



# People's Experience Of Cancer Within The First Year Following Diagnosis

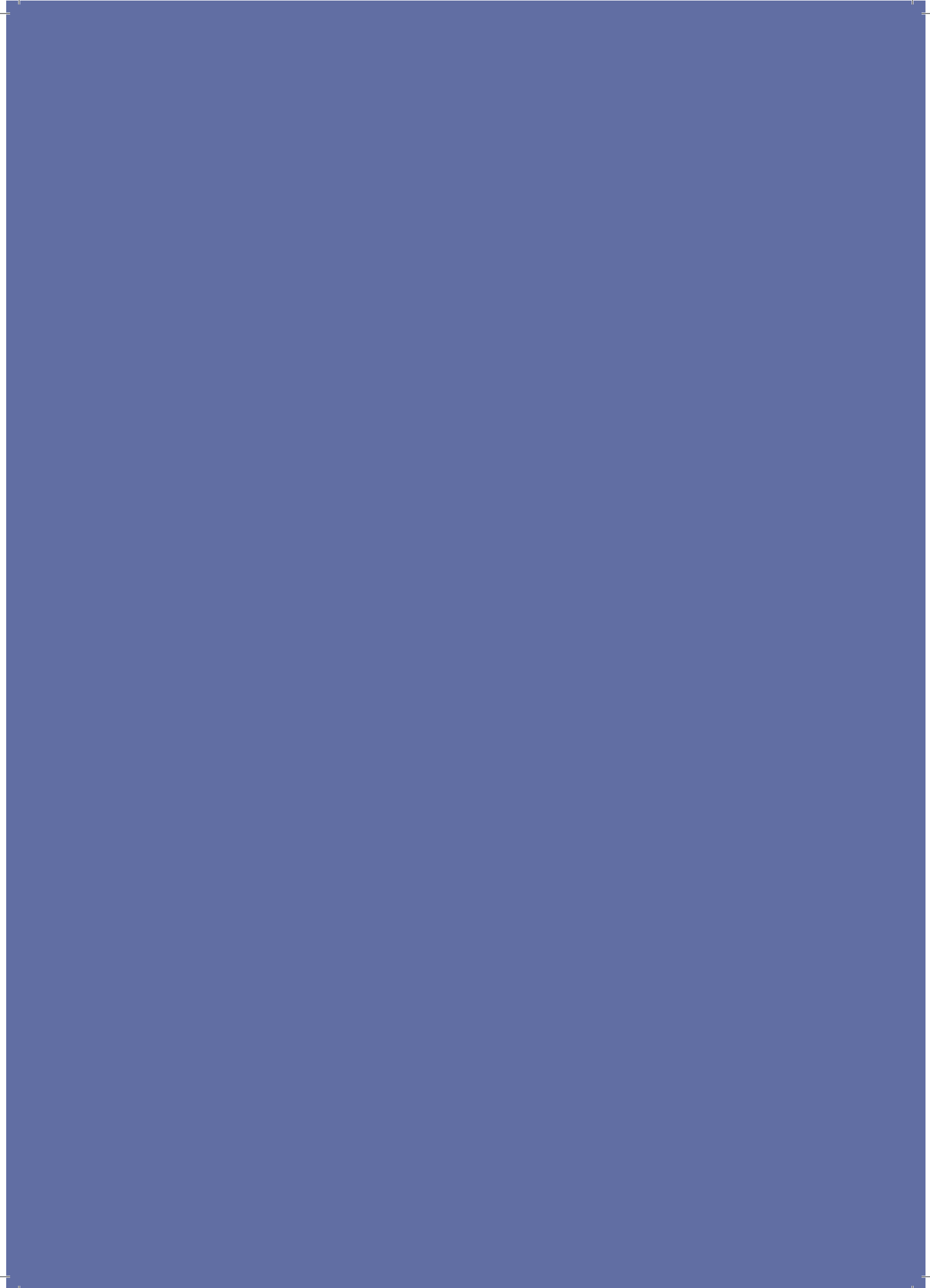
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# EXECUTIVE SUMMARY

## AIM, METHOD AND POLICY CONTEXT

The aim of the study was to explore the experiences of people affected by cancer in the first year following diagnosis with breast, lung, colorectal, prostate or gynaecological cancer.

This was a descriptive qualitative study conducted over a period of 18 months during which three serial, longitudinal semi-structured interviews with 66 people, their nominated partner/carer<sup>1</sup> (n=43) and healthcare professional (n=20) were conducted. The study included 18 people with colorectal cancer, 12 women with breast cancer, 9 women with gynaecological cancer, 17 people with lung cancer and 10 men with prostate cancer. The sampling strategy was not designed to derive a representative sample but to enable the researchers to understand experience of cancer and cancer care from men and women with a different cancer diagnosis and who had different socio-economic backgrounds and lived either in a rural or urban area. A conscious effort was made to include people from different ethnic minority groups but this was unsuccessful because no or very small numbers of people from these groups were diagnosed with cancer during the period of recruitment in the cancer centres where healthcare professionals were recruiting for the study.

This project took place in post-devolution Scotland, where health policy was regarded as a top priority and often in the media spotlight. Several key domains prevail in health and more specifically cancer policy since 2001 to present day which are:

- » patient involvement and self care
- » partnership working and community-based care
- » culture of caring
- » role of partners/carers

<sup>1</sup> For the purposes of this report, the term 'carer' is used to describe individuals who care for a friend, relative or neighbour without receiving paid income in addition to income received through the benefits system e.g. carers allowance. It is similar to the term 'unpaid carer' which is used in the Scottish Executive (2005) report *The Future of Unpaid Care in Scotland*. As the Scottish Executive point out, this terminology is currently widely accepted by carers' organisations and differentiates unpaid carers from those who receive a regular wage for the caring task.

This study explores these four domains from the perspective of the experience of people affected by cancer from diagnosis, treatment, through to follow up and living with cancer.

## KEY FINDINGS

Highlighted below are broad and general key findings of people's experiences of cancer and cancer care within the first year following diagnosis. Specific findings and relating to people's experiences of diagnosis, treatment, information etc. are presented at the beginning of individual chapters.

- » Many people in this study experienced what they regarded as excellent or good care delivered by compassionate cancer care professionals
- » All the professionals interviewed demonstrated an overwhelming ambition to deliver the best possible care to individuals with cancer
- » Nurses in particular were identified by people affected by cancer as being a key source of information and support
- » The information provided to patients was at times inconsistent and did not always meet the needs of patients or their partners/carers
- » In many situations care was fragmented for people affected by cancer and this seemed particularly so between GPs and tertiary cancer centres
- » Some patients felt let down by their GPs and primary care teams both in terms of initial diagnosis and accessing supportive care
- » Not all patients understood their diagnosis and some patients were told of their diagnosis over the telephone or by letter
- » Many people affected by cancer experienced financial hardship as a consequence of their diagnosis and provision of financial information was ad hoc
- » Some people affected by cancer experienced employment difficulties and there was limited support for them to address this
- » People affected by cancer utilised a range of coping and self care strategies to manage the physical and emotional effects of cancer and treatment side effects
- » People with cancer were involved in their own care, with some people more active in self care than others
- » There was an absence of psychosocial support available to people affected by cancer

- » Patients with cancer were not always fully prepared for the investigations they underwent and this was a significant source of distress
- » Patients with cancer experienced a range of symptom clusters as a consequence of treatment and information and support to manage these was at times inadequate
- » Postponement of treatment and waiting for the results of investigations was a cause of distress
- » People with cancer relied on healthcare professionals to make treatment decisions because they were the experts and they felt involved in the process
- » Patients had a range of needs at the end of active treatment and this was not always addressed by health care professionals
- » Even at one year post diagnosis patients were experiencing a range of symptoms which were not always addressed
- » Partners and carers played a pivotal role in the experiences of people with cancer
- » There appeared to be no formal support structure in Scotland for partners/carers of people with cancer

## CONCEPTUALISING EXPERIENCE AND RECOMMENDATIONS

The physical, emotional and social perceptions and requirements of people affected by cancer are intricately interwoven, intensely personal, many-layered, fluid and change over time. To enable policy and practice to relate to patient experience, the type of wider partnership-based healthcare required to involve and care for those affected by cancer should embody a whole system understanding of these and their roles and responsibilities beyond cancer, and harmonize and run parallel in time to their experience.

Each key recommendation below focuses on the four policy domains listed above and begins with a key point, which attempts to capture the essence of the domain and the kernel of critique of current policy. More specific and detailed recommendations are provided in chapter 19 in the full report. At the time of writing this report in 2007 we were aware that a number of national initiatives were going to be launched in 2008 including a new Cancer Strategy, Patient Experience Programme and revision of Quality Improvement Scotland Core Standards for Cancer Services Project. Their content and how they impact on people's experiences of cancer and cancer care is, therefore, yet to be seen.

## PATIENT INVOLVEMENT AND SELF CARE

**Key point:** Political understandings of the concept of citizen involvement in political and public policy decision-making cannot be uncritically applied to healthcare practice. This is because full power and control in decision-making about care including treatment decision-making is perceived by patients as unrealistic. Instead, the concept of patient involvement in healthcare practice needs to emphasise the importance of synergy between professional knowledge (healthcare professional) and personal experience (patient and carer). A vital component of this synergy between expertise and experience is information and communication. It is not sufficient for healthcare professionals to simply provide information about for example, treatments and self care, they should also constantly consider patients' understanding of it and how it relates to their social circumstances. The difficulty for most people affected by cancer and healthcare professionals is not lack of available information but knowing when and where it is appropriate and useful to access and make sense of it.

**Key recommendation:** In order to move beyond policy rhetoric, providing training for healthcare professionals and evaluating the ways that patients and carers are involved in their care (for example, in treatment decision-making and in self care) and the outcomes of their involvement is required.

## PARTNERSHIP WORKING AND COMMUNITY-BASED CARE

**Key point:** Partnership and joint working has been a key component of health policy in Scotland for nearly a decade but results from this study would suggest that more work needs to be done to deliver it, particularly in relation to bridging the gap between tertiary (cancer centre) and primary care (GP). This gap is particularly problematic given the prominent role primary care is anticipated to play in a healthcare future where people are being increasingly cared for in their local communities. Moreover, given that people experience cancer beyond the clinical environment and in social and wider contexts, welfare advice and employment agencies may also be considered as partners in supporting people with cancer.

**Key recommendation:** Clear guidance for how and when tertiary and primary care professionals communicate about an individual patient and guidance on what information and what care each

partner is expected to deliver should be developed. This has to be transparent to all partners including patients and carers. The partnership should consider extending to involve other agencies. It should be clear to them who in the partnership they should contact to support them and meet their needs.

## CULTURE OF CARING

**Key point:** The concept culture of caring suggests that care is not just about 'outcome' and providing people with the right diagnosis and treatment – although this is imperative – but also about 'process' and the ways in which healthcare professionals and people affected by cancer interact and relate. In particular, it draws attention to a person's emotional needs and mental well-being as well as their physical health from diagnosis through to follow up and living with cancer. Current policy drives towards reducing waiting times, improving morbidity and mortality are fundamental to people affected by cancer. However, without a culture of care being embedded in clinical practice and target-setting, the risk remains that the individual with cancer will be treated as a disease rather than as a person.

**Key recommendation:** Ensure continuing professional development for healthcare professionals, which is evaluated on a regular basis, in relation to all aspects of a culture of caring from diagnosis, treatment, follow up and to living with cancer.

## ROLE OF PARTNERS/CARERS

**Key point:** The role of partners/carers in supporting people with cancer is increasingly recognised in health and social policy and healthcare practitioners are expected to work in partnership with partners/carers. Evidence from this study indicates that practitioners may fall short of implementing these policies because of a lack of understanding of why and when individuals with cancer include partners/carers and how family relationships change throughout the course of the illness. Moreover, without understanding family dynamics, working with and supporting carers will be limited.

**Key recommendation:** A review of partner/carer relationship-based health care policy, to ensure that the policy frameworks reflect and acknowledge the relational context of cancer, including the influence and impact of relationships.

# Section 1: INTRODUCTION AND METHODS

## INTRODUCTION

This study is one component of a three-phase Developing cancer services: Patient and carer experiences project funded by the Scottish Executive Health Department undertaken by the Cancer Care Research Centre (CCRC). Phase 1 involved a review of literature about the agenda of involvement in cancer care (Hubbard et al., 2005), a scoping exercise to find out what involvement activity had been taking place in Scotland and England (Ryan et al., 2005), a public involvement rapid appraisal to seek the views of members of the public in Scotland about cancer and cancer care (Kearney et al. 2005) and the establishment of Patient and Carer Advisory Groups for the Cancer Care Research Centre (Worth et al., 2005). Phase 2 included three studies: secondary analysis of cancer treatment related morbidity datasets (Kearney et al., 2008), a prospective monthly quantitative survey of 66 people's experiences of symptoms and well-being in the first year following diagnosis (Knighting et al., in preparation) and prospective qualitative in-depth interviews with this same group of people to explore their experiences of cancer and care. It is the latter study that is the substance of this report. Phase 3 involved CCRC researchers working in partnership with clinicians to use some of the key findings of Phases 1 & 2 to develop cancer care services (Knighting et al., 2007) and an evaluation of the impact of the project as a whole on the agenda of involvement and cancer services in Scotland (Forbat et al., 2007).

The Developing cancer services: Patient and carer experiences project took place in post-devolution Scotland, where wider health and specifically cancer-related policy was regarded as a top priority and often in the media spotlight. Since the interview guide used in our study was largely informed by contemporary health policy related to cancer services, this report illuminates key policy themes through the perspective of the experiences of people affected by cancer. This introductory chapter summarises mainly Scottish policy but cites English policy where appropriate. In doing so, the report purposefully situates the study's findings in the current policy environment which enables conceptual and constructive policy and practice recommendations based on patient experience to be made.

In 2001, the Scottish Executive cancer strategy, *Cancer in Scotland: Action for Change*, was launched. It did not prescribe actions plans but rather set the scene, which at the time was focused on cancer prevention, reducing waiting times and delays for treatment and the introduction of Regional Cancer Advisory Groups and Managed Clinical Networks as a vehicle for greater integration. It recognised that more people will be living with cancer, thus, requiring support services and information to meet their needs. It acknowledged the role of primary care teams as key to providing care since most people with cancer spend the majority of time in the community and not in hospital, and made passing reference to the significance of rehabilitation services and clinical psychology. A number of challenges for cancer services were raised including limitations of health professionals' time to devote to talking to people with cancer to help them understand their diagnosis and all its implications; having to give a delayed and unexpected diagnosis of cancer because symptoms did not immediately suggest cancer; palliative care remaining an untapped resource due to its association with death and dying; little resource effort to manage the transition of people with cancer between primary and secondary care and an uneven quality and quantity of information provided to people with cancer.

Putting patients at the centre of quality improvement and frameworks so that services are designed round the needs of patients and better outcomes for patients are secured became a key theme for the second phase of the cancer strategy (Scottish Executive, 2004). This agenda of involving and placing the experience of patients with cancer at the centre of service organisation and delivery was emphasised in the Calman-Hine Report (1995) and has gained momentum during the last few years through projects like the Cancer Partnership Project, a three year project funded by Macmillan Cancer Relief and the Department of Health aimed at promoting user involvement activity in all cancer networks in England (Sitzia et al., 2004) and a three year project funded by the Scottish Executive, *Developing cancer services: Patient and carer experiences* (from which this report arose).

Several themes in the findings of this study - patient involvement and self care, partnership working and community-based care, culture of caring, role of partners/carers - are also highlighted in other Scottish health and cancer policy and are discussed briefly below.



## 1.1 Patient involvement and self care

The policy agenda of patient and public involvement focuses on involvement in healthcare policy and planning and in research as well as in care practice (Hubbard et al., 2005). The latter for instance, includes people's involvement in treatment decision-making and also self care. Our study coincided with the publication of key health policy documents including A National Framework for Service Change in the NHS in Scotland (Scottish Executive, 2005a). Its vision of the future includes building a health service that starts from the patient experience, engages the public, and involves patients in their own care. Further associated action plans relating to patient involvement were also published including Delivering care, enabling health (Scottish Executive, 2006), which sets out an action plan for nursing, midwifery and allied health professions (NMAHPs). It emphasises that patients should be regarded as partners rather than passive recipients of care. Partnership for Care (Scottish Executive, 2003a) and most recently, Co-ordinated, integrated and fit for purpose (Scottish Executive, 2007a), echoes the policy context outlined in Delivering for Health (Scottish Executive, 2005b) by recommending an ethos of enablement and self-managed care with people and their carers taking greater control. The latest English NHS Cancer Services. Draft Core Standards (Department of Health, 2007) have, as an essential criterion, support of patients with cancer to make decisions throughout their care. The rationale is that good communication and provision of information during the delivery of care, reduces anxieties and concerns about the patient's health and well-being. Patient involvement in decision-making works in conjunction with self care, which is defined by the Scottish Executive (2005a) as follows:

'Self-care involves the individual taking action to maintain health, prevent illness, seek and adhere to treatment, manage symptoms and side effects, accomplish recovery and rehabilitation and cope with chronic illness and disability. Engagement in self care facilitates a partnership between health service users, their carers and health professionals to ensure optimal health outcomes.' (Chapter 5:04).

The recent emphasis on self-managed or self-care within English health policy also aims to promote greater involvement of people in the management of long-term or chronic conditions such as cancer and firm support for self-care can be found in a number of additional Department of Health policy documents including, The NHS Plan (Department of Health, 2000); The Expert Patient (Department of Health, 2001); Supporting People with Long Term Conditions (Department of Health, 2005a); Self Care - a Real Choice (Department of Health, 2005b) and Our Health, Our Care, Our Say (Department of Health, 2006). Such policy reports reflect recent moves towards

greater patient involvement in healthcare generally, and decision making and management of their own care specifically, moving away from the traditional top-down 'doctor knows best' model of care to a culture where patients' experiences and contribution to their own care are considered essential to meeting their healthcare needs.

## 1.2 Partnership working and Community-based care

The direction of policy travel in Scotland is towards partnership working between different organisations and sectors and between different health and social care professions. Joint Future (Scottish Executive, 2007b) is the lead national policy on joint working between local authorities and the NHS in community care. Its main aim is to provide faster access to better and more joined up services through improved joint working. Community Health and Care Partnerships have been established locally in order to implement this policy directive. Alongside these partnerships are three Regional Cancer Networks (WOSCAN, SCAN and NOSCAN) and within these are Managed Clinical Networks that centre on specific cancer types, for example, breast cancer. How Community Health and Care Partnerships and Managed Clinical Networks formally collaborate is not clear from policy documentation although individual professionals may be involved in both.

An aim of the policy agenda for partnership is to provide seamless care and bridge any gaps between primary and acute care. Policy related to the management of long term conditions for instance, emphasises that care depends on both community and out-patient based care to support self care and on partnership working between community and hospital care (Department of Health, 2005a). A National Framework for Service Change in the NHS in Scotland, (Scottish Executive, 2005a) states that healthcare services should be delivered predominantly in local communities and be co-ordinated by primary care, operating within an integrated NHS collaborating with other partners. Traditional ways of delivering care are rejected and replaced by new ways of working including a proposal to seek alternatives to consultant-led, hospital-based follow-up care. This framework also states that patients want access to local high quality services as quickly as possible and delivered by a suitably trained professional.

A key focus of this policy, therefore, is care in local communities. Delivering for Health (Scottish Executive, 2005b) describes the main actions to implement the recommendations of the National Framework for Service Change (Scottish Executive, 2005a) and highlights the changes that patients will see, including more health care being provided locally in GP practices and carers being treated as partners in the provision of care. Co-ordinated, integrated and fit for purpose

(Scottish Executive, 2007a) provides strategic direction to health and social care services and practitioners who deliver rehabilitation services within the broad health policy context outlined in *Delivering for Health* (Scottish Executive, 2005b). It also recommends local service provision with a strong community focus, improved access and smooth transitions between primary and secondary care services, multi-disciplinary team and multi-agency partnerships. A review of nursing in the community in Scotland (Scottish Executive, 2006) re-affirms a shift towards multi-disciplinary and multi-agency teams, self-care and local community provision. It proposes a single point of contact for all nursing services – Community Health Nursing - so that people are not confused about which service or nurse to approach and emphasises the important role that nurses play in co-ordinating and organising care provided by other professions and agencies for people they care for.

The importance of partnership working has also been reiterated in England with the White Paper *Our Health, Our Care, Our Say* (Department of Health, 2006). This paper highlights the need for local authorities and National Health Service organisations to operate with shared agendas and develop strong working relationships if they are to deliver the government's vision of maximising choice for service users, as well as providing more individualised packages of care and support. NHS QIS (2007) and NICE guidelines (2004) also emphasise the importance of other services and sectors in healthcare planning and service delivery, including social care. The White Paper reinforces the need for services to extend their partnerships to include service users and also consolidates the place of independent providers in the health and social care market. Whilst Scotland and England health policy has similarities it is argued that Scotland places greater emphasis on partnership working between different NHS sectors and the NHS and other organisations whereas England has a more market driven agenda involving the private sector (Greer, 2004).

Recently, a review of the NHS in England has been announced by Prime Minister Gordon Brown and the Health Minister, Alan Johnson. This review mirrors several key challenges also faced in Scotland, including partnership working and community-based care. Due to be completed in 2008, the aim is to deliver more accessible and more convenient care integrated across primary and secondary providers (Department of Health, 2007).

### **1.3 Culture of caring**

Central to much health and cancer care policy is the importance of delivering services within a culture of caring. For example, *Delivering care, enabling health* (Scottish Executive, 2006), sets out

an action plan for nursing, midwifery and allied health professions (NMAHPs) which emphasises that at the heart of good nursing is 'caring', which is defined as 'seeing the human being – not the patient number' (2006:3), which is a vision also reinforced through current NHS QIS (2007) standards. The plan claims that NMAHPs are champions of the patient's experience and places a culture of caring with the following attributes - approachability, kindness, courtesy, empathy and an ability to listen respectfully to the person – at the heart of good NMAHP practice. Relationship and communication skills are reiterated as the essence of good nursing care in a Scottish review of nursing care in the community (Scottish Executive, 2006). The importance of listening to patients' experiences and treating people using the NHS with dignity is also reiterated in a recently announced review of the NHS (Department of Health, 2007). Moreover, the importance of communication as a key element of a culture of caring is emphasised in Cancer in Scotland. Action for Change. A Guide to Securing Access to Information (Scottish Executive, 2003b:10), which states that:

'... All staff concerned with patient care should be aware of potential problems with communication and be aware that patients often find it difficult to take in information during consultations, especially just after hearing a diagnosis of cancer or other "bad news."

## **1.4 Role of partners/carers**

The role of partners and other informal carers is increasingly recognised in policy directives. The 'caring relationship' is recognised in A National Framework for Service Change in the NHS in Scotland, (Scottish Executive, 2005a) which refers to the Community Care and Health (Scotland) Act 2002, which places a legislative duty on NHS Boards to support carers through the development of local NHS Carer Information Strategies. In addition, Delivering for Health (Scottish Executive, 2005b) highlights that carers will be treated as partners in the provision of care and Co-ordinated, integrated and fit for purpose (Scottish Executive, 2007a), echoes the policy directive outlined in Delivering for Health by recommending an ethos of enablement and self-managed care with people and their carers taking greater control. Similarly, in England NICE guidelines (2004) recognise the central role of relatives and other carers in supporting patients.

## 1.5 Continuity and change: mapping cancer experiences

Whilst the above sections highlight key policy initiatives in four domains, it is easy to lose sight of the totality of people's experiences. Categorisation is a useful tool for policy-makers and healthcare planners but is not necessarily how people with cancer perceive or experience cancer care. Moreover, as NICE (2004) guidelines point out, 'patients have different needs at different times during their illnesses', and this is also recognised within Scottish Executive (2003a; 2003b; 2005a; 2005b) policy directives. A main advantage of this study, which prospectively explored people's experiences over the course of a year, is that it is possible to map the evolving nature of people's experiences within these four domains. This approach complements previous research and debate within this field which has highlighted both continuity and change within people's experiences of illness (for example Bury, 1982). Cancer, for instance, has been viewed as a disruption of life with a before-cancer and after-cancer division, disrupting previous beliefs of life-expectancy and forcing a confrontation with the finite nature of the time people have left and a responsibility to manage that time.

As the following section explains, this report categorises people's experiences of cancer thematically chapter by chapter and also uses the four domains (patient involvement and self care, partnership working and community-based care, culture of caring, role of partners/carers) outlined above to draw conceptual conclusions and make recommendations. However, in the penultimate chapter we also include a section that maps people's experiences of cancer and cancer care within the first year following diagnosis in order to emphasise the inter-relatedness of these themes and domains and also the totality of experience that involves both continuity and change over time.

## 1.6 Structure of report

There are three sections to the report. Section 1 includes the introduction and methods chapters. Chapter 2 further describes the methods used to conduct the study including a description of the people affected by cancer and healthcare professionals involved in the study, how they were identified and recruited, a description of type of interviews that were conducted and analytical strategy.

Section 2 presents the findings of the study. The chapters in Section 2 present people's experiences thematically, highlighting both common and different experiences across cancer types and between individuals. Quotations and examples were carefully selected to illuminate a particular

aspect of a theme, concept or issue. The focus is on the experiences of people with cancer and their perspective is deliberately dominant in this report. However, the perspective of their partners/carers is also present in the main body of the text in order to illuminate and add to our understanding of their experiences. Healthcare professional perspectives are presented in voice boxes throughout the text and are designed to illuminate an experience of cancer and cancer care from their perspective. Chapters 3 and 4 report people's experience leading up to diagnosis and being told their diagnosis. Chapters 5 to 9 focus on various issues relating to people's experience surrounding treatment, including their experience of treatment, self care, referrals and investigations at this time, transport to and from hospital, and their experience of involvement in the treatment decision-making process. Chapter 10 reports people's experience of emotion within the first year following a diagnosis of cancer. Chapters 11 and 12 describe people's experience of information provided to them both verbally and in writing but also their information seeking behaviours outwith the healthcare setting. Chapters 13 and 14 focus on people's experience of nursing care and GPs. People's experience of consultants is reported throughout the report, and in particular, in relation to people's experience of being told their diagnosis and experience of involvement in treatment decision-making. Chapters 15 and 16 describe people's experience of employment and finance respectively. Chapter 17 focuses specifically on the experiences of partners/carers of people with cancer.

Section 3 presents a discussion of the main findings and conclusions. The penultimate chapter presents conceptual conclusions about cancer care and in the final chapter a series of recommendations for cancer care policy, practice and research are presented.

## **1.7 A note on terminology of experience**

The body of this report is a summary of people's perceptions of their experiences of cancer and cancer care. We make no apology for including many quotations since we wish the voice of the person who is telling their experience to prevail. We deliberately use terms and phraseology that they use which can make it confusing for academic and clinical audiences alike since concepts have both common-sense but also specific meaning within subject disciplines. For example anxiety, depression and worry have specific meaning to clinical psychologists but people affected by cancer quoted in this report have used them inter-changeably. In this report, the term 'physical' is used to broadly define experience of, or relating to, the body as distinguished from the mind or spirit, whilst the term 'emotional' is used to broadly refer to experience relating to a mental state or feeling. However, as this study shows, the physical and the emotional cannot be understood

separately and, to enable further development in this field, must be more fittingly described as inter-dependent and inter-related embodied experiences.

## Section 2: INTRODUCTION AND METHODS

### METHODS

#### 2.1 Research design

This was a descriptive study conducted over a period of 18 months. Three serial, longitudinal semi-structured interviews with people diagnosed with cancer were carried out over the course of a year following diagnosis. A partner/carer and healthcare professional nominated by the individual with cancer were also interviewed. In addition to these interviews, the same individuals with cancer completed monthly questionnaires to measure symptoms and health and well-being; this is reported elsewhere (Knighting et al., in preparation).

#### 2.2 Aim

The aim of Phase 2 of the Developing cancer services: Patient and carer experiences project was to explore the experiences of people affected by cancer in the first year following diagnosis in Scotland. As mentioned above, this report only presents findings from the qualitative component of Phase 2.

#### 2.3 Ethics

COREC and local R&D approval was obtained in the four clinical sites where people affected by cancer and healthcare professionals were recruited. All people involved in the study gave written informed consent and had the right to withdraw from the study at any time for any reason. Personal data recorded on all documentation relating to the study was regarded as confidential. Confidentiality was assured, with all data stored securely and password protected at the University of Stirling.



## 2.4 Clinical sites

The study took place in Greater Glasgow, Grampian, Lothian and Tayside. Management approval to recruit people with cancer at these sites was obtained. Three nurse consultants and one manager within each site provided access to other clinicians (consultant or cancer nurse specialist) to facilitate recruitment to the study.

**Table 1. Clinical sites and number of patients recruited**

Centre	Region	Number of people with cancer recruited
Beatson Oncology Centre	Glasgow	18
Western General Hospital, Edinburgh	Lothian	15
Aberdeen Royal Infirmary	Grampian	22
Ninewells Hospital, Dundee	Tayside	11
Total number of patients		66

## 2.5 Sampling and recruitment

### 2.5.1 Sampling and recruitment of people with cancer

Sixty-six people diagnosed with cancer were recruited to the study including 18 people with colorectal cancer, 12 women with breast cancer, 9 women with gynaecological cancer, 17 people with lung cancer and 10 men with prostate cancer (Table 1 shows which clinical site patients were recruited from). Purposive sampling was used to ensure that experiences of cancer were explored through the perspectives of people with different socio-demographic characteristics. This sampling strategy was not designed to derive a representative sample but to enable the

researchers to understand experience of cancer and cancer care from a diverse group including:

- » Males (35) and females (31) with cancer
- » People living in rural (16) and urban (50) areas
- » People of different ages (just over a third aged between 31-60 and the remainder 61 years old and over)

A conscious effort was made to include people from different ethnic minority groups but this was unsuccessful because no or very small numbers of people from these groups were diagnosed with cancer during the period of recruitment in the cancer centres where healthcare professionals were recruiting for the study.

### **2.5.2 Inclusion criteria**

- » Adults over the age of 16 years diagnosed with one of the following cancers: breast, lung, colorectal, prostate or gynaecological cancers
- » It was their first primary diagnosis
- » Able to give informed consent

### **2.5.3 Recruitment**

People with cancer were recruited through out-patient clinics within approximately 6 weeks following diagnosis. Recruitment took place in winter 2005 to early spring 2006. Working within ethical guidelines, CCRC researchers were not the first point of contact for people with cancer regarding the study. The initial approach to potential participants was by local clinicians. They briefly outlined the study and provided them with an information letter and information sheet. The clinicians asked the people with cancer if they were willing to be contacted by the researchers who would provide them with more information. Upon the request of local clinicians, the researchers attended the clinic area, and were, therefore, available to provide more information about the study after the consultation if people with cancer wished to discuss the study. The researcher, either spoke to the person with cancer in the clinic, or telephoned them to provide more information, and confirmed willingness to participate and arranged to visit for the first interview. The person with cancer was given a minimum of 24 hours between receiving information from the researcher and giving written informed consent to be included in the study.

## 2.6 Sample and recruitment of partners/carers

Each person with cancer recruited to the study was asked by the researcher before the first interview to identify a family member or close friend who also knew about their experiences (referred to as partners/carers in this study). Those nominated, were asked if they were willing to take part in the study. Only those who gave written informed consent were included. 43 partners/carers were nominated who all consented to take part and were included in the study.

## 2.7 Sampling and recruitment of healthcare professionals

Each person with cancer recruited to the study was asked by the researcher during the first interview to identify a healthcare professional who knew about their experiences. Those nominated, were asked if they were willing to take part in the study. Only those who gave written informed consent were included. 42 healthcare professionals were nominated, 26 of which consented to take part, and 20 were interviewed. A failure to nominate partly indicates that within the first few months of receiving diagnosis patients have not established relationships with healthcare professionals. Lack of willingness to consent to take part in the study on the part of healthcare professionals suggests that they do not possess in-depth knowledge about the experiences of the patient within their first few months of diagnosis but it may more likely suggest that they are very busy people who have not prioritised participation in this particular study.

## 2.8 Data collection

### 2.8.1 Serial interviews

Semi-structured interviews were designed to capture key experiences in the first year following diagnosis. The interviews were audio-recorded, with participants' consent and transcribed. The rationale for when each interview took place focused on key episodes of care in the first year following diagnosis:

1. *Experiences of symptoms prior to diagnosis and being told the diagnosis.* An interview within approximately 6 weeks of being told the diagnosis was scheduled so that people with cancer could discuss their experiences occurring at the initial stage of their illness.
2. *Experiences of the first course of treatments including surgery, chemotherapy,*

*radiotherapy.* An interview between 4 and 6 months of being told the diagnosis was scheduled so that people with cancer could relate their experiences occurring during this stage of their illness.

3. *Experiences of follow-up and after care.* An interview between 8 and 9 months of being told the diagnosis was scheduled so that people with cancer could relate their experiences of this stage of their illness.

Most people with cancer were interviewed for the 1st interviews within 6 weeks following diagnosis, with the exception of 9 people with cancer who were interviewed within 10 weeks of diagnosis. Most people with cancer were interviewed for the 2nd interviews within 4 and 6 months following diagnosis, with the exception of some people with lung cancer who were interviewed slightly earlier. Half of the people with cancer were interviewed for the 3rd interview between 8 and 10 months following diagnosis and approximately half were interviewed between 10 and 14 months following diagnosis (only 3 people with cancer were interviewed after 12 months). Table 2 shows the number of people with cancer interviewed. Ten people with cancer withdrew from the study and 4 people died. At the start of the study it was made clear to participants that they could withdraw without giving a reason and without it affecting their care, thus, it is not possible to identify why some people withdrew and did not have a 2nd or 3rd interview.

**Table 2. Number of people interviewed**

Interview 1	
	Number of People
Patient only	29
Joint Patient and Carer	37
Carer only	6
Health Professional	21
<b>Total</b>	<b>93</b>
Interview 2	
	Number of People
Patient only	32
Joint Patient and Carer	26
Carer only	5
Health Professional	1
<b>Total</b>	<b>64</b>
Interview 3	
	Number of People
Patient only	27
Joint Patient and Carer	25
Carer only	5
Health Professional	5
<b>Total</b>	<b>58</b>
<b>Grand Total for All</b>	<b>214</b>

## 2.8.2 Interview themes

The interviews were designed to capture the range and depth of an individual's experience. The interview guide (Appendix 1) was largely informed by four key policy themes (see Chapter 1), which were: people's experiences of involvement in their care (policy theme: patient involvement and self care), care received within community and hospital-based settings and the impact of cancer on finances and employment (policy theme: partnership working and community-based care), perceptions of care given by healthcare professionals (policy theme: culture of caring), and of the involvement of family and friends (policy theme: role of partner/carer). This report, therefore, illuminates key policy themes through the perspective of the experience of people affected by cancer. These key themes were also identified as important for individuals with cancer from discussions with clinicians in each of the 4 clinical sites involved in the study and from literature. Each interview lasted between 30 and 120 minutes. Interviews took place in the person's own home, although people affected by cancer were also given the option of having the interview conducted at the University of Stirling or at the hospital where they were recruited. Researchers asked an open-ended question relating to each theme for example, 'Can you tell me about your experiences of treatment?' and encouraged the people affected by cancer to address the question in-depth by probing when appropriate.

## 2.8.3 Joint or separate interviews

People with cancer were given the choice of being interviewed on their own or accompanied by the partner/carer who had been nominated by them and had consented to take part in the study. Some partners/carers were present during the interview with the individual with cancer but were also interviewed on their own. There are advantages and disadvantages of conducting joint interviews (Morris, 2001), for example a potential disadvantage is that people may not wish to talk about certain experiences within the company of their partner/carer, however, an advantage is that people reflect on and draw comparisons with what they hear from the other person.

Seventy-one first interviews were conducted:

- » 28 interviews took place with just the person with cancer
- » 38 interviews included the person with cancer and a partner/carer
- » 5 interviews took place with just the partner/carer

Sixty-four second interviews were conducted:

- » 32 interviews took place with just the person with cancer
- » 27 interviews included the person with cancer and a partner/carer
- » 5 interviews took place with just the partner/carer

Fifty-seven third interviews were conducted:

- » 26 interviews took place with just the person with cancer
- » 26 interviews included the person with cancer and a partner/carer
- » 5 interviews took place with just the partner/carer

## **2.8.4 Interview conduct**

People affected by cancer are a potentially vulnerable group and research into their experiences requires rigorous application of ethical principles in the field. The research team was aware that some potential participants may not wish to participate in research which requires regular contact with researchers over the course of a year. We therefore ensured that they were aware of the full detail of what they are being asked to do at the outset and if they found that their continued participation became burdensome, they were able to withdraw at any time without giving a reason and without it compromising their ongoing care. Willingness to participate was reconfirmed at each contact point throughout the study.

## **2.8.5 Healthcare professional interviews**

Following consent, healthcare professionals were interviewed by telephone in conjunction with the first interview with the person affected by cancer. These interviews focussed on their perception of the experiences of the individual with cancer and the services provided.

## **2.9 Data analysis**

A descriptive and thematic approach to data analysis was adopted which was theoretically informed by medical sociology and psychology and framed by recent health policy (see Chapter 1). The research team read all interview transcripts and collectively decided upon key experiences to analyse in depth. These key experiences are the subjects of each of the chapters of this report (15 experiences in total). Each researcher was allocated a key experience to analyse in-depth

using a thematic approach aided by the qualitative analysis computer package NVivo. There were five cyclical stages to analysis:

- » Each transcript read and re-read
- » Themes and sub-themes relating to the key experience identified
- » Data coded under each theme/sub-theme
- » Coded data analysed
- » Key concepts and issues identified

During this iterative process, themes were expanded or collapsed into one another, sub-themes generated and data coded and re-coded. Once the process of generating themes and coding for each theme had been completed for each of the 15 key experiences, the researcher analysed data coded under each theme/sub-theme. It was during this time, that key issues and concepts relating to the experience were identified. Finally, by comparing themes, issues and concepts across all key experiences the researcher drew conceptual conclusions and made recommendations for cancer care policy, practice and further research. People affected by cancer were involved in the process of making recommendations since they were asked to make recommendations based on their review of the key findings. The key findings of the study were reviewed by individuals from the Cancer Care Research Centre's Advisory Groups and also by individual participants in the study who were interviewed and who consented to be involved during this stage of the study.



# FINDINGS

## Section 3 EXPERIENCES LEADING UP TO A DIAGNOSIS OF CANCER

### 3.1 Key findings

- » Some people with cancer did not recall having any symptoms prior to their diagnosis. However, with hindsight, and after their diagnosis, most reported experiencing a range of physical symptoms that they now related to cancer. These symptoms included tiredness, pain, and loss of appetite and were experienced by many people with cancer regardless of the cancer type.
- » Some people were treated for other clinical conditions prior to their diagnosis. Some of these people felt aggrieved as they perceived that their healthcare professionals had misdiagnosed their symptoms.
- » Some people delayed making an appointment with their GP because they did not think their symptoms were more than 'niggles', associated them with the ageing process or with work-related stress. Some of these symptoms had persisted for years. Unusual or distressing symptoms were, however, more likely to lead to a visit to the doctor.
- » Family and friends, in particular partners/spouses, played a part in encouraging people to see their GP, which demonstrates that self care involves wider networks than the individual with symptoms and that partners/carers play a role very early on in the cancer care trajectory.
- » The decision to ignore or act on symptoms by people who then went on to be diagnosed with cancer, depended on the type, persistence and severity of the symptom(s) experienced. Additional reasons for ignoring a symptom included fear of discovering the root cause of it.
- » Many of the first interviews we conducted were around Christmas and New Year and the delay that this caused in relation to investigations and notification of results was remarked on by many, although few appeared to question it. For the women who

had been diagnosed with breast cancer at a one-stop clinic, the experience was very different. They all remarked on how good it was not to have to wait for results more than a day.

- » Diagnostic investigations could be very painful. Often the written and verbal explanation and description of the procedures failed to prepare the individual for the potential pain and distress associated with procedures.

This Chapter describes the experiences people had leading up to a diagnosis of cancer; their experiences of waiting for a diagnosis, symptoms and diagnostic tests, communication with healthcare professionals, and the role of family and friends.

### 3.2 Symptoms experienced pre-diagnosis

Some people with cancer did not recall having any symptoms prior to their diagnosis. However, with hindsight, and after their diagnosis, most reported experiencing a range of physical symptoms that they now related to cancer. All of the symptoms identified by people included in the study are listed on the Cancerbackup web site (<<http://www.cancerbackup.org.uk/>>). Further, some but not all SIGN guidelines state the importance of encouraging people to be aware of these symptoms (for example, SIGN (2005) guidelines for the Management of breast cancer in women says that

'Women should be encouraged to become aware of the feel and shape of their breasts, so that they are familiar with what is normal for them;

These symptoms included tiredness, pain and loss of appetite and were experienced by many people with cancer regardless of the cancer type. Other symptoms were specific to those with a particular cancer. Abdominal swelling was often experienced by individuals with bowel or gynaecological cancer, and on some occasions prostate cancer. Those diagnosed with colorectal cancer also experienced frequent bowel movements and/or blood in stools. Pre-diagnostic symptoms specific to gynaecological cancers included vaginal bleeding and discharge. The individuals that were to be diagnosed with breast cancer commonly experienced symptoms related to changes in the appearance or sensation of the breast for example, a lump. The symptom most commonly experienced with prostate cancer was frequent urination. By far the greatest number of symptoms was experienced by those to be diagnosed with lung cancer. These included breathlessness, coughing (including coughing blood), chest infection and weight loss.

Those with symptoms that are commonly associated with cancer such as, a breast lump or vaginal bleeding were diagnosed as having cancer within weeks of seeking advice and undergoing tests. However, many symptoms associated with cancer are not unique to the disease, which meant that cancer was sometimes diagnosed much later. Some individuals were diagnosed several months later and up to 5 years for a few individuals with prostate cancer. This proved to be a more common experience for individuals with either prostate or colorectal cancer than for other types of cancer. Many described how they were initially treated for other, presumably misdiagnosed, clinical conditions prior to being given a diagnosis of cancer. For example, some of those with colorectal cancer explained how they were treated for piles, irritable bowel syndrome, kidney stones and prostate problems when they first alerted their GP about their symptoms.

Despite experiencing distressing and specific symptoms associated with lung cancer such as coughing up blood and being breathless and having various tests, two individuals were not diagnosed with lung cancer for over a year. It was only when the symptoms persisted that they went back to their GPs who referred them for repeat investigations prior to their diagnosis of cancer. Abdominal pain appeared a particularly difficult symptom to attribute to a cancer. Two women with gynaecological cancer were initially treated for constipation and irritable bowel syndrome. Another person diagnosed with colorectal cancer described how they were initially diagnosed with irritable bowel:

***'I had been backwards and forwards to a doctor, always a different doctor, and it's been a case of "oh you suffer from irritable bowel" and just throw another lot of tablets at me.'***

*(P6, colorectal cancer, interview 1, patient).*

A GP (voice box 1) eventually referred her for further tests because she was not the type of patient to complain if there was not something wrong. A number of these people felt aggrieved as they perceived that their healthcare professionals had misdiagnosed their symptoms by failing to take them seriously:

***'I went back to see the gastroenterologist in the September, was aware of the swelling on my right hand side and some discomfort eh, and he unfortunately was, again a little bit dismissive, didn't examine me properly, didn't you know, I could feel it swelling down here and he didn't ask me to show him where it was. I mean if ever a patient came to see me and said Doctor, "I can feel something," I would say, you know, "give me your hand and show me...'***

*(P32, colorectal cancer, interview 1, patient & partner/carer)*

*'I went to my doctor complaining of the fact that I had pains in my gallbladder and I saw two GP's who insisted that it was pulled muscles. Now I've been in sports since I was a very small boy and I said, "No, I have not, it's in my gall bladder". And I was told, "No, we'll give you painkillers." Which I said, "You can keep." I saw a third GP who was a locum and she referred me...'*

*(P33, colorectal cancer, interview 1, patient)*

**Voice box 1:** A GP explained why she took P6's symptoms seriously:

*'Personally felt she had maybe seen different doctors before [...] but I think well, this is someone who isn't normally a complainer, she's obviously just not right and it just so happened to be the right person at the right time. I'm not saying I did anything different but it just, the fact that somebody was going to take it further like do blood tests and stuff.'*

*HP6, GP*

### 3.3 Reasons for ignoring or acting on symptoms

The decision to ignore or act on symptoms by people who then went on to be diagnosed with cancer, depended on the type, persistence and severity of the symptom(s) experienced. Additional reasons for ignoring a symptom included fear of discovering the root cause of it. Additional reasons for acting on a symptom were often due to the insistence or encouragement from friends and family to seek medical advice.

A large proportion of the dozen of people with cancer who experienced symptoms but delayed visiting their GP, attributed the symptom to less serious 'niggles'. Having experienced a range of 'niggles' or inconvenient problems, for months to a year before seeing a doctor, which they believed would disappear in time, was not uncommon:

*'I thought I was constipated.'*

*(P6, colorectal cancer, interview 1, patient)*

***'I felt I was having problems with my, well there was diarrhoea...I felt uncomfortable anyway, I wasn't, I didn't think it would be anything more serious than that.'***

*(P38, colorectal cancer, interview 1, patient & carer)*

Tiredness, which was reported by most people who were diagnosed with cancer, was usually put down to the ageing process or stress at work:

***'Well, you know, I think it's quite difficult because you can look back and you can conjure up things so I am not really sure. I have over the past few months been saying I am very, very tired; I have to cut back hours at work.'***

*(P5, breast cancer, interview 1, patient)*

GPs were more likely to be contacted with symptoms that were perceived as unusual and/or distressing such as persistent vaginal and rectal bleeding, lumps, breathlessness, and pain in the abdomen, chest and back. For example, most of the women who were diagnosed with gynaecological cancers went to see a GP relatively soon as their symptoms of heavy or persistent vaginal bleeding and abdominal pain commenced. There also appeared to be little delay for some of the women who discovered a lump in their breasts because they were aware that breast lumps should always be examined.

Some people experienced symptoms for over a year prior to their diagnosis, in cases of people with prostate cancer, sometimes several years. Those that reported experiencing symptoms for the longest period of time had undergone tests which had failed to show signs of cancer and had been reassured but finally sought help when symptoms persisted or worsened:

***'Yeah, about 5 years ago. I was having flow problems. And at that time they sent me for various tests. They told me that there was nothing untoward.'***

*(P4, prostate cancer, interview 1, patient)*

***'Coughing all night, experiencing extreme pain or having to go to the toilet all the time prompted reluctant people to seek help: 'It just got worse and worse and worse'***

*(P6, colorectal cancer, interview 1, patient).*

One woman, whose friend's partner had been diagnosed with cancer, recalled her friend insisting she consult her GP. Yet, she did not until she discovered a second symptom:

*'And I sort of jokingly said "Oh and of course I've got a breast lump here" and I keep thinking I must do something. She said, "You haven't done anything about it yet?" So I said, "Well no I haven't really." Then it was Christmas and New Year and I thought well I'll wait till after all that and then the thing that kind of made me move and do something about it I was standing looking at my breasts in the mirror and I thought that I could tell, I thought I could see a dimple.'*

*(P14, breast cancer, interview 1, patient)*

In many instances, family and friends, in particular partners, played a vital part in encouraging those later to be diagnosed with bowel, gynaecological and lung cancer to see their GP. In many cases a worsening of symptoms was accompanied by increased insistence from partner/carers that it was time to seek medical advice:

*'Every time he came out of the toilet, he was fed up and I said, "Please go to the doctor"... After a couple of weeks I persuaded him to go and he did.'*

*(P2, colorectal cancer, interview 1, patient and carer)*

*'Well she [his wife] picked it up. She said, "You are going to the bathroom far too much there's something wrong." And eventually she pushed me. She pushed me.'*

*(P15, colorectal cancer, interview 1, patient)*

*'I'm not a 'doctor botherer'. I would rather have my head hanging off by a thread than go and see a doctor [laughs]. Erm, so it was my husband, and another friend who happens to be a nurse, who nagged me.'*

*(P40, gynaecological cancer, interview 1, patient & carer)*

*'The family was always telling me, "You know you're losing an awful weight." I didn't want to accept that. I knew there was something wrong.'*

*(P30, lung cancer, interview 1, patient and carer)*

*'She [wife] pushed me and pushed me all the way and my daughter and my granddaughter.'*

*(P35, lung cancer, interview 2, patient & carer)*

For women who were diagnosed as having breast cancer, family and friends did not appear to play a particularly active part in their decision to consult their GPs about their symptoms. Yet indirect experience of breast cancer amongst friends and particularly close partner/carers appeared to play a significant role in both the uptake of screening and the speed at which a GP was consulted. It can also be attributed to knowledge about symptoms of breast cancer, which appeared to be more widely available than knowledge about other cancers, possibly due to health promotion and media focus.

A few people said they were scared of going to the doctor because they suspected they may have cancer:

*'It was more fear. Eh, knowing there was something wrong and not wanting to know, as simple as that.'*

*(P52, lung cancer, interview 1, patient & partner/carers)*

### 3.4 Pre-diagnosis tests and investigations

Many people who were being referred for pre-diagnostic tests believed it was standard procedure, mainly due to reassurance from their GPs that the referral was a 'belt and braces', 'just in case' or 'to be on the safe side' approach and that it was likely there would be nothing wrong:

*'...that (the PSA test) came back with slightly raised results and they said we'll send you to the consultant just to be on the safe side and he said your prostate's quite smooth so the indications are that there's nothing amiss but we'll just be safe. Well he says I don't think it's that bad, but he says we'd like to check you out in case you've got cancer.'*

*(P34, prostate cancer, interview 1, patient)*

Women later diagnosed with breast cancer reported being told the change in their breast was just a harmless benign lump, 'calcification' or 'blocked duct'. They were told they were being referred simply as a precaution based on a range of reasons such as family history of cancer or the location of the problem (i.e. in the breast). However, some people found waiting for the results of tests,

including those carried out prior to diagnosis, an anxious time and this is discussed in more detail in Chapter 7: Experiences of referrals and investigations.

**Voice box 2:** A GP described how he tried to avoid causing the individual too much worry when he was referring the individual for further tests whilst at the same time alluding to the fact that it might be cancer:

*'My usual protocol would be if I am worried that someone might have a cancer, I will say to them 'look, what you've presented to me is something that I'm concerned about and we need to follow up and check out thoroughly. It could be one of many things, it could be polyps, it could be ulcers, it could be whatever, but it could be something like cancer or it could be something unpleasant or nasty'. I maybe don't always use the word cancer, but I always give them the possibility that this could be what it is.'*

*HP2, GP*

A Clinical Nurse Specialist explained the procedures in place prior to diagnosis:

*'For the patients that are a high risk lung cancer, we try to give them support and contact numbers before their diagnosis 'cause it's quite an anxious time for them. And the reason we changed our service is because a questionnaire we did, you know, highlighted that that was an extremely anxious time for them, waiting for investigations and not really being quite clear of what the follow-up would be.'*

*HP22, Clinical Nurse Specialist*

Healthcare professionals adopted strategies to support people who were undergoing pre-diagnostic tests (see voice box 2). A GP explained how he tried to avoid causing the individual too much worry when he was referring the individual for further tests whilst at the same time alluding to the fact that it might be cancer and a clinical nurse specialist explained that they gave their contact details to people with a strong suspicion of lung cancer prior to their diagnosis in recognition that the period of pre-diagnostic testing was an anxious time.



One individual with cancer and their partner/carer highlights the shock of realising they were being investigated for cancer due to a lack of communication between them and the GP who made the referral to the hospital:

*'[The CNS] asked him the first time we saw her, I think the nurse must have made him, made her wise to the fact that P39 had gone in thinking he was getting haemorrhoids done, and she says, "why did you think you were coming here today", and well, we just said, "for the haemorrhoids, he thought he was getting an operation on the haemorrhoids", she says "so it's come as a blow", so that, you know, obviously - somewhere along the line there's been a mix up ... between the GP and the hospital, because on reading the booklets you normally get referred to the hospital and then the hospital will get you in, take all your details, examine you, and then say what you're going to, what they're going to send you for. He missed out that somewhere and he ended up just going straight in, and then it roller-coasted, I mean it was just, one thing after another, it roller-coasted and then we went back, the consultant, and the consultant asked the same question, he says "why did you think you were here", and of course he said "haemorrhoids", they didn't have the result back at the time of the biopsy and then it was two tumours, so, from going for one to two now, you know.'*

*(C39, colorectal cancer, interview 1, patient & partner/carer)*

Despite efforts to reassure, people slowly realised they had cancer often before the diagnosis, based on their healthcare professional's behaviour. This is described in the following Chapter: Experiences of being diagnosed with cancer.

Some people with cancer only mentioned the tests in passing but many described the pain and discomfort of tests such as the mammogram, bronchoscopy and colonoscopy in great detail (this is also described in Chapter 7: Experiences of referral and investigations). The pain, in addition to the lack of information about the procedures, significantly added to the distress of a few:

*'[I] hadn't got a clue what was going to happen to me, found that very, found the whole experience very distressing, because I hadn't known, got my first appointment for a mammogram, that left me black, blue and sore.'*

*(P21, breast cancer, interview 1, patient)*

Often the explanation and description of the procedures failed to prepare the individual for the potential pain, for example biopsies:

*'The worst bit was she said "we have to take a biopsy". She put an injection in and she said, "This is like a dentist injection, it's a local anaesthetic". So you think well, that's OK, it's not going to hurt and she explained that they would do three and it would make a loud noise and she let me hear the noise, 1,2,3 like a snap [snapping fingers]! You see. So she did the first one and that was OK, well I mean it wasn't very good but it was OK, but when she did the second one, it really, really hurt and it just knocked me sick. Have you ever had a pain that knocked you sick?'*

*(P10, breast cancer, interview 1, patient)*

A few people joked about internal examinations and tests being 'more embarrassing than painful' (P28, colorectal cancer, interview 1, patient and carer) and sore 'bringing colour to my cheeks and tears to my eyes' (P1, colorectal cancer, interview 1, patient and partner/carer) and others described the pain as only lasting a few seconds. However the pain of the tests was also a source of distress for many who described them as 'excruciating' (P21, breast cancer, interview 1, patient) and as 'the worst scan anyone can get' (P16, colorectal cancer, interview 1, patient and partner/carer). Violent descriptors were often applied in this context, such as tests being like being 'stabbed in the sternum' (P55, breast cancer, interview 1, patient and carer) 'like a punch' (P4, prostate cancer, interview 1, patient and partner/carer) and being left 'black, blue and sore' (P21, breast cancer, interview 1, patient). Despite supposedly being sedated, one person had found her experience of the broncoscopy, 'a nightmare' and so terrible that she would not have it again if asked (P52, lung cancer, interview 1, patient and carer).

A few, who had been in extreme pain, described the reactions of the healthcare professionals as very comforting:

*'She said, well she said, "That last one I took, is a good sample" she said, "I won't take another one". She put her arms around me and patted me; I felt so awful [voice slightly upset].'*

*(P10, breast cancer, interview 1, patient)*

*'The doctor comes in and he gives you this internal thing with three different things up your rectum and you feel it, it goes in and he's twisting and turning each one he puts into you and it completely destroys you as far as I'm concerned and [nurse] hanging over you to try and console you and talk to you and take your mind off it but it's extremely painful.'*

*(P16, colorectal cancer, interview 1, patient and partner/carer)*

For others, however, treatment by healthcare professionals who administered the tests was another source of distress or discontentment. A couple of people had not been able to have internal investigations because of the pain. One of their carers said they 'got the impression he [consultant] was a wee bit annoyed' (P17, colorectal cancer, interview 1, patient and carer) that the pain had stopped him from performing the test. One woman stated she did not like the impersonal way in which she was treated by the healthcare professionals administering her mammogram:

***'That was probably the only time I felt that they weren't that friendly, or they didn't kind of speak to you, they just put you through the system.'***

*(P12, breast cancer, interview 1, patient and carer)*

Many of the first interviews we conducted were around Christmas and New Year and the delay that this caused was remarked on by many, although few appeared to question it. For the women who had been diagnosed with breast cancer at a one-stop clinic, the experience was very different. They all remarked on how good it was not to have to wait for results more than a day and one of the women compared this experience favourably to her experience of waiting for tests later on:

***'I think that's a good thing that it's all in one day like that. Having subsequently had to wait for you know, being drip-fed results ...'***

*(P14, breast cancer, interview 1, patient)*

### 3.5 Conclusion

People may be afraid and anxious and may also experience physical pain, as they undergo tests and wait for the results of investigations during the period leading up to diagnosis. Violent descriptors of investigations include being punched, stabbed, and destroyed. People undergoing these investigations appear to be acutely alert and attentive to non-verbal communicative behaviours by healthcare professionals as they wait to find out their diagnosis. Whether consciously delivered or not, these non-verbal clues serve to lay the ground for eventually receiving bad news verbally. Despite the groundwork being done, people still find a diagnosis of cancer shocking. At this point in time, healthcare professionals may be required to tread a fine line between giving bad news whilst enabling people to remain positive and maintain hope. Ensuring care is organised around patients' immediate needs and wishes clearly did not take place for many people with cancer who underwent painful tests and investigations without adequate preparation. However, some people

with cancer also experienced a sympathetic response by healthcare professionals administering such tests: a positive example of the culture of caring. The important role of partners/carers can be seen in their insistence that the person with symptoms initially comes to seek GP advice.

## Section 4: EXPERIENCES OF BEING DIAGNOSED WITH CANCER

### 4.1 Key findings

- » Even for those people who suspected that they might have cancer, the actual diagnosis was deeply shocking.
- » Partner/carers and friends who accompanied the person who was given the diagnosis were also profoundly shocked, suggesting that they may also warrant support and advice.
- » Many healthcare professionals prior to diagnosis managed and staged a likely cancer diagnosis by providing warnings and hints over a period of time whilst taking care not to cause undue concern.
- » Most people interpreted particular behaviours by healthcare professionals as indicative that they would be given a diagnosis of cancer.
- » Relationship building and good communication skills are critical during this time.
- » Whilst the diagnosis was shocking and something that could not be totally prepared for in advance, some people found being given their diagnosis a relief because it explained their symptoms. Others coped by relating their experience to that of others and through the perception that others were worse off than them and so counted themselves as relatively lucky and fortunate.
- » Overall, there was little expressed dissatisfaction with the way healthcare professionals, mostly consultants, delivered the diagnosis. Indeed, the majority of the people affected by cancer expressed understanding for how difficult it must be for healthcare professionals to deliver bad news.
- » Some people welcomed a straightforward and direct approach to being given bad news whereas others found it too abrupt. Healthcare professionals who displayed compassion when breaking bad news were particularly praised.
- » Being given a diagnosis over the phone caused confusion.

- » Half of the people with cancer in the study were given their diagnosis whilst unaccompanied.
- » Some people affected by cancer did not understand all of the information that they had been given about the diagnosis and so could not say with complete confidence what type of cancer they had.

This Chapter describes the experiences people affected by cancer had of slowly realising they may have cancer prior to their diagnosis and their experiences of, and preferences for, the delivery of diagnosis.

## 4.2 Shock of diagnosis

Being diagnosed with cancer is a highly emotional event which most people liken to 'being knocked off my feet' or a 'total shock - like a slap in the face.' The emotional impact of being diagnosed with cancer and how the magnitude of the shock can often obscure the thought processes required to make sense of the diagnosis, is described in detail in Chapter 10: Experiences of emotion.

## 4.3 Slowly realising you have cancer; 'I knew what it was before I was told'

Nearly all those affected by cancer recalled slowly realising they had cancer before the diagnosis was confirmed by a healthcare professional. Although most were still deeply shocked, few were surprised. Several factors led to their suspicions that they would soon be told that they had cancer. These included worsening of symptoms, pre-diagnostic procedures and the behaviour of the healthcare professionals including their body language and non-verbal communication.

A few strongly suspected their symptoms were indicative of cancer before seeking medical advice:

*'I had a pretty bad cold and I think there was infection then when I came back and [wife] was hanging onto this being an infection thing but I knew from what the symptoms were, personally, that I was pretty sure it was lung cancer.'*

*(P24, lung cancer, interview 1, patient & carer)*

***'I think it was always in the back of my mind because I've had friends and people... who have went through the same thing.'***

*(P4, prostate cancer, interview 1, patient & carer)*

Despite this strong suspicion that there was 'something not right' (P1, colorectal cancer, interview 1, patient & partner/carer), these people also added that they hoped that they were mistaken:

***'I had actually decided quite a while ago that I had something. People say that people who jump to conclusions fall on their face, but in this case I was right. I realised these lumps above my 'ackie-pierie' weren't there, they shouldn't be there. I was hoping they would be benign, but as it turned out they were malignant.'***

*(P1, colorectal cancer, interview 1, patient & carer)*

Some partners/carers also 'had a fair idea that it was serious.' (P1, colorectal cancer, interview 1, patient & carer interview):

***'You were okay up to about a year ago when it started giving you a lot of bother and that's when I said, "Well this has gone on long enough." And up to that stage you just thought it was enlargement, but after that there was concern that there might have been more to it.'***

*(P4, prostate cancer, interview 1, patient & carer)*

## **4.4 Interpreting healthcare professionals' behaviour before diagnosis**

In a number of cases, the suspicion of having cancer was verbalised to healthcare professionals to gauge their reaction. Some mentioned cancer to healthcare professionals, 'as the worst case scenario type, it couldn't be type of thing' (P17, colorectal cancer, interview 1, patient & carer), while others thought it was the likely cause of their symptoms:

***'I was suspecting. I actually said to my GP when she said she had referred me, I said, "nothing sinister there, is there?" you know, and she said, "I don't believe in not telling the truth."***

*(P1, colorectal cancer, interview 1, patient & partner/carer).*

The above quotation and healthcare professional's descriptions of preparing people for a cancer diagnosis (see voice box 3) illustrates how some healthcare professionals attempted to prepare people for bad news. It is clear from most accounts that when receiving a cancer diagnosis that

many healthcare professionals managed and staged the information by providing warnings and hints over a period of time while taking care not to cause undue concern.

**Voice box 3:** Clinical nurse specialists describe how they lay the ground for a diagnosis of cancer

*'The bad news wasn't broken in one session, it was a sort of gradual disclosure I think so by the time [...] we sat her down and told her that it was lung cancer and what type of lung cancer it was and treatment options for it, she'd actually begun to get her head around-that it was serious.'*

*HP22, Clinical Nurse Specialist*

*'What we've tried to do is sow the seeds of doubt, step by step[...] Well, the assessment letter starts them worrying a wee bit and then when we show them the mammograms and show them the areas and then say we have to biopsy it, I mean most people are not daft and can work out that there's something not right going on.'*

*HP61, Clinical Nurse Specialist*

In contrast, one woman who had been reassured by her GP that she had no cause for concern was very disappointed with this reassurance which she thought had lulled her into a false sense of security:

*'She had me completely convinced that this lump was benign and no hint of anything else and I thought was that because she's trying not to scare me or was it because she really thought it wasn't and I hope that she got some feedback [that it was malignant] [...] I'd rather she just said "Well you know hopefully it'll be nothing but we need to get it checked out."'*

*(P55, breast cancer, interview 1, patient & carer)*

Even if healthcare professionals did not alert patients to a probable cancer diagnosis in a conscious way and despite their efforts to reassure, people often realised they had cancer before



they were diagnosed through perceived clues in their behaviour. One woman claimed her GP's body language made her certain that her breast lump was cancerous:

***'I went to my GP who felt it and said she thought it would be fine because it didn't have hard edges, I knew she was lying (laughs)[...] she was so uncomfortable she couldn't look at me.'***

*(P21, breast cancer, interview 1, patient)*

The immediate pre-amble to test results sometimes made people realise they were going to be given a cancer diagnosis:

***'I knew straight away that there was something wrong because he was taking that long to tell us, I'm sorry but that made me know.'***

*(P17, colorectal cancer, interview 1, patient & carer)*

Being treated differently from others often led people to believe the news they were about to receive could only be bad:

***'There was quite a few nurses around and they were all being exceptionally nice, which in a way, you think, oh my goodness, what's going to happen, because they're are actually, you know, falling over their feet to be nice to you, so you know that something's, somebody's going to tell you something, something you don't want to hear.'***

*(P27, colorectal cancer, interview 1, patient & carer)*

What is apparent from the interviews with people with cancer and their partners/carers is the way in which even the smallest nuances in healthcare professional's behaviour, both verbal and non-verbal, was noticed and interpreted pre-diagnosis:

***'I said to [my husband], "certain questions I've asked I've seen them look at each other, and certain looks" and I said to [my husband] "I just feel that there's a little bit more here than what they're telling me; you know?" They weren't doing it intentionally and they were really good with me, you know what I mean.'***

*(P65, gynaecological cancer, interview 1, patient)*

Being left to last in the waiting room: 'if they keep you to the end it's bad news', being moved from the ward to another room, curtains being drawn around the hospital bed, the meeting with

a surgeon or in the case of one individual receiving an appointment letter from a main cancer centre were additional indicators of bad news.

Two women, who were healthcare professionals, self diagnosed on seeing their mammograms:

*'I already knew what it was because I had seen the mammograms up on the wall [...]...and you know, like most people in the care profession, you can read bits and pieces, we've seen it before, eh, so I knew what it was before I was told.'*

*(P20, breast cancer, interview 1, patient)*

The other woman, also with a healthcare professional background, had scrutinised images on the Internet and knew she was looking for 'a cloudy area' (P70, breast cancer, interview 1, individual interview). She also read her own notes that had been handed to her prior to seeing the consultant as she had become frustrated with the lack of information she was given by her consultant.

## 4.5 How do people affected by cancer recall being told they have cancer?

A small number of individuals said that their own inklings had prepared them for their diagnosis:

*'All he did, as far as I am concerned, is confirm what I had suspected. It didn't come as a major shock, a bit of a shock, yes. You know, but he did explain that for the recovery rate [...] was about 80% so I have as much chance of getting knocked down crossing the road, so what the heck.'*

*(P1, colorectal cancer, interview 1, patient & carer)*

**Voice box 4:** One healthcare professional divided people diagnosed with cancer into 2 groups: the stoics who use 'gallows' humour' and those who 'fall to pieces':

*'He had been prepared by the medical staff [...] so the whole maybe 15-20 minutes when it was him, myself and the doctor, he was being very glib saying it "didn't matter" and "something has to kill you" [...] Many people are like the [P 63]'s of this world and they use this 'gallows' humour if you like so yeah, that's fairly common and yet there's the whole other end of the spectrum where people just don't look at it stoically at all and fall to pieces so in my experience it is 50/50 with regards to that'*

*HP63, Clinical Nurse Specialist*

One woman, who had received several different explanations for her symptoms (including it being wind), felt relief on hearing her diagnosis:

*'To tell the truth it was a relief. Because I thought, "well there's something wrong". That was my initial, I wasn't, I never cried, I never, it was just right there is something, it's not my imagination, it's not my nerves, it's not wind, you know it's something and I knew that they were, when the other doctor, had said you'll get chemotherapy I knew when they were saying that, then I thought that's it I'm going to be okay. So I just felt quite positive then. I still feel positive.'*

*(P49, gynaecological cancer, interview 1, patient)*

Some made sense and managed the impact of the diagnosis by comparing themselves with others with a worse prognosis because of the type or the stage of the cancer. As a consequence, these individuals considered themselves relatively lucky:

*'So yes, OK, it was a disappointment, obviously there was going to be some sort of course of action taken, but I was probably in some ways quite happy that OK right, I've been caught now and that three or four years down the line where all of a sudden symptoms appear and they say you've got a full-blown tumour there, so... Surprise, not total, and I wouldn't describe it as shock and horror, but in some ways relieved that OK they've found something but this is the stage it's at. [...] So in some ways I consider myself lucky.'*

*(P7, breast cancer, interview 1, patient)*

For the majority, despite it dawning on them that they might have cancer, the actual diagnosis was an event that they could not have prepared for:

*'I think everybody must wonder how they would feel if they were told they had cancer, but wondering about it and being told that you've got it is two entirely different things that you cannot prepare yourself for at all.'*

*(P13, colorectal cancer, interview 2, patient)*

*'Somebody tells you you've got cancer it's like somebody's reaching in, pulling your heart out, taking it away.'*

*(P28, colorectal cancer, interview 1, patient & carer).*

The hope that the news would not be as bad as feared remained until it was removed by a definite diagnosis, which led to shock:

*'Although you cough blood, when you see the GP and he says to you "well there are other things that can cause that, like an infection", you don't, although I was pretty convinced in my mind that it was more than just an infection, it's not until somebody's actually put down in front of you that it's pretty absolute that you have got something [...] it was then that it really hit [...] that was the biggest twenty-minute shock I ever had.'*

*(P24, lung cancer, interview 1, patient & carer)*

Shock, intensity of emotion and difficulty in processing the information given by healthcare professionals is described further in Chapter 10: Experiences of emotion.

## 4.6 Communicating a diagnosis

The importance of communication skills is emphasised in some but not all SIGN guidelines (for example, SIGN (2005), Management of breast cancer in women guidelines recommends that: Clinicians should be encouraged to attend validated training in communication skills.) Overall, there was little expressed dissatisfaction by people included in the study with the way healthcare professionals, mostly consultants, delivered the diagnosis. Indeed, the majority of the individuals expressed understanding for how difficult it must be for healthcare professionals to deliver bad news:

*'He came across as a very compassionate person in the way he delivered it-was done nicely, because obviously how do you tell someone something like this? Although he's probably done it a hundred thousand times, I suppose it's never easy to tell someone something like this.'*

*(P5, breast cancer, interview 1, patient)*

*'I felt sorry for the poor chap telling me (laughter). I think he felt, you know I've to tell you bad news and I don't know how to tell you. But he did it very well actually.'*

*(P33, colorectal cancer, interview 1, patient)*

*'The problem with [consultant] was not her, the problem was me and I think, you know where I'm coming from [name of Interviewer], I was uptight, I was distraught and so forth*

*and I would always say that somebody should have somebody with them now in that way because you picked it up. I was taking in bits of it and I was saying yes and no, you know, it was not her fault. You are getting news, she approached it very well.'*

*(P3, colorectal cancer, interview 1, patient & carer)*

The previous quotation also illustrates the value of being accompanied during diagnosis. Almost 50% of those interviewed were on their own when given their diagnosis. The remainder were accompanied by partners/spouses, close partner/carers or friends. One woman thought being on her own when told her diagnosis was 'unfortunate'. This sentiment was echoed by a healthcare professional (see voice box 5) who encouraged people to bring a relative to the clinic, even if they wished to be given the diagnosis on their own in the first instance.

**Voice box 5:** A healthcare professional reflects on the circumstances of diagnosis

*'I would maybe say about 40% of the patients want to come in on their own even although relatives may be present at the clinic they want to tell them in their own way. They don't want them to come in initially. Most of them like somebody to come in and we always try and encourage them to bring relatives with them.'*

*HP36, Clinical Nurse Specialist*

Audio-tapes of consultation is recommended in some but not all SIGN guidelines (for example, SIGN (2005), Management of breast cancer in women guidelines recommends that, Women with breast cancer should be offered audiotapes or follow up summary letters of important consultations). Some people had the consultation where a diagnosis was given audio-recorded and found this helpful because they could listen to the conversation again. However, once the CNS entered the room this recording was often stopped, to the disappointment of some of people.

## **4.7 The reaction of family and friends**

Partners/carers or friends who accompanied the person with cancer were also shocked on hearing the diagnosis. Both people with cancer and their partners/carers at times emphasised that the emotional impact of a cancer diagnosis was greater for the partner/carer than for the person with cancer:

*'Well, I'm slightly worried about her because she's got a memory loss, lapses have been taking place in the last month or two, I think appertaining to the shock [...] I think she's more shocked than I am to be honest with you.'*

*(P46, lung cancer, interview 1, patient)*

Partners/carers would also at times correct the person with cancer when they did not describe the full extent of the impact the diagnosis had had on them:

*P38: 'So we have, after the initial, that as I say, when we were both a bit down and we have to say that.'*

*C38: "A bit down"-we were crushed.'*

*(P38, bowel cancer, interview 1, patient & partner/carer)*

One partner/carer described how much a few reassuring words from a nurse meant to her when her husband had been diagnosed with cancer:

*'He came in and he's chatting away to me, really good, I mean they do give you a lot of attention and he said "don't worry" he says, "there's one thing, if it's the type of cancer they think it is it's curable". He says, "if you've got to have cancer that's the one you want to have". And he says "they can cure it and he says, 'I'll tell you he'll be in here before the beginning of February" and he was right. [...] Quick as that.'*

*(P37, colorectal cancer, interview 1, patient & partner/carer)*

Many healthcare professionals were aware of how the shock of receiving a cancer diagnosis could affect people. They described how consultants would say, 'you'll be in shock' and were, 'really, really nice'. People also appreciated when they understood that they could not take in too much information all at once, saying 'let the news sink in over the weekend. He made another appointment for me on the Monday' (P9, gynaecological cancer, interview 1, patient & carer) and how, in subsequent appointments, the consultants would repeat what was said in the first appointment realising, 'nothing else was going in' following a cancer diagnosis.

Healthcare professionals who displayed compassion when breaking bad news were particularly praised, 'you could tell they cared'. Despite the shock of being told, one partner/carer said she was thankful for the way in which the consultant told her and her husband that he had cancer:

*'I would say that [consultant] had the most pleasant and informative and caring manner of expressing that kind of information to us and I, I, I could see there was emotion in his eyes that day as well, along with his nursing assistants and I don't think it could have been, could have been, that news could have been broken to us more compassionately than the way it was then. I mean there's never any easy way to tell you, you know and I thought the way he did it was absolutely superb, but it was still horrendous like, you know it was almost like Judgement Day.'*

*(P69, lung cancer, interview 1, patient & carer)*

Many appreciated when healthcare professionals delivered their diagnosis in a straightforward manner:

*'Well he didn't pussyfoot about; he tells you exactly what's wrong with you. There's no round in circles.'*

*(P16, colorectal cancer, interview 1, patient & carer)*

*'They were very blunt yep, very blunt and to the point, which I think for the, for a split second was "ooohh" [makes high pitched noise], and then I thought no, I quite liked that, you know it wasn't, it wasn't you know a "soft-soap" round about it, lets soft-soap all this along and then hit her with, they just came right out with it.'*

*(P8, breast cancer, interview 1, patient)*

*'And he is the type of man, he doesn't, as we say here, hit and miss the wall, he tells you straight. So he just spelt it out. [...] I think it's a good way. You know exactly where you stand with this chap.'*

*(P15, colorectal cancer, interview 1, patient)*

For others, this 'straightforwardness' appeared to signify a lack of empathy. Consultants who 'have really not been in charm school enough' and were 'terribly matter of fact' were not appreciated. Instead they should, 'spend enough time with you' and 'just quietly talk through it' rather than, as one person said, leave people feeling that they were 'being treated like a disease and not a person.' (P48, lung cancer, interview 1, patient)

This person said she felt her concerns regarding a possible spread of her cancer were dismissed as 'highly unlikely' instead of listening to them. She said the CNS had to 'pick up the pieces'

afterwards. Another recounted how her consultant had taken away all her hope in the way in which he spoke to her and left her crying for 'three days non-stop' afterwards. She related how he would not respond to her attempts at joking about her potential hair loss, and how he said she would, 'never go upstairs again' and needed a bedroom downstairs and mentioned hospices. She described feeling traumatised following the encounter:

*'He killed me, totally, utterly demolished me, destroyed me, whatever you want to call it. By the time I left, I had nothing left, not a thing left in my body [...] If you take away all hope, all glimmer of hope from someone, they're dead, you're dead. You have to have some glimmer of hope; he destroyed it, he took it away.'*

*(P48, lung cancer, interview 1, patient)*

Later on, she revisited her regular consultant who, 'gave me back my life in two minutes' by being more positive and 'giving me some reason to continue'. In this quotation, she compared their two approaches:

*'Don't ask me what she did, she was just wonderful-w-o-n-d-e-r-f-u-l, and I suddenly thought, yeah, that's it, but there's nothing you could put your finger on, it was the way she said it and she smiled, she was happy, not like that miserable, stare, never even blinked, he was undressing you, you know you felt uncomfortable with his stare, before he even started.'*

*(P48, lung cancer, interview 1, patient)*

At times, people with cancer and their family differed in their preferences for the straightforward approach to delivering a cancer diagnosis as the following quotation illustrates:

**P2:** *[...] 'But I preferred it that way rather than beat around the bush.'*

**C2:** *'Oh no, I didn't like it that way.'*

**Interviewer:** *'What would you have preferred [C2]? What do you think would have been a better way?'*

**C2:** *'I don't know what would have been better but I just thought it was kind of mean... [...]'*

**P2:** *'I don't think beating around the bush would have done anything.'*



**C2: 'You wouldn't have felt as if you had been smacked with a baseball bat. You couldn't ask any- we couldn't think of anything to say. You know.'**

*(P2, colorectal cancer, interview 1, patient & partner/carer)*

Variation between the individual with cancer and the partner/carer response to diagnosis was recognised by a clinical nurse specialist who described the reaction of another couple (see healthcare professional voice box 6).

**Voice box 6:** A Clinical Nurse Specialist acknowledged the differing reactions between patients and families/partners and carers:

***'He deals with things by being quite flippant. His wife was a bit more shocked or she appeared more shocked. And she didn't cry but she was a bit, filled up a wee bit. And I think was aware of him being a bit flippant.'***

*HP17, Clinical Nurse Specialist*

One individual was informed by letter that he had prostate cancer while two women were told by phone that they had gynaecological cancers. Being informed by phone caused confusion for both of these women. One felt that although the manner of the doctor was fine, she would have preferred being told face to face:

***'I would have preferred to have met him face to face because, although he has a very good command of English, I have had difficulty in understanding him, and you get to the stage you don't want to ask people to repeat it five times over. So in a way, but I got the gist of his message very clearly on the phone.'***

*(P40, gynaecological cancer, interview 1, patient and carer)*

Although this woman understood that she had cancer, she was confused about the type of cancer she had (uterine or ovarian), and wasn't quite sure what she had heard on the phone. Another woman had to ring up for the results herself following the tests. She had waited for someone to ring but no-one did. She finally got through to a cancer nurse on a ward, who told her: 'That I had to have chemo, but she never told me it was ovarian cancer.' For this woman,

she was told the treatment she was to receive before she had been told her diagnosis. She was also told that the consultant would write to her; however no letter was ever received.

A few people said the word 'cancer' had not been mentioned. Instead, their consultant said 'it' was 'aggressive' or 'in the early stages' or that the tests had 'shown abnormalities': these inconsistencies in language caused confusion. When seeking clarification that it was indeed cancer or reassurance that it was not, one woman was told by her consultant that it was, '99% certain it is cancer'.

Many said that they were told their cancer was in the early stages, small and/or 'the best type of cancer to have' and that they would 'be fine' which they found reassuring. Several commented on not understanding all the information that they had been given at the time of diagnosis, and not remembering the words used to describe their cancer. As one woman put it:

*∴ I just think sometimes the way doctors speak, you don't understand, you don't take in, especially when it's something like that, you're only, it's like, your mind's like a sieve, you're only taking bits and other bits are just falling through and it's probably the main bits, and so, ah don't know like, I'm no blaming nobody like.'*

*(P26, gynaecological cancer, interview 1, patient)*

Others claimed they were informed about the stage of their cancer, but not understanding what this meant, or hearing cancer-related words that they did not understand.

## 4.8 Conclusion

The importance of giving patients and carers information is recognised in Quality Improvement Scotland (2007) draft core standards for cancer services (For example, it states that, patients, and with their consent, carers, are provided with a range of tailored information about their condition, treatment and care options, outcomes, risks, side-effects and rights on an ongoing basis). However, this Chapter has described how difficult information is to absorb by people who have been given a cancer diagnosis, possibly because of the magnitude of the impact of being given a cancer diagnosis on mental state. In our study, healthcare professionals adopted strategies in an attempt to minimise the shock or soften the blow of a cancer diagnosis. This was an incremental process, involving non-verbal as well as verbal clues, so that the shock was not as great as it possibly would have been without this preparation. There was also recognition on the part of healthcare professionals that people affected by cancer would not automatically absorb

information and, in some cases, a range of strategies had been developed to circumnavigate this including having a clinical nurse specialist on hand to answer questions and discuss issues at length and encouraging partners/carers to be involved so that they could relay information to the person with cancer. However, these well-received strategies which can be seen as displaying a culture of caring in terms of careful and considerate communication were not in place for all people with cancer in our study.

## Section 5: EXPERIENCES OF TREATMENT AND SYMPTOMS

### 5.1 Key findings

- » Surgery proved to be unproblematic for most women with breast cancer with very few mentioning suffering any severe pain or soreness. However, the opposite was true across the other cancer types, particularly so among people with colorectal cancer who found their surgery far more debilitating than they had been warned by healthcare professionals would be the case.
- » Some people with cancer experienced difficulties getting information about how the surgery had gone and about their particular situation because the person who knew this was the surgeon and he/she was not readily available.
- » Postponement of treatment for whatever reasons was a potential cause of anxiety.
- » Some people did not like having to wait for chemotherapy at the hospital, which could be for several hours. Women with breast and gynaecological cancer mentioned this most.
- » Most people with cancer during treatment suffered tiredness following their chemotherapy or radiation therapy. They also experienced more than one of the following symptoms: nausea and vomiting; hair loss; heartburn; loss of taste; loss of appetite; a metallic taste in the mouth; sweats; breathlessness; sleeping problems; constipation and diarrhoea.
- » Moving from specialist to general wards was a negative experience for some people with cancer.
- » Other negative experiences in hospital included irregular meals, lack of cleanliness, poor quality meals, and poor environment for getting to sleep.
- » Some people with cancer, particularly women, welcomed opportunities to converse with others who were also undergoing treatment. Laughing and joking was found to be beneficial for some although others preferred not to discuss their or other

people's illness.

- » Some people with cancer experienced cancer-related symptoms post-treatment and found follow up care lacking.
- » Given all of the above points, it is evident that not all people with cancer experienced a positive culture of caring. In particular, inadequate communication, waiting long periods of time for treatments, and poor hospital environments were all symptomatic of mediocre care.

This Chapter describes the treatments and resulting experiences that people with cancer had gone through. The experiences of these treatments differed. On the other hand there were some treatments and experiences in common regardless of the cancer type. To reflect these differences and commonalities the sub-sections below will either be by cancer type or by common themes.

## **5.2 A summary of treatments**

### **5.2.1 Colorectal cancer**

Eighteen people diagnosed with colorectal cancer were interviewed for this study. All but two underwent some form of surgery. Of those that did not have surgery, one was diagnosed with another cancer that required other treatment and the second suffered a heart condition that ruled surgery out. Three of the people who had undergone surgery mentioned receiving a combination of chemotherapy and radiotherapy sessions before surgery to reduce the size of the tumour. Only three people said they had surgery only, with no follow-up treatments. For the others, surgery was followed by several sessions of chemotherapy or radiotherapy. Overall, two-thirds of people with colorectal cancer (n=12) mentioned receiving chemotherapy as part of their treatment and eight mentioned radiotherapy (two of these had their radiotherapy as treatment for other cancer in other parts of their body). Two people were participating in a clinical trial of treatment for colorectal cancer. A further person refused to sign up to a trial on the advice of their GP.

### **5.2.2 Breast Cancer**

Twelve women diagnosed with breast cancer were interviewed for this study. All had some form of surgery, ten having a lumpectomy and two mastectomies, one a double mastectomy. Five women

received chemotherapy as part of their post surgery treatment and nine had radiotherapy. Three had sessions of both chemotherapy and radiotherapy following surgery, while only two women said they had surgery only, with no follow-up treatment. Half of the women (n=6) specifically mentioned that they would probably be taking Tamoxifen for the next five years. Two participated in a clinical trial as part of their treatment, one for a drug that boosts white blood cell count and the other a chemotherapy trial. A further woman refused to sign up to a radiotherapy trial as she felt too old to withstand it and was concerned at the additional travelling that it would entail. This person in fact refused to have any radiotherapy. Refusing treatment is discussed in more detail in Chapter 9: Experiences of involvement in treatment decision-making.

### **5.2.3 Gynaecological cancers**

Nine women who had been diagnosed with a gynaecological cancer were interviewed for this study. All nine received chemotherapy, and five had a hysterectomy. Two of these latter women had pre-surgery chemotherapy sessions to reduce tumour size before surgery. One was told that due to her age and the stage of her cancer she would not be operated on. Two women mentioned receiving radiotherapy and only one was asked to participate in any clinical trial. She refused, describing that the trial involved two chemotherapy drugs rather than one, with probable extra and more severe side-effects.

### **5.2.4 Lung cancer**

Seventeen people diagnosed with a lung cancer were interviewed, six females and eleven males. Only one mentioned facing any surgery, a lobe removal. Twelve said they were given chemotherapy, eleven were given radiotherapy. Seven of these people had a combination of both chemotherapy and radiotherapy. Three mentioned having pleural aspirations, the removal of fluid from the pleural cavity around their lungs. One person underwent this treatment on more than one occasion. Six people needed blood transfusions, again in some cases more than once. One of these also recounted having a platelet transfusion. Two people participated in a clinical trial as part of their treatment. Healthcare professionals had discussed with a further patient the possibility of his involvement in a clinical trial but his diabetes made him an unsuitable candidate.

### 5.2.5 Prostate cancer

Ten men diagnosed with prostate cancer were interviewed for the project. Two men had surgery: one had a prostatectomy; the other had lymph nodes removed by key-hole surgery. The patient who had prostatectomy agreed to participate in a trial for an exercise programme aimed at reducing incontinence. Five men were given hormone treatment, in most cases preceded by tablets to reduce swelling in the gland, and three of these men were also given radiotherapy. One man had brachytherapy and three did not have any treatment and had been on a monitoring programme since diagnosis.

## 5.3 Experiences of surgery

Surgery was perceived as unproblematic for most women with breast cancer with very few mentioning suffering any pain or soreness. However, the opposite was true across the other cancer types, particularly so among people with colorectal cancer who found their surgery far more debilitating than they had been warned by healthcare professionals would be the case. A small number of people suffered wound infections but the more common problems after surgery were bruising and tenderness around the surgery site.

The period immediately following surgery proved to be a concerning time for a good number of people affected by cancer particularly with regards to getting information about how the operation had gone. At issue was the availability of healthcare professionals who knew enough about their case to provide them with up to date information:

*'So, I asked the nurse, you know, if someone could tell us how the operation had gone and she said, "oh I could get a doctor for you but it won't be a doctor that knows your Mum's case." I'm thinking "what!" .....This is the High Dependency Unit which I felt there should have been someone there.'*

*(C6, colorectal cancer, interview 1, patient and partner/carer)*

A small number of people with cancer expressed concern at the large number of different healthcare professionals they were in contact with during their treatment. One woman with breast cancer found that even with all of these healthcare professionals involved, it was only the surgeon who appeared to know enough about their case to answer questions.

The tone used by healthcare professionals was a concern for a couple of partners/carers. One thought this was too casual:

***'But there are a few of them speak about things like it was a burst cylinder head gasket you know.'***

*(C40, gynaecological cancer, Interview 2, patient and partner/carer)*

One woman with gynaecological cancer, who had hearing difficulties, left a note to this effect next to her bed and was happy that most staff recognised her problem. However, there was one instance when a doctor spoke to her very quietly about the procedures for her cancer and she got very upset.

One woman with breast cancer thought she was asked to vacate her bed too soon after surgery. She lived on her own and was anxious at being released from hospital so soon after her surgery (the following day). She was concerned that she had not been given enough time to come to terms with her condition and to be confident enough to cope on her own. She was, however, allowed to stay a day longer because of her concerns.

## **5.4 Experiences of chemotherapy**

The procedures leading up to chemotherapy sessions were clearly an issue for a lot of people. Many discussed the steps they had to take before they could receive their chemotherapy drugs, namely the blood and urine sampling the day before, and then awaiting results to find out if they were fit enough to proceed. Failing these tests meant postponement of treatment and this proved to be a very anxious time. A further frustration for one person with cancer resulted from the day of the week (Tuesday) that he received his chemotherapy drugs. His blood samples were taken on Mondays at his local surgery but on two occasions this was closed due to bank holidays. As a result, his blood samples were taken on the morning of his chemotherapy sessions and meant a delay awaiting test results before treatment could commence.

Waiting times for chemotherapy appeared to be a particular problem among women with breast and gynaecological cancers, with one woman remarking that she had to wait seven hours for her medication. However, one of these women was given a bleeper that notified her when her treatment was ready and this was appreciated as it allowed her to do things other than sitting in the waiting room.



The administration of chemotherapy drugs proved a problem on several occasions. These ranged from nurses unable to get a line into the back of the hand, and in one case, a drip coming out of the vein and leaking into surrounding tissue resulting in a heavily swollen hand.

## 5.5 Experiences of radiotherapy

As with chemotherapy, waiting times were a problem for a good number of people receiving radiotherapy across all cancer types except prostate cancer. Two women with gynaecological cancer had what they called internal radiotherapy and one in particular found this to be very traumatic:

*'....for what they call the internal radiotherapy and that was a scary time as well.....that was about 16 and a half hours I had to lie flat with the rods and everything inside me. That was a very, very frightening time, lonely time. That was the loneliest I was through the whole treatment.'*

*(P9, gynaecological cancer, interview 2, patient)*

The smell during radiotherapy was particularly off-putting for one woman with colorectal cancer:

*'...at the time you were like [makes facial expression to indicate horrible smell], you know – that's not a particularly pleasant smell.'*

*(P50, bowel, interview 2, patient)*

One woman with breast cancer found the whole process of radiotherapy simulation extremely distressing:

*'I was actually lying crying, it still makes me upset when I think about it, I was lying crying and nobody said to me was I alright, it was really horrible, it was the most horrible experience of recent times, I mean it was worse than having surgery, worse than finding out I had cancer, it was just really, really horrible, horrible experience and I, I just, they just, they just were so thoughtless and, and I mean they were shouting lots of numbers and things like that but they, I wasn't even, it was like I might as well have just been a dead body, they didn't care about me.'*

*(P70, breast, interview 2, patient)*

## 5.6 Symptoms and side effects of treatments

Most of the people receiving chemotherapy or radiation therapy acknowledged that they had been warned by their CNS or consultant of possible side effects. It is difficult in this study to describe the side effects separately for chemotherapy and radiotherapy given the number of people with cancer that received both, generally at the same time too. However, people with cancer mentioned common impacts, regardless of treatment. Most of them suffered tiredness following their chemotherapy or radiation therapy. They also experienced more than one of the following: nausea and vomiting; hair loss; heartburn; loss of taste; loss of appetite; a metallic taste in the mouth; sweats; breathlessness; sleeping problems; constipation and diarrhoea. Experiences of symptoms during the course of the first 12 months following diagnosis are presented in detail in the report, A survey of self-reported symptoms by people with cancer within the first year following diagnosis (Knighting et al. 2008).

Around a half of all people with cancer stated that they had been given anti-emetic tablets to help stop vomiting but it is probable that more than this were given to them. To some, the mere sight of their medication made them feel nauseous:

*'It was getting, it was getting to the stage where you were being, you were being physically sick looking at the tablets in the box.'*

*(P28, colorectal cancer, interview 1, patient & partner/carer)*

A smaller proportion, across all cancer types except breast cancer, also mentioned suffering repeated fluctuations between constipation and diarrhoea and this was particularly distressing for some. Hair loss appeared to be a side effect only for those people with breast, gynaecological or lung cancers, with around a half of people getting chemotherapy mentioning it as a problem. Just under a half of these people went on to wear a wig.

A sizeable proportion of those getting radiotherapy suffered post-radiation skin reactions.

## 5.7 Experiences in hospital

Virtually all of the people with breast, bowel, gynaecological and lung cancers spent one or more nights in hospital. In contrast, only a third of the men with prostate cancer did so. For the majority

of people with lung cancer these overnight stays were due to the length of their chemotherapy sessions. Virtually all of the remaining overnight stays followed surgery.

Some people's experience of being in hospital was positive. One woman with breast cancer commented that, 'even the porters made you feel at ease'. However, others had negative experiences. Of concern was the environment in which people with cancer were given important information and the manner in which they got such information whilst in hospital. Several people thought of the consulting rooms as 'just terrible boxes' and uncomfortably cramped when filled with healthcare professionals, patient and partner/carer.

Also of concern, was moving from specialist to general wards. Three women with breast cancer who spent time in wards other than the specialist breast care wards each had poor experiences. They found these other wards unfriendly and run by staff unfamiliar with their requirements. One woman with cancer, in particular, found the staff unprofessional compared to those in the breast care ward. This was illustrated by a comment from a partner/carer:

***'I mean the, the whole thing is, I think sloppy and you have to contrast it with the professionalism, in the specialist section and the individual attention P53 got there.'***

*(C53, breast cancer, interview 2, patient and partner/carer)*

Ward amalgamation proved an issue for one person with colorectal cancer. This occurred on Christmas Eve and involved their movement, while in a semi-conscious state, to a cold area of a new ward with only a single sheet covering. Two people with colorectal cancer had negative experiences after moving to a new ward, one for the way his diabetes was treated, the other due to feeling treated like a five year old child:

***'I was told I was going back to Ward X which didn't bother me, because they said it was high dependency, I'd be there a few days and that, but I just couldn't stay there, I hated every minute. They treated you like a 5 year old. I mean my mind was there, so why did they treat me like that, telling me that I got to walk, I got to sit.'***

*(P6, colorectal cancer, interview 1, patient)*

Another person with colorectal cancer felt that during his six day post-operation spell in hospital he was left on his own, fed at 4 hourly intervals, with:

***'Nothing in the way of caring or soothing comments or advice as to what to do or what not to do.'***

*(P47, colorectal cancer, interview 2, patient).*

There were a range of problems experienced by the men and women while in hospital. One woman with breast cancer had to remind hospital staff about her medication more than two hours after it was due and she was also overlooked for several meals. Another woman, having previously advised staff of an allergy on admittance to hospital, had an allergic reaction to her medication.

Several partners/carers expressed concerns about the level of cleanliness in some areas of the hospital. There were also concerns at the lack of hand-washing by qualified staff when dealing with patients and being told where these facilities were. One partner/carer voiced amazement that the anti-bacterial hand wash at the ward entrance was barely used by visitors or staff.

A sizeable proportion of those staying in hospital commented negatively on the food they were given during their stay. Most thought the hot meals were cold by the time they reached their ward and some asked their family to bring food to them from home.

Getting to sleep at night while in hospital was evidently a problem for a good proportion of people, particularly among those in beds near to nurse's stations.

## **5.8 Relationship with other people with cancer during treatment**

There were mixed messages about whether or not contact with other people with cancer provided comfort or support. Generally people with bowel and gynaecological cancers found it beneficial with few making negative comments. Across other cancers the views are more mixed.

The main benefits of meeting others ranged from having discussions on common problems to having a laugh and a joke. One woman with gynaecological cancer found that the camaraderie generated while in hospital continued beyond the end of her treatment and she found this to be a great support:

***'I still find that.....you know wondering how we were getting on, there's still a great deal of camaraderie between the women, a great deal of support.'***

*(P40, gynaecological cancer, interview 2, patient and partner/carer)*

Such bonding appeared to be strong among the women in breast cancer wards. One woman with breast cancer and her partner/carer described the camaraderie on the wards:

*P61: 'So we went in and they were all women in the waiting room all 'hi, hi' chat, chat, chat, I'm so and so, I'm so and so, so and so, so and so. Everybody chatting.'*

*C61: 'Actually, it actually turned out a bit of a hoot. We were in stitches there was one woman who was a...'*

*P61: [Interrupts and exclaims] 'Ooh, we had a great time.'*

*C61: '...an unconscious comedienne, and she had a word for everything and even all through it she was fantastic.'*

*P61: [Interrupts again, excited] 'aha, we had a great time honestly.'*

*(P61, breast cancer, interview 1, patient)*

However, the three women with breast cancer that spent time in non-breast cancer wards found very little camaraderie among their fellow patients.

Some people preferred to 'close my ears to those around me', finding their conversations about illness quite depressing. In contrast to people with other types of cancer, there appeared to have been little opportunity for conversation during treatment between men with prostate cancer.

## 5.9 Follow up and living with cancer

Whilst cancer and treatment related symptoms were more evident during treatment, some people with cancer experienced them longer term. These were the same or similar to those described above and included:

- » Cognitive changes: including problems with thinking, memory and behaviour:

*'... she [healthcare professional] said "you won't be the same person again, you'll never be the same physically or mentally" ...I have to say it was between the eyes that, because I think I had been working at just getting back to, to full strength and eh, sort of I know my head's mince ... you know I know I've, I can't remember lot of things and, you know they tell you that, that's normal but it's still hard to accept ...'*

*(P14, breast cancer, interview 3, patient)*

» Neuropathy: experiencing tingling or numbness in certain areas of the body:

*'... I've been getting quite a bit of a problem ... especially in the morning when I wake up, my hands are quite tingly ...'*

*(P13, colorectal cancer, interview 3, patient and family member)*

» Chronic pain:

*'... pain and to the point that it's, you know it started to take over my life, I'm better now, like I say this is a good day ... I didn't know what was coming, it got so bad I couldn't even hold a knife, I couldn't cut a slice of bread ... the pain was absolutely horrendous ...'*

*(P21, breast cancer, interview 3, patient)*

» Fatigue: including extreme tiredness and lack of energy:

*'... just get tired and suddenly I can only do so much and then I just get very tired, no but I'm eating fine and I just, I still go out walking a lot, I like to walk most days if I can and get plenty of exercise, if I'm in town or whatever I can only do so much and then that's me I've got to come home.'*

*(P25, gynaecological cancer, interview 3, patient)*

Other physical side-effects mentioned by people affected by cancer included lymphoedema and sexual difficulties. C7 described the impact of partner impotence post-treatment and the benefits of information being received beforehand:

*'Yes he was a bit down, the impotence you know the failure to get a good erection, that's, so there is improvement, I suppose we just sort of carry on, we've got a good life and I'm sort of talking round in circles but you understand what I'm saying, don't you? I'm not blaming anybody for not giving me the information although I feel that maybe if somebody had brought it out at an opportunity when the two of us were there, worst case scenario, it would have been out in the open.'*

*(C7, prostate cancer, interview 3, patient and partner/carer).*

For some people moving beyond cancer, follow-up appointments contrasted with earlier experiences during treatment:

*'... I saw the surgeon ... cursory 5 minute examination "I'll see you in March" he says "and we'll give you a mammogram then" ... and I saw somebody from the radiography department in and out in 5 minutes again oh yes, yes you're alright.'*

*(P10, breast cancer, interview 3, patient)*

While many people with cancer praised the care received and the success of their surgery, they also described similar feelings of being moved off 'the conveyor belt':

*'... its like, there is a feeling that it's ok, treatment's finished, right bye, see you, well no, see you for the next 5 years or whatever .. it's kind of like the process is through so jump off the conveyor belt and go about your business .... I think that's the thing we need to kind of get a bit proactive and make sure that you know we get a bit of direction and a bit of, I wouldn't say reassurance but just basically how the process is going and what the next stages are ... it's a period of uncertainty just now ... what's next?'*

*(P12, breast cancer, interview 3, patient and family member).*

*'... we're the kind of couple that surgery's gone well, PSA's good, we don't want to take up a lot of somebody's time, that's our problem ... the guy, he was quite off-hand ... it would have been nice to have seen the Consultant, I think if you've had major surgery I would have hoped that the first meeting you have after could have been with the consultant...'*

*(C7, prostate cancer, interview 3, patient and family member)*

Follow-up appointments should provide a good opportunity to talk with healthcare professionals about specific issues and concerns. However, some people affected by cancer described lack of information concerning the purpose and nature of follow-up appointments and as Voice box 7 shows, some healthcare professionals equally recognised difficulties with follow up care:

*'I've to go for a check up in May which will be a year after ... I had my surgery ...' (P8, breast cancer, interview 3, patient)*

*Researcher: 'Is that for a mammogram or..?'*

*'I mean they never actually said what would happen after.'*

*(P8, breast cancer, interview 3, patient)*

**Voice box 7: Follow up care**

*'At the moment the follow-up is very much medical based and the idea is, you come back to the clinic to make sure that the cancer hasn't come back, and that's a bit negative that – isn't it?'*

*'It's not a very supportive consultation for many women, they get very anxious beforehand coming for it ... it's a quick physical check over ... I believe that women actually want more from it than that, I think they want an opportunity to discuss the symptoms they might be having and some of these tablets that they take ...'*

*HP21, Clinical Nurse Specialist*

**Researcher: 'Have you had any contact at all?'**

*'Nothing, not a thing, not a peep, not a whisper ... I mean at the hospital they basically said oh if you want to know anything, go onto the internet, that's fine but we don't have a computer in the house, so I can't go on the internet ... it would be nice if they had a bit more follow up.'*

*(P8, breast cancer, interview 3, patient)*

*'... we don't even know if he's meant to get his blood taken before he goes up or if he's just to turn up in February and get his blood, oh I think that's what he does, yeah, I think he gets it taken up there and the results sent to his GP, yeah, I think that's right.'*

*(C7, prostate cancer, interview 3, patient and partner/carer)*

One impact from unmet information needs can be confusion combined with reduced ability to self-care and weakened patient involvement (see Chapter 11: Experiences of information provision). P14 described feeling that information was withheld, albeit with the best of intentions. Asked if she knew the purpose of follow-up appointments with the surgeon and oncologist, she replied:

*'I have no idea... I do feel, obviously because of the nature of the disease you've got to try and allay peoples' ... fears by sort of saying "well, that's it eh ... I know you've got to be*



*careful and you can't say right you're totally clear" ... you know that's not the answer either but there needs to be a bit of a, a half-way house I feel where they let you down more gently or release you more gently ...'*

*(P14, breast cancer, interview 3, patient and partner/carer)*

## 5.10 Conclusion

At the time of treatment (surgery, chemotherapy and radiotherapy) physical experience takes on increasing significance and includes fatigue, nausea and vomiting, hair loss, heartburn, loss of taste, loss in appetite, metallic taste, sweats, breathlessness, sleeping problems, constipation and diarrhoea, and people with cancer may self care to mediate these symptoms. There are particular worries and concerns immediately prior to surgery, particularly for those unfamiliar with hospitals and it is the small chats, from any member of staff including porters and auxiliaries, that some people with cancer found a comfort. This Chapter details some of the gaps in a positive culture of caring which some people experienced. As mentioned in the previous chapter, the importance of communication skills is emphasised in some SIGN (2005) guidelines and in Quality Improvement Scotland (2007) draft core standards for cancer services yet, this study shows that some people with cancer and their families continue to experience poor communication. Inadequate communication and waiting for long periods of time for treatment left some people feeling uncared for and like they were on a conveyor belt. The Chapter also shows that people with cancer experienced clusters of symptoms after treatment had ended, yet, many of their information and support needs were not met.

## Section 6 EXPERIENCES OF SELF CARE DURING TREATMENT

### 6.1 Key findings

- » Some people with cancer expressed greater interest in and were more involved than others in self care.
- » Emotional self care included people with cancer making life as normal as possible by for example, limiting the visible impact of treatment, remaining positive, drawing on their religion and faith, diverting their attention away from cancer by for example, returning to work, talking about their cancer with others, and finding out information about cancer.
- » Physical self care largely comprised of people with cancer self medicating prescribed drugs to treat their symptoms and treatment side effects, wound care, getting a wig fitted, resting during bouts of tiredness, using complementary therapies, and making a range of lifestyle changes including smoking cessation, taking up exercise and altering diet.
- » The above points highlight that people with cancer are involved in their own care, with some people more active in self care than others.

In this Chapter the self care that people with cancer carried out during their treatment is described. For the purposes of this study, self care is defined as the care taken by individuals towards their own health and well-being. Whilst seeking information on health may also be regarded as self care, this activity is covered elsewhere in Chapter 12: Experiences of seeking information.

## 6.2 Self caring

Some people with cancer preferred to rely on healthcare professionals as opposed to playing a more autonomous role in managing their care. One person with cancer was relaxed about 'leaving it all in the hands of the experts'. Another man with cancer said that:

*'If the hospital can't do it, they can't do it.....I'm not going to be able to help. I'm in the hospital's hands as far as I'm concerned.'*

*(P56, lung cancer, interview 1, patient and partner/carer)*

As this Chapter shows, however, many people with cancer did self care, and as voice box 8 highlights, healthcare professionals encouraged people to make decisions and take initiatives to contact healthcare professionals as a means of taking responsibility and control of their illness:

## 6.3 Emotional self care

**Voice box 8:** Healthcare professionals recognised the importance of patient decision-making:

*'I think that's the one thing a lot of the ladies say to us that they lose control of their life when they go through something like this and I think part of our job is to try and get them back in the driving seat again. So it is kind of empowering them to make decisions for themselves rather than spoon feed them.'*

*HP5, Clinical Nurse Specialist*

*'You know we say that we're contactable at any time, and even if we're not here there's somebody that's always going to be here and we are available and we sort of encourage patients to sort of you know take responsibility for their own illness.'*

*HP39, Clinical Nurse Specialist*

Chapter 10: Experiences of emotion, highlights that a diagnosis of cancer is an emotional experience. People with cancer found ways of managing these emotions, which can be labelled

as coping strategies or as emotional self care. Emotional self care largely comprised of people with cancer making life as 'normal' as possible:

***'I feel that I just have to carry on and you know there's no use in dwelling on it and getting depressed.'***

*(P54, breast cancer, interview 1, patient)*

***'I do not want to act like an invalid'***

*(P42, gynaecological cancer, interview 1, patient)*

Within this wish for maintenance of a normal life was an aim of limiting the visible impact of treatment and to keep their illness very low key. To many, both of these desires were for the benefit of partner/carers, neighbours and friends as much as for themselves:

***'I'll continue to do my make-up and little bits and such like.....and if they can see I'm bright and it's not a face that I'm putting on, I really believe....if other people see that I'm OK, then perhaps it'll allay their fears.'***

*(P69, lung cancer, interview 1, patient and partner/carer)*

The majority of people with cancer expressed their goal of maintaining a positive attitude during their treatment, a determination to not let the effects of the cancer and treatments beat them; what a couple of people have referred to as their fighting spirit. This attitude was particularly noticeable among people with lung cancer:

***'We try to find a positive thing in everything, we don't focus on the negative things and that's kind of what we have been doing, even with just little things, we try to find a wee positive.'***

*(C52, lung cancer, interview 2, patient and partner/carer).*

***'I'm determined, I'm not going to lie down to it.'***

*(P59, lung cancer, interview 1, patient).*

One woman with a gynaecological cancer wanted all of her visitors to 'leave all the misery outside.' (P49, gynaecological cancer, interview 1, patient and partner/carer) when they came to her house.

However, a couple of people with cancer acknowledged that they regarded themselves as 'doom and gloom merchants' (P46, lung cancer, interview 1, patient & P65, gynaecological cancer, interview 1, patient), thinking the worst about their health, but in each case this was counteracted by partners/spouses who had positive outlooks.

Around half a dozen people affected with cancer acknowledged that they were using their religious faith to help them cope:

***'I've got a very strong faith. I won't die before God wants me to die, at the end of the day it's his decision.'***

*(P10, breast cancer, interview 2, patient)*

Two of these people talked of their involvement in prayer circles and how it helped them to know that others were praying for them:

***'I've had prayers [said for me], here and in Canada, you know, so it's been em, so that, that lifts you up ...cause you know prayer's really powerful.'***

*(P42, gynaecological cancer, interview 2, patient)*

Various methods were adopted by people with cancer to stop them dwelling on their illness.

**Voice box 9:** A GP described methods used by one person with cancer to cope with a diagnosis of cancer:

***'...she was keen to be getting back to work, She said for partly financial but also emotional reasons that she felt she would get on better working than sitting at home thinking about things.'***

*HP9, GP*

Most appeared to be means by which their attention could be diverted or strategies that stopped them thinking about their illness. As voice box 9 highlights, one way of diverting attention was by returning to work and this is discussed in more detail in Chapter 15: Experiences of employment.

Humour was also used in a good number of cases, ranging from watching funny TV shows to constantly making jokes about their cancer. Going to the cinema was a strategy used by one partner/carer to help forget about cancer:

***'Because you are thinking about it so much yourself, it's sometimes quite pleasant to go to the cinema and get engrossed in a film, something that for a few hours you forget about it.'***

*(C46, lung cancer, interview 1, patient and partner/carer)*

Exercise and listening to music were also mentioned by several people as means of alleviating the anxiety or stress resulting from their illness. One woman with breast cancer took up painting and found this totally absorbing.

To others however, there was a need to talk about their cancer with friends and family in order to help them cope better. To some partner/carers and friends though the mere mention of the word cancer put a block on this process:

***'If I mention the word cancer to them [friends and family], it's like "aaahhh, no!". It shouldn't be like that....because no matter what situation happens in life you've got to talk about it. I think the more you talk about it the easier it is for the person that's really hurting.'***

*(P26, gynaecological cancer, interview 1, patient)*

Talking to other people affected by cancer was regarded by many people as an effective way of coping:

***'The main thing I did was speak to other people who had either been through it themselves or had a member of the family go through it and that helped, that gave me a real boost.'***

*(P09, gynaecological cancer, interview 2, patient)*

To many people with cancer, knowing what to expect during their treatment was important and can be categorised as a form of self care. This strategy is discussed in more detail in Chapter 12: Experiences of seeking information.

## 6.4 Physical self care

Virtually all of the people with cancer had taken some form of self medication to treat their symptoms and treatment side effects. In the majority of cases this has been for pain control, particularly early on in the treatment process. Some people, while still in hospital, could control the amount of pain control medication they received via self-regulating pumps. The majority of people with cancer acknowledged that they self administered pain control drugs once at home, as and when they were required.

Post surgery wound care at home was generally carried out by community nurses but there were occasions when this was done by the person with cancer or a partner/carer. This was limited to changing dressings.

Hair loss was a problem to a sizeable proportion of people receiving chemotherapy and around a half of these mentioned getting wigs. Most wig wearers thought that doing so was important to help maintain a 'normal' life and to minimise the visible impacts of their treatment. A couple of women took the decision to use a cold cap, a device which is thought to reduce chemotherapy induced hair loss.

Many people suffered post-radiotherapy skin reactions and in nearly all cases they self administered creams or gels. One of these creams was a tea tree cream thought to be very good for treating radiotherapy blisters.

The majority of people suffered nausea and vomiting after their chemotherapy and most were given anti-emetic tablets to be taken as and when required. One couple had developed a strategy that minimised this problem and allowed the man with cancer to go to work for a few hours:

*'What we've done now is, he takes his [anti-emetic] tablets in the morning and then goes back to bed for a couple of hours, he's fine because he sleeps again and that settles his stomach and then he can go to work in the afternoon. So this is what we've found since being on the chemotherapy.'*

*(C28, colorectal cancer, interview 1, patient and partner/carer)*

Many of the people receiving chemotherapy also mentioned suffering repeated fluctuations between bouts of diarrhoea and constipation. Most attempted to control this with the appropriate

self administered medication. Several people with colorectal cancer had stomas and a couple of them mentioned purchasing new clothes that would facilitate and help hide the stoma bag when socialising.

Virtually all of the people with cancer in the study experienced extreme tiredness at some point during their treatment. In the majority of cases there was an acceptance that regardless of the time of day the best course of action was to retire to bed. However, in some instances this was not possible, either through work or family care commitments.

There were several ways that people with cancer tried to give themselves the best chance of their treatment succeeding through lifestyle behavioural changes. This included eating well, resting, staying physically fit and making some lifestyle changes. Around a quarter had changed their diet, cutting out certain foods (one woman with breast cancer becoming a vegan), consuming more fresh or organic produce or taking dietary supplements such as cod liver oil, glucosamine (thought to relieve arthritic pain) and royal jelly. One woman with a gynaecological cancer avoided juices with Aspartame in them. A couple of people with lung cancer had given up smoking since their diagnosis.

Several people talked of 'taking things easy' to give themselves the best chance of recovery. Conversely, one woman with a gynaecological cancer talked of pushing herself hard to show nurses that she could shower herself and cope on her own when returning home from hospital. Around a half dozen people with cancer stated that they had increased or planned to increase the amount of exercise they took.

Some people affected by cancer explored what are often regarded as alternative or complementary therapies and treatments, but one or two had been confused by the sheer range available. A couple of women with breast cancer and one with colorectal cancer self injected with mistletoe, a treatment that is thought to help the body's immune system. Several people with cancer tried reflexology and found it beneficial, particularly in aiding relaxation. Reiki, yoga, the Alexander Technique, acupuncture, mineral therapy and visualisation were each considered by several people with cancer. The vast majority of those that looked at alternative therapies were women, in most cases with breast cancer.

Some people with cancer stated a desire to take more control of what treatment they had. For some, this involved a decision to stop taking medication provided by healthcare professionals as part of treatment. A couple of the people affected by cancer did this because they found that the



side effects from their medication were just too debilitating. For one of these people there was a conscious decision to take control of her care:

*'Well I'll have to take control now, because I've told them I'm not taking the tablets anymore, I'll have to take control. I felt like saying to them, well if I'm dead in two years you can send flowers to my grave saying – "we told her so!" [laughing], and if I'm still alive, you can write an article to Lancet, saying – "I had this patient who refused these tablets – she's still not dying."*

*(P10, breast cancer, interview 2, patient).*

Refusing treatment is discussed in more detail in Chapter 9: Involvement in treatment decision making.

## 6.5 Conclusion

This Chapter describes the ways in which people with cancer were directly involved in their own care, which is increasingly referred to as self care. It shows how remaining positive and hopeful continues to be important during treatment. Some people start to take control by developing strength and determination to get the 'job' of having treatment completed and over with. Self care strategies for managing the emotional consequence of being diagnosed with cancer start to emerge including activities to retain a sense of normal life outwith the cancer experience and taking one's mind off cancer. Other people with cancer, however, welcome opportunities to talk about their experience of cancer as opposed to avoiding and bracketing it off from other aspects of daily life. Another strategy used by some people with cancer is humour and our study shows that laughing and joking with others who were also undergoing treatment can make the experience of surgery less worrying (this was most evident amongst women waiting for surgery on a hospital ward). All people we interviewed are thus 'self-caring' in some way during treatment to manage the emotional and physical impact of cancer.

## Section 7: EXPERIENCE OF REFERRAL AND FOLLOW UP INVESTIGATIONS

### 7.1 Key findings

- » For the majority of people with cancer who reported a positive experience of investigations, the key factors were feeling well informed about what was going to happen, why it was happening, and when it was going to happen.
- » Some people with cancer did not understand the detail of why they were having some investigations.
- » People with cancer spoke of their feelings about having to wait for appointments with a range of emotions, from acceptance and resignation to frustration and even anger at being made to wait for an appointment.
- » Many people with cancer spoke about their confusion of when they would get their test results back and how these would be delivered. People with cancer also reported problems with receiving letters/confirmations of appointments due to lack of secretarial support within the hospitals.
- » People with cancer spoke of their emotions around the investigations after treatment, waiting to see what had happened, and their anxieties about whether or not the cancer would return.

As discussed in Chapter 3: Experiences leading to a diagnosis of cancer, there are many investigations that people with cancer can experience leading up to diagnosis. This Chapter describes the investigations and referrals that they experienced after receiving an initial cancer diagnosis, and during or after their treatment.

## 7.2 Type of investigations

Investigations that took place after an initial diagnosis was given to an individual with cancer were conducted to ascertain the 'stage' of the cancer (this is used to describe the extent of cancer and, to identify whether the cancer has spread to any other parts of the body) to help clinicians make decisions about treatment. The investigations that people with cancer told us about were bone scans, CT scans, MRI scans, bronchoscopy, x-rays, ultrasounds, fine needle aspirations, core biopsy, colonoscopy, endoscopy, and blood tests.

## 7.3 Positive experiences of investigations

For the majority of people with cancer who reported a positive experience of investigations, the key factors were feeling well informed about what was going to happen, why it was happening, and when it was going to happen:

*'She [nurse] said she would give me a booklet, information pack on everything. She did as soon as we had finished in the room she went away and she came back and she gave me a pack that covered what they had just done, what scans were involved, how they did the scans, everything else, the surgery, treatments, radiotherapy, everything. It was covered.'*

*(P2, colorectal cancer, interview 1, patient and partner/carer)*

Depending on their understanding of the follow up investigations, people with cancer either seemed reassured by the number of investigations they had received or were shocked by them and wondered what this meant in relation to their diagnosis:

*'I've been very fortunate you know. I've seen an urologist, a neurosurgeon, I've had a MRI scan, bone scan, an ultrasound scan, a biopsy. I've had first class treatment from my own doctor. I've given blood twice. Before I got the bone scan I had to get a radioactive injection. And I've got transport to and from the hospital, so I've been treated like royalty! And further to that I've now received a letter to say I've to go for another ultrasound scan, which of course makes you wonder why?! And the reason I'm told is just to check the kidneys, to make sure that when they took the biopsy there was no damage done, you know because they take snips from the prostate gland, in case they've damaged anything, so apparently that's just a routine thing, it's to do be done next week. And I've to go for the injection Monday*

*coming, 10th of April, and hopefully I'll get word to go to [hospital] for radiotherapy very quickly!*

*(P66, prostate cancer, interview 1, patient & partner/carer)*

*'...he got the letter, the letter came through asking him to go for a bone scan, which shocked me! Because I thought, I wasn't expecting this, you know.'*

*(C7, prostate cancer, interview 1, patient & partner/carer)*

One woman who received additional CT scans due to being part of a clinical trial spoke of her surprise to find that this was not standard practice:

*'I got a another CT scan, the first one I had was away at the initial diagnosis in [hospital 1] before I'd been near the [hospital 2], the next one I had was at the half-way point of the chemo ...I thought that was standard practice, but it was interesting that I learned that was only because I was on the trials...I realised that, my goodness, a lot of people if they weren't on the trials would have to wait 3 months to have anything and that's a long time because the second part of the treatment has been harder I think than the first in some ways...'*

*(P69, lung cancer, interview 2, patient & partner/carer)*

Another key factor which enhanced their experience was the level of support and understanding they received from the hospital staff during their investigations. For one woman who lived alone and felt unsupported by her GP, the contact with the specialist nurse at the hospital was very important and greatly valued:

*'I had the tests on the Friday and all weekend my tummy was really, really sore. So on the Monday I phoned the nurse that I had spoken to at [hospital] and she said it's because of all the wind that they put in to you, she said they've blown you....but she phoned me every day for the next 3 days, just to see how I was, you know.....and I thought that was really nice.... but I know that if I need anything I just pick up a phone and they'll answer any questions that I've got.'*

*(P13, colorectal cancer, interview 1, patient & partner/carer)*

## 7.4 Negative experiences of investigations

People with cancer spoke about some of the negative aspects of investigations, such as having to take laxative prior to bowel investigations, the level of physical discomfort or pain experienced during invasive investigations, equipment problems, and delays or a lack of clarity around when and how they would receive the results.

For one woman, the experience of taking a laxative prior to investigations was worsened by having to take it the evening before an afternoon appointment which meant that she was awake most of the night:

*'The only thing I'm really not looking forward to is that awful laxative that you have to have, oh it's Fleet, I think it's called Fleet. [Interviewer: Is it not nice?] Oh no, it's not nice, but I mean I understand as everybody else must do that they couldn't operate or even x-ray the bowel if it wasn't empty, I appreciate it but it's just that it really is quite soul destroying that laxative, that you're empty when you're finished with it you know [slight laugh]. It's awful! The first time I had it, I took it during the day because my appointment was 8 o'clock the next morning, but this time my appointment wasn't supposed to be 'till 3 o'clock in the afternoon so I had to take it 7 o'clock at night and then 7 in the next morning. Well I took it at 7 o'clock at night but I thought 'there's something wrong, it's not worked, it didn't start to work until 1 o'clock in the morning and then from 1 o'clock I was on the toilet all night, oh, it was really.... So I said to them when I went..... before they found all this ... I said "if I need to come back I want a morning appointment" I said, "because I am not going through all that again all night". It's not so bad in the daytime, but oh the night time was awful.'*

*(P13, colorectal cancer, interview 1, patient and partner/carer)*

Most of the people with cancer who had any invasive investigations spoke about the level of physical discomfort that these investigations involved:

*'Well it's, it's through the back passage, eh, a camera ...and they use a, what do you call it, they use pincers, they take about 10 samples and it can be very, very uncomfortable. Some people do say it's painful, but there's no anaesthetic given to you or anything...it's rather uncomfortable, every time they probably take a, it's like a needle going [makes a sound], and that, that can be a wee, a second of pain, you may say ...and that's it, but they take about 10-12 samples.'*

*(P67, prostate cancer, interview 2, patient & partner/carer)*

Whilst people with cancer may have expected some level of discomfort during investigations some found the experience much more painful:

*'...they took the samples for the biopsy, which was a fairly horrendous procedure because they had difficulty even you know getting into the lump, it was very near the breast bone, so that was pretty horrid. [Interviewer: What was horrid about it?] They had three goes with the needle too, and then had to use a bigger needle.'*

*(P53, breast cancer, interview 1, patient & partner/carer)*

For some people with cancer, the experience of their investigations was so painful that they refused to go back for any further investigations. One woman spoke of the pain she experienced during an endoscopy:

*'...I mean they don't, they don't knock you out ... they just spray some stuff in your throat ... and they then ram this daft camera down your throat and considering it was my throat that was geeing me the bother it was, it was the thrapple that was giving me, it was away down here, which the minute the camera hit it, it was pure agony so, I mean it's just a, you're in and out the same day like, they sent me a, well I got word from them eventually that it was clear and they put me on some tablets and then I got a letter from them again asking me to come back and get it done again, and I thought n-o ... [laughs], so it had said on the, on the letter if, if you were not coming to the appointment just do nothing, so I done nothing I, chucked it ...and they phoned me, ... and asked me to come in and I went nut, I'm no coming in ... I says well what am I going tae pit myself through all that agony fur, he says well I, I did hear it was uncomfortable, I says well you heard wrong it's no uncomfortable, it's sore and I says I'm no coming up to get it done, well I never went yet...'*

*(P45, lung cancer, interview 3, patient)*

One man spoke about a problem that occurred while he was having his MRI scan due to a cable in the machine becoming very hot and causing blisters on his arm:

**P4:** *'It was a very confined and there was a cable. I was so tight inside it that this cable was against my arm...and it burnt all my arm and I had 4 or 5 blisters along my arm'*

**C4:** *'He was all blistered'*

**P4:** *'Because of this burning cable'*

**C4:** *'Imagine getting that in an MRI scan'*

**P4: 'It's just one of these things!' [laughs]**

**C4: 'Because he wouldn't speak up. He thought it would just be hot and then he couldn't bear it any longer, so he had to press the button and tell them there was something wrong.'**

*(P4, prostate cancer, interview 1, patient & partner/carer)*

One woman spoke about the delay in an investigation being performed while she was going through treatment and the anxiety this caused her while receiving chemotherapy:

**'I started to get black stools and I thought ah, maybe I'm, you know got a bleed, and I mentioned it, and I saw a doctor, briefly, in the chemo room and she said I think we'd quite like to do a scope and just see, we think you've got a "wee bleed"; her terms, , and I think we'll do a scope. So I was kind of worried and I've had chemos 4 and 5 and still not had the scope ... I've still not heard anything about a scope which is, you know a bit worrying, if they think I may have a "wee bleed."**

*(P14, breast cancer, interview 2, patient)*

## 7.5 People's understanding of investigations

Some people with cancer did not understand the detail of why they were having some investigations:

**'Nope, well, they take my, I didn't, they didn't, no they took blood samples off me at the doctors ...and but they didn't say what it was for. I still don't know what PSA is anyway.'**

*(P34, prostate cancer, interview 1, patient)*

**'Well I first knew about that when I asked the doctors who came round and saw us at my last chemo session and they told me, I said "well look do you think, you've got it all, this is clear" ... and they said, "well yes, we think its clear but we can't, but I'll tell your markers disappeared", and I thought, no you've, we've lost your marker ...and I sat there ...[C40: We didn't know what that meant.]...I didn't know what marker meant, I sat there thinking that's jolly careless of you [laughs], and it was until I got hold of [name], the Macmillan nurse, I said what the devil's a "marker" and she explained it to me so perhaps a little bit more explanation would have helped.'**

*(P40, gynaecological cancer, interview 3, patient & partner/carer)*

## 7.6 The speed of referrals for appointments

People with cancer spoke of their feelings about having to wait for appointments with a range of emotions, from acceptance and resignation to frustration and even anger at being made to wait for a follow up appointment. The times mentioned by them ranged from two to six weeks:

*'I phoned the hospital to see if I could get a quicker appointment. Because he was in so much pain and still losing weight and they said no, it doesn't matter you still have to wait for your appointment. [Interviewer: So how long did you have to wait?] At least a month.'*

*(C17, colorectal cancer, interview 1, patient & partner/carer)*

For one man diagnosed with prostate cancer he was annoyed by any slowness in arranging his appointments being put down to it being a slow growing cancer:

*'It's always there. You know there's something there. I'll be glad when I've had the brachytherapy. And then, you know, okay I'll feel better because I'll have done something. This sitting waiting you know it's very, very annoying apart from anything else. It's worrying because you know you always think, well okay they're saying it's slow, don't worry it's a very slow growing cancer. But you do worry. Any cancer is, doesn't matter how slow it's growing, there's something wrong there and you want to do something about it.'*

*(P62, prostate cancer, interview 1, patient only)*

The Christmas holiday was also seen as a factor in the delay between appointments during follow up investigations:

*'It is just the state of the Health Service isn't it? That they don't rush to do anything. You feel as though it could have all gone quicker and we thought it was probably because it was Christmas and everybody was off on the Christmas holidays so you were just sort of put on the back burner until all of that was over.'*

*(C2, colorectal cancer, interview 1, patient & partner/carer)*

*C28: 'I think the worst part was waiting for results, he said, the results would take 2-3 weeks and then just before [patient] got out he said it would be 3-4 weeks, because obviously it's over the Christmas period, so, I know that you know places kinda close down, labs and things close down a wee bit over Christmas and New Year, do emergency things but, you*



*know something like that, it could just wait, so I think, you know, it went from a couple of weeks to like a month waiting for the results of the biopsy, to find out if it has spread ... I do understand because it was the 22nd of December, his operation..'*

**Voice box 10:** A CNS acknowledged the importance of prompt test results:

*'She seemed actually quite calm about it and the fact that she had a date and she didn't have too long to wait meant a lot to her. She said that was helping her to cope with whole situation.'*

*HP5, Clinical Nurse Specialist*

*P28: 'It was, it was a long time, I mean your life was on hold...'*

*C28: 'but they say it does take, it does take two, about two weeks anyway, but. So it does take a wee while anyway but he did explain it would be longer because it was the holiday.'*

*(P28, colorectal cancer, interview 1, patient & partner/carer)*

Many people with cancer also spoke of wanting things to move forward quickly once they had been given an initial diagnosis and this was also recognised as important by some healthcare professionals (see voice box 10):

*'I think they did give me all the information that I needed to understand what was happening and what the process was and what was going on and what I could expect from this. I think it's possible that my head has always been ten steps in front of myself. So, I think it's always been a case of come back to what's happening here and now. Don't think ten steps ahead. So always coming back to what's happening at that point in time. My thoughts were, I don't care what kind of investigation they have to do, I don't care what I have to go through, let's just get it done. That was my thoughts....It was very quick and the people that I was dealing with were very professional and I didn't have any complaints whatsoever.'*

*(P5, breast cancer, interview 1, patient)*

Some people with cancer were pleased with the speed of their appointment:

*'I mean, speed is the main thing isn't it - when anything like that happens? There are so*

*many stages you go through you know, since initial consultation, people don't want to wait for the next stage. They want that test by; they want results; they want the outcome...'*

*(C4, prostate cancer, interview 1, patient & partner/carer)*

*"I'm surprised, yeah, when you think the time that some people have to wait for operations*

**Voice box 11:** A CNS for people with lung cancer recognised that some people wished for time for reflection as opposed to speed:

*'...so that happened fairly quickly with[ patient], she was seen fairly soon by oncology and the thing about these patients is that, they're discussed on Thursday at multi-disciplinary meeting after all the tests are completed, and, they come back to that clinic on Friday, they come back the following day ... then 9 times out of 10, they see oncology the following week. They don't have a huge amount of time in between appointments but sometimes it's a good thing and other times maybe patients just want a wee bit of thinking time.'*

*HP23, Clinical Nurse Specialist*

*and the fact that you can be fast-tracked, it's incredible.... yeah, I think it reflects very well on the health service."*

*(P47, Bowel, Interview 1, patient only)*

However, other people with cancer spoke about the lack of time they had to think about things and as voice box 11 shows, some healthcare professionals were also concerned about the speed in which things progressed, giving people with cancer little time for reflection. One individual with cancer said:

*'And now I get to worry, because on March 1st, I go back and find out the prognosis ... find out what other treatment, you know what kind of cancer, if it is likely to be aggressive or, you know whatever, so this is the worry time. Nobody can bring things forward, the pathology takes 2 weeks, it takes 2 weeks, which is fine, because I think if I had got all the information before you know the anesthetic was out my system, I had a chance to evaluate you know.'*

*(P21, breast cancer, interview 1, patient)*

For some, the speed of the follow up appointments increased their anxiety and indicated that something significant was wrong:

*'I mean it's all been in 10 days, very, very you know quite quick, I knew it was something wrong then, the NHS doesn't work as fast as that ... [laughter]... if they didn't know that it was wrong.'*

*(P48, lung cancer, interview 1, patient only)*

## 7.7 Waiting for results

Many people with cancer spoke about their confusion of when they would get their test results back and how these would be delivered. One person with cancer spoke about the lack of clarity about when or where he would get the results of his MRI scan and how he felt that he had been required to seek the information out for himself:

*'Em, there were other things cropped up after that, I was to contact them again, I got referred for a bone scan and that was fine, they actually said, initially they didn't think they'd do one, but obviously because I had a sore back as initial symptom they decided they would, so that was fair enough, that was, that was great, got the bone scan and the next thing was I got a phone call for an appointment for an MRI scan, which I thought oh ... why?! And, so it was actually C7 [his wife], I just... so I phoned CNS...so she phoned CNS and he said, oh your husband needs to go to his GP for the results of his bone scan, she says well he doesn't go to his GP unless he's ill and he's not feeling ill so, he just thought he'd be told or, so apparently what they'd done, they'd done the bone scan was clear and the MRI scan was additional information for Mr S (surgeon) for when he's operating...But I did have to seek that information out.'*

*(P7, prostate cancer, interview 2, patient)*

People with cancer and partners/carers also spoke about the frustrations around delays in hearing the results of tests and having to chase to find out about test results and appointments:

*'I had to phone up to find out when I had to see [consultant] again because he said he would be in touch after 2 weeks or what ever and if someone says 2 weeks to me then I expect them, so once we are into 17 days I don't see why I have to chase it up. If they say it's going to take 3 weeks that's fine but just that kind of thing [needs to improve].'*

*(P27, breast cancer, interview 2, patient)*

People with cancer also reported problems with receiving letters/confirmations of appointments due to lack of secretarial support within the hospitals:

*'I should have a radiotherapy check-up, I was supposed to get a letter within a fortnight of me finishing my radiotherapy which was on the 21st of July and I'm still waiting ...but I have since heard that [hospital] had some problems with some secretaries and they are trying to backlog all this work that's, that's supposed to have been done and hadn't been getting done.'*

*(P8, breast cancer, interview 2, patient only)*

## 7.8 Investigations after treatment

People with cancer spoke of their emotions around the investigations after treatment, waiting to see what had happened, and their anxieties about whether or not the cancer would return:

*'I was worried, I was actually a wee bit worried about getting this and, you know what are they going to find, you're always waiting for somebody to say to you, oh it's back, you know...'*

*(P1, colorectal cancer, interview 2, patient & partner/carer)*

**Voice box 12:** A healthcare professional reflected on the effects of waiting for test results:

*'...I don't think the people are sensitive enough to the worry that people go through when they are waiting for results and it would be wonderful if there was...a person that ...could phone them with a negative result,...and stop them having weeks of worry...I don't think there's enough communication... not knowing is ten times worse than giving them bad news.'*

*HP25, GP*

As voice box 12 demonstrates, some healthcare professionals recognised that this was a worrying time for people with cancer. People with cancer spoke about their concern that the cancer would return even after being told that things were looking good:

*'... you know, I think once I've had the first scan and I think, well that's a whole year, then I, I think deep down I'll feel well, obviously it is away, you know, but, I mean I know it is, cause they've told me it is and everything's alright, but, there is that little bit of doubt there that ... it might come back again, you know.'*

*(P13, colorectal cancer, interview 2, patient)*

*'I've been fine. I've had a few problems. I was at the hospital yesterday and I'm going to get another scan just to check he thinks everything's OK, you know. I think any wee ache and pain you have now you, you know, you, you assume that's, that it's worse than what it is.'*

*(P42, gynaecological cancer, interview 3, patient)*

People with cancer also spoke about the investigations they had during or after their treatment. These investigations tended to be repeats of prior investigations to see whether there were any changes due to the treatment received. For some people with cancer, this confirmed that there was no sign of the cancer, that the cancer had reduced, or that the cancer had spread to other areas of the body: People with cancer often spoke of their anxiety during the wait for these results:

*'I went for an X-ray and the X-ray was fine, and then I went for a bone scan and that, that whole time it was a really nerve-racking thing cause, you know I'm sat here thinking, oh I'm going to go and I'm going to have to tell the children what, and what if it is something and it, and it probably isn't but then what if I'm not here next year, you know what I mean and what ... just, just everything you know what I mean and it was, so it was quite difficult and I was, I think I was really quite tetchy and horrible to people [laughs].'*

*(P70, breast cancer, interview 2, patient)*

## 7.9 Conclusion

After treatment, people with cancer also underwent tests and investigations to find out if their treatment had been successful and also how they were progressing. Descriptors of these investigations highlight that the experience is both physically and emotionally demanding. The importance of psychological support is recognised in some SIGN (2005) guidelines, but not all. Terms used to describe the actual moment of investigation included, soul destroying, painful, uncomfortable, horrendous, horrid and agony. Yet, it is the emotional experience that comes to the fore during this time as people with cancer worry about the results of these investigations, which is further compounded if they have to wait for these results. Nerve-racking is how one

person with cancer described this experience. Worry is also heightened if people are unclear as to why they are having an investigation or do not know how to interpret the significance of the results. A clear explanation, therefore, about why investigations are to take place and what the results signify may provide support for people with cancer during this period and is an example of a good culture of caring. Whilst Quality Improvement Scotland (2007:17) draft core standards for cancer services advocate discussions of treatment and care options with the patient, this should also include discussions of investigations.

## Section 8: TRANSPORT ISSUES

### 8.1 Key findings

- » The majority of people with cancer drove themselves or got lifts from partners/spouses, friends or neighbours to either health centres or hospitals. A smaller number made use of public transport and taxis, whilst a minority used NHS transport or volunteer drivers to get to or from hospitals and clinics.
- » Virtually every car user had problems finding a place to park their car.
- » A sizeable proportion of car users were eventually given some form of car parking pass, generally a disabled driver badge, but this was often well into their treatment.
- » Other strategies adopted by hospitals to aid car parking included having an attendant park the patient's car for them and setting aside parking spaces specifically for people with cancer.
- » Most of the people using hospital transport found the drivers to be pleasant. However, they voiced their concerns at the length of time they had to wait for transport for their journey home. The longest time anyone mentioned having to wait was six hours and it was hearing horror stories of waits such as this that put other people off using hospital transport.

In this Chapter some of the transport issues that people affected by cancer faced during diagnosis and treatment are described. The majority of people drove themselves or got lifts from partners, friends or neighbours. A smaller number made use of public transport and private taxis, whilst a minority used NHS transport or volunteer drivers to get to or from hospitals and clinics.

## 8.2 Driving self/Getting lifts

The vast majority of people with cancer used a car to get to and from hospitals and health centres, either driving themselves or getting lifts. Virtually every car user had problems finding a place to park their car. Most made some allowance by arriving at their destination early in the hope of finding a parking space but even then, many described spending a lot of time driving around hospital car parks waiting for a space to become available:

*'I mean you shouldn't have to have a hassle of car parking when you're facing these situations either as a patient or a visitor.'*

*(C53, breast cancer, interview 1, patient & partner/carer)*

A sizeable proportion of car users were eventually given some form of car parking pass, generally a disabled driver badge, but this was often well into their treatment. Such passes were, however, recognised by most car users as very helpful.

A couple of hospitals had clearly recognised the problems that car-parking causes for people with cancer. At one hospital, an attendant parked the car for patients arriving at one particular ward. At another hospital, some parking bays had been set aside for people with cancer arriving for treatment. The car park attendants at this hospital also came in for praise for the way they tried to assist:

*'I was just here [at the hospital] to pick her up and there were no spaces, and he says "right OK, I'll tell you what if you just come up here we'll put you in the doctors one, just give us a shout when you come back out" ... and I'd, I'd literally parked the car and went to pick you up, came out and the guy's there again, you know, that kind of like level of care is, eh, it all helps.'*

*(C69, lung cancer, interview 2, patient and carer)*

## 8.3 Public Transport

Around a quarter of people with cancer had at one point or other used public transport as their means of getting to and from hospitals and health centres. For most of these people though, public transport was not their only means of transport, and it would appear that it was used as a last resort. Some had their own car but used buses or taxis when it was deemed easier to do so,



for example, when their appointments coincided with roads being particularly busy. Some even used their car for part of their journey, parked outside of the city centre and used a bus for the remainder of their journey. This option was particularly favoured by those who did not enjoy city driving or driving in the dark:

*'Cause I don't like driving at night, cause.....having had glaucoma, I've now got cataracts... and I don't like the dark nights.'*

*(P44, lung cancer, interview 1, patient and partner/carer)*

Only one person with cancer actually had a direct bus route from near their home to their hospital. Several people acknowledged that they could get to their hospital by public transport but the journey would take a very long time due to the number of different services they would need to use.

## 8.4 NHS transport/Volunteer drivers

Around an eighth of people with cancer acknowledged making use of transport arranged by their hospital. In most cases this involved the use of an ambulance or mini-bus but a couple of people made one or two journeys in the cars of volunteer drivers. In terms of comfort and speed the latter was by far the preferred transport choice:

*'The other thing we have done is gone for transport, it is not fair on C3 driving up there, or a number of friends that have said they would drive you up, but there is a problem with that too, but it is a control thing. People are very good at volunteering, but when it comes to the bit and you are talking about 30 times and you phone someone up, and say, here can you take me in tomorrow, [and they reply] .....I am caught up with something, whereas this way you have no worries with it.'*

*(P3, colorectal cancer, interview 1, patient & carer)*

The WRVS ran a hospital transportation service and this was used by a woman with colorectal cancer but was regarded as far too expensive:

**P6:** *'It's the WRVS.'*

**C6:** *'Which is supposed to be a voluntary service but they charge £10 to take her.'*

**P6:** *'And they couldn't bring me back out.'*

**C6: 'If they can't wait for you, it costs her another £10 for someone to go in and take her back out'**

*(P66, colorectal cancer, interview 3, patient and partner/carer)*

One person made use of a service called Dial-a-Journey. This was described as 'brilliant' but with a downside that it could only be booked the day prior to need.

**Voice box 13:** Healthcare professionals acknowledged transport difficulties:

*'The transport makes it almost worse because it leaves at 8.00 in the morning and isn't back until 3.00pm.'*

*HP54, GP*

*'She would have stayed over following the 1st treatment, which is routine, just an overnight stay, but following that they arrange patient transport to take her in, and so she would have been in the ward about 10 o'clock and then patient transport would have picked her up any time between 2 and 4 to take her home.'*

*HP20, Clinical Nurse Specialist*

Most of the people using hospital transport found the drivers to be pleasant. However, they voiced their concerns at the length of time they had to wait for transport for their journey home. The longest time anyone mentioned having to wait was six hours and it was hearing horror stories of waits such as this that put other people off using hospital transport.

In total five people turned down hospital transport, in some cases due to perceived waiting times and as voice box 13 shows, some healthcare professionals were aware of this problem. Two people did not use hospital transport through their own sense of independence, and in one case as they lived on a direct bus route. Two people thought that sitting alongside other ill people throughout a long journey would be too depressing. One of these latter people said that they preferred to use up their income support by paying for alternative transport:

*'I will not put myself through patient transport, because you get depressed, your in aside all different people with all different stages, and, and you don't always get somebody that's always joking .....and aw that time and the waiting on everybody and the uncomfy chairs, and make it a wee bit more personal if you can, because it is a personal, everybody's different, that's the reason for personal transport, especially for the older ones like.'*

*(P26, gynaecological cancer, interview 1, patient)*

A very small minority of people with cancer said they had not been offered patient transport or did not realise it existed.

## 8.5 The cost of transport

A considerable proportion of people affected by cancer commented on the costs involved in getting to and from their treatments and consultations, and in the case of partners/carers, making hospital visits:

*C37: 'It's twenty two miles each way.'*

*P37: 'So I mean that's a hammer on two pensioners'*

*(P37/C37, colorectal cancer, interview 1, patient and partner/carer)*

One or two made claims to get some or all of these costs back but it is unclear from whom they got this money. Some people had no idea if they could re-claim travel expenses, and had not been advised if any assistance was available.

## 8.6 Conclusion

This Chapter suggests that during treatment people experience an increase in expenditure as they incur travel costs for treatment. Many people encountered further difficulties including parking and long waits for transport. It seems appropriate, therefore, that the organisations responsible for NHS transport (Scottish Ambulance Service) and public transport are included in partnerships to plan cancer care.

## Section 9 EXPERIENCES OF INVOLVEMENT IN TREATMENT DECISION-MAKING

### 9.1 Key Findings

- » Only a couple of people with cancer reported not being involved in treatment decision-making.
- » Most people with cancer perceived that they were involved in the treatment decision-making process because they were kept fully informed by having treatment decisions fully explained to them. This highlights that most people with cancer perceive that they are involved in a key aspect of care, which is treatment decision-making.
- » People with cancer felt involved in treatment decision-making even if they were told that they could or could not have particular treatments. Many people with cancer for instance, were told that surgery was not an option.
- » Most people with cancer relied on healthcare professionals to make treatment decisions because they were the experts. Trust meant that some people with cancer went along with treatment decisions made by healthcare professionals even though the recommended treatment was not their preferred choice.
- » Without possessing equivalent medical knowledge and expertise many people with cancer perceived that they were not in a position to contradict treatment decisions.
- » Leaving it to the professionals to decide on treatments, however, did not imply passivity. People with cancer were aware that they could ultimately refuse to have treatment and some of them did refuse. This shows that involvement in care/self care also includes deciding not to have treatment.

This Chapter focuses on people's experiences of involvement in treatment decision-making for the main forms of treatment, which were surgery, radiotherapy and chemotherapy.

## 9.2 They just told us

Only a couple of people with cancer reported not being involved in treatment decision-making. When asked if she had felt involved, a woman with gynaecological cancer replied, 'not really' (P40, gynaecological cancer, interview 1, patient and partner/carer). This feeling of not being involved was in spite of a partner/carer reporting that the decision about whether or not to have chemotherapy following surgery was the patient's. Another woman with gynaecological cancer when asked if she felt involved in treatment decisions responded, 'They just told us' (P65, gynaecological cancer, interview 1, patient and partner/carer).

A handful of people with cancer demanded that healthcare professionals make the decision as opposed to themselves. One woman with breast cancer explicitly requested that the consultant decide what was going to happen to her: 'I said to him, "What are you going to do about it?"' (P8, breast cancer, interview 2, patient). A person with lung cancer (P30) said that he wanted healthcare professionals to 'just get on it' and that he preferred 'not to know.' He did not wish to know about prognosis or information about treatment. However, he was the exception because most people with cancer as we show below, were fully informed about why healthcare professionals were recommending particular treatments and therefore felt that they were involved in treatment decision-making.

## 9.3 The decision was made by myself

Only one person with cancer explicitly said that she had made the treatment decision as opposed to it being made by or with healthcare professionals.

***'A decision was made in my head that you know, that I am going to go for the bilateral mastectomy. That decision was made by myself.'***

*(P5, breast cancer, interview 1, patient)*

Her account of the decision-making process is similar to others because she was involved in discussions with healthcare professionals and informed of different treatments. Where her account differed, however, was that she perceived that she had made the treatment decision.

**Voice box 14:** A healthcare professional recollected that P5 made the decision:

*'We [patient and CNS] sat down and we discussed the different options... we looked at pictures of having a mastectomy without reconstruction, we looked at pictures of having a mastectomy with reconstruction.'*

*'She then came back and said that she and her husband had made the decision to have a bi-lateral mastectomy.'*

*HP5, Clinical Nurse Specialist*

## 9.4 They keep you informed

Most people with cancer perceived that they were involved in the treatment decision-making process because they were kept fully informed. These people interpreted being 'involved' as synonymous with being 'informed'. If treatments were fully discussed with them, treatment options explained, and recommendations for particular treatments justified, then they perceived that they were involved in treatment decision-making. As voice box 15 shows, some healthcare professionals recognised the importance of providing explanations and reasons for treatment.

**Voice box 15:** A clinical nurse specialist emphasised that people with cancer were provided with explanations for treatment:

*'The oncologist, actually are very good at explaining and they explain the reasons for giving chemotherapy and they explain the risks and benefits and then sort of put it back into the patient's court and say, "Look, it's your decision, what do you want to do?" We can advise you, we'll give you all the information and we'll say what we think you ought to be doing.'*

*HP39 Clinical Nurse Specialist*

This meant that people with cancer felt involved in treatment decision-making even if they were told that they could or could not have particular treatments. Many people with cancer for

instance, were told that surgery was not an option. This did not mean, however, that they did not feel involved in the treatment decision-making process. One person with lung cancer when asked if she had had a choice of treatment replied:

***'No you have a choice, I mean you could of refused chemo if you didn't want to, but obviously if it's not going to help you to do that and they go through each thing with you and tell you what's going to be, they're doing next and that. They keep you informed in every way of everything.'***

*(P23, lung cancer, interview 2, patient)*

A woman with colorectal cancer was told at the time of diagnosis in no uncertain terms that she would require surgery. She said that she had felt involved in treatment decision-making because she was kept fully informed. The surgeon 'explained exactly' what he was going to do and she did not feel that she was 'just sort of a number in the hospital' (P13, colorectal cancer, interview 3, patient). A woman with breast cancer was informed that it was likely that she would have a lumpectomy and that it was also likely that it would involve removal of glands/nodes. Like other people with cancer, she was willing to accept the treatment decision if it was justified and explained to her. She said:

***'If they can justify it to me I can accept it.'*** She also said that you had to ***'trust that you're getting the best advice there is.'***

*(P14, breast cancer, interview 1, patient)*

**Voice box 16:** A GP was aware that people with cancer trusted professionals to provide the best care:

***'She just has trust in the people who look after her... she seems to say, "Well that's that. That's what I've been asked to do and I'll do it. You know, I don't think she questions it too much. That's my understanding anyway but I may be wrong.'***

*HP6, GP*

## 9.5 I'm trusting the professionals

Trust was an important feature of the decision-making process for people with cancer and was one of the main reasons why they agreed to treatments recommended by healthcare professionals. As voice box 16 shows, some healthcare professionals were aware that people with cancer trusted them to provide the best care. A person with cancer said, 'I'm trusting the professionals and they know, maybe that's blind faith' (P17, colorectal cancer, interview 1, patient and partner/carer) Similarly, another person with colorectal cancer said:

*'They're the people that are the professionals, they are the people that are the best placed to know what's what. I'm not going to start going onto the Internet and saying, "Look, what about this, what about that." Cause, it's not, it's not my way, so I'm quite happy to listen to what they have to say and to go with the treatment' (P50, colorectal cancer, interview 1, patient). She also said, 'I think that you've got to give them a certain degree of trust you know, trust.'*

*(P50, colorectal cancer, interview 2, patient)*

A woman with gynaecological cancer when asked if she had been involved in treatment decision-making replied:

*'No I don't think so, but then I don't know enough about it! I'm trusting them! You know, so I wouldn't want to be involved, I really couldn't...'*

*(P42, gynaecological cancer, interview 1, patient)*

She also said that she did not wish to make the decision but would rather 'leave it to the experts.' Similarly, a person with colorectal cancer said:

*'I have a kind of inner-confidence that the experts know what they're doing and they'll do, they'll do the right thing.'*

*(P47, colorectal cancer, interview 1, patient)*

He later went on to say that he did not feel that there was a option whether or not to have surgery and that he was putting himself in the surgeon's 'capable hands.' A woman with breast cancer who did not question the treatment decisions made by healthcare professionals said:



***'I think I'd faith in them, you know I had confidence; I think that's what it was.'***

*(P61, breast cancer, interview 1, patient)*

Trust meant that some people with cancer went along with treatment decisions even though the recommended treatment was not their preferred choice. A man with prostate cancer was very well informed about the different treatments for prostate cancer and in the early stages of the treatment decision-making process said that it was his 'choice at the end of the day' and that he wished to have surgery. The consultants, however, made the final decision based on their clinical judgement about what was best for the patient. The surgeon said that he could not operate and the oncologist strongly advised that he have radiotherapy. He said that he 'trusted' them to make the right decision for him because they were the 'experts':

***'Cause I mean, I mean lets put, well lets face it what's the point in delving into things right, left and centre when you're no going to get anything, well I suppose I could if I said "pfft, I'm no having that, I'm wanting to get such and such", but at the end of the day you've got to by who's supposed to be the experts.'***

*(P34, prostate cancer, interview 2, patient)*

## 9.6 Obviously they know better than I do

Most people with cancer relied on healthcare professionals to make treatment decisions because they were the experts. One person with colorectal cancer said that he left it to the 'experts' to make the best decision for him because, 'obviously, they know better than I do' (P2, colorectal cancer, interview 3, patient). A man with prostate cancer said that the clinicians had decided what form the treatment was going to take and that he was, 'quite happy to let them do that' because they were the 'experts after all' (P19, prostate cancer, interview 1, patient). Similarly, another man when asked whether he was happy with letting clinicians decide which treatment was best replied:

***'Yes, I think they are the experts. And they know what they're doing and I'm quite happy to go along with what they decide is the best treatment. Because I've no idea.'***

*(P18, prostate cancer, interview 2, patient and partner/carer)*

Several men with cancer said that healthcare professionals were the experts in their job just as they were in theirs, which was why they accepted their recommendations for treatment. A man with colorectal cancer (P15) said that they would not be able to do his job and likewise, he would

not be able to do theirs. Similarly, a man with lung cancer said that he was the expert in his job and that healthcare professionals were experts in theirs, which was why he would take their advice:

*'So that's my job I'm the expert on that, and if they tell me you're getting chemotherapy they know what's best, I mean I hadn't a bloody clue.'*

*(P36, lung cancer, interview 2, patient)*

A woman with breast cancer explained at length why she trusted healthcare professionals to make the treatment decision:

*'I suppose if you're, if you're accepting the treatment you'll just have to accept what they give you really don't you, cause I had no knowledge about what's right and wrong so you're very much in their hands... and I, I ... I just had to kind of trust in them to, to know what to do with me and, and I know, and obviously it's such a specialised unit I feel very much that, you know they have protocols for everything and, and their treatment seems so refined I suppose is what I'm saying, that, they're giving you the best they know how and, it couldn't be better treatment, you know I feel like that, I feel full of faith in what they've told me. So I suppose I didn't end up questioning what they were doing and, and wanting to make my own decision... I don't really feel that I, it wasn't like I was asking to be, part of the decision making process in a way, you know, I, I think I just wanted to be told this is the best thing for you to do and, you know this is the best chance you have, but I think if I, had stopped to question, well I mean I've asked questions and things but I haven't questioned it as such... And I, especially with medical things when I feel I really have no knowledge and that I'm not going to be looking things up and reading scientific journals at, you know that's just not me, I'm afraid, I, I, maybe I should but I don't know if it would have done me any good other than just confuse me and I think, you know I think they're the, you know they've been looking it at for years, and years and years, they've refined their treatment, they see all the statistics, let them make the decision I suppose, yeah, yeah, I think yeah ... I still feel quite strongly that I want them to tell me what's the right thing to do. It wouldn't always be the case, I suppose that you know, for something that's less critical I suppose or, or less serious to me I suppose, then it would be different then, but I, I feel something like this that, I just have to be guided by them.'*

*(P55, breast cancer, interview 2, patient)*

Similarly, a man with lung cancer said that he did not wish to make the treatment decision because he would rather leave it to the 'professionals' because 'they know better than I know' (P45, lung cancer, interview 1, patient). Leaving it to the professionals did not imply passivity. This person with lung cancer for instance, had already made up his mind that he would not have treatment again and he had refused to have an endoscope for a second time because it was so painful first time round. Moreover, as already pointed out, those who left the treatment decision to healthcare professionals still felt involved in the decision-making process because they were fully informed.

Knowledge and training was a related reason given by people with cancer to let healthcare professionals take the lead in treatment decision-making.

## 9.7 I'm not medically knowledgeable enough

Recognition of the length of time it took to gain the necessary knowledge and expertise was one of the reasons given by some people with cancer for leaving treatment decision-making to the professionals. A man with lung cancer (P44) said that he was not 'qualified' to question treatment decisions made by healthcare professionals although the professionals left the decision about whether he would have radiotherapy 'entirely up to him.' A woman with breast cancer said that she did not have sufficient medical knowledge to make treatment decisions but relied upon those who had studied for years to gain knowledge to make the best treatment decision for her. She said:

*'But I in some ways think actually I'm not medically knowledgeable enough to be able to make these decisions so what I want is someone who actually does understand and is making you know deciding which chemotherapy drug is best suited for you and I, I mean 'cos there's so many. When you look on the websites there's so many combinations and so many kinds and what you want, you know, as a lay person how do you decide so I don't think what, I think what you need is someone you feel confident in that is going to make a good decision for you. And whatever your outcome at least you can say, you know at least I can say, well I think he did a good job for me.'*

*(P12, breast cancer, interview 3, patient)*

Without possessing equivalent medical knowledge and expertise, therefore, many people with cancer perceived that they were not in a position to contradict treatment decisions. One woman

with breast cancer did not argue with the consultants about surgery because she was not an expert:

*Researcher: 'And when Mr M (surgeon) was talking about the operation, and V (CNS) was talking about radiotherapy, did you feel you were part of that decision about your treatment? Did you feel that you decided to have that treatment or, how did that go, that discussion go?'*

*P10: 'Well, I don't think I saw that I was deciding, I thought they were telling me what they were going to do, but then I wasn't disagreeing.'*

However, she refused to continue with drug medication following surgery. She was initially prescribed Tamoxifen and then Arimidex, but made up her own mind to come off the medication because of the side effects. Although healthcare professionals advised her to continue with the medication, they did say that at the end of the day, it was her decision and her choice.

## 9.8 What would you do if you were in my shoes?

One strategy used in the decision-making process by some people with cancer was to ask the consultant what treatment decision they would make if they were in their shoes. A man with prostate cancer discussed the different treatments with his consultant, read about the different treatments, discussed them with his wife, and then the consultant confirmed that the decision that he had reached was the best course of action:

*'OK, well, we got onto the different treatments and because of the stage of the cancer, em, I don't think [name of consultant] said that's the one that's best for you, I think he kind of hinted at that, you know, but he didn't directly say that's the one you have to go down he just sort of said that here are the options, em, so I was able to ask him a lot of questions about possible side effects and which he thought would be best. I mean basically I was pretty clear myself what course of action I thought was best for me, so I said to [name of consultant] I said right we're about the same sort of age, and you've got my notes in front of you and you know my case history, if you were in my shoes which course of action would you take? And it turned out it was the same one.'*

*(P7, prostate cancer, interview 1, patient)*

## 9.9 Refusing treatment

As already described briefly above, a few people with cancer declined to have investigations or stopped having particular treatments. In addition, one woman with breast cancer (P54) for instance, refused radiotherapy following a lumpectomy even though she was strongly advised and felt pressurised into having the treatment (see voice box 17). Moreover, people with cancer were aware that they could refuse treatment, although most of them realised that this would be an unusual decision to make. This is how one man with lung cancer explained it:

*'He (the consultant) said, "You'll get an early death if you don't do anything about it." "Oh" I said, "I've no alternative then do I?"'*

*(P46, lung cancer, interview 1, patient)*

**Voice box 17:** P54's GP explained her refusal of treatment

*'She was then offered to go on a trial, the trial was radiotherapy or no radiotherapy. She was very reluctant to have the radiotherapy because she felt they completely excised it, it was impalpable, it was tiny, she was 76 and the radiotherapy involved her going in 5 weeks of treatment Monday to Friday. Going into Aberdeen, which was a 60 mile round trip. And she came in to discuss it because she had said she would take part in the trial and then when she was told about it, she said... she didn't want to stay in for 5 weeks to have 2 minutes radiotherapy each day... She said, "What happens if I don't take part in the trial?" They said, "We advise radiotherapy anyway." She said, "I don't want radiotherapy." There was tremendous pressure on her to do the radiotherapy and I think rightly, she had a good diagnosis, as it went and it was well, there was no, it was completely excised, and she felt she was on Tamoxifen and at 76 she didn't want to do anything else. So I agreed to support her on that.'*

*HP54, GP*

## 9.10 Other treatment related decisions

People with cancer were given the opportunity to make other treatment-related decisions including deciding whether to:

- » have chemotherapy over a shorter or longer period of time
- » have one type of chemotherapy as opposed to another
- » remain in hospital for chemotherapy or travel each day to hospital
- » have nurses care for them in their own home
- » remain in hospital for a couple of more days following surgery
- » come in to hospital on the morning of the day of surgery or the night before
- » die at home or in a hospice
- » have the results of tests prior to a holiday or on return
- » be treated in one hospital as opposed to another

These decisions and choices contributed towards making people with cancer feel that they were involved in the decision-making process. One woman with lung cancer (P69) for instance, had a choice of which type of chemotherapy to have and whether or not she would die at home or in a hospice. All treatment recommendations by healthcare professionals were fully explained to her, which meant that she felt that there was nothing that she had not been told. Whilst she accepted the treatment decisions made by healthcare professionals she, therefore, felt involved.

## 9.11 Conclusion

This Chapter suggests that treatment decision-making is a key opportunity to involve people affected by cancer in their care, which is a key policy agenda. People affected by cancer are keen to hear from healthcare professionals reasons why they are being offered particular treatment and they wish to be involved in decision-making. Furthermore, most people affected by cancer want to move beyond the 'what', towards the 'whys and 'wherefores'. They want healthcare professionals to explain why they are recommending particular investigations and treatments and why they, as individuals, are or are not experiencing specific side effects and symptoms. It is not enough to be told what is going to happen; people affected by cancer also want to know why.

This Chapter suggests that the concept of trust is an important component of a culture of caring. Verbal explanation as opposed to a written description of what treatments are being

recommended is important during the treatment decision-making process. This is because trust takes on growing significance; it is during treatment decision-making that people affected by cancer feel a need to trust and put their faith in the experts i.e. the surgeon or oncologist to make the best treatment decision for them. Trust, however, breaks down when healthcare professionals are deemed not in possession of the required specialist knowledge because without it, they are unable to offer explanations.

## Section 10: EXPERIENCES OF EMOTION

### 10.1 Key Findings

- » People affected by cancer often made reference to specific felt emotions, such as shock, fear, anxiety, worry, stress, depression, nervousness and some described feeling anger or sadness.
- » Whilst some people with cancer sought a return to 'normal' after treatment was over, others expected that they might never return to who they were.
- » The strength of the emotional impact and shock at diagnosis often acted to initially obscure the thought processes required to make sense of diagnosis.
- » Some perceived cancer as a transitory illness, an obstacle to be overcome before a return to 'normal' life before illness whereas others practised displacement and distancing.
- » Several people affected by cancer described a loss of control related to perceptions of the cancer taking over both physically and mentally.
- » Once treatment had finished, many people with cancer described fear and worry about the future and a fear of cancer recurrence irrespective of prognosis. A number of other people with cancer described feelings of isolation and feeling alone again post-treatment alongside the requirement for continuing support at this time.
- » Emotion management post-treatment included people with cancer taking one day at a time and setting future goals such as, celebrating a birthday or anniversary. For some people, it involved recognising that a return to 'normal' might not be possible given that the experience of cancer was so profound and now part of their identity.
- » Patient involvement and self care continues beyond treatment and that people with cancer may need support during this time.



This Chapter describes how people with cancer worked through and managed their emotions from diagnosis, through treatment and beyond. The Chapter illustrates emotion and the management of emotions as central to people's everyday interactions from diagnosis onwards. We highlight how cancer diagnosis, experience through treatment, recovery and dealing with prognosis presents an intense crisis and critical disruption to the lives of people affected by cancer.

## 10.2 Emotions

People affected by cancer often made reference to specific felt emotions, such as shock, fear, anxiety, worry, stress, depression, nervousness and some described feeling anger or sadness. At other times, people affected by cancer referred to emotions in a more generalised sense, such as 'my emotions were all over the place' or 'I found it hard keeping my emotions in check' or 'I felt unable to cope emotionally.'

These emotions were experienced because people affected by cancer faced a new and changed reality to their lives. While some sought a return to 'normal' after treatment was over, others expected that they may never return to who they were:

*'... I use the term "normal life", but I don't think there's a normal life as I knew it, it doesn't exist anymore, just have to create a "new normal" life ...'*

*(P69, lung cancer, interview 3, patient and partner/carer)*

## 10.3 Emotion at diagnosis

Many people affected by cancer described the emotional impact of diagnosis as like, 'being knocked off my feet' or as a, 'total shock. It was like getting a slap in the face ... "right" is basically all I said.' (P8, breast cancer, interview 3, patient) Combined feelings of panic, anxiety awaiting further information, concerns over tests and fears for the future summarise experiences at this point.

The strength of the emotional impact and shock at diagnosis often acted to initially obscure the thought processes required to make sense of diagnosis and as voice box 18 highlights, this is recognised by healthcare professionals. A number of people affected by cancer described the difficulty absorbing and making sense of information at diagnosis. Some described how the information 'didn't sink in straight away' and others recollected 'difficulties trying to think straight'.

Some described the day of diagnosis as 'a blur' while others described how they responded by, for example:

*'... shutting it all out, wasn't I? .... this is not me, this is not happening, you know?'*

*(P54, breast cancer, interview 1, patient)*

**Voice box 18:** Healthcare professionals often recognised the delayed impact of diagnosis:

*'You know I don't think it had registered with her the significance of [cancer type]. What Dr... had said hadn't really registered with her.'*

*HP2, Clinical Nurse Specialist*

*'Most people are just kind of, you know overwhelmed with it all ... they haven't often thought through em, you know what that means to them, or, you know, if they have any questions or, you know, so what happens if it doesn't cure it ...'*

*HP45, Clinical Nurse Specialist*

Talking to people affected by cancer over the course of three interviews revealed emotion work in the form of the management and control of initial feelings and emotions. People affected by cancer often began to control how they presented themselves. Some began to manage their experience and emotions by perceiving cancer as a transitory illness, an obstacle to be overcome before a return to life before illness. These types of narratives were particularly prominent during the first interviews, moving from diagnosis and approaching treatment. In some ways, this acted as a comfort as cancer is viewed as being 'repairable'. For example, one woman initially described feeling:

*'Devastated ... absolutely knocked off my feet. I didn't expect to get that diagnosis ... this absolutely could not be happening to me. I was devastated.'*

*(P5, breast cancer, interview 1, patient and partner/carer)*

Later, P5 described how she managed her emotions by taking control so that she could be:

***'More positive and able to cope with the situation ... I knew that I could work through it and I was going through a process and I was going to come out the other side.'***

Likewise, another person with cancer described:

***'... I've got to get a job done ... the damage is done, it's got to be repaired.'***

*(P16, colorectal cancer, interview 2, patient and partner/carer)*

Other people with cancer described displacement or distancing on hearing diagnosis. One person described a, 'sort of denial .... I felt like it wasn't me they were talking about ...' Another described feeling, 'not really part of the group', while one described:

***'I was just living in a dream, you know, I seemed to be floating and all these people were talking but it just wasn't registering that I had cancer ...'***

*(P13, colorectal cancer, interview 1, patient)*

Efforts to 'bracket' or displace diagnosis, or to isolate and conceptualise cancer diagnosis and cancer itself as a process with a beginning and an end illustrates the importance of control and management of emotions through the early stages of diagnosis and treatment.

Many people affected by cancer worked on their emotions and perceived cancer as a disruption to 'normal' life. By bracketing or displacing the experience, at least for a time, a return to normal life and normal interaction was viewed as a goal or possible achievement. However, a number of people with cancer revealed that maintaining this position was not always easy:

***'You're told to keep active, keep positive ... we get the Scotsman, there's something about cancer in it every day, there's TV programmes ... there's films, there's stories ... it seems to be the "in" thing ... you're being hit with all those different things.'***

*(P31, gynaecological cancer, interview 2, patient and partner/carer)*

As treatment approached, a few people affected by cancer described deliberate attempts to develop strength and determination approaching treatment. Several other people affected by cancer described a loss of control related to perceptions of their cancer taking over both

physically and mentally. Earlier constructions of cancer as a transitory stage in their lives became increasingly challenged.

**Voice box 19:** A clinical nurse acknowledged the benefits of a positive attitude:

*'At first she was ... extremely devastated ... but she actually got quite a bit of coping mechanism, she coped quite well ... she coped quite well ... she got her head around things quite quickly ... you know, had a fairly positive attitude when she was going through the treatment.'*

*HP22 clinical nurse specialist*

## 10.4 Emotions during treatment

People affected by cancer adopted a range of strategies to further manage their emotional responses during treatment. These can be conceptualised as emotional self-care (see Chapter 6: Experiences of self care) or as coping strategies.

Some used one strategy and, for example, described working to face their illness 'head on', describing how they strove to remain positive and also encouraged positivism in the behaviour of others around them. As voice box 19 shows, being positive was perceived as important by some healthcare professionals. Other people affected by cancer used different strategies or combinations of strategies as they moved from diagnosis through treatment.

### **Pragmatism**

Over a third of people affected by cancer adopted a very pragmatic, or 'what will be will be' position to manage their emotions as they moved through treatment. As one person described:

*'... the only sure thing is taxes and death in this world. So come on, you've got to die of something ... look at the day we went for a walk ... the people on the headstones were younger than we are ... if something happens that I'm snuffed, it's [partner] I'll be sorry for, cause she'll be left behind, I'll not care, I'll no be here [laughs], I'll be across the road [cemetery] my attitude is you don't live forever ...'*

*(P1, colorectal cancer, interview 2, patient and partner/carer)*

## **Comparison**

Many others managed and rationalised their emotions by situating and comparing them in relation to 'life' and the, often worse, circumstances of other people. This occurred either at a local and personal level – 'I'm doing better than [friend] did – he went downhill really quickly ... weeks wasn't it?' or at a more generalised level: 'I read about [celebrity] passing. I think I'm doing well!' (P30, lung cancer, interview 3, patient and carer)

Many people affected by cancer also described the importance of sharing experiences. At times, this happened unexpectedly: '... em, I had bowel conversations with complete strangers ...'. At other times, some people affected by cancer highlighted the importance of support at a group level:

*'We all have a confab ... and it really brightens you up when you come in here and you speak to some of the other women. I think I am badly off and then I speak to some of them and I think my God how dare I feel like this ...'*

*(P9, gynaecological cancer, interview 2, patient and partner/carers)*

As another person affected by cancer continued:

*'... the women were absolutely marvellous, they all had a, the majority, not all had a very good spirit ... And it would be wrong of me to let other people down by having such a tiny cancer and letting it get the better of me, no damn way!'*

*(P12, breast cancer, interview 2, patient and partner/carers)*

## **Seeking approval and reassurance**

In terms of managing emotions and maintaining effective psychosocial support, people affected by cancer highlighted the importance and influence of the people living and working around them. Several people with cancer for instance, revealed the importance of 'approval' from others in effectively managing their emotions:

*'I've had a few compliments from people for the way I've handled it, they've said to me they thought I'd handled it really well and that boosts me up.'*

*(P9, gynaecological cancer, interview 2, patient and partner/carers)*

## 10.5 Emotion post treatment and through follow up

Many people affected by cancer post treatment and through recovery and follow up experienced a range of strong emotions. Post-treatment narratives described the importance of recognising the need for emotional recovery, which may involve reconciliation with prognosis and the continuing need for effective psychosocial support. Many people affected by cancer described fear and worry about the future and a fear of cancer recurrence irrespective of prognosis. However, as voice box 20, highlights some healthcare professionals perceived that people with cancer were not always supported during this time.

**Voice box 20:** A GP recognised the need for improved follow up and aftercare:

*'You know we need to have a better idea of what happens to these patients after treatment ... how they're coping at home ... we're very hospital-based. Our job very much focuses on diagnosis and following the treatment, following the patients through the treatment plan and I think we are aware that we're not clear about what's happening to the patient after treatment.'*

HP2, GP

A number of other people affected by cancer described feelings of isolation and feeling 'alone again' post-treatment alongside the requirement for continuing support at this time. The difficulty of becoming used to reduced family and social contact remained a problem for some:

*'As I say everybody was so nice ... now, it's all gone a bit flat.'*

*(P13, colorectal cancer, interview 3, patient and partner/carer)*

### **Returning to 'normal'**

Although each person affected by cancer looked forward to returning to a 'normal' life, achieving this was challenging. As one person recovering from cancer described:

*'I really just didn't get the time or the chance to be able to take things in a lot because everyone was just there swarming around me and I just felt so protected and so cared for.'*

*(P9, gynaecological cancer, interview 3, patient and carer)*

A year post-diagnosis, some people affected by cancer were only just beginning to make sense of their experiences. The reality of the previous 12 months, diagnosis, treatment experience and hopes for the future, became increasingly challenging to reflect upon. A fear of cancer returning, difficulties dealing with a poor prognosis and more general perceptions of marking time were central to many people's descriptions of their experiences post-treatment.

Many people affected by cancer described the pressure of common expectations, particularly that normal life would resume, an expectation reinforced by both immediate and wider relationships and social networks. Several people described difficulties fitting back into their social networks and relationships. As one person recovering described:

***'I was certainly not prepared for coming out into the big wide world again.'***

*(P38, colorectal cancer, interview 3, patient and carer)*

Many people affected by cancer described sometimes confusion and anger arising from presumptions of a return to normal. While for some this was achievable, for many others this proved difficult. One woman recovering from breast cancer described:

***'... like I say the ones that ... just go on a bit. "oh yes you look absolutely brilliant", "you're doing fine" and you feel like saying "go away and don't come back again for another 5 years" ... it's like being on a big long lead ... Actually I did blow up at one of them one night and I went "you're saying I'm fine, you must know more than the doctors because they can't even guarantee that I'm fine ...as long as I'm on this medication I'm not fine but I know in the five years I could have reoccurrences and if I'm clear in that five years then I'll know that I'm not going to have any reoccurrences so after that I will be fine" and the pour soul's hardly spoke to me since.'***

*(P8, breast cancer, interview 3, patient)*

P8 recalled being told to 'get on with your life' by healthcare professionals at the end of her last treatment day, an instruction which became increasingly difficult to understand and which repeated through her last interview:

*'... and then, the very last day of radiotherapy ... I spoke to one of the nurses and I said – "well, you know Friday's my last day ... do I see a doctor or what happens?" ... "You come in, have your radiotherapy and go home – and get on with your life."*

*(P8, breast cancer, interview 3, patient)*

Yet the reality of the past year, let alone treatment itself, had only begun to sink in after treatment had finished:

*'... I've been back and forward to that hospital sometimes everyday, sometimes once a week, in for surgery, through horrendous pain and then they say right, that's it.'*

*(P8, breast cancer, interview 3, patient)*

### **Managing expectations**

Managing emotions at this point required a sometimes fraught negotiation between the expectations of others, the encouragement to return to 'normal life', alongside the recognition that normality as they knew it had disappeared:

*'... it really is sinking in, sometimes it hits me that it happened, other times I just, I don't forget about it but it's always, you know, in the back of my mind and I just think, it's not until someone says "how are you feeling?" And wham it hits me again ...'*

*(P9, gynaecological cancer, interview 3, patient)*

A number of people affected by cancer underlined the importance of managing emotions by taking one day at a time:

*'... well, you can't live like that, you can't live like that ... so another day and it hasn't come back and that's it, that's it.'*

*(P24, lung cancer, interview 3, patient and carer)*

Others begin to look further ahead and managed their emotions by setting goals and awaiting the future through events involving others. This involved looking forward to imminent birthdays or anniversaries or preparing for social events, celebrations and holidays.

For many people affected by cancer, managing and dealing with their emotions was also a way of reaffirming their identity not as individuals who 'had had' cancer or who were terminally ill but



as people still part of social life. A number of people identified the need for further support and contact with healthcare professionals during this time:

*'... even if it was just a chat with somebody ... telling you everything, this is all what we've done, I know they say at the time ... you take some of it in but you don't take it all in ...'*

*(P8, breast cancer, interview 3, patient)*

*'.. I don't think anybody ever sat down and said right over the next three or four years this is what will be the pattern, this is what we're looking out for, this is what we expect to happen.'*

*(P7, prostate cancer, interview 3, patient and carer)*

A number of people affected by cancer described the experience as a 'roller coaster ride'. Trying to manage emotions at a number of levels was one way of getting through the experience. For many, however, the ride stopped all too quickly:

*'It's like your roller coaster ride stops very quickly ... it stops, it stops like somebody's slapped you in the face right that's it, go away.'*

*(P8, breast cancer, interview 3, patient)*

## 10.6 Conclusion

This Chapter highlights the emotional impact of a cancer diagnosis and the ways in which people manage their emotions. For instance, people's reports of their experiences post-treatment are imbued with feelings of fear and worry of cancer recurrence. It is also a time when people with cancer become reflective and take stock of their experience. It is an opportunity to clarify with individuals exactly what cancer they had/have (some people in our study did not know), what was removed during surgery (again, some people in our study did not know) and to discuss their physical and emotional experiences since diagnosis. Some people with cancer struggle with an expectation from family and healthcare professionals to return to 'normal life' after having experienced a life-threatening illness with its associated physical and emotional impact and express a need to have the seriousness of their experience acknowledged rather than downplayed or dismissed.

## Section 11: EXPERIENCES OF THE PROVISION OF INFORMATION

### 11.1 Key findings

- » Nurses were one of the main sources of information for people affected by cancer.
- » The provision of information served to allay people's worries and anxieties.
- » Some people affected by cancer had all of their information needs met by healthcare professionals, yet others had unmet information needs in spite of trying to obtain information, including lack of sufficient information about issues relating to treatments, tests and investigations, as well as other matters, such as concerns about occurrence and metastasis.
- » Lack of sufficient information and unmet information needs meant that people affected by cancer worried, did not self-care effectively, and remained confused.
- » Many people with cancer also experienced lack of information and support during follow-up care.
- » Reasons people with cancer gave for lack of information included: a belief that healthcare professionals did not tell them everything because they did not wish to scare them; only gave information if it was specifically requested; and did not wish to give false hope.
- » People with cancer wanted the right information, at the right time, and from the right professional, however, this was not always achieved.
- » People with cancer often relied upon partners/carers to provide information.
- » Whilst it was noted that some partners/carers had good experiences of accessing information, not all partners/carers of people with cancer were satisfied with the information, or rather lack of information, that they received from healthcare staff.
- » Not receiving sufficient information can make people affected by cancer feel like passive recipients of care, rather than partners, as recommended in current health policy.

In this Chapter we describe the role of nurses as information providers, unmet information needs of people affected by cancer, the extent to which the right information is given at the right time by the right professional, strategies used to obtain information from healthcare professionals, and the information needs of partner/carers.

## 11.2 Nurses as information providers

Nurses were one of the main sources of information for people affected by cancer. When talking about nurses, most people affected by cancer referred to the cancer nurse specialist (CNS) and nurse specialist but some referred to nurses, Macmillan nurses, ward nurses, chemotherapy nurses or to the district nurse. Irrespective of job title, however, the most significant thing for people affected by cancer was that they had a nurse that they could contact for information and support. The role of different nurses and confusion around these different roles is described in more detail in Chapter 13: Experiences of nursing care.

Most people affected by cancer were provided with a telephone number and informed that they could contact a nurse for information and support at anytime during their cancer care.

People affected by cancer had their information needs met by nurses for the following:

### ***Information about treatments:***

- » To explain what would happen during and after an operation
- » To help use a catheter
- » To discuss treatment-related symptoms
- » To make an appointment with a consultant
- » To discuss drugs that had been prescribed
- » To explain whether a delay in surgery was detrimental
- » To explain why the date for surgery was being moved forward
- » To explain why having particular treatments
- » To explain what was going to happen next
- » To advise whether it would be a problem to dye their hair
- » To advise on whether they can take a shower after treatment

### ***Information about tests and investigations:***

- » To explain why they are having a scan

- » To give the results of a scan
- » To explain what a 'marker' was

**Other information:**

- » To provide information about local support groups
- » To give advice on welfare benefits, such as attendance allowance
- » To advise on co-morbidity, e.g. how to medicate for diabetes as well as cancer
- » To advise on diet
- » To put them in touch with the humanist society
- » To advise on travel insurance
- » To advise on how to talk to one's children about cancer (050)

Voice box 21 presents what information a clinical nurse specialist provides at the point of diagnosis.

**Voice box 21:** A CNS for patients with lung cancer described what information was given at diagnosis:

*'My role at that time was really information and support. So, providing him, you know, with adequate information about his diagnosis, what that involved, you know, what the treatment options were, to a degree, because you know.*

*Obviously, I also had a co-ordination kind of role too, in that I co-ordinated his appointment to the oncologists, so, you know, he hadn't actually met the oncologist at the time, I had - I gave him a idea of, you know, some treatments that were available, and you know, some of the options that would be discussed with him when he came to meet the oncologist.*

*So usually, you know, follow that up with written information, so I gave him - I also gave him a kind of written information on lung cancer. Gave him a booklet which is produced by the Roy Castle Foundation and within that booklet there are one or two other things as well. You know, I kind of slip inside which I don't concentrate too much on because I'm very much aware they get overwhelmed with the amount of information you're giving them. So, within that booklet are,*

*you know, information on things like the Scan Cancer Information Network, a charity that helps with things like benefits and cancer support. A cancer and information support centre at the hospital that is local to him...*

*But the most important thing I give them is my contact number, which is a small card with my phone number on it. And I give them that and let him know that, you know, he - there is a point of contact for him, you know, he feels, he's got further questions and I, and I encourage him to use that because, you know, I'll often say, "You've had lots and lots of information today and you'll probably not remember any of this, but you get home and your family and friends start asking you questions, at least you know you can come back to somebody to get clarification."*

### 11.3 Information to alleviate worry and anxiety

The provision of information allayed many people's fears and helped alleviate much worry and anxiety. Some people with cancer, for instance, became worried and anxious when they received a letter in the post inviting them to attend for a scan without giving any explanation why. One person with cancer became worried when a letter arrived with appointment details for a bone scan because he was not expecting it and feared that it was an indication that something was wrong. He said:

*'You don't get information, you just get the appointment. I don't suppose it would be practical to give every patient information about why they're getting a particular procedure.'*

*(P7, prostate cancer, interview 1, partner/carer)*

Fortunately, he was able to telephone the CNS who informed him that the scan was standard procedure, so he was not to worry.

Some people with cancer worried that their condition had worsened when changes were made to their treatments without any explanation given. One person with cancer, for instance, received a letter informing him that his date for surgery had been brought forward which made him fear that something was seriously wrong. He contacted the nurse, who was able to put his mind at rest.

## 11.4 Not contacting nurses for information

Not everyone sought information and support from nurses. Some people affected by cancer did not contact the nurses because they did not feel they had information needs. One person with cancer said:

*'Well, anytime you see anybody you were given a card, "If you've got any problems phone up," and all the rest of it. I'm just not that kind of person, em, I'm not, not eh, not prompted, I don't have any particular needs, I don't have any particular anxieties or hang ups but, eh, that I would need addressed.'*

*(P47, colorectal cancer, interview1, patient)*

Other people affected by cancer did not contact nurses for information because they did not wish to bother them. Even on the wards, some patients did not ask questions because the nurses were too 'busy' and 'harassed'. No matter how much encouragement nurses gave to people with cancer to ask questions, some of them chose not to. In light of this finding, one partner/carer of a person with cancer suggested that nurses should telephone patients on a regular basis to find out whether they had any specific questions (P29, colorectal cancer interview 3, patient and partner/carer). As voice box 22 shows, this suggestion was supported by a healthcare professional.

**Voice box 22:** A healthcare professional recognised the need for improved communication between healthcare professionals and patients:

*'I think it would be good if we could, if we could probably be more pro-active in phoning people, you know just saying, "How are you doing?" They appreciate that because they feel that someone's thinking about them. But it also gives you a better idea about how they really are because patients don't want to bother you, they know you're busy.'*

*HP45, Clinical Nurse Specialist*

## 11.5 Unmet information needs

Some people affected by cancer had all of their information needs met by healthcare professionals, yet, others had unmet information needs in spite of trying to obtain information. The following is a list of unmet information needs derived from analysis of the interview data:

### ***Lack of information about treatments:***

- » How long they would be prescribed medication
- » What best to wear when being fitted for a breast prosthesis
- » How to keep warm in bed, e.g., wear a hat
- » What happens if the body rejects a prosthesis
- » What they can do to remain healthy during treatment
- » How long symptoms will last
- » More realistic information about symptoms
- » Side effects of drugs
- » What to expect when they return home from surgery, e.g., whether they should exercise
- » Photosensitivity during treatment
- » Whether the chemotherapy had been effective
- » Oral care during treatment
- » Whether they will be a day patient or stay overnight for chemotherapy
- » What was cut away during surgery
- » Whether they can be cured or whether it will be controlled

### ***Lack of information about tests and investigations:***

- » Why they were having particular investigations and procedures
- » What happens after treatment, for example, whether there will be further tests
- » What were the results of a scan
- » What the results of blood test indicated
- » What the results of an X-ray were
- » Why they were having an appointment with a consultant
- » Whether they will be tested for recurrence
- » When and how many check ups they will have post-treatment
- » What a marker is

***Lack of other information:***

- » Diet
- » How to prevent re-occurrence of cancer
- » Different services available for people with cancer
- » What type of cancer they were diagnosed with
- » Where the cancer is still in their body
- » Whether the cancer will spread
- » Whether the cancer could come back
- » Travel insurance

Lack of sufficient information and unmet information needs meant that people affected by cancer worried, did not self-care effectively, and remained confused.

Some people affected by cancer wanted to know about potential side effects and symptoms of treatments so that they could gauge if the symptoms they were experiencing were normal. Insufficient information about symptoms led one partner/carer of a person with cancer to remark that they just had to, 'plod along and hope that everything was normal' (P29, colorectal cancer, interview 3, patient and partner/carer). Similarly, another person with cancer and his wife were not sure how long symptoms after surgery were meant to last and when bowel movements would return to normal, which meant that they continued to worry about symptoms. His wife said:

***'But they don't tell you anything like that (bowel movements), so we don't know what's normal and what's not normal.'***

*(P37, colorectal cancer, interview 1, patient and partner/carer)*

Unmet information needs also meant that some people with cancer were not treated as partners in their care or supported to self-care. Some people wanted information so that they could take steps to maximise their health and well-being during treatment. One person with cancer asked how she could optimise her health during treatment, but was told that there was not anything that she could do. She said:

***'I said to my nurse, "How can I best help myself while I'm going through this?" She said, "There's nothing you can do." Which I thought was really strange, because even if there is***



*nothing you can do, again, psychologically I think its important to say even things like, "Get plenty of sleep, drink plenty of water, eat as healthily as you can."*

*(P14, breast cancer, interview 2, patient)*

Some people remained confused because of lack of information. One person with ovarian cancer did not understand the results of her blood tests. One healthcare professional said that the result was a 'cancer count' whereas another said it was a 'white blood cell count'. Lack of a clear explanation about these tests left she and her husband confused. Her husband said:

*'We were sitting there saying "what does it mean? We don't know what it means." We were never told what it means.'*

*(P65, gynaecological cancer interview 2, patient and partner/carer)*

Some people with cancer lacked basic information about their diagnosis, even after completing treatment. One woman with ovarian cancer was still 'Not sure to this day' where the cancer actually was in her body; she only knew that she had ovarian cancer (P40, gynaecological cancer, interview 2, patient and partner/carer). Another person with cancer was not clear what kind of cancer she actually had. She knew it was 'lobular' but since conducting her own research, she found that there was no such thing as lobular cancer unless it was invasive and she was told that hers was not. Thus, she was not sure why she had been treated because she did not have 'real cancer;' (P21, breast cancer, interview 3, patient)

*'I don't know, I've got a lot of questions, I've never really known what kind of cancer I had, except it was lobular and that the chemo was a choice, but recommended because of the way the cancer was ... and that was the end of it. Having been on the internet, now I know I had a lump, right, which it says you don't, having been on the internet it said, there's no really such thing as lobular cancer unless its invasive and I know mine, my lymph glands were clear...Right, I do know that much, 'cause they took 95% of them, so and they were all clear, so if its no' a real cancer ... why didn't they just leave it alone ... you know? So I want to know, I don't suppose that it was what I've read on the internet, but it was, I don't think it was a real cancer, 'cause they've spent a lot of money on me.'*

*(P21, breast cancer, interview 3, patient)*

Another person was not sure if his tumour was malignant or non-malignant, although he assumed since he had had surgery that it was malignant (P43, prostate cancer, interview 2, patient). Some

people with cancer lacked information about what had happened during surgery. One woman with cancer said that nobody had told her what the surgeon had done and she wanted to know exactly what had been removed from her body (P40, gynaecological cancer, interview 2, patient and partner/carer).

## 11.6 Reasons for lack of information

Some people affected by cancer surmised why some of their information needs were unmet. They believed that healthcare professionals did not tell them everything because they did not wish to scare them. A husband of a woman with breast cancer said that they were not told about the severity of pain that his wife would experience after the operation. He speculated that it was because healthcare professionals did not wish to focus on the 'doom and gloom' or 'scare' patients before an operation. His wife wished that she had been told what to expect should her body reject the prosthesis. She said:

*'I think sometimes things can be swept under the carpet, like if they had explained to me, I would have preferred that they explained to me fully, you know, what happens in rejection, how was your body going to respond, what are the signs? I would have preferred to have known all these things because it was obviously very shocking and distressing and very frightening when it all started to happen. And what made it worse was me trying to explain to them apart from what they could physically see, what I was feeling and them not recognising what I was saying.'*

*(P5, breast cancer, interview 3, patient)*

Others believed that a lack of information was due to healthcare professionals only giving information if it was specifically asked for. One person with cancer said that healthcare professionals waited until a person with cancer had asked them a question before they gave information about symptoms and prognosis. He found this very frustrating because he did not know what he wanted to ask because this was his first experience of cancer. He said:

*'Rather than him (doctor) telling me what he knows, he wants me to ask questions about things I don't know, you know what I mean, so, I don't know, I cannot ask... All they would say to me was, "We're going to give you this, we're going to give you that, we'll put you on*

*this treatment.” But they don’t tell you the implications of it, i.e., “You’re going to be tired” or, you know? That galled me.’*

*(P36, lung cancer, interview 2, patient)*

**Voice box 23:** A CNS explained an ideal strategy for helping people affected by cancer access information by supporting them to formulate questions:

*‘The only thing that I probably think that would be a good idea, and it’s certainly something that had been bandied around in the past, is focusing patients and spending time with patients to formulate questions, you know, because I think a lot of time that patients don’t know what to ask. So whether it’s, you sit down with people and say, “Now you’ve got this diagnosis of lung cancer, what does this mean? How would you like to take this forward? What is important to you? What would you like to know more about?” So that they, because I think patients, you know, they’re just overwhelmed with so much information sometimes, you know, being verbal and written that, you know, that it’s often, the things that affect them practically are the most important things. You know, when he [P45] came, when he came to discuss treatment, you know you have to make sure he knows, so that he actually understand that, that means that you must come through to the hospital 30 times for your radiotherapy, backwards and forwards. And it’s not until you actually explain it that they suddenly think, “Oh God, how am I going to get through here 30 times?” You know, “Does that include weekends?” And I think if I had the time, you know, formulating questions with patients, I think would be an excellent thing to take forward, but I don’t have the time.’*

*HP45, Clinical Nurse Specialist*

As voice box 23 shows, some healthcare professionals appreciated that the ability to formulate questions was not straightforward and that people with cancer may benefit from support. Similarly, another person with cancer said:

*‘The staff are there and they say, “Right, any questions?” They’re more than happy to explain things, but until you actually go through things yourself, you’re not, not so aware of what you want to ask.’*

*(P7, prostate cancer, interview 2 patient)*

Some people with cancer, however, appreciated this information-giving strategy adopted by healthcare professionals because it enabled people with cancer to have a level of control about what information they were given. For example, several people with cancer had not asked about their prognosis because they did not wish to know. One person with cancer who deliberately did not ask about prognosis said: 'I presume that their approach is, that if you don't ask, they don't tell you.' (P50, colorectal cancer, interview 1, patient). Another person with cancer said that her doctor had specifically asked if she wished to see some statistics about the chance of recurrence before showing them to her (P55, breast cancer, interview 2, patient).

One person with cancer believed that healthcare professionals did not give him information because:

*'They are wary of giving me false hopes, they don't want to commit themselves or make statements that I can throw back at them at some point, I can understand that.'*

*(P1, colorectal cancer, interview 2, patient and partner/carer)*

## 11.7 The right information at the right time from the right professional

People with cancer wanted the right information at the right time and from the right professional. This expectation was not always achieved for the following reasons:

- » Surgical healthcare professionals were not experts in oncology and visa versa but were asked for information.
- » Specialists passed problems onto other specialists because they did not have a solution to a problem presented to them by a person with cancer.
- » Healthcare professionals addressed questions relating to immediate episodes of care even though a person with cancer had asked for advice about future episodes of care.
- » It was not clear to people with cancer which healthcare professional was responsible for providing information about the potential spread of cancer to other areas of their bodies than the original primary tumour site.
- » Healthcare professionals did not address questions about other illnesses even though people with cancer experienced co-morbidity, such as diabetes and chronic heart disease.

- » GPs were responsible for informing patients of the results of tests and, investigations, and for prescribing drugs. However, because they were not experts in cancer care they could not always answer people's questions.

In circumstances when there was not an expert available to address questions posed by people affected by cancer, other healthcare professionals did their best to answer these questions. One person with cancer asked his surgeon about chemotherapy and radiotherapy although the surgeon was not a specialist in this subject. Whilst he received good information, the surgeon advised that he would be better asking the oncologist. A nurse informed a person with cancer that although she could be contacted about anything, she also said that if it was related to chemotherapy she probably would not know the answers, and that the chemotherapy nurses should be contacted instead (P14, breast cancer, interview 2&3, patient).

One person with cancer found that specialists passed a problem onto another specialist because they did not have a solution to the problem presented to them by a person with cancer. In these circumstances, the onus was often on the patient to find a solution rather than the healthcare professional. One person with cancer, for instance, suffered enamel damage during chemotherapy and the oncologist suggested that she visit her dentist but the dentist suggested she make an appointment with the oncologist (P14, breast cancer, interview 2, patient). This person also had hip pain and was told by the chemotherapy nurses that it was a symptom of radiotherapy, by the radiologists that it was a symptom of the chemotherapy, and by the oncologist that it a symptom of the drug, Tamoxifen. Inconsistency of information between healthcare professionals led this person to be confused.

Several patients found that some healthcare professionals did not address questions relating to future cancer care episodes. This meant that people with cancer often had to wait for the right information despite an expression of a request for it there and then. When one person with cancer asked a specific question relating to future episodes of treatment, they were told by nurses on the ward: 'Oh you'll be told about that come the time' (P14, breast cancer, interview 2, patient). Another person with cancer said that there was nobody that she could talk to throughout her care:

***'There's not one person I can say out of any of them that have been there for me all the way through. I mean, I used to see (name of cancer nurse specialist) when I was going to the***

*clinics... I know he's a busy man, but a couple of times I have phoned him and I've never got an answer, no reply. It's as if "Oh, been there done that" now I've got to get on with it.'*

*(P6, colorectal cancer, interview 3, patient and partner/carer)*

Some people with cancer were not clear which expert they should contact for information about metastases and secondary tumours. A person with colorectal cancer who had a secondary tumour on the liver had a colorectal cancer nurse specialist but not one for the liver. When he had a question about treatment for the liver cancer he and his wife were not clear who they should contact. His wife said:

*'I don't know whether to phone her (colorectal cancer nurse specialist) because it's really nothing to do with her liver.'*

*(P17, colorectal cancer, interview 3, patient and partner/carer)*

Several people with cancer also had other illnesses, such as chronic heart disease and diabetes. Some of them were not sure which symptoms were related to which illness or how their medication for one illness impacted on the other. A couple said that they found a cancer nurse specialist unhelpful when they contacted her about dizzy spells. The nurse said that it was not related to cancer but to his heart condition and that he should, therefore, contact his GP (P17, colorectal cancer, interview 2, patient and partner/carer).

A few people with cancer found that their GP was not sufficiently informed about their treatments to provide them with the right information (the role of the GP is discussed further in Chapter 14). As voice box 24 shows, several GPs acknowledged that it was difficult providing the right information. One person with cancer was prescribed Arimidex and went to her GP to find out the results of a related blood test. She said that the GP was:

*'Just reading numbers off to me and you know, I would say, "Well is that good or bad?" She would say, "Oh not very good for someone of your age," and then I said, "Well, you know I have been through and this is why and I am on (Arimidex)," and she said, "Oh it's good for that." But its kind of, what I found is the GP doesn't have a full understanding of what's going on. She's getting the information later than I'm getting it, which isn't, you know, very pleasant and nice. You know, I was saying to (name of husband) I didn't feel that anyone had a grip of the situation.'*

*(P12, breast cancer, interview 1, patient)*

**Voice box 24:** A GP explained why it was difficult providing advice:

*'The problem we often have is the delay in communication between hospitals and us sometimes. But that's not a disastrous thing and it's better at some clinics. It's always difficult when the patients come to you say, this, that and the other has happened. And they've got a letter in front of you.'*

*HP54, GP*

Another GP explained why there was confusion about one particular patient's medication:

*'The radiotherapist had written to me to start her on Tibolene, which I'd put a note back to him just to double check because the BNF says not for pre-menopausal people, but then he did point out to me that he'd effectively made her post-menopausal with his radiotherapy.'*

*HP9, GP*

Whilst people affected by cancer wished for the right information at the right time, they also wanted information from the right professional. Some people with cancer wanted the results of investigations from their consultant as opposed to a secretary at the end of a phone:

*'And then when I phone up about, to get the results they didn't phone me back. And I phone again, and um, she said, "Oh, the doctor (name of oncologist) is away." That's my oncologist, "But the other doctor was supposed to phone you, he must have got busy but he did say there wasn't a problem." This was his secretary. And I went, "Oh that's great." So I er, when I heard that, I was quite happy with that, but I wanted it official, so, er, that was the Friday and I phoned on the Monday and I said, "Do you know, I still haven't heard from my doctor?" And she said, "I'll get (name of oncologist) to phone you." And she phoned me back at 4 o'clock and said, "Dr (name of oncologist) had a look and everything was OK." And I said, "Well, will I see him? What do I do? Is it on-going?" And she said, "Oh, I don't know." So I spoke to my Macmillan nurse and I said to her you know, that I got nothing official, and she said, "That's not good enough." So she phoned doctor (name of oncologist) and spoke to him and she got me an appointment.'*

*(P42, gynaecological cancer, interview 2, patient)*

## 11.8 Lack of information about follow up care and living with cancer

The above sections focused on information gaps with particular reference to information relating to diagnosis and treatment, however, some people with cancer also found information about follow up care and living with cancer lacking.

A number of support services were available and many people moving beyond treatment described how important they could be:

*'... I just ... wouldn't like to talk to somebody I know, I would have to put a front on ... if it was a total stranger I thought I'd never see again, I'd be quite happy, you know, to go for counselling, and I know they wouldn't end up total strangers, you know ... I might try the Maggie's at Kirkcaldy and see if they've got a space and, you know, just do a wee patch on my soul ...'*

*(P21, breast cancer, interview 3, patient)*

*'... there's a lot of information available because everybody kind of talks openly and freely so certainly it's a huge, huge source of information ... anything I need to discuss or talk over I can do so with people who have similar experiences and kind of know and understand ... whatever my difficulties are, that kind of thing.'*

*(P5, breast cancer, interview 3, patient and partner/carer)*

However, while some people affected by cancer described the benefits of these services, a number of people moving beyond treatment described a lack of information about these services. As P9 discussed, while leaflets were often available, the differing types of support available "could have been emphasised a bit more". P8 described how she had had no contact with any healthcare professionals since her last radiotherapy treatment: "Nothing, not a thing, not a peep, not a whisper" (P8, breast cancer, interview 3, patient). Further, she had received no information about support services available during her last treatments. Often, people gained information from other people who have been affected by cancer:

*'... there was another woman ... who had had the same ... and she's actually been very good because I don't see her very often but ... we have our wee conversations ... and she says to me "Oh you know about these sessions", and I'm like, "No, nobody's ever mentioned anything to me about them," ... all the things up at the Maggie Centre, no, I never got any*



*information ... I was at my last session I asked them, well, "What happens now?" I was basically told to go home and live.'*

*(P8, breast cancer, interview 3, patient)*

For some, the need for support increased after treatment, underlining the importance of being given information and advice approaching and at the end of treatment. One person with cancer commented that much information was available at the start of treatment but had received 'absolutely nothing' at the end. As voice box 25 shows, some healthcare professionals also recognised that there was a lack of support at this stage.

**Voice box 25:** Lack of support during follow up

*'We give patients lots of support at the point of diagnosis, through their treatment, and then off they go. Which is fine ... but what I think would be better, instead of just discharging them after their treatment, would be to have some kind of, em, formal teaching or group sessions where they could actually learn about what's happened to them and get some advice about how to re-adjust their lives for the future.'*

*HP 21, Clinical Nurse Specialist*

Moreover, information about common physical side-effects and symptom management could be beneficial in preparing for life after treatment. While some people affected by cancer praised the support and information given during treatment, a number questioned the lack of information, particularly written information, during recovery follow-up: 'Written information? Not really, it was mainly passed word of mouth.' (P2, colorectal cancer, interview 3, patient and partner/carer). One person with cancer described how she had received self-help information in relation to her surgery but nothing beyond that:

*'... there is a lack of information ... that's saying look, listen, you've had this, it's not the end of the world, you can carry on with what you're doing. I mean from when I came out of the operation I got a list of things about watching yourself lifting and going up and down stairs and all that stuff which was probably more relating to the surgery.'*

*(P14, breast cancer, interview 3, patient)*

This lack of information at times hindered their ability to manage both their symptoms and emotions and self-care accordingly:

*'I would like to know, you know, pain in the arms and wrists and fingers, exactly what is causing it ... I think it's getting worse ... is it because of the drugs or is there something else? Is it a side-effect of the fact that the cancer did actually migrate to the bone slightly? But they said there was nothing to worry about ... is this a side effect of that as well? I just don't know ...'*

*(P19, prostate cancer, interview 3, patient and partner/carer)*

One person affected by cancer commented how they were "sent on their way" post surgery, yet information needs remained unfulfilled. One partner/carer highlighted the need for a post surgery written information check-list for all people affected by cancer. As a result of the lack of written information, many people affected by cancer continued to rely solely on alternative information routes, including family and friends (particularly when these were healthcare professionals) and the many different forms of media and library information available. This is discussed in the following Chapter: Experiences of information-seeking out with the healthcare setting.

## 11.9 Partner/carers' information needs

People with cancer often relied upon partners/carers to provide information, which was one of the reasons why it was important that they attended appointments and consultations with them. Many couples saw themselves as a team, which meant that they both wanted information (the role of the family and the impact of cancer on families and friends is discussed more widely in Chapter 17: Experiences of families and carers affected by cancer). One partner/carer said:

*'Whatever people are saying to him (the person with cancer), he's not quite, he's only taking in what he wants to and then shutting it off. He's relying on me to remember the other parts.'*

*(P39, colorectal cancer, interview 1, patient and partner/carer)*

Partners/carers appreciated the one-to-one contact that they had with healthcare staff. One person with cancer was pleased that his wife was able to contact the CNS because he recognised that she had her own anxieties:

***‘...any worries she had is, who would she turn to? When she could come and ask me and I would only tell her what I’d been told, but she’s obviously got other anxieties. She got on well with the cancer nurse specialist because she could chat with (name of CNS), no problem, and I would think she got a lot of information from (name of CNS) who was very good.’***

*(P2, colorectal cancer, interview 3, patient)*

Another family met with the surgeon because the surgeon said that information was better coming directly from him than second hand (P25, gynaecological cancer, interview 1, patient).

Not all partner/carers of people with cancer were satisfied with the information, or rather, lack of information, that they received from healthcare staff. One husband said that it made him angry that he was not provided with information about the operation:

***‘That makes me feel angry because I didn’t get involved in what was going on. They’re got to cut this away and do this and even today I don’t know what they did and nobody told me.’***

*(P65, gynaecological cancer, interview 2, patient and partner/carer)*

Some couples had different information needs. In these situations, the needs of the person with cancer took priority. One person with cancer reported being very satisfied with the information that he had been given from healthcare professionals, but his wife was clearly not. She was in a predicament because whilst she wanted more information she was taking the lead from her husband. She said:

***‘That’s the interesting thing being part of a couple, you cannot force your husband to ask for information because it’s his thing, you know?’***

*(P7, prostate cancer, interview 2, patient)*

Her husband was being very positive, which meant that she did not think it was appropriate to discuss the ‘bleakest scenario’ with him, even though she wanted to. She also found joviality during a consultation a barrier to having some of her concerns addressed. During one consultation, although they were laughing and joking, she still wanted information:

‘We still needed information, and maybe I should have said, “Yes, but we still need information, please”... I think the doctor said, “Oh what about the erection?” and we sort of made a joke that

it wasn't there and he laughed, but that was it. But we thought that's maybe normal for 6 or 8 weeks post op. but it might have been good if they had said, "Well actually you know you may be laughing, but this could". You know what I'm saying?' (P7, prostate cancer, interview 3 partner/carer)

A husband of a person with cancer wanted to know whether the chemotherapy had been effective as soon as possible, whereas his wife was willing to wait until the appointment. He deferred to his wife's wishes:

*'I was all for phoning the hospital, get an appointment now, get it sorted, but she doesn't want to it that way, so. "Oh well, fair enough, have it your way, I'm not going to tell you how to, you know, how to cope with it or how to approach it." But I know what I'd be doing.'*

*(P12, breast cancer, interview 2, partner/carer)*

## 11.10 Conclusion

This Chapter shows that during treatment, the overwhelming majority of people affected by cancer wanted to know potential side effects and symptoms. They wanted information prior to procedures and treatments that did not downplay or disguise the fact that investigations and treatments could be very painful and carried risks. The Chapter shows that much of this basic information was available to people affected by cancer but there were information gaps. An example was lack of information to support change in lifestyle. For those people with cancer who expressed a willingness and enthusiasm to change their lifestyle in order to optimise the effectiveness of their treatment and their chances of recovery, this lack was unfortunate, particularly given recent health policy encouraging people's greater involvement in managing their care. The Chapter also highlights that people with cancer regard their relationship with nurses as a significant contributor to meeting their information needs; suggesting that the ability to provide information and communication skills are key elements of a good culture of care. The Chapter also illuminates some of the ways in which people with cancer encounter difficulties in obtaining information, due to the way in which cancer care is compartmentalised into specialist interests and sectors. Greater partnership working between specialists and sectors may, therefore, help to sew some of the seams together to the benefit of people affected by cancer. Finally, the Chapter highlights that partners/carers have different information needs and, given recent recognition in health policy of the role of partners/carers, these needs ought to be addressed.

## Section 12: EXPERIENCES OF INFORMATION-SEEKING OUTWITH THE HEALTHCARE SETTING

### 12.1 Key Findings

- » The main practical reasons for seeking information included a perception that nurses were too busy, or because it was quicker obtaining the information from elsewhere. People affected by cancer also sought information to avoid being shocked and bamboozled during consultations, to gain some control over the illness, or as a way of managing their worries and concerns.
- » Several reasons were given for deliberately not seeking additional information, including: being satisfied with the information provided by healthcare professionals; believing that any information found would make them scared, frightened or depressed; or that it would detract from 'getting on with life'.
- » People sought additional information from the Internet and from books, and as a consequence of being affected by cancer, were more receptive to media stories about cancer.
- » People with cancer perceived the quality and usefulness of information from the Internet variable. Yet, only a small minority of people in our study had been advised by healthcare professionals about which sites were particularly useful.
- » Unmet needs for information led some people with cancer to seek information from other sources than healthcare professionals.

Healthcare professionals were the main source of information for people affected by cancer. However, people affected by cancer sought, or came across, information from alternative sources and outwith the healthcare setting. This Chapter describes why people with cancer and their family did or did not seek additional information, what kind of information they sought, what sources they sought it from, what their opinions were of it, and what impact the information had.

## 12.2 Reasons for seeking information outwith the healthcare setting

There were a number of different reasons why the people with cancer who participated in this study sought information outwith the healthcare setting, some of which were practical. Other reasons for seeking information included wishing to be prepared for a consultation in order to avoid being shocked or bamboozled, to gain control, or to prevent undue worry. Some people also perceived that they had not been given sufficient information, or wished to obtain a comprehensive and more realistic picture of their illness because they perceived that healthcare staff had put a positive spin on their illness.

Practical reasons for seeking information were because nurses were perceived as too busy and so could not be contacted for information, or because it was quicker obtaining the information from elsewhere. One person with cancer said that she sought out information from her local library because she did not wish to bother the nurses on the wards who were extremely busy. Her husband, however, did not share this outlook, and had telephoned them 'day and night' (P40, gynaecological cancer, interview 2, patient and partner/carer). Accessibility of nursing staff is discussed in more detail in Chapter 13: Experiences of nursing care. Another person with cancer said that a major advantage of the Internet as a source of information was speed; she found it much quicker to find the answers to questions from web sites (P21, breast cancer, interview 2, patient).

A handful of people sought information prior to a consultation with a healthcare professional in order to be prepared in advance for what they might be told. One person with cancer said that having information in advance meant that she was 'forearmed' and was also 'less bamboozled' by all of the terms that healthcare professionals used. She said that she liked to know in advance what may happen and why. She described her information seeking behaviour as a 'coping strategy' (P14, breast cancer, interview 2, patient). Another person said that she searched for information in advance so that she would not be 'completely shocked' by anything that she might be told (P12, breast cancer, interview 1, patient).

One woman sought information because healthcare professionals only gave information on a 'need to know' basis and did not discuss future possibilities. She found this difficult because she was the type of person who liked to have 'prior warning' (P31, gynaecological cancer, interview 2, patient and partner/carer).

One woman with cancer acknowledged that the information that she had received from healthcare professionals was plentiful, but she went and conducted her own research because it was a way of 'taking control' (P5, breast cancer, interview 1, patient).

Some people affected by cancer sought information to stop themselves from worrying. One couple sought information because only having partial knowledge made them worry more. They said:

***P40: 'I want to know. I really want to know. I find that if you face things squarely it makes them more understandable, easier to bear.'***

***C40: 'You get snippets of information; it's more worrying, I think.'***

***P40: 'It is, because you could fill some little bits of gossip from other people that could worry you stupid, so you're better to go and find out for yourself. So I raided the local library and they had books on various cancers, so I brought them home and looked it up and looked up the treatment and looked up the possibility of survival.'***

*(P40, gynaecological cancer, interview 1, patient and partner/carer)*

Some people with cancer sought information to supplement or clarify what they had been told by a healthcare professional about their treatment or symptoms. This was deemed necessary, either because they had not absorbed what they had been told, or because it was not explained clearly enough. One person with cancer said that she sought additional information because she was not able to absorb the information that she had been given:

***'I just think the way doctors speak, you don't understand, you don't take it in, especially when it's something like that, it's like your mind's a sieve, you're only taking bits and other bits are just falling through, and it's probably the main bits.'***

*(P26, gynaecological cancer, interview 1, patient)*

Some people with cancer searched for information that would help them to relieve and manage symptoms. One person with cancer used internet chat rooms because she found other patient's experiences instructive:

***'Basic information, chronic constipation, "What do I take I've taken everything else?" They'll tell you what to take, you know? Em you've got skin rashes, they tell you what works for them, you know, they're not prescribing, they'll say, "This worked for me". They don't say***

*“go take,” because they cannot. You know they’ll get told off for the - you know, so it, yeah, it’s pretty good.’*

*(P21, breast cancer, interview 2, patient)*

Half a dozen people with cancer sought information about complementary therapies, including information about diet, faith healing, and the use of mistletoe. Whether or not this was because they had not received information about complementary therapies from healthcare professionals is not clear from this study. What is clear however, is that people sought out information about complementary therapies from other sources.

One person with cancer said that she sought extra information because she believed that healthcare professionals downplayed how bad things were because they wanted patients to remain positive. She said that they ‘kind of dress it down so as not to scare you.’ This strategy was not appropriate for her because she was the type of person that needed to be presented with an honest and accurate picture and that, if required, she would develop her own coping strategies to handle a negative situation. She said:

*‘I don’t like sugar coating, just tell me and I’ll make sense of it. And I’ll make my own sugar coating when I need one.’*

*(P21, breast cancer, interview 1, patient)*

### **12.3 Reasons for not seeking information**

Not all people affected by cancer sought additional information to that provided by healthcare professionals. Several reasons were given for not seeking additional information including: being satisfied with the information provided by healthcare professionals; seeing no usefulness in finding additional information; believing that any information found would make them scared, frightened or depressed; perceiving that it would amount to a breach of trust between themselves and healthcare staff; and that it would detract from ‘getting on with life’. As voice box 26 shows, some healthcare professionals recognised variation in information requirements between people with cancer and attempted to accommodate this.



**Voice box 26:** CNS's acknowledged that some people with cancer did not want a lot of information:

*'She was one of the patients that didn't particularly want to know an awful lot, you know, she was happy with the broad terms and made it quite clear, if I remember rightly, at the beginning, that she wanted the basics. And that's something that we try to address with most patients when we see them, you know, how much do they want to know?'*

*HP52, Clinical Nurse Specialist*

*'She was given a lot of leaflets to read through and I said to her, "Its really up to you if you need them or not." Some people just don't want to know, but she's certainly been given all the leaflets and there's plenty of ways that she can get hold of information if she requires it, you know, there's plenty of web site, recommended web sites at the back of leaflets.'*

*HP12, Clinical Nurse Specialist*

Several people with cancer said that they did not seek additional information because they were satisfied that they had been given sufficient information from healthcare professionals. One person with cancer said that there was nothing that she felt that she needed to know that had not already been told her (P23, lung cancer, interview 1, patient). Another relied on healthcare professionals for information because that found on web sites was of dubious quality (P18, prostate cancer, interview 2, patient and partner/carer).

A couple of people with cancer could not see what purpose seeking alternative information would serve. A person with cancer said:

*'What good is it going to do me? To find out more, what good is it going to do me? If the hospital cannot do it, they cannot do it. I don't see the point in reading up on it. I'm not going to be able to help. I'm in the hospital's hands as far as I'm concerned.'*

*(P56, lung cancer, interview 1, patient and partner/carer)*

One person with cancer chose not to seek information because she was concerned that finding out more about what would happen to her would put her off having treatment (P6, colorectal cancer, interview 1, patient).

Several people with cancer indicated that finding information would make them scared and frightened. A wife of a man with cancer who had surfed the Internet to find out about surgery wished that she had not done so. She said that too much information was a bad thing for her because it made her worry (P17, colorectal cancer, interview 1, patient and partner/carer). One person with cancer said that she was too frightened to read about what could happen to her and so chose to avoid seeking information (P25, gynaecological cancer, interview 3, patient). A couple of people with cancer, who acknowledged that they were 'typical worriers', did not seek information because it would only make them think that they had the symptoms that they were reading about.

Alongside becoming scared and frightened as a consequence of finding information, was becoming depressed. One person with cancer, for instance, deliberately did not seek information from web sites because other people with cancer had warned her that it would make for depressing reading (P61, breast cancer, interview 2, patient).

A couple of people with cancer perceived that seeking information about different treatments would represent a breach of trust between the consultant and themselves. One person with cancer said:

*'I don't see the point in looking for alternatives, because if you did, it means that you are not happy or believing what the people that you are consulting are saying. If you're looking for something else, an alternative, it means you're believing these other people and you might, if you do try something else. I've a feeling that you're letting them down, you know, and it might be doing you more harm than good.'*

*(P18, prostate cancer, interview 1, patient and partner/carer)*

Finally, a few people with cancer did not seek information because they wanted to forget about cancer and wanted to keep life as 'normal' as possible.

## 12.4 Sources of information

People sought information from both the Internet and from books. Approximately half of all people with cancer had accessed information from web sites. People with cancer either surfed the Internet themselves or partner/carers, including spouses, children and grandchildren, accessed web sites and then relayed the information that they had found to their relative with cancer. The Internet was, therefore, a significant source of additional and alternative information. One person with cancer encapsulated the Internet's utility by laughingly referring to, 'google, the consultant'. Despite the advent of the Internet becoming increasingly significant, only six of the people in our study had been advised by healthcare professionals about which sites were particularly useful.

Only a handful of people with cancer read books, for example, an autobiography by a cancer survivor that they had either bought themselves or had borrowed from the library.

Around a third of people with cancer referred to news items, stories in soap operas or television programmes. Several acknowledged that they were now more aware of, and receptive to, this type of information following their own diagnosis of cancer. People referred to stories about celebrities who were affected by cancer and information about new drug therapies and treatments.

## 12.5 Usefulness of information accessed from the Internet

Given that approximately half of all people with cancer in the study had read information downloaded from web sites, we report here their perceptions of the usefulness of this information.

Some people with cancer found that the information was too detailed for people without medical knowledge. One person with cancer found the information about his surgical operation so detailed that he suspected that it was for medical students intending to carry out the operation (P2, colorectal cancer, interview 2, patient). Another person with cancer discovered that there were so many chemotherapy drugs listed on web sites that she felt that it was impossible for a lay person to decide which were the best or most appropriate (P4, prostate cancer, interview 1, patient and partner/carer).

Whilst some people affected by cancer found that the information off web sites tallied with what they had been told by healthcare professionals and with their own personal experience, others

were critical of the information found, because it did not resonate with their own experience. One person with cancer said she was finding that her recovery took much longer than the 6 weeks suggested on the web site she had accessed. With hindsight, she therefore wished that she had not searched for information (P5, breast cancer, interview 2, patient).

Several people with cancer found the most useful information was that provided by other people with cancer. One person with cancer, who found American web sites most useful, said:

***'You kind of relate better to, when it's somebody going through the same experience, and they're saying this is how my operation went and this is what happened to me.'***

*(P7, prostate cancer, interview 2, patient)*

In contrast, others found that the information was far too general and not relevant to their own personal circumstances or case. One partner/carer of a person with cancer said:

***'There's information galore if you look at it on web sites, all that kind of stuff but it's us, it's our case that we're interested in, not anybody else's and so there's a lack of information about our specific situation.'***

*(P12, breast cancer, interview 1, partner/carer)*

## 12.6 Impact of information

Additional information to that provided by healthcare professionals had either a positive or negative impact on people affected by cancer. Some people felt re-assured, whereas others became scared.

Some people affected by cancer gained re-assurance from the information that they found. This was because it gave them an indication of how well they were recovering and whether symptoms that they were experiencing were typical. One person with cancer was distraught after his operation because he was 'squirting' urine as opposed to only having a small leak. His wife searched the Internet to find out whether this was a common symptom and found other men's stories describing the same symptom. Having read these stories he realised that his post-operative symptoms were on par with other men who had undergone the same operation and was, therefore, re-assured (P7, prostate cancer, interview 2, partner/carer). One person with cancer said that the poems and jokes that were posted by other people with cancer on web sites

provided good 'moral support' (P21, breast cancer, interview 2, patient), and another found them 'inspirational' (P26, gynaecological cancer, interview 1, patient).

Some people with cancer on the other hand, far from finding re-assurance, became scared after reading information. A person with cancer who had read in a newspaper about a patient receiving too much radiation, became scared of having this type of treatment. However, she sought further information about radiotherapy via web sites, which subsequently put her mind at rest (P28, colorectal cancer, interview 2, patient and partner/carer). A wife of a person with cancer wished that she had not read about the surgical operation that her husband was to undergo because it frightened her (P17, colorectal cancer, interview 2, patient and partner/carer).

## 12.7 Strategies for managing the impact of information

Given some of the positive and negative consequences of accessing additional information and some of the reasons for and against seeking additional information, it is not surprising that some people affected by cancer adopted strategies to manage these contradictions.

Several people with cancer said that they waited until they felt mentally and emotionally 'strong' before they sought information. One person with cancer defined being strong as being 'positive' and able to 'cope' with her diagnosis (P5, breast cancer, interview 1, patient).

Another person who had sought information before her treatment said that afterwards she stopped because she needed 'time to step back and breathe and let it go for a wee while' (P5, breast cancer, interview 3, patient). These examples of strategies for managing emotion are discussed in more detail in Chapters 5 (Experiences of self care) and 8 (Experiences of emotion).

A couple of people with cancer moderated the amount of information that they sought. One person with cancer for instance, said that she did not wish to become 'flooded' with too much information (P53, breast cancer, interview 1, patient and partner/carer). A partner/carer described how their information seeking behaviour was aligned to the different stages that the person with cancer was going through. He said:

*'I've just been looking as much as I need to know at any one stage. I don't want to race ahead of myself. So I think there's a lot to take in as well. But, eh, no, I've kind of, the initial stage, the mastectomy and all that kind of thing, we read up about that and then we got through that stage and then we'll wait until we get the results before I start delving into it again.'*

*(P12, breast cancer, interview 1, patient)*

Others were careful about what type of information they searched for and deliberately avoided information that showed the negative impact of cancer. A person with cancer who had adopted this strategy said that the Internet was a good and bad tool because it did not discriminate between stories of people beating cancer and of those who had died and he wished to avoid the latter because it was 'doom and gloom' (P28, colorectal cancer, interview 2, patient and partner/carer). One person's husband advised her to stop reading information because she was getting upset. As a consequence, she decided to only seek information about complementary therapies (P42, gynaecological cancer, interview 2, patient).

A couple of people used the information that they read to enter into a discussion with healthcare professionals about their treatment. A person with cancer who was experiencing arthritic pain searched the Internet for side effects of Arimidex, which was the medication she had been prescribed. As a consequence of finding that arthritis is a side effect of this particular drug she decided to stop taking it, against the advice of her medical team. Instead, she planned to use complementary therapies and alter her diet (P10, breast cancer, interview 2, patient). Another person with cancer, after reading about different treatments for prostate cancer, on reflection, wondered if he had made the right treatment choice but chose, not to discuss it with healthcare professionals (P7, prostate cancer, interview 3, patient).

## 12.8 Conclusion

Seeking information can be conceptualised as a self care strategy, which is an important health policy agenda. Given some of the positive and negative consequences of accessing additional information, and some of the reasons for and against seeking additional information highlighted in this Chapter, it is not surprising that some people affected by cancer adopted strategies to manage these contradictions, including waiting until they felt mentally and emotionally 'strong' enough before they sought information, moderating the amount of information that they sought, deliberately avoiding information that showed the negative impact of cancer, and using the information that they had found to enter into a discussion with healthcare professionals. The challenge for healthcare professionals, therefore, is to individualise their information strategy to accommodate people's differing information needs, which seems an essential aspect of a culture of caring.

## Section 13: EXPERIENCES OF NURSING CARE

### 13.1 Key Findings

- » Having nurses with different titles and roles caused confusion for some people with cancer because they were not clear whom they should contact.
- » The experiences of people affected by cancer suggest that the role of the CNS is very wide ranging.
- » To most people affected by cancer, the very thought of their CNS being available, either in person or at the end of a phone, was very comforting, even if they did not need to make any call on them.
- » Most people with cancer said that having the CNS present during a diagnosis was useful, particularly in terms of the manner in which information was given.
- » Virtually all of the people who made any comment on their CNS did so positively.
- » Ward nurses who cared for people with cancer during surgery and chemotherapy were also perceived in a positive light, with only a handful receiving criticism.
- » Whilst attentiveness by ward nurses was welcomed, it could also arouse suspicion in some. Some people with cancer thought it signalled that they were to receive bad news or that they did not have long to live.
- » In the majority of cases, people with cancer were given contact details for their community nurse and advised to contact them as and when required, but having a member of the primary care team contact them in the first instance, was appreciated.
- » For some people with cancer the community nurses appeared to be totally unaware of their need for support.

This Chapter describes the experiences of nursing care that people affected by cancer had through their diagnosis and treatments. Included are experiences with clinical nurse specialists (CNS),

ward nurses and community nurses. Not included in this Chapter is any discussion of the role of nurses as sources of information, since this is reported in Chapter 11: Experiences of information provision.

## 13.2 Which nurse?

There appeared to be some confusion both on the part of people affected by cancer as to the type of nurse that the people affected by cancer had been in contact with. However, as voice box 27 shows, nurses had specific roles to play.

**Voice box 27:** A CNS explained the role of different nurses:

*'When patients go and have their chemotherapy, we kind of take a step back because the chemotherapy nurses take over because they see them more regularly, so we tend not to hear from patients and then it all sort of starts up again after that, we tend to sort of see them again... they build up a relationship with those nurses for that period of time we kind of take a step, because you know having too many people gets, you know, is just a bit intense so we sort of, I'll probably take a bit of a step back. I mean, obviously, if he phones and he's got queries, then we'll deal with it, but I would imagine what'll probably happen is that they have numbers for the chemotherapy units and they'll phone there.'*

*HP39, Clinical Nurse Specialist*

In a lot of cases, the label 'nurse' appeared to have been applied generically, describing all of the various types of nurse in the one term. There was slightly less confusion when a single key nurse, for example, the clinical nurse specialist, had been identified, but even here, the job title of this nurse had been unclear to a lot of people affected by cancer. Many called their clinical nurse specialist a Macmillan nurse while others had done the reverse. In some instances, it was not entirely clear from people's accounts which one is being referred to. As voice box 28 demonstrates, one of the reasons why official job titles were not used by nurses was because some were perceived as off-putting due to their association with end-of-life.



**Voice box 28:** One explanation for lack of clarity about the role of different nurses is because some were deliberately not referred to by their official job title because it could frighten people:

*'My post was initially funded by Macmillan and one of the doctors, I always remember, at clinic had said, "I'll get the Macmillan nurse to come and see you." And the woman just point blank refused. But I did catch up with her a few months down the line and she always remembered that day. And she said to me, "You know, it wasn't that I didn't want to see you", she says, "It was because he said Macmillan. She says, "That freaked me out." She says, "I couldn't handle that..." Now they just introduce me as the "lung sister."*

*HP63, Clinical Nurse Specialist*

This lack of clarity created problems for some people affected by cancer because they were not clear whom they could contact for information and support. For instance, one person with cancer was told during chemotherapy that there was a nurse that she could phone at any time and was under the impression that she could only contact this nurse about issues relating to chemotherapy. Only later did she discover that she was a support nurse who could also be contacted for other issues (P42, gynaecological cancer, interview 3, patient).

### 13.3 Clinical nurse specialists

Only a handful of people with cancer made no mention whatsoever of any involvement with a clinical nurse specialist (CNS). A couple of people acknowledged making very little use of their CNS, but in both cases, they had close relatives who were nurses, one a Macmillan nurse.

The experiences of people affected by cancer suggest that the role of the CNS was very wide ranging, from providing diagnosis and treatment information, assisting with benefit allowance claims, to being the preferred first point of contact when the person with cancer is at home. Nurses telephoned people with cancer, visited them if they were in hospital having a consultation or treatment, or visited them in their own homes (see voice box 29 for an example). As one

person with cancer remarked, the nurse, 'obviously keep tabs on everybody' (P55, breast cancer, interview 2, patient).

**Voice box 29:** A CNS explained when she contacted her patients:

*'I do it with all the patients. I'd phone them just after they've been to the oncology clinic. And then say to them if they haven't sort of heard their dates to come and let me know. Then phone them after their first lot of treatment, whether it's radiotherapy, chemotherapy, and then leave the door open for them that if they want to contact me I'm here...You'll get the patient who sort of phone all the time or their relatives and the ones that are quite happy to plod on.'*

*HP36, Clinical Nurse Specialist*

In the majority of cases, the CNS had provided their contact details and advised their patients that they were available at any time to answer questions or to assist with problems.

To many, the very thought of their CNS being available, either in person or at the end of a phone, was very comforting, even if they did not need to make any call on them:

*'And since I spoke to [CNS], well I could ask her anything I wanted and she answers, answers sensibly.'*

*(P52, lung cancer, interview 1, patient and partner/carer)*

*'Anything that I was ever worried about I phoned up [the CNS] and rather than wait for anything, she had me within a clinic within two or three days.'*

*(P24, lung cancer, interview 3, patient and partner/carer)*

*'I'm fine as long as I know she's there I'm quite happy.'*

*(C63, lung cancer, interview 2, patient and partner/carer)*

Having the CNS as their main point of contact was highly regarded by most people:

*'But I've used the CNS a lot and that named contact who knows your case is, as I said, it's the single biggest most useful thing.'*

*(P7, prostate cancer, interview 2, patient)*

*P31: 'When CNS has to phone up, because the blood's not been right, or to change something, it's always the CNS. Which is, is quite good to have a link person.'*

*C31: 'She is, she is a good contact'*

*(P31, gynaecological cancer, interview 2, patient and partner/carer)*

**Voice box 30:** Role of CNS at diagnosis

*'I went in with the Consultant and he told her [the diagnosis]. I was just there, I sat through all that he told her and then he left the room and then I went on and spoke to P12. I got details, I got all her personal details, her home phone number, and then I arranged for her to come back into have some tests, to have the staging tests that they have done and I gave her my details, my contact details to phone me, and that was it.'*

*HP12, Clinical Nurse Specialist*

*'Usually what happens is, we tend to sit in with them if we can, we try and sit in so that then we know exactly what's been said and basically re-iterate it, if we haven't sat in, what we do is we see them after they've been seen by the oncologist and go over, say you know what they've said, we speak to the oncologist, you know, "What's the plan?" and we go through it again and we go through the side effects and things, we give them information, written information about the drugs, em, and we go away and, you know we say, you know, phone if you have any questions.'*

*HP39, Clinical Nurse Specialist*

However, one or two people preferred to discuss their problems with someone more local to them. This was particularly so for people living a distance from their cancer hospital and in these instances, a Macmillan drop-in centre or nurse was contacted instead.

In the vast majority of cases, the CNS was present throughout all or some of the first consultation discussions where a diagnosis of cancer was given (see voice box 30 for a description of an account by a couple of clinical nurse specialists of their role during diagnosis). One person thought that having both the consultant and nurse present at this first meeting was 'overkill'; however, most people with cancer said that having the CNS present was useful, particularly in terms of the manner in which information was given. This was because to some, the information provided by consultants was 'gobbledegook' and many CNS's were praised for speaking in an understandable layperson's language:

***'It was like she [the CNS] looked at the person with cancer, and he [the doctor] looked at the cancer within a person.'***

*(P70, breast cancer, interview 1, patient)*

***'Because the information that [CNS] gave us was 10 times more for our point of view.'***

*(P28, colorectal cancer, interview 1, patient and partner/carer)*

Not everyone, however, said that the language used by the CNS was understandable, although they were in a minority:

***'The breast care nurses are quite good, but I think they maybe forget that if you don't have a medical background they think that they've told you something, explained something to you that you, you're still coming away with, ah, but I didn't quite get that or, what did they mean by that, and then you've got to go, you know, the next time you're maybe bringing it up again, where they are thinking, well it's done and dusted, cause that's already been discussed, but I, I think they forget if you don't have a medical background it is very difficult.'***

*(P5, breast cancer, interview 2, patient)*

A couple of people had never previously spent any time in hospital and the thought of doing so left them worried. As voice box 31 shows, this prompted the CNS to invite a woman with breast cancer to the ward for a visit in an effort to alleviate their concerns and this was well received in both cases. The CNS was also on the ward when she arrived as an inpatient:

**Voice box 31:** A CNS invited a woman with cancer to visit the ward to alleviate worry.

*'The main worry for her was never having been in hospital before and being a bit worried about the hospital and all that kind of thing, so what I suggested was that she come up to see the ward and to see the hospital so that she could imagine where she was coming into and it wasn't going to be too dramatic, 'cause it's not, you know, it's quite a nice wee unit.'*

*HP61, Clinical Nurse Specialist*

*'I said "I've never been in hospital before," but really, they made it so simple, honestly. You wouldn't believe it, and then CNS came in and she was chatting to us and everybody was laughing and chatting.'*

*(P61, breast cancer, interview 1, patient and partner/carer)*

Many people affected by cancer used their CNS to assist them in filling in claim forms for sickness benefits and allowances and to help them get disabled parking badges. Several also mention getting help from their CNS in organising funding for items such as new showers and advising on who they should speak to about funeral arrangements. Such advice and help was very highly regarded (see Chapter 16: Experiences of finance, for more detail).

Virtually all of the people who made any comment on their CNS did so positively with comments such as 'lovely', 'very helpful', 'brilliant', 'could not do enough', 'thoughtful', 'sensitive' and 'very approachable'. This approachability was highlighted by a partner/carer who said that her mother talked to her CNS more than she did to her family:

*'And I think that says a lot for the type of person, or the role that she plays, that you've told her [CNS] things that you haven't told your family as well, because she was so understanding.'*

*(C52, lung cancer, interview 1, patient)*

A man with prostate cancer was delighted that his CNS found time to telephone him with his latest PSA score before he went on holiday:

*'Took my blood test one day, and she phoned me up the next morning to give me my results before I went on holiday just because the count came right down. She phoned me up just to let me know that before I went on holiday. And I thought that was a great touch, you know?'*

*(P4, prostate cancer, interview 3, patient and partner/carer)*

He said that this was the type of 'personal touch' that he and his wife really appreciated (P4, prostate cancer, interview 2, patient and partner/carer).

There were some negative comments. A partner/carer of a woman with breast cancer thought her hospital 'shambolic on the organisation and nurses side' (P12) and a similarly negative view about her CNS was aired by P12 in a later interview:

*'If there was something going wrong I don't feel my GP and my breast care nurse will pick it up. You know, because I don't have confidence in them to be proactive enough to sort something out.'*

*(P12, breast cancer, interview 3, patient)*

Three people experienced a change of CNS at some point during their treatment and in each case this caused problems, certainly in terms of missing out on information, loss of continuity and having to develop a relationship with their new CNS.

## 13.4 Ward nurses

Half of the people with cancer in our study referred to ward nurses who provided care during surgery or gave chemotherapy. Almost all commented positively, using descriptions such as 'brilliant', 'happy', 'cheerful', 'exceptional', 'great' and 'lovely' to describe the nurses and the care that they provided:

*'I'm impressed by the quality of nursing, it is very good...the care taken, you know doing things like changing dressings, which they can be quite brutal and it did involve time, but they were quite careful.'*

*(P7, prostate cancer, interview 2, patient)*

*'They are really good, I couldn't fault them on anything at all, that time I really felt ill, I had to be at the doctor on Monday and by the Wednesday I was worse. So I phoned up [hospital ward], and it was one of the nurses who was there when I was there and she was really, really good, she told me exactly what to get. So when [daughter] come over she went to the doctor and got them, a few days and I was feeling much better.'*

*(P52, lung cancer, interview 2, patient and partner/carer)*

*'But again, I must congratulate the nurses. The nursing staff is top class, top class, they are really, and I've got nothing but the highest praise for these people.'*

*(P46, lung cancer, interview 2, patient)*

However, there were one or two negative comments. One nurse was described as 'a bit nippy', while other negative comments concerned a lack of communication while at radiotherapy simulation and the variable ability in performing injections:

*'...some of the nurses know how to wield a needle and some of them definitely don't. I had one occasion where I, it was like I was being used like a pin-cushion, because they couldn't get the, they couldn't put it in right, you know, the nurse couldn't do it, I had it in there [indicates where the needle was put in], I had it in there, and eventually she went away and got another nurse who came in and pooof! Away in it went.'*

*(P2, colorectal cancer, interview 2, patient)*

*'In fact, at one point they all went, they all went away in to the room and I just suddenly thought, God it's gone awful quiet, and I was just lying there exposed on a, a thing and I, and I moved my head and they all come running back in. "We told you not to move, we told you not to move!" ... and I was like, "But yous all went away and left me," and she says, "Well, we found that if we tell people that, that we're going, then they're more likely to move," and I was just like, so I wish I said to her, "And can you give me a reference for that please? Because I've never heard it." Everything that I mean, we do communication skills all the time through nursing.... explain what you're doing.'*

*(P70, breast cancer, interview 2, patient [former nurse])*

Two people commented that their nurse did nothing when they said they were in pain. One woman with gynaecological cancer was in severe pain a week after surgery but her nurse did not believe this was possible so long after surgery. A man with prostate cancer had his nurse tell him

he had to be in real pain before she would administer any pain control. In both instances a doctor intervened and issued painkillers.

A sizeable number of people with cancer mentioned asking their nurses lots of questions on their cancer as discussed in Chapter 11: Experiences of information provision. Several people acknowledged that they knew the nurses were aware of how anxious they were. One person with cancer found it very beneficial to have a 'wee chat' with a nurse. This wee chat actually lasted for an hour. Some other people with cancer were of a similar opinion:

***'Once ma wife and that went away I was really upset and an auxiliary nurse on the ward came in and spent ½ an hour with me, eh, and kind of calmed me down, really, really well, God, I mean, I can never thank that woman enough for, for coming in just having a chat.'***

*(P28, colorectal cancer, interview 1, patient and partner/carer)*

***'I got the chance in hospital, the second time I went back with the infection, of having a ward all to myself. There was nobody else in it for some reason, again probably understaffed and overworked. And that was the one time I managed to burst into tears and get it out of my system. Er, one little nurse passing, did notice I was balling my eyes out and kept chundering in to help.'***

*(P40, gynaecological cancer, interview 1, patient and partner/carer)*

Several also stated that the nurses tried to make their time in the wards fun, with one nurse in particular praised for singing and dancing as she attended patients. In a reversal of roles, a man with colorectal cancer found himself consoling a nurse who was upset when one of her patients died.

Whilst the attentiveness of nurses was generally regarded very highly, a couple of people found it overbearing and it made them suspicious. One in particular, thought that the close attention he was getting made him wonder if he had 'got to that stage yet' of not being capable of looking after himself. Similarly, two other people thought that the attention they were getting was the precursor to bad news:

***'There was quite a few nurses around and they were all exceptionally nice, which in a way, you think, oh my goodness, what's going to happen, because they are actually, you know,***



*falling over their feet to be nice to you, so you know that something's, somebody's going to tell you something you don't want to hear.'*

*(C27, breast cancer, interview 1, patient and partner/carer)*

*'I knew fine when I, when I saw, it was the nurse who was just attending to me immediately after, I knew fine by the look on her face, I just knew there was something wrong.'*

*(P38, colorectal cancer, interview 2, patient and partner/carer)*

In contrast, a complete lack of attention was shown to one woman with breast cancer who found that she did not have anyone welcoming her when she arrived at the ward and she was given no dressings or painkillers. This woman had reacted badly to the surgery anaesthetic and had vomited causing a split in her wound:

*'They [the nurses] just didn't seem to react to that and get it fixed up for me you know, and I did get an infection in it.'*

*(P53, breast cancer, interview 2, patient and partner/carer)*

## 13.5 Community nurses

Almost half of the people with cancer acknowledged some contact with community nurses. Virtually all of those that had contact welcomed their input, but two people felt the opposite. Both were males with lung cancer. For example, one was concerned that having nurses come to the house would imply that he was not coping and he did not wish to give this impression.

Overall, the community nurses made home visits requiring some form of medical intervention to around a third of the people with cancer. By far the most common reason for visiting was to check post-operative wound dressings or remove stitches. Other reasons included blood sampling prior to chemotherapy, injections, enemas, general check-ups, and in one case, a check on the condition of a re-inflated collapsed lung. In one instance, the community nurses visiting a man with colorectal cancer had little experience of his severe post radiotherapy skin reaction and at the next visit, had a burns unit nurse with them.

In the majority of cases, people with cancer were given contact details for their community nurse and advised to contact them as and when required. However, as voice box 32 shows, people with cancer appreciated being contacted in the first instance. To many, the very act of the community

nurse getting in touch with them first, soon after their discharge from hospital, was very much appreciated, even if follow up visits were not required:

**Voice box 32:** Contacting the person with cancer was perceived as good practice:

*'I think what happens with some GP practices is the District [Community] Nurse or the GP will phone just to say "Look, I'm here. You know this is my number. You know I'm not going to keep phoning you, but please phone me if you need me." And I think that's good practice.'*

*HP5, Clinical Nurse Specialist*

*'Even when I came home straight away I had the District Nurse on to me, courtesy call, if I need anything she was quite willing to come out.'*

*(P6, colorectal cancer, interview 1, patient)*

*'I thought that was very good of the [community] nursing staff because there is a follow up care there with this side of things. It wasn't just, "Give us a ring."'*

*(P3, colorectal cancer, interview 3, patient)*

Equally, there were around a half dozen people for whom the community nurses appeared to be totally unaware of their need for support. It was only when they had contacted their GP, in most cases due to problems with wound recovery, that community nurses became aware of their situation and visits were triggered. In one of these instances, a woman with breast cancer, who did not drive, had to be driven to the local clinic by a friend so that problems with her wound could be addressed. Subsequently, the nurse visited her at home. In another case, a man with a catheter fitted had expected a visit from a nurse but did not get one until he telephoned his GP. One woman with a gynaecological cancer made attempts to reduce the need for community nurses to visit her as she lived a long distance from her GP surgery. She was happy to change her dressing herself but had not been told how to get more when she had used up the supply left by the community nurse:

*'Nobody had told me that I could have phoned up the community nurses and got them on prescription, because they proved quite expensive [C40 had bought them]. The next time they phoned I said I was not impressed at them having left me so few dressings. I'm trying to save you coming out here. And ever since then they have been assiduously phoning me up to make sure I'm alright.'*

*(P40, gynaecological cancer, interview 1, patient and partner/carer)*

A couple of people expressed surprise that they did not have any contact from a community nurse at any time after their discharge from hospital. One of these acknowledged that he had been in hospital so long that his wound clips had been removed so perhaps he did not really need the contact. However, he would have appreciated a short visit:

*'I know they're very busy people, but I feel they could have taken 5 minutes just to pick a phone up, or, they're passing the door, you know, they could have just popped into see how I was, and, 'cause it was a big thing being told that you had cancer but, and then, as I say, they've never bothered since I've come home.'*

*(P13, colorectal cancer, interview 2, patient)*

## 13.6 Conclusion

The role of cancer nurse specialists is recognised in some, but not all, SIGN (2005) guidelines. This Chapter illuminates what constitutes a good culture of caring provided by nurses. This includes being available to address questions and concerns that people affected by cancer have, and listening to their needs and wishes. It also involves responding appropriately so that people's physical, emotional or financial needs are met. The Chapter exposes gaps in the provision of care between tertiary and primary care, suggesting that partnership and joint working is lacking.

## Section 14: EXPERIENCES WITH GPs

### 14.1 Key Findings

- » The majority of people with cancer who commented on their experiences of GPs described their GPs as 'very supportive' and 'excellent'.
- » However, certain areas of GP care were regularly highlighted by those who referred to problems with their GP as being problematic; these were: a perceived delay of GP referral for diagnostic tests; failure to keep in touch during the first year following the diagnosis: plus the omnipresent perception that GPs were very busy.
- » Some people with cancer perceived not being able to see the same GP as a problem since it meant that they had to continuously explain and repeat their experiences.
- » Some people with cancer did not like having to wait for an appointment with a GP.
- » While some people perceived the GP as pivotal in cancer care, others viewed the GP's role as peripheral.
- » There was confusion relating to which healthcare professionals were responsible for symptom management during treatment. Some people with cancer went to their GP and were not advised to do otherwise, while others were specifically directed to the hospital by their consultant or CNS with any concerns that may arise.
- » When contacting a GP about cancer or treatment related symptoms, it was found that some GPs were unable to provide answers to the questions posed due to lack of specialist knowledge.
- » Mishaps in communication, mixed messages and lack of "joined up thinking" between hospitals and GPs was a key issue that often left both people with cancer, and healthcare professionals alike, confused.
- » The above three points highlight that partnership working and the interface between primary and tertiary care is weak, resulting in difficulties for people with cancer. These are obstacles needing addressed in policy directives for a more community-based cancer care.

Primary Care incorporates services provided by GPs and community nurses. The role and involvement of community nurses in the care of those with cancer is detailed in Chapter 13: Experiences of Nursing Care. This Chapter describes the experiences individuals affected by cancer had with their GPs.

## 14.2 The role of GP

**Voice box 33:** Examples of quick referral:

*'Well I hadn't seen her before diagnosis, she came as an emergency to one of my appointments because she was in a lot of pain and she had an obvious swelling and I admitted her from the surgery to the gynaecology and emergency that day.'*

*HP25, GP*

*'Now you've always got to be careful of the cry wolf scenario [...] you might have a good three or four people a day coming in saying they're just not right but somebody like [P6], I think there's a factor with her she wasn't, she didn't have a big set of notes, wasn't normally one to come in with minor symptoms. The fact that she was of a certain age and she was also a smoker you think first of all well, you could exclude pathology first before you can get back to other things that make it vaguely not right.'*

*HP6, GP*

When asked in the final interview what the best and worst aspects of the care they had received over the past year and what could be improved, some of those interviewed stated their GP. The majority of those who commented on their experiences of GPs described their GPs as 'very supportive' and 'excellent'. What's more, some people with cancer experienced a quick referral from their GP (see voice box 33 for examples) and remained in contact with their GP by phone, and had regular appointments with them throughout their cancer treatment.

However, certain areas of GP care were highlighted by some people with cancer as problematic; these were: a perceived delay of GP referral for diagnostic tests; failure to keep in touch during

the first year following the diagnosis; plus the omnipresent perception that GPs were very busy, sometimes to the detriment of patient care. It is worthwhile noting that a number of people with cancer appeared reluctant to express dissatisfaction with their GP, and it was often partners/ carers or friends that encouraged statements of dissatisfaction to the researcher.

### 14.3 Speed of GP referral

Many of the symptoms of cancer are not unique to the disease, resulting in repeat visits to GP prior to being referred for diagnostic tests and screening. The symptoms relating to bowel and lung cancer appeared to cause perceived delays in referrals. Often referrals were delayed for a number of months, and in a minority of cases, even years. This issue is also covered in Chapter 3: Experiences leading up to a diagnosis of cancer. Retrospective reactions from people with cancer to this delay varied - some were philosophical, others disappointed about it:

**C1: 'The only thing I am sad about is it took a long time before it was realised what [P1]'s problem was. The GPs originally thought it was prostate trouble.'**

**P1: 'Which is the usual.'**

**C1: 'It took a number of months before...I'm not saying it made any difference.'**

*(P1, colorectal cancer, interview 3, joint interview)*

Others felt more aggrieved as they perceived that they had been misdiagnosed because their GP had failed to take their concerns seriously. One such couple, where the symptoms of colorectal cancer had been initially diagnosed as haemorrhoids, appreciated that their GP had been 'pretty cut up about it', and had apologised for his failure to make the referral at an earlier stage:

**'I must admit I was angry at his doctor not picking it up. But he apologised and they did say that it can be something that can't be picked up if you're prone to haemorrhoids anyway, but the fact that they bled so long should have alerted them to something. They've caught it and that's the main thing. [...] I mean doctors are not infallible; they're human beings like ourselves. I mean, people like to put them on pedestals and think that's where there - it's an operation, and they take off the wrong leg, that it is not, but doctors are trying to do the best that they can for you and the majority of them, you'll get one or two bad ones in the bunch, you know, but I mean apart from that [...] His doctor has actually apologised and when we**

***told it to someone else he says he has never heard of a doctor apologising. So I would say that put him up in my estimation, rather than the opposite.'***

*(C39, colorectal cancer, interview 2, joint interview)*

Another woman thought all of the indicators were present for her GP to arrange for further tests:

***'I'm probably more annoyed that, considering I had been to the doctors so many times, that none of them had sent me for a chest x-ray before, they could, it should have been noticed a long time ago, and I hadn't had an x-ray for over five years. I'm a heavy smoker and when I had this fatigue and lack of breath they should have sent me for a, so I feel very strongly that they were slightly, slightly negligent but there's nothing you can do about it today.'***

*(P48, lung cancer, interview 1, patient)*

Quick referrals for screening and/or diagnostic tests were greatly appreciated:

***'I even thanked [GP] actually, because the speed of getting things organised and getting the appointments and that [GP] has been very good.'***

*(P30, lung cancer, interview 1, patient)*

Some individuals with cancer also credited their GP with discovering their cancer and were very grateful to them:

***'Actually, if it wasn't for her I don't know what would have happened. [...] She spotted it.'***

*(P25, gynaecological cancer, Interview 1, patient)*

***'I hadn't had a smear for 10 years and she noticed that.'***

*(P26, gynaecological cancer, Interview 1, patient)*

***'He arranged it [the test] for me, or I would have been sitting here today none the wiser. Because it would give me no pain. There was no pain with it.'***

*(P33, colorectal cancer, Interview 1, patient)*

## 14.4 Keeping in touch

**Voice box 34:** Variable levels of support offered by GP's:

*'The day that P5 was diagnosed we put a letter out to the GP that day. We fax a letter to the GP saying that [P5] has been diagnosed with breast cancer. Really, that's all we say in the letter. All I have to say, some GPs are wonderful and that afternoon they'll phone the lady. Others have no contact with the lady whatsoever, so it really depends on the GP. We also, a copy of that letter goes to the District Nurse, so it's then up to the District Nurse whether they want to make contact with them or not.'*

*HP5, Clinical Nurse Specialist,*

A healthcare professional describes the importance of follow-up and aftercare:

*'I think this is actually where things are variable between one GP and the other. I am concerned about patients enough to follow them up and to phone up and say "How did it go? What happened when you went to see the consultant?" and whatever, and I did make contact with.' [P2]*

*HP2, GP*

GPs that initiated and maintained contact following a cancer diagnosis were praised for their support, however, as voice box 34 demonstrates, this was variable between one GP and another. One woman with breast cancer described the role of her GP as superb:

*'So again, he said "If there's anything else", come back to see him as soon as...every time go round and see him, he always says that to me, he asks me how I am and everything, oh yeah, he really has been superb.'*

*(P9, breast cancer, Interview 2, patient)*

Most people with cancer received a phone call from their GP, or in some cases, the community nurse, soon after their cancer was diagnosed or post surgery, which was always appreciated:



*'And [GP] said "I've just had a fax about you from [hospital]"; and I went, "oh, gosh"; and she said "I just wanted to phone you up to say I'm here if ever you want to come in and talk to me" and she said also, "The other doctors, we'll all know about you"; and I thought - gosh, fame at last, y'know, everyone knows about me! I thought it was extremely nice of her to phone up, it really was, to pick up the phone at half past six at night.'*

*(P10, breast cancer, interview 2, patient)*

Often the phone call included the promise of regular contact, which sometimes never occurred, leading to disappointment:

*'He did say to me right from the outset, "We'll keep in touch, you can come and see me, and then we'll have a telephone call in between," [...] but he's never got in touch or anything, and when I did actually make an appointment he decided to phone [...] and I got the impression he was in a terrible rush, I told him what I wanted and he said he'd get that ready for me, but he didn't ask how I was, not once, just a quick rush, "That's fine, I'll get that for you"; bang down the phone went. I thought well, that's contrary to what he was saying earlier on.'*

*(P19, prostate cancer, interview 3, patient & partner/carer)*

Failure to receive a telephone call from their GP also resulted in disappointment and feelings of neglect: 'obviously you're just a reference number' (P29, colorectal cancer, interview 2, patient & partner/carer). One woman explained how she 'never even got a phone call to ask if I was alright or if I needed anything' for several weeks before and after her operation and thought this was indicative of a lack of care:

*'I know they're busy people, but I feel they could have taken five minutes just to pick a phone up, or, they're passing the door, you know, they could have just popped in to see how I was, and, cause it was a big thing being told that you have cancer but, then as I said, they've never bothered since I've come home.'*

*(P13, colorectal cancer, interview 2, patient)*

This also illustrates a common perception by some people with cancer about GPs, which was that they were 'very busy people'.

## 14.5 Busy GPs

Accounts of GPs' heavy workloads were ubiquitous in all of the interviews. It should, however, be noted that these acknowledgements of the GPs' workload were not necessarily critical. Many recognised GPs could be quick but effective. While stressing they 'can't fault him', one couple laughed at the speed of which their GP worked:

*'His ten-minute consultations are ten minutes and he moves through the Health Centre complex...he should really be on a skateboard. It would save his legs [laughs]. He goes like mad.'*

*(P40, gynaecological cancer, interview 1, patient & partner/carer)*

One couple described their GP's approach:

*'Never, never rush you [...] he goes over anything, he checks up on his screen what's been happening and checks what...and again, he asks us if there's anything you want to ask about.'*

*(P18, prostate cancer, interview 1, patient & partner/carer)*

They recognised that a consequence of this approach was that other people had to spend longer in the waiting room.

There was also an awareness of GPs' many commitments and a wish not to become 'a nuisance'. One individual accepted his GP's attempts of managing their workload by keeping in touch via the telephone as opposed to face-to-face consultations:

*'He teaches at the medical school and he's the local medical officer of health as well. So he's quite tied up. But he said he would look at arranging...you know, meetings and then alternate meetings on the phone.'*

*(P19, prostate cancer, interview 1, patient)*

It was found by some people with cancer that it was rare to see the same GP at each appointment with locum GPs regularly mentioned in the accounts of GP care. One person with cancer said that this made her feel like 'just a name':

***'And the GPs, they're so busy that I'm just a name. As a matter of fact, I think I've never had the doctor I signed on with, when I first moved into this area here, I've never had her since! And that was 14 years ago. I've always had different doctors.'***

*(P46, lung cancer, interview 3, patient)*

Seeing a different GP at every appointment was a particular cause for concern for some people with cancer, as illustrated by one woman and her daughter who thought:

***'The only thing that would make a great difference to you, if you could just get to see one doctor rather than seeing a whole load of doctors.'***

*(C6, bowel cancer, interview 3, patient & partner/carer)*

They regarded having to explain their diagnosis and treatment to a new GP each time, who may not have read the patient notes, was 'really bad' and 'appalling'. Holding on for an appointment with 'her own' GP could have taken three or four weeks, which was not felt to be appropriate, as she felt she could only 'be ill by appointment' (P6, colorectal cancer, interview 3, patient & partner/carer).

Waiting for appointments undoubtedly caused anger:

***'I says "I'm no' waiting till next week". I say, "I never come to you" and I say, "I phone up for an appointment and I've got to wait for a week, forget about it, dear. Just put the doctor on."***

*(P39, colorectal cancer, interview 2, patient & partner/carer)*

GPs occasionally instructed people with cancer to inform the receptionist they 'were one of her cancer patients' to allow prioritisation. While this was appreciated, an individual who had noticed a change for the better in her GP's availability and general demeanour following the diagnosis commented:

***'He's been really nice, it's terrible that you have to had cancer before they seem to have any time for you, but he really is nice.'***

*(P52, lung cancer, interview 2, patient & partner/carer)*

## 14.6 The GP role: pivotal or peripheral?

GPs occupied a central position in supportive care for many people with cancer prior to, and post diagnosis, and this often proved to be a very positive experience. For some individuals with cancer, the GP was also the first port of call if they had queries about treatment or symptoms:

*P25: If I ever need to ask any questions, [GP]'s always there.'*

*Interviewer: 'And would you ask her about your cancer or would you rather ask someone like [consultant]?'*

*P25: 'No, probably ask [GP] I think, I mean [consultant], I'm sure he knows his job, but I suppose I know [GP] better, I feel more comfortable with her [...] I don't need anyone else, to be quite honest.'*

*(P25, gynaecological cancer, interview 3, patient)*

*'I'm on HRT because of the treatment and even that, when I went round and asked the Doctor for the HRT, he went and got as much information as he could for me again, so every question I've had along the lines all I have to do is contact my doctor and medical services and they'll do their best to find out the information for me.'*

*(P9, breast cancer, interview 2, patient)*

While some people perceived the GP as pivotal in cancer care and 'would go into the system, through [GP]' (P31, gynaecological cancer, Interview 3, patient & partner/carer) and take their GP's advice about treatment options over their consultant's, others viewed the GP's role as peripheral, for example 'because GPs just tend to kind of rubber stamp what the consultants say.' (P27, breast cancer, interview 3, patient)

There was confusion relating to which healthcare professionals were responsible for symptom management during treatment: 'you don't quite know who's in charge, is it the GP or is it the consultant?' (P32, colorectal cancer, interview 2, patient & partner/carer). As voice box 35 suggests, communication between primary care and cancer centres did not always take place, which may have made it difficult for patients. This finding is discussed further in the section 'Miscommunication between the hospital and the GP' below.

Some people with cancer went 'straight to the GP' and were not advised to do otherwise, while others were specifically directed to the hospital by their consultant or CNS with any

concerns that may arise. Even if directed to contact the hospital, a few people with cancer stated their preference to contacting their GP in the first instance, as they were 'more accessible':

***'Well, in the first instance I would go to [GP], although [consultant] did say if I had any problems which I think is related to the cancer contact them, go directly to them.'***

*(P1, colorectal cancer, interview 2, joint, patient & partner/carer)*

Mixed messages regarding contacts resulted in some confusion and irritation for one individual who had contacted the hospital regarding a chest pain and was 'a wee bit surprised because they told me to phone my own doctor' (P46, lung cancer, interview 2, patient). He was then referred to the hospital following side-effects from the medication prescribed by a locum GP and said his consultant, 'was not amused that the hospital had told me to phone my own doctor', but he added 'that's between them and her.'

When contacting a GP about cancer or treatment related symptoms, it was found that some GPs were unable to provide answers to the questions posed due to lack of specialist knowledge:

***'I had went to see him on the initial stages of the right hand side becoming very red and sore and I was very worried, and when I went into the GP he had said I really needed to see the Consultant Surgeon at the hospital because he was very, very limited in his knowledge about this type of surgery.'***

*(P5, breast cancer, interview 3, patient)*

***'[GP] admitted that, you know, "This is not my area of expertise, you really need to go back and see, you know, the surgeon and discuss at the hospital."***

*(P5, breast cancer, interview 2, patient)*

***'He's a bit inexperienced with oncology, with the drugs and things, because when you go for a prescription when you had your infection, he doesn't know and he was scared just with the contrary medications and mixing them, I suppose, and there was a big list and you could see his face but he quite admitted that.'***

*(C52, lung cancer, interview 2, patient & partner/carer)*

*'I couldn't recognise my lower parts [...] so I went to the GP. The GP was rather, was not my usual GP, and the poor wee soul, she was, I suppose, learning the trade, and she sent me back to the hospital.'*

*(P64, prostate cancer, interview 2, patient)*

Some considered their GP's responses helpful, whereas others were not so impressed. For example, one woman asked her GP's advice on the subject of a drug trial she had been asked to participate in:

*'I was asked for an answer [about participation] and I said I'd like time to consider it, I rang my GP who'd never heard of it and never heard of the drug.'*

*(P14, breast cancer, interview 1, patient)*

One woman who had received blood tests was scheduled to receive the results from her GP and did not find this a satisfactory arrangement as a consequence of the GP's lack of understanding of the test results and the mixed messages on whether the results were good or not:

*'[GP] was just reading numbers off to me and you know I would say, "Well is that good or bad?" She would say "Oh, not very good for someone of your age", and then I said, "Well, I have been through...and this is why...and I am on", and she said, "Oh, it's good for that" [...] What I've found is the GP does not have a full understanding of what's going on. She's getting the information later than I am getting it [...] I don't feel anyone had a grip of the situation or if I felt...if there was something going wrong I don't feel my GP and my breast care nurse will pick it up. You know, because I don't have confidence in them to be proactive enough to sort something out.'*

*(P12, breast cancer, Interview 3, patient)*

## 14.7 Miscommunication between the hospital and the GP

Mishaps in communication, and mixed messages between hospitals and GPs were a key issue that often left people with cancer confused. As voice box 35 indicates, some healthcare professionals also found lack of communication problematic, and as voice box 36 shows, this can be most troublesome during follow up. In a number of instances, the hospital failed to inform a patient's GP about cancer diagnosis or remissions:

**Voice box 35:** Communication between the hospital and the GP:

*'We are not in the loop to see what, you know, there's no computer link between community and ourselves to see what's happening out in the community, but I'm sure if the GP had been running into problems then he would have referred [P20] back to the ward.'*

*HP20, Clinical Nurse Specialist*

*'The problems we often have is the delay in communication between hospitals and us sometimes, but that's not a disastrous thing and it's better at some clinics. It's always difficult when the patients come to you and say 'this, that and the other thing has happened.'*

*HP54, GP*

*'[GP] rang me up to find out just what had gone wrong. What they'd done, because she hadn't had word.'*

*(P33, colorectal cancer, interview 1, patient)*

*'When I've had to ring him about other things, other sort of smaller symptoms that I've had to get help with, it's quite clear he hasn't a clue what has happened to me since then.'*

*(P14, breast cancer, interview 1, patient)*

*'But I just still think there's a lack of communication, you know, and a lack of contact and even my own doctor never got word. I mean, I told her I was all clear. She had, still hadn't heard.'*

*(P42, gynaecological cancer, interview 3, patient)*

*'[GP] phoned me and says "[P20], can you tell me why you was discharged from the hospital? What were you in for?" And I said "Heavens above, I've been in since the end of January with cancer."*

*(P20, gynaecological cancer, interview 2, patient)*

**Voice box 36:** Difficulties during follow-up:

*'What's happening to patients after treatment? And is there gaps there? I think, really, after treatment we depend on the GP, the Community Team picking things up and although she's been referred to those, we actually don't know what's happening.'*

**HP23, Clinical Nurse Specialist**

*'If the patient doesn't tell me they can be lost to follow-up and that does happen. If I am not keeping my finger on the pulse, that can happen. Patients can be lost to follow-up and it's a year later and you suddenly think, oh gosh, whatever happened to that guy? Or the guy appears and says, "Why did you not come and see me?" or comes back with another problem.'*

**HP2, GP**

Disappointment with having to be the one to 'press the buttons' and provide the information link between the hospital and the GP was clear in some accounts:

*'It's this joined-up thinking, whenever I've had to contact him, I've been the one who's had to fill him in with where I'm at, you know, how I am and everything, and I think that's disappointing.'*

*(P14, breast cancer, interview 2, patient)*

Being 'stuck in the middle' between the consultant and the GP was not an uncommon experience and was detrimental for the person with cancer:

*'But there is always a lack of communication between hospital and the GP, because when I saw [consultant] he said "You've started on the Tamoxifen", and I said, "No", I hadn't and he said "Oh, you should have started it by now, you should have started it by now". So I got on*



*the surgery and they get all huffy because they haven't been told [...] it's awkward because you are stuck in the middle and if communication were better it would be a lot easier.'*

*(P27, breast cancer, interview 2, patient)*

One individual was aware of requiring a particular antibiotic to clear up an infection after an operation; however, this had not been communicated to the GP, resulting in a more serious infection:

*'However, when the notes came through there was no mention of this infection in them. The GP who saw me at the time tried phoning [consultant] to find out more about it but couldn't get hold of him or his secretary. And said to me, "Oh [P40], why don't you just phone him from home?" and I thought about it and I thought maybe I imagined it, so I didn't follow it up 'cause I know health professionals are at the end of their tether, they're at the end of their ropes with the NHS.'*

*(P40, gynaecological cancer, interview 1, patient & partner/carer)*

## 14.8 Follow up care and living with cancer

The hospital-based healthcare team that had cared for the individual with cancer during treatment is likely to move to the background when treatment is complete and this can be a difficult experience for some people with cancer. Many people and their partners/carers moving beyond the end of treatment described the need for further support.

While a few people praised continuing contact from their GP – 'When I came home the GP came and saw me ... I've seen him regularly, at least once a month' (P2, bowel, interview 3, patient and partner/carer), a number of people affected by cancer described the lack of contact with the GP, an experience that led to heightened feelings of isolation and 'being in limbo (P14)'. In particular, telephone contact was often expected:

*'... there was support there when she went in but as to, kind of like, them ringing her or anything like that, I know it might be a bit intrusive for them to keep in touch with people, but there wasn't really a great deal going on like check ups or anything ...'*

*(C5, breast, cancer interview 3, patient and partner/carer)*

*'... but I mean, the after care ... the authorities could have helped out more, I feel, but it's like who do you speak to when you get like an automated system or an answering machine? It's like there's no real people out there any more to speak to.'*

*(C6, colorectal cancer, interview 3, patient and partner/carer)*

For many people affected by cancer, contact from the GP was assumed: 'I think somebody to acknowledge it would have been, you know ...' (P27, breast cancer, interview 3, patient). At times, acknowledgement of patient needs was more forthcoming, yet in practice, this still proved problematic:

*'... the GP said if there was any problem just to come back to him ... "We'll keep in touch, you can come to see me and then we'll have a telephone call between," sort of thing, you know, every 2 or 3 months, but he's never got in touch or anything, and when I did actually make an appointment, he decided to phone ... and the time before that I got a message saying he was going to phone me at a certain time ... he phoned about quarter of an hour before he was due to phone ... I was crossing the road ... I got the impression he was in a terrible rush ... he didn't ask how I was, not once, just a quick rush, "That's fine, I'll get that for you", bang, down the phone went. I thought, it's contrary to what he was saying earlier on, maybe he was having a bad day, of course ...'*

*(P19, prostate cancer, interview 3, patient & partner/carer)*

P27 described a lack of awareness at her local surgery and the subsequent difficulty experienced attending to have stitches removed. Asked if she had had contact with her GP, P27 replied:

*'No, it's never mentioned ... I mean, they do the repeat prescriptions for tamoxifen, so they presumably have a vague idea what it's for ... I went to have the stitches out ... the practice nurse had no idea what it was for ... I suppose it's quite interesting because to start with she was being quite right and you've got stitches to come out have you? And she said where are they? So I told her. She said "Oh" ... the attitude changed radically in a very short space of time ... they must know, because I mean, letters seem to zoom back and forth and everything ...'*

*(P27, breast cancer, interview 3, patient and partner/carer)*

## 14.9 Conclusion

This Chapter describes how GPs were criticised because they could not always provide the answers about all aspects of cancer care as they do not possess specialist knowledge. Given the central role that many GPs play in people's care in the first year following diagnosis, including diagnosis, drug prescribing, supporting people experiencing symptoms and treatment-related side effects, and providing after care or follow-up support and treatment, this lack of knowledge is problematic for people with cancer. As community-based care becomes reality, the role of the GP and the primary care team is likely to gain in significance. Closer involvement of an individual's GP in the partnership composed of a range of healthcare professionals caring for that individual may provide a possible solution to resolving this difficulty encountered by some people with cancer.

## Section 15: EXPERIENCES OF EMPLOYMENT

### 15.1 Key Findings

- » The length of time that people affected by cancer had off work as a consequence of their diagnosis of cancer within the first year varied from individual to individual.
- » People with cancer whose diagnosis spurred early retirement not only had to contend with a diagnosis of cancer, but also with retirement: often a major life-changing event in itself.
- » Some people with cancer found it difficult adjusting to being off work for a long period of time.
- » People with cancer had time off paid employment following their diagnosis for a range of reasons, including loss of confidence, inability to concentrate or considering themselves being still too emotional.
- » Many people with cancer were not totally clear about their entitlement to sick pay, their rights, or welfare benefit entitlement.
- » Several people with cancer had negative experiences with their employers when organising sick leave and their return to work.
- » Colleagues acted as a source of support if they had experience of cancer themselves. Yet, talking about cancer with others at work could be stressful.
- » Several people with cancer, particularly men, wished to return to work as soon as they possibly could, even though they experienced pain and became tired.
- » The above points suggest that people with cancer may benefit from the participation of employers in partnership working.

This chapter describes the experiences that people with cancer had surrounding paid employment. In this chapter we do not include the experiences of partners/carers and the impact that their relative's diagnosis had on their employment since this is touched upon in Chapter 17: Experiences

of family and carers. We also do not include experiences of voluntary work. Instead, we focus on the experiences of those who were in paid employment when they received their diagnosis of cancer, which was just under half of those that we interviewed.

## 15.2 Length of time off work and retirement

The length of time that people affected by cancer had off work as a consequence of their diagnosis of cancer within the first year varied from individual to individual. Some people with cancer just took days off to attend appointments, whereas others stopped working as soon as they were diagnosed with cancer and did not return because they were near to retirement.

A couple of people with cancer in the study hardly took any time off work because they did not feel they needed to. A man with prostate cancer (P19), for instance, only took time off work to attend appointments for scans. He did not have any adverse symptoms that would warrant time off, although many of his colleagues were amazed that he had not been off work because they all assumed that he would feel ill. One woman with breast cancer (P27) only had a week off, which was during surgery, but then returned to work whilst she was receiving radiotherapy.

Some people with cancer decided not to return to work because they were close to retirement. These people, therefore, not only had to contend with a diagnosis of cancer but also with retirement, which was often a major life-changing event in itself. A man with cancer (P3), whose job involved presenting to audiences and also supporting people on a one-to-one basis, decided to retire early because he had lost confidence, could not concentrate and found his type of work too emotional. His doctor was concerned that he was retiring early because the doctor perceived that he was 'giving up the ghost'. He, on the other hand, wanted to prepare for retirement as soon as possible and said:

*'I think I would rather say now, "That's us, that's the end of our chapter". I'm not going back.'*

*(P3).*

Yet, the decision to retire early was not made immediately, but took time. The reason for this decision was because retirement for him was 'life shattering.' He, therefore, not only had to contend with a diagnosis of cancer, but also with giving up work. He was not alone; another man with cancer (P39) remained on sick pay (full pay and then half pay) until he retired. Initially he had

planned to return to work but did not feel well enough. Likewise, a woman with cancer (P52), who was only a year away from retirement, did not return to work because she felt so tired and breathless. She said:

***'I'm not thinking about work just now anyway, I just want to get better first.'***

*(P52, lung cancer, interview 2, patient and partner/carer)*

## 15.3 Reasons for taking time off work

Some people with cancer found it difficult psychologically adjusting to being off work. One woman with cancer said it was difficult because:

***'I'm not used to it, I mean I've always worked, I've always been out working, if I'm not working I'm always doing something in the house or out the house.'***

*(P8, breast cancer, interview 1, patient)*

Another woman with breast cancer said that stopping work:

***'Was quite a shock, really, when you've not had any blips for thirty years. Psychologically it's a very odd feeling to not be at work.'***

*(P14, breast cancer, interview 1, patient)*

People with cancer took time off paid employment following their diagnosis for a range of reasons, including pain, loss of strength, shock, loss of confidence, lack of ability to concentrate, sickness, tiredness, embarrassment, and sometimes they considered themselves too emotional to work.

Several women with breast cancer took time off work because they were in pain. One woman with breast cancer who was off work due to pain did not wish to return to work only be off again:

***'It would be a bit of a waste of time going back to work today and then maybe a couple of days time, saying, "Oh my God, I cannot do this because I'm sore."'***

*(P8, breast cancer, interview 2, patient)*

Another woman with breast cancer (P5), whose work was physically demanding, returned to work once she was strong enough and the pain had gone. Initially when she went back to work she did not carry out certain tasks because of a slight weakness in her chest. She said:

***'I've always stated quite clearly that I'm not coming back until I'm able. I'm not going back when I know I cannot do my job.'***

*(P5, breast cancer, interview 2, patient)*

Similarly, another woman with breast cancer (P8) was not able to return to work because she was not able to lift things.

One person with cancer was off work because she was suffering from the shock of the diagnosis:

***'It was just such a shock. I don't think I could have.... And I didn't look right at all, I looked awful. Well, down here I thought I looked awful, em, but they've [employers] been excellent, they've been really, really good... I don't know when I'll go back to work.'***

*(P25, gynaecological cancer, interview 1, patient)*

One woman with breast cancer (P14) who described her job as 'stressful' stopped work because she did not wish to pick up an infection from others prior to treatment and wished to avoid stressful situations. She was not rushing to return to work because she wanted to give herself the maximum time to recover:

***'I'm just giving it my best shot eh, giving myself maximum time to recover and if it recurs then I can't reproach myself for, you know, I should have don't this and I could have done that and I ought to have done this and ... so I've, I'm trying to approach it from every, every way.'***

*(P14, breast cancer, interview 3, patient)*

She also said that she did not have the confidence to return to work:

***'Until you're actually back at work and doing full weeks' work end on end, you know, you, you don't have that confidence and you can't say, "Yeah I'm ok"'***

A man with colorectal cancer had stopped working since his treatment because he had a colostomy bag. His job involved visiting people in their own homes and he did not think it appropriate to turn up with a colostomy bag. He said:

***'Well you couldn't really go to somebody's house with a bag of rubbish hanging off your side.'***

*(P1, colorectal cancer, interview 2, patient and partner/carer)*

Another reason why he stopped was because he would not be able to do the job if he was in pain because he would not be able to concentrate.

A woman with cancer (P21) had planned to work during treatment but the chemotherapy made her unable to concentrate, sick and dizzy. In spite of these symptoms, she was considering returning to work on reduced hours because she was worried about money (see Chapter 16 for more detail about people's experiences of finance during the first year following diagnosis). However, when she was interviewed for a third time for this study, which was after her treatment had finished, she explained that she wished to stay off work a bit longer in order to recover:

***'Well, I, I'm hoping that when I go back to the doctor on Thursday that she will let me stay off sick a little while longer, I feel I need some recovery time, some time off work that isn't for going for treatments if you know what I mean, that's all I seem to have done ... endlessly, is up and down to hospitals and people sticking needles in me or doing things to me, and I'd like just a wee while to recover, to find my feet, get a bit more hair... I want this time off just to recuperate, like I said, the time off, when I'm not looking to go up for treatment, you know, that I can just get myself together, gather my strength up and then go back and think, that's it I'm back to work, I'm healthy, life's normal, you know, that's it done and dusted.'***

*(P21, breast cancer, interview 3, patient).*

As voiced box 37 indicates, her clinical nurse specialist appreciated that she needed time to take stock and reflect on her experience. Similarly, another woman with cancer, who had a manual job, also wanted the space and time to contemplate what she had gone through and was not intending to rush back to work:



**Voice box 37:** P21's CNS explained why people with cancer needed support after treatment and time to recover:

*'One of the things I really do believe could be better is, instead of taking the patients, we... give patients lots of support at the point of diagnosis, through their treatment and then off they go, which is fine, you know. And I hope that this lady's [P21] been very well, but what I think would be better, instead of just discharging them after their treatment would be to have some kind of formal teaching or group sessions whereby they could actually learn about what's happened to them and get some advice about how to re-adjust their lives for the future, because having a diagnosis of cancer is actually a life changing event. And you, whilst you're thinking about surgery and chemotherapy, you're not usually dealing with those other issues, which is how you're going to live after it.... Because you know, technically, they could go back to work, then, the treatment's finished, but that's often when they stop and take stock and think, "Goodness, what's happened to me in the last few months, the last year."*

*HP21, Clinical Nurse Specialist*

**R:** *'And you're not going to go, you were saying before, you probably won't go back to work until you've ...'*

**P55:** *'Em, yeah I, I think I still feel that way, I feel I probably could have, well, it's difficult to know how, you know, I say my energy levels are fine but in actual fact I haven't really put them to the test that much, but I, I feel that, I just want to be a bit self-indulgent and have the chance to think it all through and dwell on it a bit and, you know, just kind of not be forced to go to work if I don't feel like it and take a bit of time out, so I still feel that way... I don't want to be forced into doing things I don't want to do, really, quite self-indulgently ... and I feel, I also feel, I pay all that money for my private insurance, I'm going to make use of it sort of thing, yes.'*

*(P55, breast cancer, interview 2, patient)*

## 15.4 Negotiating sick pay and return to work

Many people with cancer in the study were not totally clear about their entitlement to sick pay, their rights, or welfare benefit entitlement (see Chapter 16 for a more detailed discussion about welfare benefits). One woman with cancer (P8) was not sure about her entitlements because she had never had a sick line before. A man with cancer (P17) was also vague about his sick pay entitlement because when he contacted personnel they were vague. One man with cancer (P57) thought that he was entitled to 6 months' full pay, but his wife said that they had not really got a clue about his entitlements or about welfare benefits. The clinical nurse specialist, however, told him that if he were not going to be able to work she would arrange for a social worker to visit them to discuss welfare benefits.

Several people with cancer had negative experiences with their employers when organising sick leave and their return to work. One woman with cancer (P50) was trying to build up the motivation to fill out the 13-page forms for Statutory Sick Pay, and another woman with cancer (P14) was advised by her doctor to plan a phased return to work rather than immediately going back full time, but ran into difficulties trying to organise this with her employer. A man with cancer (P17) said that although he was expecting it, it was still a shock when he got a letter through the post informing him that he was no longer entitled to any wages and that he would be on Statutory Sick Pay. He said he had to sit down quickly.

A woman with cancer (P21) actually felt bullied into returning to work:

*'I had a phone call on Thursday morning, my new manager... and she wanted to know where I am in this illness and when I'm planning to come back, and I have to have an official meeting to discuss all this, and the only good thing about it is I went screaming to the Union because she's supposed to do a letter first but she said "No", and I told her I couldn't really afford to come through to Perth and it wasn't, you know, and you know, it's a bit hard to say, "Yes, I will be well enough to meet you on the 21st or the 23rd," or whatever day she picks, because I don't know, so what I've got now is her, I'm waiting for the letter to say that she's coming here, let her use her petrol up. And she's bringing Human Resources, but I did kind of feel that I'm getting bullied to get back to work, I've had 6 months off, you know, I've had, this is me, you, "You have had 26 weeks absence this year now", and that's counting my*

*hospital appointments as well, it's not all been, you know, some of them are just the odd day for hospital, so that's me, "Twenty-six weeks get back to work, girl!"*

*(P21, breast cancer, interview 3, patient)*

In contrast, other people with cancer had only praise for their employers. A man with cancer (P28) said that the Directors of the company that he worked for offered to pay for a private room whilst he was in hospital so that he did not have to share a room with others. The Directors of the company also contacted his wife to see if she needed support of any kind. A woman with cancer (P50) described her employer's response to her situation as very good. She worked for a large organisation that transferred her onto 'special' leave as opposed to sick leave, which meant that she would still need sick notes, but would not lose her pay. She described her unit as like one 'big family'. Her boss, whom she had known years, visited her at home after her diagnosis to see how she was. She also kept in touch with colleagues and met some of them for lunch because she missed the office banter.

A man with cancer (P56) suggested that he take his annual leave entitlement to attend hospital for appointments, but his boss said that he should just take time off. He calculated that he had had around 6 weeks off in total including 2 weeks whilst in hospital and the rest for radiotherapy. He said that they had been very good that way.

One woman with cancer found her boss's response to being told that she would be having 6 weeks off work very re-assuring. Her boss said: 'I don't care, as long as you're better at the end of it' (P8, breast cancer, interview 1, patient). One man with cancer (P57) who had to take time off popped in every week to chat with his colleagues. His boss also visited him and said that he could pop back to work whenever he felt like it.

## **15.5 Response from work colleagues**

Several people with cancer praised the response of colleagues at work who showed that they were thinking of them and cared. A man with cancer (P28) received various gifts during his absence from work including a basket of fruit and champagne when his results showed that he was 'all clear'. He also received plenty of text messages, cards and phone calls. This type of support, alongside the support from family and friends, helped him to get through something that he said he would never like to go through again.

Colleagues acted as a source of support if they had experience of cancer themselves. A man with cancer (P2) said that three other people in his office also had cancer, which meant that they were able to empathise and understand what he was going through. One of his boss's relatives also had colorectal cancer and so understood why he was not able to work. One man with prostate cancer (P4) said that his boss 'understood' because he had also had prostate cancer: 'He's familiar with it all. He's been through it.' One woman with cancer (P9) compared notes with a colleague at work about their experiences of cancer, which, according to this woman's relative, gave her an 'enormous boost' (C9, gynaecological cancer, interview 3, partner/carer). However, talking with others about cancer could also be stressful. This woman found talking to a colleague stressful because it was near a particular milestone for her which was a year since her diagnosis:

*'I think, well, last night I was a wee bit tearful at work, because talking to one of the girls, that was her sister that's been through the skin cancer, it'll soon be a year and I think that's what's coming up as well, it'll soon be a year and I think that's telling on me, I think, I got scared when... I don't know why, I just started getting jittery and scared and I thought look, stop it, you'll be ok, I just want to get the year past with and I think its building up to that and I know a lot of it is psychological as well.'*

*(P9, gynaecological cancer, interview 2, patient)*

## 15.6 Reasons for returning to work

Several people with cancer, particularly men, wished to return to work as soon as they possibly could, even though they experienced pain and became tired. The main reason for returning to work was to take their mind off cancer. A man with colorectal cancer (P28) worked part-time during his chemotherapy, which he found beneficial because he did not wish to be moping around the house watching television. Work took his mind off the cancer: 'The minute I go [to work] in the morning until the time I come away that it doesn't even come into my mind that I've got cancer' (P28, colorectal cancer, interview 3, patient and partner/carer). Returning to work was also symptomatic of his positive attitude during his illness:

*P28: 'And I think people see in me that, ken, I mean, everybody thinks cancer - doom and gloom, you're in your bed, you just wait until you die. They're seeing me, I've managed to go to my work, I've managed to attend functions with the work, I've managed to attend charity events where I had to drag myself out of my bed, em, I've done pretty much everything I used to do before, eh, and they've said, "Well, hold on a minute now, this, this is somebody*

*there that, eh, cancer's not the death sentence that is portrayed as all the time", ultimately it is, I suppose but, just now it is not.'*

*C28: 'But there is people that can get over it, I mean that's what you're proving, that there is people that can get over it.'*

*P28: 'But the thing that, everybody's noticed my attitude, the positive attitude and everybody I think now realises that you can get a lot out of life by being positive, I mean you, it's, the age old thing is the glass half empty, is it half full? Well, a lot of people that if, are, are changing their, their attitudes to life, I think, as a result of me, and they're saying, ken I've realised how lucky I am now because, ken, I mean, you've went through aw this and, and you're still laughing and smiling.'*

*(P28, colorectal cancer, interview 2, patient and partner/carer).*

However, he recognised that he became tired, was sick and found it difficult concentrating whilst having chemotherapy, which was why he slowly built up to returning back to work full-time and made sure that he delegated more tasks than he was accustomed to. A man with lung cancer (P56) also preferred returning to work because it took his mind off it:

*'I would prefer to feel a lot better but no, it's not affecting my work at all, none at all. In fact, it's helping, I'm tending to forget what's wrong and get on.'*

*(P56, lung cancer, interview 2, patient and partner/carer)*

He acknowledged that there were days when he did not feel well enough to go to work but he went because it took his mind off having cancer. Another man with lung cancer (P59) also did not wish to give up work because he did not want to dwell on his illness. A wife of a man with prostate cancer said that her husband returned straight back to work after surgery and was working 'harder than ever' because this was one of his ways of not 'dwelling on it' and 'dealing with it.' (C7, prostate cancer, interview 1, partner/carer)

Other reasons for returning to work were to alleviate boredom and to manage depression. A man with colorectal cancer (P2) wanted to return to work because he would have been bored, otherwise. A woman with gynaecological cancer decided to return to work because she was depressed and had discussed this with her GP (see voice box 38). She explained how returning to work helped her manage her depression:

*'It was, again, mainly through depression and well, obviously a wee bit of, you know, sitting about the house with no money and not being able to go anywhere, I wasn't really fit to go anywhere anyway, as I realise now, but I thought the... - I just kept thinking about everyone at work and thinking, right, the longer I am away, the harder it's going to be for me to come back, which it was. And I knew that having cancer as well, I thought, well, everybody's, because I've been there myself and when you hear about someone who has been ill, you don't know what to say to them. So when I went to see the doctor and I asked him if I could get back and I explained what kind of job I did and he didn't seem very happy and then I said, "Well, but I can clean the offices, it's really, really light." So he let me go back and I'm glad I did, I really am glad. I thought, I felt awful the first few nights which I would, but they were all so good. There was a few of them kind of never spoke to me, but I figured that they would do, 'cause they don't know what to say. I just thought, right, I'll go in and I'll do what I've to do and I'm really glad because it, I find that going back lifted my depression and also, it made me feel a lot, physically, a lot better. The queasiness wasn't nearly so bad, and the tiredness. The first night I came home from work I just, nearly conked out with the exhaustion but, I thought, well, that's just to be expected. But yes, I'm glad I went back. A few people thought I went back too soon, but I don't I think I felt within myself, it was time for going back because I knew that I was getting worse with the depression.'*

*(P9, gynaecological cancer, interview 2, patient)*

**Voice box 38:** P9's GP recounts their discussion about returning to work:

*'She would be tired afterwards and it would take time to recover from it and not to be surprised at that. Because I think sometimes people who get radiotherapy feel guilty because they're tired and they think, "Well, I haven't had an operation so why am I not getting on with things?" So I sort of forewarned her of that, because she's, you know, she's a typical north-east work ethic.*

*She was very keen to be getting back to work. She said for, partly for financial but also emotional reasons that she felt she would get on better working than sitting at home thinking about things.'*

*HP9, GP*

Some people with cancer needed to work because they needed the money and reducing their hours was problematic for financial reasons. One woman with breast cancer (P70) was relieved that her insurance had paid for her mortgage, otherwise she did not know how she could have coped financially. She had recently got a new job, which meant that she was only entitled to 3 months' as opposed to 6 months' sick pay.

## 15.7 A phased return to work

Some people with cancer phased their return to work. A woman with gynaecological cancer (P25) who said she was not the type of person to 'sit around doing nothing all day', was considering returning to work part-time because her surgeon had advised her not to work immediately full-time. Another woman with gynaecological cancer (P42) also adopted a similar strategy, by working a few hours every other day. She had the support of her colleagues, 'So I think the only way to build it up is, if I, I've got a great office, so I just need to say I'm tired and, and I won't need to worry.' (P42, gynaecological cancer, interview 3, patient). Similarly, a woman with breast cancer (P14) was advised by her doctor to phase her return to work.

People with cancer welcomed the opportunity to be able to phase their return to work by slowly increasing their hours, but they also appreciated changing the way in which they worked, for example, not lifting heavy items or working as hard. They needed the support of their colleagues to be able to make these adjustments. A woman with breast cancer (P8) returned to work a couple of weeks before her sick line finished: 'I got up one morning and thought, "Och I'm going back to work I'm fed up with this."' (P8, breast cancer, interview 3, patient). Before this, she did not feel able to cope with going back. She was also thankful that she only worked part-time because she found returning to work very tiring. Since she had returned to work she did not do as much as she had done before and did not lift things. Similarly, a woman with gynaecological cancer, who had a manual job, became very tired. Her strategy was to continue working but at a much slower pace:

***'My Charge Hand said, "Och, maybe you should go home" because I didn't feel that great, but I thought, no, I'll stay on, and I'm glad I did, but I just slowed down and I took my time and I got on with it and last night I had no energy at all and I'm thinking, how am I going to get on with this?'***

*(P9, gynaecological cancer, interview 3, patient)*

One woman with breast cancer (P14) who had been off work for a year was anxious and nervous about returning to work. In order to allay her fears she said that both employer and employee should prepare in advance for a person's return to work.

## 15.8 Self-employed and contract work

A couple of people with cancer highlighted some of the difficulties likely to be encountered by people diagnosed with cancer who were self-employed or on short-term contracts. These people faced particular financial difficulties because they did not get paid if they did not work. A man with cancer (P24) who was self-employed said that if he did not work he did not earn. He also was not able to get sick pay and was, therefore, in the process of applying for various welfare benefits to ease the financial situation. A woman with cancer (P27), who was on a short-term contract, reluctantly returned to work whilst she was undergoing radiotherapy because she would not have been paid otherwise.

## 15.9 Conclusion

The concepts of partnership and joined-up working is ubiquitous in Scotland's health policy documentation, and this is largely being implemented through the Managed Clinical Networks and Regional Cancer Advisory Groups. As the current policy direction of travel towards partnership gathers pace, other services and sectors have been brought in to the healthcare planning and service delivery arena, including social care. This Chapter suggests that employment should be part of the partnership, because virtually all people affected by cancer required support and advice since their employment was affected as a consequence of having cancer. The Chapter highlights that some people affected by cancer were not clear about employment rights and may have benefited from their employers being automatically involved in a partnership for care because they are key to ensuring that the person with cancer receives sick pay and has a return to work that is tailored to their individual needs. Moreover, this Chapter suggests that enabling a culture of care is not just the preserve of healthcare professionals but includes all who are in contact with people affected by cancer. In particular, employers have a duty of care, which includes supporting people with cancer. This Chapter suggests that employers who enabled people with cancer to negotiate a phased return to work and were able to change work practices by, for instance, not working as hard or not lifting heavy items, were most appreciated. Colleagues also played a role through expressions of caring for the person affected by cancer.



## Section 16: EXPERIENCES OF FINANCE

### 16.1 Key Findings

- » Many people reported financial worries and described the additional costs that they had incurred as a consequence of being diagnosed with cancer.
- » Overall, financial advice was sporadic and ad hoc. Some people appeared to have been informed about financial support and welfare benefits whereas others had not.
- » Several people with cancer had applied for welfare benefits and made insurance claims following their diagnosis of cancer and a number of them reported difficulties.
- » Difficulties making welfare or insurance claims not only caused some people with cancer physical hardship but also took its toll emotionally.
- » A small number of people with cancer obtained financial help from Macmillan Cancer Support.
- » The above points highlight that people with cancer may benefit from the participation of welfare and financial services in partnership working.

This Chapter describes the financial implications of having a diagnosis of cancer. We report the perceived costs of living with cancer, experiences of obtaining financial advice and claiming for welfare benefits.

### 16.2 Financial hardship

Whilst some people reported no financial worries, many of them did. Not surprisingly, those who were living on welfare benefits and state pensions reported the most financial hardship, whereas those who were able to claim sick pay and/or had access to other funds, such as critical illness

cover, spoke of being able to absorb the extra expenditure incurred as a consequence of having cancer.

Some people affected by cancer reported being in dire financial circumstances, including a man with cancer who was self-employed and not able to work. He was in the process of applying for Incapacity Benefit, Disability Living Allowance, Housing Benefit and Council Tax exemption. With reference to he and his wife's financial situation he said, 'We're surviving, is all' (P24, lung, interview 1, patient and partner/carer).

Others, including a woman with terminal colorectal cancer (P50), were financially secure. She was in receipt of sick pay, Disability Living Allowance, Carers Allowance, and had successfully made insurance claims for critical illness. Having her finances sorted out gave her peace of mind because she knew that when she died her family would be financially secure.

### 16.3 The costs of living with cancer

Some people with cancer described the additional costs that they had incurred as a consequence of being diagnosed with cancer. Some had higher heating bills, some incurred high costs of travel to hospital for treatment, whereas others had higher holiday insurance premiums.

A woman with cancer who felt the cold more, estimated that her heating bill had increased to around £30 each week:

*'I'm on Incapacity - over half of that was going in the electric, so I had to leave other bills and it got.... if the weather hadn't have changed, well, I'd already started turning off heating, shutting myself away in this room, even going up to the toilet was an ordeal 'cause it was cold.'*

*(P6, colorectal cancer, interview 2, patient)*

She had contacted the Department of Work and Pensions to try to get some money for heating and was informed that she could have a loan of £200 which would then be taken out of her welfare benefits each week until it was paid back. Fortunately, she had received a pamphlet just before she came out of hospital about one-off payments from Macmillan, so she telephoned the cancer nurse specialist and within 3 days she had received almost £400 from the Macmillan Cancer Fund. Although she was not expected to pay this money back, at her daughter's 40th

birthday party they raised over £400 which was given to Macmillan. A man with cancer, who was on a pension and had just given up a part-time job, had the central heating on constantly since his diagnosis. When asked if he was worried about paying the bills, he replied:

***'Tough. I've just come to that way of thinking if I can't pay, I can't pay, but I'm not sitting here bloody frozen.'***

*(P45, lung cancer, interview 1, patient)*

Similarly, another man with cancer (P1) also had the heating on constantly and felt fortunate that he could afford to pay the bills.

Another cost incurred by people with cancer was travel for treatment (this is also reported in Chapter 8: Experiences of transport). A handful of people had sought financial help to pay for travel but were not successful. One person with cancer (P21), who was struggling financially, said that she was not able to obtain financial help for travel because it was only available to those on Income Support. Another person with cancer (P6), who was living on Incapacity Benefit, wanted to claim for travel expenses so that her daughter could drive her to the hospital without being out of pocket. It was a 120-mile round trip, but she only received £6.13, which would have covered the cost of her bus fare but would not cover petrol costs. One person (P30) had his bus fare to hospital for treatment reimbursed by the NHS because he was over 65 years old and therefore eligible to claim.

Some people with cancer obtained disability-parking badges, which not only improved their chances of finding a parking space, but also helped towards travel expenses. A cancer nurse specialist for a man with cancer (P45) had helped secure him a disabled parking badge so that he would not have to pay for parking when travelling by car to the hospital for treatment, which saved him a bit of money. It was not apparent in this study that other people with cancer had automatically been encouraged to apply for a disability badge.

There were other associated costs reported by people with cancer, including the extra costs in holiday insurance premiums. A man with colorectal cancer (P28) had used the list of holiday insurance companies provided by Cancerbackup and had been quoted by one company for £1200 for 17 days, but eventually found a company that would insure him for only £60. Some people with cancer went on holiday without insurance, because it was either too expensive or they could not find a company that would ensure them within 12 months of having a diagnosis. A man with

lung cancer (P63) went on holiday without insurance because it was so expensive. A man with prostate cancer (P7) was able to obtain holiday insurance at the standard rate, but without cover for anything to do with his prostate. Another man with prostate cancer (P19) had managed to find insurance, excluding cover relating to the prostate, which covered him for 17 days for £90. A man with lung cancer (P45) who could not get travel insurance was told by someone in the NHS that if he had an E111 and used a state registered clinic he could be treated in Europe, and therefore would not require holiday insurance. The clinic would invoice the patient, but the NHS would cover the costs. He said that this should be more widely known.

People with cancer also had other additional expenses due to their illness, including extra travel costs, buying new clothes and purchasing complementary therapies and organic food. One man with lung cancer (P36), who lacked energy and strength, could not carry as many shopping bags, and this meant that he used the bus more often to go to the shops than he did before his diagnosis. A woman with gynaecological cancer (P40) wanted to purchase a freezer so that she did not have to travel so much to the shops for food. She had contacted the Department of Work and Pensions to find out if she could get a grant to purchase it. Another man with lung cancer (P63), who became breathless as a consequence of having cancer, now used taxis to get out and about. Fortunately, the cancer nurse specialist had managed to help him apply for an attendance allowance that he used to pay for the taxis. A woman with gynaecological cancer (P49) had to buy some more clothes because she had put on weight since her diagnosis. Finally, a woman with breast cancer (P10) felt fortunate that she could afford complementary therapies, because it cost £30 per appointment with a homeopath, and £25 for tablets. She also had started to purchase organic food, which was more expensive, and was also buying supplements.

A couple of people with cancer reported having to cut back in order to save money. One woman with breast cancer (P21), who was receiving sick pay, had cancelled her life insurance policy to save money, and she and her husband had taken one of their cars off the road. She had also stopped attending a couple of leisure activities that she enjoyed to save on petrol, and had given up the Art Therapy Class at the Maggie's Centre which she enjoyed, because it was costing her £5 each time. One woman with gynaecological cancer (P40), who was on a pension, did not visit friends as much now that she had cancer, in order to save money.

## 16.4 Financial advice

**Voice box 39:** A CNS explained why providing financial advice was part of her role:

*'We don't have a very good social services package in our hospital, so it tends to be me who sees to the kind of benefits side of things. But they [patients] can have access to Welfare Rights and so forth, and that's always mentioned to them.'*

*'I know a bit about Welfare Rights but I'm not a Social Worker, and I, you know, I must admit, I, with the majority of patients, I discuss finances and let them know what's available, and more often than not, it's me that sorts it out.'*

*HP63, Clinical Nurse Specialist*

Overall, financial advice was sporadic and ad hoc. Some people appeared to have been informed about financial support and welfare benefits whereas others had not. A handful of people with cancer who were fortunate, received financial advice, either from the cancer nurse specialist or hospital social worker. As voice box 39 shows, some clinical nurse specialists perceived providing financial advice as part of their role. One man with cancer (P46) did not wish to claim for any benefits because he was financially well off. However, he was encouraged by the cancer nurse specialist to apply for 'carers allowance' and a disabled parking badge because he was entitled to these benefits. The nurse explained everything to his relative over the phone, and forms were duly filled in, which led to £62 a week going into his bank account. Since his diagnosis he had also made sure that bank accounts and such like were put in his wife's name to make things easier for her when he died. A woman with cancer (P49) had a hospital social worker who told her about which welfare benefits she was entitled to apply for. Whilst she was entitled to home care, she chose not to have a home carer because she felt capable of looking after the house herself. She and her husband did, however, claim for Disability Living Allowance, which helped them out financially, because they were both living off their pensions. This claim was made despite them feeling uneasy about claiming because she had never relied on welfare benefits before and did not like the thought of it.

Not everyone, however, appeared to have received financial advice. One man with cancer, who did not know what support was available, said that everyone affected by cancer should be informed

of all benefits that could be claimed. One couple affected by cancer (P39/C39) explained that financial advice and support was necessary because they had other more pressing matters to worry about, such as their health. The main reason why he and his wife were not clear about the availability of financial support was because they had so much else to worry about. His wife explained:

*'I don't know. I mean, we've had that much going on it's the last thing that we're bothering about is money. I know that sounds silly, but em, I suppose, really, we should look into it, but it's, it's a case of it's just been put to the back of your mind and I suppose because we've got a wee bit o' money that you know it can keep us going, but we're not really thinking about it. And I suppose if there was something there it should come when you start his chemotherapy, there should be somebody connected through social works that tells them what they're entitled to, or to tell them what they could be getting or not getting, you know? There's no back up for that.'*

*(C39, colorectal cancer, interview 3, patient and partner/carer)*

## 16.5 Applying for welfare benefits and making insurance claims

Several people with cancer had applied for welfare benefits and had made insurance claims following their diagnosis of cancer, and a number of them reported difficulties. There were two reasons for this; one was due to problems with the Department of Work and Pensions, and the other was because forms had to be filled in by healthcare professionals, which was not always a straightforward process. A woman with cancer (P40) found it difficult applying for welfare benefits because the advisor from the Department of Work and Pensions who was dealing with her case went off sick and had not processed the forms. A woman with cancer (P55) found it difficult and very stressful making an insurance claim, because it relied on healthcare professionals filling out the forms:

*'That's been another of my sort of worries, I suppose. You know, it's that sort of problem that's got completely out of hand for me, em, which I suppose is kind of like a, you know, you take something small and when you're all upset it seems like this huge big problem, and that's the kind of thing I'd be flying off the handle about and, you know, saying to (Husband), "You need to get this sorted." You know, nobody's taking it seriously, you know, sort of "aahh" kind of, and it's those sorts of things I've found quite hard to deal with because it just seems like a, unimportant, compared with the bigger picture, yet very important to me, because*

*I need my wages, sort of thing, and em, so I have sickness insurance, and the broker on the phone said to me, "Well get your certificate in and we'll start processing it so that as soon as you're off it's ready to go." But the form implies that you have to know the full picture before anybody will sign it, so the surgeons won't sign it until they know what treatment I'm having, so it's still not signed, I still haven't got it up and running.'*

*(P55, breast cancer, interview 1, patient and partner/carer)*

Claiming for Incapacity Benefit was also fairly traumatic for her because she was the sort of person who needed matters sorted out quickly and this was not happening:

*'And I'm usually competent at all these things, but I didn't feel very competent at doing it at that point... But you know, my own, I suppose, my own independence and everything, I just want to be organised, yes, and I never think of myself as being controlled, but it's only other people I want to control, I suppose. (laughter) When I'm on my own everything's organised and it's, I always think I find it's other people that kind of, you know, let me down or whatever, and so I did find that quite.... The finance side of it and getting back to work at the end of it all and things like that have sort of been on my mind. Although I have again put that to the side now, as well. I think I've processed that to a certain extent and feel better about it.'*

*(P55, breast cancer, interview 1, patient and partner/carer)*

Difficulties making claims not only caused some people with cancer physical hardship, but it also took its toll emotionally. A man with cancer (P63), who was living on his pension, had trouble getting in and out of the bath, and so had applied to the council for a home improvement grant. He was initially informed that it would take about a year for the council to install a shower but that he could have a seat installed instead:

*'I'll get you a seat, now that's stupid, now imagine me getting into a bath and trying to get into it and to sit in a seat and then I've got to get up and put the shower on, the showers away up there and she's getting a seat. So I phoned up, I said, "Don't want it, don't bring it, I don't want it," "We'll just give you it anyway just put it out the road." It will take a year if we try to get any.'*

*(P63, lung cancer, interview 2, patient and partner/carer)*

**Voice box 40:** When asked if anything could have been improved for P6, her GP responded:

*'Well, I suppose if they have an awareness of other forms of support that might be available to them. I'm thinking, for example, you don't know of any financial things that she might be able to tap into but I know money is a big problem for her... She's going to be partially disabled by this just now, so I suppose knowing they've got certain avenues possibly open to them which I've not actually explored for them, you know. And maybe what could have made it better, if I had given her the phone number or the contact of some local support organisations, you know, which I didn't.'*

*HP6, GP*

Eventually someone visited him at home who said that they were not aware that he was diagnosed with cancer, and if they had been, they would have been much quicker at getting him a shower installed. Apparently, someone at the council had not pointed this out, which had delayed processing the forms. A woman with cancer (P6) also expressed her frustration with difficulties claiming for welfare benefits and, as voice box 40 indicates, her GP also appreciated that more could have been done to help her financially:

*'I mean, all right, I'm glad the weather's changed, because I was putting £30 - £35 a week in here out of my money, the money that I was getting from the ... what-you-call-it... Incapacity, course the bills have had to go, I've people yelling of money off me left, right and centre. I've been promised compensation for my clothes, I've sent off for the Incapacity Living Allowance to try and get some heating allowance and everything. Still got nothing from them yet, they keep saying that they keep writing to the hospital and the hospital not replying, and my consultant says he's not had one letter from them. Then 3 weeks ago I phoned them up and they says "Oh, but we got in touch with the hospital this morning, they're faxing all the details through this afternoon," so somebody, somewhere is lying to me and I'm getting nothing!! This is right from the beginning of February, that's 3 months I've been waiting!'*

*(P6, colorectal cancer, interview 2, patient)*



Not everyone had the same kind of frustrations and difficulties in making claims. A man with cancer (P17) was fortunate because he had been immediately successful in his application for Disability Living Allowance, which he had found out about from a friend. He and his wife also had critical illness cover, which meant that their mortgage was paid for. Claiming, however, was still difficult for them due to stigma:

*'Well I said to the Macmillan nurse, "Do you know how long this is gonna take?" because he only gets three months' sick pay, three months' half pay, and she says "Well, if you want to go to social work," I thought, we don't want social work coming in, we've always worked and we're never off work and that's what my work says "You're never off, so don't worry about it, and there was a programme on the other night about people taking time off work when they're not really sick, and I feel guilty because I just, we, both of us are the same, we just don't stay off work, he broke his leg one year, one time and he was off for a day because he got somebody to come and collect him... I don't want them to start thinking, just looking for money; you know, just one of those people who goes to the social work looking for money... I just hate the thought of it, you know, because we've always worked, never been off sick before.'*

*(C17, colorectal cancer, interview 1, patient and partner/carer)*

## 16.6 Macmillan Fund

A small number of people with cancer obtained financial help from Macmillan Cancer Support, however, most people in the study did not refer to the fund, which suggests that they were not aware of its existence. Some people found out about the fund from nurses, whereas others were told about it from other patients. A man with colorectal cancer (P35) found out about the fund from another patient. He received £350 from the fund, which he put towards the cost of a new bed. A man with lung cancer (P45) received a cheque for £200 to help cover the costs of petrol because he used his own car to travel to hospital for treatment. A Macmillan nurse had helped a woman with gynaecological cancer (P40) obtain a grant of £400. She welcomed this money because her heating bills had increased as a consequence of her feeling the cold more. She felt awkward, however, about receiving this money:

*'And I felt terribly guilty, because that's one of the first things she came out with, you know, "I can get you grant to help with that and that." And then I felt I'd got her out (to my home) here under false pretences to try and get money out of her.'*

*(P40, gynaecological cancer, interview 2 patient and partner/carer)*

## 16.7 Conclusion

For some people with cancer, their diagnosis means that they incur financial difficulties, such as an increase in expenditure, as they incur travel costs for treatment and an increase in their heating bills. Those without adequate sick pay face the additional worry of covering mortgages and other household bills during the time that they have off work, which, for some, can be a while after treatment. A financial strategy for people diagnosed with cancer should, therefore, be developed as soon as possible. This Chapter, therefore, suggests that people affected by cancer may benefit from welfare and financial advice, and from support services becoming part of the partnership responsible for planning, managing and delivering cancer care.

## Section 17: EXPERIENCES OF PARTNERS/CARERS

### 17.1 Key findings

- » The term 'carer' was resisted by a handful of people affected by cancer because they perceived it to be incompatible with their existing relationship with their partner.
- » Partners/carers played a number of roles from pre-diagnosis onwards, including encouraging their relative/partner to make initial and subsequent appointments with their GP, and in providing information.
- » Partners/carers found managing work and life a juggling act since they took on new caring responsibilities.
- » Many partners/carers described increasing levels of strain during the first year after diagnosis.
- » Some couples 'faced' cancer together and developed a shared understanding of cancer care, which strengthened their relationship.
- » Whilst partners/carers rallied round and were perceived by the person with cancer to be supportive, the person with cancer could also feel guilty about the impact of their diagnosis on partners/carers and would try to minimise this impact by downplaying their symptoms.
- » Similar to people with cancer, the experience post treatment for some partners/carers was not one of elation, but engendered moments of worry, fear and anxiety.
- » Despite an expressed need for support, some partners/carers found it difficult to ask for help because they felt that they were meant to be strong for the person with cancer.
- » These points highlight the key part partners/carers play in the supportive care of people with cancer and the strain that they are often under. Policy directed at healthcare professionals to support and involve partners/carers more as partners in care provision, appear not to have always been translated into practice, however.

Other Chapters have highlighted the importance of understanding emotional dimensions of people's experiences of cancer and cancer care and, in particular, the significance of emotion management (Chapter 10) as an inextricable aspect of the experience. Emotions, emotional support and emotion management are also features central to the experiences of many carers, partners and families of people with cancer and are central to the caring relationship. This Chapter examines the experience of cancer and cancer care from a caring relationship perspective. Here, the reciprocal and interdependent nature of care, and the complexity of care within relationships and the wider family, are explored.

## **17.2 Contesting concepts and the relationship dyad: "She's not a carer – she's my wife"**

The term 'carer' was resisted by a handful of people affected by cancer. One person with cancer described his resistance to any form of "carer/cared for" labelling:

*'... you know, at the moment I don't, you know, when you talk about "care" and so on, and how about carers, and, and I don't really want carers, I mean I'm perfectly well able to, you know ... I think there's, that, you know that you don't really want to think people into the grave ...'*

*(P64, prostate cancer, interview 2, patient and partner/carer)*

For him, the notion of being cared 'for' was incompatible with his relationship. Likewise, a wife of someone with cancer commented:

*'Well, I am a wife, I don't see my role has changed any because [partner] has developed cancer.'*

*(C3, colorectal cancer, interview 1, partner/carer)*

## **17.3 The role of partners/carers**

Partners/carers played a number of roles from pre-diagnosis onwards, including encouraging their relative/partner to make an appointment with the GP, and providing information. As already

pointed out in Chapter 3: Experiences leading up to diagnosis, many carers/partners encouraged both the recognition and investigation of symptoms before diagnosis:

*'To be quite honest with you .... I would have rotted away and the inevitable would have happened to me ... she pushed me and pushed me all the way and my daughter and my granddaughter, or I wouldn't be where I am today, right.'*

*(P35 lung cancer, interview 1, patient and partner/carer)*

Voice box 50: Different roles and needs of people with cancer and their partner/carers:

*'P63 will never phone. In all of the time that I've known P63, he's never picked up the phone to me, I always have to phone them and his wife would contact me.'*

*HP63, Clinical Nurse Specialist*

*'He deals with things by being a bit flippant. His wife was a bit more shocked, or she appeared more shocked. And she didn't cry, but she was a bit, filled up a wee bit ... the wife ... reacted probably the way we would expect people to react to news like that. More than he did.'*

*I think she will calm him down. I think she'll see that as a being her role. And being the person that's there to give him a little support and I don't know if that's the way it's been all along in their relationship ... she'll neglect herself a bit. I feel I probably need to support her more.'*

*HP17, Clinical Nurse Specialist*

*'I fought with him. I did everything. I was in tears and went myself and saw the doctor ... an explosion. "I'm not going, you hadn't any right discussing that." So I said, "If you'll not go for me what about your daughter? Your daughters and granddaughter?"'*

*(C35, lung cancer, interview 1, partner/carer)*

However, recognition of symptoms and symptom awareness did not cushion or lessen the impact of diagnosis on partners/carers. Many described feeling 'shocked', 'devastated' and 'distracted',

which are similar responses to those of their relative who was being diagnosed with cancer (see Chapter 4: Experiences of being diagnosed with cancer). Although there may be similarities in experience, such as being shocked, as we show below, and as voice box 50 highlights, people with cancer and partners/carers respond differently and have their own unique role and needs, which are, perhaps, more appropriately understood in the context of the caring relationship.

Many also described emotion work undertaken soon after diagnosis to influence, support and manage their feelings, as well as those of the person with the cancer diagnosis. The pressure of 'being there' and remaining 'positive' for the person with the cancer diagnosis was overwhelming at times. This is discussed in more detail in Chapter 10: Experiences of emotion.

At times, some partners/carers of people with cancer became the primary knowledge-givers:

*P1: 'To be perfectly honest, we got booklets. You [talking to carer/partner] read them, I just ignored them.'*

*C1: 'I can understand. I read out bits to him, the really important bits. Basically I would say he doesn't want to read them.'*

*P1: 'No, I don't want to know.'*

*C1: 'You don't want to know, but I have learnt a lot reading the booklets.'*

*(P1/C1, colorectal cancer, interview 1, partner/carers)*

## **17.4 How do carers/partners cope? From managing to juggling the work-life balance**

Upon diagnosis, many people affected by cancer found difficulty adjusting to what was a new – and often traumatic – daily reality, and one which challenged daily living and transformed caring roles. For most people affected by cancer, diagnosis and treatment resulted in an overnight transformation of a work and life reality from what had been relatively well-managed to becoming something unrecognisable.

For many people affected by cancer, managing the work-life balance was a juggling act, as they negotiated daily work-life alongside new and increased care-giving and supportive responsibilities. Working, at the same time as caring for someone with cancer, could be difficult, comprising of the need to keep work-life 'ticking over' while also diverting sufficient energy to care and support at

home. One person affected by cancer described this negotiation as beneficial: 'You don't have time to think about too much' (C20, gynaecological cancer, interview 2, partner/carer).

For some people affected by cancer, support from their working environment proved critical:

*'They've been great. Everyone has been lovely. And because I am in a team ... I can get them to help me out if I have to take [partner] for treatment or anything like that. They've been good.'*

*(C2, colorectal cancer, interview 2, partner/carer)*

*'I went into work and they were all waiting to find out how he was because they kept saying "He'll be ok, he'll be ok." I burst out crying, they sent me home ... they've been very good and I just hate the thought of leaving him on his own but they've been very good about it, the doctor's given me a line for stress reaction, because I'm turning night into day I'm not sleeping.'*

*(C17, colorectal cancer, interview 2, partner/carer)*

However, a number of people affected by cancer described having to "use up the holidays" to accompany people with cancer to appointments and treatment. Others echoed the benefits of employer support but cautioned this with concern over whether the level of long-term support would match up to early expectations:

*'I was working long hours, anyway .... so they've had their money's worth out of me, but em, I think that ... they are supportive ... I think well, we'll find out how supportive they are, depending on what happens next.'*

*(C12, breast cancer, interview 2, partner/carer)*

Further, returning to work on a daily basis proved difficult, as partners and carers struggled to deal with being absent from home:

*'He [partner] was saying "You get back to work, you get back to work," but I'm thinking, how can I go back and leave him on his own because he wouldn't even feed himself because he sleeps quite a lot just now, and he's no' got the energy ... we've started going out for walks in the afternoon because it seems to make him feel better and he's not in pain when he's out*

*walking. My mother stays down at ... so we've been walking down there ... he's been quite enjoying the wee walk.'*

*(C17, colorectal cancer, interview 2, partner/carer)*

Being a partner, carer, or partner/carer of someone with cancer, often entailed negotiating competing work and caring commitments. This included negotiating commitments to extended family, as illustrated below.

## 17.5 Stress and strain

Many partners/carers described increasing levels of strain as they progressed through the first year after diagnosis. One reason for this was because some of them precariously juggled competing care commitments, often caring for older relatives:

*'... I have got to say I am actually beginning to really feel the strain ... I have my parents to look after, too, but now P1 is becoming more unwell I am finding it difficult ... I tried to explain to the receptionist at my father's surgery that I can't be there tomorrow, because I will be with P1 at the [hospital], but I also tried to let them know that I need help with my parents, because there is a lot to be done each day there. I am doing it, but it's getting too much because it's not simply cooking for them, it's cleaning, changing beds, shopping, filling in forms, getting their money for them ...'*

*(C1, colorectal cancer, interview 1, partner/carer)*

For others, stress occurred when they were unable to attend to their own needs:

*'.. it's being up an' down an' sleepless nights, and because I've been up with him or when he's sleeping, sometimes I can't sleep, I'm just up to maybe three, four ... I'm tired, I just want to spend maybe perhaps the whole day in bed, you know?'*

*(C39, colorectal cancer, interview 2, partner/carer)*

Some people affected by cancer felt a sense of injustice at times, as they tried their best to manage:

*'... there's the day-to-day difficulties of trying to do the best you can in the face of sometimes quite difficult behaviour and being given a rough ride when you feel you don't deserve it,*



*when you're trying quite hard, and then feeling bad because you have allowed that to get to you in some way ... and it's affected the way you're relating ... I mean, I'm coping all right but eh, the biggest thing in my life, the most important thing in my life, is domestic harmony, I think this is the centre of your world, your home and your relationship with your partner ...'*

*(C55, breast cancer, interview 2, partner/carer)*

## 17.6 Interactive relationships and the care dyad: facing and conflict

A common feature, particularly in relation to couple relationships, was for the person with cancer and their carer/partner to talk about the importance of facing cancer together. In spite of their different roles and needs, many people affected by cancer constructed a shared understanding of their experience. For example, this was often illustrated by the use of the first person plural during interviews. For C12, cancer diagnosis and facing the illness was part of their reality too:

*'I think we have been able to manage a routine, I think we have been able to keep positive attitude, I think we have played it probably right with the kids ... we have now got to the stage where we're kind of trying to put ourselves, you know, first, as much as possible ...'*

*(C12, breast cancer, interview 2, partner/carer)*

Even prior to diagnosis, the possibility of ill-health for many people affected by cancer became a shared experience. This did not lessen as the cancer journey continued:

*'... we don't know what's coming ... everything else has been kind of a side-show and of lesser importance, so to be honest that's not the thing we are focusing on, we knew ... she got out the operation really well so that's great, but it's now move on ... I think if this, if this was the be all and end all, if this was it, then we would probably have a lot more to say, and a lot more to talk about, but because we know there's far greater challenges ahead, it's like OK, we've done it, move on, good ...'*

*(C12, breast cancer, interview 2, partner/carer)*

For some people with cancer and people affected by cancer, the experience enhanced, or in some ways consolidated, their relationship. P69 underlined the importance of the relationship as a form of interdependent support through the cancer experience:

*'... we really, em, we actually feed off each other, eh, under these darkest of circumstances in a really positive way em, I mean we laugh a lot, and there are tears, but there's a whole lot more laughter than, than, than there is em, tears ...'*

*(P69, lung cancer, interview 2, patient and partner/carer)*

At other times, the relationship between partner/carer was one of conflict and tension. The following quotation illustrates the importance of the relationship dyad and of carer/partner involvement in the interviews, adding a new dimension and interaction within the interview itself. For P63 and C63, cancer diagnosis, treatment experience, recovery and prognosis were inextricably intertwined within their relationship. In particular, P63 worked to negatively shape his interaction with C63 in the hope of lessening her emotional difficulties should prognosis be poor:

*P63: '... in my mind if I fall out with her, I just get crabby to her all the time, if anything happens to me, it'll ease the burden.'*

*C63: 'That's his attitude to me was, I want you to fall out, just fall out with me, don't talk to me much, I can't handle that, I says "That'll not make any difference to me, I'll still be here." "But I don't want you to talk to me, fall out with me." I mean, that's quite hard to handle, you know, when he's argumentative, just doesn't want me.'*

*(P63 lung cancer, interview 1, patient and partner/carer)*

However, as voice box 51 suggests, other partners/carers took their cues from the individual with cancer, rather than challenging the ways in which the person with cancer was behaving.

**Voice box 51:** Family members took their cues from the individual with cancer:

*'Her family, her son was very positive ... she lives alone. He did visit frequently but she was a very independent lady ... she didn't sit back and become a cancer patient ... she wanted to carry on and keep life as normal as possible. Baked oatcakes, I always remember every time she came in she said oh she was well enough to bake oatcakes so that kept everybody happy ... and that seemed to be the yard mark for the family – if she still managed to carry on while doing these tasks they were delighted.'*

*HP20, Clinical Nurse Specialist*

## 17.7 How the wider family is affected by cancer

Interviews within this study were restricted to people with cancer and partners/carers affected by cancer. Other wider partners/carers were not interviewed directly. However, despite this, the significance of the cancer experience for the wider family was a recurrent feature through the interviews. While there were many dimensions to the response of the wider family to the cancer experience, it was clear that patient experiences of cancer and cancer care could not be isolated from either personal or wider family relationships. P28 illustrated how far the ripple effect of cancer throughout his family had spread:

*'The thing that gets, I mean, a lot of people say what [partner] said there, that you're going through this hard time, but the thing that they don't realise is, it's not just me it's everybody... you'll have heard in the discussions with other people, that ... the family, I mean [partner's] been a rock through the whole thing ... my mum, my dad, eh, [partner's] mum and dad, my brother and sisters, and the family and the friends as well, I mean, I've got, we've got good friends and they would be on the phone at least once a week just checking to see how you were, and, they're all getting a bit of stress as well, I mean they're all concerned about you ... but you've got your friends that are like, well, so, and I mean, everybody's going through it, I mean they've been really concerned about her and eh, I tell them to take her on holidays and stuff like that.'*

*(P28, colorectal cancer, interview 2, patient and partner/carer)*

Some people with cancer described having to cope with more than their own feelings about cancer. Many people with cancer often discussed the wider family and/or specific partners/carers. This was in relation to concern about how they were coping and the related inability to sometimes express their own true feelings:

*'... if I'm feeling like "cack", I would tend not to really say ... 'I've got a sore head today' ... basically you don't want them worrying, you know what I mean?'*

*(P50, colorectal cancer, interview 2, patient)*

*'... my daughter ... she can't sleep at night because she's so worried ... the kids aren't coping and that's what gets me so upset, 'cause I can cope, I can, but when I see it in them it's like, it's terrible ... I'm coping with it alright, it's like, I feel as though my family aren't ... and that upsets me, if I can cope with it how the hell can they not? It's a vicious bloody circle ...'*

*(P26, gynaecological cancer, interview 2, patient)*

Some people with cancer described their own feelings of guilt in relation to the impact of their diagnosis and treatment on the family '... they've got to cramp their style because of me ...' (P44, lung cancer, interview 2, patient and partner/carer) while other people with cancer described the sometime distancing of partner/carers: '... my oldest son ... I think he's just keeping a wide berth ...' (P8, breast cancer, interview 2, patient)

Many others described the difficulties of family acceptance and adapting to diagnosis:

*'My son and daughter, they don't see any realistic signs of any demise on my behalf. They just think, well, you've been told he could last for five years ... It doesn't work out that way ... They won't accept that.'*

*(P33, colorectal cancer, interview 3, patient)*

Some other people with cancer described the wider family as a positive, sometimes critical, source of support and encouragement, and often preferred it in place of existing services, although this support, at times, was only tentatively embraced:

*'... they do, they have rallied round me and given me a lot of, given me support, but we don't go into depth about, about "the big C". 'Cause I would get up and walk away, you see.'*

*(P46, lung cancer, interview 2, patient)*

## **17.8 Moving on? How carers/partners experience post-treatment and recovery**

The sections above illustrate the reciprocal nature of care within the relationship and the family during cancer diagnosis and treatment. People with cancer, alongside people affected by cancer, provided an important – and interdependent – circle of support. This was no less evident during post-treatment. For many people with cancer and people affected by cancer, diagnosis, treatment, prognosis and recovery became a process to 'get through'. However, for many carers/partners and families, the journey did not end there. The use of prospective interviews in this project was revealing, as the following comment suggests:

*'I ... just think it was more, it was a kind of process and you were kind of part of a process ... I got a feeling it was a kind of sausage factory ... you know ... I should be feeling elated that it's all over, but you kind of feel as if, almost like I'm having my worries now, you know,*

*like I've stored them up and now they're coming through ... I shouldn't be like this ... I'm not quite what I was, kind of thing ... This is a year on, yeah, God ... it was a different first interview, wasn't it?'*

*(C12, breast cancer, interview 3, patient and partner/carer)*

Through the course of the final interview, C12 revealed a number of issues central to many people's accounts – the difficulty reconciling the experience and moving on. Some other people affected by cancer revealed continuing difficulties balancing family life, work, relationships, commitments and responsibilities. Many partners/carers found that finishing treatment was only half the journey and continued to experience physical exhaustion, stress and emotional difficulties. Several people affected by cancer identified how fear and anxiety could “come rushing back”, particularly when people recovering from cancer experienced everyday illness. C12 described experience post treatment and during recovery and reflected the comments of a number of partners/carers:

*'... there's a feeling that it's ok, treatment's finished, right, bye, see you, well no, see you for the next 5 years or whatever, every so often, but it's kind of like the process is through, so jump off the conveyor belt and go about your business as it were ... so we need to kind of get a bit proactive and make sure that ... we get a bit of direction and a bit of, I wouldn't say reassurance, but just basically how the process is going and what the next stages are, because you know, ok we've finished all the treatment but ... is it still there? Is it not there? Can it come back? Can it not come back? What happens when we've finished this course of treatment, if there's no more, well, what do we do?... it's a period of uncertainty just now ... we've gone through it all but you know, what's next?'*

*(C12, breast cancer, interview 3, patient and partner/carer)*

C63 also reflected several partner/carer experiences when she described the difficulty moving on from the experience:

*'... I'm actually finding it harder as time goes on, believe it or not. I find my life's changed completely, it's not his fault, don't get me wrong, I mean I love [partner], I'll always be here for him, always look after him, but I've got my bad days as well. You know some days I feel I need to get away from here for a wee while, but don't get me wrong, it doesn't stop me going out at all. But when I go out I feel guilty. I can't really relax.'*

*(C63, lung cancer, interview 3, patient and partner/carer)*

Fear of recurrence was a strong theme running through the narratives of people with cancer, but it also remained central to the narratives of their partners/carers:

*'... in the heavy moments and the moments when we're tired I don't say it and neither does she, but we have said it to one another once or twice, just wonders where is it going to pop up next?'*

*(C9, gynaecological cancer, interview 3, patient and partner/carer)*

A number of people affected by cancer expressed a need for support, but found difficulty asking for it because they were meant to be strong for the person with cancer:

*'... because you're not asking for help people maybe assume that you might be alright, and it would have been nice to have a bit more contact.'*

*(C55, breast cancer, interview 3, patient and partner/carer)*

*'There was a feeling in me that I was the healthy one, I was not the one that was undergoing the scary disease process.'*

*(C55, breast cancer, interview 2, patient and partner/carer)*

In light of this, some partner/carers adopted emotional self care strategies similar to people with cancer (see Chapter 6: Experiences of self care) to cope. An example was remaining positive and looking forward to events:

*'... it takes time, but as I say, well, we got good news there, as I said, our youngest daughter ... she's going to have a baby next year, so that's great ...'*

*(P34, prostate cancer, interview 3, patient)*

## 17.9 Conclusion

This Chapter highlighted the role of partners/carers and some of the tensions between the new, cancer-caregiving component of the relationship and other responsibilities, such as work and existing care roles. This tension indicates the need for whole-system understandings of people affected by cancer, and their responsibilities and roles beyond cancer.

## Section 18: DISCUSSION AND CONCLUSIONS

### CONCEPTUALISING THE EXPERIENCE OF CANCER CARE

This Chapter highlights key policy domains for understanding people's experiences of cancer and cancer care within the first year following diagnosis. As Chapter 1 shows, these are already familiar in health policy generally, and cancer policy in particular. The purpose of this Chapter, therefore, is to shed new light and deepen our understanding of these domains in relation to the experiences of people affected by cancer. In doing so, we highlight the strengths and weaknesses of existing policy that aim to improve people's experience of cancer care.

#### 18.1 Patient involvement and self care

There has been a recent policy thrust towards implementing an agenda of involvement (Department of Health, 2007; Scottish Executive, 2005a; 2005b). Our study explored two key ways in which people affected by cancer are involved in care practice: their involvement in treatment decision-making; and their involvement in self care. These two loci of involvement in practice are distinct, with one focusing on making decisions about care, particularly treatment, and the other focusing on the doing of care. However, they share common ground in the sense that they are both about involving people affected by cancer as partners alongside professionals in care practice.

Political involvement has been conceptualised as a continuum, with a citizen's ability, control, and power to make political and socio-economic decisions as representative of the highest level of involvement (Arnstein, 1969). This understanding of involvement has been uncritically applied to healthcare practice. Our study suggests that this political understanding of the concept of involvement is not appropriate in the context of people's involvement in care practice. Citizenship involvement cannot be easily equated with patient involvement in cancer care practice. It has

also been pointed out that neither can we assume that increasing opportunities for patients to have a greater say about their individual treatment decisions will automatically lead to greater opportunities for citizens and the public to have a say about public policy (Tritter, 2007).

The concept of involvement in treatment decision-making in this study emphasises the importance of synergy between expert knowledge (healthcare professional) and personal experience (patient). For instance, in relation to making decisions about treatment, control and power over treatment decision-making is not the role that most people affected by cancer prefer to play because it is perceived as unrealistic. Instead, people with cancer acknowledge that healthcare professionals are experts in their field, possessing specialist knowledge derived through medical training and clinical practice. They, therefore, trust healthcare professionals to decide on the best course of treatment for them, which is subsequently explained in detail. This type of involvement, therefore, does not imply that people with cancer are passive in the decision-making process; indeed, they demand explanations for treatment recommendations and recognise that they can ultimately refuse treatment (as several did in our study).

Alongside involvement in the process of treatment decision-making, involvement extends to the practice of care (Scottish Executive, 2003a; 2005a). Most people with cancer in our study experienced one or more of the following symptoms of cancer or side effects of treatment: tiredness, nausea and vomiting; hair loss; heartburn; loss of taste; loss of appetite; a metallic taste in the mouth; sweats; breathlessness; sleeping problems; constipation and diarrhoea; and to different degrees, self-managed these symptoms. Physical self care largely consisted of people with cancer self-medicating prescribed drugs, wound care, getting a wig fitted, resting during bouts of tiredness, using complementary therapies, and making a range of lifestyle changes, including smoking cessation, taking up exercise, and altering diet.

Together with physical self care, people with cancer also engaged in emotional self care, or what has also been described as 'coping strategies'. This is a type of self-care that requires attending to, not just the effects and requirements of treatment, but also attending to the significance or meaning of their illness. Emotion was a key feature of the narratives of people affected by cancer in our study from diagnosis onwards, with people making reference to specific felt emotions, such as shock, fear, anxiety, worry, stress, depression, nervousness, anger and sadness. Our study highlights particular anxiety-provoking experiences, including perceptions of an initial misdiagnosis because symptoms were not immediately associated with cancer, waiting for the results of tests and investigations, changes to planned treatment, being told a diagnosis of cancer,



not being clear about what was happening or going to happen, and the period immediately after treatment had finished when people with cancer were left to get on with their lives. Current policy and guidelines have striven to improve people's experiences in relation to these issues; for example, NHS QIS (2007:11) standards state that, 'timely referral, diagnosis and treatment for patients suspected of having cancer' should be achieved, but policy also needs to take cognisance of the wider social context of care and the ways in which people develop coping strategies to manage their illness in their family, work and community environments. People with cancer and also partners/carers, for instance, adopted a range of self care strategies, including: normalising their experience and as far as possible, managing their daily lives as normal; distraction for example, by continuing daily activities and/or remaining socially active and engaging in tasks that require concentration or the ability to relax; pragmatism, a step-by-step approach, including, for example, setting reachable goals, such as preparing for a birthday celebration or planning a holiday; and comparison, a strategy whereby people with cancer seek succour by comparing themselves to those whose experience is worse than theirs because they are able to perceive and define themselves as lucky and fortunate, despite having cancer.

What these strategies highlight is the importance of being able to find something positive within, what is, to all extents and purposes, the very negative experience of being diagnosed with cancer. Remaining positive is a strategy that continues from diagnosis through treatment and follow up. It is a mindset that was ubiquitous in the narratives of many of the interviews conducted over the course of the first year following diagnosis. Although there is no conclusive evidence to suggest that being positive during a life-threatening illness will improve or impact on morbidity, mortality or well-being, our study suggests that people with cancer wish to remain positive and healthcare professionals encourage this position. A positive attitude – or the need for a positive attitude – also remains strongly in evidence after treatment finishes and as people affected by cancer move further away from regular contact with healthcare professionals. Yet many of these coping/self care strategies become increasingly difficult. As people with cancer reflect on the past year, the growing realisation that they are not the same person intensifies. A life-threatening illness can amount to a 'biographical disruption' (Bury, 1982: 169) and effect change in one's sense of self that may be experienced in a number of ways, including disrupting assumptions and behaviours, requiring a response to this disruption, and, at times, a rethinking of self-identity. This also has implications for the level and type of follow up care and service provision provided for people moving beyond immediate cancer care.

Seeking information can also be conceptualised as a self care strategy. People with cancer in our study for instance, sought information about their treatment, side effects and complementary therapies, because being clear about what was going to happen or had happened was important to them and was perceived to alleviate anxiety and worry. On the other hand, information could have the opposite effect, making people worry more and become scared. This highlights that the relationship between knowledge and emotion is contradictory, since information can have the opposite emotional effect. Some healthcare professionals in our study appeared to understand this, because whilst they were willing to provide as much information as possible, there was a perception that they only gave information if requested, and downplayed the side effects of treatment. Some people with cancer appreciated that healthcare professionals only gave some information on request because it gave the person with cancer a degree of control over what information they received; others, however, found it frustrating because their experience of cancer was new and they, therefore, did not know what to ask until after the event.

Moreover, given some of the positive and negative consequences of accessing additional information and some of the reasons for and against seeking additional information, it is not surprising that some people affected by cancer adopted strategies to manage these contradictions, including waiting until they felt sufficiently mentally and emotionally 'strong' before they sought information, moderating the amount of information that they sought, deliberately avoiding information that demonstrated the negative impact of cancer, and using the information that they had found to enter into a discussion with healthcare professionals. The challenge for healthcare professionals, therefore, is to individualise their information strategy to accommodate people's differing information needs. This is because the difficulty for most people affected by cancer and healthcare professionals is not lack of available information, but knowing when, how and where it is appropriate to access and utilise it.

## **18.2 Partnership working and community-based care**

Some of this study has focussed on individual experience and the relationship between people affected by cancer and healthcare professionals. Yet, people experience cancer and cancer care in much wider contexts, including the whole care system, which is composed of different sectors (primary, acute and tertiary), and their employment and social networks. In Scotland, Joint Future (Scottish Executive, 2007b) attempts to recognise this and is the lead national policy on joint working between local authorities and the NHS in community care. Its main aim is to provide faster access to better and more joined-up services through improved joint working. Community Health

and Care Partnerships have been established locally in order to implement this policy directive (Scottish Executive, 2005a). Various strategies have been developed to encourage this type of working at both strategic and operational level in cancer care, largely through the three Regional Cancer Networks (SCAN, NOSCAN, WOSCAN), within which are Managed Clinical Networks that centre around specific cancer types, for example, breast cancer. The Joint Future Unit has recently turned its attention to patient outcomes, and an expected outcome of partnership working is that patients experience care as seamless and that communication between the various sectors and services are smooth and efficient, resulting in greater satisfaction with the service. NICE guidelines in England for instance, point out that:

'Lack of co-ordination between sectors (for instance, hospital and community) and within individual organisations has repeatedly been viewed as a problem in studies of patients' experience'.

*(NICE, 2004:6).*

Our study highlights, however, that whilst some people with cancer experienced seamless care, many others still experienced a gap in care between tertiary (cancer centre) and primary care (GP). For example, an experience of a gap in care between these two sectors was either because the GP had not been notified or because they had not acted on a notification. Some people with cancer, for instance, anticipated that their GP would contact them once they were alerted to their diagnosis of cancer by a consultant, or following surgery. This failure to respond meant that some people with cancer perceived they did not receive supportive care from their local primary care team. A further example of a difficulty at the tertiary and primary interface encountered by some people with cancer was when they received contradictory or mixed messages from consultants and cancer nurse specialists and their GP, which was identified by people as a source of anxiety. These difficulties are particularly problematic, given the prominent role primary care is anticipated to play in a healthcare future where people are being increasingly cared for in their local communities (Scottish Executive, 2005a).

As the current policy direction of travel towards partnership gathers pace, other services and sectors have been brought in to the healthcare planning and service delivery arena, including social care. For example, in England, NICE (2004) guidelines already acknowledge the need for advice on employment issues and assistance in securing financial benefits. Our study underlines that employment and financial agencies should be part of a health and social care partnership. This is because virtually all people affected by cancer required support and advice since they

experienced additional costs as a consequence of having cancer, including travel and heating costs. Yet, this type of support and advice was sporadic and ad hoc. Furthermore, some people affected by cancer were not clear about employment rights and may have benefited from their employers being automatically involved in a partnership for care because these are key to ensuring that the person with cancer receives sick pay and has a return to work that is tailored to their individual needs. Referring to a concept discussed in more detail below, enabling a culture of care is not solely the preserve of healthcare professionals, but includes all who are in contact with people affected by cancer. In particular, employers have a duty of care, which includes supporting people with cancer. Our study suggests that an employer who enabled people with cancer to negotiate a phased return to work and were able to change work practices by for instance, not working as hard or not lifting heavy items, facilitated people's recovery. Colleagues also played a role through expressions of caring for the person affected by cancer. This again illustrates the significance of a partnership perspective that moves beyond a purely clinical focus and embraces other wider and social environments.

### 18.3 Culture of caring

Current NHS QIS (2007) standards emphasise consideration of individuals' needs and preferences within a culture of caring. The development of a culture of caring within cancer care largely entails a healthcare staff that shows compassion and treats the whole person as opposed to the disease in isolation. As a conceptual framework, a culture of care recognises three critical system factors that affect the individual's experience of cancer and care: lack of resource, particularly time to devote to the care of the individual; increasing technological development, including the array of highly advanced diagnostic and therapeutic tools available; and the (related) development in specialisation and specialist practice that may encourage a technical, rather than a personal, interaction between people with cancer and healthcare professionals. To enable a culture of caring, cancer care must move beyond traditional frameworks of treatment and care and combine notions of person-centred care (ensuring care is organised around patients' immediate needs and wishes) and holistic care (extending beyond basic clinical care to address wider patients' needs and wishes). Consequently, any national strategy has to be flexible and responsive to individual coping strategies and information choices (Leydon et al., 2000). This requires an understanding of what the experience of cancer is like for people with cancer and their partners/carers, and an ability to show genuine empathy. It is often what is sometimes regarded as the small and seemingly insignificant things that make all the difference to a person's experience of care, whether that is a phone call from the GP after diagnosis, or a sympathetic response to pain experienced during

tests and investigations. Development and support for a culture of care also enables people with cancer to contribute to the planning of their own care and to further develop competency in self-care. Yet, as already mentioned, with increasing resource pressures allied to technological advances, this critical characteristic of a culture of care may be disregarded.

Whilst our study found that the overwhelming majority of care delivered by healthcare professionals was compassionate, empathic and respectful to the person affected by cancer, poor care was also indicated. At times, inconsideration of the feelings of people with cancer and lack of awareness of the effect that poor care has on them was in evidence. Some examples at the time of diagnosis include telling the person of the results of tests and of their diagnosis over the telephone and via a secretary, as opposed to face-to-face by a consultant. These difficulties highlight the significance of communication skills, which are acknowledged in current policy (Scottish Executive, 2003b). Some examples at the time of treatment include, lack of healthcare professionals with sufficient specialist knowledge able to talk to the person with cancer about their individual case, and lack of care on the hospital ward when it is perceived to be needed. Some examples, through follow-up and after-care, include: failure to link patient information between acute, tertiary and primary care sites, despite the NHS QIS (2007:16) essential criterion that 'There are clear links between primary, secondary, tertiary, supportive, and palliative care services'; failure to recognise the emotional impact of ending treatment for a life-threatening illness; and failure to meet the requirements for follow-up care beyond the treatment process itself.

The importance of developing a culture of care is evidenced in health policy as discussed in Chapter 1. The concept suggests that care is not just about 'outcome' and providing people with the right diagnosis and treatment – although this is imperative – but also about 'process' and the ways in which healthcare professionals and people affected by cancer interact and relate, both through and beyond the treatment process. However, while the development of a culture of care is considered fundamental to healthcare and nursing practice, the experiences of people with cancer indicate that this cannot always be taken for granted. NICE (2004) guidelines, for instance, highlight the need to recognise both the physical and related psychological and emotional impact of cancer and cancer care, a point that still remains relevant today. Current policy drives towards reducing waiting times, and improving morbidity and mortality, are fundamental to people affected by cancer. However, without a culture of care being embedded in clinical practice and target-setting, the risk remains that the individual with cancer will be treated as a disease rather than as a person.

## 18.4 Role of partners/carers

Current policy recognises the central role of relatives and other carers in supporting people with cancer (NICE 2004, Scottish Executive, 2005a; 2005b; 2007a). Our study clearly marked out changing roles for partners/carers of people with cancer, plainly indicating the impact of cancer beyond the diagnosed patient. Relatives took on a range of practical, physical and emotional tasks, often beginning before the diagnosis. Indeed, family members identified themselves as having a key role in encouraging the person with cancer to seek initial appointments and tests leading to diagnosis. The triadic relationship between patient, partner/carer and primary care team therefore plays a central role in the family stories around diagnosis and how symptoms were communicated and managed. For instance, the identity work within partner/carer narratives across the interviews constructs a polarity, where family members take up a position around timely diagnosis, whereas primary care physicians are implicated more often in delayed diagnosis.

The label of carer was contested and rejected by many people in this study. The meaning of carer was deemed incompatible with the existing relationship. Additionally, people associated the term 'carer' with increased severity of the disease. The idea of being, or having, a carer represented a shift in the seriousness of the cancer. Resistance to the label is important in enabling people to construct their own identity, that of the person with cancer and the expected/anticipated prognosis of the illness.

It is evident that family relationships change throughout the course of the disease. Markers of normality became important in enabling people to negotiate and document their changing relationships, their grip on cancer and cancer's grip on them. The case for prospective, rather than retrospective, studies of cancer is therefore underlined, as those affected by cancer are able to report real-time reflections on their experiences.

Our study highlighted tensions between the new, cancer - caregiving component of the relationship and other responsibilities such as work and existing care roles. This indicates the need for whole-system understandings of people affected by cancer, and their responsibilities and roles beyond cancer.

While the above sections highlight key policy initiatives in four domains, it is easy to lose sight of the totality of people's experiences. An advantage of this study, which prospectively explored people's experiences over the course of a year, is that it is possible to map the evolving nature

of people's experiences within these domains over time. The purpose of the section below is to emphasise both continuity and change as people with cancer experience involvement and self-care, partnership working and community-based care, a culture of caring and the role of partners/carers.

## 18.5 Continuity and change: mapping cancer experiences

NICE (2004: 5-7) guidelines recognise that 'patients have different needs at different times during their illnesses,' and that 'people affected by cancer should be offered a range of physical, emotional, spiritual and social support'. These points are also recognised in Scottish Executive (2005a; 2005b) directives and are confirmed by the current study. This section maps the evolution of experience as people with cancer move from diagnosis, treatment, to living with cancer following treatment.

People's perceptions of their physical and emotional experiences suggest that they change over time and that the type of healthcare required to manage them should complement and run parallel to their experience. During the period leading up to diagnosis as people undergo tests and wait for the results of these investigations, people may be afraid and anxious and may also experience physical pain. Violent descriptors of investigations include being "punched", "stabbed", and "destroyed". People undergoing these investigations appear to be acutely alert and attentive to non-verbal communicative behaviours by healthcare professionals as they wait to find out their diagnosis. Whether consciously delivered or not, these non-verbal clues serve to lay the ground for eventually receiving bad news verbally. Despite the groundwork being done and earlier policy emphasis (Scottish Executive, 2003b), people still find a diagnosis of cancer shocking. At this point in time, healthcare professionals may be required to tread a fine line between giving bad news whilst enabling people to remain positive and maintain hope.

It is also at this point in time that information is difficult to absorb by people who have been given the diagnosis, possibly because of the magnitude of the impact of being given a cancer diagnosis on mental state, a point recognised through earlier policy directives (Scottish Executive, 2003a; 2003b). In particular, NICE (2004: 9) guidelines recognise that people with cancer should be offered support to understand any information that is made available and that it should be applied to their own individual situation:

" ... patients and carers [should] have easy access to a range of high quality information materials about cancer and cancer services. These materials should be free at the point of

delivery and patients should be offered appropriate help to understand them within the context of their own circumstances.”

In our study, healthcare professionals adopted strategies in an attempt to minimise the shock or soften the blow of a cancer diagnosis. This was an incremental process, involving non-verbal as well as verbal clues, so that the shock was not as great as it possibly would have been without this preparation. In the current study, healthcare professionals recognised that people affected by cancer would not automatically absorb information and, in some cases, a range of strategies had been developed to circumnavigate this including having a clinical nurse specialist on hand to answer questions, discuss issues at length and encourage partners/carers to be involved so that they could relay information to the person with cancer. However, these well-received strategies were not in place for all people with cancer in our study.

As well as being a shock, a diagnosis of cancer can also lead to an immediate loss of confidence, an inability to concentrate, and strong emotion. For some people with cancer, this means that they immediately stop going to work and some may never go back. In this study, despite physical and emotional impediments to working, some people with cancer wished and were able to work throughout their treatment. Thus for those who wished to return to work forward supportive planning, beginning as soon as the individual with cancer signs off sick, in liaison with their employers, could be beneficial and should include strategies that take account of both the physical and emotional impacts of cancer. A financial strategy for people diagnosed with cancer should also be developed as soon as possible. Our study suggests that during treatment people experienced increased expenditure as they incurred travel costs for treatment and increased heating bills. Those without adequate sick pay faced the additional worry of covering mortgages and other household bills during time off work, which for some, can be prolonged beyond treatment. Whilst work may not be the priority for people immediately upon diagnosis, our study suggests that many people with cancer wanted financial advice and to be supported to return to work during treatment.

Throughout the treatment decision-making process information becomes increasingly significant. NHS QIS (2007) standards highlight enablement and patient support as essential criteria to patient decision-making. Our study suggests that treatment decision-making is a key opportunity to involve people affected by cancer in their care. People affected by cancer are keen to hear healthcare professionals' reasons why they are being offered particular treatment and they wish to be involved in decision-making. Furthermore, most people affected by cancer want to move



beyond the 'what', towards the 'whys and 'wherefores'. They want healthcare professionals to explain why they are recommending particular investigations and treatments and why they, as individuals, are or are not experiencing specific side effects and symptoms. It is not enough to be told what is going to happen; people affected by cancer also want to know why.

Verbal explanation as opposed to a written description of what treatments are being recommended is important during the treatment decision-making process. This is because trust takes on growing significance; it is during treatment decision-making that people affected by cancer feel a need to trust and put their faith in the experts i.e. the surgeon or oncologist to make the best treatment decision for them. Trust, however, breaks down when healthcare professionals are deemed not in possession of the required specialist knowledge because without it, they are unable to offer explanations. This partly explains why GPs came under criticism in our study because they could not always provide the answers about some aspects of cancer care since they did not possess specialist knowledge. This is problematic given the central role that many GPs play in people's care in the first year following diagnosis including diagnosis, drug prescribing, supporting people experiencing symptoms and treatment-related side effects, and providing aftercare or follow-up support and treatment.

At the time of treatment (surgery, chemotherapy and radiotherapy) physical experience takes on increasing significance and includes fatigue, nausea and vomiting, hair loss, heartburn, loss of taste, loss in appetite, metallic taste, sweats, breathlessness, sleeping problems, constipation and diarrhoea, and people with cancer may self care to mediate these symptoms. Self care has been advocated in recent Scottish policy (Scottish Executive, 2005a; 2005b) and in England, NICE (2004) supportive care guidelines value 'the knowledge, skills and resources that patients already have, enabling them to contribute to their own care and support'.

Remaining positive continues to be important during treatment. Some people start to take control by developing strength and determination to get the 'job' of having treatment completed and over with. Self care strategies for managing the emotional consequence of being diagnosed with cancer start to emerge, including activities to retain a sense of normal life outwith the cancer experience and to take one's mind off cancer. Other people with cancer, however, welcome opportunities to talk about their experience of cancer as opposed to avoiding and bracketing it off from other aspects of daily life. Another strategy used by some people with cancer is humour and our study shows that laughing and joking with others who were also undergoing treatment can make the experience of surgery less worrying.

During treatment, the overwhelming majority of people affected by cancer in our study wanted to know potential side effects and symptoms. NHS QIS (2007: 17) standards highlight that patients/carers be given tailored information about patient care rights, options, outcomes, risks and side-effects on an ongoing basis, and that there should also be a clear record of what was conveyed about such issues. People affected by cancer wanted information prior to procedures and treatments that did not downplay or disguise the fact that investigations and treatments could be very painful and carried risks. This is straightforward and practical information that is given both orally and in writing. Much of this basic information was available to people affected by cancer in our study, but there were information gaps. An example was lack of information to support changes in lifestyle. For those people with cancer who expressed a willingness and enthusiasm to change their lifestyle in order to optimise the effectiveness of their treatment and their chances of recovery, this was unfortunate, particularly given the growing body of evidence pointing to the value of exercise and diet.

After treatment, people with cancer also underwent tests and investigations to find out if their treatment had been successful and also how they were progressing. Descriptors of these investigations highlight that the experience is both physically and emotionally demanding. Terms used to describe the actual moment of investigation included soul destroying, painful, uncomfortable, horrendous, horrid and agony. In this study, it is the emotional experience that comes to the fore during this time as people with cancer worry about both investigations and the results of investigations. This is further compounded if they have to wait for these results or if they have been given insufficient information to make decisions. A clear explanation, therefore, about why investigations are to take place and what the results signify may provide support for people with cancer during this period.

Irrespective of diagnosis, narratives post-treatment are imbued with feelings of fear and worry of cancer recurrence. This study illustrates how it is also a time when people with cancer become reflective and take stock of their experience. It is an opportunity to clarify with individuals exactly what cancer they had/have (some people in our study did not know), what was removed during surgery (again, some people in our study did not know) and to discuss their physical and emotional experiences since diagnosis. Some people with cancer struggle with an expectation from family and healthcare professionals to return to 'normal life' after having experienced a life-threatening illness with its associated physical and emotional impact and express a need to have the seriousness of their experience acknowledged rather than downplayed or dismissed.

In essence, mapping the continuum of experience as people affected by cancer move from diagnosis, through treatment, to living with cancer following treatment has shown that people's physical, emotional and social perceptions and requirements are intricately interwoven, intensely personal, many-layered, fluid and change over time. To enable policy and practice to relate to patient experience, the type of wider partnership-based healthcare required to involve and care for those affected by cancer should embody a whole system understanding of these and their roles and responsibilities beyond cancer, and harmonize and run parallel in time to their experience. The following chapter presents a series of recommendations for policy-makers and service planners, healthcare providers and practitioners, as well as researchers, that is grounded in the conceptual analysis of people's experiences of cancer that has been presented in this chapter.

## SECTION 19: CONCLUSION AND RECOMMENDATIONS

As a consequence of this study it appears that there is potential to improve the experience of people affected by cancer in Scotland. This chapter sets out a number of recommendations within the context of policy, practice and research that would facilitate improvements in care within the following domains:

1. Patient involvement and self care
2. Partnership and community-based care
3. Culture of caring
4. The role of partners/carers

As Chapter 1 highlights, these domains are identified within Scotland's Cancer Plan and our study, which describes the experience of people with cancer in the first year following diagnosis, is able to contribute to the process of developing these plans and taking them forward by making a series of recommendations that are rooted in, and based on, patient experience. These recommendations are not only based on the experiences of people affected by cancer who were interviewed in this study, but as already described in Chapter 2, members of the Cancer Care Research Centre's Patient and Carer Advisory Groups who advised us as we developed the recommendations for cancer care. Furthermore, these recommendations take cognisance of existing research evidence and recent NHS QIS Standards for Cancer Services (2007). It is intended that these recommendations will be utilised in shaping future cancer care policy and facilitate improvements in the experiences of people affected by cancer.

Each section begins with a key point, which attempts to capture the essence of the domain and the kernel of critique of current policy. This is followed by some specific recommendations for policy-makers and service planners, healthcare providers and practitioners and researchers.

## 19.1 Conceptualising experience and recommendations

The physical, emotional and social perceptions and requirements of people affected by cancer are intricately interwoven, intensely personal, many-layered, fluid and change over time. To enable policy and practice to relate to patient experience, the type of wider partnership-based healthcare required to involve and care for those affected by cancer should embody a whole system understanding of these and their roles and responsibilities beyond cancer, and harmonize and run parallel in time to their experience. The policy, practice and research recommendations below focus on the four policy domains listed above and begin with a key point, which attempts to capture the essence of the domain and the kernel of critique of current policy.

## 19.2 Patient involvement and self care

**Key point:** Political understandings of the concept of citizen involvement in political and socio-economic decision-making cannot be uncritically applied to healthcare practice. This is because full power and control in decision-making about care is perceived by patients as unrealistic. Instead, the concept of patient involvement in healthcare practice needs to emphasise the importance of synergy between expert knowledge (healthcare professional) and personal experience (patient). A vital component of this synergy between expertise and experience is information and communication. It is not sufficient for healthcare professionals to simply provide information about, for example, treatments and self care, they should also constantly consider patients' understanding of it and how it relates to their social and wider circumstances. The difficulty for most people affected by cancer and healthcare professionals is not lack of available information but knowing when and where it is appropriate and useful to access and make sense of it.

**Key recommendation:** In order to move beyond policy rhetoric, providing training for healthcare professionals and evaluating the ways that patients and carers are involved in their care (for example, in treatment decision-making and in self care) and the outcomes of their involvement is required.

## 19.3 Partnership working and community-based care

**Key point:** Partnership and joint working has been a key component of health policy in Scotland for nearly a decade but results from this study would suggest that more work needs to be

done to deliver it, particularly in relation to bridging the gap between tertiary (cancer centre) and primary care (GP). This gap is particularly problematic given the prominent role primary care is anticipated to play in a healthcare future where people are being increasingly cared for in their local communities. Moreover, given that people experience cancer beyond the clinical environment and in social and wider contexts, welfare advice and employment agencies may also be considered as partners in supporting people with cancer.

**Key recommendation:** Clear guidance for how and when tertiary and primary care professionals communicate about an individual patient and guidance on what information and what care each partner is expected to deliver should be developed. This has to be transparent to all partners including patients and carers. The partnership should consider extending to involve other agencies. It should be clear to them who in the partnership they should contact to support them and meet their needs.

## 19.4 Culture of caring

**Key point:** The concept culture of caring suggests that care is not just about 'outcome' and providing people with the right diagnosis and treatment – although this is imperative – but also about 'process' and the ways in which healthcare professionals and people affected by cancer interact and relate. In particular, it draws attention to a person's emotional needs and mental well-being as well as their physical health from diagnosis through to follow up and living with cancer. Current policy drives towards reducing waiting times, improving morbidity and mortality are fundamental to people affected by cancer. However, without a culture of care being embedded in clinical practice and target-setting, the risk remains that the individual with cancer will be treated as a disease rather than as a person.

**Key recommendation:** Ensure continuing professional development for healthcare professionals, which is evaluated on a regular basis, in relation to all aspects of a culture of caring from diagnosis, treatment, follow up and to living with cancer.

## 19.5 Role of partners/carers

**Key point:** The role of partners/carers in supporting people with cancer is increasingly recognised in health and social policy, and healthcare practitioners are expected to work in partnership with partners/carers. Evidence from this study indicates that practitioners may fall short of

implementing these policies because of a lack of understanding of why and when individuals with cancer include partners/carers and how family relationships change throughout the course of the illness. Moreover, without understanding family dynamics, working with and supporting carers will be limited.

**Key recommendation:** A review of partner/carer relationship-based health care policy, to ensure that the policy frameworks reflect and acknowledge the relational context of cancer, including the influence and impact of relationships.

## 19.6 Conclusion

On undertaking this aspect of the project *Developing cancer services: Patient and carer experiences* on behalf of the Scottish Executive Health Department we recognised the challenges involved in fully engaging with the experiences of people affected by cancer. This was particularly so given the importance of capturing their prospective experience over the first year following a diagnosis of cancer and therefore, the need to recruit them as close to diagnosis as possible was a very challenging time for the patients and their partners/carers.

Whilst this study identifies important new information that can be utilised to develop cancer services, what is most important is that this is the largest study of its kind in attempting to understand, from the perspective of people affected by cancer, the actual experience of cancer and cancer treatment. We acknowledge that a number of the recommendations will not be unfamiliar (Scottish Executive, 2001; Scottish Executive, 2004; NICE 2004; Scottish Executive, 2005a; NHS QIS, 2007) **what is concerning is the need to continue to make these recommendations despite this familiarity.** This raises a number of issues. First, it is recognised that the drive to improve cancer services since the late 1990s has resulted in significant improvements in terms of reduced waiting times and improved access to treatment. The importance of these issues for patients should not be underestimated. However, this study suggests that driving an agenda that focuses on diagnosing and treating the disease may be at the cost of developing a culture of caring for the person with the illness that focuses on the entirety of their experience.

Second, much of what we discovered about the experiences of people affected by cancer is not entirely surprising. The fact is, issues such as communication, symptom management, continuity of care, financial issues, living with cancer and a number of others remain significant concerns for people affected by cancer. Within these domains there is a plethora of literature which,

if implemented, could impact on care delivery, however, full implementation has yet to occur. This calls for robust and consistent evaluation of cancer services that go beyond the standards identified within the recent NHS QIS standards for cancer service (2007) and ensure connectivity between evidence on cancer care and applications in practice.

Third, the results from this study question the development of a range of policy directives of recent times. This is not to suggest that the direction of travel is not correct or, as indicated above, that improvements have not been made, but as indicated within Cancer in Scotland (Scottish Executive, 2004) "There is much more to be done". The fundamental question raised as a consequence of this study is whether current policy is capable of making the necessary changes that will really make a difference to the experiences of people affected by cancer. From the results of this study that would seem unlikely given that the policy is not rooted in, nor derived from, the experiences of people affected by cancer. We recognise that people affected by cancer contributed in part to the development of contemporary cancer policy. This is, however, different from understanding in-depth, and over time the lived experience of individuals and their prospective accounts of that experience.

To enable optimal impact there needs to be more robust mechanisms for the development of policy, ensuring that patient experiences are at the core and drive priorities. Whilst we recognise the challenges in this approach, given the depth of information possible and the meaningful contribution this can make at a range of levels, we would urge that future policy development utilises an approach drawing on in-depth accounts of the illness to ensure that it reflects, in a substantive way, the experiences of people affected by cancer. In doing so we may begin to see far greater impact of policy and practice developments that result in cancer services embracing a culture of caring ensuring significant improvements in the experiences of all people affected by cancer in Scotland.



## SECTION 20: REFERENCES

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## Appendix 1

Patient (and carer) interview 1 Main focus is diagnosis	Patient (and carer) interview 2 Main focus is symptoms	Patient (and carer) interview 3 Main focus is follow-up
<p><b>Pre-diagnosis</b></p> <p>Can you tell me what was happening to you before you were diagnosed?</p> <p>Aim of questions is to find out about patient experiences of:</p> <ul style="list-style-type: none"> <li>• Symptoms prior to diagnosis</li> <li>• Other illnesses – co-morbidity</li> <li>• What prompted them to seek advice (unless emergency admission)</li> <li>• GP response (unless emergency admission)</li> <li>• Thoughts and feelings at this time</li> </ul>		
<p><b>Diagnosis</b></p> <p>Can you tell me about your experiences of being diagnosed?</p> <p>Aim of questions is to find out about the patient's experiences of:</p> <ul style="list-style-type: none"> <li>• Referrals for tests</li> <li>• Waiting times</li> <li>• Experiences of being told had cancer</li> <li>• Prognosis if given</li> <li>• Thoughts and feelings at this time</li> </ul>		<p><b>What has been happening since we last met?</b></p> <p><b>Purpose:</b> To find out about follow-up (or treatments if still having treatments)</p> <ul style="list-style-type: none"> <li>• Have you had any more treatment?</li> <li>• How have you been recovering since your treatment finished?</li> <li>• Have you had any follow-up appointments since your treatment finished? If so:</li> <li>• When was it?</li> <li>• Who was there?</li> <li>• What was said?</li> <li>• Any written information?</li> </ul>
<p><b>Information</b></p> <p>Can you tell me what information you were given and/or sought for yourself?</p> <p>Aim of questions is to find out about verbal and non-verbal information:</p> <ul style="list-style-type: none"> <li>• What information</li> <li>• Who gave it</li> <li>• Their information-seeking activities</li> <li>• Their thoughts and feelings about information</li> </ul>	<p><b>Information</b></p> <p><b>Purpose:</b> To compare what they said in the first interview to see whether their information needs and information seeking behaviour has changed over time.</p> <ul style="list-style-type: none"> <li>• What information about cancer and cancer care have you been given since last we spoke? Who gave it? In what format? Opinion on this verbal and written information.</li> <li>• Have you been seeking/wanting more information? If so, what, why and how have you gone about getting information?</li> <li>• Have all your questions been answered to your satisfaction? Is there anything that you would like to know or be told about?</li> </ul>	<p><b>Information</b></p> <p><b>Purpose:</b> To find out about their information needs and information seeking behaviour has changed over time at this stage.</p> <ul style="list-style-type: none"> <li>• What information about cancer and cancer care have you been given since last we spoke? Who gave it? In what format? Opinion on this verbal and written information.</li> <li>• Have you been seeking/wanting more information? If so, what, why and how have you gone about getting information?</li> <li>• Have all your questions been answered to your satisfaction? Is there anything that you would like to know or be told about?</li> </ul>

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**Symptoms**

Can you tell me about any symptoms you've experienced?

Aim of questions is to find out about:

- Experiences of, and feelings about, symptoms
- Causes
- How affect life
- How being managed

**Symptoms**

**Purpose:** To find out about (i) physical symptoms (ii) psychological symptoms during treatment

- What symptoms are you/ have you experienced since we last met?
- What do you think was causing these symptoms?
- How did these symptoms impact on your life? (work, leisure, family)
- How did you manage these symptoms? Did you get any support? (from services, family and friends)

**Symptoms**

**Purpose:** To find out about (i) physical symptoms (ii) psychological symptoms during treatment

- What symptoms are you/ have you experienced since we last met?
- What do you think was causing these symptoms?
- How did these symptoms impact on your life? (work, leisure, family)
- How did you manage these symptoms?
- Did you get any support? (from services, family and friends)

**Plus MSAS Scores**

1. Take graphs of any symptom where the person scored 3 or 4 on the distress scale in any month.
2. Show the person the graph showing distress scores over time and ask them to talk about their scores e.g.
  - What was happening when the symptom was causing distress?
  - What did you do at the time?
  - Did you get services and support at this time?
  - Why was it no longer causing distress/why is it still causing distress?

**Treatments**

Can you tell me about what treatments you've had?

Aim of questions is to find out about treatments:

- What treatments
- How affect life
- Their thoughts and feelings

**Treatments**

**Purpose:** To explore in-depth their physical and psychological experiences of treatment and symptoms during treatment.

- What treatments have you had? What happens – what is done to you? Who by? Where do you go for treatments? Any transport issues?
- What has been the impact of the treatment on your life?

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**Psycho-social issues**

Can you tell me about the ways in which having cancer has impacted on your life?

Aim of questions is to find out about experiences and feelings in relation to:

- Impact on family
- Impact on work
- Impact on finances
- Impact on social life and leisure
- Any services and support for any of the above
- Why me, why now?
- What the future holds

**Psycho-social issues**

**Purpose:** To explore the 'why me?' question

- Since we last met have you asked yourself "why is this happening to me?"
- If yes, what prompts these thoughts? What helps you deal with them?
- When you think about the rest of the year, between now and Christmas, how do you feel, what do you think?
- What about further into the future, what affect, if any, has having cancer had on the way you think about the future or what the future holds?
- What, impact if any, has your experiences of cancer and cancer care had on the way you think about cancer and on what happens to people (patient, families etc) who have cancer?

**Psycho-social issues**

**Purpose:** To explore the 'why me?' question

- Since we last met have you asked yourself "why is this happening to me?"
- If yes, what prompts these thoughts?
- What helps you deal with them?
- When you think about the future, how do you feel, what do you think?
- Can you tell me about the ways in which having cancer has impacted on your life?
- Aim of questions is to find out about experiences and feelings in relation to:
- Impact on family
- Impact on work
- Impact on finances
- Impact on social life and leisure

**Services and support**

Can you tell me about the services and support you've had?

Aim of questions is to find out about their experiences and feelings in relation to:

- Acute hospital consultants & nursing staff
- Primary and social care staff e.g. GP and district nurse
- Voluntary sector

**Services and support**

**Purpose:** To find out what support people need and get during treatments

- What has been the involvement of healthcare professionals during your treatment? Who were they? Opinions on support or lack of support?
- What has been the involvement of family members during your treatment? Opinions on support or lack of support?
- What has been the involvement of friends and neighbours during your treatment? Opinions on support or lack of support?
- What has been the involvement of other patients and carers during your treatment? Opinions on support or lack of support?
- What could have been improved or done better to support you during your period of treatment?

**Services and support**

**Purpose:** To find out what support people need at this stage

- What has been the involvement of healthcare professionals since your treatment has finished? Who were they? Opinions on support or lack of support?
- What has been the involvement of family members since your treatment has finished? Opinions on support or lack of support?
- What has been the involvement of friends and neighbours since your treatment has finished? Opinions on support or lack of support?
- What has been the involvement of other patients and carers since your treatment has finished? Opinions on support or lack of support?
- What could have been improved or done better to support you during your period after treatment?

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***Involvement***

Can you tell me about whether you've felt involved in making decisions?

Aim of questions is to find out about experiences of involvement:

- Extent of involvement in decision-making about their care
- How involved
- Choices of treatments etc
- Why they agreed to participate in this research?

***Involvement***

- Did you have a choice about (i) treatments (ii) type of support that you received? If so, how were you involved in decisions?
- Did you want to be involved in decisions about treatment?
- How, if any, has being involved in this study so far had an impact on anything to do with your care or the way that you have been thinking about cancer?

***Involvement***

- Did you have a choice about (i) services after treatment has finished (ii) type of support that you received? If so, how were you involved in decisions?
- Did you want to be involved in decisions about what will happen after your treatment has finished?

***Other issues***

- Is there anything that would improve things for you now?
- Is there anything else that you wish to talk about?
- How have you felt talking to me about this?

***Other issues***

- Is there anything that would improve things for you now?
- Is there anything else that you wish to talk about?
- How have you felt talking to me about this?

Looking back over the past year, is there anything that you think could be done better or could be improved to improve your experience of cancer care?



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