
 sit up (.) hang on hang on
 70 (laughter)
 71 S: Arthur (.) what are they like
 72 P: they're good

- 73 S: they're good are they
74 N: yesterday (.) Arthur told me you're so good I could marry you and I told
him (*unclear*) you are in a long queue
75 (*laughter*)

This extract begins with lighthearted banter, as the four participants seem to have difficulty in coordinating the patient's movements. The Sister in charge aligns herself to the patient as she asks for his opinion of the other nurses' skills in a potentially disparaging way, 'what are they like?' (71). Further banter follows with a repeat of the repartee from the day before when Arthur had joked that he could marry one of the nurses. However the lighthearted mood changes as the extract continues:

Extract 20b

- 76 N2: Arthur (.) why don't you stand up a little bit and then you can move up
the bed before you sit down and that'll be a lot easier for you (.) stand up
lovely (.) step up to where M (*other nurse*) is now (.) that's the way (.)
one more (.) a bit more towards me (.) a bit more (.) you can sit down
now (.) that's more comfortable (.) oops (.) okay
77 AN2: I can see you Arthur
78 P: you think I'm stupid do you
79 S: not at all

Banter turns to baby talk with the use of the endearment 'lovely' (76) and notably with the teasing peek-a-boo comment 'I can see you Arthur' (77). The patient makes a bald accusation, 'you think I'm stupid do you' (78), as he perhaps feels his identity as a competent adult may be threatened. This is quickly negated by the Sister in charge, although the damage has already been done.

Astedt-Kurki and Isola (2001: 453) have noted that ‘during a nursing procedure humour may manifest itself in a verbal ‘howler’ or a facetious remark and it may serve to create a positive atmosphere and relieve the tension’. The ‘peek-a-boo’ comment in the above extract failed to have this effect, as does the attempt at humour in the following extract, involving Elin during an assisted wash.

Extract 21 (IPU 11) Elin 70+

- 17 N2: right who’s the one that’s playing widow twanky in your family and
taking all the washing
18 P: well whoever comes
19 N2: whoever (.) whoever is first to visit gets the washing?
20 (*laughter*)
21 P: so everybody tries to be the last one
22 N2: so everybody tries to be the last one to come through the door
23 (*laughter*)
24 P: well it’s not much washing is it
25 N2: no (.) I didn’t know

The nurse’s attempt at verbal play begins with a lighthearted comment about ‘widow twanky’, a pantomime character associated with washing clothes (17), in reference to the relative that will attend to the patient’s laundry. The nurse expands on the joke by presenting the washing as a prize to be won by, ‘the first to visit’ (19). Elin joins in with the joke with her comment, ‘everyone tries to be the last one’ (21), which is repeated by the nurse. The repetition and affiliative laughter indicate relational alignment. However, although the humour has been successful, the patient’s next comment reflects her unease, ‘well it’s not much washing is it’ (24). As I have discussed, many patients are sensitive to the fact that they are a burden to their families. The nurse’s well meaning comments have, perhaps, exposed this vulnerability and seem to be acknowledged with the nurse’s comment, ‘no (.) I didn’t know’ (25).

7.10 Chapter summary

In this chapter I have looked at the functions of laughter as it appears across the care settings. In the home care setting it can be seen that laughter occurs in conjunction with other features of talk, including repetition and an overlapping, jointly constructed pattern of interaction to signal joint working and relational bonding. The home care setting entails a one-to-one relationship whereby the nurse and the patient 'belong' to each other according to caseload. This was the only setting where extended personal narratives by patients were observed. I have shown how this enabled the patient to share her sense of fun and affirm her identity by telling a personal anecdote. The topic of the narratives was not always medical or related in any way to the nurse agenda. Laughter was furthermore used to relieve the stress when talking about difficult issues and by nurses in mitigation of directives.

In the DTU setting, two displays of humour by the nurses were seen to be rejected by the patients who were more focused on the need to continue with their own agenda. Patients measured their identity against others and often used humour within reported speech and comparison with their peers. Here, as in the home care setting, laughter was used to manage and mitigate embarrassment and stress.

The in-patient interactions were usually between a patient and more than one nurse, and could be characterised by significantly more verbal play and banter than in other settings, especially when necessary to reduce social distance during intimate procedures. It is in this context that patients' identity is at its most reduced and the surrounding semiotics, i.e. nightwear rather than comfortable day clothes and lack of personal belongings, also contribute to this effect. In this setting I showed how misjudged banter

can cause offence and that the inappropriate use of humour by nurses may lead to relational misalignment with the patient.

The differences in the style of interaction across these three care settings will again be explored in the following chapter, which discusses a different form of verbal play, metaphor.

Chapter 8: Metaphor and metaphoric idiom in the palliative care setting

8.1 Chapter overview

In the previous chapter I have discussed how laughter and humorous lightheartedness is evident across each palliative care setting and serves a range of functions. Allied to the use of laughter in these respects, i.e. informed by the mutual need for joint appreciation and understanding, is the use of metaphor and metaphoric idiom. Metaphors may also be used to explain the unfamiliar or to see the world from a new perspective, thus allowing alternative meanings to develop. Metaphoric expressions can include a word or a phrase to accomplish the communication of complex thoughts whilst at the same time providing a mental cue to the listener to direct his/her thinking.

In section 8.2 I will provide a theoretical background by discussing basic metaphor theory and types of metaphor. This will be followed by a discussion of metaphoric idioms in section 8.3, which are mainly found in the data from the in-patient unit. Section 8.4 will provide an account of the most relevant research concerning metaphors in relation to pain and symptom description. I have discussed the taboo nature of talking about death in Chapters 2.4.1 and 5.5 and I bring this notion forward in this chapter where I will argue that metaphors are a feature of emotionality and may therefore be used to facilitate sensitive talk about dying. What I will highlight following these discussions is the notion that metaphoric expression may be used to communicate complex or difficult thoughts or concerns. Looking at patients from a social perspective, as this study does, it is clear that emotional alignment is of great importance when

dealing with patients who may be feeling increasingly withdrawn from their social networks. The ability to attune to patients' viewpoints may be made easier by a mutual understanding brought about by the effective use of metaphoric expression. Analyses of metaphor and idiom, in the context of their production and with a thematic focus on social death and hope, will then be undertaken across the three settings.

8.2 Theoretical background

Lakoff (1993: 202) notes that '(i)n classical theories of language, metaphor was seen as a matter of language not thought', a superficial literary ornament. 'The word metaphor was defined as a novel or poetic linguistic expression where one or more words for a concept are used outside of its normal conventional meaning to express a similar concept' (ibid). Lakoff and Johnson's (1980) cognitive theory of metaphor, however, suggests that metaphors are not merely poetic linguistics, but an expression of the structure of thought. They argue that 'the essence of metaphor is understanding and experiencing one kind of thing in terms of another' (1980: 5). Their basic thesis is that metaphors contribute to the creation of meaning and perspective, indicating the prominence and importance of metaphor as a linguistic construct in everyday lives as meaning is created and assigned metaphorically.

Lakoff sees everyday metaphor as:

A cross-domain mapping in the conceptual system. The term metaphorical expression refers to a linguistic expression (a word, phrase, or sentence) that is the surface realization of such a cross-domain mapping (1993: 203). (original emphasis).

In other words, metaphors not only make our thoughts more complex, they actually structure our perceptions and understanding. Lakoff (1993) reasons that metaphors

structure the social and cultural origins of metaphor models, as can be seen by the changes in metaphors across time. Due to the nature of this study, I would like to emphasise the role of metaphor in constructions of identity, which naturally leads to a discussion of the relationship between metaphors and self.

8.2.1 Metaphors and self

Damaged or reduced identities caused by the process of social death are a recurring feature in this study. The use of metaphor can relate to identity and self-image or projection. By examining nurse–patient interactions with this in mind I will show how the metaphoric ‘burden’ of disease is articulated. Moser notes that:

The self is a 'classical' research topic for metaphor analysis, because people can only speak metaphorically about the complex and abstract matter of the 'self'. Analyzing metaphors thus not only gives access to the tacit knowledge and mental models which shape the individual understanding of the self, but also to the cultural models provided by language to express individuality, self-concept and the 'inner world'. (2000: online)

Moser found that metaphorical expressions used in narrative interviews in self-description can be differentiated on different levels. Source domains, i.e. the conceptual domain from which we draw metaphorical expressions which are used to talk about the self were limited, with just 22 metaphor source domains reliably identified. These derived from a large corpus of 4,000 metaphorical expressions, with the most frequent eight metaphor source domains already describing 68 percent of all metaphorical expressions used. Moser notes that the metaphors identified most likely represent the shared cultural understanding of the self and that significant differences in frequency could be found within these 22 metaphor source domains, depending on gender, professional education and preferred life styles of the subjects interviewed.

Lakoff and Johnson's analysis of the metaphoric self sees that the self encompasses everything about the individual, and can be represented by a person, object, location, physical organ, body, motion, social role and more (1999: 268-270). From this concept arises the theory that metaphors of self usually include the schemas of self as container, as I will demonstrate in section 8.6. In an illness or identity-threatening context this may become clearer. Consider the phrase, for example, 'I'm not feeling myself today', which can relate both to feeling physically unwell and to mood. The metaphor reveals that in the patient's view their usual 'self' has temporarily disappeared to be replaced by a different, lesser self. In the context of palliative care the aim is to help the patient through psychological rehabilitation¹⁷. An awareness of how patients might express themselves through metaphor is, therefore, a valuable assessment resource.

8.2.2 Orientational metaphors

Orientational metaphors are particularly relevant to the palliative care context with their strong alignment to ways of expressing the physical self. Orientational metaphors, following Lakoff (1993), do not structure one concept in terms of another but instead organise a whole system of concepts with respect to each other. They are known as orientational metaphors since the majority of them are related to spatial orientation, up/down, in/out, front/back, on/off, deep/shallow, and central/peripheral. These spatial orientations arise from the fact of our physical make up and how we function in our physical environment. The conceptualisation of the bodily self through metaphor reveals a strong spatial alignment, with the embodiment of mind relating directly to the human worldly physical experience.

¹⁷ Following the World Health Organization definition of palliative care, Chapter 2.

Oriental metaphor is easily understood, due to shared experiences and environments. They attribute a concept with a spatial orientation; for example, happy is up and sad is down. Referring to mood, the orientational up/down schema relates well to emotional feelings in a physical way. To be low in mood is to feel burdened and weighed down in contrast to a good mood whereby the feelings are of lightness and positivity. Patients use this schema frequently, 'he was so down' and 'I'm a little bit low today', as an indicator of mood. These examples are commonly used and easily understood by nurses and patients alike.

Oriental metaphors may also be used as euphemistic terms to cover the embarrassment of naming intimate body parts, especially, perhaps, in the case of elderly female patients, who constitute the majority of palliative care patients. This can be related to Goffman's (1967) notion of facework and the preservation of self-image. Face is the favorable social impression that an individual wants others to have of him or her. The main characteristics of face are that it is social, i.e. it is only created in relational contexts. These usual aims of a social individual may be compromised within the nurse-patient relationship by the act of receiving intimate care. The use of euphemism and metaphoric expression can lessen embarrassment, especially when dealing with what are considered to be taboo terms. In the ward environment, euphemistic means of expression will be used by both patients and nurses especially in the context of intimate care, 'is it ok if I freshen up down below' (nurse), 'right I think I've creamed myself below' (patient). Another form of metaphoric expression is the use of idioms, reviewed in the following section.

8.3 Metaphoric idioms and over-accommodation

The usual linguistic definition of idiom is a group of words that has a meaning that cannot be arrived at by understanding each of the individual words and using normal principles for putting words together (Grant and Bauer 2004). For example, 'the cat's got her tongue' has no literal interpretation but, as an idiom in common usage, it means that the person referred to isn't saying anything. It is an informal use of language but not classified as slang due to its permanence, neither is it jargon or argot.

As I have shown in chapter 7, the use and functions of laughter and humour are contextually sensitive and this is also the case with metaphoric idioms. Laughter in the ward setting tends to be mainly occasioned by banter and verbal play and this is a significant diversion from the two other sites of care. As I shall discuss in section 8.8, metaphoric idioms can also be categorised as verbal play and so this section is very much linked to the previous chapter. As I have previously commented, banter and laughter are used to reduce social distance as quickly as possible in order to lessen the embarrassment and loss of dignity when giving and receiving intimate care. I suggest that the use of metaphoric language attempts to fulfil the same function.

Accommodation is defined by Giles, Coupland and Coupland (1991) as the ability to adjust, modify or regulate one's behaviour in response to another as an unconscious act. Over-accommodation is an exaggerated form whereby participants respond to the assumed qualities of a social stereotype and adjust their language accordingly. This is especially the case in younger to older speakers where the perception of the elderly is of having reduced cognitive and sensory functioning (Giles *et al* 1991). I will introduce

this concept alongside the analysis of metaphoric idioms in the context of the in-patient setting in section 8.8.

In the following section I will discuss how metaphors can be used to facilitate sensitive communication about complex, sensitive or taboo topics.

8.4 Metaphor in health consultations

Skelton, Wearn and Hobbs (2002) undertook a concordance-based study of transcripts of 373 consultations with 40 doctors in a U.K. general practice setting. They used comparators such as 'like' and emotive verbs like 'feeling' as triggers to begin a systematic exploration of metaphoric expressions within the data. The researchers concluded that 'different patterns of metaphoric expression suggest that doctors make limited attempts to enter the patient's conceptual world' (Skelton *et al* 2002: 114). The study found that although there were no significant differences between the doctors and their use of particular metaphors, there was evidence of clear distinctions between doctor and patient metaphors. Doctors tended to use metaphors using the body as machine schema. For instance, the urinary tract was the *waterworks*, bodies could be *repaired*, and joints suffer *wear and tear*. Illness is conceived as a puzzle with symptoms acting as *clues* to *problems* that have to be *solved* and the doctor is a controller who will *administer* medication to *manage* symptoms and *control* disease. Alternatively, patient metaphors, they note, were more vibrant, expressive and characteristic of their own experience with examples, such as, *It's like Satan's got into her*, *I'm the cotton wool man*, *It's like a Chinese burn, it just gets tighter and tighter* and *as though my body has been pummeled*. Even when doctors and patients used the same words, such as *tension*, *relaxation* and *nerves*, doctors tended to use them literally while

patients used them metaphorically. Patients used metaphors such as *dull*, *stabbing* and *sharp* to describe aches and pains, but these words were not echoed by the doctors taking part in the study. This seems to indicate the differing experiences and priorities of the patient and doctor. The patients' focus is on communicating their own personal experience of illness whilst the doctor focuses on the literal meanings necessary to assign a diagnosis and treatment plan. Although the researchers found that several metaphors were used equally by doctors and patients, illness is an *attack*: as in heart, asthma and panic *attacks*, *fighting* infection, *painkillers*; and illness is fire: *burning* pain, *inflamed* condition, symptoms *flaring up*, the study concluded that doctors and their patients 'talk different languages' (Skelton *et al* 2002: 118).

The use of metaphors in health care, then, can function as a means to reduce the distance between the patient and the health professional's experience of illness, but can also be illustrative of the chasms that may be evident between two domains, i.e. the clinic and the subjective illness experience of the patient.

8.5 Nurses' and patients' use of metaphor in talk of death and dying

Difficult interactions are helped by the use of metaphor, which has been shown to be a feature of emotional communication (Gibbs and Nascimento 1996). If it is true that some doctors are finding it difficult to communicate openly about death and dying, the effect on patients is to cause further isolation and withdrawal. However, since nurses provide most hands-on care and will have a greater opportunity to talk with patients it is more likely that difficult conversations will be dealt with at the nursing level. Equally, the quality of the nurse-patient relationship, with nurses using the 'discourse of the

social' (Fisher 1991: 157) as opposed to the clinically led talk of doctors, conspires to facilitate talk about sensitive topics.

The topics of death and dying are integrated into nurse education at an early stage and in practice are based on the spiritual needs of patients. Talk about dying is difficult but encouraged within the hospice. The policy is that nurses respond to questions openly or take cues to tell the patient as much as he or she wants to know and preferably no more. Discussions about dying inevitably occurred across all three settings as nurses assessed the needs of patients and answered their questions.

Death as the ultimate taboo in modern secular society is often spoken of by patients in association with spiritual metaphors, e.g. 'there's no prayer for you mate' (DTU 6), 'all of us one day have got to (.) meet our maker' (DTU 6). The death as departure metaphor is also used frequently, 'you get to know people and then they go so soon' (IPU 13). Talk of the inevitable experience common to all, recurs frequently. Some patients are comforted by the fact that everyone will have to die and that they are not alone in this, i.e. we will all go to a common place to 'meet our maker'. Alternatively, an 88 year old elderly lady living with very unpleasant symptoms was ready to die and referred to her terminal cancer as the result of her long life, accepting it as one thing of many that could cause her inevitable death, 'I'm dying of old age' (HCTRA 4).

8.6 Home care metaphors: The value of talk and symptom description

The relatively high frequencies of personal narratives in the home care interactions give patients the opportunity to talk subjectively about their illness experience. In the first of three linked extracts from the same interaction, a question from the nurse about pain is

linked to a series of further questions, assessing the type of pain and medications in detail, all eliciting vivid descriptions from the patient, Mary. In the second extract, the nurse takes further notice of Mary's subjective choices when she moves on to discuss them and thereby give importance to the patient's use of her religious faith as an alternative, non-medical coping device. This is followed in the third extract by the nurse's introduction of a patient facing similar difficulties. This acts as another viewpoint to give a sense that Mary is not alone in her situation. The use of metaphor by the patient occurs throughout these exchanges as she describes her feelings in her own words.

Extract 1a (HCTRA3) Mary 50+

- 94 N: what about pain?
 95 P: no I'm ok (.) I've um (.) had a couple (.) you know here but its
 been both sides like a tightness I was saying to S on Monday
 96 P: it feels (.) all like tight around here
 97 N: are you bigger there?
 98 P: well I I'm going up and down here
 99 N: yeah
 100 P: you know I seem to come up and then I seem to go down
 (*unclear*) I wouldn't say I'd put a lot more [on (.) no
 101 N: [no
 102 P: it just feels tight (.) you know
 103 N: that's a different sort of pain then [isn't it
 104 P: [yeah yeah
 105 P: I used to get the pain there [I haven't I haven't got that so
 much now
 106 N: [just under
 107 P: but I did have it both sides but it was like a (.) it wasn't a
 pulling [it was a tightness
 108 N: [yeah
 109 P: more than anything like you (*inhales*)[you know like that
 110 N: [yeah
 111 P: but um (.) it's ok you know and I just take painkillers now
 anyway
 112 N: you're [just taking the usual are you
 113 P: [yeah yeah
 114 N: not tried any?
 115 P: I'm just taking them you know [like I do

- 116 N: [yeah
 117 P: and then uh I got I think it's just I got so much faith in them
 that I feel better after I've taken them
 118 N: and you've not needed any morphine?

Mary describes her pain several times as 'tightness' (96, 107). The nurse initially uses this information to assess if there is further clinical significance by checking to see if the tightness is in relation to increase in size, 'are you bigger there?' (97), due to fluid or possibly tumour growth, before recognising it as a new type of pain for the patient (103). Mary expands her description by drawing on the use of contrasting metaphors to explain in greater detail, 'it wasn't a pulling it was tightness' (107). Her metaphoric description is enhanced by the imagery of one pulling in opposition to the other, thus giving a sense of the dense quality of her pain. As the interaction continues the nurse shows her alignment to the patient's world, apparently triggered by the latter's mention of the word 'faith' (117), to enquire about, and so give credibility to, an alternative, non-medical coping strategy.

Extract 1b (HCTRA 3) Mary 50+

- 120 N: what about the holy water
 121 P: well I well I use that when my legs are playing up (*laughing*) yeah I've
 used gallons of that and I mean
 122 N: where do you get it from?
 123 P: when I went to Lourdes
 124 N: yes but have you how much did you bring back
 125 P: oh God (.) I've got a big container like that you know and then I brought
 another one like that last year so I've still got quite a bit in both of them
 126 N: yeah
 127 P: in both [the containers so I use the bottles like that to put it on when=
 128 N: [right
 129 P: =um when the legs are performing (.) but like the legs and after the
 chemo like next week I'll be using it because you know you have the
 chemo on a Wednesday and on Friday until like the middle of the

following week (.) you know that you're going to have [terrible pains in
your legs you know
130 N: [yes (.) yes

Mary uses a metaphoric description of her symptoms, 'my legs are playing up' (121), and 'performing' (129), which gives a sense that she sees her symptoms as deviating from the healthy body that she might usually expect. Her switch between the use of 'my legs' (121) to 'the legs' and 'your legs' (129), I suggest, could be explained by her underlying detachment and resentment of those body parts that are causing her life to be disrupted.

Lawton (2000: 94) has noted the use of metaphors by palliative care patients in relation to loss of self when patients tend to use 'object-like self conceptions' particularly in connection to loss of mobility. Typically the patient might comment that they are a 'burden' or a 'waste of space'. I would suggest that Mary's expressions are the beginning of a process that will lead to further mental separation from her body as her physical degeneration continues. As the interaction continues, the nurse brings another voice and illness experience to the consultation when she talks about another patient.

Extract 1c (HCTRA 3) Mary 50+

131 N: yes [I was talking to somebody yesterday=
132 P: [that's when I (.)
133 P: were you?
134 N: = yes he's on Taxol and she was saying exactly the same
135 P: she has it in the legs as well
136 N: yes
137 P: yeah
138 N: yeah
139 P: yeah (.) oh terrible (.) it's something you can't explain it's like all your
veins are on fire (.) you know and your toes are [all tingling

140 N: [yes
 141 N: that's exactly the same
 142 P: yeah (.) yeah (.) it's the Taxol is it then
 143 N: I think so [yes
 144 P: [yeah

Mary gives a particularly vivid account of the strange side effects of this drug (139), seemingly animated by the thought of the other patient. It is as though by the introduction of a third person, the nurse acts as a conduit through which the patient can relate to the experience of another patient, knowing that they will empathise with her description. I have discussed elsewhere (chapter 6.7) the patients' need to make comparisons of self with their peers. This interest in comparisons can also relate to the physical aspects of illness as seen above. The feeling of isolation due to an increasing social withdrawal is eased by the knowledge that other patients have a parallel understanding of the illness experience.

In the following extract Mary speaks with appreciation of the ability to talk openly with home care nurses in their own 'language' (473), again using metaphors to convey the positive effect of being able to offload her worries.

Extract 2 (HCTRA 3) Mary 50+

441 N: =and yet [you know the difference that it makes=
 442 P: [I think it helps
 443 P: yeah
 444 N: =when you go and see somebody=
 445 P: that's right
 446 N: =who explains [things to you
 447 P: [yeah definitely
 448 N: or the times [that you meet people that
 449 P: [or you feel like I feel that I can say anything I wanted to to
 (*home care nurse*) or to (*Tenovus social worker*)
 450 R: mm

451 P: things that I wouldn't say to my own family or (.) or [to friends or anything like

452 R: [right yeah

453 P: that but you just feel you can open up you know

454 R: and cause you're in your own home as well

455 P: that's right (.) yeah I think you can just open up and say what you know what you want or ask what you want [to as well

456 R: [mm

457 R: yeah

458 P: cause I found it have helped well I told you I told them up at the hospital you know that er (.) I find it a lot and my a friend of mine her son is just is got (.) have found out he's got cancer and I told her (.) cause you do need somebody to talk to

459 N: yeah

460 P: you know (.) at certain times you really feel that you want to (.) get it all off [your

461 N: [yeah

462 P: chest (.) you know

463 N: yeah

464 R: mm

465 P: so (.) many a time I've sat here with S (*Tenovus social worker*) and I've sat and cried my eyes out but you feel better after you know

466 R: who's S?

467 N: S.H. [the *Tenovus* =

468 P: [um

469 R: oh right

470 N: = social worker

471 P: like a social worker yeah (.) she [come and

472 N: [she and I keep in touch [as well if there's anything

473 P: [touch yeah this is it and if I want to know anything I always ask (*home care nurse*) cause she tells me in our language

474 R: yeah

475 P: you know at the at the hospital I think (.) they tell you and it sort of just all goes in and you er it's the big words and you don't really know what they're talking about

476 R: yeah

477 P: so (*home care nurse*) gets my report then and then she'll tell me like you did last week didn't you I'll say well what's this [meaning what's that

478 R: [yeah

479 P: and then you know really then what's going on (.) you know much better

480 R: yeah

481 P: you know cause you don't really understand the (.) the way they tell you up there

482 R: no

483 P: you know I know it's their way of saying things but and you know when you're in there you're so nervous anyway when you know they're going to tell you the results they you'll only take part of it in

Here again it is clear that patients need to be able to talk to people outside of their social network, either due to their need to protect their family from their distress or to be able to talk to people with some understanding of how their illness is affecting them. Their sense of isolation is increased by the inability of outsiders to subjectively attune to their illness experience, 'there are things that I wouldn't say to my own family or (.) or to friends or anything like' (451).

Orientational metaphors using the body as container schema are much in evidence here as the images of the relief gained by releasing the burden of repressed communication are conveyed, 'you just feel you can open up' (453, 455) and 'at certain times you just want to get it all off your chest' (460, 462). The body is seen as the container for emotions or the 'self' and there is a need to share this self with empathetic individuals for some relief of the complex issues faced by patients. The ability to talk openly with the home care nurse is highlighted by Mary's description of the reformulation work done by the nurse to explain clinical information in a way that Mary can understand, 'so (*home care nurse*) gets my report then and then she'll tell me' (477). This is in contrast to Mary's perception of the inadequate mode of communication used by doctors at the hospital, 'you don't really understand the (.) the way they tell you up there' (481). She thus highlights the need for using language effectively to attune to the patient's subjective cognitive abilities. The following extract (not discussed) involving Olive, echoes Mary's choice of metaphors in expression of the same concept (356, 359).

Extract 3 (HCTRA 5) Olive 70+

- 356 N: here's some of the things that I think when I first came to see you (*name of patient*) was being incredibly brave um (*laughs*) it wasn't till I was going was it I was [just about to leave
- 357 P: [that's right yes that I (.) suddenly (.) opened up (*laughs*) well you're a person that I can open up to you know
- 358 (.)
- 359 P: so and I felt that I was bottling such a lot up inside me [that I had to talk to somebody about it so I did and I'm glad I did
- 360 N: [yes

8.7 DTU Metaphors: Talk about dying

As I have noted, talk about dying occurred across the three settings and commonly involved metaphor use. In the DTU setting I will consider two extracts from the same interaction; the first examines the patient and nurse's use of metaphor for death talk and the second looks at how a misunderstood metaphor results in major interactional difficulties.

Extract 4 derives from an interaction between an elderly patient of Greek origin, Colin, and a specialist palliative care nurse. The nurse has chosen to use a consulting room for the meeting. It is a difficult consultation and the patient has already broken down crying twice. He is very ill and is trying to cope with increasing symptoms including vomiting and fitting. He is very concerned about the wife and daughter that he will leave behind. This extract follows some routine talk about equipment and how the patient is managing to care for himself at home.

Extract 4. (DTU 1) Colin 70+

- 318 P: oh a lovely bath (.) oh yes
319 N: ok
320 (.)
321 N: is there anything else you can think of?
322 P: no I think er I think that's the lot really how do I know when the time comes you know
323 N: mm (.) that's tricky
324 P: tricky yes I dare say I you know we're not medical people you [know
325 N: [mm
326 (.)
327 P: say you're feeling very tired very weak and falling asleep all [the time you know (.) go in a coma something like that you know (.) then you die
328 N: [mm
329 N: I mean everyone's different [really
330 P: [of course
331 N: but generally people start to feel (.) more tired (.) things become more of an effort
332 P: that's right
333 N: and then you start spending more and more time in your bed [really
334 P: [bed
335 N: um
336 P: that's right
337 N: because people feel really really tired so I guess what a lot of what um (*Doctor*) said is er is fairly fairly true
338 P: oh yes it's alright yeah (.) yeah
339 (.)
340 N: is it worrying you how it's going to be?
341 P: not really because/ (.) no I don't think so (.) I mean if you can take the road (.) and walk with God (.) no I don't think so (.) not yet anyway (.) cancer might be (.) but you know I mean (.) I don't think so (.) but it's the knowing that you're going to go one day/ it don't bother me cause we all got to go but er (.) knowing this thing is going to kill you (.) (*sigh*)
342 N: it's hard to get your head round isn't it
343 P: extremely yes

This segment of talk occurs as the nurse begins to wind down the session. As so often happens (cf. Hunt (1991) in the home care context), patients leave it until the last possible moment before broaching their most sensitive concerns. Despite the fact that the patient has already broken down twice, the nurse allows space for further concerns with the invitation 'is there anything else you can think of' (321). Colin states that he

has finished but then, without pausing, moves straight into a very difficult question for the nurse to answer, “how do I know when the time comes’ (322). I have not transcribed the intonation but the patient uses the same pitch and tone throughout the speaking turn, as though he has not changed topic at all and ‘disguised’ the question in normal talk.

As can be seen, the word dying is not used overtly. Instead, Colin uses the metaphorical expression ‘when the time comes’ (322). What the patient wants to know is how he will recognise when he is dying, but what the nurse is aware of is that dying can take many different forms, making this question difficult to answer with any certainty. The nurse’s tactic is to avoid answering the question directly by hedging, ‘mm that’s tricky’ (323, 325) followed by a pause. Colin is forced to state his position of lesser knowledge, ‘we’re not medical people you know’ (324), and then formulate possible answers for himself (327) in order to draw the nurse into the topic. Eventually, the nurse addresses the question in the most general terms, giving a fair but euphemistic explanation, which likens the dying process to becoming more and more tired (331, 333). Death then can be assumed to be like falling asleep. Sleep has been used as a metaphor for death from the New Testament onwards, but it also has a basis in fact during the actual dying process when patients are likely to become semi-comatose when death is close.

The patient’s version (327) seems to follow the ideal of the above but the comparison of sleep to a state of semi-consciousness is simplistic and dubious. The nurse echoes the metaphor by taking up Colin’s version without further elaboration. The nurse uses hedging devices by speaking generally in the third person (331, 337) and by redirecting to a previous talk with the DTU doctor (337). In this way the nurse has been careful to answer the question in the patient’s terms and has offered no more information than

necessary. The nurse has also directed the talk away from Colin's personal domain to reduce the impact of his explanation.

However, after a pause the nurse expands on the topic from a different direction, typical of the nurse's 'discourse of the social' (Fisher 1991), i.e. how does this feel for the patient? 'is it worrying you how it's going to be?' (340). Clearly, as evidenced by repeated pauses and repetitions, Colin finds it difficult to express his feelings and uses the metaphor of death as a journey to convey the comfort gained by his spiritual beliefs, 'if you can take the road and walk with God' (341). The denial of death as the end of everything is further compounded by the metaphor of death as departure, 'you're going to go one day', 'we all got to go' (341), but in Colin's view he takes comfort in the belief that he is leaving to go elsewhere on a spiritual journey. The nurse responds empathetically using the orientational metaphor of mind as container, 'it's hard to get your head around' (342), to suggest understanding of the enormous issues that the patient is dealing with. The combination of hedging and the use of metaphor in this extract has facilitated very difficult talk for both speakers.

However, the use of metaphors must also rely on conceptual competence and mutual understanding. The figurative and subtle language of metaphor contains terms that can also be understood literally and unless participants are (metaphorically) 'singing from the same hymn sheet' misunderstandings can occur.

8.7.1 The consequences of gaps in understanding metaphor

The next extract is from the same consultation and occurs slightly later following talk about to clarify the reasons why certain surgical options are unavailable to this patient, as well as other symptoms and drugs.

Extract 5. (DTU 1) Colin 70+

- 377 N: are you getting any headaches?
378 P: sometimes (.) yes yeah but er don't bother me I don't take anything for it you know (.) once a week (.) and I get it right there is it possible to have some tablets to go to sleep (.) you know
379 N: afraid not (low tone)
380 P: 's alright fine (.) my wife again asked asked I must get I said I don't think so but anyway I did ask
381 N: no um
382 P: no
383 N: we're not allowed to do that in this country unfortunately
384 P: righto
385 (.)
386 P: no (.) I meant/ (.) to go to sleep at night
387 N: oh go to sleep at night sorry
388 P: no no no no [no
389 N: [I've got the wrong [end of the stick (*loud*)
390 P: [I thought you did but not yet not yet oh
no yes (*laughing*)
391 N: um (.)
392 P: aye something to=
393 N: = to help you sleep at night (.) we can certainly sort [that out

In this extract there is a gross misinterpretation of the dying as falling asleep metaphor, which leads to interactional difficulty when the nurse mistakenly thinks that the patient is requesting euthanasia. I will analyse the extract in the light of the previous extract to explore how this misunderstanding occurred.

Colin has previously spoken of dying in terms of falling asleep, a description that has been echoed by the nurse. He has been extremely upset several times throughout the

consultation and has massive concerns about his family, hiding symptoms, money and the how and the when of his own death. He is of Greek origin with a strong accent and he often uses non-standard grammar. When he asks for ‘some tablets to go to sleep’ (378) the nurse does not take his request literally. The use of non-standard syntax, i.e. not asking for ‘sleeping tablets’, the previous use of the sleep metaphor for dying, and the context of the interaction all contribute to the mistake. The patient, obviously puzzled and embarrassed by the straight refusal, refers the request to his wife and uses self-reported speech to distance himself from making the imposition (380). The nurse offers an explanation, which could embarrass and alienate the patient yet further, ‘we are not allowed to do that in this country unfortunately’ (383). The tag ‘unfortunately’ also stands as modifier to align the nurse’s views with the patient’s (assumed) views, albeit from a safe place.

At this point Colin pauses to digest the nurse’s response before finally comprehending and baldly clarifying his request (386). The talk becomes very loud as both nurse and patient speak over each other in their concern to explain and validate their positions. The nurse uses a simple metaphor, ‘I’ve got the wrong end of the stick’ (389) to acknowledge the mistake in a lighthearted way as Colin accepts and clarifies his position before using laughter to relieve the tension, placing the interaction back on track. The nurse completes the topic with a precise reformulation of the request, including the very specific ‘at night’ and a magnanimous and emphasised, ‘we can certainly sort that out’ (393).

In the above sections I chose to focus on the DTU setting because the data under analysis happened to occur there. A similar situation to the one I will describe could

potentially occur in any of the other settings. Metaphoric talk may be useful for discussing sensitive and affective concerns. It can also be used as a distancing device to take painful issues away from the 'here and now' context, and as a means to validate experience from a meaningful personal viewpoint. Conceptual competence, however, is vital to successful interactions, especially when dealing with sensitive or taboo topics. However, as I have shown, the potential for misunderstandings should not be underestimated as these can cause distress in the sensitive setting of palliative care.

8.8 Metaphoric idioms in the in-patient unit

I now turn to consider the use of metaphoric language in the in-patient setting. What is striking about the use of metaphoric language here is that it is all spoken by nurses and although my data is from three different care sites – home care, day therapy unit and the in-patient unit – these nurse-initiated extracts occur entirely in the in-patient setting. Also, all of the interactions occurred when the nurses were giving personal care to patients, washing them or dressing them, for example. All of the patients taped during care events were elderly and this may have impacted on the context of the interactions as nurses over-accommodate to patients' perceived understanding, thus further diminishing their psychological well-being.

The nurse–patient affiliation is an asymmetric relationship whereby the nurse will abide by the institutional routines and ultimately overrule the patients' preferences of whether to be washed or not, albeit in their own interest. In compensation for the misalignment, I would suggest that nurses may adopt an over-accommodative stance. There is an emphasis on diminutives, praise and light-hearted talk. Metaphoric idioms can be seen as linguistic sugar to sweeten the institutional pill. Metaphoric idioms have the potential

to add to the overall effect of lightheartedness, which, as discussed in Chapter 6, is a hope-fostering mechanism. However, metaphoric idioms when used in conjunction with the other linguistic devices of directive/praise sequences and simplified or over-accommodating lexical choices combine to reduce the patient's identity to a child-like state.

Directive/praise sequences occur on a frequent basis as the nurses work with the patients to complete the care task, which, in the following extract is a bed bath and change of linen. Extract 6 contains all of the features listed above, which are used throughout the transcript. I will focus on two typical extracts here and firstly draw attention to the frequent use of terms of endearment or the patient's name, Beryl. In fact, during 154 speaking turns her name is used 18 times and diminutives such as 'sweetheart' and 'my love' are used 26 times. The nurses in this extract appear to be using a high frequency of vocatives in the same way as humour, discussed in Chapter 7, as an aid to bond as quickly as possible in an asymmetric, paternal relationship whereby the patient will be ultimately persuaded to consent to care.

Extract 6 (IPU 4) Beryl 70+ *During a bed bath.*

- 2 AN: are you going to sit out today Beryl?
3 P: I don't think so
4 AN: you don't think so (.) why is that then my love
5 P: I don't know (.) I feel ugh
6 AN: now does ugh mean you have got a pain or what
7 P: I feel ugh
8 AN: right okay (.) we'll have to see what we can do about that then (.) there
we are sweetheart (.) if you can come forward a little bit for me (.) gently
gently (.) that's it well done (.) back you go (.) feel as if you have done a
hard day's work do you?
9 P: I do (.) yes I do
10 AN: not in any pain though are you?
11 P: no only a little

12 AN: where to
 13 P: only in my arm
 14 AN: this one (.) we'll go careful then love
 15 P: yea
 16 AN: pop your head through there (.) that's grand
 17 P: oh
 18 N: alright? (.) Beryl I am going to take this band off your wrist because it's
 getting a little bit tight there and I don't want it to dig in (.) so we'll get
 you another one and pop it on your other wrist where it won't be so tight
 for you (.) okay (.) here we go then my love
 19 (.)
 20 P: I don't feel like wash
 21 AN: no there's days when we get up when we think can't be bothered (.) we
 will make it as easy as we can for you sweetheart but I'm sure you'll feel
 better (.) even if it's just the bare essentials (...) you want to use your
 good hand to give your face a little wipe dry (.) that's it (.) brilliant (.)
 there we go (.) that's excellent Beryl (.) I'll see if I can just pop this towel
 underneath your arm (.) how's the sensation in this arm Beryl?
 22 P: not too bad
 23 AN: not too bad (.) you can feel me touching it can you
 24 P: not really
 25 AN: no
 26 P: not really (.) Lord knows why
 27 AN: there we are sweetheart (.) just give it a dry
 28 P: Lord knows when I'll feel that
 29 AN: feel what Beryl?
 30 P: the sensation in my arm
 31 AN: is this one okay for me to move though (.) just slightly
 32 P: yea

Beryl complains about feeling 'ugh' in an unspecified way (5, 7). The nurse checks for pain echoing Beryl's choice of word 'ugh' as a descriptor (6, 10). Beryl reports that she is suffering from moderate pain in her arm (11, 13), but the nurse does not take the cue to expand upon why she is feeling bad, choosing instead to use the metaphoric idiom, 'you feel as if you've done a hard day's work do you' (8), as her summation of the problem. This use of idiom in effect prevents the opportunity to listen to Beryl's problems. Beryl states that she does not want a wash (20) but the nurse's response is to downgrade her reasons for not wishing to be washed with a reformulation, 'there's days when we get up when we think can't be bothered' (21). This is followed by the

justification that it will make her feel better and that the nurse will make it as easy as possible (21). As the nurse presses on with the task in hand she offers encouragement and praise, using endearments and frequent vocatives as though she were addressing a child. Her choice of lexis, 'a *little* wipe dry' and '*pop* this towel underneath' reinforces the over-accommodation and is indicative of styles of overaccommodation directed towards the elderly (Giles, Mulac, Bradac and Johnson, 1987; Giles, Coupland and Coupland 1991). As the nurse continues to talk through the task it is clear that she is not listening attentively to Beryl. The reported loss of sensation in her arm (22, 24) is clearly worrying her, but she has to repeat herself (28, 30) before she can assume that the nurse has heard her. Even then her concerns are left unanswered as the nurse carries on with her task (31).

The task of washing and changing the linen of a patient with limited mobility will take approximately twenty minutes and involves a great deal of repositioning and moving. The nurses talk through each manoeuvre as they work but it can be exhausting for the patient. In the hospice, as I have noted, the nurses are careful to take the extra time to make the patients look nice and smell nice.

Extract 7 (IPU 4) Beryl 70+ *During a bed bath.*

- 38 N: try that (.) there we go (.) there we are sweetheart (.) we can straighten this now (.) do you want a nice bit of squirty under your arms (.) smell beautiful?
- 39 P: smell beautiful
- 40 N: you need your Sunday teeth in to say that Beryl (.) okay it's going to be cold (.) and a tiny little bit under this arm
- 41 P: oh my Godfathers that's cold
- 42 AN: it is but it smells lovely (.) it does smell rather nice what is it?
- 43 N2: it's Impulse (.) hint of musk
- 44 AN: oh right (.) it's lovely
- 45 N: Beryl is your tummy sore there?

- 46 P: no
 47 N: no
 48 P: I am not sore anywhere really
 49 AN: that's good (*laughter*) these staff nurses are stepping over the mark
 50 P: they are aren't they
 51 N2 I think I may be getting a bit big for my booties
 52 AN: sit up with your back (.) there we go lovely (.) now don't fall asleep on us
 now Beryl
 53 N2: Beryl are we boring you
 54 AN: we should be singing to you shouldn't we getting you to join in (.) are
 you going to join in (.) are you going to give us a song

Beryl is becoming exhausted and has begun to fall asleep by the end of this extract (52).

The nurses are continuing to address her as though talking to a child, e.g., 'do you want a nice bit of squirty' (38). When asked a question directly about pain the nurse checks her initial response to the question by repetition (47) before Beryl reports that she is 'not sore anywhere really' (48), despite her previous complaint of pain in her arm. If she were to report pain it could involve further disturbances and take longer. The nurses use metaphoric idioms to take the credit for a pain-free patient focusing on the skills of the nurse, 'these staff nurses are stepping over the mark' (49), 'I think I may be getting a bit big for my booties' (51), and do not press the point. At the point where Beryl begins to fall asleep the nurses try distraction, in order to keep her attention by suggesting that she should give the nurses a song (54), a tactic also used for small children. This is, perhaps, an unlikely request to make of an adult woman in most other scenarios and could potentially cause distress.

8.9 Chapter summary

In this chapter I have discussed how metaphor and metaphoric idiom can be used to facilitate sensitive communication about complex, sensitive or taboo topics. In the palliative care setting specifically they can be seen as an aid to assist difficult talk about

death and dying although caution is required that mutual understanding is achieved in order to avoid further damage to the patients' already fragile identities. With the focus of analysis on metaphors I have discussed how patients feel about the burden of the disease as it affects both themselves and their ability to communicate with their previous social networks. I have also discussed how the echoing of a patient's own metaphors can bridge the gap between the medical perspective on disease and the subjective experience of the patient's experience, thereby allowing relational alignment between patients and their nurses.

I have considered how metaphoric idioms add to the overall effect of light heartedness, which, as discussed in Chapter 6 and 7, is a hope-fostering mechanism. However, in this institutional setting, where the patient's identity is most at risk, metaphoric idioms used in combination with features such as the frequent use of diminutives and directive/praise sequences have the unfortunate effect of over-accommodating to the perceived cognitive abilities of the patient. This strategy can be seen as a means to persuade and facilitate consent to unwanted, albeit necessary, care, thus increasing the threat to the patient's already compromised identity.

In the following two chapters I hope to draw together the previous chapters as I present two case studies from the home care setting with an analysis of each interaction in its entirety.

Chapter 9: Contrastive styles of engagement with the end of life: A closer look at two cases

9.1 Chapter overview

In the preceding chapters I have discussed the socially situated identity status of this patient group as compromised by multiple losses and anticipatory grief during the process of social death (Chapter 5). I have suggested that the physically oriented care to cure trajectory is replaced by an inner journey and an acceptance of a series of adjustment stages in an attempt to find meaning and hope in an adaptation to both the disease outcome and its effect on individual identity (Chapter 6). As I have shown, much of this identity work is achieved without resort to direct literal expression but rather through the use of humour and metaphor. In chapter 6, I have also analysed a range of extracts from across all care settings to describe how nurses discursively manage (or not) to promote a positive reformulation of patients' current situations. I have also discussed the importance of the environment and listening to patients and how life review can be either a positive or a negative experience.

Within this chapter and chapter 10, I wish to focus on just one care setting, home care, using a case study approach, aligned to the analytic framework of the study, to draw together the discussion to this point. The advantage of using a case study approach is the ability to use cross-individual comparisons for a fuller understanding of the preceding discussion. It will be useful to look at two cases, demographically similar and including the participation of the same nurse, to examine variations in coping styles and

expectations. I aim to illustrate the real-life effects of terminal illness and social death on two patients at different stages of adjustment.

I have chosen the home care setting as this is where talk is most prevalent and extended patient narratives are most likely to occur in the context of a one-to-one interaction that is not task-based in a physical sense. Chapter 10 will specifically examine the nurse's discursive role and flexibility of professional approach when managing patients with differing practical and psychological issues caused by their terminal diagnosis.

9.2 Selection of cases

The cases that I have selected as case studies were chosen because of their contextual similarities. I will use the pseudonyms Amy and John and use extracts from each case study throughout the discussion. For the purposes of these two chapters, I will also use a pseudonym for the nurse, Sheila, because the same nurse is involved in both cases. The patients are both in their 80s, one male, one female and of a similar academic background and social class¹⁸. Amy has had a career in research and education and John is a sculptor with commissions of his work appearing in public locations in his local area. Both patients have terminal forms of cancer; Amy has carcinoid syndrome¹⁹, which causes her to have severe and frequent bouts of diarrhoea whilst John has a form of lung cancer. They each own their own house in up-market locations in the same seaside town. They were both widowed 5 to 6 years ago; John's wife died as a result of Alzheimer's disease. An obvious difference between the dyad is gender, but in this

¹⁸ Transcript nos. John = (HCTRA1) and Amy = (HCTRA4)

¹⁹ Carcinoid Syndrome is a constellation of symptoms occurring only in patients with evidence of metastatic (widely disseminated) disease in the liver. The cardinal symptom of carcinoid syndrome is flushing attacks. Diarrhoea also is common, appearing in from 30% to 80% of patients. In about 20% of cases, it is accompanied by flushing. Abdominal pain may accompany diarrhoea. (see <http://www.patient.co.uk/showdoc/40000905/> for more information. Last accessed 10/06/06.)

respect I follow the views of Lawton (2000: 166) who notes that within this patient group 'gendered differences were not generally marked'. I will not include the full transcripts within the body of this text so I would recommend the reader at this point to gain a sense of the interactions by reading through both transcripts, which are located in the appendices (HCTRA1 and HCTRA4).

I attended both of the home visits with Sheila and was intuitively aware of the wide difference in attitude between them. In simple terms, Amy, notwithstanding severe symptoms, appeared to be full of humour, serene and at peace, whereas John was bitter and brusque with unresolved issues that were troubling him. A detailed analysis of their interactions with the same nurse will, by slowing down the process, describe and make explicit what I spontaneously felt at the time. Obviously, I am unable to compare the attitudes of patients before the onset of illness, or indeed before old age so these perceived differences in attitude could be simply attributed to lifelong personality traits and have little to do with the patients' experience of their illness. However, in the light of the preceding chapters, the topics under discussion can be seen to relate to many issues relevant to the patients' acceptance of and attitudes to their illness status in relation to the overarching themes of social death and hope.

I will firstly consider the topics discussed within each interaction as indicators of the effect of social death and the psychological adjustments that may or may not have been adopted in defence. I will focus on the positive or negative attitudes of each patient towards their social networks, past life, engagement with life around them and their

philosophies of life and death. All of these categories bear a strong relationship to self-perception and identity status as I have previously discussed in Chapters 5 and 6.

I will consider Amy's and John's self-reported attitudes based on their narratives, i.e. their constructed versions of their past and present life events and attitudes towards them. These narratives will include the telling of how things were before the illness, contrasted with how things are now, as well as their self-reported attitudes and opinions. I organise the analysis in terms of salient topics (within the themes of social death and hope) to examine social networks, reflections of past lives and engagement with current life before concluding with an exploration of Amy and John's general philosophies of life and death to highlight their underlying general attitudes. In treating each of these topics I will consider Amy and John in turn in order to enable their differing styles of interaction to become apparent.

9.3 Maintaining and challenging social networks

I have already discussed how relatives' perceptions of the patients' conditions can cause a gradual disengagement, either by failure to cope with unpleasant symptoms or by the process of anticipatory grief. This disengagement can be a dynamic two-way process as it is sometimes the patients' own choice to withdraw socially due to physical disintegration and/or the need to seek isolation because of their failure to cope with their changed identity. In chapter 5 I have discussed how the preservation of family ties is an essential component in maintaining hope and in avoiding despair in the context of a terminal illness.

In the case of Amy, it is the physical effects of her illness rather than a need for social isolation that causes her withdrawal. Amy clearly has strong and much appreciated social ties with her remaining family, friends and neighbours, as can be seen from the appended transcript. Sadly though, the constraints of her illness, enforced by fatigue and embarrassing symptoms, conspire to cause a necessary rejection of all but those closest to her. Her usual social activities are curtailed by her physical symptoms especially of continual diarrhoea, which means she is suffering an ‘unbounded body’, in Lawton’s terms (2000: 7). The loss of dignity caused by socially unacceptable odours²⁰ leads her to avoid the direct presence of her social network, causing her anguish as she is forced to reject them without being able to provide an explicit account of her reasons for doing so due to the culturally taboo topic. She maintains contact by telephone or shortened visits, although she clearly enjoys the company of others in normal circumstances.

Extract 1²¹

- 123 A: yes (.) somebody generally rings me up in the evening A used to ring me up and she died up at up at people going away one after the other you know[they’re leaving
- 124 S: [yes
- 125 A: and um (.) my sister we er (.) she died a year ago now (.) possibly two years can’t believe it but we used to ring each other up (.) and K-- that’s my (.) they were coming (.) K and A A’s my other step-son and K-- is his wife (.) and she (.) more or less took on when she knew I was her so much I suppose (.) so she really somebody rings I ring her or she rings me (.) now (.) and they’re (.) up in Edinburgh and as I say they were going to come and stay but I just couldn’t do with them at all (.) I just couldn’t do

Amy’s comments in the above extract indicate the changing dynamics of her social network. She looks back to a time before the deaths of her sister and ‘A’ (*an assumed close contact*), ‘people going away one after the other you know they’re leaving’ and she

²⁰ see Lawton (2000: 135) for a discussion about odours and the ‘deodorised West’

²¹ Transcription conventions. A=Amy, J= John, S= Sheila.

contrasts this with her substitute main contact, her step-son's wife 'K'. The multiple losses of family and friends is not unexpected at Amy's age but her comment about K's role, 'she (.) more or less took (Amy) on' (125), suggests an orientation to the relationship which is more care-oriented than relationally bonded. Therefore, although Amy has supportive relatives, she may still be missing, and unable to replace, the emotional bonding of her deceased immediate family and peers. Her loss of independence is compounded by the need to be 'taken on', implying a task or burden rather than relational closeness. Perhaps because of this, in her present circumstances, she is less tolerant to the idea of receiving them as visitors as she indicated when emphatically reporting her inner thoughts, 'they were going to come and stay but I just couldn't do with them at all (.) I just couldn't do' (125).

Her changing role within the family as a result of her illness is typical of the social death process. It is therefore important that Amy can rely on her friends in support of her former sociable 'self'. Sadly, this is no longer possible as the following extract shows.

Extract 2

- 67 A: so if they come in for a visit and I just feel I don't want them and that's not natural for me
68 S: no
69 A: I've got some wonderful friends and I do enjoy talking to them and I'm better for talking to them better now (.) better now since you've you've arrived

In the above extract Amy expresses how she feels now about her diminished enjoyment of visits from friends in the context of her illness, and voices it in relation to her usual or former personality, 'that's not natural for me' (67). She has conveyed how her illness experience has had a direct effect on her previous identity, causing her to reject the

company of her friends. She qualifies her attitude by reinstating the value of *talking* to her friends; it is the visits that she is finding hard to deal with. The therapeutic function of talk is highlighted here as she comments that she feels 'better now since you've arrived' (69), which gives a further indication of her losses as she is clearly unable to accommodate visitors who could otherwise offer emotional support. Added to this is the burden of expressing her wishes without causing hurt to her loved ones as the next extract demonstrates,

Extract 3

- 26 A: that um I just I didn't expect to be here at Christmas but I am you see (.)
so er (.) I managed to get over it as you can see now (.) and then I
managed to speak up and say when my my step-son was (.) very good to
me and he said look Amy do you want us to come or not and I pulled
myself together and I said well I'd rather you didn't (.) it's a difficult
thing to do when people are so kind isn't [it
- 27 S: [yes

According to Amy's reporting of her step-son's comments she has been helped in this instance as he forces the issue saying, 'look Amy do you want us to come or not'. Her expression of her inner thoughts in the form of metaphorical description, 'pulled myself together', reveals the strength she has gathered. This is a typical example of metaphors of self using the body as container schema. Amy needs to capture her emotions and pull back to a logical position in order to face the challenges that her disease is causing her. She is torn between the kindness of her relatives and her own need to reject them which, as she comments, is 'a difficult thing to do when people are so kind' (26).

At Amy's age she has seen a reduction in her close social network due to old age, irrespective of her disease, and has had to come to terms with this in any case. As an elderly female living alone she must also cope with an appointed family member to

whom she may not feel emotionally close but who will be in regular contact to monitor her welfare. What her disease *has* added is the fact that she must manage socially unacceptable symptoms by isolating herself and by rejecting visitors to her home. It becomes clear that, even if a patient has adjusted to a terminal diagnosis and aims to make the most of their remaining time, on occasion factors outside the psychological adjustment process will inhibit their needs.

Having discussed Amy's relationship with friends and family I now move on to consider John's attitudes to his social network. Although John mentions his daughters and two friends during the consultation, each mention is negatively framed. His retained social network appears to be marked by a degree of bitterness and resentment and appears to give him little pleasure or emotional support.

Extract 4

39 J: I went yesterday for a walk on the cliff tops (.) with a youngster of seventy-five (.) and she walked far too fast (.) and I choked (.) umm (.) was (.) very bad (.) so I'm going to take it easy [today

John is able, and he chooses to get out and about and can still drive a car. In the above short extract the labeling of his companion as 'a youngster of 75', in the context of his following comments, can be seen as a self-contrast and seems to carry resentment of the age difference and a desire to distance or disassociate himself from a non peer. His criticism of her superior mobility, 'she walked far too fast', is linked implicitly to his choking episode, as though his companion was partly responsible. He is unable to share her level of mobility and therefore cannot identify with her as a peer. This inconsistency appears to cause resentment.

In the following extract, John refers to another friend he is to meet later that day. He clearly does not suffer from social isolation due to a physical withdrawal from company, like Amy, but his attitude towards his companions is marked by his negative attitude and appraisals of them.

Extract 5

44 S: and you're going with?
45 J: Emma
46 S: [Emma
47 J: [you know her
48 S: yeh
49 J: hm
50 S: yeh (.) very well
51 J: very well (.) I know her very well (.) she's in Oxford today (.) I have to meet her wretched train when she comes back (.) but I don't know what time

John states that he knows Emma 'very well' (50) and is to go abroad with her shortly. This indicator of relational alignment, however, contrasts with his account of meeting her train. Performing a favour for a friend seems to be the reasonable action of a social companion but his choice of the emotive lexis 'wretched train' gives an indication that he is performing the favour somewhat begrudgingly.

He has at least two daughters and, like Amy, he is concerned about their reaction to physical symptoms, which in his case is coughing and wheezing,

Extract 6

191 S: are you (.) nervous at all about going to Cyprus? about flying?
192 J: not nervous about flying I'm just nervous about how my daughter will react to my wheezing and coughing
193 S: is this the Staffordshire daughter?
194 J: no [no no she's not
195 S: [is she going?
196 S: right
197 J: stupid woman (.) she prefers to stay at home and sulk which is daft (.) but (.) there's nothing you can do about it (.) she doesn't know what she's sulking about (.) huh

The above extract gives some indication of his perceived relationships with his daughters, with one of them cast as 'a stupid woman' and the other as worried or possibly unsympathetic to his symptoms. He uses the nurse's question (191) to redirect to his own concern by echoing her language saying he is 'nervous' about his daughter's reaction. This seems to be a strong word to use in the circumstances and it implicitly reveals a perceived lack of emotional support from her. His relationship with his other daughter also seems to be tense. He describes her in disparaging terms and reports her thoughts unsympathetically, as he sees them, 'she doesn't know what she's sulking about' (197). He also comments that 'there's nothing you can do about it', which expresses his personal opinion and makes it clear that he is not about to attempt to realign their relationship via any efforts that he might make.

John has not withdrawn physically from his social network, although he appears to be somewhat cynical about one daughter. His psychological attitude towards his friends and family, however, is negative and marked by bitterness. He appears to lack support and understanding and is loathe to help them with favours or by healing conflict in return. I suggest that part of his problem is related to his mobility. He is at a late stage of his disease and yet he is still able to go walking, drive a car and fly abroad for a family wedding despite the fact that he is terminally ill. The concept of 'living until you die' is at the forefront of the palliative care philosophy and yet I would suggest that this attitude can sometimes be detrimental to patients who are struggling to adjust to terminal disease. In John's case there is a paradox here in that his surface appearance allows him to perform the usual social functions and yet he is estranged from his previous social group and marked by the taboo of terminal disease. At his current status

he is in neither one camp nor the other and therefore trapped in the process of social death and unable to progress to a later stage of adjustment.

9.4 Reflecting upon past life

I have discussed the use of life review as a hope-fostering strategy (Chapter 6.7.1) as an important preparation for death. The ability to look back on a life lived well can bring meaning to the terminal illness experience and facilitate adjustment. However, the opposite is also true: negative feelings about past life experiences will impact on the ability to accept a terminal diagnosis and prevent patients from moving on to acceptance.

I will firstly consider Amy's reflections. This interaction was longer than John's and characterised by long stretches of personal narrative where she spoke freely about her life in the past, present and future. Sheila's role in facilitating and encouraging these topics will be discussed in the next section, but for now the extended extract below can be seen to demonstrate her life trials and achievements, positive attitudes and personal values.

Extract 7

- 367 A: so we'll (*unclear*) we're so fortunate for a year there was six of us and um (.) R is married my other sister well my other sister was married I wasn't married until I was forty and that was my (.) stupidity I suppose really but that's the way it was and um
- 368 N: when did you (.) meet your husband?
- 369 A: when when did I meet him? (.) um well at the end of the war I went (.) back to university in London and um I did quite a bit of research work there and (.) it was a lovely it was a lovely year really and it was as I say I kind of let people down because I finished college got a job they don't want to go to work every day and they're looking for another course at college and I did it myself so I can't [say (*unclear*) done it too
- 370 S: [laughs]
- 371 S: (*laughing*) (*unclear*)

- 372 A: I understand that (.) um yes I know and we say really you know um (.) but there's something about if you get you think I'm not going to sur sur get by every day and every night and that sort of thing and it comes very wearing at the end of it doesn't it?
- 373 R: yes it [does
- 374 A: [you know at the end of the course when you're looking for the final and you've got a lot to do and you don't get a minute really to enjoy yourself as you might say
- 375 S: what sort of research were you involved in?
- 376 A: well (.) with whoever was there I did I did um my Masters degree and I got a BA before and um I got that and also my tutor in London (.) Dr (.) forgotten the name now begins with D in the fifties fifty sixty years ago now (.) I was married for forty two years anyway (.) wasn't bad was it (.) um (.) so um she was working at the unemployed nursery and it was at the beginning of a lot of (.) it's all come out now it's quite common practice now but um it was work with um (.) with um twins you know
- 377 S: yes love those
- 378 A: yes yes and she and er she (.) I had a part of in that you see that I passed it on to my tutor who was a member of her nursery in (.) in er where was I (.) Chelsea (.) in in Chelsea (.) I was living in Chelsea at the time and I had a wonderful year there a couple of years really because um (.) I met such interesting people that I'd never have met otherwise
- 379 S: yes
- 380 A: and then I came back to pick up my old job again (.) and um (.) I was invited then to apply for (.) a job (.) I was teaching (.) Roe Roeham do you know Roehampton? Roehampton?
- 381 S: yes

As Amy looks back on her life it is important for her to feel that she has made the right choices and lived it well in order to bring meaning and a sense of closure while nearing the end of her life. She compares herself to her married sister when she mentions her late marriage and expresses some regret about not marrying at a younger age, 'and that was my (.) stupidity I suppose really but that's the way it was' (367). Any regrets she may have about not having children of her own (according to her medical records) are not mentioned during her narratives although she talks fondly of her stepsons. Later in the interaction, in response to a question about her research, she lists her academic qualifications immediately, and follows this with the out of context comment, 'I was married for forty-two years anyway (.) wasn't bad was it' (376). This reveals that,

alongside her academic career, she takes pride in achieving a long marriage despite a late start. She describes her academic and career achievements throughout this extract, which are impressive in the light of her gender and the fact that it was the post World War II era when she gained her qualifications. However, she balances this with an indication of the hard work involved, 'you don't get a minute really to enjoy yourself as you might say' (374). Throughout the interaction she talks freely about her life, career and the interesting people she has met before summing up her life, past and present, towards the end of the visit.

Extract 8

- 683 A: well (.) anyway I'm I'm enjoying life in a sort of a way (.) um you know I I wish I'd gone (.) by now but um (.) um (.) it's a bit difficult but on the other hand I've got so many blessings
- 684 S: yes
- 685 A: that's what I feel like I've got I'm up in that bed I can (.) somebody comes in and rings me I don't want to see (*unclear*) I do that and that sounds selfish of me because that's because I just want my family to know I'm being looked after for their sake not my own a little bit of (.) apart from that I live for my own comfort
- 686 R: good for you
- 687 A: well (.) I've er done other things in my time haven't I
- 688 S: I think so
- 689 A: had all sorts of difficulties in my time as I'm sure you have too

She uses contrast and reported inner thoughts extensively here to position her reasoning. She is enjoying life now but it is 'difficult'. She wishes she had died already but on the other hand she has so many 'blessings' (683). She doesn't want to see her family but she wants them to know she is looked after. She deserves her comfort at this time because she has 'done other things in my time' (687). Amy feels justified in concentrating on her own needs and comforts as she prepares for death and feels confident that she has achieved enough during her life, with all its difficulties, to be able to focus on herself during her illness.

Amy appears to be content and at peace with her life but as I move on to examine John's reflections it is clear that their attitudes are very different. During the course of taping the interaction John did not talk about his past in any detail. However, at midpoint during the interaction he requested that taping be discontinued, although I was able to continue taking notes. He moved on to talk about problems that he had experienced with his General Practitioner²². His attitude towards health care services in general was bitter and resentful.

Following this discussion he talked at length about his disappointments at his past career. He expressed deep regret at the lack of adequate training he felt he had needed in order to market his artistic output. He compared himself to his peers and felt that they were far more successful than he had been, notwithstanding that he had received commissions for work still featured in prestigious locations. An outside assessment of his life would suggest that with his artwork alone he had been successful and achieved more than many. John's subjective view, however, was one of overall disappointment.

9.5 Engagement with community

Engagement in wider community issues can give an increased sense of belonging and this counteracts some of the effects on reduced social networks. It also demonstrates a continued interest and enjoyment of the wider world. Amy talks about and shows interest in a wide range of topics and clearly has an appreciation and grasp of current affairs, as in the following extract initiated by Sheila for particular reasons that I will elaborate on in the next section.

²² I cannot report this discussion in respect of patient wishes, suffice it to say that he felt he had a case for litigation and had felt unsupported during his wife's illness and subsequent death as a result of Alzheimer's disease.

Extract 9 Amy

- 84 S: what about the newspaper (.) are you do you read a daily newspaper or
85 A: I buy the Spectator I have a Spectator every week on a Friday morning
and I devour it during the week (.) I don't take another (.) newspaper
86 S: and what about (.) do you listen to (.) the radio?
87 A: oh I do listen to the radio [a lot
88 S: [which programme do you listen to?
89 A: well anything political (.) why should I be interested in politics I'd ask
but I do seem to be (.) it's all going on around you
90 S: yes
91 A: and um they put on the big bang theory again if that means anything to
you [probably doesn't
92 S: [well (.) this this stuff with the asteroids?
93 A: that's right (.) [and er
94 S: [they now think it happened at least twice don't they
95 A: yes (.) [yes
96 S: [that the world was destroyed
97 A: that's right
98 S: yes
99 A: yes (.) war in Heaven I think (.) it's all in the Bible somewhere they tell
me (.) and er (.) some some big catastrophe [(unclear)
100 S: [yeah
101 A: but um I find it very interesting

Amy is a well-educated woman and clearly has a strong interest in current affairs but her attitude towards her own engagement with wider issues is interesting and self-reported through her rhetorical question, 'why should I be interested in politics I'd ask?' (89). To use contrast in the analysis would mean asking the opposite question, 'why shouldn't she be interested?' This allows consideration of what it is that has caused her to feel that her interest is misplaced. It could indicate that she feels detached from the wider community and therefore her right to be included in the processes of politics and government. Her subsequent comment, 'it's all going on around you' (89), implicitly describes her feelings of non-involvement and detachment. She moves on to discuss the big bang theory with interest and throughout the interaction covers a wide range of

topics unrelated to the medical agenda. Her interest and engagement with people and the wider social group is very evident.²³

John does not enter into discussion of current affairs generally, or any topics that could be seen as deviating from the medical agenda, but does briefly mention a wedding, which he is to attend in Cyprus (extract 1). His attendance at a wedding to take place abroad is a significant undertaking at his age and state of health and does show a strong degree of commitment and interest on his part.²⁴

In the extract below John initially engages with Sheila and myself, as researcher, in a discussion about his artwork but despite our interest, is easily discouraged and either takes his work away or allows the topic to tail away. There are no extended personal narratives in the entire interaction and the vast majority of the interaction is in relation to the clinical agenda. The topic of John's work is initiated by Sheila.

Extract 10²⁵

- 146 N: what about your work? (.) are you working at the moment?
147 P: (.) I just (.) oh gosh (.) highly unsatisfactory (.) that's the trouble (.) get no satisfaction because it's second rate (.) um shall I get it and show you?
148 N: yes please
149 P: it's bloody awful
150 N: (*laughs*)
Patient leaves room, coughs
Returns shows polystyrene mould to researcher
151 P: I made it (*unclear*) a house in France, you know, being rich (.) and um (.) all this is to feed the metal
152 N: yes
153 P: you stick it in sand (.) it's a technique of my own (.) dry sand (.) which just pours where I've made all these holes

²³ In fact I visited Amy again, before she became too ill. She was very interested in this research and asked me to call in and let her know how I was progressing.

²⁴ This topic was not initiated by John but strategically by the nurse and will be discussed in the next chapter.

²⁵ I have used this extract previously in Chapter 3.5.1 in discussion of the researcher role.

(shows to researcher)

154 R: mmm

155 P: so the sand goes through so it'll have a core (.) I hate the thing but they say it's alright so why bother (.) and then

156 N: and this is going to go in a well

157 P: there's their well (shows photos to Nurse)(.) this is p'raps a bit better

158 N: oh I think it'll look lovely (.) is that going to be in bronze?

159 P: say?

160 N: in bronze

161 P: aluminium

162 N: alumimium

163 P: mmm

164 R: oh right

165 N: a nymph

166 P: (unclear) so who is the wretched man? (.) doesn't matter (.) take him out of sight
(Leaves room)

167 R: he's carrying a fish, we should know that (nurse) I know (.) it's not Pan is it?

168 N: is it? who is it
(Re-enters)

169 R: who is it then?

170 P: who's the lady?

171 N: who's the man? who's the sprite

172 P: Bacchus (.) oh [no no no it's not no/Pan

173 N: [Bacchus

174 N: Pan

175 R: Pan I said Pan [(unclear)

176 P: [(unclear) but he should have hooves

177 N: yeh

178 P: and anatomically they're extremely difficult

179 N: hooves are/

180 P: that's why I found this (shows art book) obscure (.) page (.) you see the hoof (.) they (.) difficult to explain (.) they've got an extra joint haven't they (.) oh, there's one look

181 N: yeh

182 P: so: (.) this is quite wrong (.) that's all foot

183 N: yes

184 P: isn't it [and that's his knee

185 N: [yes and we tend to think of that as the knee but in [fact

186 P: [yes yes

187 N: yeh

188 P: (.) mmm

189 N: mmm

190 P: (unclear)

191 N: are you (.) nervous at all about going to Cyprus? About flying?

John's response to a question about his work is hesitant and negative; he says that it is 'second rate' (147) and yet he is willing to show it to Sheila. When she shows interest in agreeing to see it, he reformulates his opinion of it more emphatically as 'bloody awful' before he produces it for inspection. Turns 151 and 153 see John explaining his technique with some animation and interest before contrasting his own opinion with that of the people who commissioned his work, 'I hate the thing but they say it's alright so why bother' (155), as though to say that he is not even concerned that his work is, in his own eyes, substandard. After a short while he takes his work away, 'take him out of sight' (166), as though he can't bear to look at it any longer. He becomes animated once more as he engages with the nurse in an anatomical discussion and goes to the trouble of using a book to add to his explanations (176-186). But he soon appears to lose interest and lets the topic tail off using a pause and a minimal response to signal the end of his speaking turn (188). His account in this extract highlights a tension and contrasting attitudes to his work. He appears to be frustrated with his work but is keen to show it and talk about his techniques. He has engaged with the nurse in talking about the work but finds it difficult to maintain his interest. If John is unable to maintain interest and gain pleasure from his art, a major part of his personal life that has functioned as a career and as a source of satisfaction, it seems unlikely that John will take interest in issues relating to the wider social world.

In the discussion above it is possible to see differences in Amy's and John's underlying attitudes and their progress through the trajectory of adjustment along the process of social death towards an acceptance of past, present and future, and in a limited sense, lives. With the previous discussions in mind, I now move on to consider their general philosophies of life as disclosed to Sheila.

9.6 Philosophies of life and death

I have previously discussed the notion of transcendence and spiritual growth during the course of a terminal illness, or indeed old age. If an individual has no outstanding issues, feels supported, has lived a good life and accepts that death is approaching then he/she will feel at peace having achieved a new integration of 'self' and, moreover, may wish to share the wisdom gained from a life lived well.

As I have demonstrated above, Amy has a strong and mutually appreciated social network; she is positive about her achievements in her past life and remains fully engaged with current events in the wider world. Her enjoyment of life is clearly compromised by the discomforts imposed upon her by her illness, including the subsequent fatigue, which is a major side effect and not to be underestimated. With this combination of age, illness and a positive attitude to her life, past and present, she is accepting of and ready for death and expresses this clearly and often whilst also offering her learned wisdom during the course of the interaction, as these short examples demonstrate.

9.6.1 Amy: Total acceptance

Amy's acceptance of her anticipated death is total and it is mentioned frequently throughout the interaction. She appears to have had enough of living and is ready to die. She states her wishes clearly concerning treatment options and her wish not to be resuscitated.

'so she told me (.) and um (.) I wa.. I wasn't (.) I was going to say I wasn't bothered (.) I wasn't bothered about it and she said it's not good news and I said no I know I've got cancer and she said oh'

'I've said to them please if you just find I'm passing out please just leave me
(.) so perhaps I shouldn't have told you that you don't know anyway (.) um
but I just don't want to be revived'

She has accepted her diagnosis in a matter-of-fact manner and relates her terminal status
to old age rather than cancer, which she sees as the natural order of things.

'I don't want to um (.) I want I don't really want treatment I'm (.) dying of
old age and that's the way I think it should be'

With the serenity she has achieved in the successful completion of her life she is able to
offer wisdom to those remaining.

'yes (.) and it's you see (.) you don't worry old age does count for
something after all it doesn't matter (.) I've I've made a fool of myself so
many times you might say it doesn't matter one [more time]

'you don't know what's in store do you (.) um what's in the present moment
is all that matters (.) hold onto that'

I suggest that old age plays a major part in her ability to adjust to different stages in life
and transcend to this level of psychological well-being and inner peace. However, using
Amy's case as a basis for comparison it is also clear that old age alone is not the only
factor as I move on to discuss John.

9.6.2 John: Bitter and 'half dead'

In contrast to Amy, John had very little to say during the interaction that indicated a
positive attitude. He is living with a combination of old age, terminal illness, a negative
perception of his social and supportive network and unresolved issues in his past and
present life which are causing resentment and bitterness. In addition, he is experiencing
a futility which he expressed after taping had been suspended. He commented that he
failed to see the point in taking certain courses of action surrounding any of his

problems because he felt 'half dead' already. This is the concept of social death, as I have discussed throughout this study, put into words by a sufferer. Sheila's response was to reformulate immediately to a positive outlook, telling him that he was also 'half alive'. I think that either or both of these descriptions embody the essence of how the concept social death must feel emotionally to patients such as John.

9.7 Summary of chapter

I have aimed in this chapter to show, from the topics of interaction and based on discussion throughout the preceding chapters, that Amy and John are at different stages of acceptance and rehabilitation or healing in the context of living with a terminal illness. In comparison to Amy, at this stage John had fewer physical difficulties to cope with. The physical trajectory of the disease is not a major issue in the process of social death. What counts is an individual's ability to maintain their social networks and find meaning in their lives, past, present and future. John's description of himself as 'half dead' is accurate; he is not living a good life. In the same terms, if I were to describe Amy I would say that she is 'half alive' and making the best of the time she has remaining.

In the next chapter I will examine Sheila's discursive management of each patient and her flexibility of professional approach as she manages two patients at differing stages of psychological adjustment and their subsequently varying needs.

Chapter 10: Repertoires of communicative trajectories:

The professional perspective

10.1 Chapter overview

In the previous chapter I have used a case study approach to identify and discuss the various components deriving from one of the focal themes of this study, social death, as it is evidenced in the topics of patient talk. The comparison of Amy and John has revealed differences in how they perceive their social support in the context of their illness as well as in their attitudes to their past and present lives. These differences in adjustment to their illness experience are likely to affect their ability to accept and find meaning in the circumstances of terminal disease and will affect their interactions with Sheila. As I have discussed in the previous chapter, Amy appears to have accepted her prognosis with a positive philosophical attitude whilst John appears to be very negative and has expressed a futility in taking action that indicates an overarching feeling of hopelessness and loss of self which are indicative of social death.

My focus in this chapter is Sheila's discursive management of Amy and John as two patients at different stages of adjustment, which calls for a different way of working with each of the two patients. I will consider her responses to psychological issues and the relational alignment between nurse and patient during each interaction. As a basis for considering Sheila's strategies for engaging the patients I feel that it will be useful, in section 10.2, to begin with an examination of the attitudes that these patients express about other health care professionals during the end-of-life stage. In the interest of a positively aligned relationship, it is essential that patients trust and have confidence in the many health care professionals that they will meet in the course of their illness. Their

attitudes to other members of their medical teams may impact, by generalisation, on the way in which they receive Sheila and her ways of working.

I will then examine the ways in which Sheila discursively manages and promotes the philosophy of palliative care with these two very different patients. I will consider both cases but will particularly focus on the interaction with John who presents perhaps the more challenging test of Sheila's discursive and relational skills. In section 10.3, I will consider the overall structure of each interaction as an indicator of Amy and John's levels of participation and engagement in discussion with Sheila. Section 10.4 is where I will consider the function of questions raised by Sheila, focusing both on questions used with a relational orientation and those used strategically towards clinical outcomes. In the following three sections, 10.5, 10.6 and 10.7, I concentrate on Sheila's ways of working with John, drawing attention to the rhetorical tactics that Sheila employs when faced with a 'difficult' patient.

10.2 Amy's and John's attitudes to health care professionals

The following extract taken from Amy's interaction gives an indication of her attitude, both to her diagnosis and to her primary health care team. Her positive experience of communication and support from her GP is highlighted by the fact that Amy raises the topic in direct response to Sheila's question (169) about the benefits gained from her experiences during her illness,

Extract 1

- 168 S: I think that um (.) one of the interesting things you said when I first came to meet you was that um (.) in a way having cancer had (.) um brought a whole lot of different experiences (*laughing voice*) and some of them [quite good
- 169 A: [mm m [mm

- 170 S: [experiences
 171 A: indeed (.) indeed and um (.) at the time it seemed to be such a clear
 diagnosis that (.) the doctor was very (.) I I can trust her she'll tell me the
 truth and that's wonderful you see isn't it?
 172 S: yes
 173 A: so she told me (.) and um (.) I wa/ I wasn't (.) I was going to say I wasn't
 bothered (.) I wasn't bothered about it and she said it's not good news
 and I said no I know I've got cancer and she said oh (.) and she said
 that's alright (.) I (.) I'm here for you whenever you want me and that
 was [er
 174 S: [has (.) Doctor D done any more blood tests recently?
 175 A: yes
 176 S: [or did Doctor S
 177 A: [that's right yes (.) no she had them (.) I don't know whether she wants
 them (.) she she wants them for herself (.) she's doing them for her [own
 research as well
 178 S: [yes
 179 S: yes yes
 180 A: she said in seventeen years I've never come across this carcinoid thing=
 181 S: yes
 182 A: =and she said the doctors in the surgery gave me all they could (.) in the
 way of information but they said don't be disappointed=
 183 S: yes

Amy is clearly grateful to receive a firm and honest diagnosis, 'I can trust her she'll tell me the truth' (171), and by using the reported speech of her GP, 'I'm here for you whenever you want me', she acknowledges the support offered by her doctor (173). She reports her inner thoughts at the time of diagnosis, 'I wasn't bothered about it'. She was expecting bad news and was prepared to receive it, 'she said it's not good news and I said no I know I've got cancer' (173). Her accommodating attitude is reinforced by the fact that she appears to be more interested in the fact that her type of cancer is uncommon and takes pleasure in the fact that her GP has gained prestige by diagnosing a rare form of cancer (177-180). She accepts her diagnosis readily and, aided by the open communication between herself and her GP, is also able to reciprocate with straightforward expressions of her wish not to be treated, as I have shown in the

previous chapter.²⁶ Amy has received a confirmed diagnosis with the full support of her doctors and has been able to accept her prognosis quite readily and make her own decisions regarding treatment. This frank exchange of information has enabled the trust and confidence that is so clearly evident in this patient's attitude to her doctors.

In contrast to Amy, as I have mentioned above, John suspended taping halfway through the interaction and went on to discuss the case he feels he has for litigation against his GP. He therefore comes to his interaction with the nurse carrying enormous resentment and loss of faith and trust in the health care system.

Without a full degree of trust in a health care relationship it is unlikely that patients will put their faith into health care professionals or accept advice, help or treatment choices. Non-compliance²⁷ with prescribed medication is seen as a serious problem in the medical field with up to 50 percent of patients not fully adhering to their recommended drugs regime. Russell, Daly, Hughes and Hoog (2003) and Lannon (1997) both argue the need for a 'therapeutic alliance' that will allow the recognition of 'the importance of social factors in shaping health behaviour and outcomes' (Russell *et al* 2003: 286). The key to this is the nurse-patient relationship, together with effective communication and a holistic view of the patient's circumstances. It also requires the establishment of trust. The issue of patient compliance will be taken up more fully later when I will discuss John's non-compliance with medical advice or his specific drugs regime and his initial resentment of practical help when offered by his nurse. There are several occasions

²⁶ See section 9.6.1

²⁷ "Compliance" is generally used to mean the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice.

throughout the appended transcript HCTRA1²⁸ that illustrate non-compliance but I will use just one longer extract later in this chapter (92-125) to demonstrate the patient's resistance to his nurse's advice and attempts to help.

Notwithstanding John's negative attitude and apparent lack of faith in his primary health care team, he appears to have a great degree of respect and faith in his palliative care team, at home and abroad, as evidenced in extract 2 below.

Extract 2

- 303 P: well done (.) I'd like to ask (.) Doctor M if I have his authority to complement the people in Cyprus (.) I shall certainly meet them
- 304 N: yes
- 305 P: an I (*laughs*) I think he was quite pleased with what they'd done you know
- 306 N: I think he was very impressed
- 307 P: pardon
- 308 N: I think he was very impressed
- 309 P: yes
- 310 N: yeh (.) an' I was very impressed
- 311 P: mm (.) mm (.) the chap the specialist (.) I forgot his name immediately in the hospital (.) um (.) his wife had cancer and this H M cured her completely
- 312 N: right
- 313 P: and so she got you know this close relationship (.) he thinks very highly of H (*unclear*) she still walks about as though she has a train of apprentices behind her you [know (*laughs*)
- 314 N: [right right

In contrast to how John feels about his U.K. primary care professionals, he is full of praise for the expertise of the Cypriot doctors (311). His attitude to his U.K. palliative consultant is revealed when he asks to use his weight to complement the doctors in Cyprus, 'I'd like to ask (.) Doctor M (*palliative care consultant*) if I have his authority to complement the people in Cyprus' (303).

²⁸ For examples see lines 8-24, 54-61, 198-206, 248-263.

10.3 Styles of interactional involvement

The transcript of Amy's interaction is approximately three times longer than John's and even allowing for the portion of John's consultation that was not taped, it was twice as long in time. Much of Amy's interaction consists of discussion of non-medical topics, although, as I shall discuss, there is on occasion an implicit clinically-oriented element underlying and masking what appears to be purely socially situated talk.

Although the interaction is, on the whole, led by Sheila through her strategic use of questions, Amy holds the speaking floor for the majority of the time. Sheila enables her to do this by signalling her listening and interest with supportive minimal responses. A typical exchange begins in response to a question by Sheila, which is answered at length by Amy, with Sheila encouraging an expansion of the topic by using empathetic agreements. This extract, taken from the beginning of the interaction, is representative of the structure of the majority of the session.

Extract 3

- 3 S: what about you?
4 A: not awfully good today (.) I don't know why (.) it comes and goes (.) I've taken my medicine which is quite wonderful (.) um (.) so I you know it seems to be working quite well (.) but um (.) yes I'm a little bit low today (.) that's all I can say
5 S: low in (.) in mood [or?
6 A: [well er what am I why am I low um (.) I've had a bad week or two (.) for some reason um (.) I was expecting um well the children and that's why dear and if you won't tell anybody else it's my birthday on Sunday
7 S: this coming Sunday?
8 A: well yes and I'm I was afraid everyone was going to descend on me and I asked them not to they just came in for a chat because um [(.) I just can't you know how long I can (.) pretend perhaps that's the worst
9 S: [yeah

- 10 A: but um I thought they were going to I was going to have some people staying but I I knew (.) I knew it wouldn't be the the right thing to do (.) but I'm sure the (*unclear-name of drug*) is excellent and you've told me how to use it (.) which I didn't know before I'd asked you really (.) I'm not a medicine sort of person I suppose really (.) [but I
- 11 S: [you've never liked taking
- 12 A: no (.) no
- 13 S: medication (.) have you

Sheila enquires about her patient as soon as possible at the start of the session with a direct question, 'what about you?' (3). Amy answers the question negatively and expands to try and explain just what it is that is making her feel bad. She signals the end of her speaking turn with a summation, 'I'm a little bit low today' (4) and syntactic completion, making it clear that she has finished talking, although the content of her speech reveals that she has not managed to express herself sufficiently, 'that's all I can say' (4). Taking Amy's cue, Sheila offers a repetition of Amy's own description with an expansion, thus encouraging her to express herself more fully. By these means, and by the use of repetition to check and signal attention, she offers encouragement to Amy to reveal a greater amount of detail, which then signposts her underlying difficulties of dealing with her disease without compromising her usual social role, 'I just can't you know how long I can (.) pretend' (8).

In further explanation (10) Amy comments on her medication almost as a justification for not apportioning blame to Sheila, as her health care provider, for how she feels although she has stated her compliance to her medication at the outset (4). Sheila responds by using an empathetic statement 'you've never liked taking medication have you' (11). This statement combines to express understanding of the patient's perspective and to give historical reference to Sheila and the patient's past relationship. Sheila

demonstrates that she knows the patient and can understand her particular point of view. In the context of this well-aligned relationship and the interactional support supplied by Sheila, Amy is able to talk without constraint throughout the interaction.

Amy, however, in the safety of her well-aligned relationship with this nurse does not feel constrained to a purely medical agenda or indeed to an asymmetrical, institutional relationship whereby she is not expected to ask non-clinical questions or to be the only participant expected to make self-disclosure.

Extract 4

- 109 A: no what do you do you like that sort of programme?
110 S: um (.) I'm a big radio listener I listen to a [lot of radio four yes
111 A: [(unclear)
112 S: and I tend to go to bed and listen to =
113 A: yes yes it's worth having
114 S: =and I listen to the world service throughout the night half the times
115 A: yes (.) do you sleep well?
116 S: I'm not a brilliant sleeper
117 A: no
118 S: no (.) but that's if I've if I've got the radio I will lie um=
119 A: yes
120 S: = and [listen
121 A: [that's that's and um [that's good
122 S: [yes (.) yes

Regulations detailing the professional boundaries²⁹ of the nurse–patient relationship specifically advise against inappropriate self-disclosure from the nurse to the patient. Sheila is potentially placed in a slightly uncomfortable situation when Amy directs personal questions to her (109) and takes on a caring role herself, ‘do you sleep well?’ (115-122). Hunt (1991) notes that personal self-disclosures are evidence of a developing

²⁹ Crossing of professional boundaries include sexual misconduct, physical abuse, financial abuse, dual relationships, breaches of confidentiality, inappropriate acceptance of gifts and inappropriate self-disclosure. Normal conversation such as in these extracts is permissible so long as the needs of the patient are met and any information given to the patient is not for the advantage of the nurse. Source: Hinchcliff, Norman, and Schober (2003).

friendship but were unusual in her data which derived from the home care setting. However, Sheila responds easily and allows Amy insight into her world away from her profession. A question about the quality of Sheila's sleep could be seen as small talk rather than any form of personal self-disclosure. However, a more difficult situation for Sheila, who is perhaps mindful that her conversation is being recorded at this point, is in the following extract when Amy initiates a topic originating from a previous visit which concerns the serious ill health of Sheila's relative,

Extract 5

Following talk about Sheila's occasional need to change appointments

- 152 A: but you're (*unclear*) back in your routine [what is it (*unclear*) one of your patients is she?
- 153 S: [yes
- 154 A: were you weren't you worried about somebody on (*unclear-day of week?*) recently? I might be thinking of someone else (.) I think you said I'll be in again unless (.) um (.) something happens? no not you? oh dear I thought I'd I thought I'd got everybody in [order
- 155 S: [well I think you have really
- 156 A: mm (.) perhaps you could trace it
- 157 S: yes I think I'd mentioned to you that I'd got um a family [member who's not well=
- 158 A: [aah (.) yes
- 159 S: = and that it might necessitate me [being away for
- 160 A: [you were just saying I'm away for (.)
yes
- 161 S: and just to warn you [that if if I had to cancel an appointment that's what it would be
- 162 A: [yes yes
- 163 A: things are not too bad at the [moment?
- 164 S: [but but things are managing at the moment
- 165 A: you don't know what's in store do you (.) um what's in the present moment is all that matters
- 166 S: yes
- 167 A: hold onto that (*unclear*) difficult moment

Amy is trying to remember, or cueing Sheila to talk about her relative, which is clearly a conversational topic from a previous call. This type of self-disclosure from nurse to patient could be viewed as inappropriate in the circumstances of Amy's own ill health. In turns 152-156 Amy asks question after question becoming anxious that she is confused about her facts, 'oh dear I thought I'd I thought I'd got everybody in order'. Sheila reassures her (155) that she has her facts straight but does not provide an explanation until Amy asks her to check her position (156). In credit to Sheila, who does not want Amy to think she is confused, together with Amy's persistence, she eventually clarifies matters and adds a valid justification for the disclosure (lines 157-161). Amy is then able to contribute to the relationship with sympathy and advice.

Having a well-aligned relationship with open channels of communication appears to bring benefit to the patient, but it can have drawbacks from the nurse's professional perspective if control of the interaction is lost. In the next extract, Sheila appears to have fulfilled her agenda and is preparing to end the session. Her final topic shift question is an open one to allow Amy to highlight any issues she may have that have not yet been discussed.

Extract 6

- 433 S: Amy is there anything particular you want to discuss with me today? (.)
anything that's worrying you at all?
- 434 (..)
- 435 A: you mean privately (.) without Annmarie? (*researcher*)
- 436 S: well well if you want [(unclear)]
- 437 A: [(unclear)] no no she no [(.) unless you want to (.)
say something
- 438 S: [no ok
- 439 S: no there's no there's nothing that
- 440 A: no
- 441 S: I just wanted you to know that whatever (.) you know that

- 442 A: no you really when you told me about the um (.) that was very useful to me (.) how the thing worked
- 443 S: yes
- 444 A: so whether it's that or not [I don't know
- 445 S: [yes
- 446 A: anyway that's um (.) we're straying from the point (.) now (.) [I I'm prattling I'm afraid
- 447 S: [so
- 448 A: I have to look at people after quarter of an hour and say now (.) are they beginning to yawn because if so [shut up and (*unclear*)

The non-specific question causes a degree of confusion and checking for clarification by Amy (435, 437), and is not taken up. Instead, Amy takes the lead in the interaction and signals her intention with her self-deprecating comments, 'I'm prattling I'm afraid', 'are they beginning to yawn' (446 and 448). She proceeds to ask Sheila for permission to talk to me about the research, which leads the conversation onwards to cover the multiple topics of communication with health care professionals, treatment of old people, a story from her life as a teacher in Manchester and my own career. Sheila makes little contribution during these topics until eventually:

Extract 7

- 622 P: how do you stop me [now when you want me to stop
- 623 R: [*(laughing)*
- 624 S: no (.) couple of things I want to ask you [but
- 625 A: [you won't be able to I'll be quick
- 626 A: anyway she went down to have her nervous breakdown with friends

She challenges Sheila to interrupt her (622, 625), which is unfortunately not made easier by my own laughter. As Sheila interjects, Amy talks over her and carries on until she has finished her topic. Eventually, when she has finished, she says to Sheila, 'yes dear what did you want to ask' (634 not shown here). Amy has taken control of the

conversation, which may have caused Sheila difficulties in managing her time efficiently to attend her next appointment. Although, as I shall discuss shortly, Sheila has commented during a post-interview recording that Amy had been allowed to talk freely and at length purposively, 'that's why I let her go on a bit'. It appears that Amy is also able to exercise her own agency with little regard to the institutional nature of the relationship. The combination of Amy's acceptance of her illness, as discussed in the previous chapter, and her perception of her relationship with her nurse conspire to allow a freedom of expression with minimum constraint.

Unlike Amy, an overview of John's transcript (HCTRA1 in appendix), in comparison, shows clear differences in format. It is characterised by short speaking turns, a high frequency of nurse questions, with typically short responses and little elaboration from John. As I have discussed, John has a negative attitude to his present circumstances and a mistrust of many health care professionals and he does not appear to engage in discussion easily. A physical consideration is that he is also quite breathless and is possibly incapable of long stretches of talk. Although this is not Sheila's first visit (she has in fact met him several times), she has to work hard, discursively, to complete her agenda, which covers mainly clinical issues, and the performance of relational work with this patient.

10.4 Sheila's questions: Social and strategic

Many of Sheila's questions throughout the interaction with Amy were used supportively, as conversational fillers or reformulations of Amy's comments. This enabled Amy to expand on a topic under discussion as in the extract below as a typical example (also extract 3 lines 3, 5, 9-11)

Extract 8

- 48 A: well um Harriet's coming at in May and uh (.) Doctor tells me she's
going to see me in May so I suppose [(unclear)
49 S: [you had an appointment have you?
50 A: I've been I went a week ago [since since I saw him (unclear) so um (.)
yes she's
51 S: [yeah yeah yeah

In the event of a topic shift initiated by a question from Sheila it was often clinically-orientated, although this was not always immediately apparent.

Extract 9³⁰

- 82 A: =and that seems to be working since I can eat again and that (.) I was
much better until this last couple of [(.) days? or weeks? I don't know (.)
time is (.) time has left me (.) really (.) but um I don't know
83 S: yes what about the newspaper (.) are you do you read a daily newspaper
or
84 A: I buy the Spectator I have a Spectator every week on a Friday morning
and I devour it during the week (.) I don't take another (.) newspaper
85 S: and what about (.) do you listen to (.) the radio?
86 P: oh I do listen to the radio [a lot
87 S: [which programme do you listen to?

The extract above contains questions (83, 85 and 87) that started a topic that subsequently developed into a discussion of the big bang theory and general chat about TV and radio. It occurred to me during the observation of the interaction that the topic shift had an underlying reason as it seemed to be triggered by the patient's last comments, especially her remark, 'time has left me' (82). I asked Sheila to explain the question during an interview on the way back to the hospice.

³⁰ This extract was also discussed in Chapter 9 in relation to Amy's engagement with current life

Extract 10 (HCTRA 4: 747-820)

- 747 S: I was actually trying to find out how with it she was in space and time
because the impression given when she went to day centre (DTU)
- 748 R: um
- 749 S: was that she was not with it
- 750 R: I picked up your time orientation thing with the newspapers=
- 751 S: yes
- 752 R: =and the radio programmes (.) because of course she'd initially said
hadn't she she didn't know what day it was which probably didn't help
matters
- 753 S: but she did because she knew it was her birthday at the weekend
- 754 R: yes
- 755 S: and I checked that and it's right
- 756 R: yes
- 757 S: um
- 758 (.)
- 759 R: that's interesting
- 760 S: so I thought those sort of things were
- 761 R: yes
- 762 S: were why I let her go on quite a bit as well
- 763 R: mm
- 764 S: and that she would still come back to the point though (.) so she's
actually appearing really quite different at home=
- 765 R: definitely
- 766 S: =to how she is in the day centre

So, in this case, Sheila has enabled Amy to engage in discussion for reasons that are fundamentally clinically-based. Amy, however, has also been able to enter into discussions about current affairs, her past life, family and attitudes to her illness and prognosis, as described in the previous chapter. What is evident here is Sheila's orchestration (747) and how she has strategically managed conversational topics according to her own agenda, i.e. as a monitoring device to assess Amy's competency.³¹

³¹ It is also important to note here, in the light of the contextual differences that I have so far made explicit across the range of data settings, that nurses themselves are often aware that patients may be affected by the contextual differences of different care settings, 'so she's actually appearing quite different at home'.

This style of questioning is also apparent in the interaction with John. In the next section I will consider Sheila's discursive strategies as she attempts to engage with John and earn his trust. I will also focus on how, while this relational work is being accomplished, clinical outcomes are achieved as strategic questioning is interwoven throughout the interaction.

In this instance, John has drawn attention to a symptom, migraine, which is new to Sheila and which must be assessed to see if it is significant to John's disease or medication. This is the topic, initiated by John, which starts the consultation:

Extract 11

- 1 J: could my (.) medicine (.) have anything to do with me having migraine
attacks (.) I've had four (.) four days in succession
2 S: have you ever had migraines before?
3 J: oh yes yes but never (.) four days in succession (.) no p'raps four months
(.) or four weeks but not/ (.)
4 S: so it's just over this this last few days is it
5 J: the last two days I've not had (.) an attack [Friday was the last=
6 S: [right
7 J: = (.) Saturday Sunday Monday (.) p'raps they'll go away again p'raps it's
sheer coin[cidence
8 S: [so before that how long was it that you had migraine?
9 J: it used to vary tremendously (.) hum/
10 S: (.) and what did you take for them (.) [anything
11 J: [nothing
12 S: and did you take anything over the weekend?
13 J: mm (.) no

The question and answer format is typical of the structural framework within doctor-patient medical interviews (Cicourel 1985). Here Sheila uses questions as a knowledge elicitation device to gather information in order to classify and categorise John's symptoms in the context of his disease. Having established the history of the symptom

in this initial extract it is possible to track Sheila's trajectory of questioning and problem solving across the course of the entire interaction.

Extract 12

- 26 S: and is that the sort of thing you used to have when you had them before?
(refers to visual disturbances)
- 27 J: yes (.) yes
- 28 S: and no sickness?
- 29 P: no sickness
- 30 S: no dizziness?

Extract 13

- 36 S: this breathlessness (.) is that worse?
- 37 J: yes yes

Extract 14

- 40 S: when do you fly to Cyprus?

Extract 15

- 54 S: right (.) d'you know (.) last time (.) we talked about (.) you talked about possibly bringing the steroids down?
- 55 P: yes
- 56 S: did you?
- 57 J: yes (.) to three
- 58 S: (.) and of that d (.) does that coincide with the migraines at all?
- 59 P: (.) oh (.) once or twice I've missed altogether (.) the second one
- 60 S: right
(6 turns omitted)
- 67 S: I'm just thinking change your medication at this point=
- 68 J: yes
- 69 S: =when you're going away=
- 70 P: right
- 71 S: =might have something to do with the breathlessness (.) and (.) and with your (.) migraines
- 72 J: (.) right that's easy
- 73 S: so could you go back to? (.)
- 74 P: you excuse me whilst I go out and count the pills

Extract 16

- 126 S: oh (*laughs*) (.) so you go back to the original dose of the steroids (.) umm
- 127 J: four a day

- 128 S: and I think that you'll probably be drinking more wine on this trip [won't you?=
 129 P: [that is
 the truth
 130 S: =so I think it would be a good idea =
 131 J: jolly good
 132 S: = to take those [regularly
 133 J: [then I shall have some (.) there are only three left
 134 S: yeh

Extract 17

- 248 S: yes (.) I think that the steroids reducing the steroids (.) might be part of that problem
 249 P: I have been missing (.) [the third (.) you know
 250 S: [yeh yeh
 251 S: I'm sure (.) I think you've got to probably got to try and be quite strict with yourself
 252 J: mm
 253 S: (.) because your breathing before you went to see Doctor B the first time was quite bad wasn't it? =
 254 J: mm (.) oh yes
 255 S: =and it did get a lot better quite quickly=
 256 P: yes yes (.) yes yes mm
 257 S: =so I think to go back to taking the steroids twice a day
 258 J: ok

Sheila's questions have ruled out further symptoms of sickness and dizziness (26-30) but have established John's obvious breathlessness as a significant factor (36-37). Turns 54-60 contain the reason for his headaches, steroid withdrawal syndrome, indicated by his comment in turn 59 and mainly as a result of his non-compliance to medication. This is a difficult situation for Sheila to manage without appearing to have the upper hand in a relationship that is already tentative. John has been advised to reduce his steroids from four to three per day. By his own admission (59) he has been careless about taking all three doses and as a result his symptoms have worsened.

Sheila needs to be able to offer mitigated advice and provide effective reasons in order that John can fully understand the consequences of his failure to comply with medication, notably in turns 248-258 above. Within this short extract, Sheila has provided the cause (248) and effect (253) of his actions and shown him the potential for improvement (255). She also uses her rhetorical skills to appeal to his personal responsibility (251) and gives a precise confirmation of the correct action to take (257). Throughout this exchange, she uses a high degree of modal verbs, 'might', and 'think', 'try' and uses intonational emphasis to position her argument in a mitigated yet forceful manner. John shows he accepts her advice by making positive minimal responses and an admission of the actions that may be responsible for his present symptoms, 'I have been missing the third you know' (249).

However, this extract has occurred at a point when John appears to be open to advice and after, what I believe, is the turning point in this interaction. This follows an exchange where Sheila has used her communicative skills and provided practical help with the effect of altering John's negative approach and positively aligning their relationship. I consider this extract next.

10.5 Advice giving: Resistance and resilience

This next extract typifies John's initial resistance to engage with his nurse and his overall negative attitude. It is a protracted sequence of persuasion and resistance, which requires Sheila's resilience and rhetorical skills for a positive outcome. As I have mentioned, I see this as the turning point in this interaction, with John becoming less resistant after he eventually capitulates and accepts Sheila's help in this instance.

Extract 18

- 88 J: =then I get violent acidity [so then the next day I=
89 S: [well you know the cure for that
90 J: =drop back to my acid blocker tablets
91 S: right
92 P: but then I've only got three left so I'm conserving them
93 S: well you'll need some more to take with you
94 J: (.) it's not as easy as that (.) you've got to give them forty-eight hours
(John leaves the table enters the kitchen and returns)
95 J: you can't do a prescription can you
96 S: no but I can talk to them
97 J: you can what?
98 S: I can talk to your surgery
99 J: they yes (.)
(John leaves table to fetch tablets)
100 J: oh it's enough really I don't take one every day
101 S: I think you ought to have some more
102 J: mm
103 S: I think so shall we give them a ring and see?
104 J: uh (.) have you got their number [there wait a minute
105 S: [yeh
106 J: uh (.) I tell you what (.) I have a thing which I squirt up my nose (.) eh (.)
the idea being to keep my head clear so as I don't breathe through my uh
mouth make me cough uh it it cured my cold I think
(John leaves room-Sheila dialling on mobile phone)
107 J: oh it's upstairs and I don't want to go up
(Sheila stops using phone)
108 S: (.) can I get it for you?
109 J: ha you wouldn't know where (.) it's a green (.)s s s squirt
110 S: well I'll try it (.) shall I try phoning the surgery first?
111 J: (coughs) they wouldn't know, they don't know anything (.) I shan't be a
moment
112 S: ok
113 P: but I'm not going to run
(John goes upstairs. Sheila still trying to dial on phone)

Sheila works on a strategy of countering each of John's comments and attempts at resisting her help by appealing to his own knowledge, 'well you know the cure for that' (89), making direct statements of fact and opinion, 'I think you ought to have some more' (93, 101), offering alternatives (96, 98) and offering direct help (103, 108, 110).

Her use of the interjection 'well' (89, 93) functions as a buffer to soften the otherwise more forcefully direct expressions, which state the obvious.

John counters by producing an obstacle to Sheila's suggestion, i.e. a low supply of tablets, for which she in turn suggests a resolution, 'I can talk to your surgery'. This offer is dismissed by John with a downgraded 'I don't take one every day' (which, in effect, leads full circle to the cause of his stomach acidity). Sheila's more insistent 'I think you ought to have some more' using the first person to challenge John to directly contradict her opinion. Rather than contradicting, he gives a minimal response (102) whereupon Sheila takes the opportunity to retain her advantage and switches to a collective pronoun to include and draw John in with, 'I think so shall we give them a ring and see' (103). After an initially positive contribution (104) John makes another tactical move as he attempts to distract the focus of attention to somewhere else (106) for a seemingly unrelated reason. At the point when Sheila is actually performing an act of help, John drops a broad hint that he needs her to do something else instead (107). She immediately makes an offer of assistance (108), which is again countered by John with an interjection 'ha', giving a reason for her inability to help, i.e. she won't be able to find the object he wants. Sheila again uses 'well' as a buffer as she says she'll try anyway, but then, as a priority, asks permission to call the surgery in pursuit of her original aim. Finally, despite John's negative outlook on Sheila's chances of success (111), he concedes with minimum loss of face as he exits the room and leaves Sheila to her task.

Following this prolonged negotiation Sheila completes her task and arranges a prescription. She receives emphatic gratitude and a positive acknowledgement of her professional role from John.

Extract 19

- 122 S: so that should be [fine
123 J: [thank you very much
124 S: that's ok
125 J: the nurse in action

Sheila has ultimately engaged John in interaction by her persistence and by proving her practical worth. I will consider further examples of Sheila performing this aspect of her professional role in the following section.

10.6 'The nurse in action': Information giving and practical help

John's negative attitude to health care in general will also have an impact on his compliance to treatment and the relationship with his nurse. In order to establish her competency and credibility, she needs to transmit the information that John requests, or needs to know, effectively. The interaction begins with a knowledge elicitation request from John, as discussed above, which is followed by a reasonably technical anatomical question (207) below.

Extract 13

- 207 J: where is (.) mucus generated? (.) where is (.) the gooey stuff [born?
208 S: [yeh
209 S: either from the lung tissue or from the bronchus
210 P: oh
211 S: any of those places
212 J: oh (.) oh (.) oh I see (.) there isn't a special gland or something
213 S: well yes (.) you do have some (.) it's going to be an anatomical test I
can't bear it [(laughs)
214 P: [yes (laughs)

- 215 S: usually you'll get that sort of thing if if you're coughing a lot it will just
tend to make the mucus increase=
216 J: [yes
217 S: =[and this is why we talked about possibly (.) giving you a cough
suppressant

Interestingly, although John is well able to articulate his question using a medical term he immediately repeats and reformulates his inquiry, downgrading the term 'mucus' to 'goeey stuff', possibly to play down his own knowledge in deference to Sheila's professional expertise. Sheila then has a choice of how to respond. She could offer a straightforward technical response using the correct medical terminology or she could follow the patient's lead and downgrade the anatomical jargon accordingly. She chooses the former option (209) but with a limited response, which leads John to seek fuller information (212). Sheila answers but does not expand, choosing instead to use humour, again as a distancing device in a possibly threatening situation, to deflect from a more serious topic that she cannot or does not wish to enter into at this stage. Instead, she uses her response to redirect to a relevant issue in her agenda, 'this is why we talked about possibly giving you a cough suppressant' (217).

In a clinical sense, Sheila has given mitigated advice, problem solved and provided information tailored to John's needs. I will now consider a non-clinical aspect of her role as she performs relational work to further align with John.

10.7 Relational work: Acknowledging John's world

So far I have concentrated on the interactional strategies undertaken by Sheila that have been more oriented to her participant role as a health care professional. As I have noted previously, interactional work related to clinical outcomes is one part of this

consultation but is interwoven with the interactional work directed at the holistic care of the patient. Relational alignment and social assessments occur simultaneously. Sheila uses usual social strategies to facilitate an alignment or bonding with John. These include acknowledging mutual contacts, demonstrating knowledge of the patient's circumstances, showing an interest in his activities, and using humour.

Finding mutual contacts is a means of acknowledging the wider social group or community. When Sheila does this (albeit in these extracts the contacts derive from her professional role) she is implicitly reinforcing John's role as a member of the community alongside herself. This has a multiple effect, firstly of aligning Sheila and John with each other and, more importantly in John's situation, reminding him that he is still a social individual with links to family, friends and the community. It also links to knowledge acquired by Sheila during previous conversations, which demonstrates her interest in him and thereby enhances his sense of self-worth.

Extract 14 (pseudonyms used)

- 40 S: take it very easy yeah (.) when do you fly to Cyprus?
41 J: Wednesday
42 S: what time are you going?
43 J: six in the morning (*laughs*) seven in the morning summing like that hm
44 S: and you're going with?
45 J: Emma
46 S: [Emma
47 J: [you know her
48 S: yeh
49 J: hm
50 S: yeh (.) very well

The mutual acquaintance above is a relative of a previous patient whom Sheila has come to know well as a result of her holistic, whole family approach. In the next extract, John

shows his interest in their mutual professional acquaintance and Sheila's disclosure of 'backstage' conversation between professionals.

Extract 15

- 198 S: I had a chat with Doctor B this morning=
199 J: ah
200 S: =and said I was coming to see you (.) umm (.) and you know that (.)
hadn't cancelled your appointment with him=
201 J: ha
202 S: =and you've already told me off about that
203 J: so he's going to slap my hand is he?
204 S: no (.) no (.) I thought it would be a good idea though for you to see him
when you come back from Cyprus

It seems that Sheila had omitted to cancel an appointment, which had displeased John (200-202). John again uses the interjection 'ha' (201) in response and uses a metaphoric expression (203) 'he's going to slap my hand is he', to ascertain whether there are any repercussions for him as a result of Sheila's mistake. It is important for John to feel valued by his health care team and not to feel that he is perceived as unreliable in his patient role as a result of missing appointments.

When Sheila retains information from previous visits it demonstrates that she has listened, remembered, and is interested in building a picture of John's world. In the next extract, she refers to one of John's daughters by location rather than by name. This shows that she has retained enough information to know that he has more than one daughter and where at least one of them lives. The fact that she has not remembered the daughter's name (if she was given it) is not really significant given any one individual's limited capacity to remember every detail.

Extract 16

- 191 S: are you (.) nervous at all about going to Cyprus (.) about flying?
192 (.)
193 J: not nervous about flying, I'm just nervous about how my daughter will
react to my wheezing and coughing
194 S: is this the Staffordshire daughter?

By the end of the taped part of this interaction with John, Sheila has proved her professional usefulness and skills by:

- problem solving his increased breathlessness and offering symptom control
- performing an act of practical help by arranging for a prescription to be written
- giving clinical or anatomical information when requested
- offering mitigated advice in a non-prescriptive manner
- showing that she knows her patient by using strategies of relational alignment
- resiliently countering John's negative attitude and unwillingness to engage

Finally, using all of the above and despite a difficult start, the taped consultation ends in humour, a distinct indicator of successful relational bonding, used in this instance as a means to tease Sheila (with her encouragement).

Extract 17

- 315 S: and you'll see her will you (*refers to consultant*)
316 J: certainly yes mm (.) mm (.) she's nice but bossy
317 S: nice but bossy
318 J: yes (*laughs*)
319 S: life seems to be full of bossy women
320 J: isn't it isn't it (.) tyrants
321 S: tyrants (.) that include me?
322 J: absolutely [*absolutely laughs*]
323 S: [right (*laughs*)]

Sheila's use of repetition (317) highlights the mischievous comment directed at a female professional (316), causing John to laugh. Sheila expands his comment to use as a stereotype for women generally (319), which is in turn taken up by John in an exaggerated form for comic effect (320). A high level of relational bonding occurs (321-323) as the stereotypical description is individualised specifically to Sheila, which she encourages and allows for John's obvious amusement. At this point in the session, John asked for the tape recording to stop. He now appeared to feel confident in his relationship with Sheila and had several issues he was now able to disclose. Having finally gained trust in Sheila the consultation continued for a further 20 minutes.

I have shown how Sheila has employed a different interactional style as she works with a more challenging patient. She has had to use a range of strategies and prove her worth before she is eventually successful in engaging with him and earning his trust. The patient, John, is struggling to adjust to a range of issues relating to his disease and Sheila's success in her use of discursive strategies and her resilience have enabled him to feel secure enough in the relationship to unburden himself of his worries to her.

10.8 Chapter summary

In this chapter I have discussed how the nurse discursively manages two home care patients at different stages of adjustment to their terminal disease. I have considered the fact that their attitudes to previous interactions with health care professionals may impact on the quality of the interaction, notwithstanding any personal issues as discussed in the previous chapter.

I have shown how Amy is able to talk at length in a social mode about topics unrelated to her clinical status. I have also shown that Sheila has clinical outcomes in mind when she allows Amy to do this, but that despite this purposive reasoning it would appear that Amy is able to exercise her own agency to take control of the interaction. I suggest that she is able to do this from the safety of a well-aligned relationship where she is not restricted purely to the patient role but feels able to demonstrate her own personality without restraint.

In her interaction it appears that Sheila has skillfully managed to adhere to the philosophy of palliative care by taking account of the social and spiritual needs of her patient in addition to the clinical and planning aspects of her role. This has been achieved by a relationship that has been built to the limits of her professional boundaries, using an interactional approach of targeted and supportive questioning and positive support.

The interaction with John has caused Sheila to take a different approach. As I have shown she has had to use a range of rhetorical strategies and demonstrate her effectiveness as a nurse before she is eventually successful in engaging with him and earning his trust.

It becomes clear that not only are there differences in the styles of communication across settings but also that within the home care setting at least, nurses will have to adapt their interactional styles according to each patient. The value of a one-to-one relationship and skilful communication in the home care setting is clear and evidently effective. In the following chapter I will draw together the contextual differences

between care settings from all of the previous chapters and discuss implications for practice and service provision.

Chapter 11: Conclusions

11.1 Chapter overview

In this final chapter, I hope to draw the threads of this study together and return to the issues that have arisen in previous chapters before addressing the research questions that I set in Chapter 1 as the basis for my study. I will firstly consider the arguments that have been raised concerning the concept of death as a taboo topic (11.2) and the implications of palliative care in old age (11.3). I will then take each of the research questions in turn and revisit them in terms of each care setting, before considering the methodological approach and the discursive patterns that were observed across settings (11.4). Finally, I will discuss the implications for practice (11.5) and the limitations of this research (11.6).

11.2 Death as a taboo topic?

I have noted that death in modern society is often seen as a failure of medical practice and as a result the event of dying has become increasingly medicalised and has become an institutional rather than a community concern. The result of this is that talk of death is increasingly taboo. Dying patients are stigmatised and isolated from the wider social group to be cared for in institutions such as the hospice that is the site of this study. I have discussed that palliative care has also been criticised for focusing on the clinical aspects of care as a priority, leaving little time for the psychologically oriented communication with patients that forms the basis of the palliative care philosophy.

I have also noted the tension between the societal position and the individual's position who will, according to current medical guidelines, have an open awareness of diagnosis and prognosis but, if the above argument holds, little opportunity to talk about issues relating to their terminal status.

However, this study has shown that talk about dying is a regular and frequent aspect of hospice care across all three settings in this study. In the home care setting a patient talked about how she was subjected to unwanted attention because she was dying (5.9). Another patient was able to express her wish about where she would like to die and her wish not to be resuscitated (9.6).

In the DTU, talk occurred about the actual experience of dying (8.5), prognosis, families' attitudes to death and dying (5.9.2.1), comparisons of other patients' own attitudes to their prognosis and a favoured topic, patients' reviews of the television documentary about death that had recently been broadcast (5.9).

In the IPU setting, the majority of taping occurred during task-based care, which appeared to preclude such talk. However, one consultation did not occur during clinical care and was specifically oriented to the assessment of one patient's reaction to the deaths of other patients on her ward (6.8.1).

On the basis of this evidence it is clear that death is not a taboo topic in the data which constitute this study and that nurses are willing to take the time to address patients' concerns.

11.3 Cancer and palliative care in old age

I have consistently highlighted issues relating to old age throughout this study (2.2.1, 5.8.1, 6.5.2, chapters 9 and 10). My rationale for this has been the fact that the vast majority of patients receiving palliative care are aged 65 and over. The data from my study reflects the national picture as is shown in the demographic tables presented in chapter 3. Of the 37 patients that were taped for this study just 7 were below the age of 65. As one patient commented, 'it is a disease of old age'. It will nevertheless present some patients with complex issues as they simultaneously orient towards old age and terminal illness.

I have noted that the definition of social death, as used in this study, takes a broader view of the concept and can include old age, or rather the *effects* of old age, when physical and/or mental decline contribute to a loss of personhood in an individual. I have considered that trajectories of adjustment to terminal disease may be different due to the usual processes of life review and personal evaluation associated with old age. Erikson's (1959) model of life stages equates the acceptance of death with the acceptance of a life judged to be lived well. The case studies, Amy and John, were a demonstration of the differences between two patients with different outlooks. The combination of old age and terminal illness appears to present a particularly complex situation and a paradox that can be seen in the care management and interactions with these patients. A terminal diagnosis in old age has the potential to create a different impact and orientation than would be the case in a younger patient. In old age many of the adjustments to terminal illness that younger patients will face have already occurred and been dealt with. I have shown that, in the best case scenario, terminal illness may be faced with absolute open awareness and acceptance. In the home care and DTU

settings this ability was well accommodated in the communicative and psychosocial management of patients.

The 'wisdom', in Butler's (1963) terms, of many elderly people can equally be applied to the context of adjustment in terminal care and used as a resource for younger patients to draw upon. One of the major motivating reasons for undertaking this study was the realisation that during communication older patients, as Grainger (2002) and others have also found, were often not being afforded full respect. There is a challenge here for nurses to share a greater awareness across all settings in order that the trajectory of positive adjustment in old age is not compromised by interactional mismanagement.

11.4 In response to the research questions

1. To what extent can the process of social death be evidenced in nurse-patient encounters as they present at each of these care settings: home care, day therapy unit and in-patient unit? (Chapter 5)

Based on the data deriving from 30 interactions, the three settings can be seen to deal with a range of issues that are sometimes particular to each and are relative to the stages of disease and adjustment that the patient is experiencing at the time of attendance. In the home care setting the focus on just one younger patient explored her difficulties in accepting the physical and relational effects of diminishing health (5.9.1). The process of rejection and withdrawal from social and family ties is evident at this point as the patient begins to split from the wider social group as a consequence of her disease and changing identity. Part of this process could be seen to relate to the transition to the status of a terminal patient and the onset of factors associated with social death. Whilst a

patient is still at home and in a superficially normal social role, there is a tension between struggling to carry on as before by not asking for help, by receiving visitors and by not disclosing a terminal prognosis whilst at the same time having to cover up unpleasant and socially taboo symptoms and reject the acceptance of the stigma of terminal disease.

The DTU setting was characterised by talk by several patients of their own and their families' attitudes to symptoms and prognoses (5.9.2). Patients have open awareness about their prognosis and, of course, their symptoms, but at this point much is left unsaid as patients seek to protect their families, as they see it, from the burden of knowledge. At this point in the disease stage it is very unlikely that friends and family are unaware of the terminal diagnosis and so collusion and secrecy is now likely to take the form of withholding symptoms or avoiding distressing topics of talk. This conspiracy is difficult to maintain when the family members are also likely to be repressing their own grief to present a controlled front. The potential result is a tension leading to further damage to relationships with family and friends.

The in-patient unit is a setting where patients' identities are already at risk for several reasons separate from communicative effect. Environmentally, there are few personal effects that can provide social signals. Patients are often experiencing severe symptoms, pain, diarrhoea and vomiting, constipation or confusion, and many need total care. Much of this care will be of an intimate nature and patients will therefore be subjected to a loss of dignity, despite all measures taken by the nurses to prevent this. The varying degrees of loss of independence and the need to accept help are also a major threat to the self of the patient before the illness episode. Social death can be seen to equate with

loss of identity, agency and dignity. Evidence of the process of social death can be seen as an escalating trajectory as patients become more dependent on physical care. There is little opportunity for one-to-one talk between patient and nurse and so the majority of communication occurs as small talk during task-based care. As a result many of the patients' contributions during interaction were minimal and spaced around the nurses' constant commentaries on how they are about to approach the patient or what they are going to do next (5.9.3). It was therefore very difficult for patients to express themselves as individuals when the clinical needs assumed priority, as they often did. However, interactions are dynamic and patients are also reacting to the nurse as the other interlocutor. One reason for patients' inability to function as social individuals in this setting is the nurses' tendency towards over-accommodation in interaction. I will take this up in more detail in response to research question 4.

2. How do nurses and patients counter social death within interaction? (Chapter 6)

Hope and healing, in the palliative sense, may be seen as a counterpoint to alleviate the effects of social death. The ability to 'feel better' relies on attending to outstanding issues, accepting the prognosis and moving on to find meaning in the life that is remaining. Despite the inability to join in with most social activities, patients need to feel valuable as social individuals to avoid the feelings of isolation that can lead to a gradual withdrawal from the wider world.

The home care setting enables patients to talk freely outside of institutional care. This is the setting where patients can present themselves in their own homes and align positively with the nurse. It is a one-to-one relationship, built up over time and repeated

visits so that knowledge gained from previous consultations will be recycled, thereby giving a sense of continuity to the relationship between patient and nurse and a feeling of self-worth, as a social individual, to the patient.

Talk of patients' home environments occurs here that does not occur in the other settings to such a degree (6.6). Hope and potential healing are manifest through patients' appreciation of their physical surroundings. At home, this appears to be keenly felt as patients' facility to enjoy and control their own personal space is liable to be of a limited duration. The knowledge that the ability to remain reasonably independent is not indefinite therefore lends acuteness to patients' experience of their physical surroundings and impacts on topic choice in conversation.

The main feature of the DTU, as it occurs throughout this data, is the element of peer support that is evident. It is the only palliative care location where terminal patients are able to meet on an informal social level. Patients are able to be themselves amongst equals and have the opportunity to enjoy socialising with like-minded individuals, in contrast to the wider world where they may be marked by the stigma of terminal illness. This is an important aspect in countering social death as new community bonds are formed. The study design precluded taped data between patients alone and so their views of their peers were reflected in their talk with nurses as they made comparisons between themselves and other patients in order to locate themselves in a new social grouping (6.7).

In the ward setting there was significantly more verbal play and banter than in other settings. The use of laughter and verbal play has been shown to function as a device to

lessen the impact of embarrassment and loss of dignity when giving and receiving intimate care. Patients and nurses teased each other and there is often a feeling of light heartedness within the interactions, an emotion that is strongly allied to hope. Nurses used reformulation strategies in interaction to reposition distressing events and lessen embarrassment for the patients' sakes (6.8). They also took great care with the personal appearance and comfort of patients in order to make them feel better. In the IPU there is an overarching mood of lightness, banter and positivity, which may serve to replace the negative feelings associated with terminal disease and social death.

3. What communicative resources do nurses and patients draw upon to capture the differences associated with the terminal journey? (Chapters 7 and 8)

In the palliative care context, with analyses across the three settings, I have shown how laughter and metaphor may be drawn upon to mitigate the impact of sensitive and taboo topics and events, in addition to the hedging devices that may be used. I have also discussed the function of a range of additional rhetorical devices that may be seen to have a similar effect. Reformulation, contrast and reported speech can be seen to have a common function. Each of these can be seen as devices that enable speakers to appropriate different perspectives in order to position and assert their own viewpoint. The occurrence of personal narratives indicates that self-expression is enabled by the other speaker. In the context of the analysis of the focal themes, whereby the aim was to show how negative aspects of social death can be alleviated or replaced by the positively slanted elements of hope and healing, this level of analysis worked well. The contextual differences that were discovered during the analysis of the focal themes are reinforced by the distribution of these devices across settings.

In the home care setting there was a high degree of relational bonding between patient and nurse. The lengthy one-to-one consultations revealed jointly constructed patterns of interactions where laughter occurred in conjunction with repetition and overlapping turns to signal joint working and relational bonding. Nurses contributed by expanding on patient-initiated conversational topics with positive expansions and reformulations, taking care to avoid contradicting patients' styles of coping. The notion of bearing witness and life review was put into practice in this setting as nurses listened to patients' accounts of their lives past and present, thereby accommodating their potential to find meaning and self-worth in their illness.

In this setting, where patients were dealing with the transition from a usual social role to that of the stigmatised role of a terminally ill patient, contrast was used temporally to position their perceptions of life and people during the 'then' of pre-diagnosis to the 'now' of a life changed forever. Reported speech was used as a tool in justification and support of their perspectives, to create a stage for the listener. Personal narratives of topics relating to past and present lives were used extensively in this setting where patients were enabled to do so by the nurse.

In the DTU attention was paid to families and their attitudes to patients' illnesses. The tension between what patients knew about themselves and their disease and symptoms and what they did or did not disclose to their family members was expressed using reported speech to bring in the voices of relatives as patients sought to protect them from distress and vice versa. Contrast was used as patients compared themselves to their peers by examining favourable and less favourable characteristics of other patients, as they saw them. Personal narratives were in evidence here but differed from the home

care setting in that patients' accounts were concerned with recent personal events, such as patients' routines at home or their activities rather than talk of past lives or current events. This reinforces the notion that DTU is a location where patients feel that they can pay attention to their own selves and act on their own terms.

DTU is a 'haven' and therefore patients are able to relax away from their families and be themselves without the fear of distressing their families with talk of their illness or symptoms. In this setting, patients are able to talk amongst themselves and with nurses about their families' reactions to their disease and their concerns and worries about their loved ones. Family relations are addressed here as nurses attempt to facilitate open talk, rather than collusion, between family members. As I have discussed, the palliative care philosophy takes a holistic, whole family perspective, and, as such, the DTU nurses made assessments about patients and their relationships with other family members in order to maintain open communication to reduce the isolating effect that social withdrawal might otherwise cause.

For patients, the sense of connection with a like-minded community entails a sense of belonging that may have been lost by social withdrawal. The value of this to patients was clear. There was also evidence within the data that this social network was maintained outside of the DTU by telephone contact.

In the IPU, there was little evidence of patients using reported speech or contrast. As I have discussed, there was little opportunity for patients to express themselves at length and much of the talk related to the direct experience of the task under hand at the time. As this was inevitably led by the nurses, patients had little choice but to follow.

Reformulation was used by nurses in this setting in a positive sense to preserve patient dignity or to find meaning in death and dying but also negatively as a form of persuasion when downgrading patients' attempts to refuse care. Unsurprisingly, personal narratives were not observed in this setting due to the limited contributions allowed by patients and the lack of opportunity to talk at length.

However, in this highly compromising setting nurses skillfully used language to reformulate potentially stressful events such as incontinence and even death and dying. They were able to find a positive side in the worst of circumstances by moving the emphasis to a different aspect each time. Even during talk of death and dying, nurses and patients were able to jointly construct a perspective that found positive meaning in a terminal diagnosis. The nurses on the ward, especially, took a great interest in helping patients with their personal appearance. Nurses attended to patients' sense of self-worth and value as social individuals by paying special attention to grooming and personal appearance or to the birthday cards that will enhance the patients' surroundings and draw attention to them as special. Banter and verbal play occurred in this setting regularly during task-based care and patients often appeared to enjoy and join in with the laughter thereby strengthening their relational alignment with the nurses.

4. How do nurses manage the contrasting styles of adjustment used by patients? (Chapters 9 and 10)

There are overwhelming benefits of attending a patient at home in relation to dealing with the sensitive issues of social death and hope and healing. A one-to-one ongoing relationship that allows time to talk in the privacy and security of the patient's own home has obvious advantages that far outweigh the other two settings in facilitating

sensitive discussions. Patients were enabled to talk at length to cover any issues that were causing distress.

However, this is only applicable if the patient is open and ready to talk. If not, the nurse's communicative repertoire must be used to engage the patient. I have examined nurse practice in the home care setting in two case study chapters and found that this was characterised by the use of a range of strategies and actions. These included discursive work using rhetorical strategies to counter one patient's negative attitude, including giving mitigated advice and performing relational work. The nurse also contributed on a practical level as she gave information, problem-solved and liaised with other health care workers to complete everyday tasks.

In the DTU, nurses sometimes talked to patients as part of small groups, facilitating others to join in as well. In this setting nurses were able to take patients to private areas to talk about more sensitive topics and they appeared to be well equipped to answer difficult questions from patients about dying, their families or why treatments had been stopped.

In contrast to the other settings, the in-patient setting consists of teams of nurses and auxiliary nurses. The therapeutically styled talk of the other two settings is replaced by talk that occurs, in the main, during physical care of the patients, as I have discussed. There are obvious disadvantages to this setting and way of working as far as communication is concerned. Patients often rely on the IPU nurses to attend to their personal hygiene and appearance. It is inevitable that patients will suffer a loss of dignity in this setting due to the intimate care that takes place. In addition, Lawton's

'unbounded body' is often in evidence here. Nurses used skilful reformulation to reposition the distressing event of incontinence with an alternative positive perspective.

In one instance a nurse took particular notice of patients' reactions after a death and undertook a discussion of death and dying that did not take place during task-based care.

This was an exception to the rule of the remainder of the taped interactions but is evidence that therapeutically styled talk does occur in this setting, although it is unlikely that it occurs to the same extent as in the two other settings. It was also the exception to the rule that this was the only patient in this setting who was not elderly.

The mainly task-based agenda of the IPU is reflected in interaction. I have shown how one patient was persuaded to consent to care despite her fatigue (8.8). Nurses were shown to use reformulation here to downgrade the patient's reasons for not wanting care and seemingly missed the patient's cues to voice her concerns. The frequent use of vocatives and diminutives in conjunction with child-oriented lexis, metaphoric idioms and attempts at distraction by singing, for example, combined to over-accommodate and disrespect the patient's adult status.

I have described how banter can lead to an inappropriate use of humour that can cause offence in the same way (7.9). I have also described how patients are subject to insensitivity when they are asked questions about their life in the past tense as though their life was already over and when comments are made about the identical appearances of patients and references to patients in terms of jobs of work (7.9).

11.5 Implications for practice

For the patients in this study that have gained access to specialist palliative care, a diagnosis of terminal illness will typically bring a relentless decline of physical functioning and a progressive journey through the three care settings linked to the hospice. The potential for a negative psychological effect on patients is linked to the concept of total pain, i.e. physical deterioration, social changes and the spiritual search for meaning and acceptance.

In an ideal situation the patient's physical pain will be well controlled and an internal search for validation and meaning of life and death will have brought acceptance of the prognosis. In the worst case scenario, social and psychological pain will lead to a loss of self and despair. For these patients, their total pain becomes difficult to control, as it is multi-faceted and communication issues come to the fore. Palliative care nurses have the opportunity to help patients on the terminal journey by mediating towards the positive and allowing patients to express themselves, as I have shown in this study. Nurses' caring work is rooted in the interaction with patients and therefore also has the potential to harm if communication is not effective.

This study has explored real life interactions between nurses and patients in a variety of settings and aims to create an awareness of the dynamics of interaction that will allow nurses to reflect on what is and is not effective communication in these circumstances. It has aimed to explore nurse-patient communication in palliative care with a view to contributing to the research evidence base with implications for training and practice. I have come to this research with a background in nursing and have taped, analysed and discussed real life interactions between nurses and patients during usual care. I wish

now to bring forward some of the points and comments from earlier discussions in order to address implications arising as a result of this research.

In chapters 1 and 2, I have discussed the current status of palliative care and concerns about equity of service and patient choice, particularly the choice to die at home. I have also called upon research evidence to show that although palliative care is usually seen as a model of excellence in the care of the dying there is room for improvement. The NHS Cancer Plan report (2000) has stated that too many patients are still experiencing distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from health care professionals during the final stages of an illness. The National Institute for Clinical Excellence (2004) has commented that good communication skills are key to the delivery of effective supportive and palliative care services, but patients and carers frequently report that the communication skills of health and social care professionals are poor. I have also discussed research noting that half of all patient deaths occur in the acute hospital setting where there is evidence to show that the care of the dying is of poor quality and results in an undignified death for the patients and in the experience of relatives. There is also firm evidence to show that the majority of people would prefer to die at home. This research, using empirical data, has contributed to the existing evidence base of how palliative nursing care is practiced in interaction.

There is an opportunity here for nurses to capitalise on this knowledge as a basis for reflective practice. There is also a potential for cross-site training, especially in the case of the auxiliary nurses. As nurses working in just one site of care they are unlikely to have any experience in other settings and are therefore devoid of exposure to other

nurses' communicative practices. An awareness of the interactional patterns of nurses working in other areas will provide an opportunity for in-patient nurses to incorporate relevant resources into their own practice.

11.6 Limitations of this research

This study has taken a theme-oriented approach to the study of nurse–patient interaction in the hospice setting. I feel that both the focal and analytic themes have been appropriate to explicate the function of talk in this context. However, the tape-recorded data has not allowed consideration of non-verbal language and therapeutic touch, which are of major significance in nursing care. I feel that the analysis is the poorer for this exclusion but could not personally justify the use of video taping in this sensitive area of care.

Just one recording captured the discourse between a nurse and a patient on the IPU that did not occur during task-based care, which does not mean that this is unusual in this setting. My argument has been steered towards the quality of discourse and how this can be affected by the distraction of essential nursing. I had initially considered taping during the initial assessment interview that occurs soon after admission to the IPU. This is an opportunity to gather information about the patient and also to see physical, psychological, spiritual and social issues from the patient's perspective. However, as I was interested in the contextual differences across settings I excluded this line of enquiry to maintain relative equality as in the other two settings patients would, to some degree, already have an established relationship with nurses.

It would also have been of great benefit to obtain longitudinal data in the form of one patient's progression throughout all three care settings. In fact, this was very nearly achieved whilst collecting data for this study. The nurse that had been taped with the same patient at home and in the DTU had also very kindly agreed to go back into uniform and work in the in-patient unit should the patient be admitted for care. Fortunately, however, the patient had been able to stay at home until his last two days and I decided that I couldn't impose on him further as he was so near to death.

11.7 Final reflections

I came to this study with the intention of offering a linguistically-based analysis of the patients' journey through care. I wanted to look at the start, middle and end points to examine the effect of discursive practices on the identity of the patient and what it is that causes patients to 'disappear' and become less of an individual, especially in the IPU setting. However, as I collected the data and observed and talked to patients across settings it became clear to me that this was not necessarily a downward trajectory; something was happening in the middle, some patients were standing out as individuals full of humour, grace and wisdom. These observations led me to select the counterpoint focal theme for the study, hope and healing. I have been impressed by the positive attitudes of some patients and the contributing work of nurses. I also feel that I can now understand (and hope I have shared) the difficulties of patients struggling to achieve some kind of meaning in their illness and the psychological effect this may have.

I think that, in considering the trajectory of the social death process and discursive practices of patients and nurses, combined with the contextual semiotics of the IPU setting, I have explicated the main reasons for patients' 'invisibility' or diminishment of

self here. I also believe that this is not an inevitable outcome. I have also shown how the journey at end-of-life can be a positive progression for many and intend to take my findings back to the hospice to share this knowledge.

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APPENDICES

Appendix 1: Transcription Conventions

The transcription conventions used in this study are as follows:

N:	Nurse
AN:	Auxiliary nurse
P:	Patient
R:	Researcher
(.)	Short untimed pause (less than 0.5 of a second)
(...)	Longer pause. One dot represents 0.5 of a second
=	Equal signs for 'latching,' that is, two utterances that follow one another without any perceptible pause.
[A square parentheses between turns indicates the point at which overlap by another speaker starts.
{Guess}	Words between curved parentheses in the transcripts represent a guess at talk which was difficult to hear.
<i>(Laughing)</i>	Material between brackets in italics provides extralinguistic information.
/	Forward slash indicates cut off speech or interruption by other speaker
?	Question indicated by high rising tone and syntax
<u>word</u>	Underlined words indicate stressed intonation

Appendix 2: Data Transcripts

HCTRA1 John

Patient Male 80+

Nurse Female 50+

- 1 P: could my (.) medicine (.) have anything to do with me having
migraine attacks (.) I've had four (.) four days in succession.
- 2 N: have you ever had migraines before?
- P: oh yes yes but never (.) four days in succession (.) no p'raps four
months (.) or four weeks but not/ (.)
- 4 N: so it's just over this this last few days is it?
- 5 P: the last two days I've not had (.) an attack [Friday was] the last=
6 N: [right]
- 7 P: = (.) Saturday Sunday Monday (.) p'raps they'll go away again
p'raps it's sheer coin[cidence]
- 8 N: [so before that how long was it that you had
migraine?
- 9 P: it used to vary tremendously (.) hum/
10 N: (.) and what did you take for them (.) [anything
- 11 P: [nothing
- 12 N: and did you take anything over the weekend?
- 13 P: mm no
- 14 N: no?
- 15 P: I've only got one pill left and it's been there for about ten years and
I've never taken [it
- 16 N: [what sort of pill is that?
- 17 P: (.) migravele or summing
- 18 N: right
- 19 P: (.) I think they're very expensive
- 20 N: they are (.) you can get them on prescription
- 21 P: can you?
- 22 N: yeh
- 23 P: I shan't bother because it only lasts half an hour (.) an' I don't get
'eadache merely a blindness =
- 24 N: right
- 25 P: =which is a damned nuisance if you are driving a car
- 26 N: and is that the sort of thing you used to have when you had them
before
- 27 P: yes (.) yes
- 28 N: and no sickness?
- 29 P: no sickness
- 30 N: no dizziness?
- 31 P: but I used to when I was very young (*unclear*) sick and it's the
memory of the early=
32 N: right
- 33 P: =migraine attacks that (.) you know (.) makes (.) the rest (.) trivial (.)
struggling for words

34 N: yes

35 P: your turn to ask a question

36 N: this breathlessness (.) is that worse?

37 P: yes yes

38 N: how long has that been like that?

39 P: (.) I went yesterday for a walk on the clifftops (.) with a youngster of
seventy-five (.) and she walked far too fast (.) and I choked (.) ummm
(.) was (.) very bad (.) so I'm going to take it easy [today

40 N: [take it very easy
yeh (.) when do you fly to Cyprus?

41 P: Wednesday

42 N: what time are you going?

43 P: six in the morning (*laughs*) seven in the morning summing like that hm

44 N: and you're going with?

45 P: Emma

46 N: [Emma

47 P: [you know her?

48 N: yeh

49 P: hm

50 N: yeh (.) very well

51 P: very well (.) I know her very well (.) she's in Oxford today (.) I have
to meet her wretched train when she comes back (.) but I don't know
what [time

52 N: [what you're going to pick her up?

53 P: she'll ring me

54 N: right (.) d'you know (.) last time (.) we talked about (.) you talked about
possibly bringing the steroids down?

55 P: yes

56 N: did you?

57 P: yes (.) to three

58 N: (.) and of that d (.) does that coincide with the migraines at all?

59 P: (.) oh (.) once or twice I've for missed altogether (.) the second one

60 N: right

61 P: near lunchtime or later one

62 N: (.) I would just [wonder whether you p'raps (.) ought to (.) go back to
the original dose

63 P: [(unclear)

64 P: really?

65 N: just whilst you're in Cyprus

66 P: hm (.) ok

67 N: I'm just thinking change you medication at this point

68 P: yes

69 N: when you're going away

70 P: right

71 N: might have something to do with the breathlessness (.) and (.) and with
your (.) migraines

72 P: (.) right that's easy

73 N: so could you go back to (.)

74 P: you excuse me whilst I go out and count the pills

75 N: certainly
76 P: what have we got seven [times seven days
77 N: [yeh seven days
78 P: and four eights are thirty-two but I know I've got them
79 N: you've got enough
80 P: mmm
81 N: right
82 P: hm (*coughs*)
83 N: (.) and you're still taking the: (.) umm stomach protection
84 P: no (.) but (.) no (.) but if I (.) for example drink too much wine=
85 N: yeh
86 P: = (unclear) very acid cheap wine=
87 N: yeh
88 P: = then I get violent acidity [so then the next day I=
89 N: [well you know the cure for that
90 P: = drop back to my acid blocker tablets
91 N: right
92 P: but then I've only got three left so I'm conserving them
93 N: well you'll need some more to take with you
94 P: (.) it's not as easy as that (.) you've got to give them forty-eight hours
(Patient leaves table enters kitchen and returns)
95 P: you can't do a prescription can you?
96 N: no (.) but I can talk to them
97 P: you can what
98 N: I can talk to your surgery
99 P: they yes (.)
(patient leaves table to fetch tablets)
100 P: oh it's enough really I don't take one every day
101 N: I think you ought to have some more
102 P: mm
103 N: I think so shall we give them a ring and see?
104 P: uh (.) have you got their number [there wait a minute
105 N: [yeh
106 P: uh (.) I tell you what (.) I have a thing which I squirt up my nose (.) eh
(.) the idea being to keep my head clear so as I don't breathe through
my uh mouth make me cough uh it it cured my cold I think

Patient leaves room. Nurse dialling on mobile phone

107 P: oh it's upstairs and I don't want to go up
108 N: (.) can I get it for you?
109 P: ha (.) you wouldn't know where (.) it's a green (.)s s s squirt
110 N: well I'll try it, shall I try phoning the surgery first?
111 P: (*coughs*) they wouldn't know (.) they don't know anything (.) I shan't be
a moment
112 N: ok
113 P: but I'm not going to run

Patient going upstairs

Nurse still trying to dial on phone

Patient re-enters gives tablets to Nurse

- 114 P: if you think it's a good idea
115 N: *on phone* oh good morning um my name is I'm palliative care nurse
down at (*name of hospice*) I'm with Mr. (*name*) who is going to Cyprus
on Wednesday (.) and he's going to run out of his Pantaprozol tablets (.)
is there any chance a prescription could be done for him today? (.)
thankyou (.)

*Patient is moving around room looking for something. Eventually sits
down, very breathless*

- 116 N: hello (.) it's the Panta (.) yeh yeh yeh that's that so (.) umm (.) could
could you pick them up tomorrow? That be alright/
117 P: I can yes
118 N: yes he could pick it up tomorrow (.) what time? (.) that would be lovely
(.) thank you very much thank you byee
119 P: it'll give me time to go to the chemist?
120 N: half past twelve
121 P: oh fine
122 N: so that should be [fine
123 P: [thank you very much
124 N: that's ok
125 P: the nurse in action
126 N: oh (*laughs*) (.) so you go back to the original dose of the steroids (.)
umm
127 P: four a day
128 N: and I think that you'll probably be drinking more wine on this trip
[won't you?=
129 P: [that is the truth
130 N: =so I think it would be a good idea=
131 P: jolly good
132 N: =to take those [regularly
133 P: [then I shall have some (.) there are only three left
134 N: yeh
135 P: ha thank you
136 N: when is the wedding?
137 P: Wednes there only two left three umm (.) Wednesday I'm going
Thursday they're having an enormous party and Friday I think is the
wedding and Saturday is another party (.)
138 N: so it definitely sounds as though (.) the um (.) stomach protection
would be a good idea
139 P: ha
140 N: and p'raps they buy more expensive wine?
141 P: (.) I hope
142 N: you hope
143 P: not the Tesco plonk
144 N: right
145 P: which I usually drink (.) umm
146 N: what about your work? (.) are you working at the moment?

147 P: (.) I just (.) oh gosh (.) highly unsatisfactory (.) that's the trouble (.) get no satisfaction because it's second rate (.) um shall I get it and show you?

148 N: yes please

149 P: it's bloody awful

150 N: *(laughs)*
Patient leaves room, coughs
Returns shows polystyrene mould to researcher

151 P: I made it (*unclear*) a house in France you know, being rich (.) and um (.) all this is to feed the metal

152 N: yes

153 P: you stick it in sand (.) it's a technique of my own (.) dry sand (.) which just pours where I've made all these holes
(shows to researcher)

154 R: mmm

155 P: so the sand goes through so it'll have a core (.) I hate the thing but they say it's alright so why bother (.) and then

156 N: and this is going to go in a well

157 P: there's their well (*shows photos to Nurse*) (.) this is p'raps a bit better

158 N: oh I think it'll look lovely, is that going to be in bronze?

159 P: say?

160 N: in bronze

161 P: aluminium

162 N: alumimium

163 P: mmm

164 R: oh right

165 N: a nymph

166 P: (*unclear*) so who is the wretched man? (.) doesn't matter (.) take him out of sight

Leaves room

167 R: he's carrying a fish we should know that (*nurse*) I know (.) it's not Pan is it?

168 N: is it? who is it

Re-enters

169 R: who is it then?

170 P: who's the lady?

171 N: who's the man? who's the sprite

172 P: Bacchus oh [no no no it's not no/Pan

173 N: [Bacchus

174 N: Pan

175 R: Pan I said Pan [(*unclear*)

176 P: [(*unclear*) but he should have hooves

177 N: yeh

178 P: and anatomically they're extremely difficult

179 N: hooves are/

180 P: that's why I found this (*shows art book*) obscure (.) page (.) you see the hoof (.) they (.) difficult to explain (.) they've got an extra joint haven't they (.) oh, there's one look

181 N: yeh

182 P: so: (.) this is quite wrong (.) that's all foot

183 N: yes

184 P: isn't it [and that's his knee

185 N: [yes and we tend to think of that as the knee, but in [fact

186 P: [yes yes

187 N: yeh

188 P: (.) mmm

189 N: mmm

190 P: (*unclear*)

191 N: are you (.) nervous at all about going to Cyprus? About flying?

192 P: not nervous about flying (.) I'm just nervous about how my daughter will react to my wheezing and coughing

193 N: is this the Staffordshire daughter?

194 P: no[no no she's not

195 N: [is she going?

196 N: right

197 P: stupid woman (.) she prefers to stay at home and sulk which is daft (.) but (.) there's nothing you can do about it she doesn't know what she's sulking about (.) huh

198 N: I had a chat with Doctor B this morning=

199 P: ah

200 N: =and said I was coming to see you (.) umm (.) and you know that (.) I hadn't cancelled your appointment with him=

201 P: ha

202 N: = and you've already told me off about that

203 P: so he's going to slap my hand is he?

204 N: no no (.) I thought it would be a good idea though for you to see him when you come back from Cyprus (.)

205 P: and you'll ring me with a date

206 N: I've got the date

Patient leaves to get calender, coughs

207 P: where is (.) mucus generated? (.) where is (.) the gooey stuff [born?

208 N: [yeh

209 N: either from the lung tissue or from the bronchus

210 P: oh

211 N: any of those places

212 P: oh oh oh I see (.) there isn't a special gland or something

213 N: well yes (.) you do have some (.) it's going to be an anatomical test I can't bear it [*(laughs)*

214 P: [yes (*laughs*)

215 N: usually you'll get that sort of thing if if you're coughing a lot it will just tend to make the mucus increase=

216 P: [yes

217 N: =[and this is why we talked about possibly (.) giving you a cough suppressant

218 P: yes, yes
 219 N: (.) but we haven't done that yet
 220 P: not just lemon juice and stuff
 221 N: (.) quite often honey and lemon juice
 222 P: ha
 223 N: you've got that
 224 P: (*unclear*) I've got that yes [(.) so I should take it?
 225 N: [yeh
 226 N: yes (.) yeh
 227 P: I will [(*unclear*)
 228 N: [(*unclear*) and even and even just sucking something like you
 can get those little lemon and honey pastilles=
 229 P: right
 230 N: = and they would probably be very useful [for (.) the flight
 231 P: [right
 232 P: and the more I cough (.) the more [(.) the thing is stimulated
 233 N: [yeh
 234 N: yeh. I mean I think that if the cough is still major problem when you
 come back then we'll ask Doctor B about a cough suppressant (.) umm
 and we've talked about some of the morphine mixtures (.) can be
 particularly useful
 236 P: yes
 237 N: some of it [so
 238 P: [yes
 239 N: but I think probably (.) we won't try that 'til you come back
 240 P: right
 241 N: hmm but it might be [reassuring to your daughter=
 242 P: [(*unclear*)
 243 N: =to be able to tell her that you have got an appointment with Dr.
 when you get back=
 244 P: right
 245 N: =if [she's worrying about the/
 246 P: [right, right
 247 P: she hates me wheezing
 248 N: yes (.) I think that the steroids reducing the steroids (.) might be part of
 that problem
 249 P: I have been missing (.) [the third (.) you know
 250 N: [yeh yeh
 251 N: I'm sure (.) I think you've got to probably got to try and be quite strict
 with yourself
 252 P: mm
 253 N: (.) because your breathing before you went to see Doctor B the first
 time was quite bad wasn't it?
 254 P: mm (.) oh yes
 255 N: and it did get a lot better quite quickly
 256 P: yes yes (.) yes yes mm
 257 N: so I think to go back to taking the steroids twice a day
 258 P: ok
 259 N: stomach protection

260 P: mm

261 N: and get some pastilles

262 P: I will do that (.) you're going to put a date down on my [diary

263 N: [I am (.) I am

264 P: have you got anything with which to write?

265 N: I should think so

266 P: oh here

267 N: (.) he's given me the twenti [eth (*unclear*) must be

268 P: [you've got the wrong month

269 N: must be the twenty second

270 R: you're in November (*nurse*)

271 N: oh (.) thanks very much (*laughs*) September (.) (*unclear*) Carol away

272 P: good idea to get the right month

273 N: they will write to you as well=

274 P: yes

275 N: =to confirm it

276 P: I had two this morning from Doctor (.) M (.) correcting things, correcting (.) one

277 N: what you've got another appointment with Doctor M have you?

278 P: he said December

279 N: right

280 P: but this morning the letter said (.) (*unclear*)
Patient leaves room

281 P: so this is wrong now, they're a bit careless (*unclear*)

282 N: they've changed to October the tenth

283 P: yeh (.) that's new you see

284 N: yeh

285 P: they didn't have one in October (.) we went from now until December (.) that's the December one isn't it

286 N: yes

287 P: mm (.) so either you've ticked it in or he's ticked it in or (.) I am not un/ I'm glad that they have because it's a long time til December.

288 N: yes (.) but that will work out quite well if you're going to see Dr. B (.) [when you come back

289 P: [well I

290 N: from Cyprus

291 P: um

292 N: and then (.) if there was a question of possibly having any more treatment

293 P: yes

294 N: then it would tie in with you going to [Doctor M's clinic and sorting it out there

295 P: [mm

296 N: (.) because Doctor B meets with Doctor M every_week

297 P: oh they have a [(*unclear*)

298 N: [and they talk about any of the patients [that they (.) share

299 P: [um um

301 N: and so they'll he'll be able to discuss it with Doctor M [and get things organised

302 P: [well done
303 P: well done (.) I'd like to ask (.) Doctor M if I have his authority to
complement the people in Cyprus (.) I shall certainly meet them
304 N: yes
305 P: an I (*laughs*) I think he was quite pleased with what they'd done you
know
306 N: I think he was very impressed
307 P: pardon
308 N: I think he was very impressed
309 P: yes
310 N: yeh (.) an' I was very impressed
311 P: mm (.) mm (.) the chap the specialist (.) I forgot his name immediately
in the hospital (.) um (.) his wife had cancer and this H M cured her
completely
312 N: right
313 P: and so she got you know this close relationship (.) he thinks very
highly of H (*unclear*) she still walks about as though she has a train of
apprentices behind her you [know (*laughs*)
314 N: [right right
315 N: and you'll see her will you?
316 P: certainly yes mm (.) mm (.) she's nice but bossy
317 N: nice but bossy
318 P: yes (*laughs*)
319 N: life seems to be full of bossy women
320 P: isn't it isn't it (.) tyrants
321 N: tyrants (.) that include me?
322 P: absolutely [absolutely (*laughs*)
323 N: [right (*laughs*)
324 N: is that a problem?
325 P: (*to researcher*) have you done your ration?
326 R: I can turn it off if you want (.) do you want me to turn it off now?
327 P: well (*unclear*)
328 N: p'raps yes

Afterwards

Discussed patient's problems with G.P. – possible missed diagnosis
Patient feels he is now being 'courted' socially by G.P. because he has a case for
neglect.
Didn't feel supported by the surgery during his wife's illness.
Felt art work was disappointing, regrets not having adequate training to market his
output.
Talked about friends that are successful sculptors (yet his own work features in many
public places and galleries, museums)
Talks about the futility of certain courses of action because he was 'half dead' – Nurse
neatly said that he was also 'half alive'.
Discussed whether he minded the taping. He said not but nurse said she felt a bit
'constrained' because it was her first time but still appears very open to the project.
Nurse and researcher discussed patient and what he'd said on the way home.

HCTRA2 Sarah

Patient Female 30+ years

Nurse female 40+ years

1. N: Annmarie's doing a PhD
2. P: oh right
3. N: (.) for her sins
4. P: (*laughs*)
5. R: so I'll make a note of it, it'll just be of anything else that makes a noise and how we're sitting and things like that (*unclear*)
6. P: that's fine (.) well I was thinking actually that (*unclear*) forget what's going on (*refers to taping*)
7. N: right (.) how are things?
8. P: well (.) they're not the best they've ever been. They didn't get back to me about my bloods so I phoned them (.) well that's how we do it anyway really I phone after a couple of days and if it's raised then arrangements (*unclear*) unit and um I phoned and I just think a number of doctors (*unclear*) over the bank holiday because Dr. C's secretary isn't in at the moment and so there's a replacement secretary she's very nice and she took all my details and said she'd phone back.
9. N: and she didn't
10. P: so I phoned today bu on Friday but it's still worth getting the old result because I'm sure my calcium's high
11. N: yeh
12. P: (*unclear*)
13. N: today?
14. P: no no in the last couple of weeks but then that's a lot for me
15. N: when did you have your last (.)?
16. P: um I can't remember exactly but it's about three: (.) roughly (*unclear*) mmm
17. N: and you don't usually go much longer than that do you
18. P: I've not been going longer than a week
19. N: no [no
20. P: [since Easter
21. P: so (.) I phoned today just to ask if the results had shown up cos I thought they might have done and it's quicker than having another one done set up and taking three days (.) umm plus I don't want anything on Friday (.) I feel it just adds a bit more pressure that I feel [they've got to get it done they've got to get it done by a certain time and=
22. N: [right
23. P: = not the best (*unclear*)
24. N: right
25. P: so if they don't phone me tomorrow I think I may have to go and [(*unclear*)
26. N: [do you want me to do it (.) in the morning

27. P: (*unclear*)
28. N: what I'll do is I'll phone them in the morning but by the time I get back we won't get it
29. P: mmm
30. N: (*unclear*) did you get through to (.)
31. P: got through to A's replacement for this week (.) but I don't know what her name was
32. N: probably [I'll be better doing it at (*hospice*) because if they said (.) to phone me back with them and I give this number
33. P: [ok
34. N: they've no way of knowing you know at least they know I'm working in (*hospice*) if [I do it on that
35. P: [yeah
36. N: so I'll do it in the morning (.) what did you have umm (.) calcium (.) U's and E's? (.) urea?(.) electrolytes?(.)
37. P: I think they've probably just a normal [*unclear*] electrolytes sort of thing [but they didn't do the blood count
38. N: [full blood count [yeh
39. P: (*unclear*) [without doing the bit they didn't do this week (.) up til now anyway
40. N: [course yeh yeh
41. N: right right
42. P: [so mainly calcium
43. N: [I'll do that in the morning I'll make a note of it before I go
44. P: ok [thankyou
45. N: [and if I phone your answerphone will be on
46. P: oh yes that's on all the time
47. N: so just listen to the answerphone and see/
48. P: / the other thing is the telephones are actually doing something very peculiar now we sort of get half a ring on the upstairs phone followed by half a ring on this phone and sometimes we genuinely don't know the phone is [going off now (*laughs*)
49. N: [yes
50. N: did you say you'd got a mobile?
51. P: I have (.) would [you like its number?
52. N: [when do you turn it on ?
53. P: I turn it on [about
54. N: [you don't you don't turn it on!=
55. N: = during [the day (*laughing tone*)
56. P: [I turn it on once a day to see if I've got any messages on [it
57. N: [oh right
58. P: so [i if Big Brother's been on and I've been watching that I phone up and see if my friends have texted me a message about it
59. N: [so it would be worth
60. P: so (.) shall I go and get it and give you the number?
61. N: when you well we'll do it before [I go

62. P: [ok
63. N: leave my pen [out to remind me
64. P: [but yes I've got one (*unclear*)
65. N: so how was the weekend?
66. P: well that was fine the whole of the last week has been really good because umm L..... isn't a problem anyway she's lovely/
67. N: / is there anybody in the house?
68. P: no they've gone there shouldn't be anyway she's gone home for her operation to be done [so she won't be back for a couple of weeks
69. N: [yeh
70. P: and J... went away for (*unclear*) a week and two weekends (*unclear*) and its been really nice all week, I've laughed and laughed
71. N: mm
72. P: my other friend J...who (*unclear*) Cardiff [(.) she came down
73. N: [yeh
74. P: and umm I should've been going up to J....'s Mum's house for the weekend which would've been really nice cos its not that far away and if they have to bring me back (.) [they can get me anywhere as fast as I can go from here really
75. N: [that's near enough
76. P: (.) but I couldn't go on the day because I just can't get up in the morning I didn't wake until half one (.) today (.) and (.) it's great for me and its sort of what I've always done a little bit like you know students (.) student land! ages ago that's when I'd have got up and I'd have stayed up half the night and things like that (.) but it's alright then now its not because I have to be able to fit in with other people [and I just can't do it=
77. N: [yeh
78. P: = at the moment umm so anyhow I'm sick that night must've been a Friday night cos I phoned up and said look I'm sick and J... 's got a little boy who's two, two and a bit and I thought I don't want to be sick in front of him because children won't know what's going on (*unclear*) and I don't want to go upstairs with the children (*unclear*) so I didn't go in the end (.) as it happened I had a lovely evening on Tuesday no Saturday I know my Palfium is high because Tuesday and Saturday are crossing over into each other again um I ended up with two phone calls one in the sort of late afternoon that was my friend L from Darlington and then one sort of later on in the evening about nine o clock that was my friend S... from Leeds so I had really long phone calls with both of them and I ordered an Indian takeaway in between (*laughs*) but I just I really felt like it so I ordered quite a lot actually and just had a taste [that was=
79. N: [mm

80. P: = all I felt like so I didn't make myself sick with it
(*unclear*)and it was really nice (*unclear*)
81. N: and you're drinking plenty
82. P: I'm trying my best yes
83. N: have you been sick at all today?
84. P: no no (*unclear*) even though I haven't taken my medicine for a few days which is fairly unusual but um
85. N: what about pain
86. P: the pain is back um the the two things I don't like at the moment are (*unclear*) the pain's back just where it was starting after Easter in this leg it's right up in that joint again and it's in my knee and last night I couldn't get to sleep for the pain=
right
87. N: right
88. P: =in my legs mmm
89. N: right (.) and is that the leg that they x-rayed
90. P: yes Dr. K.... told me he'd phone if there was anything wrong with the x-ray (.) well I do wonder whether he's seen the x-ray perhaps as yet
91. N: yes
92. P: and also
93. N: I'll try and check that one up
94. P: I know[I know he doesn't want to come back (*unclear*)
95. N: [what I might do is [get S...B... to go and check up on (.)
or M.. ...
96. P: [right
97. P: or S...D.... actually is the one (*unclear*)
98. N: or S...D... right ok
99. (.)
100. P: but it is/
101. N: so what are you taking for the pain
102. P: well I'm still taking the patches and [(*unclear*)
103. N: what strength
104. P: 75
105. (.)
106. N: that could go up
107. P: it could go up
108. N: what have you got
109. P: I dread to think what would happen going to the toilet if the patch goes up though
110. N: (*unclear*....*Senokot*...*constipation*)
111. P: well it's not constipation that I've got I think it's tiring and it's better remember that day in the hospice when I was a cow for about two days
112. N: yes
113. P: well it's better than that now because I can sort of go up there take my Palfium hold on for as many minutes as I can while the Palfium kicks in and then I'm sort of telling myself now come on it's been worse than this
114. N: do you put the palfium underneath your tongue?

115. P: I tried that! and I've done it a couple of times yes
116. N: good
117. N: it's [much quicker
118. P: [most of the time I have to swallow it fairly fast
119. N: yes
120. P: but the other day it [did actually dissolve almost before I got
the water=
121. N: [yes (.) yes
122. P: = on the go and everything so I always keep a mug in there or a
little drink anyway and its convenient in the bathroom if I'm
having tablets or anything um and I managed it dissolved
completely and I think it did work faster that day unfortunately
the last time I had to go I'd just eaten a very large piece of
strudel and um I had to go to the loo and I had to swallow my
tablet *almost* instantly and I thought this has got to fight its
way through strudel now and allsorts! but it still worked and
even if it doesn't work instantaneously its nice to know its
going to work fairly fast so [you know you're not going to
123. N: [so you know that even if you're left
[with the pain you've got something on board
124. P: [yes it won't last for long
125. P: so that's not too bad I'm managing and it is getting better but I
asked Dr. K... about it again and um the district nurses said you
know she said it might be piles so I said oh I don't really know
but it is getting better than that day at the hospice and I asked
Dr. K... and he said oh 90% of people on painkillers will
have piles and I thought oh right (*unclear*)
126. N: well I don't know where he got that bit of information from
127. P: (*laughs*)
128. P: [(*unclear*) I don't ask him to quote his sources
129. N: [(*unclear*)
130. (.)
131. N: and you wouldn't want anybody to examine you
132. P: well I I (.) that that would be fine but I know I'm not the best
but I mean I'm not doing it just to be funny but I just cannot
relax at all (.) just after that day when um C... tried (.)
133. N: yeah
134. P: um and I mean I was quite desperate to find out what it was
then as well because it had been so horrible the day before and
she couldn't see any fissures which is what she was looking for
at the time but I know it's not nearly as (*unclear*) pain category
135. N: right
136. P: because that was (*unclear..fast?*)
137. (.)
138. P: I just well I I don't know perhaps I could go up a little bit on
the patch then
139. N: have you got any other patches? um what have you got

140. P: I've only got 75 uhum but I noticed when I put my last one on to today's batch I've not got that many left so I'll have to be ordering some anyway soon
141. N: so do you want me to ask him to give you some hundreds
142. P: does Dr. B... know?
143. N: well I'll speak to Dr. B... in the morning but I'll ring your Dr. K...
144. P: ok (.) he came round to see me the other day all unexpected
145. N: did he
146. P: yes (.) it was on Friday it was half twelve and I was awake but I hadn't got up and I heard the doorbell and I think I told you I've ordered some slippers and I thought it must be my slippers! and I got all really excited about it/
147. N: / have you sent your shoes back?
148. P: [I have
149. N: [aah
150. P: they looked fabulous on they were they were brilliant but the heels were they were three notches on the crutches and I just thought I'm so careful to try and not fall over and break my leg I mean [the (*unclear*) that I wore before I mean I =
151. N: [and everyone would think too yeah
152. P: =if they had low heels I would have kept them
153. N: yeah
154. P: and I think if they'd been (*unclear*) with high heels I could have justified that cos even if I'd only worn them once in a wheelchair that would have been ok but they're going to look really really nice but they were too high (.) they arrived when the district nurse was here really and er I put them on while she was writing up her notes and things and when it came time for her to go I said oh I won't adjust my crutches at the moment because I need to take them off again and I went to get up and she went don't get up wearing those I'll see myself out and I thought if that's what the district nurse is saying that's what I'm going to be thinking realistically(.) (*laugh*)
155. N: and did you have a little pressure area
156. P: yep still got it
157. N: still got it
158. P: I notice that V... has been filling my folder saying that it's getting a bit better
159. N: right
160. P: but last night it was hurting [(*unclear*)
161. N: [and are they still putting something on there
162. P: yes Tegaderm
163. (.)
164. P: [(*unclear*)
165. N: [and have you got a special mattress?

166. P: I have I've got a Propad one now which is (.) well from all the ones I've tried that's the best one I've ever tried but for some reason last night I just couldn't get comfy (.) I have realised a sort of little ritual now when I'm falling asleep I can only really stay on my back having my legs out straight and then having my legs bent [(unclear)
167. N: [have you got pain in your leg when you're in that position?
168. P: yeah it is [(unclear)
169. N: [have you got the pain all the time
170. P: pretty much yes I've got it now but it's only minor now it wouldn't keep me awake I'd get to sleep with this amount
171. N: are you using Oramorph at all?
172. P: no I thought about last night (.) and I just felt no I managed to get my Biox down and keep it down and all the rest of it [(unclear)
173. N: [you would be better with a patch I would have thought
174. P: mmm
175. N: I'll have a chat with Dr. B... [but um I think he's in *Local oncology unit* tomorrow but um
176. P: [ok
177. P: really? does he go there very often
178. N: he does um (.) he's running a masters course (.) in palliative care (.) so I think Tuesday's his day in *Local oncology unit*=
179. P: mmm
180. N: [=but I might catch him
181. P: [cos I got the impression when I was in hospital not that I'm supposed to get impressions that he wanted me trying other things rather than just keep putting the patch up but he might have changed his mind now cos I have been trying the Bioxin so I have been whereas Dr. K... is always saying if the patch isn't working we'll give you a stronger one
182. N: oh
183. P: so I'm always having sort of two different approaches (.) that's why I feel a bit trapped
184. N: yeh (.) I'll talk to him though because if you've got pain all the time=
185. P: I have in my leg [really (.) it's difficult for me to get in the bath
186. P: [=and you're saying you're more sleepy (.) I know that might be calcium but at the same time it's just going to exhaust you and the things that you enjoy doing
187. P: well I've got my little brochure now for the evening class [and stained glass windows (unclear)
188. N: [right
189. N: is it
190. P: it is and it's at um (unclear) or however you say it which isn't very far away I could easily get there in a taxi and
191. N: it's an evening class is that
- 192.

193. P: it's evening yeah and daytime ones (.) yeah it's re it's one of the best courses for the number of days it's running it's sort of Monday Tuesday Wednesday there's a there's one on a Thursday for people who've done it before who can just drop in which is encouraging because really I've got to phone them up and make sure that I can just drop in (.) because some weeks[(*unclear*)
194. N: [yes yeh you're not going to
195. P: and there's another course that I like as well (*unclear*)
196. N: don't you get it quite a lot cheaper as well
197. P: it's very reasonable have to be fair (*laughs*) otherwise I have some proof now (*from the courts?*) which I don't have to (.) but I am still quite interested in (.) Monday 1 til 3 (.) I was thinking of an evening one (.) cos I know I'd struggle for one o' clock [at the moment
198. N: [um?
199. P: I'd struggle for one o' clock at the moment
200. N: would you
201. P: yes
202. N: what are the evening ones
203. P: they're sort of 7 til 9 and usually I'm feeling my best in the evenings I'm just wide awake
204. N: and you could probably get the same taxi couldn't you
205. P: oh yeah
206. N: you know and arrange for them to pick you up
207. P: mm well I've been using the same company now for the last three months and I don't request one on Tuesday so the drivers (*unclear*) but they're really good I've never had a problem with them
208. N: (*unclear*) is not going to be far for you
209. P: no that's what I thought
210. N: when do they start?
211. P: the end of September (.) 29th is the first week
212. (.)
213. N: mm sounds really good
214. P: mm the other thing that I'm quite interested in at the moment is the Hindu religion and um I'd like to know more about it but I don't want to have to try and take any exam in it because I can't sit for the length of time of an exam *let alone* try and concentrate as well um so I thought if I could get a sort of module for an 'A' level because most of them are modules now and just do Hinduism that would be really good because I could just go there and listen and not have to take notes and it would be so much different than anything I've done before because before is just well I don't know I've just [taken notes to pass exams and things
215. N: [why do you think Hindu?

216. P: oh I'm very interested because I lived with D... my friend from up Coventry for two years and so it's all sort of the second year I lived with her I got this book and it wasn't about Indian life or mythologies or Indian life or religions or anything it was just a fabulous book it was about a girl from South Africa who went for one of her summer holidays to live with her older sister you know (*unclear*) and that was all it was about the people she met during the summer and things like that but it had a few little bits about the Indian gods in it cos part of the community she went to stay with was Indian and they had various festivals and things so we asked D... all about it and D... told us and we were quite interested from then and she always has her little um (.) statues for want of a better word of gods that you get over at weddings we found out lots of little things you know like how it sort of how it works on sort of a day to day [basis (*unclear*)
217. N: [have you got a computer?
218. P: no I've not you see if I got my own little flat I know I'd get a computer as the first thing and then I'd be online shopping and (.) [I'd play freecell all day it would
219. N: [so
220. P: probably even get me up quicker in the morning
221. N: could you afford one
222. P: yeah I could afford one
223. N: we could probably get a Macmillan grant you know
224. (.)
225. P: but the problem is living here I'd need to get a second phone line in cos J... 's let it be known before that she wants a computer but nobody's allowed a computer unless they have a second phone line in because she's not having the phones blocked (*unclear*) never very happy (*laughs*)
226. N: that's the other thing we have to talk [about really
227. P: [yeh even if (*unclear*)
because I was telling E... about it because I thought I thought well I don't want it to be a big secret cos somebody's going to leave a message one day saying have you filled in your forms and sent them off or something so I said well look (*unclear*) and so I said to A... look I'm going to need a ground floor bedroom at some point but she made it fairly clear that she's not going to move from her bedroom and um N... said well how about if I pretend to move out J... will be in my room before we know it I'll move into your room and you move into J... 's so I thought well we could do that but I'd have the atmosphere to contend with later (*laughing*)
228. N: do they use this room?
229. P: yes (.) yes? there's no there's just no reason why J... would have a problem moving upstairs because our rooms are identical (.) they're they're just one directly on top of the other they're identical and she doesn't have problems well E...

- doesn't make a noise or anything so it's not as if she doesn't want to be next door to somebody else because there's noise to contend with and um we know for a fact that if E... went because E... 's got the biggest room at the front J... would be in there like a flash [because=
230. N: [yeah
231. P: =I'm not interested in a big room all cold and what have you
(.) we know she'd be up there and then she wouldn't need to have the ground floor umm (.) she's just a bit awkward really
232. N: spoke to E...
233. P: oh right she's back!
234. N: she's back yes I told her I was coming to see you today and that I would ring her tomorrow=
235. P: ok
236. N: =tomorrow or Wednesday (.)one of the days she's not in but I'll phone straight away in the morning and see if she's there
237. P: well I'll give her a ring tomorrow[I know she gets home at half past (*unclear*)
238. N: [yes (.) yeah
239. P: um and she said either we could come round together and go through your things um or she'll just come round and see more to you when you're going in to *Local oncology unit* (.) so really if I just check up about your bloods [(.) and the x-ray (.) um (.)=
240. P: [that'll be good
241. N: =and then get through to E... and see it might be that if you're going in she can come and see you in (.) (*Local oncology unit*) couldn't [she
242. P: [oh yes
243. N: mm cos she'd want to go to *Local oncology unit* to her
244. P: have my bloods done yes you won't believe how good I am either I mean I still do a bit of face pulling and chatting to myself well it's going on but it doesn't bother me to take it from there (*unclear*)
245. N: yes (.) and who's doing it?
246. P: um M...P... and J...P... and I'd have no problem with J... having a [go when she comes back=
247. N: [right
248. P: =cos J... 's taken it from there before and we just look back and still think well she laughs and I don't I'm thinking how did she ever do it (*laughing*) (.) but um she's really pleased with the (*unclear*) so a few of them have tried
249. N: yeah have you got a cleaner at the moment?
250. P: no I've not (.) um and I'm not worrying about it at the minute because it was J... who (*unclear*) with the roster and her effort at cleaning the kitchen wasn't worth doing=
251. N: right
252. P: =so I thought (*unclear*) I can just arrange to do the kitchen because I can't do the floor obviously and things like that but I

can do the worktops and the top cupboards and bits and bobs and that's what I tend to do this week because it wasn't my week for then but I thought no rather than two days after I hadn't done them done them myself J goes and pretends she's done them for her week so I thought (*unclear*) benefit from them

253. N: yes (.) is there anything that (.) they do for you (.) at all
254. P: no (.) E... E... is very thoughtful unless she's like having a new depression for whatever reason she still sees M... umm (.) I I come down and the kettle's full of water and she's very very thoughtful for little things like that (.) and she used to do things like that all the time when I was first diagnosed and then we went through those months when really I was fine I could do everything and like this morning E... was last up last night and I got down and the kettle was full of water whereas usually I get down and there's not a [drop in it and I have to go around (.) which doesn't bother me but
255. N: [no
256. N: what about the bathroom?
257. (.)
258. P: no they've [it's it's a phewph!
259. N: [no problem
260. P: yeah there is a problem with the bathroom (.) the problem with the bathroom is it's more difficult for me to get into the bath now cos of this leg it sort of hurts to get into the bath (.) so I've had hardly any baths at all I smell atrocious I don't feel clean
261. N: is there a shower?
262. P: yes but I can't use it because when the OT came to assess it they can't put any kind of bar across (.) across the bath purely because the side of the bath that connects to the wall is really narrow and its not (.) [it's not
263. N: [did she look at the bath for a [bath(.)
master
264. P: [I've got
a bath (.) that's what I've got
265. N: you've got one
266. P: and it's been brilliant up until now the only problem with the bathmaster (*unclear*) that bathroom is really cold like I'm shivering when I'm in the bath because the only bit (.) I can get these parts on the Bathmaster when I go to my Mum and Dad's and [it's just fine at the back as well as anything else
267. N: [yes (.) yeah
268. P: but I can't straighten my legs out on the Bathmaster and I have sort of (.) up to there with water (.) and I can get my bottom underneath the water and then the whole of the rest of me and the tops of my legs are poking out (.) and we've got one of those ventilation rings in the window
269. N: yeah

270. P: in the bathroom it's not an electronic one that you switch on and off when you want it's one that's constantly going round and it's really chilly in there and that puts me off going in as well (.) cos I know I shouldn't do but I was thinking if I could ever get my own little flat you know I could if I had a little window like that I could very unhygienically block it up with something and then I'd get in the bath I know I would (.) so (.) um the bath's there anyway (*unclear*) but I've got used to that (.) if I can't clean it (*unclear*)
271. (.) long
272. P: but yes the bath
273. (.....)
274. N: so
275. (.)
276. P: what I'm really hoping and I know I shouldn't hope that it should spread in there but it's so much like it's so much like what it was before Easter when I had that tumour of the [(*unclear*) side (.) churning out loads of calcium=
277. N: [mm
278. P: = and they didn't know about it I thought if there could just be another one (.) right at the top so it's not so very far you know (*laughs*) right at the top that they weren't aware of giving loads of calcium (...) I want a second one (*laughs*) cos it's been going on since Easter now that my calcium is not at all controlled
279. N: how much more radiotherapy can you have?
280. P: well (*unclear*) more to the pelvis really
281. N: right
282. P: because I've not had any to that area of my leg anyway
283. N: to the top of your leg?
284. (.)
285. P: I I still have a sneaking suspicion that this thing that I've felt is a (*unclear-huge?*) lump (*unclear*)
286. N: where's that?
287. P: it's right in the pit of my groin
288. (.)
289. P: cos I cos I've just just I think I've had it before (.) because you know I've had problems with the muscles tensing up around there [many times=
290. N: [yes
291. P: =(unclear) to try and move the muscle [I'm sure it's part of the lump
292. N: [yeah (.) is it part of the tissue?
293. P: no (*unclear*)
294. (.)
295. P: it's as hard as the one on my back I suppose
296. N: the one on your back has that changed at all?
297. P: oh bigger yes (.) that changed as we were doing the tests

298. (.....)

299. N: so how [many things have we got now?

300. P: [unclear-laughing)

301. P: well the important one really is calcium I think=

302. N: yes

303. P: = first off

304. N: yes that's the most important one I would agree

305. (.)

306. N: [pain is controlled (.) the x-ray (.) E

307. P: [when you get in you could ask about it

308. P: yes (.) why don't I ring E because I can't fill the form in and
[unclear)

309. N: [do you want to phone E... then

310. P: yes I'll do that

311. N: yeah and then I'll phone the other phone (.) but um and then let
you know

312. P: ok thankyou

313. N: um because then if you're going in to have Chlodrinatate you
could see E...

314. P: yes

315. (.)

316. N: are you feeling sick now? (*notices patient retching*)

317. P: no I'm not feeling sick (.) sorry it's the word Chlodrinatate I'm
alright if you say (*unclear*) fine mention that word Chlodrinatate
and I immediately think of those horse tablets [and the horrible
perfumey taste that made me sick right afterwards

318. N: [yes

319. N: right

320. P: (*laughs*) I'm sorry that'll be why that was I didn't even know
I'd done it (*laughing*)

321. (.)

322. N: yes(.) [they're terrible things to try and take

323. P: [they're horrible little tablets

324. P: do you know I found a couple of them (.) I was having a good
tidy up behind the sofa (*unclear*) and um I came across two
Chlodrinatate tablets in their box (*unclear*)

325. N: what about your parents?

326. P: they didn't phone this weekend[*unclear*)

327. N: [(*unclear*)

328. P: after I spoke to you about that awful weekend on the Tuesday
night it was my next (*unclear*) phone call so Mum phoned up
and she had two friends staying with her for two nights and
these friends they all worked together when they were sixteen
seventeen and usually they have very nice boozy (*unclear*)
laughing and what have you when they get together (.) so
checked that they were there and I said right perhaps I'd better
(*unclear*) if you want to phone (*unclear*) so I told her why and
I'd had a good think about it and was quite clear and had four
things that I wasn't really very pleased with two things that

she'd said and two things that she'd done and that Nanna's ignoring the fact that my Dad's saying (*unclear*) see me again and then I came out of the thing and I was really pleased with and then I said what I'd done at the day centre which unfortunately wasn't very much (*unclear laughing*) but um I told her that to try and prove to my Mum that there I was not thinking and usefully but my Mum being my Mum you can't say anything (.) everything is taken as a great big criticism so before you've even finished the first sentence you've got her saying I did not I did not and even if it's not about her about what was said (*unclear*) she did it in the past and I managed to keep going in between all these outbursts until I said what I'd wanted to say and then she began with is there one thing that we did right? so I said well I just told you of one nice thing that you did just this weekend you know (*unclear*) can you remember me saying it? cos I you know the number of times she tells me everything I have said so she did actually when she thought of it and she said huff you can give one thing and I actually (*unclear*) and I said well you only asked for one thing and I'm just trying to prove that I 've already said it and not very much of trying to be awkward you know (.) I just don't want it to happen again and if I don't tell you it's happened how are you going to know (.) but she (.) wouldn't have any of that (.) so (.) then it got to (.) well I'm just being your kicking board well if I have to be your kicking board so be it (.) and (.) it normally that would've really annoyed me I said you're not being my kicking board at all you know if I've got a problem with other people I 'd (.) I would tell them at the first thing you know whether it be relevant thinking god my Mum and then we got past that and then I said well how about a compromise because she's got this thing now that she's not allowed to speak on the phone (.) and I said you are allowed to speak on the phone Mum I'm only stopping the phone calls when (.) you've been talking about the weather obviously as a fill in (.) [cos there's nothing left to say=

329. N:

[mmm

330. P:

= or you're telling me the same things as the first time and I said we we're not having a couple of minutes phone calls because I'm doing that you know last time we were on the phone for forty five minutes (.) I (.) I can't believe you can think of things to say every two days for forty five minutes because it was getting over an hour=

331. N:

yes

332. P:

= and I can't sit for over an hour anyway so I was ending up (*unclear*) the phone calls and things (.) I told her all of that and then I said well how about a compromise (.) um (.) I will talk to you about the weather (.) if you (*unclear*) the way you talk to me (.) just for a few weeks (.) I talk to you like I talk to everybody I thought I've gone for a compromise and she

- won't even go for this (*ironic laughing*) or anything (.) so I got absolutely nowhere (.) with the phone call (.) but I think it did a lot for me =
333. N: right
334. P: =cos I actually stood up to her and I know (*unclear*) and she won't be able to report to anybody else on our phone calls now (.) but
335. N: is she coming down this weekend?
336. P: (.) yeah (.) oh yeah yes (.) I told her on that phone call that I'd rather she didn't come the weekend after you know I said I've only been given one weekend off these visits since I've been diagnosed and bearing in mind that we only used to see each other once or twice a year before that time (*unclear*) then it's really difficult you know for me to suddenly know or have to have one weekly visits (.) I said that later on actually in another phone call I said because I don't feel ill the way you think I feel ill all [the time
337. N: [yes
338. P: I said I feel fine I said yes sometimes my leg's sore or sometimes I can't sit and that reminds me and I said I'm on crutches but I've been on them for ages you know it's not that I wake up thinking oh I'm ill or go to bed thinking (*unclear*) I said it's not like that it's not like having a cold or anything I feel fine (.) but you know perhaps one day I will get a cold and then I'll feel really rotten and go and tell everyone I've got cancer but she didn't believe me (.) and I (.) I think (.) even if she were to ask anybody else then they'd probably say the same cos I can't imagine anybody I've met at sort of day centre or the people I meet on the wards at *local oncology unit* would be waking up (*unclear*) and spending all day (*unclear*) (.) cos you don't feel ill (.) I mean yes [if you=
339. N: [bad night
340. P: = finish your radiotherapy treatment and you try to eat a block or cube (*unclear*) but other than that you don't (.) because what had happened id that she came down for that weekend anyway even though I said I didn't want them to and one of her friends had sent down um a little plastic bottle shaped like (.) um (.) Our Lady with stagnant water from Lourdes in it (*laughs*) I'm awfully sorry (*laughs*) but it's not me at all that and Mum [knows
341. N: [somebody gave me a [bottle of holy water yesterday
342. P: [and that's
343. P: oh did they well this particular one I happen to know was fourteen years old which is why I'm saying it definitely had stagnant water in it (*laughing*) and I said Mum look you know I'm not going to have that in my bedroom (.) but then (.) she actually left it when she went out to get the shopping which was (*unclear*) left it and it was pointing at me you know and (.) oh crumbs (.) and I dropped my crutches every time I

stood up and I just thought I can't quite decide a coincidence because I do drop my crutches but it's usually in the kitchen or bathroom where the floor's slippery and I'm sort of I put one to rest in a not very clever place and it falls (.) I very rarely drop them if I'm standing=

344. N: yeah
345. P: =because I'm actually using them
346. N: what have you done with
347. P: (*unclear*) I said no
348. N: take that
349. P: and she's got this other friend who isn't a friend of mine I don't even know her and when I was first diagnosed M... felt dreadfully guilty and sent round presents for me and I can't remember what they were but you know she sent round some nice presents as did lots of people when I was first diagnosed but M... 's still doing it and er a couple of months ago I said Mum this isn't very nice you know receiving these presents just cause I'm dying of course you're not allowed to say that to Mum so um (.) (*unclear*) and um then I said well that's what it feels like I said I feel perfectly fine and then every second week I'm sent down poorly presents (.) a carrier bag full of tissues (.) I haven't got a cold (.) why do I need a carrier bag full of tissues for (*laughing*) you know things like this but Mum's told me that M... can't afford these presents (*unclear*) she sent me down another pair of pyjamas (.) she last sent me a pair of pyjamas when I was in (*hospice*) so that was about a month ago and I said to my Mum I'm sorry I'm not accepting them (*unclear*) to tell your friends to stop sending me things because you know I know they're all thinking about me and I know they're all saying their prayers and things like that and they don't have to send presents (*unclear*)
350. N: do you think that some of the things that (.) really irritated you in (*hospice*) are these same things that your Mum does [that sort of=
351. P: [oh
yeah yes
352. (.)
353. N: =trying to give you things or [trying to say what we're doing for you
354. P: [it was well well food was the problem in (*hospice*) (.) it was just it was too rich I'd be able to eat it now if I wanted and I would enjoy it I like having contraptions and quite rich food (*unclear*) and all the rest of it but the last time I couldn't do it (.) and you know [(*unclear*)
355. N: [cause you were terribly down when you were in
356. P: I know
357. N: it's [interesting since you've been back home
358. P: [well I have been

359. P: I don't feel that I have regained my usual chirpiness yet (*sing song*) but I mean I'm certainly [more myself than I was then
360. N: [you're much
361. P: no I was thoroughly miserable when I was in (*hospice*) but I think it just didn't help because on the first day I heard them whispering about how little of my dinner I'd eaten outside my door (.) and then I heard it again on the second day and I was upset about it because I was only eating what I could eat you know and I felt like saying bring me a bowl of peas I'll be able to eat every last one but no you bring me in really rich food (.) I could I couldn't do anything about this really rich food apart from when I had my visits my [visitors went out and got sandwiches
362. N: [mmm
363. P: and so I'd been sick a lot as well but I knew it could have been prevented (.) so I wasn't I wasn't best pleased with that (.) and then the other thing was just you know (*unclear*) (.) but apart from the fact that we knew them and just said to them don't sort of chat about what's going on in the room you're in the world outside and everything (.) and chat about what I was watching on telly (.) you don't think it makes (*unclear*)
364. N: yes
365. P: and I'd be a different person again on the ward cause I'd I'd probably wake up so this is where I got into my bad sleeping routine because I was in the room by myself and of course I could stay up all night watching films and things like that because I had nothing to get up for in the morning (.) now if I was on the ward everybody else would be be up (.) and I'd still be in bed but I would at least be awake (*laughs*)
366. N: but you might be the fittest person there
367. P: well I might be but I can honestly say to you K.. the number of times I've been into *local oncology unit* and stayed on the ward I've always not been the fittest person there (*laughing*) cause that was a real eye opener you know when I was in a couple of weeks after being diagnosed I walked right the way the length of the ward and I'll always remember I was looking at the people and (.) looking back were these sort of sickly group of people that they had in at the time and nearly everybody had sort of a cast with their leg in and everybody was a lot older than me and I remember walking up thinking I shouldn't be in here you know I'm not this ill and (.) looking as ill it wasn't half an hour before I was being sick into the sick hat and I really was very poorly at the time (.) and it was one of our little jokes that I was obviously the youngest much by far the youngest in our little corner and I was the one moved the most slowly (.) can you get the chair out the way frequently so I can get to the bathroom and (.) yeah (.) so I'm used to not being the fittest
368. N: mm

369. (.)

370. P: so that's what it did feel like (*unclear*)

371. N: mm

372. (.)

373. N: are you (.) you're not planning to come into (*hospice*)
tomorrow are you

374. P: um I don't think so no because if it's like today (*unclear*) I was
feeling sick after I got dressed

375. N: yes

376. P: mm

377. (.)

378. N: so (*sighs*) (.) I was [planning to write some of this down

379. P: [(*unclear*) to (*hospice*)

380. N: mm?

381. P: going to send a letter to (*hospice*) for (*Beryl?*) (.) I'll give her
my phone number and then if she wants to phone she can and I
can phone her back (*laughs*)

382. N: so I'll tell J... you're not coming in tomorrow

383. P: ok cause rea really particularly I won't be able to get up early
enough to go in the bath [get my hair washed and ready

384. N: [right

385. (.)

386. N: I'd better make a list then

387. P: ok

388. (.)

389. N: right (.) one (.) check (.) bloods

390. P: I'm sure it's high

391. N: mm?

392. P: I'm sure it's high

393. N: yes (.) have you been confused at all do you think?

394. P: no more than normal the only thing I've been doing is Saturday
and Tuesday (.) consistently for the whole week called
Saturday Tuesday (.) and that's one of the things that I do

395. N: yes

396. (*unclear*)

397. N: you're going to ring E....

398. P: I'll ring E.....(*unclear*)

399. N: ring Dr B....? right (.) er

400. (.)

401. P: he came round with the forms about the wheelchair and I
dashed down thinking it was my slippers and I opened the door
and of course didn't recognise him (.) and then I eventually did
about five seconds later and said oh I'm ever so sorry come in
(*laughs*)

402. (.)

403. N: (*unclear*) after discussion with (*unclear*)

404. P: mm

405. N: how much Palfium are you taking a day?

406. P: um well I don't go every day and I've never had to take um two
in a day cause I didn't know whether I was allowed to

407. N: and they're five milligrams

408. P: they're five milligrams

409. N: you can take them

410. P: I had noticed that my pupils were um like pin pricks (.) about
half an hour after taking a Palfium that was about one of
the only times I took it (.) cause I know that is (.) sort of Heroin in
its working and I thought gosh this is very strong stuff

411. N: it's it's because it's absorbed quickly that you will get an
immediate well not immediate about twenty minutes

412. P: oh I don't know I'm going to continue to fool myself into
thinking that it's only about three minutes (.) from now on

413. N: well=

414. P: laughs

415. N: = if if you take it sub-lingually [that's the quickest way

416. P: [yeah

417. P: [well I may more and more

418. N: [like a variation there (.) normally they would say if you
swallowed it that it would take about twenty minutes for you to
get the full effect of it

419. P: right

420. N: but the good thing is it wears off quite quickly as well so you
[get

421. P: [about three hours or so

422. N: yes

423. (.)

424. N: um

425. (.)

426. P: ok [so if I have one in the morning and then I have to go again
in the evening

427. N: [I would

428. P: there's no problem

429. N: there's no problem no

430. P: I've never taken two in a day (.) and to begin with when I first
came back from (*hospice*) I used to go every Thursday and I
wasn't taking that much at all I'm on a little bit more than that
now

431. N: yes

432. P: but I don't take them every day

433. N: any bleeding?

434. P: yes (.) there's bleeding when I go to the toilet still and with the
Palfium and also the discharge has got blooded up again

435. N: fresh?

436. P: um well I think so (.) but

437. (.)

438. N: those lumps in your groin do you want me to have a look before
I go or?

439. P: I'm very smelly today

440. N: I think I can cope with that
441. P: if you can cope with that you can have a look ok
442. N: we'll turn the tape off before I think we (*unclear*) (*laughing*)
443. R: I'll turn it off shall I
444. N: is there anything else that you particularly want to bring up?
445. P: no (.) the main problem for me at the moment is calcium and that's getting [a bit
446. N: [yes
447. P: just you know if you make a note
448. N: yes
449. P: um (.) and then there's all sorts I was just thinking about the x-rays because there's usually nothing wrong with my leg I was wondering what this (.) you know where (.) well I've got into my head now that there might be a little tumour that they don't know about that's causing the problems the calcium and if that was the case (*unclear*)
450. N: then they could tell you
451. P: yes (.) if there's (*unclear*)
452. End of tape

HCTRA3 Mary

Patient Female 50 + years

Nurse 50+ years

1. N: and if you wanted it turned off at any point we could do that
2. P: o.k.
3. N: Annmarie used to work at (*hospice*) um as an auxiliary nurse while she was doing her university course
4. P: oh
5. N: and now (you're doing a PhD are you?
6. A: yes
7. P: yes (.) lovely
8. N: so it's really looking into (.) um communication
9. P: yes
10. N: um (.) with with patients with cancer (.) so she's tape recording me for (.) four patients?
11. A: yes
12. N: so it's really great of you to agree to it (*laughing*)
13. P: that's all right (*laughing*)
14. N: and basically we'll do as we usually do
15. P: yes that's alright
16. N: Is that o.k.?
17. P: yeah fine
18. N: so how have you been this week?
19. P: not too bad oh yesterday I was just really tired (.) just my legs my you know like I was before just really (.) tired and my mouth is still sore but otherwise I'm (.) I'm not too bad this week (.) you see usually the last week you are ok anyway
20. N: yeah
21. P: and then 'til you go back [to the
22. N: [when's your next ?
23. P: Wednesday
24. N: this Wednesday [coming
25. P: [yeah (.) yeah
26. N: and you're just going to have (.) Systatin
27. P: and (.) Tac Taxol
28. N: and Taxol
29. P: yeah have the Taxol first=
30. N: yeah
31. P: =and the Systatin [after
32. N: [yeah
33. N: (.) and have they given you a scan date[yet?
34. P: [no no
35. N: no because we were talking [about that weren't we
36. P: [yeah yeah
37. N: um (.) I would have thought that if that's what you want to check with them about that [missed one as well

38. P: [that (.) yeah
39. P: to make sure (.) yes but he's already cancelling one anyway=
40. N: yes
41. P: =I've only got to have five this time instead of six=
42. N: yes
43. P: =because of the reaction that I've been having – you know (.)
so um (.) don't know (.) well I'll see him or one of them on
Tuesday when I go Tuesday and give[blood=
44. N: [yeah
45. P: =and Wednesday for the treatment
46. N: and have a talk about it
47. P: yeah (.) I'll ask ...
48. N: and it may be that if you want and it's up to you (.) when you
have the scan (.) and you're going for the results if you want I
could come [along =
49. P: [come P: with (.) ok thanks
50. N: =with you (.) would that be useful?
51. P: I'm going to ask them this time if I don't have to wait so long
in between (.) because that's what I/
52. N: / for the reporting?
53. P: yeah (.)that seems to take you know you've usually got to wait
a few weeks after the chemo I did last time (.) before they do
the scan and then it's something like three weeks after you've
had the scan before you get your results[you know=
54. N: [yeah
55. P: = I think that's the part that makes you (.) you know so anxious
if if you knew sort of the week after or something like that...
56. N: You've seen A.B. haven't you?
57. P: yes
58. N: you went to [*hospital*
59. P: [yeah yeah
60. N: what I'll do when we've finished today remind me at the [end
61. P: [yeah
62. N: and I'll (.) put a note down to talk to him=
63. P: ok
64. N: =and see whether if you would like (.)
65. P: yeah
66. N: we could get the scan results sooner
67. P: ok quicker yeah
68. N: um (.) that should be possible [because you got so anxious and
(.)=
69. P: [I think I'd rather do that because
I (.)
70. P: = the waiting (.) yeah (.) and (*husband*) gets all uptight/
71. N: /that's
what I was thinking he got really upset last time=
72. P: this is it yeah
73. N: = didn't he

74. P: he gets all uptight about it you know (.) just the anxiety after
you've had all the treatment then and you've had the scan and
knowing you know what the results [are
75. N: [yes
76. P: I think three weeks is such a long time to wait [after you've had
you
77. N: [yeah
78. P: know (.) unclear because they havn't mentioned a scan yet
except you know I know you have one at the end
79. N: (.) well what I can do is after you've been (.) next Wednesday
is give you a ring=
80. P: yeah
81. N: = and find out what they've said
82. P: ok
83. N: then we can sort out for me to come in between [just for some
support
84. P: [between that's
right
85. P: yeah yeah
86. N: and I'll also talk to A. at the community [meeting this week
about=
87. P: [ok lovely
88. N: =whether we can get the results sooner
89. P: quicker yeah
90. N: because (.) they don't take that long
91. P: no no this is it (.) but um you know it was such (.) oh God it
seemed like forever last time waiting you know (.) it's hard
enough you don't know what they're going to say anyway but
when you've got that long wait in between (.) you know that's
what er (.) so I was going to ask them if I could come back
quicker this time
92. N: that's what we'll do about that
93. P: ok
94. N: what about pain?
95. P: no I'm ok (.) I've um (.) had a couple (.) you know here but its
been both sides like a tightness I was saying to S... on Monday
96. P: It feels (.) all like tight around here
97. N: are you bigger there?
98. P: Well I I'm going up and down here
99. N: yeah
100. P: you know I seem to come up and then I seem to go down
(unclear) I wouldn't say I'd put a lot more [on (.) no
101. N: [no
102. P: it just feels tight (.) you know
103. N: that's a different sort of pain then[isn't it
104. P: [yeah yeah
105. P: I used to get the pain there [I haven't I haven't got that so
much now
106. N: [just under

107. P: but I did have it both sides but it was like a (.) it wasn't a pulling [it was a tightness

108. N: [yeah

109. P: more than any thing like you (*inhales*)[you know like that.

110. N: [yeah

111. P: but um (.) it's ok you know and I just take painkillers now anyway

112. N: you're [just taking the usual are you

113. P: [yeah, yeah

114. N: not tried any?

115. P: I'm just taking them you know [like I do

116. N: [yeah

117. P: and then uh I got I think it's just I got so much faith in them that I feel better after I've taken them

118. N: and you've not needed any morphine?

119. P: no no I haven't taken that

120. N: what about the holy water?

121. P: well I well I use that when my legs are playing up (*laughing*) yeah I've used gallons of that and I mean

122. N: where do you get it from?

123. P: when I went to Lourdes

124. N: yes but have you how much did you bring back?

125. P: oh God (.) I've got a big container like that you know and then I brought another one like that last year so I've still got quite a bit in both of them

126. N: yeah

127. P: in both [the containers so I use the bottles like that to put it on when=

128. N: [right

129. P: =um when the legs are performing (.) but like the legs and after the chemo like next week I'll be using it because you know you have the chemo on a Wednesday and on Friday until like the middle of the following week (.) you know that you're going to have [terrible pains in your legs(you know

130. N: [yes (.) yes

131. N: yes [I was talking to somebody yesterday=

132. P: [that's when I...

133. P: were you?

134. N: = yes he's on Taxol and she was saying exactly the same

135. P: she has it in the legs as well

136. N: yes

137. P: yeah

138. N: yeah

139. P: yeah (.) oh terrible (.) it's something you can't explain it's like all your veins are on fire (.) you know and your toes are [all tingling

140. N: [yes

141. N: that's exactly the same

142. P: yeah (.) yeah (.) it's the Taxol is it then

143. N: I think so [yes
144. P: [yeah
145. P: (.) oh well (.) never mind (.) you know you've got to put up with it so you've just got to get on with it and as long as I've got my painkillers and my holy water I (.) I'm alright (*laughs*) it eases it for a while and then it comes back and you know it's going to go by [*(unclear)*
146. N: [are you planning to go again?
147. P: I'm not going this year (.) no
148. N: because you got exhausted
149. P: I did yeah I was really tired last year (.) the travelling you know and there's a lot of walking involved as well (.) and like last year I couldn't do it I was in one of those things they pull you along in you know
150. N: yeah
151. P: no but (.) no I'd love to go again I do want to go again but not (.) I couldn't do it this year
152. N: no
153. P: I just haven't got the energy (.) you know
154. N: yeah (.) what about the waterworks?
155. P: that's fine now
156. N: that cleared up
157. P: yeah lovely
158. N: so you've been taking cranberry juice
159. P: yes and I've got um (.) barley lemon barley water (.) I've been drinking a lot anyway (.) yes that was that was lovely (.) I don't know what I don't know whether there was an infection or it was to do with that stuff you know the new one (.) but um (.) it's been ok this time (.) thank God
160. N: yeah (.) what about tumble dryer?
161. P: well(.) um (.) Sue came and [*(K turns to researcher)*
162. N: [waterworks it follows did you get that
163. P: (*laughs*)
164. A: yeah very good (*laughs*)
165. P: Sue (*tenovus nurse*) came and um she rang me then I had to give her a she had to bring a form back for me to take to my doctor (.) so I filled that in and I gave it to her on Tuesday (.) so she said I should hear from Comet now or something
166. N: that's great [(.) they're usually quite quick as well
167. P: [yeah
168. P: are they?
169. N: yes
170. P: oh well I took it Tuesday afternoon up to the office
171. N: that 'll make a big difference
172. P: oh it will
173. N: are you still?

174. P: I'm drying we went yesterday with a big bag of drying you know that I'd washed at home you know it's the towels [and my my trousers and the tops and everything like that
175. N: [yes
yeah
176. P: and um with me I go through so many pants and [things like that
177. N: [yeah
178. P: you know that um you need to have it/
179. N: /they're usually [quite quick=
180. P: [yeah oh
good
181. N: =so that'll be great
182. P: yeah
183. N: any news on the bathroom?
184. P: nothing I um rang them last week or the week before because I had a letter about the ordinary grant that I put in for
185. N: yeah
186. P: well there's no chance of that until you've gone sixty or whatever they're not doing windows or things so I rang and asked while what about the one I put in for for the bathroom and she said oh yeah I was still I was priority for that although I been waiting over a year she said it was like on the priority list and they're up til about November at the moment (.) of ninety nine and mine went in in March of two thousand so it was only a few months behind like she said I should be hearing soon you know hopefully within the next few months
187. N: and Sue doesn't think that there's anything else we can do about [that
188. P: [well I I haven't I haven't really mentioned it to Sue no the lady said on the phone the thing is you could um you could sort of they could just come out and give you a bath or something like that but for the time I've been waiting now I'm better off to carry on waiting because I've got a grant I will have a grant then for the bathroom plus central heating she told me the (*unclear*) put in for she told me the occupational therapist that came out said that I needed central heating as well so I said that I might as well wait for the time you know
189. N: I suppose one thing we could do would be after you've had this scan
190. P: yeah
191. (.)
192. P: see what
193. N: depending [upon what it is
194. P: [that's right yeah
195. N: that we might use the scan and the results to say this is [where you're at=

196. P: [yeah I
need it yeah

197. N: = and it might just push [them

198. P: [that's right yeah

199. (.)

200. P: see what happens (quietly)

201. N: (*coughs*)

202. (.)

203. P: because otherwise I've said well I've waited ov well it's been
twelve months since March now so another couple of months is
not going to make any difference (*unclear*)

204. P: otherwise

205. N: do their people have to come out [or do they do all of that

206. P: [yes

207. P: no she said somebody will come out (.) and she said they are in
front of the office these people you know they're um

208. N: yes

209. P: more advanced um with their work than they are their's so she
said I (*unclear*) I could hear S... so I'll just wait and hear what
(.) they say I mean it definitely needs some work done [upstairs

210. N: [oh yes
yes

211. P: I said to I...(unclear) it's just um climbing in and out of there

212. N: when we've finished this perhaps you could show Annmarie

213. P: yes well there's beds the room is in a state up there at the
moment

214. N: ah [if you don't want me to

215. P: [we had to open the beds we had to open the beds
remember when my aunty came?

216. N: yes

217. P: from (*unclear*) so I've had to put all the black bags of er
everything that we got in that bedroom plus we got a bed settee
that moves just in that part and it's just in a terrible mess up
there at the moment

218. (.)

219. P: and all I got is a bath (.) just there (.) boxed in (.) and it's a
shower and it's like you got to climb in to up to a little step
[because they had to build it up

220. R: [yes

221. P: well it was ok when I was fit but I'm afraid to go in there now I
slip see you know and then I'm just afraid to climb in there and
plus cause the space is so small I *get all* unless T... will come
up there and wait with me I won't go in there

222. R: yes (.) my Mum's just had a grant

223. P: has she?

224. R: yes she had the same problem couldn't get in and out very well

225. P: that's it

226. R: and my Dad (*unclear*)

227. P: no that's right well that's what I just done

228. R: (*unclear*)it must have taken about nine months [to come through?

229. P: [yes well this is
it

230. P: but she did tell me the lady when she came here that um I'd have to wait over a year cause that is like a standard thing [you know

231. R: [yes

232. P: but she said it would take a long you know so I suppose it will be (.) like that

233. R: mm

234. P: I don't mind it like we got the toilet and the bath er toilet and the sink downstairs and the bath upstairs so I need it all in together yes

235. N: it would make a real difference

236. P: yeah yes it does and having said at the moment I mean it's black all the ceiling's are black and everything in there

237. R: mm

238. P: and it's just like a junk shop you know and there's just everything cause (.) we had visitors come from America in October and like we moved everything out of this place into there and (.) we had to put a bed-settee up there that opened out into a bed and that's where my husband and I stayed because my Aunty had our bedroom

239. N: mm

240. P: and it's all been stuck there ever since (.) I haven't got the strength to move anything (*laugh voice*) you know (.) so er (.) it's a right shambles you can't even well you can only just about get in through the door (.) at the moment

241. (.)

242. P: so (.) never mind

243. N: how's the family

244. P: fine (.) yeah (.) yeah T.. was up early but I sent him back to bed I said wait (.) til you've been and gone (*laugh voice*) and then I'm going to call you (.) cause he gets himself all (.) uptight you know my husband he's got a nervous complaint had it since my children were little (.) since I've been ill he's sort of got himself so (.) het up and he's given up smoking which he used to smoke no end (.) you know

245. R: yeah

246. P: cor I said to him the other day I'd rather you go back on the cigarettes! [than he's so [um (.) like a time bomb

247. N: [*laughs*

248. R: [*laughs*

249. R: [how long's he given up for

250. P: about four months now

251. R: very good

252. P: yeah (.) just like that (.) he he surprised me because he used to smoke very heavy(.) and um he had a pain in his chest the one

night and he started to get trouble with his legs and things like that (.) so (.) it was the day my daughter moved into her new house (.) and we were on the way home and he had one left and he smoked it and he said that's it I'm not smoking any more and he hasn't you know (.) so I'm really pleased with [him

253. N: [has he
felt better?
254. P: well he said his chest is still um (.) not much easier but [he said
255. N: [when I
gave up smoking which was years and years ago (.) um and that
was because I'd developed a cough
256. P: yeah
257. N: and my cough was worse for (.) quite (.) quite a while
[afterwards
258. P: [yeah
259. N: because I used to think well (unclear)
260. P: no this is it (.) he put on a lot of weight
261. N: yeah
262. P: he can't stop eating at the moment [you know that's all he
seems to be doing
263. N: [yeah
264. P: but he has put quite a bit of weight on
265. (.)
266. N: is there anything else at the moment=
267. P: no
268. N: =that you can think of?
269. P: no I don't think so (.) no I should think things are (.) fine you
know (.) like I said I just (.) just feel so tired that's all I don't
want to do anything
270. N: I think all you can do is as [we've said before
271. P: [just yeah rest
272. N: is just (.) sleep as much [as you can
273. P: [well this is what I've done and I've
sort of been laying out like this morning I was laying on there
for a bit and then I got a bit chilly so I came [and sat over here
[yeah
274. N: [yeah
275. P: but then I seem to go to sleep early like I must have been asleep
about just after ten last night (.) but I'm awake then (.) five past
one this morning it was five past one yesterday (.) last week it
was like four o' clock and five o' clock you know (.) I dozed
back off after I went I wake up to go to the toilet [see (.) so
many times in the night
276. N: [yeah
277. P: and um (.) then I seem to go off but I'm awake about four or
five o' clock and watch that and watch that channel 'Gold' I've
been watching Bergerac at four o' clock! and then what's the
other one that comes on after that Knot's Landing and then

there's um the farm the one with the vets um (.) oh what's his name? (.) that's on about seven o' clock I've been watching all those every morning [and then by tea time then

278. N: [have you

279. P: I'm [really tired

280. N: [then you're shattered

281. P: yeah yeah

282. (.)

283. (*unclear*)

284. N: I'll tell you when I fill it in (.) so if I check what we're doing um (.) I'll ring [you

285. P: [I should know on I well I should know Thursday if they've given me a date for um (.) if he's going to give me a date for a scan

286. (.)

287. N: Thursday (writing)

288. (.)

289. N: so if I ring you on Thursday [and check what the date is for the scan and then I can

290. P: [yeah

291. N: [book it in my diary

292. P: [right (.) if he don't say anything I'll have to ask him won't I I'll have to say well will I be having a scan [(*unclear*)

293. N: [yes definitely [I think it will be a good [idea to say you know=

294. P: [right yes

295. N: =what's the next step now

296. P: that's right

297. N: nearly always after=

298. P: I know I had it [last time=

299. N: [=a course of chemotherapy [you'll get um

300. P: [=but I had to wait a few weeks I'm sure I had to wait because they said oh you've got to wait [for the (*unclear*)

301. N: [yeah I think they might they [might say that but the thing that we want to try and (.) change =

302. P: [yeah

303. N: =[is the period after you've had the scan the period

304. P: [is the (*unclear*) soon as possible

305. P: yeah

306. N: so I'll discuss (.) with (.) A...(writing) B... (.) what we could do about that

307. P: right

308. N: because I think it's really [(.) it's not fair on you and T.. to have to go through that

309. P: [oh it is the waiting you know it gets you so um

310. N: yeah

311. P: that's the only thing is the waiting (.) cause I mean they do them don't they and they know more or less soon as they've done the the [scans you know I know they like to check over and everything but=
312. N: [yeah
313. P: =I'm sure if they said come back next week it makes you feel a bit easier than having to wait like three [weeks
314. N: [yeah yeah
315. N: and query a letter (.) re (.) bathroom (writing)
316. (.)
317. N: was there anything else?
318. P: no don't think so
319. N: anything else? (to researcher)
320. R: no
321. N: no? [think that's it
322. P: [no
323. N: no change in medication
324. P: no
325. N: um (.) and the problems from last time
326. P: well my water have got=
327. N: =is [better
328. P: [better
329. N: and your mouth is still [a bit sore
330. P: [oh my mouth is still sore (.) I got oh the doctor gave me a spray this time (.) Difflam [the same as what I'm using for a mouthwash
331. N: [Difflam yeah
332. P: but (.) like my tongue (.) (*shows tongue*) all (.) underneath and down there and all underneath of my palate aww it really (.) it's so sore if I try to eat anything
333. N: yeah
334. P: and it makes you jump you know but then (.) I been doing a mouthwash quite a lot
335. N: yes
336. P: then I been using this spray it's a funny sort of thing it's a big one like that (.) and you just got to press [it in you know
337. N: [yes
338. P: but because it's in such awkward places it's awkward to get at it
339. N: yes
340. P: you know even my lips are er
341. N: and everything feels big [doesn't it in your mouth it's
342. P: [awful yeah yeah
343. P: yeah but this one is like um (.) I 've never seen one before (.) you got to pump it so many times to um (.) to get it out (*Background noise - finding pump*)
344. N: I haven't seen one of those
345. P: and you got to keep pressing that so many times but if you sort of (*unclear*) like that it don't work (*laughs*)

346. P: oh (.) my grandson was trying to do it for me last night so I managed to get some out on the end of my tongue (*unclear*)
347. N: I wonder if there's um (.) there's a drug that's given for pain that's just come out in a new form in the form of a lollipop
348. P: oh yeah (.) good gosh
349. N: have you heard about that?
350. R: no
351. N: (*unclear-name of drug*)
352. R: no I didn't know
353. N: I just wonder whether anybody's ever thought of [using it
354. P: [trying it
355. N: think it's quite expensive
356. P: yeah
357. N: I'll have a have a chat with A... and find out whether
358. P: good God
359. N: because (.) it's a really big problem for people with=
360. R: sore mouths
361. P: yeah
362. N: =chemotherapy
363. P: it's like on the end of my tongue my tongue goes like as though it's split in the middle
364. N: yeah
365. P: there
366. N: yeah
367. P: and (.) and that's sore as well (.) now you try and eat a packet of crisps or something and the salt or try and eat anything that's
368. R: tomato
369. P: yeah whoo you know (*laughs*) and we went to my sister-in-law's um (.) I'm trying to think (.) this week Tuesday and she'd made soup and if you'd seen me trying to eat it it was so (.) it was hot and then it sort of whatchercall down my neck I thought I'd burned it
370. N: mm
371. P: and I was letting it cool and then this morning I've had all my milk down here you're trying to (.) and every so often it makes you jump yeah and I dribbled it all down me this morning (.) it's really sore on the end you know but it seems to have gone down underneath? (.) last time and this time down there
372. R: so do you manage to get enough to eat or do you give up half way through
373. P: no well I ate most of it and I give the rest to T... to finish when we were up there (*laughing*) you know (.) I'm eating little bits you know I'm not um (.) I'm not going hungry
374. R: no
375. P: but it's just (.) you can only have like soft things plenty of I made soup myself yesterday and I sort of like drink the juice you know
376. R: mm

377. P: it's alright like that (.) but cornflakes I let them go so soggy (.)
so they you know you don't have to really crunch them or
anything (.) but um I'm getting things down me but
378. R: it's agony
379. P: yeah
380. (.)
381. P: mind the taste is better these last (.) couple of days because aw
last (.) when I first started chemo last ti you know two weeks
ago everything taste like poison (.) oh it was horrible it was like
no matter what you ate (.) it just tasted horrible you know it
was really and I was going for all sweet things I was trifles and
cheesecake (*listening*) T... 's in the back bedroom now you
know why he's got um (.) you wouldn't believe me yesterday
(.) I turned the tap on and the radio went on (.) and I turned it
on and T... was out the kitchen he was out the toilet and I
shouted to him he thinks I'm going mad anyway (*laughs*)
382. R: (*laughs*)
383. P: I said the wireless just come on and it's not switched in he said
well don't be so stupid then it's got to be switched in I said and
I'm looking at it and the plug is not swi the switch is not down
and of course he panicked then because he said it must be live
then (.) it just come on! the wireless I've like something you
see on the telly you know how they all disconnect everything to
the wrong places and I turned the tap and the wireless came on
(.) so I get my friend's an electrician so I phoned him straight
away (*laughing*)
384. N: (*laughs*)
385. R: (*laughs*)
386. P: and I said John I just turned the tap on and the wireless came
on he said what are you talking about
387. (*all laugh*)
388. P: anyway I came home last night well then he T... we unplugged
everything then (.) and when we when we came back in T...
plugged it in again and it came on again (.) not switched on it's
just um going the plug's going (.) so um anyway one of my
friends came over last night took it all out and he cut (.) all the
wires or whatever and he blocked them all up so (.) you can't
use it (.) but to get to have it done properly you got to go up in
that room where the bathroom is
389. N: yes
390. P: because that's where the (.) whatever it is comes from you
know where he's made the plug so what he's going to do now
tonight J.... T.... going to take up all the carpet in there (.) and
then they're going to bring new wires down through and then
I'll have a new plug after (.) it was like (.) it was like something
(.) I couldn't believe it I went like that (*facial expression?*) you
know
391. R and N: (*laughs*)

392. P: and the one that came on (.) I mean lucky we knew I suppose really because the other the other one I got the toaster in although they're not on I got like a toaster in one and the wireless in the other one but um anyway my son's going to put that right (unclear) but it's all going I told you (.) my washing machine my tumble dryer the hoover (.) my kettle (.) sometimes it'll turn off and sometimes it won't that's temperamental as well and now (.) this went yesterday
393. N: yes
394. R: job [lot from Curry's
395. N: [(unclear)
396. N: we'd better turn the tape recorder off! before that goes
397. (*all laugh*)
398. N: that's great anyway [M... I think
399. P: [right (.) yes
400. N: so we'll do those things and I'll ring you on Thursday
401. P: Thursday morning [yeah (*unclear*)
402. N: [next week
403. N: then um
404. P: yeah? (*aloud to husband upstairs*)
405. (.)
406. P: K....'s here
407. (*unclear passage*)
408. P: we're going to have to chuck that bed out so I said just close it up for now and just stand it up against the wall and put all the (.) junk in it (unclear) I've got handbags and all sorts of things in black bags and things that we haven't used for years but I just don't want to chuck them out I'm a terrible um (.) hoarder I am
409. N: yeah (.) yeah I am as well
410. (.)
411. N: well (.) we'll get off then [I'll ring you next week
412. P: [ok lovely
413. P: right
414. N: and um and tell T... if the scan comes up after it [if he wants I'll come and talk to him
415. P: [yes he told (*unclear*)
416. N: ok
417. N: thanks ever so M...
418. P: (.) do you need that form?
419. R: yes please yes (.) is there anything you want [to ask me?
420. P: [I didn't put a thing on there cause I didn't know what you wanted me to say have you had the opportunity to ask questions and discuss the study
421. R: would you like to ask any questions?
422. P: no not really (.) well it's to do with like helping other [people

423. R: [yeah
424. N: yeah
425. R: yes
426. P: so that's um
427. R: thank you very much
428. P: but I think it does help don't it if um people (.) er
429. N: it's the sort of thing that a lot of people get anxious [about
doing
430. P: [yes
431. N: um do you want to put yes to that or do you want to [leave that
432. P: [yes I can
if you like (*unclear*)
433. R: (*laughs*)
434. (.)
435. N: and and if if anybody feels that they don't want to do it then
[that's fine
436. P: [they don't no
437. N: but it's one of the areas that (.) is very little researched [really=
438. P: [yeah
439. R: [mm
440. N: =and yet [you know the difference that it makes=
441. P: [I think it helps
442. P: yeah
443. N: =when you go and see somebody=
444. P: that's right
445. N: =who explains [things to you
446. P: [yeah definitely
447. N: or the times [that you meet people that
448. P: [or you feel like I feel that I can say anything I
wanted to to K.. or to S...
449. R: mm
450. P: things that I wouldn't say to my own family or (.) or [to friends
or anything like
451. R: [right
yeah
452. P: that but you just feel you can open up you know
453. R: and cause you're in your own home as well
454. P: that's rightyeah I think you can just open up and say what
you know what you want or ask what you want [to as well
455. R: [mm
456. R: yeah
457. P: cause I found it have helped well I told you I told them up at
the hospital you know that er (.) I find it a lot and my a friend
of mine her son is just is got (.) have found out he's got cancer
and I told her (.) cause you do need somebody to talk to
458. N: yeah
459. P: you know (.) at certain times you really feel that you want to
(.) get it all off [your

460. N: [yeah
461. P: chest (.) you know
462. N: yeah
463. R: mm
464. P: so (.) many a time I've sat here with S... and I've sat and cried
my eyes out but you feel better after you know
465. R: who's S...?
466. N: S... H... [the Tenovus =
467. P: [um
468. R: oh right
469. N: = social worker
470. P: like a social worker yeah (.) she [come and
471. N: [she and I keep in touch [as
well if there's anything
472. P: [touch
yeah this is it and if I want to know anything I always ask K...
cause she tells me in our language
473. R: yeah
474. P: you know at the at the hospital I think (.) they tell you and it
sort of just all goes in and you er it's the big words and you
don't really know what they're talking about
475. R: yeah
476. P: so K... gets my report then and then she'll tell me like you did
last week didn't you I'll say well what's this [meaning what's
that
477. R: [yeah
478. P: and then you know really then what's going on (.) you know
much better
479. R: yeah
480. P: you know cause you don't really understand the (.) the way
they tell you up there
481. R: no
482. P: you know I know it's their way of saying things but and you
know when you're in there you're so nervous anyway when
you know they're going to tell you the results they you'll only
take part [of it in
483. R: [yes that's right yes this is what I'm looking at
484. P: this is it yeah yeah you only take er well I do anyway [(unclear)
485. N: [you'll
have to remember that when you're famous Annmarie
486. End of tape

HCTRA4 Amy

Patient female 80+ years

Nurse female 50+ years

1. N: we've had loads and loads of meetings today without really having a break so um
2. R: I can imagine
3. N: what about you?
4. P: not awfully good today (.) I don't know why (.) it comes and goes (.) I've taken my medicine which is quite wonderful (.) um(.) so I you know it seems to be working quite well (.) but um (.) yes I'm a little bit low today (.) that's all I can say
5. N: low in? (.) in mood [or?
6. P: [well er what am I why am I low um (.) I've had a bad week or two (.) for some reason um (.) I was expecting um well the children and that's why dear and if you won't tell anybody else it's my birthday on Sunday
7. N: this coming Sunday?
8. P: well yes and I'm I was afraid everyone was going to descend on me and I asked them not to they just came in for a chat because um [(.)I just can't you know how long I can (.) pretend perhaps that's the worst
9. N: [yeah
10. P: but um I thought they were going to I was going to have some people staying but I I knew (.) I knew it wouldn't be the the right thing to do (.) but I'm sure the (*unclear*) is excellent and you've told me how to use it (.) which I didn't know before I'd asked you really (.) I'm not a medicine sort of person I suppose really (.) [but I
11. N: [you've never liked taking
12. P: no (.) no
13. N: medication (.) have you
14. P: I've never I've er been er healthy you see I've never been in in hospital in all my eighty-seven now it's nearly eighty-eight years
15. N: you've never been admitted?
16. P: I've never been in hospital for anything that illness that they keep people (.) I've got a very healthy body (.) and er that lasted until about um (.) when was it (.) about five years ago no my husband died about six years ago so (.) and er at that stage I rushed out to get a lot of um (.) have I told you this before? I [don't think you want to hear it again again dear
17. N: [no (.) no
18. P: um er (.) my my scottish people they all like always like a little alcohol so I [go up to the shop to get some quickly=
19. N: [yes
20. P: = and (.) picked up the bag you see and came out I could walk [up to Penarth town
21. N: [right
22. P: and [back without any trouble then (.) well anyway I had some Brufen and I don't I thought it doesn't like Brufen and so I've had this diarrhoea on and off since

23. N: yes
24. P: but it was only last year last May that it seemed to be perpetual and I've been a bit miserable since then but of course and of course the August just when I met you the first time
25. N: yes
26. P: that um I just I didn't expect to be here at Christmas but I am you see (.) so er (.) I managed to get over it as you can see now (.) and then I managed to speak up and say when my my step-son was (.) very good to me and he said look S do you want us to come or not and I pulled myself together and I said well I'd rather you didn't (.) it's a difficult thing to do when people are so kind isn't [it
27. N: [yes
28. P: and so that really cleared it up for me because I've been thinking oh now what what'll I do I can't you know be [(unclear)
29. N: [entertaining really
30. P: and and (.) diarrhoea and two men in the house I thought [was a bit too much for me
31. N: [yes
32. N: yes (.) you look more tired this week
33. P: yes
34. N: I thought it [when I saw you in day centre
35. P: [I know
36. P: that's right (.) I wonder why because I just had the um yesterday a Brufen yesterday
37. N: yes
38. P: because I didn't have that lovely reflexology you see and I should've come in (.) but I think I'm a bit (.) um um lack of hearing is one problem when it's people I don't know and of course everybody's different
39. N: yes
40. P: and um (.) I hadn't (.) well I'd been once but I was then trying to to learn the names of the [the
41. N: [the new [people
42. P: [yes (.) so um that was possibly but I think it's just that I got very worried about having [visitors staying at the house
43. N: [yes
44. P: I don't know somebody's coming from Australia yet I'm very fond of him (.) very much loved that son I've got two (sigh)
45. N: when are they coming?
46. P: mmm?
47. N: when are they coming to visit?
48. P: well um Harriet's coming at in May and uh (.) Doctor tells me she's going to see me in May so I suppose [(unclear)
49. N: [you had an appointment have you?
50. P: I've been I went a week ago [since since I saw him (unclear) so um (.) yes she's
51. N: [yeah yeah yeah
52. P: uh yes Doctor D's put her finger on the right spot it would seem
53. N: yes
54. P: um and it was this rather rare (.) carcin(.) a (.)oid? carcinoid?

55. N: carcinoid
56. P: carcinoid and she's been warned by the doctor there the older doctors there not to be disappointed so she's rather (.) pleased with herself obviously that she spotted it
57. N: yes
58. P: and that's dreadful yes =
59. N: = but that's it
60. P: yes (.) and she can she said she can treat it and so no matter how long as I've probably said to you before I don't want to um (.) I want I don't really want treatment I'm (.) dying of old age and that's the way I think it should be (.) and so um I said I rather avoided any treatment that um (.) people [have been tempting
61. N: [well (.) did Doctor S say what sort of treatment?
62. P: no (.) Doctor um D came in but she (.) in a hurry (.) they're very loaded in surgery (unclear) [you're all loaded at the moment aren't you?
63. P: [yes
63. P: so um I'd almost r run out of medicine and I asked her if she'd come anyway and er she just told me that um that that they were going to something (.) for me and she didn't say when they were going to start or anything but um (.) at any rate as long as I can avoid this diarrhoea which is wonderful (.) and I think the other little worry that I had was I thought it was coming back I do sometimes but it it's better than it has been for a long time (.) um and so I think that's been worrying me a bit and I think oh dear I can't bear this again [(unclear) I was going sometimes I mean the past couple of days=
64. N: [yes
65. P: = without much trouble and then I've had somebody I don't know all that well like everybody gets and I've had to go out three times =
66. N: yes
67. P: = in an in an hour or so if they come in for a visit and I just feel I don't want them and that's not natural for me
68. N: no
69. P: I've got some wonderful friends and I do enjoy talking to them and I'm better for talking to them better now (.) better now since you've you've arrived
70. N: do you (.) do you still get up late in the mornings?
71. P: um (.) well it depends (.) I always get up late in the morning now these last couple of months I suppose over Christmas um but I no somebody gives me a cup of tea and a piece of toast [and that's at nine o'clock =
72. N: [yes (.) yes
73. P: =and then I'm dying to go to sleep again unless somebody's coming in for coffee in which case I like to prepare myself because I sleep so (.) I sleep very solidly
74. N: yeah
75. P: I suppose that's part of the medicine
76. (.)
77. N: It could [well be it could well be
78. P: [(unclear) whatever it is it's very good because I've had no trouble in sleeping since (.) I'm on this medicine

79. N: good
80. P: and that's a big help (.) so I generally reckon to come down about eleven o' clock I've made myself a little programme and I have er a cup of Bovril and I (.) I have Rice Crispies (.) I think I've got a pattern for [(unclear) now=
81. N: [yes
82. P: =and that seems to be working since I can eat again and that (.) I was much better until this last couple of [(.) days? or weeks? I don't know (.) time is (.) time has left me(.) really (.) but um I don't know
83. N: [yes
84. N: what about the newspaper (.) are you do you read a daily newspaper or
85. P: I buy the Spectator I have a Spectator every week on a Friday morning and I devour it during the week (.) I don't take another (.) newspaper
86. N: and what about (.) do you listen to (.) the radio?
87. P: oh I do listen to the radio [a lot
88. N: [which programme do you listen to?
89. P: well anything political (.) why should I be interested in politics I'd ask? but I do seem to be (.) it's all going on around you
90. N: yes
91. P: and um they put on the big bang theory again if that means anything to you [probably doesn't
92. N: [well (.) this this stuff with the asteroids?
93. P: that's right (.) [and er
94. N: [they now think it happened at least twice don't they
95. P: yes (.) [yes
96. N: [that the world was destroyed
97. P: that's right
98. N: yes
99. P: yes (.) war in Heaven I think (.) it's all in the Bible somewhere they tell me (.) and er (.) some some big catastrophe [(unclear)
100. N: [yeah
101. P: but um I find it very interesting
102. N: which programme have you listened to radio four?
103. P: I'd west yes yes and the west mostly (.) rather than than er than Wales as a rule
104. N: yes
105. P: but I did as a matter of fact I didn't come down I went into the little bedroom where I've got a little television then then I listened to David Dimpleby last night and that [was very (unclear) for me
106. N: [right (.) yes
107. P: about a quarter to eleven wasn't it he started [I think
108. P: [right (.) you didn't stay up for that ?
109. N: no what do you do you like that sort of programme?
110. N: um (.) I'm a big radio listener I listen to a [lot of radio four yes
111. P: [(unclear)
112. N: and I tend to go to bed and listen to =
113. P: yes yes it's worth having
114. N: =and I listen to the world service throughout the night half the times

115. P: yes (.) do you sleep well?
 116. N: I'm not a brilliant sleeper
 117. P: no
 118. N: no (.) but that's if I've if I've got the radio I will lie um=
 119. P: yes
 120. N: = and [listen
 121. P: [that's that's and um [that's good
 122. N: [yes (.) yes
 123. P: yes (.) somebody generally rings me up in the evening A used to ring me up and she died up at up at people going away one after the other you know [they're leaving
 124. N: [yes
 125. P: and um (.)my sister we er (.) she died a year ago now (.) possibly two years can't believe it but we used to ring each other up (.) and K that's my (.) they were coming (.) K and A A's my other step-son and K-- is his wife (.) and she (.) more or less took on when she knew I was her so much I suppose (.) so she really somebody rings I ring her or she rings me (.) now (.) and they're (.) up in Edinburgh and as I say they were going to come and stay but I just couldn't do with them at all (.) I just couldn't do
 126. N: you would (.) start worrying
 127. P: well I (.) yes stupid isn't it (.) how can one be so stupid
 128. N: I think when you're feeling really quite (.) and you can just about (.) get yourself (.) the idea of pushing yourself to do the sort of things that you would have liked to have done
 129. P: yes (*unclear*)
 130. N: yes
 131. P: (*unclear*) I haven't anybody (.) well I since I have been di/ fortunately I went back to a meeting that I used to have with friends (.) R who runs the meeting there his wife died at the same time you know it's been one going after another (.) what can you expect at my age (.) I shouldn't be here (.) but he brought me this (*footstool*) (.) you couldn't perhaps tell me (.) he thinks it's supposed to be that way but I thought it would I thought the legs were supposed to be up higher [but (*unclear*)
 132. N: [no they shouldn't be too high
 133. P: they should be on the (.) [the the
 134. N: [yes
 135. P: because the chair that I had them on was too (.) er high he said [so (*unclear*)
 136. N: [yes they shouldn't be that high
 137. P: well he brought me this one and er (.) and er
 138. N: does it feel comfortable [like that?
 139. P: [very comfortable indeed
 140. N: yes
 141. P: so um in fact he only brought it yesterday but he rings me up when he can he's he's another one of my friends (.) I've found these men are so good and so kind but they're unpredictable they will go their own

142. way [I can't control them (*unclear*)
143. N: [(*laughs*)
144. P: and um so I you know I'm feeling a bit keyed up because four people have got a key (.) now (.) and um (.) now since I've had this um I don't put the key in=
145. N: yes
146. P: =but I might have done it if I thought I was going to go to sleep=
147. N: yes
148. P: =and I was getting very drowsy with the sun in here=
149. N: yes
150. P: =and I thought I wonder if I'd better (.) put the key in the door (.) which I could do knowing you'd be here round about this time but I decided not to (.) you see just in case of course you came to time with the (.) you er you get held up or if you come from one [to another you can't be quite sure what time you're [going to be
151. N: [yes
- N: sometimes it's um
152. P: but you're (*unclear*) back in your routine [what is it (*unclear*) one of your patients is she?
153. N: [yes
154. P: were you weren't you worried about somebody on (*unclear*)? (.) recently? I might be thinking of someone else (.) I think you said I'll be in again unless (.) um (.) something happens? no not you? oh dear I thought I'd I thought I'd got everybody in [order
155. N: [well I think you have really
156. P: mm (.) perhaps you could trace it
157. N: yes I think I'd mentioned to you that I'd got um a family [member who's not well=
158. P: [aah (.) yes
159. N: = and that it might necessitate me [being away for
160. P: [you were just saying I'm away for (.)
yes
161. N: and just to warn you [that if if I had to cancel an appointment that's what it would be
162. P: [yes yes
163. P: things are not too bad at the [moment?
164. N: [but but things are managing at the moment
165. P: you don't know what's in store do you (.) um what's in the present moment is all that matters
166. N: yes
167. P: hold onto that [(*unclear*) difficult moment
168. N: [I think that um (.) one of the interesting things you said when I first came to meet you was that um (.) in a way having cancer had (.) um brought a whole lot of different [experiences (*laughing voice*) and some of them [quite good
169. P: [mm mm [mm
170. N: experiences

171. P: indeed (.) indeed and um (.) at the time it seemed to be such a clear diagnosis that (.) the doctor was very (.) I I can trust her she'll tell me the truth and that's wonderful you see isn't it
172. N: yes
173. P: so she told me (.) and um (.) I wa/ I wasn't (.) I was going to say I wasn't bothered (.) I wasn't bothered about it and she said it's not good news and I said no I know I've got cancer and she said oh (.) and she said that's alright (.) I (.) I'm here for you whenever you want me and that was [er
174. N: [has (.) Doctor. D done any more blood tests recently?
175. P: yes
176. N: [or did Doctor S
177. P: [that's right yes (.) no she had them (.) I don't know whether she wants them (.) she she wants them for herself (.) she's doing them for her [own research as well
178. N: [yes
179. N: yes yes
180. P: she said in seventeen years I've never come across this carcinoid thing=
181. N: yes
182. P: =and she said the doctors in the surgery gave me all they could (.) in the way of information but they said don't be disappointed=
183. N: yes
184. P: =because it's very very rare so she's very very pleased in one way that she picked up on it (.) um (.) but she's already asked I'm finding it very difficult to take a (.) a foetal (.) a faecal? (.) sample
185. N: yes
186. P: it's running down me all the time=
187. N: yes
188. P: =and it was that was adding to my problems (.) and I couldn't seem to get it and I didn't know how to (.) do it (.) I've never (.) only once have I had to take it before (.) we had to do it years ago in school (*unclear*) children you know (.) but anyway I didn't know how to set about it and it seemed to be going on week after week and then when she'd got this um (.) carcinoid (.) thing she wanted a urine sample which made me smile because I've got a that was no trouble so she had half a gallon I think of that and S you know S?
189. N: from the=
190. N: [=health centre (.) yes
191. P: [surgery (.) the surgery
192. P: so she came and and took that off and they've had (.) er it went then (.) I didn't get any results for a week
193. N: yes
194. P: and then the next week Doctor D came and said um (.) I only rang them up to say why hadn't they had the results and they said well they though they'd done them they must have done it wrong there were so many (.) hormones in it
195. N: yes

196. P: I don't know how I'm making sense to you it doesn't make a lot of sense to me but I'm interested just the same
197. N: I think if um (.) if you don't mind I'll give Doctor D a ring next week (.) and find (.) and find out
198. P: I'd be very pleased if you [would
199. N: [would that be [alright
200. P: [oh lovely yes (.) because really I know she's busy=
201. N: yes
202. P: =and she said I'll let you know as soon as I know anything definite
203. N: right
204. P: but of course she doesn't come in on a Monday so it's a very long weekend (.) it comes to Friday [and I think this is going to be a weekend again [that I
205. N: [yes [yes
206. P: I can't do anything about it and it seems to be going on (.) so if you would
207. N: yes (.) I will do
208. P: I'm sure she'll be pleased you know she (.) put me on onto your Dr P
209. N: yes
210. P: and so I (.) he he was very good he (*unclear*) me (.) but he was quite convinced that he could help me with my (*unclear*) [really couldn't cure the cancer [obviously
211. N: [yes [no
212. P: I don't want him to cure it (.) my er old age I think at this stage (.) um (.) but he said he had this particular (.) uh I can't really say in my ignorance uh a blue pill you knew the name of it it's probably in the book there and um (.) he said if you had that I'm sure it would help your digestion and that's [the problem
213. N: [yes
214. P: but of course it didn't it inflamed it [it's dreadful
215. N: [yes
216. P: so I did take it for (.) nearly a fortnight and then I stopped (.) it was getting terrible (*unclear*) it was painful [in the extreme as well
217. N: [yes
218. P: and I thought this is ridiculous so then (.) I'm only surprised that I um I'm up to talking (.) then she said well the only other thing I can give you is (.) Co-drymol (*means Co-dydramol?*) and I said um I can't take that either and she said well you've had Co-codamil (*unclear*) but I can give you er um (.) [what do they call it
219. N: [codeine linctus
220. P: what do they call a mixture?
221. N: codeine linctus
222. P: a linctus I think that was the word I was trying to get um (.) and she said that was very mild codeine and um she said if if you can take it and it's worked like a dr now this is where I say to you again is this my imagination because I had the the er prescription she wrote the prescription I took the first dose on the Tuesday after she'd been (.) and I didn't have diarrhoea for more than a week

223. (.)
224. N: [now
225. P: [and I started eating she said you must eat [you're you're hungry and I was starved
226. N: [yes
227. P: really I was hungry (.) so um and then um (.) every now and again I get a choca chocolate cake now am I going to get diarrhoea again (.) or am I going to get the opposite aren't we stupid now how much I ought to know enough I've studied enough of this background to be able to er(.) [monitor myself you'd think
228. N: [what (.) codeine linctus does is slows down the activity [(.) of the (.) yes
229. P: [that's what you've told me I know
230. P: but you see I haven't I didn't know any of that and it still I mean all I can think is (.) (*sighs*) my imagination [of some sort
231. N: [yes
232. N: but if if the whole system is slowed down it also allows for some of the fluid part (.) content to be drawn out of the (.) um gastro-intestinal system so instead of your faeces coming away very loose and watery [and you having to dash off
233. P: [mm mm mm mm
234. N: they become [more formed
235. P: [that's why I couldn't even take a sample it's just too liquid if you see what I mean
236. N: yes yes
237. P: so um
238. N: so that's been a good thing
239. P: it's been wonderful (.) could it could it be the medicine itself or [is
240. N: [oh yes I'm certain it's the medicine itself
241. P: well I think that's quite wonderful
242. N: what about the pain?
243. P: um (.) I (.) in my stomach? the the the gas gastric side of it
244. N: yes
245. P: um (.) well (.) that hasn't been that painful all along it's diarrhoea that's been the trouble [because I've had to keep running
246. N: [yes
247. P: but um (.) I can get a it's not anything that worries me terribly there's a little this is why I was interested in the reflexology [you know
248. N: [yes
249. P: I remember somebody telling me that (.) he said um (.) I can (.) I can I'll never diagnose this is the one I had before I came to (.) you know [I had a course for a time with him
250. N: [yes
251. P: and he said I'll never diagnose (*unclear*) but I can tell you whether there is an imbalance within the system
252. N: yes

253. P: now I'm quite sure I'll say to him what is that you see and just here instead of there was nothing in the stomach you see I had all those scans and things (.) and nothing to see (.) it seems so extraordinary and um (.) so (.) when um (.) er I thought at the time when he was giving me some treatment (.) now what is it the solar system? sodus system (.) or soda what's the what's the bit of the body that's um that's here be (.) just behind the stomach [I've got a book (*unclear*)
254. N: [diaphragm?
255. P: um (.) something solar
256. N: solar plexus
257. P: solar plexus (.) now the solar plexus now I'm in (.) I get this rush
258. N: yes
259. P: and I've always had this on and off you know but nothing like this now but this is what she found for the er carcinoid
260. N: yes
261. P: is that right?
262. N: yes
263. P: she took it on two symptoms which were um (.) hot flushes
264. N: yes
265. P: and um (.) er (.) and what was the other one (.) diarrhoea
266. N: yes
267. P: and those two is what she (.) was (.) hoping would give her these results (.) so um now she's had the results and they did all the the um urine ones um again and there were so many [hormones (.) hormones is it?
268. N: [hormones
269. N: yes yes
270. P: that they thought they'd made a mistake with the test (*unclear*) you see so they were doing them again for her (.) that's why we were so low so slow in getting them
271. N: yes
272. P: yes now you said you'd ask Doctor [D
273. N: [but I will speak to Doctor D and find out exactly what it is that she has discovered [and what sort of treatment going to mean yes
274. P: [yes that's right yes that's what I need to know the way it stands at the moments I'm just waiting I don't want to bother her now until she comes to me [you see
275. N: [yes no that's [that's [I will do that [(.) Tuesday =
276. P: [and I'll (*unclear*) [oh bless you = when she's in [I'll sort it with her
277. N: [that would be helpful
278. P: and you're coming in for (.) reflexol[ogy?
279. N: (*unclear*)
280. P: yes
281. N: I've got um (.) J did it before you know J?
282. P: yes
283. N: J was absolutely wonderful and (.) this young lady as she is
284. P:

285. N: L
286. P: L you know L?
287. N: yes
288. P: of course you know what's the matter with me and she's very she's very sweet natured isn't [she
289. N: [isn't she
290. P: yes and so I I mean (.) I feel very er (.) taking taking it over and if I can come in I do enjoy it (.) it's the most soothing
291. N: and they send a car for you?
292. P: they do yes now
293. N: does it exhaust you going there?
294. P: um well any anything I've got I've got it now for Thursday I must remember Thursday and I don't (.) although it's different again now (.) but um it was a bit
295. N: yes
296. P: it was a bit difficult quite honestly (.) I thought the first time that I'd have a cup of tea before somebody takes you home and um (.) er (.) somebody came over and talked to me they're so nice all of them do you know you wouldn't believe this you wouldn't believe this (laugh voice) I sat there (.) yesterday not knowing any of them really (.) I I recognised you didn't I
297. N: yes
298. N: and then E is it in charge? under this is it a ma/ a male nurse
299. N: A
300. P: the sister he's a sister [he runs the
301. N: [yes
302. P: is he is he in charge of the day [(.) centre now?
303. N: [yes yes
304. P: (*unclear*) that's what I understood her to say
305. N: yes
306. P: well do you know I sat there and I thought (.) I felt um (.) that these were the old people I felt quite young really (.) and I I I it was so funny when it (.) I thought I'll put my foot in it in a minute I'll be talking down to them because I felt much older than any of them (.) and then of course somebody was teasing me and saying now come on when when's your birthday you see they realised that I was (.) hedging I thought those people were coming for my birthday and I was trying to avoid it and and that sort of thing and I thought well look at all those (*unclear*) they're much older than me (.) can you imagine it you can't of course you can't
307. N: and you had visitors in day centre yesterday? (.) I hear (.) there were [visitors to the centre
308. P: [oh you (*unclear*) did you? yes that's right and indeed (*unclear*) so so er stupid really (.) I still have the er (.) brought up how many years ago (.) eighty years ago you know you tried to keep the conversation going and I felt these people were all so tired (.) and um (.) and when these people all came in I thought oh goodness this is going to be an inspection you know they'll all be nervous and I think I tried some conversation (.) of course it wasn't the right thing to do at all but um (.) I I thought it was just silence

you know for goodness sake say something somebody (.) but you weren't there for that

309. N: no no
310. P: well of course it wasn't my business thought I'd have someone thank me for coming in the end [thought I would (*laugh voice*)
311. N: [*laughs*)
312. P: [*unclear*)
313. N: [was there a very tall man?
314. P: that's right
315. N: that's it yes
316. P: he came (*unclear*) from London didn't he
317. N: Chief Executive
318. P: of of *hospice organisation*
319. N: of [*hospice organisation*
320.
321. P: [*hospice organisation*
322. N: *hospice organisation*
323. P: *hospice organisation* (.) that's a load isn't [it
324. N: [so he's the new Chief Executive
325. P: he's new is he?
326. N: yes
327. P: oh is he going to shake us all round then?
328. N: he's got lots of ideas
329. (.)
330. P: well ideas are fine if you know (.) if you try them out (.) gradually I think otherwise it's very unsettling
331. N: yes
332. P: as I know um (.) inspectors always (*unclear*) they shouldn't be terrifying should they [you see?
333. N: [no
334. P: so (.) I'm not afraid of inspectors any more I've had so many in my time (*laugh*) but I get worried about that and um (.) I thought keep it quiet dear (.) don't start because I could see myself taking over if I wasn't care nobody was speaking (.) terrified that was a terrifying experience when [nobody speaks
335. N: [yes
336. N: and you feel that you've got to somehow (.) [provide the conversation
337. P: [well (.) well
338. P: I can't stop myself doing it that's all (.) I say mind your own business for goodness sake (.) such a silly habit isn't it (.) but um (.) we were brought up that way you see =
339. N: mmm
340. P: =and you've got people (.) you don't leave them saying nothing (.) um (.) and it's an art of a kind if you can do it=
341. N: yes
342. P: =helpfully
343. N: and some people are (.) particularly good [aren't they um=
344. P: [yes

345. N: = put people at ease very quickly
346. P: yes (.) and it's you see (.) you don't worry old age does count for something after all it doesn't matter (.) I've I've made a fool of myself so many times you might say it doesn't matter one [more time
347. N: [I can't imagine that
348. (.)
349. P: but there it is
350. (.)
351. P: now you asked me if I was tired coming [and I was a bit tired (.) yesterday anyway (.) um because um (.)=
352. N: [yes
353. P: =I don't hear easily and if I'm not hearing what they're saying I'm asking and I make some remark but I know it doesn't fit you see and you don't know what to do for the best then so I'm really better without people [until I know them
354. N: [(cough) excuse me
355. N: yes
356. (.)
357. P: and that was a new session so I might have been looking a bit tired
358. N: will (.) will you be seeing anybody on your birthday?
359. P: yes um (.) I've got um (.) er er I've got my (.) my niece and my nephew my eldest [(unclear)
360. N: [is that A?
361. P: A A A is my niece (.) I've got one niece and one great niece they're doing a doctorate at the moment and A she's she's the one that's left the country (.) says she's not going to have her fiftieth birthday (.) so she's leaving the country for my fiftieth birthday but she went off yesterday and she'll be [back
362. N: [where did she go?
363. P: Cyprus (.) and um so (.) she she would (.) well she wouldn't (.) she would be appreciating if she could [but she was she was born two days before me=
364. N: [right
365. N: =but she was born fifty years she was born fifty years goodness me um
366. (tape finishes)
367. P: so we'll (unclear) we're so fortunate for a year there was six of us and um (.) R is married my other sister well my other sister was married I wasn't married until I was forty and that was my (.) stupidity I suppose really but that's the way it was and um
368. N: when did you (.) meet your husband?
369. P: when when did I meet him? (.) um well at the end of the war I went (.) back to university in London and um I did quite a bit of research work there and (.) it was a lovely it was a lovely year really and it was as I say I kind of let people down because I finished college got a job they don't want to go to work every day and they're looking for another course at college and I did it myself so I can't [say (unclear) done it too
370. N: [(laughs)
371. N: (laughing) (unclear)

372. P: I understand that (.) um yes I know and we say really you know um (.) but there's something about if you get you think I'm not going to sur sur get by every day and every night and that sort of thing and it comes very wearing at the end of it doesn't it?
373. R: yes it [does
374. P: [you know at the end of the course when you're looking for the final and you've got a lot to do and you don't get a minute really to enjoy yourself as you might say
375. N: what sort of research were you involved in?
376. P: well (.) with whoever was there I did I did um my Masters degree and I got a BA before and um I got that and also my tutor in London (.) Doctor (.) forgotten the name now begins with D in the fifties fifty sixty years ago now (.) I was married for forty two years anyway (.) wasn't bad was it (.) um (.) so um she was working at the unemployed nursery and it was at the beginning of a lot of (.) it's all come out now it's quite common practice now but um it was work with um (.) with um twins you know
377. N: yes love those
378. P: yes yes and she and er she (.) I had a part of in that you see that I passed it on to my tutor who was a member of her nursery in (.) in er where was I (.) Chelsea (.) in in Chelsea (.) I was living in Chelsea at the time and I had a wonderful year there a couple of years really because um (.) I met such interesting people that I'd never have met otherwise
379. N: yes
380. P: and then I came back to pick up my old job again (.) and um (.) I was invited then to apply for (.) a job (.) I was teaching (.) Roe Roeham do you know Roehampton? Roehampton?
381. N: yes
382. P: we never mentioned it did we before?
383. N: no
384. P: at the um (.) oh oh (.) oh dear um (.) who is it the er great educationalist?
385. (.)
386. N: um?
387. P: I know his name so well well I got the post of um (.) Roehampton is their college and um I went (.) I got a post there as a tutor (.) to teachers (.) in Manchester and district who had done there done at least five years qualified and then done five years they wanted in another job by then I was tutoring them you see
388. N: yes
389. P: and so that was most interesting [and
390. N: [that wasn't um Max Steiner?
391. P: that wasn't?
392. N: Steiner
393. P: no it wasn't Steiner at school I I [do
394. N: [no
395. P: I [am
396. N: [what about A.F. Neil?
397. P: A.F. Neil oh yes A.F.Neil (*laugh voice*) I sort of grew up I
398. went to[(.) I've danced with him

399. N: [Summerhill
400. P: I danced with A.F. Neil on one [occasion I can tell you just to tell you=
401. N: [did you?
402. P: =great tall huge man (.) most interesting [(unclear)
403. N: [was he quite charismatic
404. P: oh yes
405. N: I would imagine [that
406. P: [do you know you know you know that story do you
you know [his er
407. N: [um yes about [the development of (.)
408. P: [yes yes
409. P: yes (.) so um (.) that was about the time when I could do all these things
that I (.) couldn't do during the war in the same way (.) but um (.) I'm
told to say er (.) um (.) who was I going to Montessori (.) and um (.)
Furbel (spelling?) F.R. Furbel the great educationalist and Steiner (.)
apparently learned from him to some extent you see so then all were
involved (.) and um (.) so I had the (.) I I had done a two year course for
the teachers who were doing it part-time and working in school and I
could go in and help them in the in the classroom you see which is what
is wanted really it seemed to me (.) you seem to be very much teacher
minded as well (.) did you have to make a choice of whether you were
going to do nursing or (.) or um
410. N: well I do quite a bit of teaching (.) um (.) with [nurses
411. P: [you do teaching yes
412. N: but it's (.) for me it's very nice to stay (.) involved with patients
413. P: yes
414. N: which is=
415. P: yes (.) of course
416. N: =what I became a nurse to do
417. P: yes
418. N: but I do enjoy teaching
419. P: yes
420. N: um
421. P: um (.) well if you're a (.) if you're a teacher and you can do it and
you've got a suitable situation (.) um (.) it's a wonderful job but in
schools at the moment what I hear about them horrifies [me and I can't
think how you (.) some say the Prince of =
422. N: [yes
423. P: =Wales had (.) had um written personally to that teacher that (.) had the
child (unclear) around the waist and kicking her and she couldn't do
anything in resistance (.) what's her name? (unclear)
424. N: in in Wales?
425. P: that's right in Wales yes (.) and er she's still still off (.) and I do know
that if if you're working in the same room with another teacher (.) and a
child accuses you of molesting her or him in some way the the the
teacher is off work they can't work
426. N: yes
427. P: until they [they (.) and if they don't get on with them they don't get on
with it

428. N: [we get an awful lot of that at the moment
429. P: so it's pretty awful at the moment (.) as well (.) I mean not all schools
430. N: no
431. P: some of them are just doing wonders (.) through it all
432. (.)
433. N: Amy is there anything particular you want to discuss with me today? (.)
anything that's worrying you at all?
434. (.)
435. P: you mean privately (.) without Annmarie? (researcher)
436. N: well well if you want [(unclear)
437. P: [(unclear) no no she no [(.) unless you want to (.)
say something
438. N: [no ok
439. N: no there's no there's nothing that
440. P: no
441. N: I just wanted you to know that whatever (.) you know that
442. P: no you really when you told me about the um (.) that was very useful to
me (.) how the thing worked
443. N: yes
444. P: so whether it's that or not [I don't know
445. N: [yes
446. P: anyway that's um (.) we're straying from the point (.) now (.) [I I'm
prattling I'm afraid
447. N: [so
448. P: I have to look at people after quarter of an hour and say now (.) are they
beginning to yawn because if so [shut up and (unclear)
449. N: [I think it's really nice to hear
something about (.) about your teaching and your (.) life [in London
(unclear)
450. P: [how did we
get on to that?
451. N: [it's very interesting
452. P: [and why?
453. P: you asked me you did ask me
454. N: I did
455. P: didn't you
456. N: I did lead you
457. P: you said [where you said where
458. N; [yes
459. P: and usually she doesn't ask me I'm here to tell her without asking but
this time you did say (.) what were you doing when you went up to
college or [something (.) you did
460. N: [yes
461. N: yes
462. P: I don't think I [(unclear)
463. N: [I doubt it was just because
464. P: I wouldn't have burst out with it (laughs)
465. N: no because Annmarie is doing research and we talked about it [last week

466. P: [that's
right yes
467. P: yes yes that's right
468. N: I thought that um (.) [that was best
469. P: [(unclear) can I talk to her now?
470. N: you can certainly talk to her
471. P: is it alright to [talk?
472. R: [feel free yes
473. P: oh how good (.) how long have you (.) are you just starting or are you
just finishing or are you in the middle?
474. R: I'm um I'm six months into it and there'll be about another two years
475. P: so you've got a a pattern have you made out?
476. R: yes
477. P: because I was wondering whether I would talk too much in the wrong
lines because I'm so used to interviewing students and they're (.) not to
be interviewed now you see (.) and [so I was waiting to be asked
478. R: [no no
479. R: no it was fine I just wanted to capture everything you both said=
480. P: yes
481. R: =but you were just talking normally (.) which you seemed
482. to be [doing
483. P: [because um
484. P: you don't know until you've said (unclear) until you've got so many
how many (.) how many [have you got to find
485. R: [you're number five
486. P: you know how many?
487. R: you're number five
488. R: I'm?
489. R: number five
490. P: I'm the fifth (.) so um is it every time we've we've done I'm thinking of
not only who's with you (.) that you want the information from (.)
combined (.) um situation where the nurse is talking to the patient isn't it
491. N: yes
492. P: that's what I understand really
493. R: yes and it it's how how comfortable [you feel because you're in your
own home
494. P: [yes yes that's right
495. P: and it will be so different for different people
496. R: yes
497. P: so how many are you wanting to have to make it statist I think I got stuck
with the twins I could've I I had to get twenty-one or something or other
and I could only only get nineteen (.) um
498. R: yes this is a problem
499. P: yes
500. R: um twelve patients at home I need
501. P: twelve is alright for you
502. R: yes (.) at home and then another twenty four [other patients
503. P: [and they might be quite
different

504. P: but are they the same nurse?
505. R: no three different nurses
506. (.)
507. P: ah (.) that's a complication isn't it
508. R: um so far um it's been S on all five
509. (.)
510. P: four five
511. N: four
512. R: four
513. (.)
514. N: [yeah
515. P: [it'll be
516. (.)
517. N: first (.) group (.) will be me
518. P: ah
519. (.)
520. N: um
521. P: and so you'll you'll have another nurse?
522. N: yes
523. R: yes
524. P: and you see (.) well of course it will be most interesting
525. R: yes
526. P: will you tell me about it? (.) I do hope you will if you can
527. R: ok
528. P: most interesting to know because it isn't until you get started that these difficulties will come up too [and you don't want to get too far before you waste something you know
529. R: [that's right
530. R: yes yes
531. P: but um it is interesting (.) um meeting people even even that I think will er
532. N: do you find that talking to different health professionals (.) that it's different?
533. P: yes oh [yes
534. N: [yes yes
535. P: oh everybody is different now um I must say that you and um the um the practice the surgery are are wonderful I wondered how well (.) I never feel there's any feeling of fo sensed any feeling between the ones on the others you know (.) now on one occasion J J J? who was the um in charge (*sighs*) J (.) before Christmas who was the very (*unclear*)
536. N: J?
537. P: and she also um
538. N: JN
539. P: and somebody was with her
540. N: J
541. P: J that's right now J um (.) they were so different both of them and yet quite different in themselves
542. N: yes

543. P: er and yet they were both absolutely adequate what a thing moving something that was doing so well (*refers to day centre changes*) doing so well (.) I mean I'm sure it was doing well
544. N: yes
545. P: well of course I'm not (*unclear*) of judging this (.) gentlemen friends do (.) I have a friend who's just taken on quite a good job he works for Glamorgan (.) county and he goes round the homes (.) and he I remember he was so (.) er enthusiastic when he got the job first of all and he was all for introducing um um and um we had some er tapes on (.) you know they put the music on you see these old people moving (.) moving and coming alive almost with what was happening and he was very thrilled about that so I did hear quite a bit from him (.) and other ways (.) people trying to be helpful aren't they and um (.) you know I'm sure our lives are very empty I don't know why they say that old old people aren't looked after I've been very very well looked after (.) you were asking a question I haven't lost it um do I find a difference in the people that come and visit um yes but um I have to find out is it? I mean Christmas has been something everybody means business (.) they have a lot of things to do themselves
546. N: yes
547. P: they've all been busy at Christmas
548. N: yes
549. P: not a fair judgement you see
550. N: no
551. P: but um it's a bit bewildering first of all because um I think I had eight in the first [fortnight
552. N: [did you
553. P: and er
554. N: I can remember we um wrote them down [in your diary didn't we
555. P: [that's right yes that's right
556. N: yes
557. P: that's right you started me off you see
558. N: yes
559. P: and er anyway
560. (.)
561. P: and so I've been talking ever since (.) I don't of course I don't talk all the time
562. R: have you ever stayed on a ward (.) A?
563. P: I've never (.) never been in a ward
564. R: [no
565. P: [the only time I've been in a ward was when I had a teacher (.) in Manchester (.) who was in hospital you know (.) they had a a (.) this was a trained teacher who was doing education
566. R: mm
567. P: and that was back in the fifties you see when I went to Manchester first and it was a very difficult position for her (.) because um (.) she wasn't a teacher she wasn't a teacher she was a teacher but she wasn't a nurse and of course at the beginning and it happened with J you know JE [do you remember JE?

568. N: [yes yes
569. P: um and she had the same difficulty you see having come to me as a new
(.) almost first job and of course we had all the toys and things about and
of course once she started in the hospital (.) um (.) they didn't want them
having books to put in their mouths even books

570. R: yes
571. P: now the teacher in er Manchester um (.) she had she was working as a
nurse in charge of course you see and um she didn't we were trying to be
as tactful as possible but you see they didn't like all these things in the
children's mouths [and in the sandpit and all that sort of thing

572. R: [mm
573. P: she was trying to get going
574. R: yes
575. P: well well it takes it must take it out of you when you (.) at that stage
576. R: yes
577. P: don't you think so?
578. R: yes (.) as a patient I meant
579. (.)
580. P: um I've never been as a (.) as a patient?
581. R: yes
582. P: I've never been in hospital as a patient (.) in [all my eighty eight years
583. R: [I haven't
584. N: you haven't?
585. R: no (*laughs*) [only having babies
586. P: [you haven't either?
587. R: no never (.) never broken a [bone touch wood
588. P: [and yet you you decided to be a nurse too
589. (.)
590. R: well [an auxiliary nurse I've been
591. P: [yes
592. P: what made you decide?
593. R: really (.) um to be (.) truthful it was so I could do night shifts so that I
could look after the children myself

594. P: yes
595. R: and that was why (.) and I did it then when I was doing my degree (.) but
um that's the real (.) the initial reason so I could do night shifts

596. P: yes
597. R: but saying that when I started it I loved it
598. (.)
599. P: so that you you (.) you had your er you had nights free do you mean or
600. R: I worked through the night
601. P: you worked [*(unclear)*
602. R: [so that my husband was there while I was working and I
was there while he [was working
603. P: [while he was working yes I see
604. R: didn't get a lot of sleeping [done in those years but um
605. P: [*(unclear)*
606. P: that was taxing wasn't [it
607. R: [yes it was (.) hard

608. P: and then so now it was day time you were there (.) you were with the children daytime?
609. R: yes
610. P: yes
611. P: so that you had (.) your evenings no you were working in the evening
612. R: yes
613. P: oh
614. R: only two nights a week though
615. (.)
616. P: yes (.) well that was enough wasn't it
617. R: yes I was on my knees by the time I finished
618. P: now H's wife that's my stepson that's in (.) um (.) he's just re re-married he was er (.) he was divorced years ago or er they were divorced I would say and he's just um (.) met (.) this girl her husband died (.) she was a a nurse she was one of these sort of Royal College of Nursing?
619. R: uhum
620. P: and er (.) she had done that sort of thing when her children were growing up and then she had a very bad nervous breakdown I'm prattling again dear
621. N: no no no
622. P: how do you stop me [now when you want me to stop
623. R: *[(laughing)]*
624. P: no (.) couple of things I want to ask you [but
625. P: [you won't be able to I'll be quick
626. P: anyway she went down to have her nervous breakdown with friends and she met H out there and um (.) and he came down to see me because he's very close (.) we are very close he rings me very often and he's coming in April so (.) I I'm not refusing him (.) he's coming to stay but um last time he came to stay he comes every year (.) last time he came he he stayed for two or three nights and then (.) they went away and came back to say goodbye afterwards you see
627. R: mm
628. P: so that they weren't here for long
629. N: umm
630. P: and that we managed that very well (.) um (.) so (.) she was a a (.) I'm only saying something about my knowledge of nurses she did that stuff is all I'm really saying
631. R: mm
632. P: but while her children were young um she could've I think she said the roof blew off um and they had to get some money one way or another [her husband was very good but um she wanted to earn some more=
633. R: [yes
634. P: = and um so she started voluntarily I think in the beginning and then decided and she took her took the whole course through and how people do it I don't know I mean I was on my own (*unclear*) yes dear what did you want to ask
635. N: I wanted to go back to something that we talked about when I very much the very first time I came to see you

636. P: mm
637. N: and A
638. P: M
639. N: M yes and it's that time I asked you about where you would want to die
640. P: [aah
641. N: [whether you would want to be (.) at home
642. P: [yes
643. N: [and I really want to check up=
644. P: right
645. N: =if [you're feeling still the same
646. P: [I don't want to be
647. P: I don't want to be (.) revived I've told my my surgery you know that
648. N: yes
649. P: quite well and um I don't want to be revived and in fact I've told them (.) I'd better not say it (.) to my neighbours she's er they're nurses next door too did you know that?
650. N: yes yes
651. P: I'm much blessed you see and they're awfully good (.) but um (.) I've said to them please if you just find I'm passing out please just leave me (.) so perhaps I shouldn't have told you that you don't know anyway (.) um but I just don't want to be revived
652. (.)
653. N: and you want to [stay here
654. P: [I want to die as naturally as possible
655. P: yes I do
656. N: in your own bed
657. P: yes yes it's one thing's always worried me going to (*hospice*) I think supposing they keep me (.) keep me in
658. N: that's why I wanted to check with [you because=
659. P: [that's fair
660. P: I wouldn't want to
661. N: =I know what you want and I will write it [down again I did when I first came
662. P: [oh bless you dear thank you
663. P: yes
664. N: but I'll check it out from time to time
665. P: yes thank you
666. N: and if you [change your mind=
667. P: [(unclear) change it goodness knows
668. N: =you can yes but if not I'll just check it out[(unclear)
669. P: [(unclear)
670. P: I say I say I don't want any of these drugs I don't know what Doctor S intends to do would be pleased to know (.) I don't know that you see what the [(unclear)
671. N: [well that's what I'll do (.) is next week I'll speak to Doctor D um (.) and find out what they're planning to do (.) and then when I next see you we can talk it through
672. P: yes

673. N: possibly be in day centre
674. P: that's right [(.) you see if I'm if I'm found on the floor
675. N: [and
676. P: and not able to look after myself as you know I got very (*unclear*)
through last week just to make everything more difficult that's (.) I had a
bad week [or two so
677. N: [yes
678. P: I think better now than when I was in pain now I'm not better
679. N: you you're much better [than when I saw you in day centre
680. P: [yes (.) but you see
681. P: a lot of it is imagination of some sort .(.) and why can't I control myself
a bit better at my age (.) my great age (.) as my (.) my nephew is putting
it now
682. N: I think you do wonderfully well
683. P: well (.) anyway I'm I'm enjoying life in a sort of a way (.) um you know
I I wish I'd gone (.) by now but um (.) um (.) it's a bit difficult but on the
other hand I've got so many blessings
684. N: yes
685. P: that's what I feel like I've got I'm up in that bed I can (.) somebody
comes in and rings me I don't want to see (*unclear*) I do that and that
sounds selfish of me because that's because I just want my family to
know I'm being looked after for their sake not my own a little bit of (.)
apart from that I live for my own comfort
686. R: good for you
687. P: well (.) I've er done other things in my time haven't I
688. N: I think so
689. P: had all sorts of difficulties in my time as I'm sure you have too
690. (.)
691. N: I think we probably need to be finishing (.) now
692. P: yes right
693. N: um (.) so (.) plan for next week (.) will be that you will come
694. in (.) [reflexology
695. P: [(*unclear*)
696. N: [on Thursday
697. P: [yes yes
698. N: and I'll try to have spoken to Doctor D=
699. P: yes
700. N: =before that
701. P: now J? J? J brings me home again
702. N: yes
703. P: and I did find that difficult I haven't (.) done that afterwards I haven't
had a cup of tea afterwards because I've I've been longer there or
something and she has been ready to bring me home (.) now I could get a
taxi
704. (.)
705. N: right
706. P: if if necessary (.) I don't want (.) to make a special case
707. N: yes

708. P: but I (.) you know (.) she showed me the um (.) (*sighs*) the room (.) that
with the they've got all pictures in it (.) the church [so that
709. N: [yes
710. P: there is a chapel
711. N: chapel
712. P: and um J... opened the door (.) and I thought and I thought oh I felt like
saying to her could I just sit here for ten minutes (.) it would have been
wonderful (.) would there be (.) is that used for anything that church is it?
713. N: yes
714. P: it was in in memory of of my neighbour
715. N: yes
716. P: who um (.) JL [L
717. N: [L
718. P: and I just wondered when they did it she used to sing for the opera
company and um they put the money together and made this and donated
this as a chapel
719. N: yes
720. P: and of course I'd been watching I used to go to the old one (.) to visit (.)
people (.) um it was much more homely in one way
721. N: yes
722. P: it was very very (.) well thought out and um they took all these pictures I
was there (*unclear*) for somebody they used lovely [(*unclear*)
723. R: [yes the stained glass
is beautiful
724. P: yes (.) well I thought it was lovely I was so pleased to see it um her
boyfriend came and took me round=
725. R: right
726. P: =and showed me the room I haven't seen the room now cause there's
(*unclear*)
727. N: well perhaps we could bring you in a little bit earlier and you could
spend some time and sit in there
728. P: could I?
729. N: yes that would be fine
730. (.)
731. R: they have a service there don't they S?=
732. N: yes
733. R: = on um
734. P: (*unclear*)
735. N: I'll find out about that
736. P: but afterwards is a bit difficult because I'm very stiff and I'm longing to
get into bed [you see
737. N: [yes
738. P: each time I came before I've been brought home fairly soon=
739. N: right
740. P: =and um I've been able to go to bed and sleep when I needed to sleep (.)
you know at the end of it (.) but don't give me any don't give anybody
more jobs because of me please I seem I seem to be um (.) living on what
(.) largesse at the moment
741. N: I don't think so (.) I think we'll probably finish there

742. P: (*unclear*)
 743. N: and I'll have a chat with them in day centre and we'll see what we can sort out
 744. P: don't let them be funny will you or (*unclear*)
 745. N: not at all
 746. Tape ends

Conversation with nurse on way home

747. N: I was actually trying to find out how with it she was in space and time because the impression given when she went to day centre
 748. R: um
 749. N: was that she was not with it
 750. R: I picked up your time orientation things with the newspapers
 751. N: yes
 752. R: and the radio programmes (.) because of course she'd initially said hadn't she she didn't know what day it was which probably didn't help matters
 753. N: but she did because she knew it was her birthday at the weekend
 754. R: yes
 755. N: and I checked that and it's right
 756. R: yes
 757. N: um
 758. (.)
 759. R: that's interesting
 760. N: so I thought those sort of things were
 761. R: yes
 762. N: were why I let her go on quite a bit as well
 763. R: mm
 764. N: and that she would still come back to the point though (.) so she's actually appearing really quite different at home=
 765. R: definitely
 766. N: =to how she is in the day centre
 767. R: what do you think about the um (.) how we saw her in day centre and we both thought that she was a little bit vague do you think that was directly a result of the reflexology? (.) cause it makes you so soppy doesn't it
 768. N: well it can do but the other thing is I would wonder is just the sheer energy of getting in there
 769. R: yes
 770. N: and how much tumour burden she's got is causing her (.) to to really feel quite unwell by the time
 771. R: mm
 772. N: so that's one of the reasons why I want to (.) check her liver function tests and just see what's happening with her disease (.) I mean she looks more frail to me
 773. R: yes
 774. N: umm
 775. R: that amount of diarrhoea (.) gosh

776. N: and
777. R: I could see on the tissue box by the side of me she had written down (.) times and it was [obviously how often she was going to the [loo
778. N: [yes [yes
779. R: and it was really frequent
780. (.)
781. N: which is why oral morphine will probably be quite useful with her when [we need it
782. R: [yes block her up a bit
783. N: and it will (.) yes um (.) help with the diarrhoea
784. *Gap in tape*
785. R: yes we couldn't have taped her (.) [if she'd appeared (.) the same as she was at day centre
786. N: [no yes yes
787. *(unclear) (laughing)*
788. R: I said to my supervisor that we had really interesting talks on the way home and I need to write it down cause there's lots of you know your perspective which is really useful (.) so he said well tape it
789. *(unclear) (laughs)*
790. N: well the other things that I was doing there obviously was trying to find out a bit about symptom control=
791. R: mm
792. N: =issues (.) and about how she's managing generally (.) um (.)
793. R: and the dying at home as well
794. N: and the dying at home was really really important and (.) quite often when you see somebody the first time (.) if they're reasonably well then
795. R: mm
796. N: they'll be talking about something that they're hoping is quite a way in t the future
797. R: yes
798. N: um (.) and feel that they could cope with (.) but when they become less well then sometimes they (.) I couldn't bear it (.) I'd prefer to be at (.) home alone
799. R: mm
800. N: so what I like to do is check it out (.) every week [sort of thing
801. R: [like an ongoing process
802. N: weeks (.) and with a patient like Amy she's somebody I wouldn't consider putting her on an obedience list
803. R: no
804. N: because she's on at the moment a steady decline
805. R: mm
806. N: but is still getting (.) enjoyment out of life and there is still quite a lot of (.) quality of life issues
807. R: yes
808. N: you know I think (.) if she's going to use all this energy to come into the day centre (.) then we ought to make certain that that (.) visit gives as much to [her as we can
809. R: [yes if she can go and see the chapel [and

810. N: [yes that would be nice
811. N: I got the feeling I wasn't too certain that she did want a cup of tea
812. (*both laugh*)
813. N: did you?
814. R: yes
815. N: at first I [thought
816. R: [but she wants it before
817. N: but she wants it before [is it?
818. R: [yes that's the point
819. N: and then somebody be ready to take [her home when she needs to so she
can lie down
820. R: [yes straight away she wants it
straight away (*laughs*)

HCTRA5 Olive

Patient female 70+ years

Nurse female 50+ years

Interaction takes place in nursing home.

1. N: when I was here last time Olive we were talking about (.) whether you were going to try back at home again
2. P: yes
3. N: or whether you were going to stay here [and invest
4. P: [I'm going to stay here
5. N: I thought perhaps you were [moving that way
6. P: [yes
7. P: it was quite definite [because when S... (.) the er (.) S...B...
8. N: [yes
9. P: gave me the choice of another room
10. N: mm
11. P: above the tree which (.) is taking part of my view away um I didn't like the room as well I didn't like the size of it and I didn't like um (.) the fact that I was (.) on the outside you see this is the only room with a balcony
12. N: yes
13. P: and it has its great advantage in summer when it's very hot that the (.) um sun only comes to this edge of my bed
14. N: right
15. P: and I can lie in the shade and be not too hot
16. N: yes
17. P: cause I can't stand being you know I get (.) as they say in Yorkshire mafted
18. N: mafted? I don't know that word mafted? (*laughs*)
19. P: a new one (.) too hot for words
20. N: yes (.) that's an interesting word
21. P: yes it's never used down here no
22. (.)
23. N: and one of the things with O... and um this tree because it's a really nice nice view (.) but from Olive's flat=
24. R: mm
25. N: =in Penarth O... could see Flatholm and [Steepholm
26. P: [and Steepholm [and er
27. R: [yes
28. P: you know I was er on the third floor as I am here (*coughs*) but my um (.) you I was actually nearer the sea because our (.) gardens went down to the edge of the cliff
29. N: yes
30. P: there was just the gardens between me and the edge of the cliff
31. N: yes
32. P: and although the trees did (.) obliterate (.) the view it was down towards Barry
33. N: yeah

34. P: and I could still see Flatholm and Steepholm which was my (.) which I could see from my own flat
35. N: yes
36. P: you see when I was still at home (.) and so er I this is the best er (.) compromise that I can make you know (.) and I like this room
37. N: and this/
38. P: and eventually I'm going to have it redecorated [so that I make it more my own than it is now
39. N: [yes
40. P: cause er (*laughs*) thats not exactly my taste you know (.) anchors and things
41. N: sort of rear admiral had this [*unclear*] before
42. P: [*laughing*]
43. N: um (.) seagoing man
44. P: but I've found a (.) I think I've found a colour scheme that I like (.) like a sort of er (.) mauve mauvy colour um (.) which I could do one wall at a time you see (.) if you left the ceiling as it is (.) wh what shade's the ceiling is it a blueish white or is it [just white
45. N: [white
46. P: just white white
47. N: mm
48. P: right cause my my um colour (.) colour acuity [is going
49. N: [yes yes
50. P: and I've got a little book here called the Methuen book of colour
51. N: right
52. P: and I'm going to pick out a colour from that which for all the colour scheme works (.) you know that you could possibly get um (.) and ask someone to find (.) some shade cards
53. N: yes
54. P: you know [and things
55. N: [yes
56. P: that I could use um (.) and I would just have the top part you up to the cream (.) the top part
57. N: yes
58. P: so it wouldn't take too much to to do one wall and put the things back
59. N: yes
60. P: and then do that wall and put the things back and then do this wall and put the things back
61. N: oh it could be done all very quickly
62. P: it could be done very quickly
63. N: [mm
64. P: [yes
65. (.)
66. P: and then-I shall feel it's really mine then
67. N: the thing that I think would be lovely here would be some blinds
68. (.)
69. P: I know but (.) they don't have blinds do they?
70. (.)

71. P: I'd like some (.) but then I could only do (.) I could only activate these
72. N: yes
73. P: reach those (.) without getting out of bed
74. N: right
75. P: and I can't er (.) I haven't got any (.) strength you see I can't raise my arms higher than that (.) and I haven't got any (.) push power (*laughs*) to to um either to lift the that thing up and hold it well I [pull it out
76. N: [yes
77. P: um (.) so I have to ask people to open and close my windows for me which [I (.) I don't I didn't want to have to do but there we are
78. N: [right
79. N: and this is is this a bubble tube?
80. P: yes!
81. N: that wasn't here was it [when I came that time was it?
82. P: [yes it no it wasn't
83. P: on the um little strip of er the white strip you see one marked fish (.) fish lamp
84. R: oh yeah
85. P: can you press it down
86. R: yes
87. (.)
88. P: and then you just have to press the little er node knob
89. (.)
90. N: here?
91. P: yes (.) pull it on the hum
92. (.)
93. P: that's it (.) the fishes start to swim
94. N: when did you have that?
95. P: I brought it from home
96. N: I love the sound [don't you?
97. R: [mm it's lovely
98. (.)
99. R: is there a lamp in it as well?
100. P: there is a lamp but er there there's too much light here for the lamp to show
101. N: [yes
102. R: [mm
103. P: especially when it's against the sky
104. R: nice in the evening
105. P: mm but at night it changes from um (.) red to green (.) to er to (.) white you know silver and then blue (.) then [red green silver and blue
106. N: [yes
107. N: we're going to have at *hospice* in the day centre
108. P: yes
109. N: a s sensory room
110. P: oh how [wonderful
111. N: [with different [sorts of lighting (.) and music
112. R: [are we? oh

113. N: [yes the the chap came from the firm that (.) did the catalogue=
114. P: [oh how lovely
115. N: = and I got quite carried away with [this um
116. P: [I'm very familiar with er those
audio visual shows
117. N: yes
118. P: because my friend P... um used to go round nursing homes and giving
shows with audio visual he can't do that now because (.) he's had an
operation and he can't lift his equipment now to take it round but er
(.) he's er (.) he's taught me an awful lot about [them those sort of things
119. N: [yeah
120. N: cause they use them a lot as well in with (.) children with learning
difficulties don't they [those sort of (.) rooms
121. P: [yes they do
122. R: mm
123. (.)
124. P: is there (.) a tissue for me up there?
125. R: is there anything in there or
126. N: yes
127. P: do you mind [leaning over it?
128. R: [not at all
129. (*unclear*)
130. N: and have you been back to your flat [since we since I last came?
131. P: [just the once and [I overdid it
132. N: [just the once?
133. P: and I paid for it and I realised then that I wouldn't be able to go back
to live (.) not without 24 hour care which I can't really afford to [to do
134. N: [yes
135. P: and I'd rather have the 24 hour care in one place
136. N: yeah
137. P: so (.) I've plumped for this
138. N: this was one of the big problems for O... when um after she'd been
into *hospice* when we were looking at (.) what was going to happen
next
139. P: yes
140. N: and initially you felt really (.) almost pushed into making very
141. P: mm
142. N: quick decisions
143. P: well it was quick you see because at Christmas time I was living at
home with just my um daybreak carers (.) and coping extremely well
but of course it was in January that I was diagnosed [as having cancer
and er (.) um
144. N: [yes
145. P: although it didn't affect me greatly at first I had to get rid of the (.)
jaundice which was (.) part of it and er I had the the most frightful
itching all over my body which was almost worse than pain [really
146. N: [yes
147. P: and um (.) when I got over that um and they sent me home I realised
that I couldn't cope with without much more care so I decided to (.)

telescope my um (.) things together and cut out the (.) um (.) the going back home point (.) but I did go back for a visit as I say I (.) overdid it [they (*unclear*)

148. N: [but you were able to sort through some of your things [(*unclear*)
149. P: [oh yes and I'm still able to do that they bring them in V... is absolutely marvellous she's a wonderful person
150. N: yes
151. P: and er unfortunately yesterday when she came I had er (.) er (.) a bad day as far as being sick or wanting to be sick and not being able to be sick (.) um and she was with me for a whole hour and she was holding my hair and she was (.) you know (.) being with me and I didn't have time to talk to her at all [I just was so poorly
152. N: [no no
153. P: when she was here and I hope I'll be better when she comes [today
154. N: [was that (.) the first time this week that you've had sickness like that?
155. P: oh no no I've been getting (.) gradually better from sickness
156. N: yes that's certainly last time I came
157. (.)
158. P: but er (*coughs*) I find that if I don't have any breakfast at all
159. N: yeah
160. P: and just have my first meal at lunchtime (.) and then today I I thought well I've been so (.) um dehydrated and sick that I really ought to try and eat something so I had a little muesli this morning which stayed down so I feel as though that was a plus
161. N: yes
162. N: but that if you're dehydrated that will also make the constipation worse
163. (.)
164. P: it will (.) but I do my best [to to keep drinking er (.) but I don't want to er
165. N: [yes
166. P: start off the sickness [again you see so it's difficult to know what to take
167. N: [yeah yeah
168. N: right
169. P: somebody brought me some um (.) er [(*unclear*)
170. N: [sparkling water
171. P: sparkling water yes (.) but I found that that just made me feel sicker
172. N: right
173. P: you know and I couldn't cope with that (.) so um I shall wait until I'm much better than this before I (.) have that again each time just on water [now
174. N: [yes
175. (.)
176. N: you know when I was here before we were talking about you possibly coming back to the day centre?
177. P: mm
178. N: to have some aromatherapy

179. P: mm
180. N: or reflexology
181. P: mm
182. N: what do you feel about that at the moment?
183. P: I'd love to I'd love to if we can get a day when I'm (.) well [(unclear)
184. N: [(unclear)
185. P: yes (.) um as I say after yesterday which was a (.) awful day you
know I can't remember a day as bad when I was being sick for an
hour or trying to be sick for an hour
186. N: yes
187. P: and not being able to and I was I was trembling you know I was sort
of shaking with the (.) trying to relax you know and not oh dear we
were in a real mess (*laughing*)
188. (.)
189. N: and when you went back to the flat
190. P: yes
191. N: did you go in a taxi or did V... come and pick you up?
192. (.)
193. P: V... came (.) and er I think that's where we went wrong (.) instead of
staying two hours I stayed three
194. N: yes
195. P: and that was just too much
196. P: and I was I had to stop the lot on the prom because I felt as though I
was going to be sick any minute you know
197. N: yeah
198. P: you know and I didn't want to be sick in the car
199. N: no
200. P: so I sort of (.) put my legs outside the car (.) I I wasn't actually sick I
just [retched and retched
201. N: [it was that (.) sensation
202. P: yes that feeling of being wanting to be sick (.) anyway she got me
back here and (.) I paid for it the next day in (.) you know (.) sort of
one step back
203. N: yes
204. P: um (.) but then I thought well I musn't do that again and I I mean
they're willing to take me back again if I want to go
205. N: yes
206. P: but I don't know whether I could (.) cope with it just at the moment
because I'm too (.) upsy downsy [at the moment
207. N: [yes
208. P: that's all (.) anyway (.) we're fine
209. N: were you up and about yesterday?
210. N: at [all?
211. P: [a little a little sitting [in the chair
212. N: [cause last week you were using this quite a
lot weren't you? (.) your three?
213. (.)
214. P: what [is that?
215. N: [your frame

216. P: oh yes I used to go down [to the to the loo
217. N: [yes
218. P: um two days ago I think I went the last time but they asked me to go
219. N: so that they [could see
220. P: [yes so that they could see yes
221. N: yes
222. (.)
223. N: what I think might be a good thing if if they agree if the matron
agrees is poss possibly get you checked up with one of our doctors (.)
um next week to see if we need to just readjust things
224. P: yes
225. N: and it really depends upon you if you're well enough I think it would
be quite nice to bring you into the day centre because then you could
have either some aromatherapy
226. P: yes
227. N: or some reflexology to relax you [and we could get one of the doctors
to
228. P: [yes
229. N: see you [there
230. P: [there
231. N: and still only keep the you being out to about an hour to an hour [and
a
half
232. P: [yes
233. N: so we could
234. P: I'm sure I could cope with that
235. N: so what I think I might do is is if it's alright by you is ring you on (.)
Tuesday morning and [see how you've been over the
236. P: [yes you've got my number have you?
237. N: yes I have got that (.) um and if you felt like coming in perhaps we
could try and [arrange something and bring you in (.) um
238. P: [yes
239. P: yes
240. N: sometime next week do you think that would be a good [idea?
241. P: [I think it
would yes
242. N: yes
243. (.)
244. P: yes I would like that
245. (.)
246. N: is your niece still here?
247. P: no they've both gone [now
248. N: [right
249. P: they went back last (.) was it last Sunday? (.) what date was last
Sunday?
250. N: date (.) don't know let me [think
251. P: [twelth?
252. R: [twelth today
253. P: that's right (*unclear*)
254. N: and are they going to come back again?

255. P: no she won't be able to come back again she is between jobs at the moment she said it was a good time to come because she was being interviewed for various jobs (.) and er (.) she's (.) got the promise of the one that she wanted so she knew
256. N: what does she do?
257. P: well she was a teacher um and then she went onto the admin side (.) er in Australia it's known as (unclear) um (.) and she was (.) more on the admin side of er education generally and then she began to er be asked to (.) do things (.) in a specific (.) direction you know it was very (.) um (.) put her on various projects which she did well on apparently and now she's going back to (.) do a project in the Phillipines (.) and er she's got grown up children they're they're (.) what ages are they (.) eighteen and twenty I think or something like [that
258. N: [yes
259. P: quite able to manage at home (*laughing*) so she can take a job that will take her farther afield and I think with having brought up the children to that (.) stage and especially the son who is less adventurous than the daughter
260. N: yes
261. P: um (.) she he's um (.) definitely a (.) mum's boy and er he's going to (.) er he's got a job (.) I must think now what he's doing (.) er (.) think he's with a firm of (.) something to do with art artwork and things that sort of thing and he's er he's doing quite well he's he's been head boy at school [and you know that sort of thing=
262. N: [yeah
263. P: =she felt quite happy about leaving them (.) at home um J... is already er sorry yes J... is already has already left home and gone to live in Aldway which is um (.) some miles from C... where where um D... lives (.) so (.) so um D... is in C... and she is in Aldway
264. (.)
265. N: so was it sad when she went back?
266. P: oh yes she was so lonely too she was (.) well family's family [isn't it
267. N: [yes yes
268. (.)
269. N: I must mention to Annmarie about that piece of artwork there
270. R: mm
271. N: was (.) done by um (.) L...R...(wife of John HCTRAI)
272. R: oh right
273. N: F... R... 's [wife
274. R: [yes
275. P: [the top one here
276. P: [the top construction that was one of L... 's
277. R: you knew each other did you?
278. P: pardon?
279. R: did you know each other
280. P: oh very well
281. R: oh I see

282. P: she and I taught together (.) you know taught art er (.) further education class
283. R: yes (.) let me move round (*so patient can see me properly*)
284. P: we shared a class in fact
285. R: you can't quite see [me can you
286. N: [you shared a [class?
287. P: [we shared a class yes
288. R: mm
289. P: the class got too big for her and she said rather than (.) er commit herself to another day (.) cause it was a day class [during the day class
290. N: [yes
291. P: um would I come and so that she could get (.) get take in all the people that wanted to come
292. N: yes
293. P: um would I come and help with her and for quite a number of years she and I taught the class together (.) what we used to do was we'd start at one end and cross in the middle and then the next week we'd start where we'd crossed and do it again you see and cross over so they all got a bit of both of us
294. R: is there any of your work here then [O...?
295. P: [yes um the two wool pictures
296. R: oh yeah
297. P: matching (.) ones and the one below N... 's
298. N: yeah (.) I was thinking when you mentioned about using um (.) some purple (.) paint (.) that would look quite stunning [against that wouldn't it
299. P: [that would yes
300. P: some light mauve [not a not a deep mauve
301. N: [yes yes
302. P: um yes it would
303. (.)
304. R: yes and with the green outside it would look lovely
305. P: [yes
306. N: [yes
307. P: that tree's come out a lot since er I first came here [it has its little pointing boughs up to the
308. N: [it has
309. P: and then they came they came to sticky buds (.) and now they're actually coming into leaf [aren't they
310. N: [yes
311. R: can you see past these lower trees?
312. P: mm?
313. R: can you will you be able to see these when they [leaf?
314. P: [yes I can see that part of the sea has got Steepholme [but Flatholme is just behind the right hand side of the tree from here
315. R: [mm
316. P: er can't see that once the tree's um (.) in leaf (.) but of course when those leaves come off the tree I'll be able to see

317. N: there's also quite a lot of activity in this [(.) upon this headland which
is rather nice
318. P: [oh yes yes there is
319. R: all the bottle banks and everything [are by there aren't they
320. P: [often there there's a childrens'
playground down there [and you often get flying kites
321. N: [yes
322. N: yes
323. P: and you know
324. N: and in the Summer people picnic across [on here don't they and play
(.)
325. P: [mm mm
326. N: miniature golf and things
327. P: that's right
328. N: yes
329. (.)
330. N: cause I used to come across the top of here with my dog (.) before
going to work
331. P: that's nice (.) (*coughs*)
332. (.)
333. N: so you feel quite happy in yourself about the decisions that you've
made
334. P: I do now
335. N: because [that was the really big thing wasn't it
336. P: [I'm quite happy now
337. P: mm
338. N: I'm really [pleased about that
339. P: [it was because I I just had to check [that I'd I'd er (.)
tested all the possibilities
340. N: [yes
341. P: I (.) I feel that it was really important for you to go [back to the flat
and be there
342. P: [yes it was
343. P: and I was very very pleased that every decision that they have made
for me was the right one
344. N: yes
345. P: but I had to make sure it was (*laughs*)
346. N: absolutely
347. P: not that I didn't trust L.. I did I did but um (.) and er she's a person
with both feet on the ground you know
348. N: yes
349. P: so you know you can be sure that what she thought was best for me
was best for me (.) but I had to just check it
350. N: yes yes
351. P: well when you've been (.) it seems to me that you've been passed
from one place to another willy nilly er and then when you get to a
point of no return you think hey wait a minute is this what I really
want to happen you know (.) (*laughs*)
352. N: yes absolutely

353. P: (*unclear*)
354. N: yes
355. (.)
356. N: here's some of the things that I think when I first came to see you Olive was being incredibly brave um (*laughs*) it wasn't til I was going was it I was [just about to leave
357. P: [that's right yes that I (.) suddenly (.) opened up (*laughs*) well you're a person that I can open up to you know
358. (.)
359. P: so and I felt that I was bottling such a lot up inside me [that I had to talk to somebody about it so I did and I'm glad I did
360. N: [yes
361. N: and Olive's friend is absolutely lovely but she was sort of trying to do everything to save (.) to save you really wasn't she to and was concerned that it would really be just too upsetting (.) for Olive to go [there
362. P: [well it wasn't really she was just trying to make life easier [for me which I knew she was doing and I
363. N: [yes
364. P: knew that ten to one it would be (.) like this but I just had to make sure that that I had sounded out all the possibilities as you might want to yourself you know
365. R: mm you've [got to make your own decisions
366. P: [but it just seemed such a short time between
367. N: being indepe[ndent
368. P: [being independent and being completely not independent (*laughs*)
369. (.)
370. P: hmm yeah
371. (.)
372. R: is V.. our V.. from *hospice* [that you're talking about?
373. N: [no
374. R: oh ok
375. N: no
376. (.)
377. N: so I think (.) from today (.) I need to just have a chat with matron here and just just (.) have a look at your (.) um (.) medication in terms of the laxatives
378. P: that's right yes well they're not they're sort of working in the dark you know I am cause I don't know really what is the best thing to do [and you're the only people who can tell me and you have got
379. N: [yes
380. N: I I think it would be quite a good thing to have a review a medical review with the doctors at *hospice* (.) if you were not well enough (.) to come there (.) um then I could arrange for a doctor to come out to see you
381. P: yes
382. N: cause I think it from [what we talked about it would be really rather nice if

383. P: [be nicer
384. N: [you could come to the day centre
385. P: [yes if I could come and see the the new things that are happening
there
386. N: yes
387. P: even [if it's only for one day
388. N: [and
389. N: and have some aromatherapy I think that would be really nice
390. P: mm
391. N: really
392. P: it would
393. N: and quite often some of those treatments like reflexology and
aromatherapy can actually help with (.) internally with (.) balancing
things like digestive things
394. P: well I certainly felt very much (.) less up and down
395. N: yes
396. P: when I was with you [because you you did these things in between
397. N: [yes yes
398. N: so what I'll do Olive if it's alright with you is I'll /
399. P: you see here there is some different staff coming on all the time
400. N: yes
401. P: and you have to keep on re-explaining yourself to them and um some
of the new ones who come in haven't a clue er about what your (.)
previous needs have been (.) and er it just seems to me that (.) er I'm
I'm forever trying to explain to people why I can't (.) do things they
they say come on then get up you know (.) and they don't realise I
have to be helped up
402. N: yes
403. (.)
404. P: could I ask you to (.) refill that please dear
405. (.)
406. P: it's a it's a [jug of water there yes
407. N: [jug yes
408. P: so you find it awfully hard to get off oh right I'll do it myself
409. (.)
410. N: it's heavy as well isn't it
411. P: oh oh well I could only do it by tipping it out
412. P: mm
413. N: yes the jug I meant
414. P: the jug?
415. N: water jug
416. P: the [jug
417. N: [is heavy
418. P: yes it is I can only do it by tipping it
419. N: mm
420. (.)
421. N: I will ring you on Tuesday morning
422. P: yes
423. N: and we'll go from there

424. P: thank you
425. N: and hopefully things will have settled down bowel wise
426. P: I hope so
427. P: do you consider that it's wise of me not to have breakfast at all?
428. N: (*sighs*) I think I have to go with what you feel and the last time I came you said that since you've stopped having breakfast (.) that you'd felt [more comfortable
429. P: [this morning I did try with a small amount of muesli (.) and a very small amount [of milk
430. N: [yes
431. P: er I wasn't able to finish it
432. N: no
433. P: but I did feel that I (.) kept down what I=
434. N: yes
435. P: =had so I haven't been actually sick today I've not been feeling too comfortable down [there particularly but er
436. N: [no
437. N: and you you don't look anywhere near as comfortable as you did
438. P: don't I?
439. N: last week cause you looked absolutely wonderful [last week
440. P: [yes yes (*laughs*) I know I go from one to [another and I can't understand why
441. N: [yes
442. P: why this sort of upsy downsy (.) business
443. N: I think that (.) because (.) your symptoms of sickness fluctuate when you haven't got them you're probably taking quite a lot more fluid (.) and that helps with everything else (.) but when you have a [day when you're feeling
444. [yes and I don't know what fluid to take [you see dear because um (.) water is is all very well but you
445. N: [yeah
446. P: can't just go on drinking water [all day long (*laughs*)
447. N: [no
448. N: the other thing as well is as soon as you start to feel sick you start to move far less so you tend to stay in one posit[ion
449. P: [position
450. N: we all do it you know if you're feeling nauseous you sort of tend to you [get into a position and think
451. P: [you think oh if I if I move
452. N: yes it's going to start (.) so again that has an impact then on on [your digestive system
453. P: [yes (.) I that's right well I did try to get up as you [saw when you came in um was expecting you=
454. N: [yes
455. P: = but I thought perhaps I would get a quick one in before you came (*laughing*)
456. N: (*laughs*)

457. P: I wasn't quite quick enough was I
458. (.)
459. N: now does that sound a reasonable plan
460. P: it does
461. N: that we look to bringing you [in to have a medical check up?
462. P: [yes
463. N: to have either some reflexology or some aromatherapy
464. P: on Tuesday
465. N: um and have a change of scene which I think but keep it to fairly
shortish visits [to not tire you too much
466. P: [yes that's right
467. P: how I I'm not certain about this movement whether [this would be
available
468. N: [yes
469. P: to [anyone
470. N: [well p'raps we I mean we're not really going to know until
Tuesday
471. P: we're not [really
472. N: [I mean if if when you see V...=
473. P: =I ask her if she's free on [Tuesday
474. N: [you ask if she's got any time and then
when I [phone you
475. P: [she does locums for the local um (.) optician's you see [she's
an optician in B.... before she retired and um
476. N: [yes
right
477. P: she does um locums for him on certain [days of the week and I've
forgotten really which hours she has
478. N: [yes
479. N: well what I might do anyway is sort of tentatively (.) um book one of
our drivers (.) for a specific time so that if V.. couldn't do it [we could
perhaps use one of our drivers
480. P: [mm yes
because I can get into a car
481. N: yes (.) and you'd be able to get down to the front and get [into the car
482. P: [into the car
483. N: and we could help you out at the other=
484. P: that's right
485. N: =end (.) and then again coming back [there'd be the nurses here
486. P: [right
487. P: yes
488. N: so [let's let's sort of (.) look at that as a possibility
489. P: [that's how we did it before
490. P: I think it's er (.) a good one
491. N: is there anything else you want to ask me at the moment?
492. P: mm (.) no I don't think so dear
493. N: anything you want to [ask Annmarie?
494. P: [I feel a lot more happy in my mind than I did
when last you saw me [but not quite as well in the body

495. N: in the body
 496. P: no
 497. N: hopefully next week we'll get the balance [a bit more
 498. P: [the two together
 499. P: yes please
 500. N: yes
 501. P: (*laughs*) (.) I hope
 502. (.)
 503. N: is there anything you'd like to ask Annmarie?
 504. P: yes um no you ask me if there's anything you
 505. R: there's not actually Olive I wanted to make a tape and I'll I'll work
 with that then
 506. P: that's right yes
 507. N: have you been involved with linguistics at all? (.) which is your
 508. P: not before this not before this er happened to me (.) it's only four
 months isn't it
 509. N: yes
 510. (.)
 511. P: since er since Christmas
 512. N: yes
 513. P: you know it's amazing to me that it's all happened in so short a time
 this up up and down [business
 514. N: [mm
 515. P: and um I'm only just getting my mind round it really
 516. R: [big shock
 517. N: [yes yes
 518. N: I think particularly when you've managed (.) having (.) your (.)
 arthritis for years
 519. P: I have
 520. N: and coped
 521. P: yes and er I think you know your own body and you know what's
 good for you then
 522. N: yes
 523. P: and I can't believe that it's not good for you now
 524. N: yes (.) I think that's an important point you've got to listen to your
 body and it will tell you
 525. P: I think so
 526. N: what you can do and what you can't do
 527. P: my cousin one of my cousins (*laughs*) she rings me every day she
 wrote to me once and in one part she wrote my daughter and I say
 how's BB? (.) and it's either bloody body back BBB or it's beautiful
 body better (*laughs*)
 528. N: right
 529. P: (*still laughing*) my (.) my body's been more bloody than beautiful
 530. N: (*laughs*) (...) I think I've interrupted you Annmarie have I?
 531. A: Um yes I was only meaning to ask O... if you'd sign the consent form
 f or me?
 532. P: Um uh um (.) consent for what love?
 533. R: To being taped

534. P: To being taped?

535. R: [yes

536. P: [ooh yes of course

537. R: did you have one already?

538. P: I did bring a [form

539. P: [I think it may be in the little pull out (.) top (.) um

540. R: the little slim compartment?

541. P: slim compartment yes (.) if you look through those I think it's in there

542. R: yes

543. (.)

544. N: was this bed here O... when you came?

545. P: no (.) that's

546. N: this bed=

547. P: =was there

548. N: was over there (.) but it it this belongs to the nursing home does it?

549. P: yes it does but I've got one just like it at home

550. N: at home yes I thought you had

551. (.)

552. N: see you've got your palm cross

553. P: yes three of them three people brought me them

554. (.)

555. P: now you'll have to tell me what I'm/

556. R: ok (.) it says have you read the information sheet

557. P: do I ring it?

558. R: yes please

559. R: um have you had the opportunity to ask questions and discuss the study

560. P: yes

561. R: do you understand that copies of the tapes will not be made available to anyone other than me at any time

562. P: yes

563. R: so we won't be broadcasting them this week

564. N: or ever

565. R: (*laughs*) do you understand that you may withdraw your consent at any time during the study

566. P: yes

567. R: that's even after today

568. (.)

569. R: do you agree to take part in this study and to participate in one or more audiotaped sessions it'll only be the one though

570. P: yes

571. R: and just to sign your name by there please

572. (.)

573. P: date?

574. R: here we go (.) twelfth (.) April (.) I keep writing March (.) and I still haven't got used to 2001 yet

575. P: (*laughs*)

576. (.)

577. P: April 2001 name of name in capitals

578. R: that's it
 579. (.)
 580. R: it's hypnotic this view
 581. N: isn't it
 582. R: especially with the fish going up [and down
 583. N: [yes
 584. (.)
 585. N: it is very soothing [unclear
 586. R: [really is yes
 587. (.)
 588. R: and it's quiet
 589. P: are they going fast or slowly
 590. R: they're going quite fast
 591. P: if you pull pull put it down to the (.) thin end of the wedge you'll (.)
 they do it a lot more quietly and a lot more gently (.) so you can have
 it (.) frenzied or otherwise
 592. N: yes
 593. N: and then your mobile's nice isn't it
 594. P: ah I made that
 595. N: did you?
 596. P: yes
 597. (.)
 598. N: if you come/
 599. R: it's holographic isn't it
 600. N: yes
 601. (.)
 602. R: mm
 603. P: there you are dear
 604. R: oh thank you (.) thank you very much
 605. N: right then [Olive
 606. P: [there you are we made that very well didn't we
 607. N: did it distract you a bit?
 608. P: it did it did
 609. N: good
 610. (unclear)
 611. P: all my visitors on Sunday I had seven visitors one after the other (.) I
 was just never alone all day
 612. N: all bringing palms
 613. P: all bringing [palms and flowers and cacti and all sorts of lovely things
 614. N: [laughs
 615. (.)
 616. N: it's rather nice though isn't it to know that you've got/
 617. P: I'm so fortunate [to have so many good friends=
 618. N: [yes
 619. (.)
 620. R: ok?
 621. N: ok
 622. P: =and they're all lovely
 623. N: I'll ring you on Tuesday morning

624. P: right
625. N: and I'll have a word with (.) Matron if she's down there if not I'll ring her and just talk to

626. End of tape

Nurse and Researcher leaving visit (talking about previous visit)

627. N: I was about to to leave and I looked at her and I suddenly realised she was fighting
628. R: mm
629. N: um (.) with tears and her mouth was shaking
630. R: aah
631. N: but I had almost a strong feeling of wanting to to go
632. R: mm
633. N: partly because I had another visit planned and I'd already been there my sort of allotted time um and then I sat back down and then it all came out she felt that even with her friend V.... who she loves dearly and who's got power of attorney that she was being totally taken over
634. R: mm
635. N: and sort of packaged into and that they were saying that she could never go back to her flat again (.) um but in fact once she'd talked about it she didn't need cause I's wondered about getting M.... (nurse) involved or somebody to act for her but in fact she didn't need it she was able to
636. R: she just needed to [air it
637. N: [say it herself [yes
638. R: [yes
639. pause tape
640. N: and I said to her she um wanted to discuss with me the possibility of going back home again
641. R: mm
642. N: and I'd already had a very panicky phone call from V... in fact V... turned up at *hospice* and spoke to V... centre director to say really could you say to K... when she next visits to try and persuade O... that she doesn't (.) she can't [cope alone
643. R: [I was with you wasn't I?
644. N: I think you might have been and I think and V... said you know I've said that she would pass the message on but it wasn't something that she thought I'd want to do or be willing to do (.) but in fact once again when I came in and talked to Olive and I went down to see the manager S....[she was talking about
645. R: [mm
646. N: and um (.) and I said I ha by the time II'd finished talking to O... there were lots of other things like possibly could she change her room

possibly could she decorate her room [that I just I just felt it was
much more a thing that she wanted to explore all the options

647. R: [mm
648. R: yes she wanted to not [have them explored for her
649. N: [yes and once she'd done that she was
650. (.)
651. N: she [she felt ok about it
652. R: [once she'd made her own mark
653. N: yes
654. R: mm
655. (.)
656. N: but she she's not so well today
657. R: isn't she
658. N: I mean I nearly decided that we wouldn't do it
659. R: mm
660. N: but she was quite keen to and she said it'll take my mind off
661. R: mm
662. N: cause she was very keen last time I talked to her
663. R: she wasn't particularly easy to speak to today was she
664. N: no
665. R: I noticed you were giving her pauses for her to start something off but
she didn't [pick them up
666. N: [and she yes she also missed couple of times I think
667. R: and she repeated a couple of times
668. N: a couple of things yes (.) I just there's an overall impression that she's
just not as well
669. R: mm
670. N: now prognostically I would have said that I mean last week I thought
she looked really really good and I could see her coming into day
centre and probably getting quite a lot of benefit (.) I am aware of
offering it though I think it's important she has something that she
can she can look towards doing that's outside of the nursing home

671. R: yes definitely
672. N: but I'm a bit pessimistic about how realistic it's going to be
673. R: I can tell you want more symptom control for her [don't you
674. N: [yes yes
675. N: that again is a really difficult thing because/ I don't know whether this
should be taped bit of a problem but you see patients I've been to see
recently

676. End of tape

HCTRA 6 Irene

677. N: is there anything you need to go through before (.) [we start
678. R: [no no
679. R: not really just that I'll give you a consent form afterwards to sign if
that's alright just to say that you've allowed me [to do the
680. P: [yes that's lovely
681. N: ok so the furniture's a big problem at the moment
682. P: yes
683. N: ok
684. P: I I it's er well it is you know I mean you can't (.) you can't this room
looks really untidy you know what I mean
685. P2: til you got the furniture and the pictures on the wall
686. P: (*unclear*) pictures on the wall (.) see?
687. N: ah ok (.) you can't do that til you 've got your furniture in
688. P: well no you can't can you
689. N: no you can't
690. P: no you can't
691. P: I know that you know we're not the only ones but it's unc/ and I of
course my son did a silly thing he paid for the full sui/ gave the full
money
692. N: ah right
693. P: see? so I mean we're lo/ we can't say anything can we (.) only if we
hadn't paid the money we could say (.) go and get lost
694. N: right
695. P: but then I'd have to wait another six or eight weeks [(*unclear*)
696. P2: [(*laughs*)
697. N: probably (.) probably
698. P: can't go anywhere [(*unclear*)
699. P2: [can't win today
700. R: no
701. N: so how've things been
702. P: well um N.....(*husband*) hasn't been very well at all
703. N: right
704. P: and I am worried about him because um he's getting/ I know he you
know he's got this blood with the water in
705. N: yes
706. P: but you know he he must be getting dizzy um you know with his um
low low (.) temperature
707. P2: blood pressure [yes
708. P: [and I think he's had a knock since that because he's
covered in bruises
709. N: are you?
710. P: yeah yeah [honestly (.) got a big one there (*unclear*)
711. P2: [yes i've got some big ones big ones yes round there
712. P: and all (.) funny places you know
713. N: oh dear
714. P: yes

715. P2: so wherever I get them they've been about as big as that [like really
(*unclear*)

716. P: [so I have I
have been a bit worried about him

717. N: yes you're bound to be you're bound to be

718. P: so I don't I haven't been going with him since I did my hip

719. N: right

720. P: and um because you know I can't sort of walk [all down them
corridors

721. N: [mm

722. P: but if it's the um Dad has a wheelchair they take him and put him in a
wheelchair but um if it's the um heart place it's only a little short
corridor at the Heath

723. N: right

724. P: and go in the lift and then you're right up on there I can do that much

725. N: you can do that bit

726. P: you know (*unclear*)

727. P: and he can say what he wants to say and I can listen to what/

728. N: yeah and that will be reassuring for you won't it

729. P: yes I'll be there because I don't remember everything that's said and
he doesn't remember it so [between the two of us

730. N: [between you you can manage

731. P2: (*laughs*)

732. R: you can borrow my tape recorder

733. (*all laugh*)

734. P: I was thinking that yes

735. (*laughter*)

736. P: oh dear

737. N: so has the district nurse been round to take your blood and to check
your warfarin level and everything?

738. P2: umm yesterday they came

739. N: right

740. P2: and it had gone from one point/I've got the reading in there if you'd
like to see it

741. P: one point five (.) [one point three to three point five

742. P2: [one point two

743. N: oh right ok

744. P: yes and it's dropped to

745. P2: and I've got to take five [ml everyday I was taking five and six

746. P: [five ml every day

747. P: he was taking

748. N: so you're taking five every day

749. P: [yes

750. P2: [yes (.) for a fort night then in a fort night she'll come [again

751. P: [see when he
was in hospital (*unclear*) they put him on this one tablet er for the
heart and it was two a day

752. N: yes

753. P: so I used to put out one in the morning and one at night and and his Losec he's been on for a long time (.) after the heart as well
754. N: mm
755. P: and that one in the morning and one in the night while when he had this trouble they took one of the Losec and one of the other ones off him
756. N: right ok
757. P: and when the nurse come she said more probable they might take (.) you know the other two
758. N: yes
759. P: you know but [Dr C/ Dr S couldn't do that our doctors you know it's up to the doctors in the Heath
760. N: [(intake of breath)
761. N: mm so when are you due to the doctors at the Heath
762. P2: um Monday
763. N: Monday
764. P2: the heart specialist [Dr T....
765. P: [Monday afternoon
766. N: good
767. P2: so that's why the nurse was (.) was a bit whatsername cause it was so low
768. N: mm
769. P2: and I think then when I said I've got to see the heart specialist on Monday then they didn't know (unclear) in surgery
770. N: ok
771. P2: they'll leave it until I
772. N: they'll leave it til then
773. P2: go to them I mean that's up to them to
774. N: ok
775. P: and I'm getting (*unclear*)
776. N: are you?
777. P: I went on Thursday (*cough*) and they syringed it
778. N: uh hm
779. P: the nurse syringed it and um she got A.... in to look and he said oh yes it was all clear
780. N: uh hm
781. P: and he said so she said well Mrs B's ear is all red
782. N: right
783. P: so he said well it's bound to be inflamed a bit
784. N: yes yes
785. P: because of whatnot so he said (*coughs*) I won't give her anything now but when I came home I was very pleased (.) shoot me but since then it's gone I can't hear and I feel like I've got something in this ear
786. N: ok well perhaps it might be an idea for you to get your GP to look in your ear again
787. P: that's what I said but mind they did say the nurse did say that A... said he said if I'm not happy [you know then to go back
788. P2: [come back in a few days time
789. N: when did you have it syringed?

790. P: last Thursday
791. N: last Thursday well if it's no better by this Thursday [I would make an appointment
792. P: [yes
793. N: to see your GP
794. P: GP yes
795. N: the inflammation will have had a chance to go down [then
796. P: [down (*coughs*)
797. P: cause they you know my son said er my three boys said it's a wonder he didn't put me on antibiotics because it was inflamed
798. N: yes
799. P: see/ but of course he knows we're on all these tablets [you know
800. P2: [we're on (.)
26=
801. N: well yes
802. P: you know
803. P2: =(.) prescriptions between [us
804. P: [so they don't (*unclear*) but um
805. *Conversation divides into two here nurse and P and R and P2- cannot hear N/P conversation clearly.*
806. N: they're breakfast (.) tablets
807. P2: twelve in the morning with breakfast seven for me and I got five at night plus the one I take throughout the day (.) and er that sort of kept us going because it started when I had to retire when I was 62 I'm 82 now 83 this year so you can't com complain about medication cos it has kept you (.) has kept us going see yeah
808. N: full hip replacement
809. P: yeah
810. N: ok
811. P: so I was wondering if I would mention it this afternoon to (.) you know say anything
812. N: well
813. P: it's nothing to do with them really is it (.) that
814. N: well (.) you need to (.) who are you seeing this afternoon?
815. P: er um (*coughs*) Miss (.) S.....
816. N: and she was your
817. P: yes for [the (.) tummy
818. N: [for your for your tummy wasn't she
819. P: yes
820. N: it might be worth mentioning to her that you know you are getting this problem with your hip
821. P: yes
822. N: but you definitely need to talk to your GP about that cos he can refer you back to the orthopaedic people
823. P: oh I see
824. N: ok
825. P: oh well I can mention [it
826. N: [yet more doctors to see I'm afraid

827. (all laugh)
828. P: I I as I say I I I'm not looking forward to I mean I know what it's going to be like but I mean I'm going to be in there I know at least three weeks
829. N: mm
830. P: and I'm worrying about leaving Dad
831. N: well [I think what we'll need to do is you know perhaps talk a bit about what's =
832. P2: [I'm alright
833. N: =going to happen if if even when we do get a date
834. P: yes yes [yes
835. N: [for you to go into hospital for an operation
836. P: you know cos/
837. N: and we can talk about that in the future can't we
838. P: mm
839. N: (breath intake)
840. P: only he was so poorly when I was [in this last time you know
841. N: [yes I know
842. P2: well I'd have joined her you know but the trouble was they put me the other end of town
843. N: yeah put you in
844. P2: I was in the Heath and [she was in Llandough
845. N: [she was in Llandough
846. P2: (laughs)
847. N: the last time I came to see you you were waiting for J S to get back to you about going to Porthcawl (holiday home) for a week
848. P: yes
849. N: has anything happened about that?
850. P: no
851. N: no
852. P: she she didn't exactly give us a date
853. P2: oh [n no
854. P: now what she/go on [darling
855. P2: [what what she did say it it's definitely there cos she said I've got two vacancies =
856. N: right
857. P2: =and they are definitely for you =
858. N: right
859. P2: =but she said it would be either the end of August or the beginning of September and you'd have to pay so much towards it (.) that was er
860. N: ok
861. P2: that was er [(unclear)
862. N: [so is that funded by social services
863. P: yes
864. P2: yes
865. N: [yes
866. P: [yes
867. N: how (.) how are you standing financially to pay out for that?

868. P2: well th this depends on the (.) c the cost whatever (.) to be poorly down there at the pre at the moment and so it it's a lot of money it's about 370 for a we for a week down there
869. N: [mm
870. P: [the last time we went there [we
871. P2: [but the last time we went they only charged us 50 each
872. P: oh 50 was it
873. P2: 50 each
874. P: yes
875. P2: but this time I think it'll go up to about er I'm only surmising this about a hundred and odd we don't know until the time comes
876. N: and how will you be (.) it's a very personal question [but how/ will you be able to pay for that?
877. P2: [yes
878. P2: well we we what we do we get our money and we work our money as though I'm working (.) our two pensions(.) is it going? (*to researcher*)
879. R: no it's not going (.) oh it is it was on slow sorry
880. P2: our two pensions are due on the Monday but I don't draw on the Monday I draw them Friday then it's as though I'm working
881. N: uh hm
882. P2: we're the same way we have wages I have pocket money and er the pocket money is mine but it's hers you know what I mean?
883. (*laughter*)
884. P2: we don't/ I put my pocket money away and if there's anything wanted as er/ we've done this all our(.)=
885. [(*Laughter*)
886. R: [good system
887. N: a great system
888. P2: =all our 56 years
889. R: mm
890. P: we started off when I was working any overtime was mine and I gave here her wages every week when (.) was anything wanted for the boys I had [the money to give her
891. P: [or or me
892. P: or me
893. P2: or you and there was no discrepancy of getting a lot this week and when you had no overtime you were dropped by [3 or 4 pounds
894. N: [yes yes
895. P2: then a little bit of whatsername used to come up with my friend a little/ oh I had so much last week I haven't got this/ well we didn't wait fair dos (.) we've been down low but we haven't had any problems about (.) money and if there's any holiday we're trying to put
896. P: we put so much a week
897. P2: the the things that gone out naturally we got to pay (.) we pay for our car which is an hundred and ?
898. P: yours has gone up to a hundred and twelve

899. P2: yes
900. P: and [mine is only forty
901. P2: [yours is (.) forty
902. P: I don't know why mine hasn't gone down
903. P2: and on top of that then there's [the this this now got to put a hundred pounds a week
904. P: [(unclear)
905. *Talk splits into two conversations. P and N / R and P2. Cannot transcribe both.*
906. *P2 talking about poor vision*
907. N: well if you do need to go into hospital we'll look at care for your husband
908. P: will you?
909. N: yes
910. P: oh that's alright then
911. N: um (.) the only reason why I'm asking that is that we could look at is p'raps some kind of grant or something to help pay for the holiday when that comes through
912. P2: mm
913. N: um and I can talk to our welfare rights department about that um so it's important that you you know you keep me informed about what's happening with that
914. P2: oh I I (unclear) /
915. N: because we can look at [certain factors [(unclear)
916. P2: [see/
917. P: [it generally come about (unclear)/
918. P2: I'd say one thing that er that's really upsetting really upsetting me um through the naval association I've been trying to get (.) er a grant (.) for the (.) taking the bath out and a shower
919. P: that's what we were having in the other house
920. P2: in there and we're trying to do it now (.) and they more or less refused to do it so my son has had to pay £1800 to take the bath out and put a shower in which I think is er (.) a is a lot of (unclear) for our
921. benefit [you know what I mean
922. N: [mm
923. R: mm
924. P2: but it seems I/ what gets me I've never been out of work I finished when I was 14 in Sunderland on the Friday I started work on the Saturday morning I'm never out of work I went through all the war came out (.) me demob was finished went into a job I stayed there put this factory on its feet and it went on short time so I went into engineering and I stayed there for 37 years (.) and out comes the time now (.) did you work with asbestos? I worked 37 years with asbestos and we were cutting it up like (.) plywood
925. N: mm
926. P2: there was no/ we just sawed we got on the drill to put half inch holes in to put (.) bolts in and all that then and then 3 or 4 of my friends that

worked with me out more or less died with their chest because I've got emphysema myself

927. N: mm
928. P2: but I'm not putting that as er (.) an excuse but it seems as though if you've done this and to try to fight for anything it seems (.)
929. R: hard work
930. P2: hard work you know and it makes you think (.) if (.) and I'm going to be honest with you now if (.) if (.) I knew all what goes on now when I was 62 and I had to retire (.) I might have been a bit of a liar
931. R: mm
932. P2: you know
933. N: mm
934. P2: Cause it's only now that you realise that=
935. P: he says that
936. P2: =being forward or straightforward you're not getting your rights you've got to fight for them
937. R: mm
938. P2: um I'm putting in for a small seat now for the
939. P: shower
940. P2: shower I sent a big one back because it was too large and me son took it back

End of tape

DTU1 Colin

Patient male 70+ years

Nurse male 30+ years

1. N: do you want a chair?(.) sure?
2. (.)
3. N: you're not sleeping much
4. N: I'll be back in a second ok
5. (.)
6. N: (*to staff*) can you let Annmarie know that I'm going to see Colin she wanted to see him
7. (.)
8. N: sorry about that
9. P: that's alright
10. N: Annmarie may be joining us she wanted to talk to you
11. P: yes er Dr... said that (.) oy (.) about the scan
12. N: aha
13. P: and I haven't had it
14. N: and you haven't had it
15. P: no
16. N: ok
17. P: (*unclear*) next week week after or this week so I don't know to do this myself or if you like/
18. N: ok I'll chase that up
19. P: ok thank you (.) um (.) this week I been damned too sick (.) really [sick
20. N: [mm mm
21. P: just vile you know er (.) I been out (*unclear*) I been out I went to a fete
22. N: oh right good
23. P: I walked around
24. (*door opens*)
25. R: Hi Colin is it ok if I come in?
26. P: yes by all means
27. R: fantastic
28. P: and er Wednesday last Wednesday I went with my grandson's (.) um (.) sports day
29. N: oh right yeah
30. P: sorry for
31. N: that's alright you're not
32. P: only thing I was cold you know
33. N: (.) but you managed alright did you?
34. P: yes lovely lovely
35. N: not too breathless or anything
36. P: not too bad not too bad (.) I've been using the epi/ er nebuliser (*unclear*) [sometimes twice a day
37. N: [aha

38. P: three times today I think saying that I walk everywhere and
(*gesticulates*)
39. N: panting (.) how's the weather affecting you
40. P: I don't know not used to all this weather (*hot and sunny*) you know I
try to avoid (*unclear passage*)
41. P: I had my blood pressure taken this morning right because my eyes
going like this you know (.) some something in the eye going like that
you know round and round and round
42. N: feel dizzy
43. P: sometimes yes
44. (.)
45. N: have you had any seizures or anything
46. P: I did (.) glad you mentioned that (.) I had three (.) since last week
47. N: you've had three
48. P: I did but nothing really to really to decide my ... you know
49. (*unclear passage*)
50. P: I'm glad you mentioned that (.) after a long time
51. N: mm it's a long time since you've had any
52. P: I don't take any tablets [you know
53. N: [mm we might need to increase those
54. N: I'll talk to um
55. P: right you are
56. N: Dr G....
57. P: yes (.) I er (.) my (.) yes all of a sudden you know sleeping I'll be
watch television or just relaxing in a chair (.) starts it off shoo (.) and
then I hardly and it's gone
58. N: do you have any warning that it's going to happen
59. P: no
60. N: no
61. P: (*unclear*) least of my problems honestly I feel like er (.) er (.) how can
I put it (...) like (..) I could not feel ..
62. N: no
63. P: no
64. N: ok
65. (*unclear passage*)
66. N: how's your wife dealing with it all?
67. P: alright she's (.) ok
68. N: because it must be quite distressing for her when she sees this all
happening
69. P: yes (.) and my daughter
70. N: mm
71. P: (*whispered*) I'm not sure I can tell her (.) I'm not sure ... honestly I
don't know (.) what to do (.) like the first one but I didn't know I'd
was going to have a second one (.) I didn't tell her the first one but it
was nothing it was sorted I feel sick for seconds and it gone (.) and it
was gone
72. N: ok
73. P: but I mean
74. (*unclear*)

75. P: as I say I've been sick a couple of times
76. N: twice was it
77. P: twice yes once my house and once at my son in laws at the fete you know and Estelle look it and she say what's wrong (.) it's no problem I always carry a bag now=
78. N: aha
79. P: =with me (.) a bag a bag a sick bag (.) not much it look like it looks like (*complan?*)
80. N: so it was undigested food really
81. P: yes it was you know and I make sure I (*unclear*) too much as well you know (.) er
82. N: mm are your bowels working ok
83. P: yes I got (.) piles
84. N: have you
85. P: we don't want to talk about those I been pushing (.) what do you call them (.) inside
86. N: oh suppositories?
87. P: suppositories (.) not bad this morning (*unclear*) but ooh is terrible and and I and I'm not even pushing you know (.) sore (*guess-wife helping?*) itchy itchy
88. N: they are very itchy
89. P: oh my God go mad (.) but as I said we put it in yesterday because she didn't know how to put this suppository but is a tube you put in the tube you push it in like that (.) it was easy
90. N: oh ok
91. P: this morning it was lovely (.) the suppository
92. N: mm
93. P: just push it in and that's it
94. N: are you managing that yourself or is someone doing it for you
95. P: my wife
96. N: your wife's doing that for you
97. P: yes
98. N: is she happy to do that for you
99. P: yes
100. N: are you sure?
101. P: oh yes I told her are you happy doing this (.) yes I don't mind (.) honestly
102. N: mm
103. P: I feel sorry for her (.) come to this you know (.) started with a sore (.) bottom/not really sore sore you know becoming red put some cream but now
104. N: mm
105. P: goodness me (.) anyway she's suffering as well/ not so much now (.) she used to be like that you know after she had her first child I think it was
106. N: oh right
107. P: (*unclear* she had it ever since so she don't mind she does her share to help me now (*unclear*) she had it a long time
108. (...)

109. P: I don't know (.) she's going somewhere Wednesday and she won't tell me where she's going (.) with my daughter
110. N: mm?
111. P: my daughters come down (*unclear*)
112. N: (*laughs*)
113. P: I don't know I got an idea but again I don't want to mention it to her er (.)
114. (*unclear*)
115. N: right ok (.) so you've been doing all that checking up on
116. P: oh yes I have (*unclear*) my daughter is a good girl eldest daughter
117. (*unclear - Talk about money scheme*)
118. N: is that like a pension plan?
119. P: pension plan oh yes I used to put something three pounds a week and the rest of it I don't know how much can't remember ... I think I got some papers there I kept all my papers (.) er that's the only one I've got to find out how much it is
120. N: mm
121. P: because the last letter we had it mentioned (millions) I said phew old age pension I suppose (*unclear*)
122. N: you're not sure what [you're entitled to
123. P: [no exactly see will I have it all will it be(.)
124. N: pension
125. P: my pension or what that's all unsure (.) really when I do die will my wife get the same as I used to get you know (.) things like that (.) give it to her I hope (.) I know she won't want to work again but again at the same time it's it's better to work you know to go to work forget things you know I think so anyway
126. N: mm
127. P: (*unclear*)
128. N: you worry about your wife quite a lot [don't you
129. P: [I do it's good it's been marvellous she's very house proud (.) house garden ground she's fantastic (.) no not I say ideal but she's good
130. N: cause I've not seen your wife very much really have I I've only met her a few [times
131. P: [once I think you did she's very good [she's simple really you know she's not clever you know
132. N: [mm
133. P: (*unclear*) still working at Tesco's now brings in money you know she's not supposed to
134. N: I just wondered if it would be useful if I saw your wife at some point
135. P: by all means
136. N: and then we can have a chat about what her concerns are [really
137. P: [that's right er (.) today every Monday is her day off
138. N: yes
139. P: because I'm not there she rings a friend and goes into town

140. N: oh lovely
 141. P: for lunch a little bit of shopping and by half past two she's back she's back before me
 142. N: yes she always make sure she's back before you
 143. P: yes I say what you doing here why don't you stay out? no no no no no
 144. (.)
 145. N: so I was just wondering whether it would be worth me ringing just to um make an appointment to see [her
 146. P: [by all means
 147. N: it may be she wants to see me on our own is that ok
 148. P: no don't mind no
 149. N: it's just so we can have a chat about what her concerns are really and then it may be that we all get together at some point
 150. P: right [that's fine
 151. N: [to
 152. N: is that ok?
 153. P: that's fine yes yes (.) yes

154. *Patient breaks down crying*

155. N: it's not easy for you at the moment is it
 156. P: it's not no (.) it's not (..) I can't even win the lottery (.) give me a million pounds (*unclear*) I had to looked after in hospital as well but you know big hospitals
 157. N: mm
 158. P: small case (.) one thing in hospital yesterday *oncology hospital* is the only place that is cancer right?
 159. N: well that does chemotherapy and radiotherapy yes
 160. P: I see (.) they got beds up there you know
 161. N: mm
 162. P: I stay there for four days
 163. N: mm
 164. P: (*unclear*) now was transferred in October the beginning of October from *university hospital*
 165. N: mm
 166. P: to *general hospital*
 167. N: right
 168. P: now *general hospital* is is ok it just the freshness infections
 169. N: mm
 170. P: is not really a cancer hospital is it
 171. N: well a lot of patients with with chest cancers go there
 172. P: right ok (.) you know I thought/
 173. N: because it's got the big respiratory unit there
 174. P: I've been thinking of these things lately you know sitting in my chair and er but er

175. *Patient crying- nurse waits, no physical contact*

176. N: are you worried about having to go back into hospital

177. P: er no no (.) no no (.) like I said to the doctor I'd like to die in
178. hospital [if that's possible
179. N: [right
180. P: I don't want my wife [to
181. N: [right right
182. P: (*unclear*)
183. N: have you talked to her about that?
184. P: no (.) I don't think so (.) I should
185. N: well it might be an idea [for her to talk about that because she might
have different ideas to you
186. P: [yes
187. P: I don't think so I mentioned many times but have I mentioned to my
wife I'm not sure
188. N: because I know we've talked about it before and we've said if we've
got a bed here we'll try and get you in here
189. P: yes (.) oh she knows
190. N: I think you've talked about it with me quite a while ago and you've
talked about it with *doctor* as well I think
191. (.)
192. P: I don't know
193. N: well I think that might be something that when you and your wife
together we could talk about then (.) how does that sound?
194. P: fine fine fine
195. N: ok
196. P: yes
197. N: and perhaps what I'll do is arrange to come to your house one day in
the next couple of weeks
198. P: by all means by all means
199. N: is that ok?
200. P: you're welcome you're welcome
201. N: but I'll give your wife a ring to see if she wants/ would want to see
me on my own
202. P: she will she will (*unclear*) you done more for me/ how long I been
here month two months? off and on you know than *general hospital*
and *university hospital* altogether (.) you found my clot (.) in the leg
203. N: mm
204. P: as they were saying aah it's only water give some water lovely and it
was a clot in my leg and they sent me for a scan and on the scan they
found it (.) yes what else the scan my head er
205. N: mm
206. P: my er warferin counts are right 2.40 2.4↑
207. N: yes
208. P: but I still take 13 grams [minimum amount of tablets
209. N: [hm
210. N: yes you do take a lot
211. P: but they checked me this morning
212. (.)
213. P: (*unclear*)

214. N: well you're here all day and so am I so if you think of anything else
I'm around

215. P: (*unclear*)

216. N: so the things that we need to do/ I need to do at the moment (.) I want
to give your wife a ring

217. P: right

218. N: at some point today (.) she'll be out at the moment having lunch I
guess will she?

219. P: she will yes

220. N: and um (.) we need to chase up your (.) what we're going to do about
your scan

221. P: yes

222. N: I'll have it/ and I need to talk to Dr B. about these seizures that you've
had

223. P: yes I've had them again (*unclear*)

224. (.)

225. N: is there anything else that you can think of at the moment

226. (.)

227. P: it's only/ well my body to do with my body or (.) my legs are
worrying me (.) they come down a lot but they still swollen you know

228. N: mm

229. P: (*unclear*)

230. P: I put my hand there and there's a hole like that and it's not/

231. N: oh indent

232. P: indent?

233. N: yeah an indent

234. P: what you call it?

235. N: an indent

236. P: indent (.) ay god swelling (.) it went you know

237. N: yes that's due to fluid if you push on it it will leave a dent in there

238. P: oh it's a big hole you know

239. (.)

240. P: god god (.) yes my legs swell now (.) from there to there

241. N: the other one's not swollen

242. P: yes this one is a lot (.) and er there there's red on here there you know

243. N: is it?

244. P: well quite red you see (.) not so much now because my wife puts a lot
of cream on it

245. N: is it sore at any point

246. P: not er/ itchy itchy

247. N: let's have a look

248. P: sorry (.) course I was looking at Clive's legs

249. N: mm?

250. P: Clive's legs

251. N: oh right yes

252. P: they were red from down here to here

253. N: perhaps I need to look at his

254. P: yes (*laughs*)

255. N: (*laughs*)

256. P: no/ I don't know I I thought you know
257. N: unless he's been out in the sun of course
258. P: yes yes of course
259. *(laughter)*
260. *nurse examining leg-unclear talkof cream etc*
261. N: you need to keep an eye on that (.) what I'm concerned about ... but
the other thing is sometimes people can get an infection on the
262. skin [and that comes up as quite red and hot
263. P: [good god
264. N: and angry [I don't think you have it at the moment
265. P: [yes yes
266. *Patient talking to me during exam -unclear*
267. N: so if it becomes very painful and hot (.) um (.) you need to have you
need to have antibiotics for that really
268. P: *(unclear-talking very low and quiet)*
269. *(Unclear passage)*
270. P: I can't wash (.) my face (.) I stand up in the bathroom (.) you know
and (.) I can't
271. N: mm
272. P: no she got to wash me you know my face my head she washes my
head and all because she's er ..
273. N: yes
274. P: so that hand's weaker is [it
275. P: [no no no not weaker (.) this (.) is the boy
here look [my stomach
276. N: [right mm
277. P: I can't bend over so I can only/ how can I put soap or lanolin (.) I
should do that (.) but not any more (.) I know I don't know this is I
put it I had the other one for some time you know off and on you
know like all (.) she washed me this day this morning (.) I can't
(unclear) honestly
278. N: mm
279. (.)
280. N: do you feel quite tight (.) round your [stomach
281. P: [tight
282. P: you know it's supposed to be 42 and if I'm wearing pullover it's not
bad because I can *(unclear)* you know
283. N: yes
284. P: you see this is what worries me you know worries cause I can't (.)
freely move you know
285. N: mm (.) it restricts you quite a lot doesn't it
286. P: as I say the washing (.) if I stand up yes I'm alright you know
(sighs) *(unclear)* and er when I shower shave I don't know there's
something there you know *(unclear)*
287. N: who helps you with that?
288. P: oh my wife
289. N: your wife
290. P: oh yes (.) she tries to get down to the bath you know *(unclear-*
papers rustling)

291. P: oh yes yes she washes my face my back I can't turn around much
you know wash my back my arms (.) face (.) all that (.) yes

292. *Papers rustling*

293. N: I just (.) I just wonder whether it would be helpful (.) for the
occupational therapist to re review your home situation

294. P: I see

295. N: see if there's any extra equipment that you're needing

296. P: I don't know

297. N: have you got a seat? a bath seat

298. P: yes oh yes

299. N: is it one that comes up and over the bath [or is it

300. P: [no

301. P: eh? yes

302. N: an electric [one that comes up and over the bath

303. P: [oh no

304. P: I had one/ well somebody lend it to me cause he had the same
problem he had a stroke

305. N: oh ok

306. P: so I think I used it once I need to be careful because er how can I
say (*unclear*) and I can't stretch my legs so I was in a parlous state I
couldn't use it I'm sorry I couldn't use it

307. N: mm

308. P: was er something like a corner like a (.) see babies you know

309. N: yes

310. P: drop down take it off and that's it you know put it back on again
and er (.) I don't know if I seen one before but er (.) no I couldn't
get on with it

311. N: I'll have a chat with the occupational therapists and [see if/

312. P: [bless you
thank you I'd like to get down to the bath

313. N: mm

314. P: all of my body you know

315. N: yeah yeah

316. P: doesn't matter how much I go down (.) with that you see it only
comes down here the water and I can't stretch my legs you know

317. N: mm

318. P: oh a lovely bath (.) oh yes

319. N: ok

320. (.)

321. N: is there anything else you can think of↑

322. P: no I think er I think that's the lot really how do I know when the
time comes you know

323. N: mm (.) that's tricky

324. P: tricky yes I dare say I you know we're not medical people you
[know

325. N: [mm

326. (.)

327. P: say you're feeling very tired very weak and falling asleep all [the time you know (.)go in a coma something like that you know(.) then you die
328. N: [mm
329. N: I mean everyone's different [really
330. P: [of course
331. N: but generally people start to feel (.) more tired (.) things become more of an effort
332. P: that's right
333. N: and then you start spending more and more time in your bed [really
334. P: [bed
335. N: um
336. P: that's right
337. N: because people feel really really tired so I guess what a lot of what um *doctor* said is er is fairly fairly true
338. P: oh yes it's alright yeah (.) yeah
339. (.)
340. N: is it worrying you how it's going to be
341. P: not really because/ (.) no I don't think so (.) I mean if you can take the road (.) and walk with God (.) no I don't think so (.) not yet anyway (.) cancer might be ... but you know I mean (.) I don't think so (.) but it's the knowing that you're going to go one day/ It don't bother me cause we all got to go but er (.) knowing this thing is going to kill you (.) (*sigh*)
342. N: it's hard to get your head round isn't it
343. P: extremely yes
344. (..)
345. P: I wonder if Estelle (*unclear*) I felt sorry for them and they're dead
346. P: I want to know how bad that was you know (.) they make a decision cut that off we'll see how it goes (.) would you say? (.) no they just/ offering surgery is quite difficult because what they wouldn't want to do is put you through an operation unless they thought unless they thought it was going to (.) cure you of it
348. P: yes (.) I hope so
349. P: um and also you've got to be well enough to withstand quite major [surgery
350. P: [that's right
351. N: so in your case I guess they felt that surgery wasn't really
352. P: wasn't surgery tumour as well you see
353. N: yes
354. P: (*unclear*)
355. N: mm
356. P: I do know there's something there [because now and again [I can feel it you know
357. N: [mm [mm
358. P: and here as well but er (.) doesn't bother me like er painful to take a paracetamol or something like that you know

359. N: the biggest problem it's giving you at the moment is these few seizures you've had isn't [it
360. P: [this is it yes yes of course the right side as well this is this side is very painful
361. N: mm mm
362. (.)
363. P: I don't know
364. (.)
365. N: what dose of steroids are you taking at [the moment Colin?
366. P: [one
367. N: just one (.) 2 mg is it
368. P: I think I just get my paper my wife gave me a paper (.) I think
369. N: she prepared you didn't she
370. P: oh yes
371. (.)
372. P: this is the tab tablets I'm [on
373. N: [oh right ok
374. (.)
375. N: yeah 2 mg°
376. *Chats to me –unclear*
377. N: are you getting any headaches?
378. P: sometimes (.) yes yeah but er don't bother me I don't take anything for it you know (.) once a week (*unclear*) and I get it right there is it possible to have some tablets to go to sleep (.) you know
379. N: afraid not (*low tone*)
380. P: s'alright fine(.) my wife again asked asked I must get I said I don't think so but anyway I did ask
381. N: no um
382. P: no
383. N: we're not allowed to do that in this country unfortunately
384. P: righto
385. (.)
386. P: no! (.) I meant/ (.) to go to sleep at night
387. N: oh go to sleep at night sorry
388. P: no no no no [no
389. N: [I've got the wrong [end of the stick (*loud*)
390. P: [I thought you did but not yet not yet oh no yes (*laughing*)
391. N: um (.)
392. P: aye something to=
393. N: = to help you sleep at night (.) we can certainly sort [that out
394. P: [I'm awake so many times sitting out of bed
395. N: yes
396. P: (*unclear*)
397. N: I'll just have a little look at/

398. P: (*unclear*) go to bed 2 o' clock I'm up by 4 half past three I can't sleep (.) I don't know if it's my nerves↑ I can't relax (.) I get up my chair something like this well it was from hospital the one I got this is the chair that goes with the wardrobes simple you know so somebody had the wardrobe and they asked me the site manager asked me Paul you want this Paul they call me yes fine ... yes I take it's worth a fortune
399. N: (*laughs*)
400. P: you know it's lovely and it's a marvellous chair
401. N: come in handy now though
402. P: oh it's marvellous (.) sit down on the settees we got in our room and I can't (.) this chair you just sit down relax you know (.) lovely
403. N: can I just have another look at your bit of paper so I can have a look what tablets [you're on again
404. P: [oh right (..) here you are
405. N: thank you
406. P: the steroid was it (.) does it say
407. N: yeah it's 2 mg [once a day yeah yeah
408. P: [oh it does (.) I take one a day she says I take one a day (.) 3 times 4 times a day I take the antacid
409. N: mm
410. P: tablet and the new tablet you gave me I don't know what is it (.) oh my god I don't know
411. N: metachlopramide (.) tegretol (.) oh imeprezol
412. P: that's it
413. N: that's for your tummy
414. P: tummy that's right
415. N: cause you're on steroids and they irritate people's tummies
416. P: yeah (.) and er (.) what shall I say (.) that's alright I think
417. N: you don't take very much really do you
418. P: no really no no (.) now (*unclear*)
419. N: so I'll write to your G.P. to see if we can get you something to help you sleep at night
420. P: lovely
421. N: um but I need to talk to Dr B about whether we increase increase your your anti-epileptic tablets
422. P: yes (*very quiet. radiotherapy drugs etc?*)
423. N: well we might need to tinker with them (.) just increase them a little bit or we might need to increase your steroids a little bit (.) one of the two
424. P: fine fine (.) I start them on Saturday
425. *Patients speech too quiet to transcribe –getting tired? Talk about speech difficulties in morning??*
426. (.)
427. P: (*unclear- daughter sleeping tablets?*)
428. N: I'll write to your G.P.=
429. P: oh right

430. N: = so if you give him ring in a couple of days time=
 431. P: right
 432. N: =you should be able to pick something up
 433. P: right you are (.) try that I don't know I don't like all these drugs
 434. N: mm well try them see how you get on
 435. P: last night was not bad I took the headrest off and (*unclear*)(.) er (.) I sat in my chair
 436. N: mm
 437. P: for example you know (.) I had something in my ears as well you know (.) about 2 o' clock I woke up (.) it's ok you know I feel very heavy very very weary so said right I go to bed you know I'll try you know
 438. N: mm
 439. P: stretch my neck (.) normal (.) ooh (.) was alright
 440. N: mm
 441. P: I woke up about 5 something like that
 442. N: mm
 443. P: I still can't get (.) a good nights sleep
 444. N: a good nights sleep (.) (*unclear*) I can sleep in the day
 445. N: mm is there anything that wakes you up
 446. P: I don't think so (.) I can't remember (..) no I don't think so
 447. (..)
 448. N: ok
 449. P: nothing honestly
 450. N: alright
 451. (.)
 452. P: as I said before hospital (*unclear*) wards 40 people you know (.) they were very good though (.) very good (.) marvellous (.) they were marvellous people in both I think
 453. *Few minutes talk about fellow patient that died in hospital, how he was and how he died-researcher talking as well*
 454. N: well I'd best get you back for lunch
 455. P: thank you very much/ what time is it
 456. N: ten past 12
 457. P: good god
 458. N: or else I'll be getting told off by Jill and Jane
 459. P: ah yes (.) er (.) I don't eat very much but what's there (.) lovely
 460. N: mm mm
 461. P: I try to tell my wife you know
 462. *Extended passage chatting animatedly about food, the school sports day etc-nurse makes minimal responses*
 463. N: I'm not quite sure what's on the menu today
 464. *More talk food, appetites other patients etc*

465. N: right I'll get you back

466. End of tape

DTU 2 Bill/ George/ Phil

Taping occurs in communal area. Nurse speaks to three patients (P1, P2 and P3) seated next to each other

1. N: um how you getting on Bill?
2. P1: not too bad
3. N: oh right [ok
4. P1: [is that off
5. N: pardon me
6. P1: is it switched on or
7. N: I am (.) see it's switched on (*laughs*) say hello to Annmarie (*laughs*)
[*laughs*]
8. P1: [stop/ (.) I'm/ yeah go on (*impatient tone*)
9. N: yeah/ no no it's just a talk to see how you are it's really just a normal transaction
10. P1: yeah yeah I'm not too bad but I've started to get a lot of indigestion very bad again now
11. N: yeah which gives you an indication of
12. P1: well well that's the first indication (.) now it's three weeks since I/ (.) three weeks last Tuesday that I came in (.) right
13. N: [yeah
14. P1: [um
15. N: is it three weeks? good Lord it does seem less than
16. P1: three weeks (.) see (.) now the week after next is five weeks [til I'm due it again
17. N: [yeah yeah yeah
18. N: Jill has written out (*to coordinator*) Jill you've written [out a referral haven't you
19. P1: [she she she
20. P1: she's written [it in your book (.)I'm going to clinic next Thursday
21. N: [lovely lovely
22. N: yeah yeah and we we'll have no problem getting you in (.) so you'll come in again probably the Monday
23. P1: yeah well or the Tuesday [*unclear*]
24. N: [or the Tuesday
25. P1: the Tuesday I came in last time
26. N: right
27. P1: and then they took the six litres off me on the Tuesday
28. N: right
29. P1: another (.) er five litres between the Wednesday and the Thursday morning
30. N: right eleven li/
31. P1: so eleven (.) [eleven litres all together=
32. N: [excuse me
33. N: ok
34. P1: =that they drained from me right
35. N: alright
36. P1: and um (.) and then say cause I say (.) I go home and I don't do anything for
48 hours

37. N: [right
38. P1: [I just rest because when I've had it drained as it's getting towards the drain is coming off like I start to lose and I've got to talk in pants you know
39. N: yes
40. P1: because I can't take a good breath
41. N: mm
42. P1: see (.) and um which I can't anyway [when I'm filling up
43. N: [I know I know I can see it's going getting quite uncomfortable for you isn't it
44. P1: oh oh it is by the end of it I've got to start now start using my sock er er (.) aid to put my socks on cause I can't I can't get my socks on I can't I can't get I can't get up no further than that with this leg I don't [know
45. N: [no do you think you should come in sooner
46. P1: I don't think so [no
47. N: [no
48. P1: 5 weeks is [about
49. N: [are you sure?
50. P1: I/ well (.) [yeah I think so
51. N: [ok
52. N: well really it's next Thursday now so it'll be the following Monday [so it won't be so bad
53. P1: [yeah
54. N: [ok ok
55. P1: [yeah yeah
56. N: let us [know if we can do anything
57. P1: [it's about it's about
58. P1: it's about ten days now
59. N: alright
60. P1: it will be about ten days time that I'll be coming in won't it
61. N: [alright
62. P1: [and that'll be about [ready that'll be about ready
63. N: [that'll be about right
64. N: ok I'm [sure you will
65. P1: [if I have to wait any=
66. N: = longer [than
67. P1: [=than a week (.) I would be= [really=
68. N: [=extremely uncomfortable
69. P1: =uncomfortable by that time I would have thought (*unclear*) a week because my stomach can't expand (.) you know and things like that like I just take um a couple say spoonfuls if you like or forkfuls whatever I'm eating (.) and I feel a bit bloated so I I um I got I got to eat [so I force myself to eat
70. N: [yes I know yeah you do
71. N: oh right
72. P1: I try to eat as much as I can of what I cook
73. N: yeah
74. P1: I cook for myself/

75. N: /yes probably little and often Bill would be the best thing
[wouldn't it
76. P1: [yeah yeah
77. N: not big meals [little meals (*unclear*)
78. P1: [well well I don't I can't eat a big meal
79. N: yeah yeah
80. P1: so I don't eat like for instance I might have an egg on toast (.) I bought some eggs like prior and then I have/ I don't have them every morning (.) I I might have or it will be just a piece of toast and there's just a sliver of marmalade on it because of the diabetes
81. N: yeah
82. P1: see
83. N: that's right of course
84. P1: so I only I just have a I don't buy the diabetic marmalade because it's too blooming dear
85. N: yes I know
86. P1: and so so I don't put it on thickly
87. N: yes yeah no I know you [balance it out
88. P1: [one of those one of those little sachets will do will do me and if I only hases say one round of toast half of that one so that shows you how much marmalade I would put on it
89. N: no I know don't worry about [that I know Bill it's you it's your body in the end so you'll you'll you'll be able to balance it
90. P1: [but then for dinner
91. P1: yeah (.) oh um for my dinner I have a tin of soup
92. N: right
93. P1: then then I have my main meal at 5 o' clock (.) see I eat regular 9 o' clock in the morning
94. N: yes
95. P1: then 12 o' clock half past 12 midday then 5 o' clock at night (.) right↑
96. N: right
97. P1: then I have a sandwich or something like that before/ after 10 o' clock (.) prior to going to bed at 11 half past 11 depends what's on the television
98. N: yeah well I know depends whether it's worth sitting up for or not/ ok about that then (*rapid*) well we'll book you in for that week and I'll see you next week anyway [and book you in for the Tuesday then
99. P1: [yeah yeah
100. P1: I think I think that'll (.) that should be ok I should be right by then
101. N: right
102. P1: that'll be the the right time to do it
103. N: oh right if it's if it's [different we can organise it
104. P1: [if it gets it's hard again now
105. N: yeah (.) I can see
106. P1: so that's another indication [isn't it
107. N: [yeah
108. P1: see so by then I will be ready
109. N: you will be ready/ lovely well look I'll I'll double check that it that the referral (*unclear*)
110. P1: [and I'll I'll confirm it next week shall I

111. N: next week (.) Thursday
 112. P1: yes yeah
 113. N: shouldn't be any problems is that alright Bill
 114. P1: yeah (*unclear*)
 115. N: ok lovely lovely (.) that's great (*to colleague*)you knew that there was therapy booked (.) for Bill (*writing*)oh marvellous lovely lovely lovely lovely (.) I was just going to che/
 116. P1: (*unclear*) on the Tuesday see
 117. N: yeah
 118. P1: and they do it Tuesday Wednesday [and they take me in Thursday
 119. N: [you can go home
 120. P: I can come down here then
 121. N: I know and go home [Thursday
 122. P1: [I can go home from here see
 123. N: I know yeah
 124. P1: if I come in on the Monday and it's done Monday Tuesday then I'm ready to go home then Wednesday [that wouldn't
 125. N: [so you'd prefer Tuesday
 126. P1: well I wouldn't I wouldn't be coming in on the Thursday then I couldn't
 127. N: no I know it's too much for you
 128. N: (*to colleague*) yeah yeah what date (.) the the second of July(.) yeah second that's fine (.) I'll see them tomorrow and I'll be able to confirm [it for you next week
 129. P1: [I prefer it that way cause it works out better then [doesn't it
 130. N: [yeah yeah (.) yes that's good (*keep the plan?*)
 131. N: alright gentlemen? (.) alright? (.) have you heard George?
 132. P2: no
 133. N: no nothing yet ok
 134. P2: I had a phone call and spoke to the secretary and she was going to have a word with him (*unclear*)
 135. N: yeah yeah yeah
 136. P2: and feel happy about it
 137. N: yes he needs to feel happy about it
 138. P2: yes yes
 139. N: mm (.) whether um he fancies putting you/ cause he needs to be able to put you to sleep and bring you back round again isn't it
 140. P2: mm
 141. N: ok so you're hoping to hear in the next week or two then is it? TB rang and asked how you were you remember TB↑so I said I'd let you know she was asking you remember TB from Tenovus↑she just rung and I said that you were you were hoping for the operation hip operation and at the moment that was your main concern really so she said we're both keeping our fingers crossed for you alright?
 142. P2: yes
 143. N: ok (.) any other problems or worries (.) none (.) is that getting worse
 144. P2: (*unclear*)
 145. N: seems to be (.) ok

146. P2: *(unclear)*

147. N: do you think it's because of (.) the pain are you getting more pain (.) you see that wears you down

148. P2: *(unclear)* leg yes

149. N: yeah (.) that can wear you down you see

150. P2: *(unclear)* I know when I'm laying down I've got the pain sometimes xxxx

151. N: laying down yeah (.) so really a lot of your time is laying down

152. P2: yes

153. N: and you'd like to be more active wouldn't you

154. P2: *(unclear)*

155. N: well you will you'll be doing a lot of stuff (.) yeah no yeah I know

156. P2: *(unclear)*

157. N: I know yeah well I know I know (.) you do well to come here so that's good

158. P2: yes

159. N: yeah

160. P2: *(unclear)*

161. N: I know I know and you you're used to doing far more mm (.) you eating all right?

162. P2: quite well

163. N: oh quite well ok (.) ok ok well we'll just wait to hear won't we

164. P2: yes

165. N: see what happens (.) ok (.) and I'll see you next week

166. P2: yes

167. N: alright Phil?

168. P3: [yes

169. N: [oh good

170. P3: I've been on one of those *(unclear)* this week

171. N: yes yes yes

172. (.) *(writing)*

173. P: I won't be coming [next week

174. N: [oh right

175. P3: because I'm on holiday

176. N: oh (.) fabulous where to?

177. P: south er (.) south Avon somewhere down there er

178. P2: Somerset way?

179. N: Somerset Somersat (*accent*) Somersat excuse my accent it's dreadful

180. P3: yes

181. N: *(laughs)* well it makes a change me doing somebody else's accent than the other way round

182. P3: oh yeah aye (.) it's only for a week

183. N: for a week (.) who you going with

184. P3: with my wife

185. N: oh right how you getting down there

186. P3: bus

187. N: oh you're getting the bus down oh that's [lovely

188. P3: [er ah well it's the main bus er well
you know family (.) other people in the bus

189. (.)

190. N: it's kind of a tour thing is it

191. P3: tour thing
 192. N: yeah yeah been organised oh that's lovely
 193. P3: yeah
 194. N: oh that's good (.)so what day are you going
 195. P3: on the Monday [I think
 196. N: [so it's Monday to Monday
 197. P: yeah
 198. N: oh right Monday to Monday
 199. N: oh that/ are you looking forward to it
 200. P3: yeah
 201. N: oh good that's [good
 202. P3: [well that's difference
 203. N: it is yeah
 204. P3: now you see (...) doctor (.) has (..) taken me from the car
 205. N: right right
 206. P3: he won't let me drive [see
 207. N: [yes I know I know
 208. P3: and he won't let me=
 209. N: =fly
 210. P3: fly
 211. N: mm
 212. P3: so I
 213. N: you're restricted
 214. P3: well I got a daughter in America
 215. (.)
 216. N: mm
 217. P3: so I can't go and see [her
 218. N: [yeah
 219. P3: so she's got to come and see us
 220. N: yes
 221. (.)
 222. P3: and (.) she's (.) she's busy (.) so=
 223. N: =it's a bit difficult but she will come and see you/ she will I mean
 224. P3: yes
 225. N: you know
 226. P3: and er (.) we've had to give up our (.) caravan
 227. N: why because of the driving
 228. P3: driving
 229. (.)
 230. P3: (*unclear*) 18 years
 231. N: so it feels like you've given up a few things I'm sitting on Frank's feet I hope
 he doesn't mind it must feel like you given up a few you've given up quite a
 few things doesn't it
 232. P3: yes (.) well I've had to see
 233. N: yeah
 234. P3: had to (.) I don't mind I'm honest see my wife said to me stop driving
 (*laughs*)
 235. N: yeah (.) I think you see you you see Phil it's not just you it's other people as
 well you see

236. P3: yeah yes
237. N: I suppose it's a bit/ cause Phil had to give up his um his car as well didn't you
Phil yeah and I I I think it's quite difficult because it's it's it's er
independence isn't it [you you know
238. P3: [yes
239. N: not actually the car it's it's um real independence you're giving up
240. P3: yeah that's it
241. N: and then having to rely on other people to get from A [to B is=
242. P3: [yes
243. N: it's not very satisfying
244. P3: no (.) no (.) but er I I I'm eating well I'm living well
245. N: that's good
246. N: are you sleeping alright at night
247. P3: yes I wake up about half past five six o'clock (.) which is early really
248. N: early in my book (*laughs*) but that's because I'm not a morning person tha
that's good
249. (.)
250. P3: it's lovely being down here
251. (.)
252. N: well I suppose it gets you a chance to um
253. P3: ooh it do and to talk
254. N: to talk yes I know because that's another thing yeah because (.) because
that's another thing George you're in a similar situation it's only/ you don't
get a chance to talk to other people really
255. P2: at home
256. N: no[yes
257. P2: [*unclear*]
258. N: which is actually very difficult isn't it I mean you/I think you've coped with
it very well you're quite strong (.) um (.) but it is very difficult(.) mm and I
think it's cause it's imposed on you makes it worse (.) do you know what I
mean if it was if you if you had the choice still to go out (.) that's a choice
isn't it
259. P2: yes
260. N: but because you don't have it it sort of compounds it a bit (.) doesn't it (.) a
little bit yes/yes I think I think that's an important thing about here is you get
a chance to meet other and talk to other people
261. P3: yes that's right yes it's marvellous here (*unclear*)
262. N: yes (*laughs*) anyway I'll miss you next week
263. (*unclear*)
264. P3: people here are marvellous
265. N: I know (*laughs*)
266. P3: even the other/
267. N: the other people I know
268. P3: and (.) if I say so (.) I've got the same fear I've got the same (.) er (.)
269. doings [as what they got
270. N: [yes
271. P3: you know
272. N: yes
273. P3: not in the same place but er/

274. N: yes the same problems yes so /you/ peop/they understand
275. P3: yes
276. N: yes
277. P3: that's right
278. N: yes
279. P3: but it's (.) marvellous
280. (.)
281. P3: I still can't er think (.) about what I've got [because I don't/I eat well
282. N: [I
283. P3: I go to sleep
284. N: yes so it's hard to believe
285. P3: aye
286. N: yes
287. N: do you think the art therapy is helping with that because you both you both
/you're seeing F..... again aren't ye?
288. P2: haven't seen her yet
289. N: oh have you not F.. is the art therapist (.) you have seen her though haven't
you
290. P3: yes once she said she'd er I'll go and see her on a Monday
291. N: yes so she's to bring you in on a Monday
292. P3: but she's er (.)
293. N: she's got other people at the moment there's a bit of a waiting list
294. P3: yes
295. N: ok
296. P3: and er (.) she she 'll tell me when she can see me
297. N: yes I think she's trying to go/trying to get more time (.) for here but it's kind
of
it's none of my/mm I think we'd have her here five days a week/four days a
week if we could but it's not up to me so we'll just have to see she's going to
try and get some more time so maybe she'll get to see you sooner (.)sorry
F.....I stopped you in your place
298. P3: she said to me (*unclear.insomnia?*) you know
299. N: sorry Bill see you next week *other patient* take care
300. P3: but she listens marvellous
301. N: yes you said that yes
302. (*unclear*)
303. N: well it's a different way of expression which is nice [yes
304. P3: [yes
305. lovely girl
306. N: she's nice
307. P3: and it is here it is here (.) every one of you
308. N: oh yes
309. P3: are are are marvellous
310. N: ah thank you (yeeze) Bill (*laughs*) I'll go out [I know I know I know
311. P3: [*(unclear)*
312. P3: you are (.) because you're in charge
313. N: oh right well I try to be I don't know Bill now I don't know if that always
comes off (*laughs*) (.) I think though it's groupwork (.) everybody working
together
314. P2: (*unclear*) that's what it is

315. N: yes
 316. P3: which is good (.) what you say is good
 317. N: well I hope so
 318. P: no o
 319. (unclear)
 320. N: yes I know what you say you kind of need a bit of a captain don't you
 321. P3: ay?
 322. N: you need a captain to run this ship
 323. P2: that's right
 324. N: even if it's (laughs)
 325. P2: no
 326. N: yes you do don't you
 327. P: marvellous
 328. N: mm
 329. P: (unclear)
 330. N: no no no I think everybody we could (.) [run together yes
 331. P [yes
 332. P: (unclear)
 333. N: oh yes (.) ok that's great I/ so I won't see you next week
 334. P3: no
 335. N: I'll see you the following week
 336. P3: yes
 337. N: enjoy your holiday (.) ok I hope you get decent weather for [it
 338. P3: [well that's what
 we're hoping
 339. N: yes I know I think/
 340. P3: er/ we going um/ we're going in a bus (unclear) we're going out in the bus
 341. N: oh there's um um tours organised
 342. P3: yes
 343. N: yes that's good that's good (.) takes a bit of the pressure off doesn't it
 344. P3: yes
 345. N: mm
 346. P2: well that's it
 347. P3: otherwise I used to go all the way around (unclear) in the car
 348. N: oh right (.) yes
 349. P3: I'd be all round here
 350. N: yes car I know (.) how long ago was that then was that a while ago
 351. P3: yes (.) yes
 352. N: yes/ to be honest it's got so busy it it's more difficult now Phil it's got very
 very busy you know you have to be a very confident driver to do that now it's
 just there's more cars more vehicles
 353. P3: yes
 354. N: I was in France with somebody a couple of years ago and phewph (.) it it's
 um stressful to cope (laughs)but you went with your caravan did you
 355. P3: no oo
 356. N: just drove with the car
 357. P3: with a car
 358. N: oh right different places
 359. P3: and er we er we had er a canvas tent

360. N: oh right just a tent then
 361. N: well that was great
 362. P3: yes
 363. N: wasn't it
 364. P3: yes
 365. (*unclear*)
 366. N: well hopefully the week will work out well for you and
 367. P3: yes
 368. N: well
 369. N: okey doke I'll let you sit down where where you were oh you're making a
 (*unclear*)Bill are you?
 370. P1: I'm trying this wool I had the wool given to me
 371. N: it's thicker wool isn't it
 372. P1: like an arran wool or summit four ply or something
 373. N: oh yes it's thick
 374. P1: what they call four ply I expect
 375. N: yes
 376. P1: and er
 377. (.)
 378. N: well give it a go
 379. (.)
 380. N: great there's a lot of/ it's a thick thread isn't it
 381. (*unclear*)
 382. N: (*laughs*)
 383. P3: that's right isn't it I thought that's the one I'm having
 384. P1: yes I tell you (*unclear*)
 385. N: depending how it turns out
 386. P1: it's a very thick one thick wool [so I said if it turns out alright
 387. N: [exactly
 388. P1: so I said if it turns out ok and he likes it he can have it
 389. N: oh right there you [go
 390. P1: he bought one off me in the other (.) thing see/ but I couldn't get it til about
 half past four last night tried all over Barry yesterday to try and get the proper
 string (*unclear*) string like
 391. N: oh right
 392. P1: four o'clock half past four I thought oh I'll go in that in the pound shop right
 393. N: oh right
 394. P1: in the pound shop and I said do you sell string (*unclear*) string like and she
 said yes in that box over there look
 395. N: oh well done
 396. P1: and I only paid a pound for a big ball like that look
 397. N: that kind of haberdashery stuff is hard to get these days [isn't it
 398. P1: [ooh
 399. N: people don't do so much of it Bill you see
 400. P1: I I can't [get the
 401. N: wool shops are shutting down nobody knits any [more
 402. P1: [no no
 403. N: and my mother I/ she she noticed that/ it's very hard to get things like wool
 and material people don't make any more

404. P1: they don't no
405. N: they they leave it very much up to
406. P1: these youngsters coming on don't knit like we my my mother used to and my
wife used to
407. N: no no
408. P1: your generation
409. N: yes no
410. P1: they don't seem to/
411. N: well it's mass produced and it's cheaper
412. P1: yes well of course it [is
413. N: [yes
414. N: and that's what they do
415. (.)
416. P1: you take them (.) them (.) flowerpot hangers (.) you can still find them in
whatsername shops er (.) pound shops or wherever like that they sell them (.)
you can buy them for a quid couple of [quid
417. N: [couple of quid so who's going to
bother making it then
418. P3: I can I can make them
419. N: but not for [that money
420. P3: [but not for that price
421. N: no I know I know I know
422. P3: you know and I can't get the materials the proper [materials
423. N: [I know I know textile
424. P3: so II so I'm that's why I'm sticking to these type of things like and um (.) and
the pull cords
425. N: yes
426. P3: of course the pull cords is my own (.) design like [you know
427. N: [oh the pull cords are great
428. P1: you know
429. (.)
430. N: the pull cords are great
431. P1: and A... wanted me to make half a dozen of them to send over to his daughter
to sell in America
432. N: yes oh ha export (*laughs*)
433. P1: Welsh export from *hospice*
434. N: you/ there you go (.) see (.) put us on the map
435. P1: you know I go to it's a hobby to me so I got to do it when I want/ when I feel
like
436. N: yes exactly
437. P1: nice day like this you don't want to sit in the house doing it do you
438. N: no no [exactly
439. P1: [you know if it's raining
440. [It's a
441. N: [it's er (.) perfect [thing to do
442. P1: [I get it out then=
443. N: =and do it
444. P1: and there
445. (.)

446. N: okey doke (.) ok gentlemen I'll see you all next week apart from you Bill(.)
enjoy your holiday
447. (*unclear*)
448. N: that's alright
449. End of Tape

DTU 3 Alan

Patient male 40+

Nurse male 30+

1. P: there's no reason that you can't have (.) a pack of these because she tends to get (.) she tends to run down to the last 4 or 5 before she gets a prescription every month (..) so this is (.) what I've been (.) or was taking but they've taken me off these completely [and put me on the phenytoin
2. N: [ok
3. P: now that is the standard tegretol that I was taking
4. N: Tegretol 200 mgs [yes
5. P: [that's right now she takes that and because the tablet is is physically different
6. N: ah no they are different (.) they're ordinary tegretol tablets the ordinary carbomiazipine tablets and they're tegretol controlled release (.) so they're different
7. (.)
8. P: right (.) ok
9. N: that's why they're (.) they look different cause they're a controlled release tablet and they're [not
10. P: [so they release over a period of time and they release [all at once
11. N: [all at once
12. P: so they are different
13. N: they are different
14. P: so she can't have [them
15. N: [she can't have them
16. P: ok all right
17. (.)
18. P: I I thought that they would be (.) the same alright
19. (.)
20. N: not that you should be swapping to changing tablets between patients anyway
21. P: no no
22. N: ha ha
23. P: so when I was in hospital and and they were giving me (.) um (.) Losec which was was in a brown lozenge thing like that [as opposed to the Losec I was taking at home
24. N: [mm
25. P: which are capsules
26. N: capsules
27. P: they're no [different
28. N: [no no they're exactly the same they're just made by a different manufacturer
29. P: that's what I thought these were you see
30. N: ah no
31. P: right (.) ok
32. N: one's a controlled release tablet that's why it's got CR at the end of it=
33. P: right

34. N: =and the other one's just an ordinary Tegretol
35. P: ok then (.) so er what what I would advise her to do is get the doctor to/
36. N: go to the doctors earlier (.) that way she's not on her last [one
37. P: [go to the doctors a
bit earlier or get her to s s stick (*unclear*)supply (*unclear*)damn things (*very quiet now*)
38. N: or (.)
39. P: she takes them for epilepsy you [see
40. N: [yeah yeah
41. N: she just needs to get a repeat prescription a week early [really
42. P: [yeah
43. P: (*unclear*) once or twice a day (*unclear*) yes (.) right um (.) so if I were to
bring those in here
44. N: mm
45. P: could you use them
46. N: no (*abrupt*)
47. P: no?
48. N: you need to take them well give them back to the chemist
49. P: right well I've lost / I did bring some things in before (.) that you were able
um (.) er (.) inhalers
50. N: mm
51. P: inhalers that they had taken me off
52. N: mm
53. P: the bec/ they'd taken me off the becotide inhaler cause they'd put me on
something else um serotide (.) and I had 2 or 3 of those (.) which I brought in
54. N: mm
55. P: they had sort of three years life [I suppose
56. N: [mm yeah
57. N: they would send them back to *oncology hospital* (.) is is that when you were
an in patient (.) when you [came in
58. P: [no it was when I was coming here [but it was early
days
59. N: [ah
60. N: that'll/ we don't do that
61. P: no
62. N: no we don't interchange people's tablets (.) still
63. P: no but these these are sealed
64. N: mm mm no we (*unclear*)
65. P: well you've got to buy them from somewhere
66. N: oh we do we get them from *oncology hospital*
(.)
67. N: yeah we do we get them all from *oncology hospital* but it's all about um
dispensing drugs and things you're not allowed to give have them back once
you've had them
69. P: oh right
70. N: (.)
71. N: in case they've been tampered with you see (*whispered voice*)
72. P: oh right
73. N: well we know you you wouldn't do that but you know

74. P: yes
75. N: talking about risk management nowadays
76. P: yes yes
77. (.)
78. N: everything ok otherwise
79. P: otherwise things are marvellous I've got so much movement (.) back
80. N: I know you're great
81. P: I can even write (.) right handed now [pencil and pen
82. N: [mm yeah
83. P: (*unclear*) providing its not too tough [(*unclear*)
84. N: [mm mm
85. P: yes (*cough*) marvellous
86. N: good to be more independent now isn't it
87. P: it just feels so good to be able to do it again
88. N: mm
89. (.)
90. P: and not feel all lop sided
91. N: mm
92. P: and my back has stopped aching
93. N: you're not holding yourself [awkward
94. P: [no
95. N: yeah
96. P: just (.) I'm sure all that's done it is because I was sleeping with my hand on a pillow or a cushion (*unclear*) the only problem now is my (.) feet (.) um (.) I put Vaseline intensive care on this morning (.) I keep doing that because (*cough*) the skin (.) is so bad
97. N: right (.) mm (.) district nurses been in[↑] (.) actually the redness is better than it was
98. P: yes but the the I've had a bath this morning (*unclear*)but if I don't it feels like these are going to split
99. N: yeah
100. P: because big lumps of skin come off (.) in the middle of it if they don't have something there to soften it up then it just feels like loads of bits are going to come off
101. N: mm
102. P: you know when I'm towelling it has to be very very gentle and just pat it (.) pat them dry
103. M: yeah
104. P: it's only from (.) there down but I I never seem to (.) remember to go to (.) bed lying down properly with my feet up (.) that's the nuisance (*unclear*) isn't it
105. N: yeah it is
106. P: so if she wants me to have some stuff here she said there's no prayer for you mate unless (*unclear*) apparently
107. N: mm
108. P: and the doctor just keeps saying oh I'll leave it dry for now I'll leave it dry for now and that's all you get out of him (.) so I'll see what (*unclear*)it's got no (.) perfume or scented stuff in it (*unclear*)
109. N: ok have you brought your (*unclear*) or something like that

110. P: yes I think that's what I got
111. N: is she getting you there?
112. P: yes
113. (.
114. N: ok

115. End of tape

DTU4 Bernard

Patient. Male 70+

Nurse. Female 30+

1. N: nobody is going to um judge you here (.) uhu (.) oh I did (.) that's on isn't it
2. R: yes
3. N: um (.) so um (.) how are you feeling today Bernard how are you how has the week gone?
4. P: well not too badly (.) had my feet done
5. N: that's right you had your feet done and you see/
6. P: only (*unclear*)[you go so far and then you have to sit down
7. N: [yes and take the rest
8. P: this this is always sore it's been like that for weeks
9. N: oh has it ok well what we'll do I'll keep an eye on that and if it gets any worse (.) we we we'll have a doctor look at that (.) mm gorgeous day today isn't it
10. P: lovely
11. N: do you think we're getting summer now (.) huh
12. P: rain tomorrow they said
13. N: oh ok knew it wouldn't last for too long (.) well I suppose we should be glad (.) so er (.)any other problems have you been getting out and about and
14. P: oh I'm getting out it's just the burning feeling that's [the problem
15. N: [right
16. P: like a burning feeling on my chest
17. N: right
18. P: which I've had that for a long time now
19. N: are you taking your tab/ you were going to bring in some tablets for me this week
20. P: aye I forgot them [(*unclear*)
21. N: [don't worry I'm here next week if you can remember to bring them in next week
22. P: aye I'll bring them next week
23. N: did you did you did you go back to weren't you running short of some tablets
24. P: yes I've er (.) phoned the doctor up and I can't can't see her til Monday [next Monday
25. N: [right ok how are you for tablets then
26. P: well I've got er I've got painkillers and water tablets and a vitamin tablet
27. N: right so you've got enough til Monday have you?
28. P: yes
29. N: ok (.) ok
30. P: I only take one of each
31. N: you need to take/oh right you can take more than that you know
32. P: not according to the book [the doctor gave me with instructions
33. N: [ok
34. N: what does it say on the instructions
35. P: one a day
36. N: one a day is this now (.) the water tablets
37. P: and the and the vitamin tablets

38. N: and the vitamins well what does it say on the painkillers
39. P: well you take them four times a day
40. N: you don't take them four times a day at the moment though
41. P: no I've been taking them regularly love but I think I should start[(unclear)
42. N: [I think well
if you get a little of er chest pain(.) cause er it's cocodamol you take isn't it
43. P: aye
44. N: yes ok (.) how's your bowels working Bernard are they working every day?
45. P: aye aye
46. N: ok ok (.) um (.) so what you can do is sort of (.) try two (.) as long as you
don't take more than eight [in a day
47. P: [no maximum [(unclear)
48. N: [but you know yes just you know
try two in the morning and two in the evening [and see if that makes you feel
any better
49. P: [in the evening aye (.)I'll start
doing that
50. N: ok ok
51. P: cos I've got about a hundred there in the box
52. N: yes you've got loads of them I know that you haven't used any at all
53. P: no I haven't used many of them
54. N: is that because the chest pain goes away
55. P: no no it's always there love in in the night and all it's only gone really when I
was in hospital [it gives me pains in the legs
56. N: [right (.) yes
57. N: well tha that's why you've got those tablets to take them and you can even try
taking them one four times a day if you didn't want to take two=
58. P: yes
59. N: =and see if that provides relief for you
60. P: right
61. N: ok?
62. P: yes
63. N: um (.) you stopped taking the steroids yourself didn't you
64. P: ye yes um I've run out of them now I had taken and finished [the
65. N: [well you need
to/alright so you need to let the doctor/ you're actually going [to see your
doctor Monday
66. P: [yes
67. N: you need to let the doctor know that (.) yes? (.) that you're on steroids and
you stopped taking them
68. P: yes
69. N: ok (.) but you feel do you feel any (.) you don't feel any worse
70. P: no I I hadn't had those giddy turns lately
71. N: right
72. P: which I did have one last week when I was up the hospital=
73. N: ok
74. P: =on the Tuesday
75. N: right
76. P: but er since then I haven't had any

77. N: right (.) nothing since then ok
78. P: they said what they put it down to up there (.) they said it could be an infection in the ear
79. N: yes they mentioned that and that's (.) why you'd been feeling a bit dizzy
80. P: yes and that's why I had to sit down=
81. N: right
82. P: =when I was being weighed
83. N: did they look in your ear
84. P: no love
85. N: right ok
86. P: I did have a bit of wax out of it
87. N: right ok ok so maybe maybe that's helped a little (.) ok (.) um (.) is there anything else [um Bernard?
88. P: [no I don't think so love
89. N: nothing at the moment (.) no
90. P: nothing at the moment I can't [think of anything
91. N: [ok ok (.)ok
92. N: well if /you know (.) just remember to bring in the tablets for next week just so I can keep an eye of what you're on
93. P: that's the sleeping tablets
94. N: you're on sleeping tablets [as well
95. P: [no not the sleeping tablets=
96. N: it's the painkiller
97. P: =though I used to get them in hospital but my doctor won't prescribe them she says because you get too addicted to them
98. N: right
99. P: Dr M (.) won't give me [them
100. N: [well
101. P: cause it did tell her on the letter from the hospital that I did have sleeping tablets but she said no you can't have them you get too er too addicted to them so
102. N: do you know what kind of sleeping tablets they were
103. (.)
104. P: little little round little round ones
105. N: white
106. P: yes
107. N: ok were they Temazepam do you think
108. P: I think so love (.) think [so
109. N: [ok
110. N: are you sleeping?
111. P: not very well
112. N: well when you go back Monday (.) mention it again that you're not sleeping [very well and that you'd like them
113. P: [yes
114. N: ok?
115. P: yes
116. N: and then I'll see you next Thursday
117. P: ok love [yes
118. N: [ok

119. N: cause we need to look into that/I there/we wouldn't worry too much about the addiction we we we'd want you to get some sleep really which would probably about it (.) maybe I'll ring the GP (.) who who's the doctor you're going to see on Monday is it SC
120. P: aye if she's there cause she's been off on er maternity (.) she's expecting her second baby
121. N: right so who are you hoping to see Monday
122. P: well (*unclear*) call a locum (.) Dr J
123. N: Dr J ok
124. P: it's the same number anyway [same (*unclear*)
125. N: [oh yes no I know but its just medical doctor
locum Dr J
(.)
126. (.)
127. N: Dr J (*writing*) (.) right (.) I might ring (.) and see what's happening there (.) ok?
128. P: yes
129. N: anything else worrying you Bernard?
130. P: no no/ well I don't know what (*unclear*) I'm seeing an art therapist Tuesday
131. N: right
132. P: and she thinks I've got things on my mind I'm worrying about so she made/ put me on a waiting list to let me know when I can go and see her and she said she thinks I should have that treatment
133. N: right
134. P: but that'll be on a Monday
135. N: right (.) that's ok they'll organise transport for you to come in on [Monday (.) if I'm not here my colleague Andrew will be here=
136. P: [ooh I've got to sort that out afterwards
137. N: = so um and then they'll put you back then when that/ when the art therapist has finished her her treatment she will come back (.) you will come back to my day Thursday
138. P: yes
139. N: ok
140. P: that's right
141. N: is that alright?
142. P: yes
143. N: ok ok (.) anything else?
144. P: no I don't think so love
145. N: ok?
146. P: right
147. N: so what I'll do is I'll see you next week
148. P: ok love
149. N: okeydoke
150. P: right
151. N: alright Bernard?
152. P: yes
153. N: great alright
154. End of tape

DTU5 Catherine

Patient female 50+ years

Nurse female 50+ years

1. (laughter)
2. N: I'll just confirm you know about (*name of patient who died recently*) do you
3. P: I do (.) had a phone call last weekend no way I can get to the funeral at that time of morning though
4. N: well I don't think (*unclear*) she'll know you're thinking about her
5. P: (*unclear*) traffic in Penarth to get through the traffic by half past nine (.) I've written a little note to (*patient's daughter*) to say that I'll be thinking of them (.) which I will
6. N: we'll get (*hospice chaplain*) to do a service which will be quite nice
7. P: yes yes that will be nice (.) I feel a little bit (.) well I've always had a a slightly pinker bit there for donkey's years they thought I had lupus in my 30s (.) but yesterday and the day before absolutely blood red
8. N: it's redder than it was last week [isn't it yes
9. P: [yes I can't touch it there it's so sore
10. N: perhaps I'll get (*doctor*) to have a [look at it for you today
11. P: [mm you know whether it's chemo or
12. N: mm
13. P: but you know even my little grandson said to me on Sunday your head's gone bright red Grandma (*laughs*) (.) and it has but it's totally sore to touch (.) the bone feels sore to touch you know that feeling?
14. N: yes
15. P: so (.) did you see that programme on death last night
16. N: I haven't I didn't see it I've got it on tape [to watch it
17. P: [do you know it's ever so good
18. it's not /
19. N: / (*other patient*) was saying he'd watched it
20. P: yes I watched it and its not a bit depressing it was obviously made two years ago because (.)the young lady the young lady that died was in my paper yesterday and was writing about how life was two years on
21. N: oh how strange (.) have you kept the paper Catherine?
22. P: yes it's at home
23. N: will you keep it?
24. P: yes
25. N: cause I'd like/it would be quite interesting to read=
26. P: yes
27. N: =after I've watched the programme
28. P: yes
29. N: yeah
30. P: yes it's in my paper bag to go out with the recycled papers you know
31. P: um (.) so it (.) she had a column in the Daily Mail [that's right
32. N: [mm
33. P: and she had bright yellow peroxide (.) last night she was (.) almost reddish brown you know so she'd obviously (.)
34. N: mm

35. P: the (.) the elderly lady she was almost 79 (.) she was still going strong (.) and
er
she was lovely I just thought she was so lovely [(laughs)
36. N: [(laughs)
37. P: you know she reminded me of me [(laughs)
38. N: [(laughs)
39. P: cause they said to her would you like a carer to come round and help you and
she said no I most certainly would not!
40. N: (laughs)
41. P: and I thought good on you girl
42. N: (laughs)
43. P: and er
44. (.)
45. N: mm
46. P: she was amazing because er eh eh eighty she was eighty and she had her
eightieth birthday (.) in a day centre
47. N: oh did she! (laughs)
48. P: yes in a day centre and they sang happy birthday to you (.) and she was still
going at eighty two (.) pretty ill living on her own (.) she'd given up all
treatments (.) and (.) she'd fought and fought and fought (.) yet she was the
loneliest (.) out of all of them
49. N: mm
50. P: very strange isn't it (.) how you hang onto life regardless
51. N: it is isn't [it
52. P: [yes (.) cause she was saying how lonely she was with nobody
there/it it's a lovely programme
53. N: mm
54. P: but my daughter rang me she said now don't you go watching that
programme tonight (.) I want to see how other people get on you know
55. N: mm
56. P: it was good very good (.) I'll get that paper
57. N: yes please cause I have I've taped it so I am going to watch it
58. P: mm
59. N: yes (.) I didn't watch it last night because my husband was there and he
wasn't very keen on [watching it so
60. P: [no
61. P: no men don't like things like that do [they
62. N: [although (other patient) watched it and
he said his wife came in and was quite angry that he'd watched it
63. (.)
64. P: see it's like my [family
65. N: [yes (.) hmm
66. (.)
67. P: they don't like it do they (.) cause they have (.)to face our mortality (.) I
didn't go and see Molly and John yesterday(.) cause I was all over the place
(.) falling down drunk (.) umm I went to painting in the morning and I just
came straight home (.) and watched the telly (.) so bloody cold isn't it
68. N: (unclear)
69. P: I had the heating [on last night
70. N: [we put the heating on last night

71. P: I've never had the heating on in July (.) but I'm happy to sit and watch tennis (.) and I'm very very unbalanced (.) at the moment
72. N: mm (.) and how's your chemo going?
73. P: I took my last dose this morning
74. N: oh good
75. P: so I've got my week off (.) I'm taking a friend to lunch on Saturday (.) at Gilby's (.) two friends I counted my pennies and my pieces in my coffee jar and there were £44 (.) and I thought right (.) the two friends who do the most for me I'll take them up to Gilby's
76. N: oh that'll be [nice
77. P: [to use that money
78. P: yep
79. N: mm
80. (.)
81. P: so that's [what I'll do
82. N: [so everybody will enjoy your 20 pences then
83. P: mm?
84. N: everybody will enjoy your 20 pences
85. P: they certainly will (.) I was amazed it's only a little coffee jar
86. N: mm
87. P: you know (.) I used to save my 2ps and 1ps but you fill a coffee jar and you'll find there's 50p in there so I keep them in a bag now and I give them to the boys and they come in and put them in (.) the whirly thing (.) up by the [(unclear)
88. N: [oh yes yeah
89. P: they love that (.) so it goes to a good cause
90. N: mm
91. (..)
92. P: *indistinct...I'm watching*
93. (*indistinct few sentences about what's in room*)
94. P: she's having the children's bereavement counsellor go up I see
95. N: she was interested and I knew Joy had been here
96. (..)
97. N: mm
98. (..)
99. P: she's quite convinced she's not going to make it
100. N: it's a shame really because (very quiet)
101. P: awful shame (.) because you're wasting time
102. N: mm
103. Tape turned off

DTU6 David

Patient male 40+

Nurse female 50+

1. P: carry on then
2. N: carry on then (.) carry on what?
3. P: interviewing
4. N: (*laughs*)
5. P: uh?
6. N: no I've just come to see how you are and what/see what we can do cause it might be a miserable day in here today for (*unclear*) anyway
7. P: yes and her daughter isn't it
8. N: Yes well (*bereaved member of staff*)'s off obviously
9. (.)
10. P: I think er I think er (.) did you watch that programme on last night (.) death
11. N: I recorded I [haven't seen it yet did you?
12. P: [on cancer
13. P: my wife came in she said what you watching that for
14. N: mm?
15. P: my wife came into the room (*unclear*) watch it (.) she come in and she said why are you watching that (.) cause we all die you know
16. N: mmm
17. P: through ovarian cancer two had (.) and one had treatment after treatment in the end (.) I told my wife after six months and my quality of life was going down (.) and you can stop don't want no more (.) another one hadlife she had a tumour on the head (.) she died I thought oh what (*whistles*) (.) you know
18. N: what did you feel about watching it then (anon) and why did you watch it
19. P: (.) oh (.) don't worry me (.) see how people cope
20. N: yes
21. P: I suppose (.) same type of you know
22. N: mm
23. P: and one one woman the older one I think she's so she's a kirk you know (*unclear*) a real Catholic or something
24. N: yes
25. P: she's the one who took all the treatment (.) went on and on and on and all this treatment (.) and I thought this faith like dying wasn't/(.) you know it doesn't (*unclear*) at the end of the day we're all still human
26. N: yes
27. P: no matter what people think I've got a strong faith in this
28. N: yes
29. P: when it comes to the nitty gritty
30. (.)
31. N: everybody's got to try that one last
32. P: yes
33. N: mm
34. P: but I said all of us one day have got to (.) meet our maker
35. N: that's right

36. P: that's one thing you can't get away from
37. (.)
38. P: (*unclear*) don't know
39. N: so was your wife upset that you'd watched it
40. P: yes (.) she was I said what? you know (.) doesn't upset me I just want just curious see how people cope different you know (.) disabilities they have (.) but one had a patch over her eye same as me (.) balance
41. N: yes
42. P: that's the thing see how she coped she was young she was only 28 29 you know
43. N: mm
44. P: one spent (.) £7000 went abroad and had something (.) wonder what that was
45. but I don't know you know doesn't worry me but yes yeah (*laughs*) I just live with it day by day that's that (.) that's the way you know could be two years could be twenty years no one knows that's do they
46. N: nope
47. P: (*unclear*) anyone could walk out there and a bus knocks you over or (.) no one knows if you knew that you'd go on about (.) It's people that go to these readers innit
48. N: yes
49. P: I wouldn't go to them going to them to find out what's in years to come (.) what's that?
50. N: mm
51. P: they want to know like I wouldn't want to know that to be honest (*unclear*)
52. N: yes
53. P: you know (.) like the doctor told me when (.) Dr (*anon*) in (*oncology hospital*) she told me the first one after the operation (.) I asked I said (.) how long (.) have I got (.) said five years (.) average (.) I might have ten then (*laughs*) (.) I didn't like it didn't like her attitude
54. N: yes
55. P: a very down person (*quiet/indistinct*) I came out I wanted to cut my throat (.) I haven't seen her since thank God I don't want to see her
56. N: yes
57. P: made me depressed and that's not me see
58. N: mm
59. P: you know (.) sometimes I still think of that I think oh I've had two years I've got three years left sometimes it comes in my mind (.) I try and get it out of my mind then (.) you know I don't think being positive all the time helps but it does help a bit
60. N: [I'm sure it does yes
61. P: [in some ways (.) I'm not saying you got being positive you're going to survive another thirty years but I think it helps in in yourself (.) has for me down (.) remember poor Peter? (.) Peter remember?
62. N: yes
63. P: he was so down wasn't he
64. N: yes
65. P: most of the time after (*indistinct*)
66. N: sorry?
67. P: he was just down all the time

68. N: yes
69. P: I'm not saying he would have survived beyond that but it would help I mean
(.) for him and (.) for other people for his family as well don't forget his
family have seen that (.) he's going home and being (.) his kids would see it
(.) makes them down as well
70. N: yes
71. P: goes through you doesn't it (.) as I always try in front of my son(*unclear*) I
always (.) have a laugh
72. N: but does your son never say anything David?
73. P: no (.) just get on with life (.) but at the time when I had it (.)like I said (.) he
coped (.) he just went on /what was he then he's 15 1/2 he's 12 he went on the
computer every day(.) every day(.) on brain tumours and cancer (*unclear*) he
knows more about cancer than the doctors I think (.) treatments afterwards
and different side effects (.) and that's the way I think that's the way he
coped you know
74. N: mm
75. P: (*unclear*) comes in from school and we do tea you know and get on with it (.)
that's what you've got to do
76. N: mm when do you go to hospital again
77. P: eh
78. N: when do you/when's your next appointment
79. P: about six months now I think isn't it
80. N: mm
81. P: be quite happy now as long as I don't get any symptoms (.) it's not worth/it's
really not worth unless/ six months
82. N: yes
83. P: less you get ill then obviously you phone up and just come up (.) but alright
carry on (.) got more trouble with my leg (.) seeing a surgeon on that I've got
to go into the *hospital*
84. N: you're going to the *hospital* are you with that?
85. P: normally they do it in the *cottage hospital* day op (.) day op is it (.)
obviously cause you got cancer they have to take you in (*quiet tone*)
86. N: yes
87. P: so they've got everything there day patient day patient obviously isn't
suitable for that and they keep you in for a few days (*unclear*)
88. N: you're just waiting now
89. P: I'd be happy to go in for the day and just come out (*laugh*) I think I'll be
knocked out as well won't I
90. N: yes
91. P: I wanted I wanted a local (.) half a local (.) something for all your sciatic
nerves?
92. N: that's right yes
93. P: (*unclear*) I thought that one in the back isn't it
94. N: mm
95. P: probably be knocked out (.) we'll see (.) but I didn't really want it after
what I had with this
96. N: yes
97. P: cause ten and a half hours (.) I won't do that again (*laugh*)
98. N: wouldn't be as long as that though this [time not for your knee David

99. P: [half hour
100. N: yes
101. P: (*unclear*) half hour (.) never mind
102. N: yes you've got no idea how long it will be
103. P: yes I had the scan that's the main thing I had the scan done but no one asks like six maybe months years so by the time I've organised this to go in the (*hospital*) so looking at that I don't think it'll be years a few months I imagine the way he was talking (*unclear*) sort it out nothing I can do now can I (*unclear*) just wait (.) there we are (.) terrible pain with it (.) terrible (.) get more pain than I get with that you know walking sitting in the car oh... like an old man
104. N: mm
105. (.)
106. P: you haven't been taping me have you
107. N: no

End tape

DTU7 Steve

Patient male 40+

Nurse male 30+

In community area-patient very hard to hear, mumbles and quiet.

1. P: when when I was in hospital they gave me some (.) tablets (.) er it was just (.) after after um (.) having a fit and I didn't know what they were so I asked the gir/ one of the and she didn't know what they are (..) um I got the doctor to prescribe me 20 of them (*unclear*)
2. N: oh Diazepam
3. P: (*unclear*) (but it's it's pleasant now it's um rallying)
4. N: mm that's right yeah
5. P: (*unclear*) but they want me to take one every morning
6. N: mm
7. P: but if I take one in the morning (*unclear*) (.) I start getting the shakes (.) where my (.) arms and shoulders are going and they do sometimes [(*unclear*) one leg is quivering like mad
8. N: [mm mm
9. P: then (.) I want to take another one
10. N: mm
11. P: so I do (.) so there's not many left [and are are they going to um (.) will they well (.)
12. N: [yes
13. P: prescribe me more? or (.) shall I ask him (.) or what what 's going to happen
14. N: I should think so I shouldn't think it'll be a problem but I think we also need to be thinking about alternative ways of managing your anxiety other than just giving you tablets=
15. P: hm
16. N: =and I know you saw Dr J (*hypnotherapist*) before and got a lot of benefit from that=
17. P: mm
18. N: = and I know you've spoken to J about anxiety management before and I'm just wondering whether we need to repeat some of that process (.) what do you think (.) either give it another go with Dr J. or with J
19. (..)
20. P: mm (doubtful)
21. N: cause it's all well and good giving you tablets but we need to be thinking of alternative ways of managing that too really (.) what do you think
22. (.)
23. P: I hadn't thought about it like that
24. (..)
25. P: it's a question of practising more often what I've been doing because I haven't been doing (*unclear*) (*very quiet*) because I have been (.) well ignoring some of the routines the basics
26. N: that you were doing before
27. P: yeah

28. N: think you need a reminder of some of those?
 29. (.)
 30. N: refresher course perhaps
 31. (.)
 32. P: (*very quiet, stilted, unclear*) try reinforce what I already know (.) I think I'd prefer to do it that way first
 33. N: ok (.) ok see how you get on and I'll see you next week and see how you're getting on with that and then if you need to be looking at someone to see you again they can do and that might just reduce the amount of Diazepam you're needing to take because the problem with Diazepam is it can make you feel quite sleepy too
 34. P: yes
 35. N: and we don't want you sleeping the clock round (.) pointless us getting all this work back [if
 36. P: [I don't I don't sleep the clock round I might fall asleep from 8 o' clock in the morning til ten but then I'm up and awake pottering about doing things and I don't go to sleep til [night(?)
 37. N: [hmm ok (.) so you're your sleeping is out of sync as well
 38. P: oh yes terrible
 39. N: well perhaps if we can control your anxiety in a different way other than stretching for pills we um (.) that might knock your um body clock back in place as it were
 40. P: yes (*unclear*) be more disciplined about going to bed
 41. N: mm
 42. (.)
 43. N: well you know sometimes at bed time when your body clocks out of sync is a good idea for a while if you're going to go to bed at eleven o' clock or midnight or whatever every night for a week (.) and see how you get on
 44. P: (*unclear*)
 45. N: I mean the first couple of nights you probably won't sleep a wink but after a while because your body gets used to you going to bed at the right time it should hopefully catch up
 46. P: (*unclear*) I promised myself I would (*unclear*) up til four o' clock (.) silly
 47. N: mm busy though
 48. P: I think I had two hours sleep then um woke up (*unclear*)
 49. N: what you need to do is go to bed do it in the morning
 50. P: I know you're right I know I should be doing it (.) just habit
 51. N: mm (.) we'll see how you're getting on next week
 52. P: need more discipline
 53. N: mm (*unclear*) sometimes a routine some semblance of a routine can be quite good
 54. P: (*unclear*)
 55. N: ok well I'll see you next week Steve

End tape.

DTU8 Pat

Patient female 50+

Nurse female 50+

1. N: so how are you doing?
2. P: I'm fine thanks
3. N: and you knew about (*patient recently died*)
4. P: I didn't (.) til I came in
5. N: oh didn't you?
6. P: n[o
7. N: [oh I'm/
8. P: mm
9. (.)
10. P: it's hard
11. N: tis hard yes
12. (..)
13. P: mm
14. (*unclear*)
15. N: and I didn't um / I ou I ought to have phoned you at the beginning of the week hadn't I (.) sorry
16. P: that's alright
17. N: cause I thought well I won't ring you cause you'll all ring each other and (.)
hmmm
18. P: mmm
19. N: and Angela's away isn't she
20. (*unclear*)
21. N: so how are you
22. P: ok (*uncertain*) (.) (*unclear*)
23. N: have you?
24. P: yes (.) really bad
25. N: oh dear
26. P: mm
27. (.)
28. N: does that worry you?
29. P: (*unclear*) they reckon
30. (..)
31. N: it's frightening isn't it
32. P: it's horrible you know (.) it's just um from (*unclear*)
33. (.)
34. N: is it still as bad or is it a bit easier?
35. (*unclear*)
36. N: so you've not been drinking a lot?
37. P: no
38. N: or you're taking it through your tube
39. P: yes (.) mm
40. N: we'll get (*doctor*) to see you...
41. (.)
42. N: I think you've been pretty stable haven't you

43. P: yes yes I have (.) yes I'm lucky
44. (.)
45. N: well let's just hope it's another little hiccup [(unclear)
46. P: [yes
47. N: ok then (unclear)
48. P: no
49. N: everything else alright?
50. P: yes
51. N: you're quiet today
52. P: umm (.) I've just had my friend down from Birmingham that's why I'm late
coming in (.) we've been friends for years and she's only down for a couple
of days (unclear)
53. N: oh that was nice
54. P: mm
55. (unclear)
56. N: has she got relatives down here Pat or?
57. P: yes um she used to live down here she used to live in Radyr
58. N: oh there you are
59. P: and we got together when David and her son Paul were born there's only two
months between them
60. N: is there
61. P: mm (.) and um (.) she's got her mother in law still down here in Whitchurch
62. N: yes
63. P: so um she of she often comes down (.) her daughter's getting married from
Norfolk
64. N: is she
65. P: yes (.) it's all excitement at the moment
66. N: up in Birmingham
67. P: yes (.) really exciting
68. N: yes
69. (.)
70. N: is she all ready for the wedding then
71. (unclear)
72. (..)
73. N: so is the daughter older than (unclear) or younger
74. P: she's older (.) seven (.) mm seven (.) yes
75. (long pause.....)
76. N: when did it start with your difficulty swallowing?
77. P: a couple of days ago (.) yesterday it was horrendous (.) absolutely horrendous
I
could eat hardly anything or get it down
78. N: oh dear (.) what have you been like today
79. P: a bit better (.) so long as I sit quietly (unclear) and make sure it's not too
much (.) you know
80. N: (unclear)
81. P: yes
82. N: and you're not having too many problems
83. P: no
84. N: mm
85. (.)

86. P: thankfully
87. (unclear)
88. N: do you
89. P: and I can't breathe I can't...
90. N: oh dear so you're really don't like (unclear)
91. P: got real difficulty breathing (.) horrible
92. (.)
93. N: had you used to like the hot weather before or?
94. P: never used to mind it
95. N: yes
96. P: no never used to mind it (.) probably used to enjoy it (unclear)
97. N: mm (.) are you going to church this morning or
98. P: yes if there is any
99. N: there is yes (.) well (*hospice chaplain*)'s with us permanently now
100. P: I know [I know
101. N: [starts his new job today
102. P: today [I didn't know when
103. N: [no Monday
104. P: oh Monday
105. (.)
106. N: I'll get your notes now and get (*doctor*) to see you (.) ok then?
107. P: yes fine
108. N: you go off with (*nickname for hospice chaplain*)
109. (*laughs*)
110. Tape turned off

IPU1 Bill

Patient male 70+ years

Nurses. 2 qualified females 20+ years. Philippino.

Interaction takes place during a bed bath

1. N: you have your bowels open?
2. P: uh?
3. N: did your bowels open? (.) your bowels (.) did they open?
4. P: no (.) nothing happened at all
5. N: I put the suppositories in this morning
6. P: I don't even want to go (.) nothing
7. N: we will open it with this with very little hurt
8. P: yes
9. N: is it too cold for your (.) this one
10. P: pardon
11. N: Is it too cold?
12. P: not at all not at all
13. N: can you move your legs?
14. P: what?
15. N: can you move your legs
16. P: eh?
17. N: can you move your legs
18. P: a little bit
19. (.)
20. N: a little bit
21. P: in fact I'd rather get out (.) I'll try to get on the floor
22. N: you don't want to get out any more
23. P: no, I can't (.) I can't put my legs down.
24. N: I think the syringe driver is in the bed (.) we changed it yesterday
25. P: eh
26. N: we changed it yesterday (.) right
27. P: (*unclear*) I just sat on the bed.
28. N: and you have the freedom now to put your head up if you want to (.) right.
29. P: yes
30. N: I guess it's just the right bed for you (.) you stay in the bed just flat
31. N2: could you manage to roll over that side so that I can wash your back(.) can you see me now? (.) can I just protect your head in here oh you have had your bowels open but that's great
32. N1: yes you have it here.
33. P: is it?
34. N1: yea that's great
35. N2: I bet you have been waiting for it for probably some time.
36. P: yea yes
37. N1: when you were able to feel it went
38. P: all of sudden.
39. N1: we'll put your head back down on the bed so we can wash down here.
40. N2: okay (.) you lie back now.

39. N2: can you put the bed up a bit higher (*nurse*)
40. N1: well how do you feel now
41. P: tired I am now
42. N1: but a bit relieved now that you've opened your bowels.
43. P: yea yea
44. N1: suppositories will help you (.) are you comfortable lying like that
45. P: yes I am
46. N1: it's about to finish now (.) right (.) I'll just put some cream there
47. N2: she will just put some cream
48. P: yea yea
49. P: (*unclear*)
50. N1: sometimes when patients are lying on the bed most of the time they develop sores that is why we are putting some cream (.) and moving you from side to side makes a lot of difference in preventing this
51. P: (*ward manager?*) does that.
52. N2: you have been helping yourself (.) I know you have his last few days you have been moving (.) so that is a good one (.) that's great (.) don't stay in one position for a long time.
53. N1: do you feel difference here now (.) do you feel difference
54. P: uh?
55. N1: you feel different because you open your bowel.
56. P: yea yea
57. N1: not yet (.) do you feel like you want open still.
58. P: yea yea
59. N1: now you are over towards me (.) want to go.
60. N1: now you roll over towards me and there is a (*unclear*) under you.
61. N2: I do like that alright
62. N1: we need to change the draw sheet and this one as well
63. N2: it won't take long (.) we just need to change everything in here.
64. N1: we will change the linen and bring you fresh one
65. (.)
66. N1: up to his shoulder (.) yea (.) I think it would be more comfortable.
67. N2: so how is it (.) better?
68. P: yes (.) yea
69. N2: good (.) right (.) how does it feel (.) comfy?
70. P: yea yea
71. N1: is that comfy?
72. P: yea
73. N2: so we are done (.) I'm just going to comb your hair
74. N1: I'll do a chair for him.
75. P: can you find my razor
76. N1: oh he wants to shave
77. N2: oh sure (.) we can do it.
78. N1: just don't hesitate to tell us what you want to do
79. P: yea
80. N2: you think you can do it?
81. P: yea (.) I can try
82. N1: over hear
83. P: now (.) it's easy now

84. N1: well done
85. N2: you are doing it great (.) you are doing it great
86. N1: are you using after shave cream?
87. P: no
88. N1: you have some here (.) you have a cream here
89. P: yea
90. N1: okay (.) styling cream (.) does it make a difference by doing it alone (.) by doing it your own.
91. P: yea (.)*(unclear)*
92. N1: yea (.) it is giving you freedom to grip (.) at least we are here just in case you need us and you can tell us (.) but at the moment you are doing it right (.) that's great
93. N2: we think you've got a mirror here so we can see (.) well done (.) well done (.) somewhere in here (.) here.
94. P: *(unclear)*
95. N1: yea a couple of days before it will come again.
96. P: radiotherapy before
97. N1: when you had your radiotherapy before.
98. N2: but you look really different after coming here.
99. P: yea yea
100. N2: brighter (.) brighter and brighter every day (.) that's great (.) I think it's time (.) very good.
101. *(Laughter)*
102. N2: oh well nice perfume (.) you are making it as a perfume eh?
103. N1: it's a special perfume of course (.) very good.
104. N2: we are done.
105. P: is there a comb there.
106. N1: yea (.) combing your hair (.) that's great.
107. N2: personal grooming (.) you are doing so well there (.) you are different than when you came here (.) yea. you look so different (.) it get's better.
108. P: *(unclear)*
109. N1: how do you like your stay here
110. P: oh, it's alright (.) yea (.) yea.
111. N1: are you enjoying the people around you?
112. P: yea yea
113. N1: that's good (.) take care (.) that is the most important thing in life you know (.) to enjoy people around you and that makes really different (.) seeing someone who is smiling early in the morning (.) greeting you good morning and it makes a difference to the day (.) it makes your day brighter (.) that's why you look brighter today
114. N1: ready for supper.
115. N2: dinner (.) it's supper in the night (.) there we go.
116. N1: I will just get the trolley in your reach (.) your water is in here (.) everything (.) alright?
117. P: yea.
118. N2: just feel free of buzz in (.) just in case you need something alright? (.) don't hesitate to call us we are just around here.
119. P: yea thank you
120. N1: you're welcome

End tape.

IPU2 Alice

Patient female 70+

Nurses on introductory walk around

- N: hello there (.) this is (*nurse*) here.
P: I haven't seen you in a long time.
N: I saw you yesterday (.) I was on yesterday and we did our singing with M one of the patients (.) how was your night then
P: very good.
N: good
P: where are you going out tonight
N: tonight? I am going out tomorrow (.) my husband is going to fetch me (.) do you want your tea now (.) let me just hold this for you
P: what time are you going to go
N: half past two (.) I'll drop by here before going alright? (.) just to check if you are alright
N: here is your tea (.) you look brighter today
P: I wonder why that is
N: well (*unclear*) you feel like sleeping again? It's already half past nine (.) you have had your breakfast
P: yes
N: did you enjoy it. (.) how do you feel now love
P: alright .
N: alright now
P: yes
N: generally not in pain
P: no
N: very good
P: okey doky
N: what do you want now (.) your wash now.
P: no
N: not now
N:: so tell me just what time you want to have your wash alright (.) if you are ready (.) we are happy to help you (.) alright?
P: half past six
N: half past six ↑ (.) I think you not in here already.
P: yea half past six
N: half past six ↑ (.) it's half past nine in the morning
P: oh my God
N: it is very nice that in the morning that we have our wash to freshen up our day,
P: yes
N: yea (.) do you think you feel like having it this morning.
P: yea half past nine.
N: very good

N: okey doky
P: okey doky
N: alright (.) I like that
P: you like it.
N: there you are (.) now I see you smiling.
P: half past six then
N: half past six
P: half past nine
N: okay I will go and prepare it now

IPU3 Louise

Patient female 70+

Nurses' introduction

1. N: hello Louise how are you? (.) I am your nurse this morning (.) how was your night?
2. P: well I had a very had night last night.
3. N: very bad
4. P: I had two bowel/ oh very bad ones
5. N: I thought you had a very good night
6. P: no very bad ones (.) but this morning I am much better
7. N: so how do you feel now
8. P: yes
9. N: much better
10. P: yes much better
11. N: that's great (.) I am happy go hear that (.) I heard that you want to go to the toilet right now
12. P: well I can wait if that's what you want
13. N: but I don't want you to wait
14. P: you don't want me to wait
15. N: of course I will help you do that (.) do you think you can use your zimmer frame or do you want to have your wheelchair instead do you think
16. P: I will try with that really but when I am on my own I will probably use this more than anything.
17. N: are you comfortable using it.
18. P: yes
19. N: any pain in your legs
20. P: no/ well unless I/ well I have to keep my legs up (.) not paining so much
21. N: not painful
22. P: it hasn't been for the last two days because I've been in bed for the last two days and it's brought them down no end
23. N: how do you find it (.) remember the other day I told you to keep it up a little bit
24. P: yes that's right (.) it's been much much easier (.) lots easier
25. N: you think it helps.
26. P: yes yes
27. N: are you comfortable doing that
28. P: yes well you know (.) it's if I stand in one spot for any length of time then you know (.) I feel it (.) I really feel it (.) so I can only walk small distance
29. N: I think you need to go to the toilet now
30. P: we will be free then won't we
31. N: we will try to assess if you can use it for today (.) alright.
32. P: yes

33. N: and then if you are not comfortable using it I can give you the wheelchair and help you go in there.
34. P: of course age now has made a lot of difference
35. N: so we can relax in here.
36. P: that is the main thing that I like (.) they don't force things on to you.
37. N: here?
38. P: if you are doing something you don't want to do (.) you know↑
39. N: so you mean you love your stay in here
40. P: yes
41. N: oh that is great to hear (.) thank you for that
42. P: lovely place (.) well this is the highest I have been I think
43. N: I feel great for that
44. N: are you comfortable being here.
45. P: oh yes (.) I will want to go back to my home you know
46. N: oh (*laughter*) I love talking to you
47. P: it would be different if I didn't have a family
48. N: well seeing you like that I felt so great being a nurse in here (.) you have been so very happy being in here with us and that is really wonderful (.) wonderful right (.) at the end of the day I am feeling great because of what I did and because you have been so satisfied with what we are doing here
49. P: I have not been a very good person as regards my appetite (.) but you don't force it and I do manage to eat something
50. N: that's great to hear (.) oh well thank you
51. P: B... (*other patient*) seems to be progressing no end to me so that's proof enough (.) watching somebody else progress
52. N: she's doing well here (.) she's been cracking jokes already
53. P: I know she's amazing
54. N: she enjoyed her singing yesterday (.) I heard her and you too I gather I will see you in a minute okay
55. P: okay

IPU4 Beryl

Patient female 70+ years

Nurses.1 auxiliary 50+ years, 1 qualified 30+ years.

Interaction takes place during a bed bath

1. N: not so smelly for you
2. N: are you going to sit out today Beryl?
3. P: I don't think so
4. N: you don't think so (.) why is that then my love
5. P: I don't know (.) I feel ugh
6. N: now does ugh mean you have got a pain or what
7. P: I feel ugh
8. N: right okay (.) we'll have to see what we can do about that then (.)
there we are sweetheart (.) if you can come forward a little bit for me
(.) gently gently (.) that's it well done (.) back you go (.) feel as if you
have done a hard day's work do you?
9. P: I do (.) yes I do
10. N: not in any pain though are you
11. P: no only a little
12. N: where to
13. P: only in my arm
14. N: this one (.) we'll go careful then love
15. P: yea
16. N: pop your head through there, that's grand
17. P: oh
18. N: alright? Beryl I am going to take this band off your wrist because it's
getting a little bit tight there and I don't want it to dig in so we'll get
you another one and pop it on your other wrist where it won't be so
tight for you (.) okay (.) here we go then my love (.)
19. P: I don't feel like wash
20. N: no there's days when we get up when we think can't be bothered (.)
we will make it as easy as we can for you sweetheart but I'm sure
you'll feel better, even if it's just the bare essentials (.) you want to
use your good hand to give your face a little wipe dry (.) that's it (.)
brilliant (.) there we go (.) that's excellent Beryl (.)I'll see if I can just
pop this towel underneath your arm (.) how's the sensation in this arm
Beryl?
21. P: not too bad
22. N: not too bad (.) you can feel me touching it can you?
23. P: not really
24. N: no
25. P: not really (.) Lord knows why
26. N: there we are sweetheart (.) just give it a dry
27. P: Lord knows when I'll feel that.
28. N: feel what Beryl?
29. P: the sensation in my arm.

30. N: is this one okay for me to move though (.) just slightly?
31. P: yea
32. N: that one's alright (.) I've got the good side then
33. N2: you planned that didn't you (*laughter*)
34. N: I'm not daft (.) I think she's a little tinker at heart you know(.) I've been doing it for too long now Beryl (.) I know all the dodges (.) I need to be a bit quicker off the mark
35. P: how long you been doing it now?
36. N: oh (.) 17 18 years now sweetheart (.) a long time (.) so if I don't know the dodges now
37. P: you never will will you
38. N: try that, there we go (.) there we are sweetheart (.) we can straighten this now
39. N: do you want a nice bit of squirty under your arms (.) smell beautiful
40. P: smell beautiful.
41. N: you need your Sunday teeth in to say that Beryl (.) o kay (.) it's going to be cold (.) and a tiny little bit under this arm
42. P: oh my Godfathers that's cold
43. N: it is but it smells lovely (.) it does smell rather nice what is it
44. N2: it's impulse hint of musk
45. N: oh right (.) it's lovely
46. N: Beryl is your tummy sore there?
47. P: no
48. N: no
49. P: I am not sore anywhere really
50. N: that's good (.) (*laughter*) these staff nurses are stepping over the mark
51. P: they are aren't they
52. N2: I think I may be getting a bit big for my booties
53. N: sit up with your back (.) there we go lovely (.) now don't feel asleep on us now Beryl
54. N2: Beryl (.) are we boring you?
55. N: we should be singing to you shouldn't we, getting you to join in (.) are you going to join in (.) are you going to give us a song
56. P: yes (.) ready for tomorrow
57. N2: what do you want to practice
58. N: what's tomorrow my darling
59. P: I'll have to practice.
60. N: What's your favourite song Beryl
61. P: I don't know (.) I don't know
62. N: what were you singing yesterday(.) a little birdy told me it was my way
63. P: oh yes I did (.) yes that's what is was
64. N: If you had your CDs or records (.) what did you used to collect Beryl (.) anybody in particular? did you have favourites
65. P: me
66. N: yes (.) who did you like to listen to
67. P: I don't know what I'd say
68. N: now don't go as far back as the inkspots will you

69. P: *(laughs)*
70. N: Frank Sinatra?
71. P: it's the two young ones doing all the singing
72. N: now I heard you join in and you had a beautiful voice
73. N: we could be classed as that but you got an old one and a young one today sweetheart.
74. N: I couldn't carry a tune in a bucket
75. N2: and *(relative)* was really pleased that you'd been singing and seeing you up in your chair
76. N: you persevered with that chair yesterday then Beryl?
77. P: we did
78. N: there you are then darling. (.)
79. N: I'll just take this towel out (.) I put gloves on these trolleys but if the girls use a trolley they put the small gloves on and I can't get my hands in (.) tiny little hands
80. N2: Beryl (.) excuse me sweetheart, but I am going to give you a little freshen up down below (.) okay here we go (...) it's actually much better (.) got some cream here
81. P: alright
82. N: yes (.) let's give you a little turnover now (.) now that arm is the worst sweetheart but do you prefer to turn on there or turn to me (.) which is the easiest for you to turn
83. P: uh (.) this way
84. N: turn to face me and bring this one that's swollen up and over
85. P: yes
86. N: okay (.) what I'll do because you're a little bit near the edge (.) I shall just put that there for a little bit of security and we'll swap sides my darling right (.) here we go
87. (.)
88. N2: you know I didn't know that. It's got a hook on.
89. it'll be doing a song and dance routine next (.) this bed is super duper
90. P: is it
91. N2: it is (.) my word (.) all built in mod cons
92. P: that's good super duper isn't it?
93. N2: it's wonderful (.) a la carte bed I say
94. P: a la carte bed
95. N: okay (.) over gently my darling (.) that's it (.) well done Beryl (.) you are doing very well (.) okay sweetheart we'll be as quick as we can (.) you've done well (.) okay (.) would you like to support that arm (.) there (.) that's it
96. N2: We are going to give your bot a little freshen Beryl.
97. (.)
98. N2: Is it sore Beryl (.) is it sore?
99. P: a little bit (.) now how have I got that?
100. N2: sorry my darling what did you ask?
101. P: how have I got that
102. N2: really(.) you've been spending a lot of time in bed
103. P: I see

104. N2: so even though we are changing your position regularly and even though on this wonderful bed (.) a lot of pressure can sometimes make your botty a bit sore
105. P: I see
106. N: It's just looking a little bit pink darling, it's not anything to be/ well we're not worried anyway
107. P: ouch
108. N: sorry my sweetheart (.) just freshen you back now alright (.) okey doke
109. P: okey doke
110. N: you know you are really good with this (.) I'll give you a little bit of talc then (.) well I don't know what you're going to smell like Beryl (.) you Lily of the Valley on your back and Wild Musk under your arms (*Laughter*)
111. N2: nothing like a little bit of variety
112. N: depending on which way the wind is blowing
113. P: of course it is.
114. N: it's blowing (*nurse*)'s side at the minute (.) I've got the musk my side
115. N2: okay Beryl nearly done (.) we're going to roll back over the other way now Beryl (.)over a lump in the bed
116. P: oh (.) oh
117. N2: gently (.) to the middle first (.) let's just take this one out
118. N: alright (.) you're doing well (.) nearly there (.) let's make sure its not there we go (.) gently back down
119. P: thankyou
120. N: okay
121. P: yes
122. N: I don't know when you had that nightdress on the ward just taken off Beryl (.) it did look as if/
123. P: / they took two home yesterday
124. N: is there another one there though
125. N2: now I saw one there a green one
126. N: oh right (.) here we go (.) lovely and fresh (.) Lilies of the Valley (.) same colour
127. P: see that's the clean one
128. N: you'll be a little summer garden
129. P: oh my God
130. N: arms through, there you go, no, you're fine, arm up on that one (.) tell you what (.) this is lovely and roomy for you to get your arms in and out and nice and cool as well (.) the other one looked nice but was till not as fresh as this one (.) gently through with this one Beryl
131. P: oh (.) ow oh oh
132. N: well done (.) come forward sweetheart (.) that's a good girl (.) there we go (.) gently back again (.) there we are
133. P: I'm tired now
134. N: is that hard work Beryl?
135. P: yes.
136. N: do you feel fresher though Beryl?
137. P: yes

138. N2: Beryl do you want to try sitting out in your chair for a while?
139. P: no I don't
140. N2: maybe later on (.) maybe this afternoon?
141. P: yea
142. N2: before (*relative*) comes in
143. P: I need a cup of tea.
144. N: okay lovely
145. P: oh dear
146. N: it's taken it out of you a bit today Beryl
147. (.)
148. N: let's get this nighty (.) it's a little bit of cockled up on this side (.) do
you actually lie on your nighty or do you generally have it up a bit
higher?
149. P: generally have it up a bit higher
150. N: okay (.) roll over to me and we'll try and put it in nice (.) there we go
(.) over again
151. N2: gently over to me
152. N: ss that comfy?
153. P: that's lovely (.) that's beautiful

IPU5 Nancy

Patient female 70+ years.

Nurses female qualified x 2

Interaction takes place during a bed bath

1. N: we will do this quickly. (.) have you got your own toilet bag love?
2. P: yes dear, I don't know where they've put it.
3. N: is this the one? (.)
4. P: I want to go to sleep now
5. N: maybe after the wash, we will freshen you up.
6. (.....) *Long pause*
7. N: did you enjoy your breakfast?
8. P: yes thank you, yes that was fine, just enough.
9. N: what did you have?
10. P: cornflakes
11. N: do you have your own flannel?
12. P: yes dear (.) there's two there actually
13. P: they laid it out flat I remember (.) it may be in another drawer (.) I don't know
14. N: okay I'll have a look
15. P: yea (.) no that's my handbag
16. N: I am sure you'd want a fresh nightie on
17. P: yes please
18. N: Nancy I'll start with your face
19. P: if you can find it (.) I know there's one there
20. N: is it too cold (.) is it alright?
21. P: yes it's fine
22. N: here's the towel
23. P: I have some of my own towels (.) I did bring them (.) it doesn't matter though
24. N: is that alright (.) we have to take your nightie off (.) is this okay?
25. P: yes I am used to it now.
26. N: okay (.) I will cover you with this towel
27. P: good
28. N: any visitors coming over to see you this afternoon?
29. P: I don't know (.) my daughter's at work so she won't be able to come (.) she will come this evening but my son and daughter in law are travelling up from Worthing so they'll probably
30. N: Worthing (.) where is that?
31. P: Sussex
32. N: Sussex (.) is that in London?
33. P: outside London
34. N: outside London
35. P: yes (.) Sussex
36. N: is it alright if I do the front?
37. P: yes I'm used to it now
38. N: open your arms love (.) do you want some talcum powder on your back?

39. P: yes please
40. N: do you speak Welsh?
41. P: no (.) no
42. N: I'll do your arms because Mary the lady next to you speak Welsh.
43. P: no I'm not Welsh I am English
44. N: are you English? (.) is it dry now?
45. P: not really, rub this a bit will you
46. N: is it alright if I do you down below (.) I have to take this out for the time
(.)I nearly finish
47. P: yes righto
48. N: sorry
49. P: it's a bit sore, it's alright
50. N: is it sore?
51. P: it's where I had to take opening medicine and I went so much it made me
sore
52. N: are you applying something on it.? (.) just one more (.) okay love (.) now I
have to do your legs (.) just the legs. (.) how many children do you have?
53. P: four (.) two boys and two girls (.) and two grandchildren
54. N: two boys and two girls.
55. P: you tend to get chafed
56. N: all dry now (.) let me get your talcum powder
57. N: okay (.) now your hands
58. P: excellent (.) oh that is nice and fresh it is
59. N: now we have to see your fresh nightie
60. P: you don't need to undo it (.) it's alright
61. N: I'll give you a hand with that
62. P: thank you
63. N: let me do this for you (.) do you want to get back to your bed or do you
want to sit by the window?
64. P: no I'd like to get back to bed (.) I'm so tired
65. N: do you want a pad on (.) just your knickers? can you stand up?
66. P: not on my own (.) you could push that rail back
67. N: ah yes okay
68. P: I can stand if I'm helped
69. N: are you alright? slowly (.) slowly
70. P: if you hold me I'll pull them up I think that's the easiest way
71. N: okay
72. N: it is alright if you sit on the commode for a moment because I need to sort
out your bed (.) I will do it very quick
73. (.)
74. N: I think I have to change the linens (.) fresh linen
75. P: do you?
76. N: it's moving (.) you find this hard?
77. P: yes I do (.) I find it very tiring
78. *Long pause*
79. N: hold on to me love
80. P: have you got any pillows there?
81. N: pillows? alright
82. P: yes I might need some (.) one I sit on

83. N: slowly (.) that's it that's it (.) okay turn around (.) you have to go with me
now slowly (.) slowly (.) that's it (.) almost there almost there
84. P: ooh, I took the bed with me
Background noises
85. P: okay
86. N: carefully now
87. P: you can lift it now
88. N: I will get you another pillow (.) do you want a blanket on?
89. P: yes please (.) you'd better take this off
90. N: this pillow?
91. P: yes
92. N: are you comfy now? do you need the blanket on?
93. P: yes
94. N: here it is,
95. P: just in case
96. N: just in case
97. N: if you need anything just buzz (.) I think we are done (.) thank you

IPU6 Sally

Patient female 70+

Nurse male 30+

Interaction takes place during a bed bath

1. N: hello are you alright there?
2. P: thank you ever so much
3. N: did you sleep alright?
4. P: off and on
5. N: off and on
6. P: yea (.) not the sort of sleep I would have liked
7. N: okay
8. P: but there we are, it doesn't matter (.) I will catch up now on the 2 til 4 (.) I might have a snooze now actually
9. N: okay (.) are you expecting any visitors today?
10. P: this evening
11. N: ah this evening (.) you will have a long chat again
12. P: yes my sister's coming back from West Wales (.) you know the one with the dog (.) the dog went down with her for a couple of days so she is coming back to my house this afternoon (.) so she'll be in this evening
13. N: is she there on holiday?
14. P: she is coming up to look after me
15. N: oh good (.) let me fill the bowl
16. P: what is it you'd like me to do?
17. N: just stay still and I'll do the rest
18. P: bless you (.) thank you (.) oh dear
19. N: do you (*unclear*)
20. P: I do yes (.) I miss all my past life (.) I was so active (.) never mind
21. N: you are enjoying it
22. P: Oh I loved it (.) never mind we just have to
23. N: anyway you can be just Welsh
24. P: and you can tease me
25. N: Tagalog (*Philippino language*)
26. P: Tagalog is it?
27. N: yea Tagalog (.) can we use this one love?
28. P: yea that's great, bubbles (.) nothing wrong with that
29. N: do you want it very bubbly?
30. P: no, that's fine (.) shall I take this off?
31. N: yes but I'll have to cover you with a towel
32. P: yes (.) thank you
33. N: this smells good
34. P: lavender
35. N: lavender
36. P: it's supposed to soothe and relax you. So you be careful if you fall
37. N: I'll start with your face
38. P: okay thank you (.) that's good (.) oh you do get hot in the nights don't you and you feel sweaty

39. N: my room is very hot
40. P: at home? is it really?
41. N: because of the weather today (.) it is very warm (.)very humid
42. P: have you got a fan or something at home?
43. N: no I don't have one
44. P: perhaps you should get one
45. N: I can manage
46. P: how many of you share a house?
47. N: we're six but I have got my own room
48. P: do you all work here?
49. N: all of us (.) I will do your back first
50. P: lovely (..) oh that's good (.) oh that's really good
51. N: I am wiping your back and massaging it at the same time
52. P: you are (.) excellent (.) oh yes thank you
53. N: how is your tummy?
54. P: bloated unfortunately (.) I wish I could get rid of it (.) I hope the doctor will give me something for it
55. N: okay, did you inform the doctor about that?
56. P: but the day before yesterday I opened my bowels
57. N: that's good
58. P: but nothing happened yesterday and then I am feeling bloated today
59. N: is it alright if I do your front?
60. P: that would be wonderful (.) here give it to me (.) I am not that useless (.) gosh my arms are skinny (.) mind it is good food here (.) lovely food in here I just wish I had a bigger appetite.
61. N: and you can ask for whatever you want.
62. P: they are so kind.
63. N: what was your weight before?.
64. P: I have always been about 8 stone 8stone two pounds (.) I have been very very careful with my weight all my life (.) and here we are (.) never mind (.) I don't know what I am now (.) if I give you that we'll do a swap
65. N: okay (.) what else have we got here
66. (.)
67. N: down below.
68. P: okey doke (.) can I (.) I have got a sore with some dressing on it (.) can you just have a little peep?
69. N: may as well change this with a fresher one.
70. P: that will be lovely (.) thank you very much (*nurse*) (.) oh gosh it's itching (.) can you give it a wipe for me (*nurse*)
71. N: okay I'll get you a fresh one (.) the skin is broken but only superficial (.) not that deep so you have to turn from side to side
72. P: do I need a dressing on it or would the fresh air do it good?
73. N: I think so (.) just to protect it
74. P: okay I'll take your word on it (.) I thought maybe the fresh air might be good for it
75. N: I think we have to apply one just to protect the wound
76. P: are you going to get one? I'll carry on with this then
77. N: I'll be right back

78. P: thank you

Long pause

79. N: I am back

80. P: that was quick (.) right I think I have creamed myself below

81. N: I'll do your legs

82. P: okey doke

83. N: is it really sore?

84. P: no it's itching (.) which is a good sign they say when it itches

85. N: oh it's healing

86. P: yes

87. N: but don't scratch it too fine

88. P: no okay

89. N: now I will do you legs (.) do you want a fresh pair of knickers as well?

90. P: if possible yes please (.) oh, they've gone all funny

91. (.)

92. P: I tell you what I would like (.) when you finish doing my legs can I put my feet in the bowl.

93. N: okay

94. P: yea

95. N: no problem

96. P: do you know I can smell the rubber (.) it is horrible

97. N: shall I take these off now, what do you call these shoes?

98. P: they are called, well in hospital (.) they are called snowboots

99. N: snowboots! what is this for?

100. P: they are for feet that have gone swollen

101. N: I see

102. P: and stop them getting bed sores and things

103. N: okay

104. P: because my feet

105. N: they are very swollen

106. P: I had a lot of water

107. N: in here

108. P: oh wonderful (*Nurse*)

109. N: I am giving you a foot massage

110. P: you are, excellent (.) thank you very much

111. (.)

112. P: apparently there is someone here to do massages

113. N: I forget

114. P: yes I've forgotten too

115. N: ah the Reflexologist (.) ah yea (.) she is visiting (*hospice*) at least once a week

116. P: and does she do everyone or just some

117. N: no she will do everyone

118. P: bless her

119. N: and she is very good

120. P: is she?

121. N: Yes she is

122. P: excellent (.) that is lovely (.) oh that's clean

123. N: okay
 124. P: that really is good massaging there (.) thank you
 125. N: okay.
 126. P: yea okay
 127. N: okay that's it (.) give me your feet love (.) hold on to this (.) stay here
 128. P: lovely jubbly (.) that is wonderful (.) there is still a lot of swelling in them
 isn't there
 129. N: yes all swollen (.) I will get you fresh knickers
 130. P: thank you very much
 131. *Long pause*
 132. N: here it is
 133. P: thank you wonderful, thank you.
 134. N: you got this
 135. P: okay (.) what made you go into nursing?
 136. N: I really don't know (.) because my mother told me to take up nursing
 137. P: did she? Awh (.) was she a nurse as well?
 138. N: no she was just like you (.) she was a teacher before
 139. P: oh right
 140. N: back home (.) but she only taught for two years then she married my father
 141. P: and that was it
 142. N: yea that was it
 143. P: and then you came along
 144. N: yea
 145. P: have you got any brothers or sisters?
 146. N: yea (.) I have one brother two sisters
 147. P: oh that was it
 148. N: she enjoyed being a housewife
 149. P: did she?
 150. N: before (.) I wanted to get to teacher but changed my mind
 151. P: very hard to be a teacher (.) okay (.) you want me to stand?
 152. N: put your top in (.) where is it
 153. P: right (.) okey doke (.) I may be able to put it over my head now (.) there
 we are I think it is big enough (.) you will have to turn me just in case I
 need a bra (.) I might have to put one on (.) it's in one of my cases have a
 look
 154. (...)
 155. P: well done
 156. N: this is the bra for you
 157. P: lovely jubbly (.) excellent
 158. N: okay (.) let me put this thing away
 159. P: well done (.) I need more bras I have lost so much weight I can't even fill
 it (.) never mind.
 160. N: is it too tight?
 161. P: mm no it's not too bad (.) it's just (.) we'll see how it goes (.) may take it
 off later (.) oh dear dear dear
 162. N: there you go
 163. P: I'm a bit small (.) never mind I can live in hope (.) I must put on the
 weight again
 164. N: you must

165. P: I must (.) I agree with you.
166. N: got it on
167. P: all I need is
168. N: no buttons
169. P: right now then (.) if I can I tell what you can do (.) oh cripes
170. N: shoes
171. P: yes I'd better put those on (.) okay
172. N: okay
173. P: brilliant
174. N: I have to take this off okay
175. P: now then how are my feet?
176. N: okay(.) one (.) two (.) three
177. P: oh well done (.) thank you (.) let's pull these up
178. N: alright
179. P: I am not so useless as I was yesterday
180. N: okay (.) how do you put this on
181. P: It's supposed to go round my waist
182. N: mm
183. P: and it is a hole somewhere where one of the (.) in there somewhere
184. N: so I have to pop this in
185. P: yes please (.) and oh now then lets have a look (.) if we do that bit
186. N: there we go
187. P: it should be okay (.) right thank you (*nurse*)
188. N: I think we are all done
189. P: I think we are (.) I tell you one thing I don't think I can walk back
190. N: oh let me get the chair.
191. P: thank you very much
192. N: okay

End of tape.

IPU7 Jean

Patient female 70+ years

Auxiliary nurse 40+ years

Interaction takes place during an assisted bath

1. N: do you want your hair washed (.) up to you
2. N: see how we go.
3. N2: how you doing Jean
4. P: oh okay
5. N2: we're getting you on the chair first Jean
6. N: you ready
7. P: not too hot is it
8. N: well put your feet in first
9. P: I don't like it hot
10. N: okay Jean (.) put your hands on the rail (.) okay
11. P: 1 (.) 2 (.) 3 (.) ooh
12. N: it's a long way down for you
13. N2: shall we wash our hair while we're in there
14. P: do what you like as long as you don't drown me
15. N: you had it cut yesterday (.) was it your daughter who cut it
16. P: no a friend
17. N: she cut it quite nice yesterday (.) where do you live then Jean.
18. P: Radyr
19. N: I'll take your wheelchair out ok Jean
20. N: try it with you feet first (.) what do you think
21. P: okay
22. N: it's when it hits your tushy you know whether it's hot or not
23. (*Laughter*)
24. P: it is a bit
25. N: see
26. N2: you don't need me now Cher
27. N: when you come back can you bring some knickers (.) if you need your oxygen (.) you can have it on in there
28. N: so where are you from (.) Radyr
29. P: yes but I wasn't brought up in Radyr (.) I was born in Grangetown Cardiff.
30. N: was you (.) I was born in Grangetown.
31. P: Wedmore Road
32. N: round the corner from me (.) you know Virgil Street.
33. P: yea
34. N: so Wedmore Road is the next one down
35. P: it's a while since I lived there mind.
36. N: my daughter was there (.) she just moved from there now (.) I knew there
37. was something about you (.) you're a Grangetown girl
38. P: Grangetown girl see
39. N2: knock knock its me (.) I'm just bringing these in because I know I'll forget them.

40. N: how old was you when you moved from there
41. P: oh quite young (.) carry on love I'm not stopping you.
42. N: do you use soap?
43. P: no
44. N: can you manage (.) were your parents from there were they
45. P: yea (.) my granddad had a house there and my mother had rooms
46. N: round in Wedmore Road.
47. P: and then (*unclear*)
48. N: that's okay (.) do you want some oxygen
49. P: what happened then (.) Oh moved to Neville Street
50. N: where's Neville Street (.) I know Neville Street.
51. P: St. David's Hospital (.) opposite there oh that must have been just about
when the war broke out (.) 38 (.) 39
52. N: oh right
53. P: must have been when the war broke out because a land mine knocked one
half of Neville Street down and we'd just moved from there
54. N: oh you were lucky
55. P: and my gran and granddad moved up to Ely (.) so we moved in with them.
56. N: she's a Grangetown lass (.) knew there was something about you (.) that's
where my daughter lived (.) just moved from there
57. P: they've tarted it all up now
58. N: yea it's not bad (.) where does your daughter live
59. P: Senghenydd
60. N: where's that?
61. P: up the Valleys
62. N: need a train to get there (.) is that her little girl I saw the other day
63. P: yes (.) she's got two little girls (.) 12 and 9
64. N: was that the twelve year old in the other day
65. P: yes (.) the tall one
66. N: how many children did you have Jean?
67. P: me (.) two (.) two husbands and two girls
68. N: two husbands
69. P: two husbands and two girls
70. N: two husbands (.) are you alright with that arm (.) it's your bad arm.
71. P: my eldest daughter is 52
72. N: you don't look old enough to have a daughter at 52
73. P: yes and Jane was born 1965 (.) what does that make her 38? (.) 39 ?
74. N: 63 I was born and I am forty this year
75. P: she was born in 65 (.) 38
76. N: that's the one that came yesterday
77. P: the other one lives in Devon
78. N: it's nice down there (.) do you go down there often
79. P: no (.) my son in law and me don't get on
80. N: that's a shame (.) it's nice down there.
81. P: she's into Rottweillers
82. N: she breeds them does she
83. P: no (.) not breed them (.) shows them (.) and the other day (.)the first one she
had which was four year old had to be put down.
84. N: what for?

85. P: I don't know (.) there was something wrong with her heart
86. N: they are lovely dogs (.) they're big dogs
87. P: you know they've got such a bad reputation I don't know why
88. N: it's the one bad one gives them a bad reputation
89. P: well they bred them for fighting
90. N: yea (.) same with the staffs isn't it (.) but I mean you get one bad one and it gives the rest of them a bad name
91. P: but they're so quiet
92. N: now do you want hair or not (.) if you're not up to it don't matter
93. P: okay just a little wet (.) we have got a dryer (.) if not I won't bother cos I don't like wet hair
94. N: there's bound to be a drier somewhere (.) which one did you use yesterday?
95. P: my friend's
96. N: she brought it in did she (.) if there's not one here there'll be one downstairs
97. N: here you are (.) how's that (.) not too hot (.) so where's your husband now
98. P: should be on his way in I hope
99. N: I only came back yesterday (.) I've been off for two weeks
100. N: do you know what my son does on the shower (.) he wears goggles (.) he won't have a shower unless he's got his goggles on (.) looks ridiculous (.) he's ten (.) what about when he's older (.) he can't go in a shower with the lads
101. P: he'll get over it by then
102. N: do you think (.) I mean to think he's ten
103. P: he'll get over it
104. N: I don't like being shut anywhere (.) here, put this towel round you
105. P: thanking you (.) I feel better now (.) I was getting sore (.) because I can't move myself see
106. N: that's a shaping (.) did you have breakfast this morning?
107. P: I could only eat it one handed
108. N: what did you have?
109. P: weetabix but it takes you an hour to get through ten tablets
110. N: and you had all that messing about yesterday as well didn't you
111. P: marvellous she was (.) marvellous she was
112. N: cos you worried about that (.) bet you feel better after that don't you
113. P: sure do (.) the job some of your girls do (.) you know fantastic
114. N: ah (.) we meet some fantastic people as well don't we
115. P: well I don't know
116. N: yea we do (.) we meet some fab people (.) you okay lifting your legs Jean
117. P: yes
118. N: that's good (.) you're getting better
119. P: now don't be afraid to rub me (.) don't be afraid to rub me
120. N: I'm going to shout for another towel.
121. *Pause*
122. N: there we go kid (.) did you have a good night's sleep then?
123. P: you can't push you know it's there
124. N: but you did most of it yourself yesterday (.) you were pretty good (.) is she going back and fore then your daughter
125. N: going back and fore then your daughter
126. P: who Jane (.) yes she's got some good friends you know (.) like the

127. one yesterday who came and cut my hair (.) of course they' ve had free
swimmings haven't they
128. N: yes that's right they have
129. P: oops steady on (.) so a friend have been taking them swimming for her
I don't really know (.) takes her about 10-20 minutes to get my house
and then the rest of the way to Cardiff
130. N: how long is it to your house (.) does that feel dry.
131. P: not dry enough (.) but it's quite dry.
132. N: how's that
133. P: you got children
134. N: yes five (.) my daughters are both having babies five days apart.
135. P: oh golly gum drops.
136. N: five days apart (.) one comes home and says she's pregnant and a couple
137. of days later the other one says oh and me (.) both due November (.) both
138. having boys (.) how's that
139. P: they've had a scan have they
140. N: yea and they both wanted to know so two boys it is (.) I'll put you down now
141. okay.
142. P: (*unclear*)
143. N: she didn't fall anywhere (.) are you down.
144. P: I'm down I'm down (.) give my head a good rub now
145. N: how's that (.) got a brush in your bag?
146. P: no love I think it's in my locker
147. N: cos if it dries like that (.) just pop back up (.) if I sit on the bin it'll collapse.
148. N: you have a little fringe don't you
149. P: don't be too fussy I'm not going anywhere
150. N: hey you're going to look gorgeous (.) doesn't matter you're not going
anywhere
151. P: how old are you?
152. N: oh I'm forty this year (.) I should have lied and said I was 31 again (.) let's
have a look (.) bloody gorgeous.
153. P: (*Laughter*) no swearing.
154. N: I've been very good
155. P: it's needs a lot of work on it
156. N: it'll come.
157. P: surprised when they told me it was a mini stroke
158. N: when did they tell you that
159. P: yesterday
160. N: how long have you been here Jean
161. P: just over a week I think
162. N: I've been off (.) did you have the mini stroke here
163. P: woke up one morning couldn't move my legs or my arm.
164. N: that's frightening isn't it (.) very scary isn't it
165. P: well I am 73
166. N: well you don't look that kid (.) you don't look that at all (.) got lovely skin.
167. P: all it is is (*unclear*)
168. N: all it is is (*unclear*) (.) I'd better invest in some (.) you swear by that
169. P: no not really (.) Ken got it from Boots for a rash so I bought that and we
170. never looked back

171. N: it worked (.) is your bot sore Jean
 172. P: it doesn't feel sore at the minute
 173. N: It looks a bit sore (.) what you been having on there sudacrem
 174. P: sudacrem yea (.) some on my table.
 175. N: I'll pop your nightie on so you've got some clothes (.) any in there
 176. P: no I think it's on top of the thing
 177. N: okay (.) I'll pop this on first (.) you're doing very good with it considering it's only a week since
 178. P: these were bought in Caerphilly.
 179. N: what's it say on there
 180. P: Primark
 181. P: I shop in Caerphilly
 182. N: nice and cool as well isn't it
 183. P; how old's the youngest you got
 184. N: he's ten
 185. P: that's the one is it
 186. N: he's ten (.) he's got four big sisters so it's like he's got four mothers (.) it's ridiculous they ruin him (.) I don't ruin him (.) they ruin him (.) he goes round them all (.) one says no and he goes round us all til he gets what he wants (.) he's not daft (.) he knows which day we all get paid on (.) he's not daft at all
 187. P: I think I'm going to do another wee wee
 188. N: I'll put the thing down for you (.) put your glasses on Jean.
 189. P: yes please, can't see a lot without them
 190. N: I'll put the high seat on for you (.) you are still tall (.) it's quite a way to go isn't it
 191. P: one calls one way (.) one calls the other.
 192. N: there's only one on here Jean (.) no good (.) it shouldn't been in here
 193. P: you mind to be on your own over there
 194. N: we'll get you as close as we can (.) put the brake on (.) too close there ready (.) steady (.) how's that
 195. P: okay (.) I'm ready.
 196. N: I'll tell her this (.) we need to get another on in here (.) need some oxygen?
 197. P: a little bit I think
 198. N: that's alright I'll take that back okay (.) you're doing great (.) you're doing fab (.) Jean (.) it's going to work
 199. P: what's the red and yellow button for?
 200. N: that one is if I want assistance (.) so if I am standing you up and I need assistance I press that one (.) you press that red one and you'll have the whole building in here (.) they come out of the woodwork (.) you'd have the whole building in here.
 201. P: get off (.) look what I've done (.) stupid article
 202. N: you're worse than the kids Jean.
 203. P: I know I am
 204. N: hang on (.) while you stand there I'll dry down below okay (.) there we go (.)
 205. I'll come back for your stuff (.) okay Jean

IPU10 Margaret

Patient female 70+ years

2 nurses and occupational therapist

Interaction takes place during a mobility assessment on stairs

- 1 OT: too quick for us (.) are you going to walk down to the stairs again yep
2 N2: happy birthday to you happy (*singing*)
3 N1: don't sing that too loud
4 N2: you all right Margaret?
5 N1: it's a cat wailing
6 N2: ohhhh (.) that's not nice is it Margaret?
7 P: am I recording
8 N2: yes (.) is that ok
9 P: yes
10 N1: here we go then girls (.) ok
11 P: whatever
12 N2: I'm coming
13 (.)
14 N1: when you were sitting (*unclear*)
15 N1: you did (.) just say something like that when you speak
16 N2: alright (.) come on then
17 P: (*unclear*) alright then
18 N1: ah (*unclear*) against the door
19 N2: a wet floor sign's up
20 N1: want me to come with you
21 N3: can you hover close by (.) just just (*unclear*) I don't think we need it
though do we
22 P: no I don't think so (.) I'm fine (.) you carry on
23 N1: ok lets go and get your (*unclear*)
24 N3: I'm sure I wedged that against the door
25 N2: (*unclear*)
26 N1: ok (.) is that holding
27 P: yep
28 N1: now then can I go on that side
29 N2: oh yes of course you can
30 N1: (*unclear*) more comfortable
31 P: (*unclear*) it's wrong on that side there (*unclear*)
32 N1: don't have to do anything (.) you alright?
33 P: (*unclear*) thank you
34 N3: good enough to do (*unclear*) from the top there (.) that big yellow
thing
35 (*laughter*)
36 N1: well done
37 N1: oh yes (.) might as well do it all
38 N2: (*laughter*)
39 N3: why not

40 P: take your time (*unclear*)
41 N3: and then we lever up down there then don't we
42 P: yes (.) if that's all right
43 N3: fine
44 (.)
45 N3: well done
46 N2: want me to go that side? or doesn't it matter
47 P: no (.) stay (*unclear*)
48 N1: sure?
49 N2: (*laughter*)
50 N3: (*unclear*) don't we
51 P: yes (.) the question (*unclear*) here
52 N1: (*unclear*) bit crabby yes
53 N3: working (*unclear*) I'll see if you can work (*unclear*)
54 N2: (*laughter*)
55 N1: do you want me to um xxx.
56 P: yep
57 N3: (*unclear*) your area
58 P: yes it does (.) it really does and what should I have eaten more of
(*unclear*)
59 N1: well you're not going to know (.) I mean (*unclear*)
60 N3: that's right (.) when we go down now we'll have a long walk down to
the admin office don't we
61 N2: (*laughter*)
62 N1: interesting (*unclear*)
63 N2: this is a regular thing is it (*unclear*)
64 N1: what I'll do
65 N3: (*unclear*) different (.) can you just (*unclear*)
66 P: if I can put my arm (*unclear*)
67 N3: just up the side
68 N2: ok
69 N3: it's only just in case
70 P: yep fine no problem whatsoever girls
71 N2: how many stairs you got at home Margaret?
72 P: 13
73 N2: fine
74 N3: so that a (*unclear*)counting 7,8,9,10,11,12 - 14
75 N2: that's more than full
76 N3: 13 (.) well every little extra helps
77 P: if I can do at least twice a week once a day you know (.) it would be
good at least twice a day
78 N2: (*laughter*)
79 N3: it's easy done isn't it
80 P: god (*unclear*)
81 N3: (*unclear*) walks what you are used to
82 P: that's right (.) it all helps
83 N3: hmmm that's right (.) ok good
84 P: excellent girls
85 N3: good (.) one more

86 N2: well done Margaret
 87 P: thank you
 88 N3: do you want a rest?
 89 P: no
 90 N3: you sure
 91 P: no I'm fine (*unclear*)
 92 N3: you sure?
 93 P: absolutely (*unclear*)
 94 N3: which side do you want me to go on
 95 P: this side if that's ok
 96 N3: that's alright (*unclear*) you alright (*unclear*)
 97 N2: fine thanking you
 98 (*laughter*)
 99 P: here boy (.) retreat (*talking to pat-a-pet dog*)
 100 N3: oh has he been in to day Di (*volunteer*)
 101 Di: no he's down west wing
 102 N2: oh she's going to have the dog visit is it
 103 N3: have you met Di?
 104 P: no
 105 N3: he's gorgeous isn't he
 106 P: that one mustn't sit down (*unclear*)
 107 N2: what dog is it Margaret
 108 P: a mongrel
 109 N2: don't you start (.) they are usually the best aren't they
 110 P: so lovely (.) oh, she was so (.) I couldn't believe the way he acted in
 (*unclear*)
 111 N3: he wants to come up the stairs to see if you were alright
 112 P: oh he's lovely
 113 N2: how far do you go? (.) she'll be walking home
 114 N3: well I'll need a breather now (.) at the end here
 115 N2: hello (.) hiya boy
 116 P: where you going now love
 117 N1: (*laughter*)
 118 P: running around
 119 N3: running away
 120 N2: not on my shift
 121 (*laughter*)
 122 N1: wonderful girl (.) thank you so much
 123 N3: you'll find that that sort of crampy feeling goes once you've xxxx
 124 P: yes
 125 N2: yes
 126 N1: it's like everything else when you don't use muscles (*unclear*) in
 right (*unclear*) turn around
 127 P: yep
 128 N3: yes (.) much more steady today
 129 P: now this side feels very confident
 130 N3: yes
 131 N1: no problem at all as you go (*unclear*)
 132 N2: (*laughter*) that'll shut us up won't it

133 (.)
 134 N3: do you want to head back to your bed or in (*unclear*)
 135 P: back to bed yes
 136 N3: (*unclear*)
 137 P: oh Miss Marple
 138 N3: oh you've finished it have you?
 139 P: mmm
 140 N3: good very good (.) very good (*unclear*)
 141 N1: lovely
 142 N3: brilliant
 143 P: thank you very very much
 144 (*unclear*)
 145 N2: I thought that was her not you Margaret
 146 N3: me turning corner bumping into you (.)sorry
 147 N1: full in control though
 148 N2: (*laughter*)
 149 (*unclear*)
 150 N2: it was you
 151 P: thank you very very much that was lovely
 152 N2: well done Margaret
 153 P: I'm very very pleased with that (.) see you tomorrow oh no no weekend
 154 N3: we can practice some walking (*unclear*) you know people who we said (*unclear*)
 155 N2: yes I'm on all weekend (.)if you want to go up and down the corridor
 156 P: oh would you mind
 157 N2: no that's fine
 158 N3: brilliant
 159 N1: in case you're (*unclear*) coming up at least twice a day
 160 N2: righty oh (.) and I can do it twice a day tomorrow because I'm a 9-5
 161 N1: oh lucky girl
 162 P: yes please (*unclear*)
 163 N2: that's ok
 164 N3: start of the weekend now you'll be jogging
 165 P: just about right
 166 N2: by the time you see her Tuesday (.) yep (.) well done Margaret
 167 P: thank you
 168 N3: well done

IPU11 Elin

Patient female 70+

2 Auxiliary nurses

Interaction takes place during an assisted wash

- 1 Sister: excuse me, excuse me I think you may have mislaid this.
2 N1: no it was making ummm (.) it's okay we have put a new tape in.
3 N1: why does, when these tapes are on why does everybody talk posh (.)
4 she's talking posh all the time this (*name of other nurse*)
5 N2: this is yours as well as mine (*nurse*) you can have hold as well
6 P: oh don't you bother.
7 N2: now Elin it was you that got us into this jam (.) you agreed to do it
8 P: I disagreed when I was in the bath the other day
9 N1: do you want the sides back up on the bed?
10 P: no
11 N2: it was you that got us into this mess.
12 P: (*unclear*) but you do see life.
13 N2: you're right there.
14 *Lot of laughter - unclear on tape. Lot of chatter unclear on tape.*
15 N1: there we go.
16 P: thanks very much.
17 N2: right whose the one that's playing widow twanky in your family and
taking all the washing
18 P: well whoever comes.
19 N2: whoever whoever is first to visit gets the washing?
20 (*laughter.*)
21 P: so everybody tries to be the last one.
22 N2: so everybody tries to be the last one to come through the door.
23 (*laughter*)
24 P: well its not much washing is it?
25 N2: no (.) I didn't know.
26 P: (*unclear*)
27 N2: possibly she was ready to come back.
28 P: yes she was I saw her.
29 N2: and (*unclear*) and we need to get those cards up (.) you're the only
one that hasn't got a board (.) I wonder why
30 P: (*unclear*)
31 N2: no I'll certainly see if I can find you one.
32 P: oh don't bother.
33 N2: well no its important you've got birthday cards to go up (.) right (.)
ummm
34 P: don't worry about it you've got other things far more important than
cards
35 N2: well there will be (.) well if I find a board it will give your daughter
something to do won't it
36 P: yes (*laughs*)

37 N2: it will be all hands on deck today (.) all hands on deck.
38 P: my son should be coming (.) well two sons
39 N1: there are patients in the day room apparently
40 N2: where?
41 N1: in the day room.
42 (?) I have put them into umm (*unclear*) but I have warned them
(*unclear*) Conversation between (N1) and (N2) but *unclear*
43 N1: are you hoping that Elin is going to sit in that chair?
44 N2: well she might
45 N1: is this your flannel?
46 P: yes
47 (*unclear*)
48 N1: so it doesn't matter if you would rather stay in your bed
49 P: yes (.) just sit here listening to everything and everybody praying I'll
survive (*unclear*)
50 N1: that's right
51 N2: and lots of drawing pins
52 P: oh no (.) don't put them up
53 N2: I'll leave that there and when she comes back that's a job for her
54 P: oh no (.) don't do it
55 N2: right.
56 (*unclear*)
57 P: I don't know if I saw my daughter walk by
58 N2: I'm sure she'll be back now
59 (*unclear*)
60 N1: Is that your birthday present?
61 P: yes (*unclear*)
62 N2: okay well I'll pop back to see you
63 (*unclear*)
64 P: what's going on?
65 N1: you can't have it left on (*unclear*) to play
66 N2: oh you can't?
67 N1: we have got to take it with us when we go
68 (*unclear*)
69 N2: magic stuff this Velcro (.) if it goes in the place you want it to go (.) I
think (*unclear*) right that's okay (.) now can I take this pillow out
because at the moment its just pushing you (.) or if I take this one out
and just leave that one because its pushing your head forward (.) is
that better? yes? (.) righty ho (.) right lets find that (*unclear*) right
where's your toilet bag sweetheart? oh I know I can see it's over
there (.) oh you've got a (*unclear*)
70 P: (*unclear*)
71 N2: right lets see (*unclear*) (*Laughter*) we think (.) oh look it was all the
way to there
72 P: (*unclear*)
73 N2: there we are (.) I don't think we can go wrong now(*laughs*) famous
last words(*laughs*) there's two (.) that's fine (.) right we should be
okay with that now Elin (.) let's put your bed up a little bit for you(.)
would you like a fresh nightdress on this morning Elin?

74 P: no

75 N2: you had one last night did you? you feel that ones okay then? yeah?

76 P: yes

77 N2: yeah (.) that's fine there's nothing else to go in the water(*unclear*)

78 well you'll certainly feel a lot better for having this now sweetheart (.)
umm right (*unclear*) was it because that you were ill and your nightie
was soiled darling that you had an extra one on?

79 P: yes yes.

80 N2: that's fine(.) you feel this one is okay to put back on again, right oh
(*unclear*) there we go (.) take this side down (*unclear*) I think you've
got a similar nightie to Phyllis next door haven't you

81 P: (*unclear*)

82 N2: I think so (.) that's the problem you know with Marksies they're so
nice that everybody ends up (.) I think at one time we washed a ladies
ward like we are now and by the time we finished I think we had
three ladies in the identical and colour nightdress and the other lady
had the identical nightdress on but it was a different colour (.) all in
the same room one morning (.) that was Kim (.) Kim (*unclear*)
alright yeah

83 N2: okay my love, lets get your towels (.) alright can I pull you a little bit
more centre to the bed sweetheart?

84 P: (*unclear*)

85 N2: oh that's not going to work at all (.) its all cockeyed this side

86 N1: (*unclear*) trouble there are we? have you got a towel there love?

87 N2: I got up this morning (*unclear*)

88 (*unclear chatter and laughing*)

89 N2: it is nice isn't it

90 N1: I was saying to (*nurse*) about your talcum powder

91 N2: oh yes

92 N2: that's nice as well (.) it's only a baby one but its got a lovely smell on
it (.) what was you knitting did you say?

93 P: (*unclear*)

94 N2: oh, yes

95 N1: camomile is soothing

96 N2: yes

97 N1: calming

98 N2: perhaps that's why we should be (*unclear*)

99 N2: What did (*doctor*) say Elin about that pain? does she feel its just a bit
of
cramp (.) you know

100 P: (*unclear*) give me something

101 N2: ah yes(*unclear*)

102 P: (*unclear*)

103 N2: okay(*unclear*) in the bath because we've got that big umm polythene
bag over your arm (*unclear*)

104 P: yeah.

105 N2: yeah so if we can just get them (*unclear*)

106 N2: you've been very lucky so far with this plaster so far keeping it dry
(.) when you think of all the baths you've had (.) it'll be just my luck
to get it wet.

107 P: *(unclear)*
108 N2: did they not say?
109 P: no
110 N2: I suppose it's better than the first one you had 'cause that one was
right here wasn't it you know right the way through the whole
length of the arm (.) yeah so in that respect it is
111 P: *(unclear)*
112 N2: I must admit I don't know.
113 P: *(unclear)*

End. Tape too unclear

IPU12 Rose

Patient female 70+
2 auxiliary nurses
also present Physiotherapist (phy)
and pharmacist (pha)

Interaction takes place during an assisted wash

- 114 N1: yes it is there it's record
115 N2: yes but you've got to stop the record
116 (*Laughter*)
117 N1: I'm going to poison a chain round your neck
118 (*Laughter*)
119 N2: now am I going to fit in happy birthday as well on Thursday (*laughter*)
you are looking forward to it aren't you
120 N1: so am I going to sing happy birthday on this tape are we (*laughter*)
oh dear (.) I'll pop it there
121 N2: I'm looking for a (*unclear*)
122 N3 I saw one up there
123 N2: (*unclear*)
124 (.)
125 N1: one drop at night (.) hi (*physio*)
126 Phy: hiya how are you (.) alright?
127 (.)
128 Pha: I might as well get the other one as I'm getting one Rose and then you've
got both in there
129 P: yes that's right
130 (.)
131 Pha: are they both in both eyes
132 P: no the one eyes with one (*unclear*)
133 Pha: ok
134 (.)
135 N1: (*unclear*) together slowly
136 P: (*unclear*)
137 N1.: Yes hopefully on the same day as your birthday
138 (*Laughter*)
139 Pha: what are you like
140 N2: you won't let me forget this
141 N1: no I know
142 N1: you might get a wash (*unclear*) your birthday
143 P: I'll have a wash after
144 N1: yes if you don't have a wash any other day you've got to have one for
your birthday
145 P: never
146 N1: yes definitely (.) no messing about (.) um
147 (*unclear*)
148 Pha: and this one's one drop at night
149 P: I've got it, lovely (.) thank you

150 N2: will they?
151 Pha: yes they are finished now
152 N1: oh thanks (*pharmacist*)
153 N: should I look it up
154 N1: yes love
155 N: thank you
156 N2: right (*unclear*)
157 N2: as if I would
158 P: as if yes (*laughter*)
159 N1: you finished your teeth
160 P: no
161 N2: no no no that's fine (.) so they're to stay on there are they
162 P: yes
163 (.)
164 N2: right well I'll put this back outside (*unclear*)
165 (.)
166 N2: alright
167 P: ok
168 N2: do you want to go to the toilet or anything (.) no?
169 P: not yet
170 N1: right
171 (*unclear*)
172 N1: I've passed the message on Rose ok (.) I think I'd better try and get
(*doctor*) up(.) I think it's more like a crampy pain
173 N2: over
174 N1: yes for Rose's pain, sorry (*Nurse*) I think that's more over your side
175 N2: right
176 N1: do you know what? I think they all feel ashamed of Brian
177 N2: do you
178 N1: yes I think it must be something in the water
179 N2: did you bring a nightie?
180 P: yes
181 N2: yes
182 N1: oh that's a lovely one that
183 N2: is it (.)I haven't seen that one
184 N1: she got it from marks and spencers
185 N2: oh you don't have to tell me about marks and spencers now
186 (*Laughter*)
187 N2: oh I do
188 N1: I think it will look nice and fresh and cool
189 N2: really really pretty
190 N1: there's a lovely pretty pink one I've seen as well
191 N2: yes (.) these are all very well and good these things but
192 P: (*unclear*) mmm not very good
193 N1: no
194 (*unclear*)
195 N2: it's a good idea but (..) never mind (.) did you have anything nice for
your birthday?
196 P: yes

197 N1: That why I thought she was having a wash cos it was her birthday.
 198 P: no
 199 N2: to carry her
 200 (Laughter)
 201 N1: have you got anything nice in there that you want to put in the water
 202 P: no I'll get a (unclear)
 203 N1: no okey doke (.) right
 204 P: they can find me bits and bobs to (unclear)
 205 N2: nice
 206 N1: right (.) can you lift your botty out (.) would you like to sit out in the
 chair for a little while
 207 P: no
 208 N1: now you will definitely have a (unclear) for the queen aren't you
 209 P: today
 210 N2: got a flannel there
 211 N1: um (.) no I don't think there is
 212 N2: yes
 213 N1: is that your daughter or your (unclear)
 214 P: my daughter yes
 215 N1: I'm assuming she's taking your washing for you Rose?
 216 P: yes
 217 N1: ok
 218 P: she's staying in our house with my son and daughter in law who have
 come up from (unclear)
 219 N1: you're not a local lady though (.) going by your accent yes (.) how did
 you end up in Wales then
 220 P: I had (unclear)
 221 N1: ahhhhhh (.) oh that's where my son is going to live now in a fortnights
 time (.) well blow me.
 222 P: they were from (unclear) farm they were
 223 N1: oh well this is just
 224 P: yes
 225 N1: in a little area (.) the houses are about 25 years old there (.) he'll be
 moving now in about 2 weeks time
 226 P: ohh
 227 N1: a nice little estate
 228 P: yes
 229 N1: it's his first house so we are all quite pleased (.) well there you are small
 world (.) never heard anybody mention that before
 230 P: don't say (unclear)
 231 N2: I'll do under your (unclear)
 232 N: (calls nurses name)
 233 P: pink
 234 N: (calls name again)
 235 (unclear)
 236 N1: right
 237 N2: I can put soap on it
 238 (.)
 239 N1: so you must have liked this part of the world then

240 P: my son's got relations here as well too
 241 N1: ahhh right
 242 P: so he used to come up when he was (*unclear*)
 243 N1: Where do you live now then?
 244 P: Bridgend
 245 N1: ah Bridgend (.) ah that's (*unclear*)
 246 (.)
 247 N2: oh I see
 248 N1: (*Laughter*)
 249 N2: if you haven't got it it's right
 250 (*Laughter*)
 251 N1: thanks (*other nurse*)
 252 N2: yes, thank you (.) you have sweetheart
 253 (*Laughter*)
 254 (.)
 255 N1: I'm wondering whether do you want to sit in the chair by here or would
 you prefer to go and sit in the lounge
 256 P: (*unclear*)
 257 N1: oh right (.) ok
 258 P: she likes (*unclear*) she likes to bring it here (.) right ok
 259 (.)
 260 N2: after (.) that's alright
 261 (*unclear*)
 262 N1: do you find it warm in here?
 263 N2: it is worrying
 264 (*unclear*)
 265 N2: it is warm in here
 266 N1: yes (*unclear*) not really strong
 267 N1: (*unclear*) this weekend travelling to get here (.) it's going to be (*unclear*)
 forecast long delay with the trains and (*unclear*)
 268 P: (*unclear*)
 269 N1: should be
 270 P: it would be helpful
 271 N1: (*unclear*) phone calls
 272 P: (*unclear*) lucky devils(.) you know you like a break
 273 N1: yes (.) ahhhh (.) if you'd like to relax back now onto the (*unclear*) we
 can do that
 274 P: (*unclear*)
 275 N1: no it's not a problem, there you go (.) whatever reason was just that
 little bit easier
 276 P: yes
 277 (.)
 278 N1: oh was that the sore one
 279 P: yes
 280 (.)
 281 N1: your daughter going stay the day or she (*unclear*)
 282 P: well she's um (.) she'll think about it (.) she's staying with (.) the
 other daughter is working so she comes in after she leaves the office and
 (*unclear*) leaves earlier

283 N1: *(unclear)*
 284 P: I don't know (.) you never know
 285 N1: we're coming up towards a bank holiday weekend on Friday *(unclear)*
 might very well finish a little earlier
 286 P: yes (.) she's a stockbroker you see
 287 N2: And sit on the banister
 288 P: she's a stockbroker (.) she's a stockbroker
 289 N1: oh right
 290 N2: oh look see we could have a little chat to her now with a bit of advice
 with what to do with all our millions
 291 *(laughter)*
 292 P: oh well you've got to give my *(unclear)*
 293 N1: no
 294 N2: I wish I had one to start (.) no I don't want *(unclear)* I wouldn't mind
 one million
 295 P: its like that(.) bits makes them steady *(unclear)*
 296 N1: I think it would be nice to *(unclear)*
 297 P: yes that right (.) it's *(unclear)* things that you do have in mind
 298 N1: wouldn't that be lovely
 299 P: yes (.) I don't know why they always smoke a fag straight away
 300 (.)
 301 P: I can't get it myself otherwise I would you see
 302 N1: no
 303 N2: do you want deodorant or talc or anything on
 304 P: yes I've got some
 305 N1: yes
 306 N2: have you ever tried that
 307 N1: no but one of the girls
 308 N2: let me show you
 309 N1: one of the girls
 310 N2: you don't mind a little squirt for me to show her
 311 P: of course not
 312 N2: just close your mouth or I'll do your chest
 313 P: shut your mouth here comes the boss

End tape

IPU13 Lorna

Patient female 40+ years

Qualified nurse 40+ years

Interaction takes place by bedside. Lorna has been an in-patient on a four-bedded ward and has witnessed several deaths.

19. N: you've felt a bit distressed because there have been so many (.) you know so many of your colleagues
20. P: you know you get to know people (.) there was Tina (.) I was talking to her and then Marie and sort of thing (.) you get to know people and they go so soon (.) not that I know them
21. N: no but you know that things have progressed with them
22. P: yes
23. N: does that make you feel apprehensive?
24. P: I think about myself (.) I understand that this is (*unclear*) every family has to got through (.) I see how different families are coping with different things (.) it's silly really (.) it's as though I am an onlooker on these things (.) I don't know (.) I can't say it's done me any harm
25. N: right (.) okay
26. P: you know I think there's three people in here (.) I don't know what it is
27. N: do you feel there is an extra burden on your shoulders?
28. P: no I don't think it's an extra burden on my shoulders
29. N: does it make you think about what's happening with you?
30. P: yes it makes me think about what is happening with me (.) makes me think that will there be a time sometime in my life when the same thing will be happening for me (.) and I think this may be happening because different people cope with different things differently and I don't know (.) I just find it amazing (.) many just go out leave and get hit by a car (.) they don't know anything about it (.) and you know the relations are totally different do you understand what I'm saying
31. N: yes cos you've got time to think
32. P: yes I have time to think about it all
33. N: you've had a warning kind of thing haven't you
34. P: yes (.) no surprises
35. N: and we have seen this before as well (.) when somebody relatively well like yourself, who can potter about and look after yourself what have you (.) and when you're in for control of your pain (.) and seeing others around (.) we have seen this in the past and we know that it can be distressing (.) but others have turned round and said it's been a comfort because they know what is ahead of them
36. P: yes I would say that (.) I mean you all know your own emotions (.) you know (.) well I though (.) it's a bit like a privilege to be here sometimes
37. N: do you feel like your intruding sometimes?
38. P: I don't know whether to them because then everybody would have to be in their own rooms you know and then you wouldn't be in on it so what would you get (.) like Marie up there now (.) her relations are up there and more than likely some time you see them come down crying and

- things will be over for them (*unclear*) I don't understand myself half the time (.) it just seems so unreal that I can talk about it
39. N: no but that's good if you are able to express how you feel (..) I think you might have some visitors actually (.) is that lady with you?
40. P: with you.
41. N: I am going to leave you to it and I know you've not been so well yourself
42. today (.) which is a bit of a shame really
43. P: yes but I am feeling a bit better now
44. N: what I was going to say (.) I know there's been no definite discharge date or anything (.) I was just wondering whether/ because of this whether you would want to go home sooner than what we were thinking of
45. P: it doesn't worry me (.) I think my husband wants me to stay until you turn round and say yes, she's well enough to go home (.) I think that's what he wants and I wouldn't want to go home unless he felt that way as well
46. N: what do you feel then?
47. P: well I feel that way as well (.) it's always the same (.) you are in hospital and you think oh you want to go home so many times and then when you've gone home you have a setback or you don't feel well and you think oh my God did I do the right thing leaving hospital (.) but then you can't have the hospital there all the time for running back to (.) you've got to get on with our own thing
48. N: well at the moment you've still got symptoms that we would just like to get better controlled before you went home (.) but if you feel I want to go home tomorrow we would try and get you home
49. P: as I say I would like to *get all* of this straight and make sure I don't get any more sickness (.) if next week I can get my medication sorted out when I go home touch wood I'll be alright(.) I hope that makes sense to you cos it does make sense to me
50. N: of course it does (.) but if you said you wanted out we could get your prescription sorted out so if over the weekend you feel things are getting a bit heavy and you feel you want to
51. P: I know what you mean
52. N: maybe just go out for the afternoon and if you have warm clothes and you want to go out for lunch (.) if you felt well enough for a couple of hours (.) just let us know where you are going
53. P: lovely (.) okay that would give me a break (.) good idea
54. N: yes a change of scenery (.) but only do it if you feel ready (.) but it would definitely be a change of scenery
55. P: not straight out yes
56. N: and the other option (.) if you didn't want to be in the four bedder there are two single rooms still if you wanted us to transfer you upstairs
57. P: unless you want the bed I am quite happy to stay here (.) as I say you can't hide behind closed doors all the time with people in and out (.) no no I can't see that
58. N: if you need anything or want anything by all means let us know (.) are you comfortable at the moment (.) a bit of pain?
59. P: yes (.) by here and by there (.) I've been pretty good because I haven't any of my plus ones today have I

60. N: shall I get you an oxynorm now?
61. P: yes that's a good idea
62. N: I have just been suggesting to Lorna that she might like a bit of time out at the weekend (.) go out for a couple of hours (.) spot of lunch and then come back.
63. P: yes that would be nice
64. N: we try and encourage our patients to use the weekends (.) to go up to the town (.) even if it's just down to the pier if it's a nice sunny day
65. P: oh my husband will decide on somewhere to eat
66. N: okay that's fine (.) but you do it because you want to do it (.) alright?
67. P: yes yes
68. N: okay (.) lovely (.) I'll get your some oxynorm okay
69. N: sorry to keep you

End tape

IPU14 Arthur

Patient male 70+ years

2 qualified nurses and sister (S).

Interaction takes place during an assisted move from chair to bed.

1. N: now Arthur I'll check your chart because I knew the nurses gave you=
2. P: yes alright
3. N: =eye drops
4. P: yea go on.
5. N: let's see (.) they gave it to you this morning
6. P: have I got one to come now?
7. N: no the next one will be during supper (.) five thirty or something or six o' clock
8. P: okay (.) they were hurting a bit
9. N: you have just had your pain killer (.) just tell me if that helped you okay love?
10. P: yea
11. N: something wrong?
12. P: name?
13. N: *(nurse's name)* love
14. P: *(nurse's name)*
15. P: *(nurse's name loud)*
16. N: oh don't shout at me like that
17. P: he he
18. N: your hair's all up
19. P: I can't find my comb can you
20. N: I think you have one in the wardrobe (.) let's see
21. P: have a look
22. N: no (.) none in there
23. (.)
24. P: they can't straighten me out
25. N: well I can look in the cupboard in the sluice and look for a
26. comb for you (.) yea
27. P: yea (.) I've had a pain killer haven't I and the doctor said she was going to *(unclear)*
28. N: we told her about you and she'll be coming in, she just have her break right now
29. S: hello
30. P: is this the doctor ?
31. S: no I'm the Sister (.) how are you?
32. P: yes you told me this morning
33. S: yes (.) *(gives name)* (.) how are you feeling?
34. P: not too good
35. S: not feeling too good today (.) would you prefer to get on to the bed
36. P: well I don't know Sister it's such a long way to go
37. S: we can help you
38. P: yea but I'll have to have an arm up

39. S: that's no problem
40. P: oh it is
41. S: if you are not feeling very good do you think maybe an hour would
42. be helpful
43. P: I don't mind (.) my oxygen is there I want to get to is
44. S: just for an hour it may help (.) we'll give you a hand now put your
45. legs up
46. P: I will try
47. S: you just hold on
48. P: I need about three sisters
49. S: three sisters (.) a glut of sisters
50. *Long pause*
51. P: what we going to do with this
52. N: over there
53. P: *(nurse name)*
54. N: oh don't shout my name (.) call me *(shortened name)* (.) you know what
55. when my brother calls me the whole name=
56. P: *(shortened name)*
57. N: =when my brother is cross he calls me my whole name (.) he calls
58. *(full name)* (.) that's why I don't like to be called *(full name)* (.) so
(shortened name) is (.) okay (.) alright love
59. P: what are you going to do now
60. N: we will transfer you to bed now love
61. P: it's/ I don't know where the footstool has gone
62. N: it's not very good though (.) okay.
63. N: move it (.) then you put your *(unclear)* place on the bed
64. P: lovely
65. N: do you want sheets on (.) yea (.) no
66. P: well
67. N: we'll put that there (.) you can always use it
68. P: if I feel cold I'll tell you
69. N: right 1 2 3 stand up (.) 4 up up (.) hang on (.) come on (.) go back (.) sit
up (.) hang on hang on
70. *(laughter)*
71. S: Arthur (.) what are they like
72. P: they're good
73. S: they're good are they
74. N: yesterday Arthur told me you're so good I could marry you and I told
him *(unclear)* you are in a long queue
75. *(laughter)*
76. N2: Arthur (.) why don't you stand up a little bit and then you can move up
the bed before you sit down and that'll be a lot easier for you (.) stand up
lovely (.) step up to where *(nurse's name)* is now (.) that's the way (.)
one more (.) a bit more towards me (.) a bit more (.) you can sit down
now (.) that's more comfortable (.) oops (.) okay
77. N2: I can see you Arthur
78. P: you think I'm stupid do you.
79. S: not at all
80. P: more comfortable than I was before (.) the top button (.) oh gees I want

81. S: to go to the toilet
the fan is facing the bed (.) I'll move it now two secs

Appendix 3: Consent forms and information sheets

Consent Form

Study into nurse/patient communication at (anon)

Please circle as appropriate

- Have you read the information sheet? Yes/No
- Have you had the opportunity to ask questions and discuss the study? Yes/No
- Do you understand that copies of the tapes will not be made available to anyone other than the researcher at any time? Yes/No
- Do you understand that anonymised transcripts of the tapes may be published or presented at conferences? Yes/No
- Do you understand that you may withdraw your consent at any time during the study? Yes/No
- Do you agree to take part in this study and to participate in one or more audiotaped sessions? Yes/No

Signed.....
Date.....
Name in capitals.....

Signed.....
(Researcher)
Date.....

Signed.....
(Witness)
Date.....

Patient information sheet

(anonymised)

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This will not affect the standard of care you receive.

- **Why is the research being done?**

Every part of the care that you receive from your nurse, and the information that she receives from you, relies on the use of language.

It will be useful to make a specialised study of the communication between patients and nurses to provide new knowledge about how our use of language supports and affects the relationship between patient and nurse.

There have been several specialised studies about doctor/patient conversations but very few about nurses and their patients, even though most contact will be made by the nurse.

It is hoped that the research findings will provide new knowledge and a greater understanding of this vital area.

- **What will it entail ?**

Audio taped recordings will be made of nurses and patient's actual conversations at (anon)

The researcher may be present at the time of recording but will not take part in the conversation.

A small hand-held tape recorder will be used.

If, at any time, you should feel uncomfortable or wish for privacy with your nurse, the researcher will leave.

If, at any time, you feel uncomfortable or concerned with the recording, you are free to leave the study.

Your participation will be very helpful but it must be stressed that your cooperation is entirely voluntary.

You are under no obligation to give your consent.

The tapes can be erased at anytime, upon your request .

- **Confidentiality**

The study is funded by the Economic and Social Research Council (ESRC) and, as such, it may be published or presented at conferences. Anonymity of participants will be protected by the use of pseudonyms.

The tapes will be erased when the study is complete.

- **Questions?**

please contact Annmarie Nelson tel
or leave a message at the switchboard

Nurse information sheet

Study of patient/nurse interaction at (anon)

Why is the research being done?

All patient/nurse contact involves the use of language.

Effective and sensitive communication is necessary for best patient care.

Previous nurse-led research into communication has been mainly observational or intuitive and has not often utilised a detailed linguistic analysis.

Research that has used linguistic analytic methods has focused on doctor/patient interaction although the majority of patient care is undertaken by the nurse.

This study will aim to provide new knowledge towards a greater awareness of the impact of choice of language use on the patient/nurse relationship.

What will it entail?

Audiotaped recordings will be made of nurses and patient's actual conversations in the course of their normal activities.

The researcher may be present or nearby at the time of recording but will not take part in the conversation.

A small hand-held tape recorder will be used.

If, at any time, you should feel uncomfortable or wish for privacy with your patient, the researcher will leave.

If, at any time, you feel uncomfortable or concerned with the recording, you are free to leave the study.

Your participation will be very helpful but it must be stressed that your cooperation is entirely voluntary.

You are under no obligation to give your consent.

The tapes can be erased at anytime, upon your request .

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The tapes will be destroyed when the study is complete.

Questions?

Please contact Annmarie Nelson tel.

