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Title: Imaginative anticipation: Towards a theology of care for those with dementia

Date: October 2011

Originally published as: University of Chester DProf

Example citation: Goodall, M. A. (2011). *Imaginative anticipation: Towards a theology of care for those with dementia*. (Unpublished doctoral dissertation). University of Chester, United Kingdom.

Version of item: Submitted version

Available at: http://hdl.handle.net/10034/253633

# Imaginative Anticipation:

# towards a theology of care for

# those with dementia

Doctor of Professional Studies

in Practical Theology

Goodall, M.A.   October 2011

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# towards a theology of care for

# those with dementia

Thesis submitted in accordance with the
requirements of the University of Chester for the
degree of Doctor of Professional Studies in
Practical Theology

by Margaret Ann Goodall

October 2011

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# <u>Acknowledgements</u>

**Margaret Ann Goodall**
**Imaginative anticipation: towards a theology of care for those with dementia.**

## Abstract 1

Dementia is a degenerative disease which appears to take away personhood and identity and calls into question how we understand what it means to be a person. My argument is that how people with dementia are seen and imagined is key both to the understanding of their value and the care that is offered.

The aim of this study is to determine how the Christian ethos of Methodist Homes (MHA) influences the care of people with dementia in order to develop a general theology of care from within practical theology.

The thesis explores the ways in which the Methodist emphases of social justice and prevenient grace offer a basis for dementia care, and how MHA has drawn on its origins within the Methodist Church to develop an ethos of care that places respect for the person with dementia at the centre. This concern for those with dementia is then surveyed and the themes of respect and relationality emerge offering the potential for human becoming.

Within MHA the care offered is based on a person-centred model. In order to discover how the Christian ethos of the organisation influences care this thesis explores patterns of delivering care in three homes of each of three types; well-established, recently-acquired and new-build. In each home the views of the staff were surveyed. Three in-depth interviews were conducted when questions were asked in order to understand their perception of the person with dementia. The interviews uncovered what carers regarded as good care and when care did not meet the needs, and why they believed that happened. Browning's 'strategic practical theology' was used to evaluate these findings from within a Christian context to examine the influence of MHA's ethos on the care offered. The core value chosen as the most important for care was 'respect'; and while the care offered across all types was 'person-centred' the way it was delivered varied.

The culture of MHA that gave rise to the values is investigated, along with the challenge of retaining 'mutuality' as an ideal as the needs of older people changed. The themes that emerged were those around quality of life and the things that enable the change in thinking from basic 'caring' to 'caring for the person' as the person is seen in a different way.

Dementia is sometimes called the 'theological disease', and this understanding of dementia and the person is explored to discern what can be offered from theology to the best ideals of care in order to provide true person-centred care that is respectful of the person.

I argue from within practical theology that a new way of seeing the person with dementia is needed in order to anticipate the possibility for human flourishing that is possible in a person, even in dementia. And that, offered with respect, good person-centred dementia-care can be a sign of the Kingdom.

**Abstract 2: Summary of professional doctorate portfolio.**

Part 1 of the D.Prof. comprises four sections in which I explore dementia from within practical theology; how it impacts on personhood, how I, as a practitioner within Methodist Homes (MHA), could enable others to offer care of the whole person; and how the carers' understanding of the person makes a difference.

In the first section, the literature was surveyed in order to discover the historical development of the term dementia. Until the middle of the twentieth century, there was little care as the condition was not named. But then drugs were discovered that could control unsocial behaviour, and the medical model of care developed. However, a new culture of care developed (person-centred care), because of the better understanding of the social nature of the disease. From within the context of theology, I explored how personhood can be understood within dementia and how, even in dementia, it might be possible to grow into the fullness of Christ as spirituality is enhanced.

The second section was in the form of a publishable article which explored how it might be possible to evaluate spiritual care within a dementia-care setting. This took the form of a case study in which I worked with staff in a home that had difficulty evidencing spiritual care. It raised issues about the nature of care and assessment of spiritual care, as well as the rationale behind, and the delivery of, that care. What developed used the biblical concept of 'fruits of the spirit' as a way of recognising spiritual dis-ease as it is these qualities which enable inspiration, reverence, awe, meaning and purpose even in those who have no religious beliefs. The model used to offer this care was through the 3 R's of reflection, relationship and restoration.

Section three, reflective-practice section, emerged out of my practice as a chaplaincy adviser for MHA, in which I reflected critically on the contexts and understanding of the manager and chaplain, and how a chaplaincy manual was developed. The ability of the chaplain to work effectively and enable good spiritual care in the home, depended on the relationship between the manager and chaplain. By exploring the culture of both manager and chaplain, a way to enable good communication was discovered. The role of pastoral care and how it is seen within an organisation, that must have a professional management, was investigated and ways suggested for mutual understanding using the chaplaincy manual.

The last section examined whether the Christian ethos of MHA encouraged a model of person-centred care. I suggested that a way of making sense of the data is by using types to describe personhood and how that can be made visible by their care. Considering the way that therapeutic interventions (reminiscence therapy, reality orientation, validation therapy, drug therapy) were used offered a way to enable the ethos of the home to be seen more clearly. Central to theological anthropology is the concept of the person which includes an ethical dimension. MHA has the strap line, 'care informed by Christian concern', so the study investigated whether this Christian ethos is lived out in the care offered

These aspects of study have led me to begin this thesis to research how care is delivered and what carers understand to be appropriate care. An appreciation of the context in which this care takes place also highlighted a need to conduct a theological exploration of the nature of the person with dementia.

# Introduction

In May 2010 the Alzheimer's Research Trust published a report that revised the number of people currently living with dementia in the UK from 700,000 to 820,000, with an overall cost of £23bn a year rather than £17bn.  This figure is set to double, some suggest treble, over the next 30 years (Samuel 2010).  Samuel's article is titled 'Dementia Crisis Beckons', and looking at the figures the enormity of the problem can seem overwhelming for society as it affects not just the person with the diagnosis (or symptoms) but their circle of family and friends. The impact on public or private health-care resources would appear almost insurmountable.

My context is within the Methodist Church, and more specifically Methodist Homes (MHA), so I examine, through a reading of its theology and specifically the themes of grace and social justice, how this has been worked out in the formation of MHA, which has as its strap line '*caring for older people inspired by Christian concern'*.

In 1989 MHA opened its first dementia-care home with an emphasis on person-centred care and for fifteen years I was chaplain to this home. The idea of person-centred care presumes that there is a person to care for, even in dementia, something which is debated in the media and amongst care staff. Person-centred care demands that the person with dementia is recognised as a fellow human being and respected for who they are.

It is often suggested that those with dementia become less human as the disease progresses, so in this study I begin to map this aspect of our understanding of the self and the nature of the person. Recognising the changes that take place within the person with dementia I introduce the writings of theologians who have explored these problems. Voices are included which offer suggestions for what it means to be human, and,

using the insights offered by Macquarrie and Jantzen, I will explore how even in dementia there could be the possibility of more than a general and unremitting decline. The research was conducted in three groups of three MHA dementia-care homes and data collected by the use of survey and interviews. Browning's five dimensions are used to inspect the data in order to interpret what is happening in the homes.

I examine how care is affected by values and look more closely at those who have influenced care using a social model. That model seeks to respect the individual and so to affirm personhood through relationality rather than rationality, recognising how this demands a shift in our understanding of what it is to be a person.

Dementia is a disease that calls into question how we see the person, so through research I examine what model of care the Christian ethos of MHA offers as staff give accounts of how they live out these values within the context of offering care. These insights are used to develop a theology of care in which the personhood and potential of the person with dementia is respected, and through theology and theological anthropology the idea of 'becoming', in relation to those who are not who they were, can be explored.

In this thesis I argue from within a Christian context that in order to care for someone with dementia it is important to show respect and recognise the potential of the person. This means recognising both who the person with dementia is now and who they are becoming, imagining the new thing that God is doing within them.

# Chapter 1: The tradition expressed in practice

'I think that caring is centred around love. You need to have a loving heart' (Interview).

## Introduction

In order to appreciate the care for those with dementia offered within MHA, and to then begin to work out a theology of care, I first need to uncover the roots of MHA within the Methodist church to understand what informs the ethos and values of the organisation. In this chapter I will situate the study within practical theology and begin to explore the problem of dementia, especially in relation to our understanding of identity and what it means to be human.

## Methodist Theology

Theology is a way of making sense of God's revelation and as such needs to be always in review because our understanding of what is happening in the world is constantly changing. So the church 'must be ready to consider whether any given change is in fact the Holy Spirit calling it forward out of its past and into its future' (Stacey 1977:361). Within the Methodist Church this is acknowledged in its emphasis on 'the need for Christians to grow in grace and holiness' (Shier-Jones 2005:1). Today there is a renewed interest in 'the relationship between Wesley and contemporary forms of liberation theology…(which) stems from Wesley's concern for the poor and his wider commitment to reforming society' (Abraham and Kirby 2009:vii).

To find out what Methodist Theology is in the UK today Shier-Jones suggests one needs to know where to look. It is often assumed that Methodist doctrines are contained within Wesley's *Explanatory Notes on the New Testament* and the first four volumes of his sermons.  But few Methodists, including the majority of its preachers and ministers, have studied these and there is a diversity of theological approach among

Methodists. There are those who question the 'viability of inherited theological formulations' (Langford 1998a:78) while others would wish to reaffirm the tradition. However while the Methodist Church is not based on confessional documents it does have a distinctive theology, and speaking of itself to the World Council of Churches, 'Methodism insisted that Methodists "are held together by a common life of worship, fellowship and service rather than by subscription to a series of articles" ' (Shier-Jones 2005:4). Methodist theology is therefore understood as something that is vocational rather than a 'series of propositional doctrines and is characterised by ecumenical openness and by a concern to communicate Christian faith to the contemporary world' (Langford 1998a:78). John Wesley is generally appreciated as the 'inaugurator of a movement rather than as a continuing theological guide' (Langford 1998a:78).

The theological style of the 'founder' of the Methodist church, John Wesley, was 'that of an active "missioner"'. He worked out his theology in order to make his message as clear as possible…and replied to pressing challenges as they arose' (Langford 1998a:3). Wesley's theology is practical, it 'grew out of practice, was a reflection upon practice and aimed to enhance practice' (Langford 1998a:3). For Wesley theology belonged to everyone not just the clergy, and was for shaping life in Christian ways. Langford reminds us that Wesley's theology made him sensitive to human need, or 'perhaps his sensitivity….helped to shape his practical theology' (1998a:4). He believed that Christians had a responsibility to serve the needs of people in whatever form they took. 'Practical theology…set a direction for the Methodist tradition' (1998a:4). Like other traditions Methodists are taught that the church does not exist for its own benefit but as the body of Christ that it might live out the good news of the gospel.

While it did not begin as a liturgical movement it has increasingly become one and the *Methodist Service Book*, although it contains much taken from other churches' liturgy gives an insight into what is held to be theologically important by the church. The Methodist Church was founded by John Wesley but Rupert Davies, quoted by Langford, suggests that

'Modern Methodists have no Wesley…[*so*] are no longer tied down to one man's interpretation of the Christian faith…and can therefore, if they are so moved by the Spirit, go ''forward from Wesley'' into a deeper understanding of God's purpose' (Langford 1998a:95). Theology is not then something abstract but develops through involvement in life experience.

Methodism is not unique in its concern to hold together theological interpretation and Christianity in action, but this inter-weaving of faith and practice is 'characteristic of the Methodist tradition throughout' (Langford 1998a:75). The Methodist Church has struggled to keep these in balance and sometimes failed, but always has 'attempted to serve God with mind as well as heart and strength fully involved' (1998a:76). Michael Townsend wrote that, 'The Church will be wise these days to take its doctrinal standards as guides rather than chains' (1980:40), so the work of 'doing theology' continues.

In the Methodist Tradition there are four main theological or doctrinal emphases, commonly known as the 'four all's': all can be saved; all can be saved by grace through faith; all can know that they are saved; all can be saved to the uttermost. It is through these that the doctrines of salvation, justification, and sanctification are made evident (Shier-Jones 2005). Wesley made a distinction between 'sins' and the imperfections of human nature and bodily infirmities, for example being 'slow' (John Wesley's words) or unable to understand. He believed that humanity would never be perfectly free from these 'infirmities' until 'the spirit returns to God who gave it' (Shier-Jones 2005:184), but that it was possible to be free of sin, sin being something that a person has chosen to do that they understand is against God's law.

*Prevenient Grace*
The doctrine of 'grace' is at the heart of much of Wesley's teaching, and while the emphasis is 'sometimes on God's initiative, sometimes on man's

response, grace is always the dynamic, underlying reality' (Langford 1998a:7). Wesley was opposed to any doctrine that called into question free will; that made humans not responsible for their actions and so not free to respond to God with love and faith.

But Wesley argued that salvation begins with the love of God expressed in what he called 'preventing grace' and which the Methodist Church now understands as prevenient grace. Wesley wrote, God 'first loves us, and manifests himself unto us. While we were yet afar off, he calls us to himself, and shines upon our hearts' (Shier-Jones 2005:42).

This teaching has been re-emphasised in the words of the newest revision of the baptismal service when the young child is baptised before any promises by the parents. 'God's Spirit is poured out on God's people in baptism, as a gift of prevenient grace, even though it is neither deserved, nor understood. As the text notes: "All this for you before you could know anything of it"' (Shier-Jones 2005:113). In infant baptism this is '*entirely* the action of God. It is the sacrament of sovereign grace' (Stacey 1977:336). Morisy reminds us of the power and life-giving significance of this *'undeserved merit'* (2009:98) that we understand from positive psychologists, that helped the early Methodists face the challenges of the times rather than having their spirits crushed.

It is this doctrine that offers hope to those with dementia as they are not able to reason their faith or confess as they call to mind their sins. Some think that this inability has made them beyond the love of God, but the idea of prevenient grace puts the emphasis back on God as the source of value and personhood.

*Social justice*
Wesley believed that God's justice was at work in his people and that they should work to bring the love of God to people in practical ways. 'The Methodist movement's involvement in the struggle against injustice is a part of Methodism's proclamation of the justice of God' (Shier-Jones

2005:50).  As the nineteenth century closed the influence of Hugh Price Hughes was evident. He was 'captured by a new vision of the relation of faith to its social setting' (Langford 1998a:43), and he saw that the church should be 'a moral participant in the life of the nation' (1998a:43). His style of theology was a return to the practical theology of Wesley, 'The interaction between faith and practice … so tight that each draws shape from the other: thought provokes action, action provokes thought. Theology is not developed independently of concrete involvement in actual life experience' (1998a:44). He did not consider himself a theologian concerned with abstract ideas, but with how the Kingdom of God could be seen in the land.  He reminded people of the need to live a life of involvement in the present world and, 'encouraged Christians to seize this day for the work of love… just as Christ… was "moved with compassion"' (1998a:45). The effect of his influence was felt through the challenge he issued in the name of conscience, not intending a revolution but 'a thorough renovation of dominant values and practices' (Langford 1998a:44), and this continues to be felt as Methodists work out their faith in the world.

*The challenge of dementia-care*

In 1990 Jonathan Miller, who was then president of the Alzheimer's Disease Society, said of dementia that, 'There is this grotesque thing in the corner… an uncollected corpse that the undertaker cruelly forgot to take away' (Miller 1990). Even more recently the 2002 Alzheimer Scotland campaign had the by-line 'Are you losing the person you knew' (Killick 2004:144) and in 2008 the book 'Could it be Dementia?' had the subtitle 'losing your mind doesn't mean losing your soul' (Morse and Hitchings 2008). The common view of the importance to identity of memory, and the belief that the failure of memory will result in the loss of the person is expressed by Draaisma, 'The prospect that ultimately you will forget all you have forgotten and that you won't miss it either, is no consolation, for it means that you will have ceased to exist as a person' (2004:236).

In recent years there has been a change in attitude and good care of those with dementia is now recognised to be person-centred. The goal is to give quality of life through affirming the individual's self, rather than a biomedical model which depends on drug therapy to contain the person. However David Sheard writes that, 'across the UK, other than in small pockets, it is hard to find significant … evidence of people with dementia receiving truly person-centred care' (Sheard 2004:22). He asks if through the increasing 'industry and professionalism' dementia care has been 'camouflaged in professional ideologies' (Sheard 2004:22). To enable this extravagant caring to take place demands much of both the carer and the organisation through which the care is offered.

Drug therapy has been used to control dementia, but this medical model of care is criticised as the 'problem behaviours' (Kitwood and Bredin 1992b:54) are what is seen and the person is defined by the problem. The problems may begin with the loss of reasoning and logic and, as dementia progresses, the ability to communicate and control bodily functions may also be lost. If the person has lost the ability to behave as a person then we must not be surprised if the care they receive reflects that they are of no intrinsic worth.  However there is a sense in which we see what we expect to see.

> It is all too easy at present to give care-workers a let-out by prescribing this kind of medication. It does, in a way, make an individual more 'manageable'; but the trouble is, it makes them less of a person (Kitwood and Bredin 1992b:54).

One aspect of social life that is challenging us today is that of the care of older people, especially those with dementia. The person living with dementia often requires institutional care for the final stages of the disease as family and friends are no longer able to continue caring at home. This is usually prompted by a crisis situation or a change in family circumstances. As the number of older people in the UK increases, and the incidence of dementia is found to increase with age, it seems likely that the number of people living with dementia and needing institutional

care will continue to grow. This will have an impact on those providing care, both at organisational and personal levels.

Kitwood calls for a new kind of carer, one who is 'making an attempt to understand and establish continual contact; 'it involves filling out what is lacking, so that the confused individual remains a person.' (Kitwood and Bredin 1992b:94). He emphasises that good care is more than doing things to or for another person. 'It also means developing awareness about ourselves' (Kitwood and Bredin 1992b:94).

Post argues that the moral challenge for those involved in care is to enter the world of the person with dementia, and to practise respect through 'the mystery presence' (2000:13). The cost of providing this type of care, which encourages carers to look again at the person and use their imagination, is costly to both carers and the organisation in which they work, and so care ideals are expressed as a 'utopian vision'. Innes sees the undervaluing of care work and the stigma surrounding dementia as factors that most influence what is possible. She suggests that as long as 'dementia remains a medical category … [there are] social consequences for those who are given the label and those who provide care' (Innes 2009:70), and good care will only develop in isolated areas. Looking forward to the establishment of special units for people with dementia Mace quotes Koff who warns that new knowledge and new methods are needed or 'facilities will be no more effective than those currently caring for this group of people' (Mace 1990:338). Care offered to those with dementia depends on how they are seen by others, either as people of value or of no account.

The principle of person-centred care has been around for some years now (Brooker 2007), and yet while it is known it is not always understood. Good person-centred care comes from a powerful drive for social justice and inclusion and is concerned with the building up of authentic relationships.

Morisy writes that the possibility of needing residential care with a diagnosis of dementia is one of the most dreaded aspects of growing older. 'It is more feared than death itself. In this context, the possibility of a hope-filled future was made manifest through the capacity of Methodist Homes to *enact hope* sufficiently to reassure people….and offer a hopeful life into the future' (2009:108).

Reflecting on Methodism's origins and how it has used its resources Morisy wrote:

> When Methodism was gaining momentum poverty was endemic. Methodism enabled the chronically poor to choose life. Now, when Methodism contemplates the abyss we have for the first time in human history more people over the age of sixty than we have youngsters under the age of sixteen. And note well, Methodism once again has organised, better than any other denomination, to respond to the endemic fear associated with old age.
>
> (Personal communication November 18th 2009).

Methodist Homes for the Aged is an example of the working out of the core principles of the Methodist Church's doctrine centred on the hope offered by social justice and grounded in prevenient grace.

What is commonly known as the Wesley 'Quadrilateral' is a methodology for theological reflection. Wesley never used the term, but this is understood as the way that four different sources are used when reflecting theologically. The four sources are: scripture, tradition, reason and experience. Wesley was a perceptive observer of human behavior, and he was also pragmatic, so his approach was to describe in a practical way how things actually work in human experience.

**Practical theology**

Until the thirteenth century the term 'practical theology' was used to describe the genre of theology as a whole.  But with the emergence of the universities, especially those of the German Protestant tradition, the term

was used to distinguish it from 'speculative theology' (Maddox 1991, Woodward and Pattison 2000). Theology can seem remote from ordinary life, but practical theology 'has its starting place not in detached reflection on scripture and tradition but in present life' (Rowland and Bennett 2006:8), with all the influences, experiences and traditions that inform practical theology being formed into a web.

Practical theology is defined by Swinton and Mowat as 'critical, theological reflection on the practices of the Church as they interact with the practices of the world with a view to ensuring faithful participation in the continuing mission of the triune God' (Swinton and Mowat 2006:25). Once a church has embarked on a certain course of action it is important to reflect critically and theologically on that action to discern if it is still accomplishing the mission that was intended. The pastoral cycle (Cameron 2010:8) is one way of enabling critical reflection and theological thinking to be brought to the experience, with the aim of 'finding new and more faithful ways of acting in the future' (Cameron 2010:8). Browning writes about *fundamental* practical theology, which emphasises his belief that what is of utmost importance is that all aspects of theology are practical as they enable us to live a more effective Christian life. So theology 'begins and ends in the collective practice of faith–communities which seek clarity about their mission in the context of the contemporary world' (Ogletree 1992:904).

This reflective cycle starts with what is happening, gleaning knowledge from that experience, reflecting on that as we 'dialogue with the Bible and Christian Tradition' (Cameron 2010:9), and then responding with a new action. And so the cycle begins again as a constant spiral of reflection and action. The aim of this reflection is, 'not simply to understand the world, but also to change it…by critical discernment' (Swinton and Mowat 2006:27).

One benefit of this cycle of action and reflection is that, 'It is a commitment to a way of seeing that involves participating in oral and

written traditions as well as a commitment to reflect upon your practice' (Cameron 2010:12). Graham, Walton and Ward argue as others have done that theory and practice are inextricably joined as 'praxis' and that, 'proper theological understanding cannot be formed independently of practical engagement' (Graham et al 2005:170). For those in the church involved in offering care for people it is vital that this integration of theory and practice happens as '"talk about God" cannot take place independently of a commitment to a struggle for human emancipation' (2005:170). This emancipation or liberation finds echoes throughout the Bible as the oppressed or imprisoned are freed from that which binds them. What this emphasises is that learning the story of God's interaction with humanity is not an academic exercise, but must affect the way we act in the world. 'In other words, liberation deals not so much with content as with the method used to theologise in the face of our real-life situation' (Graham et al 2005:188). Segundo, in Graham et al (2005:189), speaks of the importance of beginning from an immersion in the context not from theory: 'Christians should not redefine social praxis by starting with the gospel message. They should do just the opposite. They should seek out the historical import of the gospel by starting with social praxis'. But in turn our starting place determines our understanding of God. This then is practical theology, not a way of applying theology to a situation, but a method that 'begins and ends in practical engagement' (2005:189). This requires a reading of theology that does not seek to offer 'timeless certainties, but seeks to inform and inspire faithful praxis' (2005:190).

The four stages of the pastoral cycle are: immersion in the situation; critical understanding of the experience; theological reflection; and then faithful practice informed by the theological reflection (Graham 2005:188). Each stage building on the next and the process then begins again as new practice is reflected on and we, 'seek to discover and translate into real life God's truth for us today in relation to particular situations through the hermeneutic of scripture and tradition' (Thompson, Pattison and Thompson 2008: 9). Osmer uses a different style but describes a very similar process, using questions to identify the task. He asks: 'what is

going on?' (*descriptive-empirical task:* gathering information*):* 'Why is this going on?' (*interpretive task:* using theories of arts and sciences to better understand*),* 'What ought to be going on?' (*normative task:* using theological concepts to guide and learning from 'good practice'*),* and 'How might we respond?' (*pragmatic task:* determining strategies and reflecting on their implementation) (Osmer 2008:4).

These writers affirm that pastoral theology is not the same as applying theology to a set of circumstances, but emerges from letting God and church tradition speak through the situation.

The voices above have informed my project in as much as I start from my experience and, through field work, examine the care offered within Methodist Homes. By reflecting on this theologically I aim to begin to develop a theology of care for those with dementia.


**Methodist Homes (MHA)**

The aim of Methodist Homes is to improve the life of older people inspired by Christian concern, with an emphasis on caring for the individual. MHA was founded in 1943 when the Rev Walter Hall persuaded the Methodist Conference to take action on care of the elderly. Hall discovered that at that time, for an elderly woman having lived in tied accommodation with no personal or family resources, there was no alternative to the workhouse. He wrestled with the challenge until he was able to make others aware of the problem and what he considered was the Christian response to it. 'In a time of war, danger and destruction,…Walter Hall focused his energies on one issue, care for the elderly; and MHA was born' (Wigley 1988:16). Pope John Paul II spoke in support of this ideal of care during a service for the sick at St George's Southwark in 1982:

> Today I make an urgent plea to this nation. Do not neglect your sick and elderly. Do not turn away from the handicapped and dying. Do not push them to the margins of society. They teach us

that weakness is an important part of living and that suffering can be embraced with no loss of dignity (Wigley 1988:20).

The recognition of the importance of respect and the dignity of each individual has always been a feature of Methodist Homes care. In 1983 the President's Council of the Methodist Church asked MHA about care for an elderly Methodist who was very dependent and needed dementia care. The organisation was challenged by this and two special projects resulted; one in Letchworth for physically frail elderly and one in Newport Pagnell for those with dementia. It is this latter care which is becoming the new focus as those people with dementia were often kept within the family or in long term psycho-geriatric units in hospitals, but are now in care homes placing an increasing demand on quality care. The experience at Westbury, Newport Pagnell, has been particularly influential in guiding the development and expansion of Methodist Homes' dementia-care programme where dignity, security and quality of life are important.

A former senior chaplain of Methodist Homes, Albert Jewell, wrote in *The Methodist Recorder* [1994:11] that as Methodists we were committed not to making a profit but to helping those who were in most need: 'John Wesley encouraged us to go not to those who need us, but to those who need us most'.

Throughout its long history the church has initiated institutions for the benefit of the community such as schools, colleges, and hospitals, many of which in time have been devolved to the state or other providers. David Wigley, a former chief executive of Methodist Homes, argued in an address to the Chaplains' Conference, titled *Compassion and/or competence* (November 22nd 1995) that there is a case for Methodist Homes continuing because as an organisation it offers Christian-based care where the importance of the individual is stressed as being, 'loved by God and of infinite worth'. This love and care extends not only to the fit and alert, but also to the confused and the frail. It is care that seeks to

attend to all the needs of the individual, not just those that are most readily observable.

Some of the changes in MHA have been in response to the needs of society and government legislation, while others have been because of the 'changing aspirations of older people and their families' (Albans 2010:66). But the most significant change was to offer care, not just for the 'old-well', but the most frail and vulnerable including those with dementia.

Tom Kitwood was MHA's advisor as they planned to begin offering dementia care. He was convinced that the types of care-giving inherited from the past were in the main practised without real meaning, with those caring for people with dementia being among the worst affected. He writes that, 'It is as if the presence of what used to be called "organic mental disorder" places some kind of veto upon normal human encounter' (Kitwood 1997:7). Care can be given without meeting the recipient, and this can lead to dehumanisation. If care-giving can involve a true meeting with the other person then it 'protects, preserves and validates his or her personhood until the end of the dementia process' (Miesen 1997:338).

**Dementia and identity**

Perhaps the modern dilemma of identity is one reason why dementia is recognised as one of the most frightening diseases of our age because there is pressure to use 'self' to give meaning to life in a way not known in earlier times as the self itself is, seen 'as a source of value' (Baumeister 1991:94). Dementia has often been associated with a 'loss of self' and this 'implies that the person travelling the journey with dementia at some stage loses what it is to be human' (Bryden 2005:152).

*Who do we see?*
'Person-centred care' as applied to dementia care was first seen in the work of Tom Kitwood, who developed a new understanding of caring

through his work with the Bradford Dementia Group. His aim was to bring together ideas and ways of working with people that emphasised communication and relationships. In 'Person to Person' (Kitwood & Bredin 1992) he encourages the reader to look beyond the presenting problem to the person and relate to that individual. Even noticing something as simple as a facial expression can enable us to connect with the person as, 'the facial nerve is connected to the very old and newer parts of the brain' (Ostwald 1978:42). Kitwood and others argue that dementia is not simply a neurological change in the brain but something that alters social interaction. He calls this 'malignant social psychology' as it is seen in the isolation and alienation of those with dementia from the society in which they live. He quotes the 'depersonalizing' of those with dementia and uses the word 'malignant' not to 'imply evil intent on the part of the caregivers…the malignancy is part of our cultural inheritance' (Kitwood 1997:46), as, almost instinctively, people shy away from those with dementia.

Supporting this work of Kitwood, Sabat and Harre, through their research and analysis of interviews held over a period of time with someone with Alzheimer's Disease, describe the 'self1' that remains intact despite the effects of dementia, and is seen as the pronouns 'I' 'me' and 'my' continue to be used; and the 'self2', the social and public face of the person that can be lost by 'nothing more than the ways in which others view and treat' (1999:88) the one suffering from dementia. They argue that our 'social selves depend for their existence on the cooperation of others in the social context' (1999:93), so knowledge of the background of the person is necessary, 'a storyline' (1999:94), in order to help construct this 'self2' and so understand actions that could otherwise appear bizarre and just a result of the disease.

However while there are those who would see dementia as a loss of self so severe that the person is no longer there as they are unable to exhibit the qualities of a normal human being, there are other cultures who see this disability as pointing to a special relationship with God (Edmonds

2011). Gilleard states the understanding of some that 'dementia reflects the deterioration and decay of the person or self' (1984:10), while Singer argues that 'what is essential to human nature is the individual's personality, his conscious life, his uniqueness, his capacity for remembering, judging, reasoning, acting, enjoying, worrying, and so on' (Singer 1995:48). Rachels (1986) speaks of the importance of being human, being made in God's image, as we are unique in having rational thought. He asks if there is a place for non-rational humans and quotes Nozick's traits of a normal human being 'rationality, autonomy and a rich internal psychological life' (Rachels 1986:75), which are the very qualities that diminish as the disease takes hold. But, when faced with the possible diagnosis of dementia in his mother Singer, who had previously defended 'senicide' (Post 2005:225), became a care-giving son. The ties of relationship would seem to override the entirely rational arguments he had proposed.

This loss of reasoning ability, and lack of understanding of logical thought, distances those with dementia from others, and society in effect can turn away. For when faced with a person whose main problems are memory, language and reason, dementia ceases to be simply a medical problem and becomes a denial of the attributes on which western society is built, consequently it appears threatening. Those who are deeply forgetful are at risk of being excluded from society because, 'we know how important good memory is to our full functioning and power and thus the very last thing we want is to suffer through the diminution of what is a nearly sacred human capacity' (Post 2005:224).

Confused speech is one of the ways that dementia becomes evident and Shakespeare notes the underlying social consequence of not being able to do 'ordinary talk' (1998:4) as it is an indication of not being a normal person. 'But language is not the whole of the emotional experience. Personhood is retained and to this we should relate' (Garner 2007). We assume that those who cannot communicate are of lesser value and,

'overestimate the moral significance of the capacity for speech' (Post 2005:230).

One of the reasons that Kitwood has been so influential is that he moves the debate away from rationality to relationality. He asserts in quoting Buber that 'all real living is meeting' (1998:11), and that people with dementia have to be understood in terms of relationship and their own personhood because these are the characteristics of all lives. Writing about a 'new culture of care' for those with dementia Kitwood and Bredin (1992) showed how appreciating the emotional and relational aspects of a person could bring about quality of life. Post suggests that there needs to be a shift in our understanding about what it means to be human and that, ''I think, therefore I am'' should be replaced with the 'less arrogant notion "I feel and relate, and therefore, I am"' (Post 1999:233). This relating can enable a different kind of communication that does not rely on reason. Butler and Orbach reflecting on this suggest that 'You can touch people where we really come together' (1993:153).

This different way of relating to people with dementia suggests a shift in our understanding of what is important in a person and the need to respect who they are. Post (2005) reminds us that the root of the word 'respect', *respectare,* is Latin for 'look again'. He suggests that we should 'look more carefully at the experience of people with dementia, rather than dismiss them after a first superficial glance' (Post 2006:223). And he argues that as we recognise the similarities between their life and ours we will be less likely to dehumanise them and more likely to believe that their life is worthy of respect and care, suggesting that 'Hypercognitive snobbery is moral blindness' (Post 2005:223). This is echoed in a comment made by Garner in a review of the book, '*Dementia: mind meaning and the person*', where he states that it 'introduced a new way of thinking. Ostensibly it is about dementia; actually it is about what it is to be human' (Garner 2007).

*Dementia and being human*

What we understand as being human is connected to our understanding of personal identity, the self. John Locke proposed that memory alone (consciousness) would constitute personal identity (Shoemaker and Swinburne 1984), while bodily theory suggested that what made a person was the sameness of body. The brain was seen as the most important part of the body, 'controlling not only physiology but the way one behaves, talks and thinks' (Shoemaker and Swinburne 1984:7). So the functioning of the brain is seen as what maintains personal identity as it guarantees 'continuity of apparent memory and character' (Shoemaker and Swinburne 1984:49).

The ideas of the Enlightenment influence much of what is valued in the human, particularly the triumph of reason and the mastery of the human mind over the external world (Lakeland 1997). The modern human being is the one who tries to invent 'himself', and it is often a gendered view. However Lakeland explores this idea of the human in the light of postmodern thought, which he says has no 'big stories, no metanarratives including what is the agreed story of what it is to be a human being' (1997:23). This way of thinking could add a new dimension to what is understood as 'self' when someone has dementia as there is no fixed idea of what this 'self' is so the person is free to become who they will. However Baumeister reminds us that while there might be the freedom to become, that can cause difficulties in relating as 'people who lack a firm identity…tend to lack stability. Their interactions with others are more unstable… [*and*] behaviour is confusing… inconsistent' (Baumeister 1991:94). He suggests that in a world that is changing so quickly we yearn for stability of meaning, and find it uncomfortable and sometimes threatening when people behave in unexpected ways. This encourages the 'them and us' culture which can make us feel more secure.

**The experience of being cared for**

Garner expands on Post's concern with the elitism that supports a 'them and us' culture and says that, 'Our job …is to preserve identity' (2007). Following their article, 'Towards a theory of dementia care: personhood and well being' (Kitwood & Bredin 1992a), their book *Person to Person* (Kitwood & Bredin 1992b) was to be influential in encouraging carers to think differently about care they were offering. This book was not simply an expanded version of the journal article, but it included stories of how people had been living under the old model of care, and then how their well-being and sense of personhood had been transformed by recognising them as 'people like us' and learning to understand their new way of relating and finding ways to come alongside them. Graham Stokes's book, *And Still the Music Plays* (2008) continues this way of writing about people with dementia as new ways of caring are introduced not through scholarly arguments but by the description of the lives of real people and how through detective work their quality of life has been improved. Stokes is also realistic in that he includes the stories of those who they were not able to help.  He reminds us that good dementia-care can only be as good as the life-story carers are able to piece together, the relationship they are able to develop, and the qualities of sensitivity and insight that they have.

It is this recognition that people with dementia are 'people like us' who need help with being themselves that has enabled a shift in care. Kitwood identified that what was needed from carers in their caring was, 'a generous, forgiving and unconditional acceptance, a wholehearted emotional giving, without any expectation of direct reward' (1997:81), people who could reveal to them their value by 'providing attention and tenderness in love' (Post 1999:232).

However memory and power are closely linked and Post reminds us that 'Power is the ability to punish and we do punish people for being forgetful…. and we see this ''power to humiliate''...in…cases of a family

caregiver who now finds opportunity to assert a new-found dominance' (1999:224). People are then described as 'no longer there', as they are no longer able to fulfil the roles in family and society that they once did. Sabat and Harre write of their bewilderment at the book title, *Alzheimer's Disease: The loss of* self by Cohen and Eisdorfer, asking 'How could a ''self'' be lost?' The same sense of puzzlement was felt when I came across the book *Could it be Dementia?: losing your mind doesn't mean losing your soul,* which seemed to state as a fact the idea that the mind, that which makes us ourselves, is 'lost'.  But Sabat and Harre affirm that 'Personas are joint productions' (1999:93), and that all social interaction either confirms the 'self' or diminishes it: that our personas are socially constructed and 'require the mutual cooperation of individuals. Such mutual cooperation allows a human being to flourish as many different selves, often in the most unpromising situations' (1999:101).

In contrast, Seymour, writing about disability says, 'Self identity is constructed through social relationships.  We learn who we are and our place in the world through our relationships with others' (1998:7).  And in writing about care she offers this observation, 'I can remember feeling that I needed to be touched… your body is handled [during care] not touched' (1998:76).  The way that care is offered is of immense importance as that affects our feelings of self-worth and identity and Nouwen, quoted in Bunkers, comments that care at its best is, 'Loving attention given to another…because the person is a child of God, just as we are' (Bunkers 2004:63).  This view recognises that care is not offered because of sympathy for the person, but simply because of their intrinsic value.

*Ways of coping*

Bunkers quotes a woman with mental health problems who says, 'When I really feel cared for I don't feel the burden of expectations. It takes time because there's the whole issue of trust' (2004:63). This is supported in Mace and Rabins' observations on caring for someone with dementia, 'She liked it best when they just held her and loved her' (1999:4). This time given by carers in loving attention can help those with dementia with

the losses they face, 'It is not possible to cope with …meaninglessness, depersonalisation and dehumanisation unless the human dimension is … included' (Frankl 1979:15). People with dementia are in many ways just like everyone else in how they react to situations: 'Being hurried, being watched, being upset or being tired can affect an impaired person's ability to do things – just as it does any person's' (Mace and Rabins 1999:41). However people can also be demanding and difficult but because of the diagnosis of dementia the resulting actions are interpreted in a more negative way than would normally be the case.  Bryden says that this can make her feel 'a degenerating sense of nobodiness' (2005:55).

Each person's journey of dementia will be different, and for the onlooker it can seem puzzling and beyond imagining. But we have now information that was not available to previous generations that can give a glimpse into the world of those living with dementia as we have their accounts of dementia (Davis 1993, Bryden 2005). Christine Bryden writes through her own experience and, to those who suggest that in losing rational thought those with dementia become less human she says: 'I believe that people with dementia are making an important journey from cognition through emotion into spirituality. I've begun to realise that what really remains throughout this journey is what is really important. (Bryden 2005:159)

Dementia has been associated with the loss of self, which implies that at some stage the person ceases to be human (Goldsmith 1999). This can cause stigma that threatens identity. Bryden (2005:152) suggests that 'this is silly… Exactly at what stage do I cease being me? My spiritual self is reflected in the divine and given meaning as a transcendent being.' If identity is not diminished with dementia then people continue to have needs that we have a responsibility to meet through our care, recognising that whatever happens there is a core that remains oneself, a 'continuity of self' (Mowat 2004:51).

**Human becoming**

From a theological perspective, and especially through writing in feminist and process theology literature, the concept of self goes further than personality and identity and can be seen in the potential of human flourishing (Jantzen 1998) and human becoming (Cobb, Macquarrie 1982). Even in dementia researchers have found people being changed and developing through relationship with God and with others:

> As I lose an identity in the world around me, which is so anxious to describe me by what I do and say, rather than who I am, I can seek an identity by simply being me, a person created in the image of God. My spiritual self is reflected in the divine and given meaning as a transcendent being (Bryden and MacKinlay 2003:71).

In this quotation Bryden is speaking from within a diagnosis of dementia to a world in which she sees her life as having meaning only because she is a child of God.

Discussion about human personhood has long been in the realms of theology and philosophy, and in 1982 the theologian John Macquarrie published *In Search of Humanity.* In this work he brings together ideas from psychology and sociology as well as a variety of philosophical approaches. Macquarrie examines the word 'human', which he says can be used both as a descriptor of being a member of the human race, and also a word that gives value and 'means something like 'truly human' or 'authentically human' or 'fully human' (Macquarrie 1982:1). Reflecting on the expression used by Paul Lehmann, 'making and keeping human life human' (1982:1), he suggests that this implies being human as an unfinished project, and also offers criteria for deciding who is 'truly human'.

How we study what it is to be human is different from other forms of study as we are studying ourselves. After examining views of what it means to be human (1998:4), Macquarrie concludes that what is believed about the

theory of the human will govern how life is lived, 'so in philosophical anthropology theories of the human disseminate self-fulfilling models' (1982:4). But all are subject to particular ways of seeing, shaped, in part, both by the individual themselves and the culture in which they live (Berger and Luckmann 1966).

*Rationality*

Macquarrie speaks about the qualities, or possibilities, of being human that are a 'chaotic mingling of positives and negatives' (1962:5), so much so that it is sometimes not easy to distinguish which is which as the 'contradictions run so deeply' (1982:5). This leads him to question what quality of life differentiates human beings from other forms of life.

From ancient times the image of God has been seen in the ability to 'reason', man traditionally defined as the 'rational animal' (Macquarrie 1972:30) although he says that along with that must be put 'irrationality' as there are in the human 'these extraordinary juxtapositions of opposites...though it is not even easy to distinguish which is which' (Macquarrie 1982:5). He argues that 'The tendency to exalt rationality…can lead to a one-sided and eventually impoverished view' (1982:6). One quality he says that we do not share with other creatures is death-awareness, suggesting that this awareness influences the way humans live. So Macquarrie uses 'the word 'personal' to describe the new quality of life that appears with the human and that transforms…death' (1982:8). Jean Vanier writes of a study showing that as humanity has developed people have 'become more human as they opened up to the weak and to the reality of suffering and death' (Vanier 1998:97).

It is this new quality of life to which Macquarrie refers that seems to point to a shift in our understanding of the person, a shift that offers something from the losses experienced by those with dementia, and which encourages us to look again at those from whom society would turn away.

**Conclusion**

To those who would say that people living with dementia are beyond the love of God, Methodist theology would argue that the doctrine of prevenient grace can offer hope that is beyond what we can see. The concept of 'undeserved merit' opens up an alternative way of seeing how people with dementia can still participate in human becoming. Methodists' belief in social justice is seen in MHA offering of care to those most vulnerable and voiceless in our society: those with dementia.

By using the four stages of the pastoral cycle, the following research will aim both to analyse existing practice and to develop a theology of care for those with dementia: 'not simply to understand the world but also to change it… by critical discernment' (Swinton and Mowat 2006:27).

The question of human identity, and those who live with dementia, has been explored through investigating the literature, and the link made between who is seen and the care that is offered to them. For some identity and what it means to be human is ultimately connected with memory, while for others being human is seen as a process in which potential is realised.

# Chapter 2: Uncovering the culture

'You have to be kind, loving: you have to respect. It's so different here, the priorities are different' (Interview).

**Introduction**

The aim of my research is to examine the care of those with dementia in homes managed by MHA and to discern what influence the aim of MHA, 'to improve the life of older people inspired by Christian concern', has on this care. The research question that emerged from my study of the literature around the care of those with dementia and from my experience working for MHA became: what model of care does the Christian ethos of MHA offer for caring for those with dementia?

The methodology outlined in this chapter is designed to service this research and to enable me to excavate and make explicit the values that are at the heart of the care offered to older people with dementia in MHA homes. In designing this research one aim is to identify and gain a deeper understanding of the influence of the Christian ethos on care.

Nolan et al. (2002:194) suggest that one of 'the most significant challenges to our health and welfare systems over the next 50 years is to improve the capacity to provide quality of care for people with dementia'. And while one-to-one care could be the ideal, as there would always be someone there to remind, reassure and react to needs, it is not something that is likely to be possible because of the cost implications. However, above a basic level of staff provision, it is not the amount of money given to care that makes a difference, but the quality of the care given. It is the attitude with which people are encountered that will enhance or diminish their lives, and how staff do this will be influenced by the values they hold and their understanding of who it is they are caring for.

Care staff are the recipients of any change in methods of caring as new initiatives are introduced, but by offering to share their experience of care through this research they could be instrumental in effecting change. Dementia is a social disease in that it has the ability to isolate the person because of the 'behaviour change that overtakes the individual and the "malignant social psychology" that exacerbates and punishes the behaviour' (Kevern 2009a:208). So the way that staff interact with residents with dementia can enable them to either feel loved and cared for or of no account. This research has practical implications for care but will also reveal deeper issues about the understandings of human nature of those with dementia underlying that care.

The research will have benefit for me in my role as Chaplaincy Advisor as the influence of the Christian ethos of MHA has always been assumed but how or if it affects care in dementia-care homes has not been evaluated. It will also inform the training that I do with chaplains and other staff, both within MHA and more widely, on the care for people with dementia. I also believe that it will be of benefit to those who manage and offer training in our dementia homes, as the research will explore what staff understand of MHA's values and how these values affect care.

In their day-to-day work staff can be so immersed in their role that they fail to realize the significance of the care they give and what influences that care. By offering them the time to tell their stories it is hoped that they will feel affirmed and valued as they share their experiences. The intention is to come alongside the care staff and make it a positive experience and to affirm the 'neglected sources of satisfaction and reward' in their role (Nolan et al 2002:195), as well as showing respect for the challenges and difficulties they face in caring for those with dementia.

In this chapter I discuss myself as a reflexive practitioner, the design and conduct of the research along with the ethical implications, methods and tools of data collection. I also explore the criteria by which the data was analysed.

**Reflexive practice**

Practical theology gives a framework for my research as it invites the movement from 'practice to theory and back to practice' (Browning 1996:9) as 'in this model the whole process of research is seen as theological' (Cameron et al 2005:23). In order to move from the simple exploration of the way that care is offered in the homes I needed to be aware of myself as a reflexive practitioner. Throughout the research a journal was kept and was used to record thoughts and themes that emerged in relation to the research, and to capture moments, events, and impressions that might later inform the analysis (Lee 2009:42). Scott says that 'Reflexive practices are therefore considered essential elements…they relate to examination of both the researcher's own research traditions and ... examination of both the researcher's own conceptual and effective maps, the way those maps mediate and structure reality for the researcher and what is being researched' (Scott 1997:156).

Graham, Walton and Ward (2005:19) in their chapter on 'Theology by Heart' write about the practice of 'turning-life-into-text' by developing verbatim accounts in order to analyse pastoral practice and so enable reflexivity. Writing in a journal without constraints allows deep thoughts to surface to aid reflection. So through personal reactions, noted in my research journal, I have become aware of how my understanding both of myself and the organisation in which I work, has changed. In recording events, personnel, literature and situations encountered in the context of my life of research and faith, even when it was difficult, I have been able to feed these observations back into the research as the 'researcher and research affect each other' (Fox, Martin and Green 2007:156).

My role as Chaplaincy Advisor for MHA could be seen both as an advantage in my research, as I am aware of the complexities that make up the organization, but also as a disadvantage, as people could say and do things that they think I am expecting because of my role. I had been

involved with MHA as a Chaplain for 15 years before beginning my present role so have prior knowledge of the research settings.   But there was a danger that I might be over-familiar with the homes and might not be able to perceive the nuances someone with fresh eyes could.  It is for this reason that I decided not to use the chaplain of each home as part of the research. They are directly responsible to me and, while they are the focus for the spiritual life in the home, they are not directly involved the ordinary care of residents.  The staff involved may recognize me, but they are not accountable either to me or the department of Chaplaincy and Spirituality within which I work.

Another disadvantage of being part of the organisation for so long is that I could have blind spots, or see what I want to see. In good faith one can believe that a journal is 'open and honest', but all of us have blind spots. Once a question is known an answer can be teased out; the difficulty sometimes is in knowing what the questions are (Moon 2004:216).  By using an interview schedule that related to the care of those with dementia and asking people to tell their story I hoped to learn about care in a way that was different to my usual contact with the homes and so enable me to experience new thoughts and questions.

Being aware of these conflicts meant that I could be, 'reflexive by taking into account subjectivity [that] will involve knowledge of who I am as a whole being…. and understanding the effects this has on the knowledge I perceive and create,' (Fook and Gardener 2007:29).  Recognizing that the researcher's background helps to shape both the research and the results Fox et al (2007:11) remind us that 'the aim is still to be objective but there is a recognition that this is impossible.'

Reflexivity is the ability for the researcher to reflect on their role in the research and to be 'conscious of how participants' behaviour is affected by the awareness of being observed' (Hall and Hall 1996:42). From my experience first as a teacher, counsellor, minister and more recently in my role as chaplaincy advisor I know this to be true. However I am also

aware that I need good interpersonal skills in order to normalize what could be a stressful situation so that I can enable a true response from those involved in the research.

This study comes subsequent to earlier research undertaken by me as part of a masters degree.  There I explored the role of a chaplain in a dementia-care home and began to be aware of the complexities of dementia, and just how much residents rely on those around them to support their identity. From the literature discussed in an earlier chapter have come the themes of self and identity and although theology speaks into that area it is still in the early stages developing a theology of care. It is into this emergent area that I offer this study.

Into this research I bring precommitments that have influenced my perspectives and value judgements. These include my background within the Methodist Church and my commitment to and continuing involvement in MHA. Being aware of the potential for bias that could be present enabled me to offer a more honest reading of the data.

**Methodology**

This section is an exploration of how my research was carried forward; the advantages and disadvantages of different methods are weighed up, and a rationale offered for the method chosen. The purpose of the research is to examine the model of person-centred care for those with dementia in the homes by collecting appropriate and relevant evidence. Considering the way that therapeutic interventions are used will enable the ethos of the home to be seen more clearly.

*Practitioner research*
In order to conduct research into the care offered in the homes practitioner research offered an appropriate model as it is 'an area situated between academia-led theoretical pursuits and research-informed practice' (Furlong & Oancea 2005:1), and covers all research

into and about practice. It implies that practitioners will learn from researching their practice (Campbell 2007) and Groundwater-Smith and Mochler (2006:107) argue that 'those involved in practitioner inquiry are bound to engage with both 'theoretical' and 'practical' knowledge moving seamlessly between the two.' Critics of practitioner research believe it to be a 'blot on the landscape of inquiry' because of its lack of scientific pedigree, while advocates see it as 'more authentic' because of its proximity to daily work (Bruck et al. 2001).

How high quality research of relevance can be undertaken in care homes has been addressed by Froggatt, Davis and Mayer (2009:16). They suggest that the research should not 'distance the researcher from the care home or the people living or working in it', by 'moving from an approach that is about doing research 'on' people to researching 'with' them'. Fox et al. (2007:15) suggest that the researcher wants to understand the subjective experience of the participant, what they do and the meaning they give to it. By getting to know a small number of people in depth the researcher is able to explore their understanding of their role and collect thick description that builds on an understanding of the framework and context of their situation which produces evidence of 'both behaviour and meaning' (O'Leary 2004:119).

These writers support my chosen method, which was to uncover the hidden assumptions behind how care is provided through encouraging staff to share their experience and understanding of care and then reflecting on the thick descriptions they offered.  However staff exercise their care within a specific environment so in using this approach 'the fieldworker is careful to connect the facts that s/he observes with the specific features of the backdrop against which these facts occur' (Baszanger and Dodier 1997:10). Katz (2001) speaks of data being compelling when it is rich with mysteries and paradoxes and so offers resources for appreciating the emotional meaning of what is going on.

In order to explore the way the values of MHA influence the care of those with dementia, the assumptions that are made, the norms of behaviour and the practices adopted, I considered using an ethnographic approach since it is concerned with entering the world and the lived experience of others' world. Ethnographic research seeks to explore as this is to 'understand, discover, describe and interpret' (O'Leary 2004:119). However I decided that this approach was not appropriate as I was unable to spend the necessary amount of time working alongside care staff in order to enter their world to understand why they did what they did.

*Insider v. outsider*

In order to examine what model of care the Christian ethos of MHA offers to those with dementia the study has been designed to study staff in three groups of three MHA homes all of which offer specialist dementia care. The focus of the research is my workplace setting where I have knowledge of the homes and staff within them, and I am seeking to excavate the ethos of the care offered and the values of the organisation that underpin the care. I come from within the organisation and so am seen as someone 'safe and trusted' (Fook and Gardner 2007:59), wishing to see it in its best light. However my role is not as a carer but as a Chaplaincy Advisor, so although I come to the research with an understanding of what literature suggests is best practice, and a grounding in MHA's values, I have not shared the role of care.

This 'tension between strangeness and over-identification' is recognised by Coffey (1999:23) and she advocates a 'managed strangeness' in the interaction between the researcher and the subject. She goes on to give an example of 'over-identification' (Coffey 1999:31f.) such as lack of awareness of self in relation to the field and the key informants which make the researcher 'unreflective of his/her own situated position'. However she suggests that the extremes of 'stranger' and 'over-identification' are too simplistic and the key to the process is awareness. It is the space created by the professional distance in which the analytical

work is done.  O'Leary too suggests that there is the potential (2004:119) for the researcher to have an effect on the research which could affect the data.  She also says that there is a need to guard against 'homogenization' when no voice is given to those of different views.

This 'space' for research and reflection is a vital component of this research as it gives the opportunity for staff to reflect on what they do and for stories to be told. In speaking of 'truth' Goodall and Reader (1992:139) suggest that 'Authentic contact with others occurs not through our deliberate and calculating speech, but only when there is an open space within which the truth can be revealed'.  By offering staff time to tell stories about their care I hoped to provide this space in which some truth might be revealed.

It was important for my research to understand the underlying ethos that informs the practice of care in the Home so that the carers' role could be seen in context.  While qualitative research is sometimes dismissed as 'only descriptive and impressionistic' (Miller 1997:24), it offers the opportunity to learn from practical experiences because it requires that issues of everyday life and practice are addressed.

By selecting such information-rich situations in care homes for those with dementia I hope to be able to make logical generalisations from the weight of evidence produced in studying these critical cases. Patton suggests that by using critical case sampling we can generalise because, 'if that group is having problems then we can be sure all the groups are having problems' [1990:174].

The research has an interpretive approach as I met the carers where they were working so could understand what meaning they put into 'how they get things done.' I decided not to do any observation in the home as there are often visitors looking around, and this is sometimes disruptive for the residents. I did not want to disturb the running of the home and believed in

this way I would be respecting their privacy. But by simply being in the home I understood that I would alter the dynamics of the situation. Researching the actions and beliefs of care staff raised questions about how to enable them to tell their story, as people are not always able to articulate their thoughts. Katz suggests that, 'The path from describing how people do things to explaining why they so act must initially be sensed more than articulated' (2001:446). This relies on a heightened sense of awareness of the person, and a relationship in which the person feels able to express him/her/self freely. I was mindful of the difficulty some people have in getting their thoughts together and had a series of questions to guide our conversation and was ready to offer my observations through my knowledge of their home in order to help them begin.

**Ethical considerations**

The purpose of the research is to examine the care for those with dementia and discover what influence the Christian ethos of MHA has on that care. Given the nature of the study, my role as Chaplaincy Advisor within MHA and my designation as a minister of religion, the importance of the ethical issues are at the heart of the methodology. There must be a care and support role as well as that of maintaining the integrity of those involved, not merely designing research in order to do no harm to participants. I am reminded that ethical codes were developed in the aftermath of the Second World War and that The Nuremberg Code 1947 states; 'there should be voluntary consent of participants; they should have the power to choose without being placed under duress; they should be given information on which to base their decision to be involved; participants need to understand the nature, duration and purpose of any research' (Lee 2009:144). A participant information sheet and a consent form were produced in order to conform to good practice (Appendix i).

In order to receive permission to conduct the research an ethical statement was submitted to the University of Chester for consideration, and a synopsis of the proposal research was submitted to MHA's Central Management Team. Permission was also given by MHA to use the participant information sheet and consent form, along with the survey questionnaire and the interview schedule.  I found that preparing the participant information sheet and consent form made me more aware of the ways in which I needed to be mindful of those who agreed to take part in the research, valuing their involvement and respecting their knowledge and expertise. It was important for me to stress that they had the choice not to be involved, even if the manager had suggested that they should. I also needed to reassure them of ways in which the confidentiality of their interview would be respected, especially as I was part of the organisation. On reflecting on my field notes I found noted on several occasions how trusting staff were towards me, whom they did not know. All the managers had met me before so we had the beginnings of a relationship on which to build, but staff members had not talked with me before. I found this assumed trust to be humbling and perhaps indicative of an understanding of the fairness and honesty within MHA.

In designing this research I was careful to ensure that it reflected the values that are at the heart of MHA as I believe that they would show best practice in the involvement of the staff and of myself as an ethical researcher. It also offered an ethical framework that was not simply defensive in trying to foresee problems, but presented an opportunity to affirm and encourage staff in work that is often difficult and challenging. The MHA values are:

- We will strive for excellence in everything we do
- We will meet everyone's spiritual needs along with their other needs
- We will respect every person as a unique individual
- We will treat others with the dignity we wish for ourselves
- We will encourage personal growth and development
- We will care for one another especially the most frail and vulnerable

- We will be open and fair in all our dealings

(MHA 2007a)

*Confidentiality*

Those who agreed to participate in the research were reassured by the commitment to confidentiality as expressed in the participant's information sheet. As members of staff in specific homes within MHA they relied on me to enable them to tell their story honestly and not to misrepresent them, while doing my best to ensure that, as far as possible, they were not able to be identified.

Three dementia care homes were identified in each of the groups I wished to research: those MHA had built and run for many years; those homes that MHA had taken over from other owners in the last five years; and those homes recently opened by MHA.

To limit identification each home was coded with a reference numbers 1-3 for the first group; 4-6 for the second; 7-9 for the third. In this thesis staff at the homes will be referred to using lower case letters; *a, b* or *c.* It may be possible that specific events referred to would identify a home, so some details from the interviews have been changed to make identification less likely, though to those who know the homes well there may be something that will enable it to be recognized.

The interviews were transcribed and while the transcriber will know from the tape the first name of the participant and the track number, they will not know the identification of the home so confidentiality was maintained.

*Participant Involvement*

The participant information sheet explained that participants had the right to withdraw from the research at any time. At the beginning of the interview they were asked if they were happy with their involvement, and at the close of the interview they were asked if they had anything else to say. I wanted to allow people to say what they felt, to tell their story and

be careful not to influence them to say what they thought I wanted to hear in order to support my own theories.

Katz (2001:445) suggests that 'If research subjects can reliably report why they do the things we want to understand, who would need us?' This seems obvious, but what is missing is someone to ask questions in order to make what is happening visible and then to reflect on what is learned.

To enable the staff to feel comfortable I had to work to form a relationship with them, especially the care staff, none of whom I had met before. It was easier to build a relationship with the managers as even if they did not know me they knew of my role and my place within MHA, whereas the care staff would have had no reason to know of my existence although they would be aware of the chaplain attached to their home. All participants were given my phone number in case they wanted to discuss anything in relation to the interviews or wanted to withdraw. I was surprised and honoured when, although the interviews lasted for no more than an hour, three of the staff participants phoned me or sent a text after the interview. This was not because of discomfort with the process or because they wanted to withdraw, but because they wished to continue to talk to me about their work. I felt that I had succeeded in developing a trusting relationship because they felt comfortable in contacting me. These conversations have not formed part of the research, but could form the basis for further work on completion of this study.

It was made clear to participants that if they wished to make a complaint about the conduct of the research they would have direct access to my line manager, the Director of Chaplaincy and Spirituality, and his direct line phone number was made available to them.

At the conclusion of this research the sections of this thesis that involve analysis of the interviews will be made available in each of the homes that took part. I will also visit the homes and be available to talk to participants about the way the information collected was used.

*Funding and potential conflict of interest*

My paid employment is as Chaplaincy Advisor for MHA, so there is the potential for a conflict of interests as MHA supported my research. However no restrictions were placed on my access to the homes; the only caveat was that if a disclosure was made during interviews that could call into question the legality of what was happening in the home, then I had a duty to report it.

As I may have been seen as part of the establishment there might have been some participants who said what they thought I wanted them to say. However, in my role as Chaplaincy Advisor I come into contact with both managers and care staff and have been respectful of their professional responsibilities. This meant that they were less influenced by the fact that some of them knew me. I was also known to them as a fellow professional who had worked alongside managers to recruit chaplains and, when needed, to offer guidance in the line-management of their chaplains. By the use of careful questions and the telling of stories I hoped to show that there was no 'right' answer and that what I wanted to learn about is their experience as I respect their understanding of care.

It could be claimed that because of my role within the Chaplaincy and Spirituality Department I was too close to what happens in the care homes, and that could have affected the outcome of the research. However, although I work with chaplains in the homes, I am not at all involved in either the provision of care or policy concerning the day-to-day care of residents.  Like any other employee of MHA I had an obligation, to the homes and to the organisation, to protect MHA's interests by ensuring that I conducted the research in an ethical and honest manner so as not to cause damage or harm to the staff involved.

The research was carried out as I visited homes in my role as Chaplaincy Advisor so incurred no extra costs.

Due care was given to minimise the effect I had on the home just by being there, and I kept in mind the morale, self-esteem and confidence of the staff involved. The British Sociological Association states that: 'where possible they (researchers) should attempt to anticipate, and to guard against consequences for research participants which can be predicted to be harmful. Members (of BSA) are not absolved from this responsibility by the consent given by research participants (Scott 1997:163).

Within any organisation there can be a fear of outsiders, or in my case an insider (Scott 1997:160), so assurance needed to be given to reassure all involved that my intention was not to 'catch them out', and that there were no right answer to any of my questions. I also needed to explain carefully the safeguards in place for confidentiality and anonymity.

I believe that the ethical considerations listed above are not incidental to the research, but fundamental to it and consistent with both the design of the research and my role as an ethical researcher.

**Method**

*Design*

The importance of the ethos of the home and the quality of care the staff are able to offer are difficult to evaluate based on the usual ways that assessments are made. The insistence on immaculate decor and colour themed areas seem an easy marker for quality, while attitudes such as affection and concern are less tangible but more important for long-term care. For example, the ethos of one home that encouraged 'Laura Ashley' type of care where everything matches and nothing is out of place seemed the most important factor in care of that home, not the well-being of the person. These factors can be observed, but my aim was to look beneath the surface at what factors influenced the home to offer the care that it does. The research has been designed to explore the care offered to those with dementia and to discover something of the ethos of the home in the way it works.

*Participants*

I decided to conduct the research by inviting staff of the homes to participate, not the residents. The decision to engage with the staff was made because I believed that their participation would best help me answer the research question as it is concerned with the care offered in MHA dementia care homes and how that is influenced by the Christian ethos of the organisation.  In order to do this I needed to explore what care staff believe about why they do what they do.

In recent years much has been written about involving those with dementia in research as they are able to be involved in their own care and also comment on it.  'Goldsmith's  call for researchers, policy makers and practitioners to hear the voices of those with dementia…has been one that has since been responded to by many researchers' (Innes 2009:107). But those living with dementia are extremely vulnerable people, and some have asked, 'should we be "mining the minds" of these disempowered people for our own research purposes?' (Liamputtong 2007:25).  In some sense we are all vulnerable, so care has to be taken with all people involved in research, but with those with dementia there is need for even more care.  Another difficulty is of obtaining consent for the research, even if they were willing and able to take part. I believe that in order to allow those with dementia to take part fully there has to be an awareness of the risks involved. These risks can be minimised if there is a relationship with the one being interviewed as one can more easily be conscious of any discomfort or distress the person is feeling. Therefore in this study I decided not to involve the residents because I was not in the position of having a relationship with them, as my regular visits to the homes are usually confined to meeting chaplains and managers.

There is an element of purposive sampling as I chose the homes that I believed would best help to answer the research question. The corporate management team (CMT)  and then service managers needed to give consent, following which the managers of the homes were contacted directly to see if they would agree to take part in the research. Members

of the care staff to be interviewed were selected by the home manager, but also had the opportunity to accept or decline.

The first group of homes were those designed, built and managed by MHA from their outset. The second group were built and run by other care organisations before being transferred to MHA. The third group were new MHA homes built within the last two years. My hypothesis was that any Christian influence in the care offered will be embedded in the ethos of the first group of homes, less evident in the second group and still developing in the third group.

The difference between attitudes in the groups of homes could be because they have not yet assimilated MHA's core values. Douglas talks about a 'common shape' (Douglas 1986:91) that becomes important when new projects are commissioned.  With new residents and new staff it becomes important to find some stability and, 'To become stable means settling into some recognisable shape' (Douglas 1986:111). Establishing this 'recognisable shape' in new projects has not been easy and recently there have been changes in way new homes are managed, with an experienced manager acting as a commissioning manager to establish the web of relationship between the organisation, the project, and the staff and residents.

Three homes were chosen in each group so as to give a way of evaluating the validity of the data collected. If two homes were used, the resulting data could be contradictory and then it would be difficult to come to an understanding. By using three homes there was a triangulation against which to base a judgement.

*Gatekeepers: Power and access*
Ethical clearance and permission to begin the research was granted by the University and MHA. The service managers in whose patches the homes were located were asked for their permission. They gave it

willingly and asked to see the results as they found the research question interesting.

However access involved more than being given permission to begin the research by the University and MHA. It involved negotiating access that was a continuing process with different people at different levels: 'though access is granted by the principal gatekeeper this may not reflect the interests and wishes of all members of that organisation' (Scott 1997:159). So after receiving permission from the service managers I contacted the individual home managers, as I wished each level of the organisation to have the same opportunity to accept or refuse the invitation to be part of the research. Time was given to service managers and managers to talk through the research in order to reassure them that I was concerned with exploring what is happening in the homes, not researching in order to be critical of the care that they offer.

Initial access to the homes was by a phone call to the manager followed by a précis of what has been said in an email for their reference. They were asked to contact me if they wanted more information. I then arranged a time with the manager when I could visit to talk through the participant's information sheet, consent form and the questionnaire. I asked if the manager was prepared to be interviewed, and if s/he could identify two other members of staff with varied experience who could be approached with an invitation to be interviewed.

**Data collection**

The purpose of collecting data was to discover how an individual constructs his/her own world, and the focus was on the individual's own experience (Fox et al. 2007:15). This research was designed to use a qualitative method supported by a survey in order to obtain as wide and in-depth a view as possible of the homes. Fox et al (2007:21) suggest that 'Different sorts of research can complement each other…[and] can be a way to 'cross-validate' or 'triangulate' results on the same research

question' (Fox et al. 2007:22).  Fox goes on to explain that by combining methods, data can be strengthened.

My method was to use qualitative data gathered from in-depth interviews (Appendix ii) with three staff in each home, and to follow this up with data collected by use of a survey (Appendix iii) to see if the data collected in the individual interviews were representative of staff in the home.

*Qualitative data*

Swinton and Mowat state that the research quest is not for 'objectivity and explanation… but for meaning and deeper understanding of situations' (2006:37) and 'in order to understand what is *actually* going on within the situation it is necessary to understand the *meaning* of the actions, the way the situation is being interpreted… and the reasons behind the ways individuals and communities act in the particular ways that they do' (2006:38).  Qualitative research enables what is said and done to be given value within the context in which it takes place.

Patton (1990:280) notes that there are three approaches to collecting qualitative data through open-ended interviews: the informal conversation interview which relies on the spontaneous generation of questions; the general interview guide in which sets of issues to be explored are outlined before interviewing and are then used in any order; and the standardised open-ended interview in which sets of questions are carefully worded and arranged and asked in the same sequence so that essentially the same words are used.

I chose the standardised open-ended approach as the most appropriate model of interview because of the desirability of having the same information from each person interviewed. Clarifications, elaborations and probing questions were written in to minimise deviation.

The standardised open-ended interview also minimised the effect the interviewer had on the research as the same questions were asked of each person. The interview was systematic and so the necessity for interviewer judgement during the interview was reduced. By using this approach I also ensured that interviewee time was carefully used as the questions were highly focused.  However there was a weakness, in that it did not permit the interviewer to pursue topics or issues that were not anticipated when the interview questions were written, nor did it allow insights particular to that home to be addressed. This was weighed against the constraints mentioned above and on balance I felt that the standardised open-ended approach was the most appropriate despite its weaknesses. However I did allow for unstructured questions to enable the carers to tell stories of when care did or did not work well.

Three members of staff in each home were interviewed using an interview schedule that included both structured and in-depth unstructured questions to obtain subjective and interpretative data (Lee 2009:72, O'Leary 2004:119). I hoped to gain their trust and help them feel at ease by first asking more general questions about care, and then asking them to share their stories with me.  In some interviews there was a need to ask for clarification of the content of the stories, or for help to be offered through 'what then?' or 'why?' questions. I used good counselling practice to enable me to gain clarity without leading the interviewee. The interviews were recorded and transcribed, and the transcriptions held by me on computer and as a hard copy on file.

Fox et al. (2007:18) suggest that the criteria by which qualitative research is evaluated should be in terms of trustworthiness, validity and generalisation. This can be observed in the way data is generated, collected and analysed.  The concept of being trustworthy is important to me as a researcher, both because of ensuring the honesty of the research within an organisation with a Christian ethos and because of my own identity as a minister of religion and Chaplaincy Advisor within MHA.

By using both two different ways of collecting quantitive data, and by involving a range of homes in order to triangulate the results, the research is generalisable and may be reproduced by another researcher. However, both the descriptions and the interpretation of the interviews are 'filtered through theories and analysis frameworks in the researcher's own worldview' (O'Leary 2004:119), so that I am part of the research as a reflexive practitioner. I understand that qualitative data is rich in the values, beliefs and practices of real people so that they can be explored in order to shed light on accepted norms (O'Leary 2004:119). But in order to do this themes and inferences need to be drawn out by the researcher and the data thoroughly excavated.

*Data from survey*

In order to obtain the widest possible information from the homes that are to form the basis of my research I decided that as well as using interviews I would collect qualitative data by the use of survey questionnaires. The advantage with this is that in each home data was collected that enabled a snap-shot of understanding to be obtained from as wide a range of staff as possible in each of the designated homes. They had the choice to take part or not, so were a self-selecting group.

The use of questionnaires to obtain basic qualitative data was chosen in order to canvas widely within the particular staff group to give an objective overview (O'Leary 2004), and the questions were specific statements about different ways of caring that ask the participant to agree or disagree. This data will be evaluated alongside the interviews to see if the ways of caring for people with dementia of those interviewed are representative of the home as a whole. I believe this research to be reliable and valid and generalisable within MHA care homes.

*Pilot study*

A pilot study was carried out with the manager at a dementia-care home that was not part of the project. She completed the questionnaire while I was there, and I wished I had had the recorder on as she explained all her

answers as she wrote.  My intention had been to ask staff to complete the questions while I was with them, but I realised that I had either to give them the space to do it privately, or keep notes to supplement their answers.  In order for me to have less influence on the outcome of the questionnaires I decided not to hand them out, but place them in a box in the staff room for carers to take and complete. The completed forms were collected by me at the end of the day.

One reason that the pilot interview was successful was that I was already known to this manager. I became aware that, while being professional, I had to have some introductory time to get to know the member of staff, and to give time for them to get to know and trust me. When I began to ask the interview questions I realised that although the questions looked fine on paper I could not ask them in that way: the questions needed an introduction to set them in context and to give the participant time to respond.  I also recognised the need to be flexible in the language I used to ask the questions, and while the questions were to the point, when asked of the participants they had the potential to feel like a test. This could be unsettling for care staff who, being in the unfamiliar situation of an interview, might be less sure of themselves than managers who had to justify their actions in different settings.  One advantage was that the staff would be on home ground so would be more likely to feel comfortable.

In the pilot study the manager's responses to the questions were that they had made her think and enabled her to share her thoughts and beliefs. I believed that because I was familiar and at home in the care homes I would be able to ask questions that enabled the participants to find a way to express their experience of care. But there was always the possibility that the questions would leave them 'cold' and unable to become involved. When I asked for feedback on the process the manager suggested that it might be good to have a group of staff discussing the questions so they could 'bounce ideas off each other'. I had considered this, but taking advice on the difficulty of enabling a group of staff to have time away from the residents, I decided to conduct individual interviews.

**Data analysis**

*View of the person*

The qualitative data provided a thick description of care for those with dementia within MHA. The questionnaires were analysed by care home to show which ways of caring/care therapies staff believe should be offered to those with dementia. From this it is possible to obtain a picture of the ethos of caring that home supports. From this evidence it is possible to suggest what it is that staff in that home believe about the person with dementia.

The criteria I used were:

1.     Those who believe people with dementia should be reminded of the past use Reminiscence Therapy (RT), and see them as 'ex-people'; people who once had a life.

2.     Those who believe that people with dementia are 'like us' but with a disability use Reality Orientation (RO) that reminds people what they should know.

3.     Those who believe that people with dementia are 'people like us' would use Validation Therapy, that asks people to listen to the emotions behind the words spoken and respond in a way that will meet emotional needs (VT).

4.     And those who believe people with dementia are shells as 'the person has gone, we are waiting for the body to catch up', and so need to be sedated in order to help them cope with the disease. (drug therapy when necessary: keep clean and calm).

The analysis of the qualitative data will also use these therapies, (RT, RO, VT, None) to examine the view of the person along with Browning's organisational analysis tools. This allows both the ways in which those with dementia are interacted with, and the organisation that enables this to happen, to be analysed.

**Browning's five dimensions**

Browning (1996:48) writes about the importance of researching practice; what reasons and ideas are used to interpret actions and what our sources of authority are.  While his book was written some years ago it is still at the cutting edge of grounding theology in practice.  Browning's aim is to show that Christian theology is practical, that 'theology begins and ends in the collective practice of living communities of faith' (Ogletree 1992:904).

He uses the concept of 'thick description' in order to see the situation and to identify the questions and offers five dimensions to enable an evaluation to take place. He says that 'theological ethics in its abstract form attempts to gain the distance required to make general statements about the norms of practice – statements that find their meaning as they arise out of a return to the concrete challenges of living' (1996:96), a practice-to-theory-to-practice model.

Browning's concepts relate well to researching the culture of a care home that has consequences for staff and residents, as the 'unique culture of a home has allowed practice to develop that enables a constant fit between the environment and the culture to be maintained' (Dewing 2009:224). Browning's five dimensions (1996:105) helped me analyse the qualitative data and so build up a picture of what influence the ethos of MHA has on the care of those with dementia.

His five dimensions are :
- Visional:  the use of particular narratives, stories and metaphors that shape the self understanding of the community.
- Obligational: how the organisation operates given the above.
- Tendency-need: theories about our human nature and how they are worked out in practice.
- Environmental-social: constraints of the working environment.

- Rule-role: how the above are put into practice.

These dimensions offer a model for the evaluation of both the organisation and the work of the care homes within the context of moral thinking. The 'visional' offers insight into the stories MHA has of its founding and how Methodist Conference responded to the need that was brought to their attention, and how that could be seen as a working out of Methodist Theology. In the late 1980s MHA then moved into dementia care influenced by the pioneering work of Tom Kitwood. How this came about and how this still influences care is part of the story. Since then MHA has developed the work and has both taken over the running of dementia-care homes from other organisations and built new homes.

The stories important to each individual home will also show what is important to the home and so give insight into its values. One of the fears expressed by staff as MHA grew so quickly was that the ethos would be 'lost'. This research will try to discover if this is so.

The 'obligational' gives the opportunity to examine the ethos of the organisation in the light of the standards and values statement. It is believed by some long-term supporters of MHA that when there were fewer homes the ethos was perhaps better understood and acknowledged by staff, however there is now more structured training in the values and regular audits and standards and values assessments (SVAs) take place.

Theories we have about our human needs come under the 'tendency-need' dimension and can be found in the work of Maslow, while Erikson offers insight into the needs of older people and Frankl those looking for meaning at the edge of life. The work of MHA is constrained by both internal and external factors which Browning calls the 'environmental-social'. These factors include government polices, funding, resources, staffing, and new research.

The 'rules-roles' dimension allows us to examine how all the above work together to offer care. It could be that values are constricted by other factors so that ideals cannot be lived out in all areas.

Dewing (2009:252) suggests that the 'main problem with the current system of long term care is that it is lacking in clear, coherent, conceptual underpinnings'. Using Browning's five dimensions offers a structure for evaluation using tradition; experience; practice, and other disciplines, and helps to explain and articulate why MHA offers the care it does and value is placed on the ethos of the organisation. Browning's model was conceived in order to enable research within Christian communities so it may be that the five dimensions are not all suitable for analyzing the data. For although MHA is a Christian organisation the staff employed do not have to be Christian.

Appendix iv contains the research questions and their relation to Browning's dimensions.

**Conclusion**

The foundation of this research is summed up by this definition: 'Practical Theology is a critical, theological reflection on the practices of the Church as they interact with the practices of the world, with a view to ensuring the enabling faithful participation in God's redemptive practices in, to and for the world' (Swinton and Mowat 2006:6).

Through examining the care that staff wish to offer, and discovering through the stories they tell of care that worked well, or that failed, a picture is built up of the care that is offered to those with dementia in MHA homes. Evaluating the data collected enabled me to discover what is thought of the person with dementia, what care is thought appropriate and how that fits with the ethos of MHA.

MHA was founded by, and still has its place within, the Methodist Church. My research is to investigate how far the values of MHA are still influenced by the theology of the Methodist Church and to develop a theology of dementia care that can be offered to the Church.

In the next chapter the results of the survey and the interviews will be analysed in order to offer insights into what care for those with dementia within MHA can be.

# Chapter 3: What is actually going on

'So in the middle of breakfast … we danced!' (Interview).

**Introduction**

'communities…seek clarification about their mission in the context of the contemporary world' (Ogletree 1992:904).

The questions that emerged both from my study of the literature around the care of those with dementia, and from my experience of working for MHA was: what model of care does the Christian ethos of MHA offer for those with dementia?

In order to answer this question I reflected on the model of strategic practical theology as developed by Don Browning. He says that all practices of a religious community are 'theory laden' and that 'thick description' is needed to uncover various meanings present and embedded in that practice. He encourages us to ask: What, within a particular area of practice, are we actually doing?; What reasons, ideas and symbols do we use to interpret what we are doing?; What do we consider to be the sources of authority and legitimation for what we are doing?' (Browning 1996:48).

To help me to excavate what staff understand to be good practice of care for those with dementia, interviews, supported by a survey, were conducted to collect qualitative data. More detail of this process is included in the previous chapter. A total of nine MHA dementia-care homes were involved in my research: three in each group of homes in order to triangulate the data. Three were well-established homes rooted in MHA ethos; three homes that had been acquired by MHA in the past five years; and three new build homes. Data from each home were examined and then put side by side with other homes within the group. The three groups were then compared to see the model of care that emerged, and

also to note if the length of time the home had been putting into practice MHA's ethos made any impact on this care.

In the following inspection of the data the scores from the survey will be in both as fractions, with the base number as the cohort, and in percentage points. Although the numbers are small, the scores expressed as a percentage enables a comparison between the homes to be made more easily. Numerical data of questions 7 to 11, regarding models of care, are shown in the figures within the analysis of the home, as this group of questions showed the most marked differences between the homes and is at the heart of the research. Appendix v shows the table of results for each home.

The surveys were followed by semi-structured interviews in order to gain a more in depth understanding of each situation. The interviews from each group of homes were studied and then weighed against the other groups using Browning's framework of analysis with the supporting data analysis used to confirm that the interviews were representative of the home as a whole.

Together with supporting data from the questionnaires the interviews gave a picture of the care each group of home believed was good and what support enabled this to happen. This enabled me to begin to understand what might be special about the values and norms of behaviour within MHA as they are influenced by the Christian ethos.

**The survey**

*Questionnaires*
As discussed earlier in the methodology chapter, questionnaires were used as part of a survey to provide an overview of the home and to provide an indication as to how representative of the home the interviews with three staff members were. The sample completing the questionnaires was as random as possible, being those on duty on that day and who

were willing to answer the questions. Staff members who were later to be interviewed did not complete the questionnaire.

Data were not examined to test the statistical significance as, because of the small numbers, the results would have a high margin of error. But they were used to draw inferences related to what staff believed about the care offered within their home to people with dementia.

Questions 1-4 were to gain general information about their care experience; questions 5-6 were about their religious affiliation and their own spiritual awareness; questions 7-11 were concerned with the best way to care for someone with dementia with one question being repeated in the negative to see if the questions were being read carefully. Answers were chosen from 1: strongly agree to 5: strongly disagree with 3 being uncertain. Block graphs for this section of questions will enable the differences between the homes to be seen more clearly.

While all the questions concerning care addressed the web of meanings that constitute identity within the Christian ethos of MHA, question 12 explicitly asked about the relation of the Christian values of MHA to care.

## Analysis of survey questionnaires
(see Table of results in Appendix v)

### Group 1: well-established MHA dementia-care homes

Homes **H1**, **H2** and **H3** comprise the group of well-established MHA homes. These homes are of a similar size and usually have between 13 and 20 care staff on duty on any one shift.

*Experience*

At home **H1** three out of ten (3/10) (30%) of the staff completing the survey had over 10 years experience of working in care within MHA.  At

home **H2** 2/10 (20%) members of staff had more than 10 years experience with MHA, 2/10 (20%) had more than five years experience and 8/10 (80%) had less than five years experience. At home **H3** 1/20 (5%) members of staff had more than 10 years experience with MHA and 10/20 (50%) had more than five years experience. However, 11/20 (55%) of staff had more than 10 years experience of caring within other care settings.

*Church attendance and spirituality*

In **H1** 1/10 (10%) member of staff said they attended church occasionally and 1/10 (10%) described herself as 'spiritual'.

Only 3/12 (25%) staff in **H2** attended church occasionally and others rarely or never attended. However, 6/12 (50%) either agreed or strongly agreed that they were spiritual.

Home **H3** had 4/20 (20%) who attended church sometimes or occasionally with others attending rarely or never. However, 9/20 (45%) agreed that they were spiritual.

Very few staff were churchgoers although many described themselves as 'spiritual' and so may have found it easier to sign up to the MHA values.

*Care preferences*
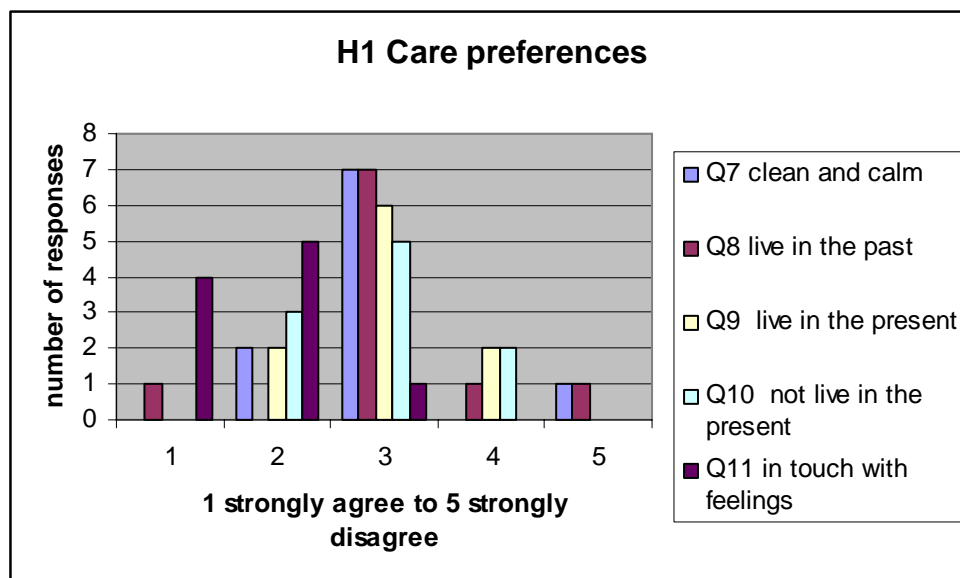


Fig 1

Questions 7-11 were concerned with the care offered in the home. In answering Q7-9, 7/10 (70%) of **H1** (fig. 1) were 'uncertain' as to the best way of caring. Only one member of staff strongly disagreed that the best way was to keep them clean and calm, while one strongly agreed that they the best way to care would be to remind them that they live in the past. 9/10 (90%) agreed that the best way to care was to enable people to be in touch with their feelings.

As with H1 the questions concerning the best way to care in **H2** (fig. 2) were marked by an average of 8/12 (66%) saying that they were 'uncertain'.

**H2 Care preferences**
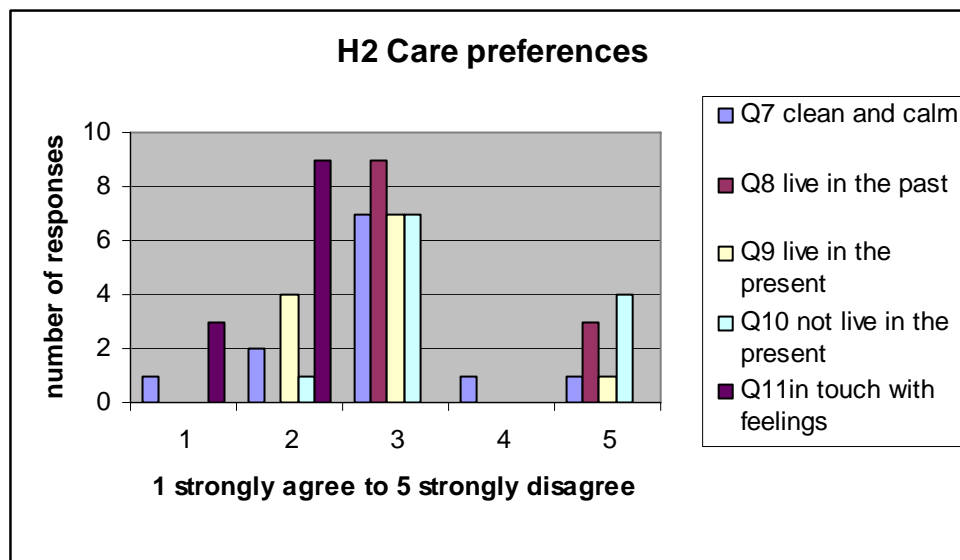


Fig. 2

4/12 (33%) strongly disagreed that they should not be reminded that they live in the present and 4/12 (33%) agreed that they should, showing a consistency of approach. All either agreed or strongly agreed that the best way to care was to help them be in touch with their feelings. Two of the questionnaires had responses added by the member of staff. One added the comment that questions about care, *'depended on the individual'*, and the other augmented their strong disagreement that the best way of care was to make sure people were clean and calm by saying, *'but they are people first'*.

While the uncertain nature of the best way to care was a feature of this home, all either agreed or strongly agreed that being in touch with their feelings was the best way to care. When the questions about reminding, or not reminding, people that they live in the present were examined there was no contradiction. So a positive observation can be drawn about the careful reading of the questions.

The scores in home **H3** (fig. 3) differed from the other two regarding the best way of caring. 16/20 (80%) either agreed or strongly agreed that the best way to care was to keep people clean and calm suggesting that they believed that appearances were highly important. Half the staff said that they should not be reminded that they live in the past suggesting that what matters to them is what is happening now. On other questions they were equally divided.
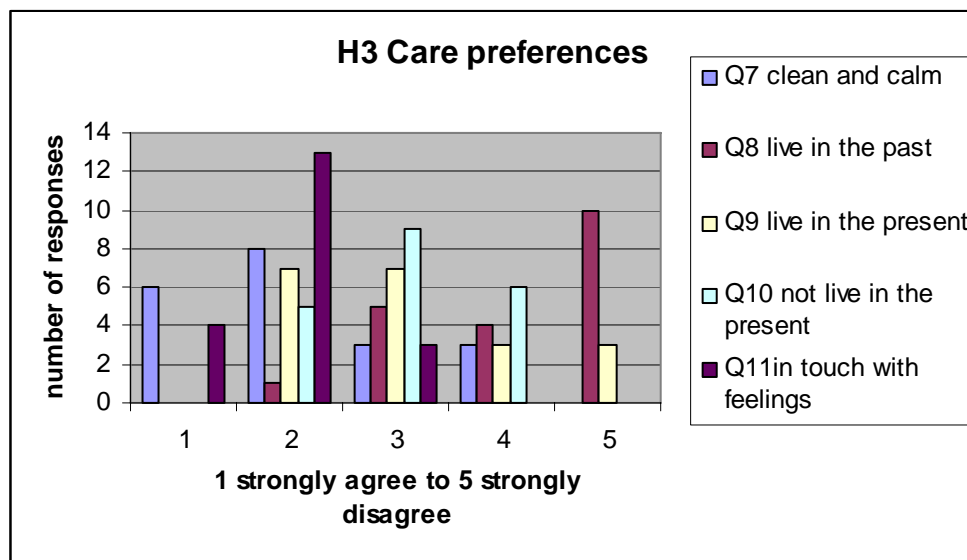


Fig. 3

The results from homes **H1** and **H2** showed a similar attitude to care, with the largest responses being 'uncertain', while home **H3** had a greater number of 'agree' or 'disagree'. However all three homes scored highly when asked if the best way to care was to enable people to be in touch with their feelings.

*Christian values of MHA*

In homes **H1** and **H2** all of the staff either agreed or strongly agreed that the Christian values of MHA, as expressed in the Standards and Values displayed in each home, helped them to offer better care to people with dementia.

In home **H3** 14/20 (70%) of the carers either agreed or strongly agreed that the Christian values of MHA helped them to offer better care to people with dementia. 5/20 (25%) either disagreed or strongly disagreed that the Christian values enabled better care to be offered.

*Inferences from group 1 homes*

From the combined scores for Group 1 homes, analysis of the data revealed that the highest scores for the questions on the best way to care (questions 7-11) were in the 'uncertain' category, which surprised me as I thought that because of their experience this group of staff would be very clear as to what they considered 'best practice'. I went back to home **H1** and asked five members of staff what they thought 'uncertain' meant in that context. I was told that it meant that they could not answer the question as 'it all depended on the person and the type of dementia they had'.

However the scores of **H3** were less uncertain with more definite 'agree' or 'disagree' answers as to the best way of caring. This would suggest that they have definite ideas about who the person with dementia is and that from that they can generalise about care for all people with dementia.

It was noticeable that in all these homes only 4/42 (9.5%) were uncertain about good care as enabling people to be in touch with their feelings. The other 38/42 (90.5%) either agreed or strongly agreed that this was the best way to offer care. To be in touch with their feelings suggests that those with dementia are seen as people like us.

Only 2/42 (4.8%) said that they attended church 'sometimes' while other staff 'occasionally, rarely or never' attended. However 36/42 (85%) either agreed or strongly agreed that 'the Christian values of MHA help us to offer better care for people with dementia'.

By examining these data it appears that staff in this group of homes believed that MHA's Christian values enabled better care and so were concerned to discover more about the person with dementia before deciding what 'best care' can be for them. This could point to a well-developed and established ethos of person-centred care that does not make it possible to generalise care as it 'all depends' on the person and their needs at that moment.

The added comments written into the questionnaire gave weight to this understanding, when the easiest action when faced with those questions would have been to circle one given answer. Their extra care to explain what they believe went so far as to amend my questions to make them fit. This is a small thing, but it points to a care for the person, not a prescribed method of care.

Home **H3**'s results are more evenly spread than the other two and, if this is looked at alongside the shorter length of time carers have worked within MHA it could point to a underlying link.  For although staff at home **H3** had long experience within other care settings their exposure to MHA values was more limited, suggesting that MHA values do make a difference to care.

**Group 2: recently acquired MHA dementia-care homes**

This group of three homes, **H4**, **H5** and **H6**, are dementia-care homes that have been acquired in the last five years by MHA.  All staff on duty at home **H4**, except those to be interviewed, completed the questionnaire, while more than half of staff at homes **H5** and **H6** took part in the survey.

*Experience*

Of the staff members on duty at home **H4**, 6/15 (40%) had more than 10 years experience of care, while 13/15 (86%) had less than five years experience within MHA.

In home **H5** 2/7 (28%) of staff had more than 10 years experience of care, with 5/7 (71%) of staff having less than five years experience within MHA. 5/8 (62%) of staff completing the questionnaire in home **H6** had more than 10 years experience of care, while all had less than five years experience within MHA.

This group of homes had a good proportion of staff with over 10 years experience in care, but as MHA had taken over management of these homes about five years ago most of this experience was with other care providers.

*Church attendance and spirituality*

5/15 (33%) of staff at home **H4** said that they occasionally, sometimes or often went to church, and 10/15 (66%) said that they thought themselves to be spiritual.

In home **H5** 4/7 (57%) rarely or never attended church, while 5/7 (72%) agreed that they were spiritual.

At home **H6** 4/8 (50%) of staff were regular church goers with 2/8 (25%) attending occasionally and 2/8 (25%) never attending. However all said that they thought that they were spiritual.

A greater proportion of staff in this group said that they thought of themselves as spiritual. This could be because they had a better understanding of spirituality or because they knew of my role as chaplaincy advisor within MHA and so thought that answer would be more acceptable.

*Care preferences*



**H4 Care preferences**
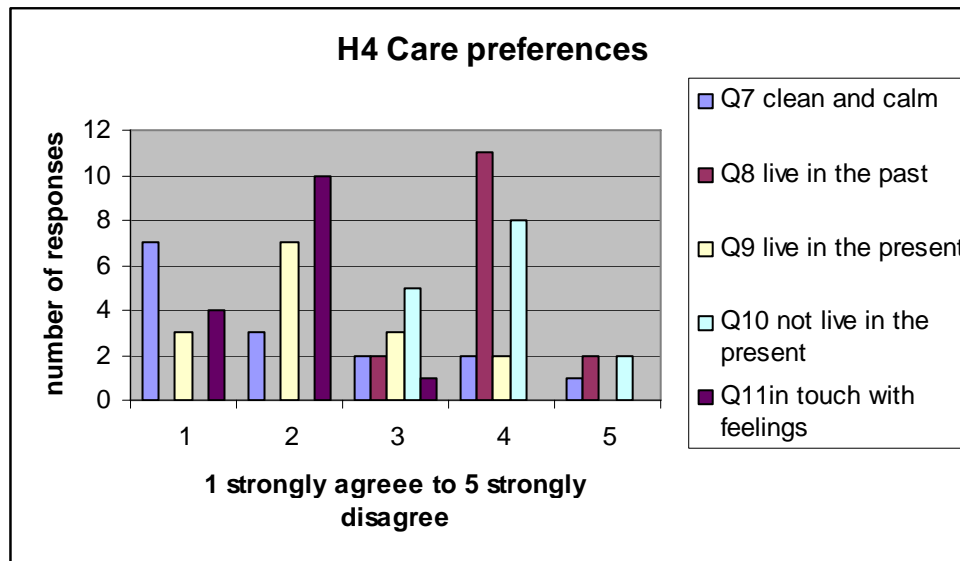
Fig 4

Most of the answers in this set of questions in home **H4** (fig. 4) were less uncertain and had a wider spread than the first group. 10/15 (66%) either agreed or strongly agreed that best care would be to make sure that the person is clean and calm while 13/15 (86%) either disagreed or strongly disagreed that people should be reminded that they live in the past, and 14/15 (93%) either agreed or strongly agreed that the best way of care was to enable people to be in touch with their feelings.

In this group of questions those choosing 'uncertain' were on average 2/15 (13%), which seemed to point to staff being more sure of the best way to care. A similar number of replies agreed with reminding them that they live in the present, and disagreed that they should not be reminded that they live in the present. This seems to support the idea that this group of staff were careful in their reading of the questions.

**H5 Care preferences**
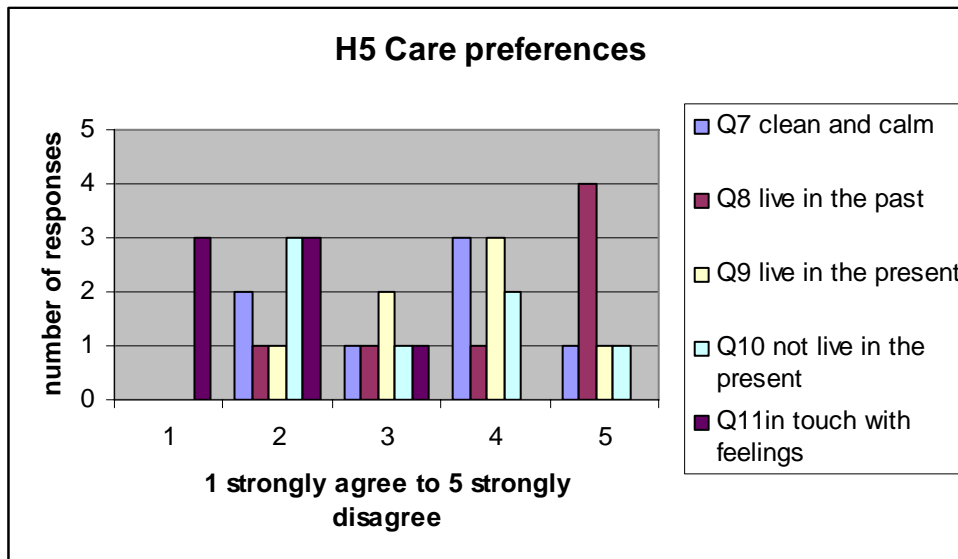
Fig. 5

The scores for **H5** (fig. 5) followed a similar pattern to those in home **H4**, with most answers being in the 'agree', 'disagree', or 'strongly disagree' sections. Asked about the importance of keeping people clean and calm 4/7 (57%) disagreed or strongly disagreed. While 5/7 (71%) disagreed or strongly disagreed that they should be reminded that they live in the past, and a similar number disagreed or strongly disagreed that they should be reminded that they live in the present. Most answers were either agree or disagree, with no more than 2/7 (28%) being 'uncertain'. (Note: this was however the home that had the smallest response of any of the homes that took part, suggesting that they were either too busy to take part in the survey or that they were not interested.)

Home **H6** (fig. 6) was a little different to the other two in this group with all respondents believing that the best way to care was to keep the person clean and calm. 5/8 (62%) of staff disagreed or strongly disagreed that the person should be reminded that they live in the past.

There was almost unanimity that the person should not be reminded that they live in the present as 7/8 (87%) disagreed that they *should* be reminded that they live in the present and 6/7 (75%) agreed that they *should not* be reminded that they live in the present. Only 2/8 (25%) of

answers in this section were 'uncertain', all other answers being either agree or disagree.

**H6 Care preferences**
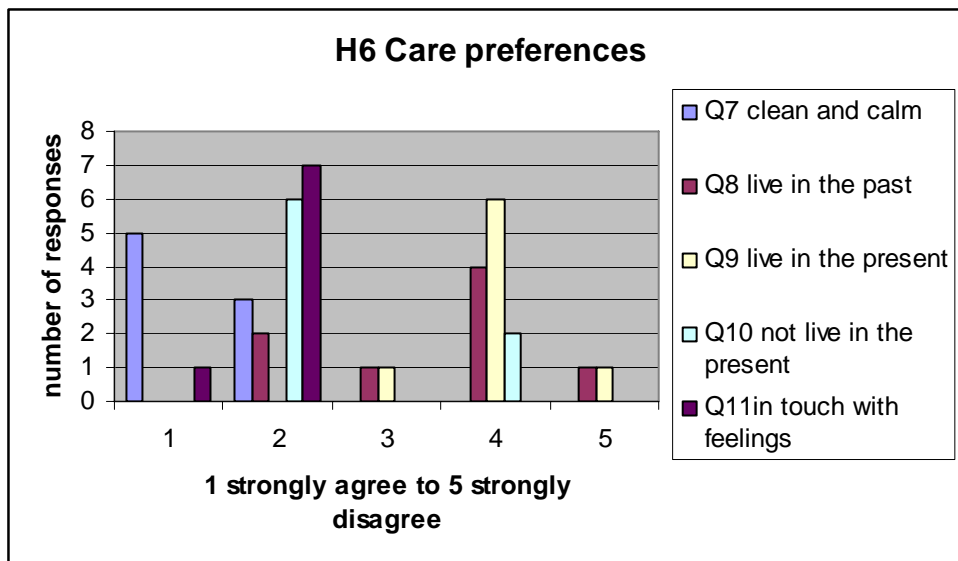


Fig. 6

*Christian values of MHA*

9/15 (60%) of replies from home **H4** either agreed or strongly agreed that the Christian values of MHA enabled them to offer better care. However 3/15 (20%) were uncertain and 3/15 (20%) disagreed that it made a difference. This is curious as there is a higher percentage of churchgoers and those who thought themselves spiritual in this home.

However it is interesting that the proportion, 9/15 (60%) of those who were in agreement that the Christian values of MHA enabled them to offer better care, and who thought themselves spiritual were the same, which suggests that there might be a link between the two results.

In home **H5** 5/7 (72%) of staff said that they believed that the Christian values of MHA enable them to offer better care, with 2/7 (28%) being uncertain. Once again the percentage of staff agreeing that the values are important was the same as those who thought themselves spiritual, hinting to a pattern within this group.

7/8 (87%) of replies from **H6** either agreed or strongly agreed that the Christian values of MHA enabled better care to be offered, while 1/8 (12%) said that they were 'uncertain' that this was the case.

*Inferences from group 2 homes*

Looking at the combined scores for Group 2 homes it is noticeable that the highest scores for the questions on the best way to care (questions 7-10) are in the 'agree' or 'disagree' categories. It appears that staff in these homes are confident of the best way to offer care.

It was noticeable that in this group of homes 5/30 (17%) were uncertain about good care as enabling people to be in touch with their feelings while 28/30 (93%) either agreed or strongly agreed that this was the best way to offer care.  However 20/30 (66%) believed that the best way to care was to keep the person clean and calm which is a high proportion and does not fit with the best way to care being to enable the person to express a range of emotions. This suggests that staff in these homes might think of someone with dementia as a person like us, but that they are not sure how to cope with emotions that might be expressed.

14/30 (46%) said that they attended church 'often, sometimes or occasionally' while 16/30 (54%) said they 'rarely or never' attended. However 21/30 (70%) either agreed or strongly agreed that 'the Christian values of MHA help us to offer better care for people with dementia'.

These data suggest that the majority of staff in this group of homes believed that MHA's Christian values enabled better care. They were aware that they should keep the residents clean and calm, but that they should also help residents to be in touch with their feelings. This has implications for care as to which model of caring would take priority.

**Group 3: recently opened MHA dementia-care homes**

This group of three homes; **H7, H8** and **H9** are dementia-care homes that have been built and opened in the last five years by MHA. All staff on duty at homes **H7** and **H9**, except those to be interviewed, completed the questionnaire, while three-quarters of staff at home **H8** took part.

*Experience*

In this group of homes, no home had more than a third of respondents with more than 10 years experience of care while in home **H7** 11/20 (55%) had less than 5 years experience. As they were homes that had been built within the last five years no group of staff had more than five years experience of working for MHA.

This group of homes had the least experience in offering care.

*Church attendance and spirituality*

Home **H7** was unusual in that 14/20 (70%) of staff said they attended church 'often, sometimes or occasionally', with 16/20 (80%) saying that they were spiritual or fairly spiritual.

3/10 (30%) in home **H8** said that they attended church often or sometimes, and 7/10 (70%) said that they attended rarely or never. However 8/10 (80%) believed themselves to be spiritual while 2/10 (20%) did not.

4/15 (27%) of staff at home **H9** said that they attended church often, sometimes or occasionally while 11/15 (73%) rarely or never attended and 6/15 (40%) said that they were not at all spiritual.

*Care preferences*

In home **H7** (fig. 7) 10/20 (50%) of staff agreed or strongly agreed that the best way to care would be to make sure residents were clean and calm, in home **H8** (fig. 8) this rose to 8/10 (80%) while in home **H9** (fig. 9) only

8/15 (54%) of staff either agreed or strongly agreed that the best way to care. At home **H9** 5/15 (33%) either disagreed or strongly disagreed that this way of caring was best practice.

**H7 Care preferences**
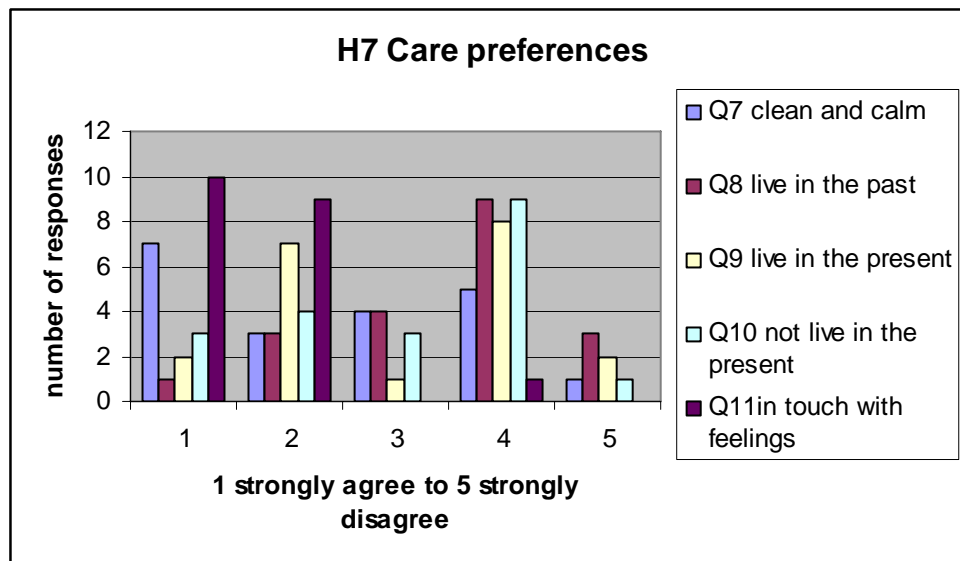


Fig. 7

12/20 (60%) of staff at home **H7** and 8/10 (80%) at home **H8** either disagreed or strongly disagreed that the best way to care would be to remind the person that they lived in the past, while staff at home **H9** seemed even more persuaded that this was not the best way to care with 13/15 (87%) disagreeing.

The scores at home **H7** of the two contradictory questions about reminding the person that they were living in the present were evenly split, with 10/20 (50%) disagreeing and 9/20 (45%) agreeing that people should be reminded that they lived in the present, while 10/20 (50%) disagreed or strongly disagreed and 7/20 (35%) agreed that people should not be reminded that they live in the present. At home **H8** they were undecided about reminding people that they live in the present as 4/10 (40%) disagreed that this offered best care while 6/10 (60%) believed that it did. 8/10 (80%) disagreed with the statement that people should not be reminded that they live in the present, with only 1/10 (10%) agreeing with the statement. Comparing these two questions home **H8** presented some disagreement as to what is best care. (Note: this could have been

because they were not sure, or because the questions were not read carefully so as to spot the reversal.)

**H8 Care preferences**
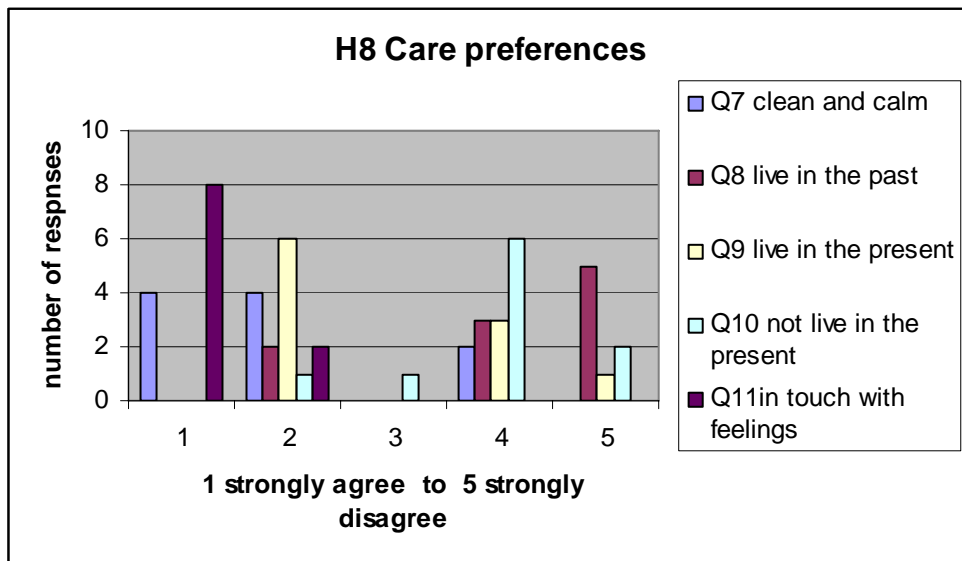


Fig. 8

In home **H9** the scores of the two questions about reminding the person that they were living in the present were evenly spread. 6/15 (40%) disagreed or strongly disagreed that people should be reminded that they lived in the present, while 6/15 (40%) disagreed or strongly disagreed that people should not be reminded that they live in the present. An equal number of staff agreed with these two questions.

**H9 Care preferences**
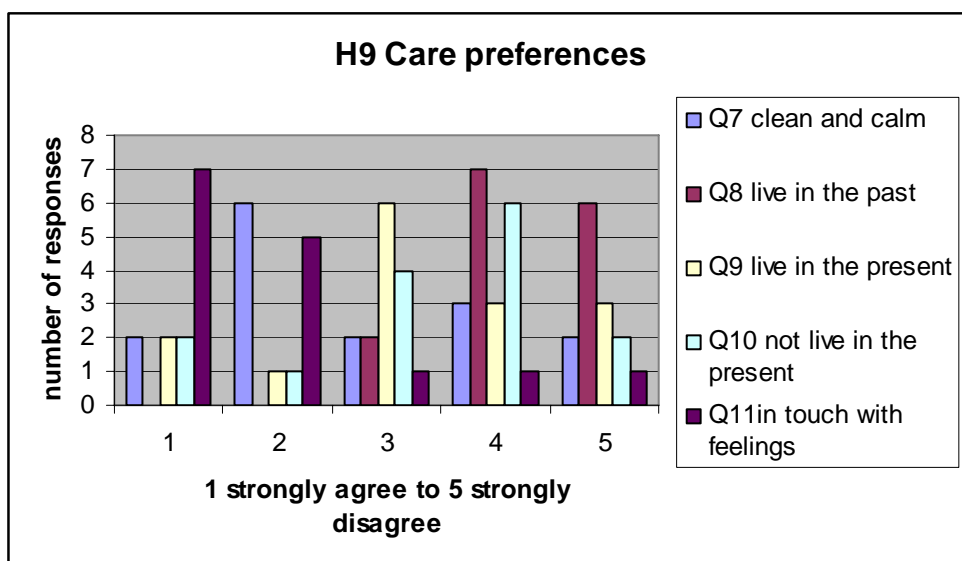


Fig. 9

The most consistent answers came with staff agreeing or strongly agreeing that the best way to care was to enable people to be in touch with their feelings. In home **H7** 19/20 (95%) were in agreement, in home **H8** this rose to 10/10 (100%) while in home **H9** it was 12/15 (80%). Home **H9** had the largest percentage disagreeing with this, but this was only 2/15 (13%).

*Christian values of MHA*

At home **H7** 18/20 (90%) of staff said they agreed or strongly agreed that the Christian values of MHA helped them to offer better care to people with dementia, this went to 8/10 (80%) in home **H8** and 9/15 (60%) in home **H9**. In homes **H7** and **H8** between just two replies were uncertain that this made a difference to care while in home **H9** this rose to 5/15 (33%) with one reply disagreeing that it made any difference.

*Inferences from group 3 homes*

The homes in Group 3 had less experience of care, both in their previous employment and within MHA. Like the homes in Group 2 the scores in the 'agree' and 'disagree' categories were markedly higher than the 'uncertain' category. This was especially noticeable when answering the question about best care being to make sure the person is clean and calm, where the combined percentage who either agreed or strongly agreed was 26/45 (58%) and those who disagreed with that statement was 13/45 (29%). Those who were uncertain only accounted for 3/45 (7%).

This group of homes were very sure that people should not be reminded that they live in the past, while they were almost equally divided on the statement that people should be reminded that they live in the present. This would either indicate that the question had not been read properly or that they were undecided about reminding someone that they live in the present perhaps because the realisation that this way of caring might be too painful for residents and families.

From this group of homes what seems to be important in caring for the person with dementia seems to be to make sure they are clean and calm. And while they do not remind them that they live in the past, they are not too sure about them being in the moment either.

More than half of this group said that they rarely or never attended church while 33/45 (73%) thought of themselves as spiritual. 35/45 (78%) either agreed or strongly agreed that the Christian values of MHA helped them to offer better care, with 9/45 (20%) being uncertain if this made any difference and only one disagreeing. These findings seemed to point to a link between those who were aware of being spiritual and who were also able to appreciate the special nature of MHA's values.

**Conclusions from the data**

I discovered that the three groups of homes differed more than might have been expected, especially in their choice of 'uncertain' as an answer to questions about 'best care'. It would be reasonable to think that the well-established homes would be more certain about what constituted best care as they had more experience, but this was not the case in these questionnaires. It was staff who had less experience of MHA who were much more definite in their answers.

All the homes scored highly on the question about best care being to help people be in touch with their feelings. This seemed to point to an understanding of the person as a person 'like us'.

One well-established home, unlike others in that group, scored highly on best care being to make sure residents are clean and calm. One recently acquired home, also unlike others in that group, had a low score on the same question. The inference could be that the role of the carer in homes that scored highly on this question is first of all to make sure that the person and the home looks right. This may be because of the way the staff see their role and take pride in making sure that people retain their

dignity, or because they have a low view of what the person is able to respond to.

92/117 (79%) of staff in all groups of homes said they agreed that the Christian values of MHA enabled them to offer better care. This could be because staff knew that I, or someone from MHA, was involved in the survey so thought they had to give the 'right' answer even though there was no name on the sheets. However some of the staff had a great deal of experience working with people with dementia in other non-MHA homes, so the understanding they have that the Christian values of MHA enable them to offer better care could to point to the values based on the Christian ethos making a difference to care even though carers themselves did not profess a faith.

These conclusions were examined by further analysing the interviews with staff.

**Interviews**

The questionnaires provided an overview of each home and in-depth semi-structured interviews were then carried out with the manager and two other members of staff chosen by the manager. The quotes from interviewees are referenced with their home number e.g. H1, and then a, b or c to differentiate the three interviews within the home. Transcripts of the interviews are available.

Browning's five dimensions (1996:105) provide a framework through which to examine the experience of staff and through stories to gain an appreciation of their understanding of what constitutes good care and what type of care MHA encourages, as explored in more detail in the methodology chapter.

Browning's five dimensions and how the questions relate to them are as follows:

- *Visional*: the use of particular narratives, stories and metaphors that shape the self-understanding of the community.
Questions 1-4 relate to how staff understand the community in which they work as they tell their stories of when care did or did not work well – and offer some appreciation as to why this was so.

- *Obligational*: how the organisation operates given the above.
Question 5 asks what type of care the organisation of MHA encourages, while question 7 asks which of our values are the most important in caring.

- *Tendency-need*: theories about our human nature and how they are worked out in practice.
Question 6 asks what our care says about what they believe MHA thinks of people with dementia.

- *Environmental-social*: constraints of the environment in which they are working.

Question 8 asks what helps or hinders the care they want to offer.

- *Rule- role*: how the above are put into practice.

Question 9 asks about working in their situation and what it means.

*Limitations of using Browning's model*

Working with Browning's categories I discovered that the last two dimensions, environmental-social and rule-role had already been covered within the first group of questions. The environmental-social is concerned with the constraints of action: what hinders their work, and I found that this has been answered as staff suggested reasons why care did not work. The last dimension 'rule role' asks how all the above are put into practice, but as I was only concerned with exploring this from the perspective of care staff, the stories in the first section (Visional) showed that.

Browning invited his readers to try out his proposed categories, and he emphasised their 'open-ended and modest character' (Ogeltree 1992:907), and finding that some categories are incorporated into others supported by Browning himself, who he said rarely used the final section. So it is in this spirit that I use Browning's model of 'strategic practical theology' to explore how care practice within the home is affected by the ethos and values MHA espouses, and what in turn that means for the care of the person with dementia, as this model places itself at the intersection between ideas and choices.

Another reason that Browning's model was not a perfect fit with my research was that it was designed for use within Christian communities. Methodist Homes, while a Christian organisation, does not require staff to be professing Christians, only that they are able to agree to the values statement as set out in the methodology chapter. These values, while not explicitly Christian, contain the Christian understanding of the value of

each individual but in words that are understood by people of faith or none.

The 'thick descriptions' offered by staff brought into focus the practice of care in its social and cultural settings. In order to describe the views of staff a wide range of extracts to represent each home will be offered. These descriptions allowed me to see the theory-laden practices that give rise to practical theology as the questions generate theological reflection.

In order to remain true to the culture of the homes I will refer to the men and women who are residents as ladies and gentlemen, as the staff do. These terms are used as a sign of respect.

### *Visional*

### *Overview*
Through the telling of stories about when they believed care had or had not worked well, and offering an explanation as to why that was the case, care staff showed an understanding of what they believed was good care, or where they felt that care had been lacking and why that was the case. As experts in their field they appeared to illustrate through their stories what was of value within their community. This would be further tested by information gained in subsequent answers that asked for information about the care that MHA encouraged and its values.

More time was given in the interviews to this group of questions as the 'thick description' of care and how it was offered was central to the research within the home and within the research I did the 'Visional' is best illustrated by the following themes.

### *It's the little things*
The interviewees in group 1 were agreed that what makes care for those with dementia work well are attention to 'the little things'. One person gave this example; 'we were having a meeting… and there was a piece of

music on that Mrs A wanted to dance to, so in the middle of breakfast we danced!' (H3b).

When asked to give examples of good care carers said,

> There are just loads and loads of things and when they smile…you could go on for ever. You could think of a million things through the day that makes your job worthwhile, just little things, even when you are running around and going daft and you don't have time to have a drink …but little comments like 'You are very kind you are', and 'You are beautiful',… a little smile, it just makes everything worthwhile (H1c).

'It's the little things like saying 'You look vey nice today', sitting with them and doing their nails' (H3c).

Supporting this view of good care another said,

> We have students come in and I think they are looking for something they can say with big words to encapsulate what is happening, but it's not about that, it's about the little things. Sometimes there is a little glimpse of something… . it could only be seconds (H1a).

'It's not just caring. Its looking outside the box…its not what is written down… it was part of the extra bits that people were sensitive to' (H3a).

Some residents find it very difficult to settle into the home and its routine. One carer spoke about a lady who used to work in care so didn't want anyone to know she was living there. She said that they enabled her to settle not by doing anything special, but 'by just talking to her' (H9b).

These vignettes show attention to 'the little things' that contribute to making life meaningful for people who happen to have dementia, but are not defined by it. 'It doesn't turn people stupid' (H1a). Staff in these homes were aware that what was important was not what should happen at a certain time and in a certain way, but what was right for that person and that gave them access to a world that was 'normal'.  The give and take of

compliments and the sharing of everyday life in the little things was what made the difference.

> I pretended to talk but we were watching her as she went through the picture book with the little one, making all the animal sounds. It went on for 45 minutes and everything was 'normal' and that's what we do here… As they went home J said 'I have had a wonderful time' and she squeezed me (H1a).

Many of the managers said that what also enabled good care was the sharing of information with other staff and family. After telling of a special moment with a resident she said, 'I wrote it down in the care plan and I then rang her and left a message to tell her about the evening we had just had' (H1a). Record keeping and the passing on of information can be time consuming (see comments under environmental-social), but these staff had learned that sharing good moments with family and other staff enabled them to change the emotional 'tone' of the next meeting.

On another occasion a carer spoke about hiding medication in food so the resident would take it, 'but when he came here we tried... and he took it straight away so I'm not sure if anyone had actually asked him' (H8b).

She also told the story of a lady who had moved from another home where carers had, 'put her in a wheelchair because it was quicker for them…. Her daughters cried the first time I walked their mum up the corridor... Nobody had taken the time before' (H8b). She emphasised that it was taking the time to ask the little things that made the difference to the resident and their family.

Good care was also seen as responding to where the person was and a carer told of a gentleman who can become agitated and wanted to walk, so walked to another unit where he made himself comfortable.

> There was an empty bedroom and they let him sleep there for the night. He was settled and happy and there was no point dragging

him back. It was a little thing that could have turned into a big thing if staff had let it (H9a).

A carer suggested that good care 'depended on the carer's approach…and how much the carer knows little things about the individual' (H9c), while another suggested that 'if you can catch them at just the right moment… they enjoy it' (H7c).

An understanding of the person's moods and personality was identified as being key to good care; 'All he wanted to know was that there was someone there to talk to. Little things like that' (H4c), because while other things are important it is ways in which 'you have to be sensitive to the little things' (H5a) that makes a difference. 'Its understanding their ways… Everybody has different ways and its understanding them' (H6a).

Staff seemed to say that it was being attentive to 'the little things' or 'the right moment' for that one person seemed to be a key theme in offering good care.

*Care offered through relationship*
Staff said that it was important to pick up the mood of the person, and that depended on 'how you were as a person' (H3c). When asked what enabled good care to happen one said simply, 'Us!' (H1c). 'The staff are a little like detectives (Stokes 2009), using their skills to find out the little things about the person'.

> She used to go for long walks with her husband and they would take sandwiches and if she wouldn't eat her dinner, sometimes she would sit down at night and have jam sandwiches and I would sit with her and have a jam sandwich (H1b).

.
The care offered becomes good care when 'you make it work' (H1a). Being in a location that was unlike a hospital was seen as a benefit to good care as, 'in a hospital setting they are just left' (H3a), as was having a relationship that enabled them to offer good care.

> There is a lady who is an old nurse. I found her in the corner crying and every time … she comes with me, everything I do she comes with me and I ask her if I am doing it correctly. … it stops her crying… takes her back to the day when she was in control (H2b).

Another said, 'She remembered every time she saw me and she had a bond with me' (H2b).

When conducting these interviews many of the staff became animated when asked about what made the care work. Some had been working in care for many years and one said,

> You can't give them the care that you would want to. I used to do a lot of things for them that I shouldn't have done, [but here] it's just like a home from home to me… it is hard work… I always treat these ladies and gentlemen …like Nana or Granddad and sometimes I benefit myself (H1c).

One carer spoke of the 'bond between me and him' (H5b), and of how she invested time in the relationship, but that when he died there was a cost; 'I was devastated… it just knocked me for six. You say that you are not going to get close to them… but I had that click with him. My aim was to comfort him. I accepted him as he was' (H5b).

Relationships with relatives often carried on after the resident's death, 'I still keep in touch with the daughter and talk about her mom and the things we did well' (H6b). And another said 'I think caring really is centred around love. You need to have that loving heart…. because as much as they are suffering from dementia the person inside is still alive' (H5a).

Staff who recognised good care often did so because of the relationship that developed. One said that it was not part of the job description but; 'I suppose I get close to residents, that's my nature' (H6a). Another carer said,

I think they need to feel loved and supported and feel that their views and opinions do count. That they are not just a resident in a care home and can only have a cup of tea at 3 o'clock' (H7c).

I would introduce a word of caution here as there could be a concern with these results. One needs to ask how those who are less likeable, and so difficult to build a relationship with, are cared for. This could be something to follow up with further research.

Care works well when, 'you have good staff, sensitive staff, it's the basis of care. You have to be kind, loving, you have to respect' (H6b) .

*Taking a risk*

Sometimes, offering person-centred care means taking a risk or thinking outside the box as to what was possible. When asked about a time when care had been good one carer told the story of a lady who had always looked after her sisters and when she reached the stage of needing end of life care she became very distressed. Her sister was in a nursing home a few miles away and, through careful planning, visits were arranged with staff providing care for her too. When the sister could no longer visit a tape of her speaking was played which calmed the other sister. Both sisters died on the same afternoon and commenting on the care offered the carer said;

to be able to have continuity of her sister being there and being able to care for a family member who was not residential with us, and both of them having dementia - it was lovely… I think because we understood her needs and looked beyond her dementia – looked at her as a person. Good care is very much taking risks (H7a).

One member of staff told of a gentleman who was finding it difficult to settle and as a result of one event had to be reported as a POVA (protection of vulnerable adults) incident and of the battle she had in order to stop him being labelled as having 'deviant behaviour'.

> A new social worker came in … she chose bits the staff had said, sort of opinion things … and it looked bad. I said …he needs time to settle in and they said we have an assessment here from the hospital… In the meantime (this went on for weeks) he settled in. we got him a small computer and he could look at his sailing…someone came in …and he recognised him straight away. I got the family involved and they didn't want him to move as he was happy here… The man is still with us and he is happy. I had to take that risk (H2a).

Another example given of good care was when a resident who was known to have a love of music was taken to the ballet. There was no family to help and this carer was told, 'we can't do that because he won't deal with it well'. She decided to take him in her car and 'everyone was tense and worried', but 'he sat there and he never moved his eyes from the stage'. At the end of the performance, and with the manager's permission, they went to the grand piano and,

> He started playing the piano and I will never forget that experience as long as I live… I didn't know he could play… there was a reason why I wanted to take him… but it was a risk though (H4a).

Taking a risk in care was a more common theme in the second group as staff seemed aware that others had less experience. Some also offered thoughts on what they believed caring should be;

> some think that care is about making sure they go to the toilet, that they are washed and dressed, that they have their lunch…but the emotional side is important especially to people with dementia… I think that's …lack of experience (H4c).

*When care doesn't work well*

There appeared to be a marked difference between the three groups of homes as they described occasions when care did not seem to work. Many of the staff in the first group found telling stories about when care

did not work well very difficult and often also told me what they had learnt from it.

> One lady asks and asks if her daughter has been. Her daughter comes every 3 days and sometimes staff tell her that her daughter is coming on different days so she gets confused so I ask staff to make sure they know which day she is coming (H1a).

She had learnt that care needed to be consistent in order to be effective.

*We do not understand*

Staff in the first group of homes often blamed themselves when care did not go well; 'I just can't find that key to get through to her' (H2c), ; 'its when we can't manage that we feel we have failed' (H3a), and '..when you need a referral and you see someone suffering... like I am now' (H2b).

The level of commitment to the person was evident as was their belief in 'person-centred care', 'there are no hard and fast rules. It all depends on the resident' (H1a), and feel disheartened when things don't go well: 'Most of the time you have to let things go over your head or you would be crying because you feel disheartened' (H3c).

Another carer told of a resident who says every couple of minutes, 'I want to go home, where's my mum?' I do answer all these questions but with this particular lady I can't get it right' (H9c).

She was conscious that she had not found the answer that would satisfy this lady, and would try to distract her but not tell her untruths. She had found that, 'looking at photos and talking about their whole family, give them a hug and a bit of love as well and they usually forget about their mum' (H9b).

She saw this as failing to offer good care whereas it is an example of what good care can be as the carer learns to respond to the resident's needs.

These responses suggest a community where the person comes first. But this will be tested by answers to subsequent questions.

*Residents do not co-operate*

This second group of homes had more stories to tell of when care did not work well.  One said that sometimes there appears to be a 'barrier', 'you feel like you are trying your best and give your all and I think that is the hardest bit' (H4b).

There appears to be little satisfaction in looking after residents when they don't respond and they 'don't want you to touch and yet you know that it will be good for them to wash, dress and sit up nicely… so sometimes it is hard to get things done' (H5c).

One carer suggested that good care was sometimes not possible because residents were either too aggressive or too violent and spoke of a resident who,

> was very aggressive.. lash out at anything and everything… just showing violence and no one could get near him. I suppose that we as a home let him down and he was transferred to another home… I wanted to persevere but you have to think of the other residents… (he) was too violent (H5b).

*Lack of experience of carers*

Another gave an example of care failing because of the lack of experience of carers**.**

> he was pushing his chair back and banging the wall…the carers were sitting and talking and he was going hello, hello, and they were just ignoring him and that is why he became agitated and in the end lost it… I asked if anyone had responded and well he kept doing it….his behaviour became challenging just because somebody didn't say hello (H4c).

Care not working because of lack of patience or, 'ignoring their needs or it could be to rush people and not pay attention, or when people really just don't care' (H5a) and lack of 'communication, understanding and time' (H6a), were reported by some staff and echoed by another who said, 'we didn't think long enough maybe' (H4a).

Most of the experience of staff in group 3 homes was about other care situations. They were eager to tell me stories of bad care they had witnessed; of residents being chased by staff in order to give an injection, and of being called to assess a lady who was bandaged to a commode because the home felt this was appropriate. But they also said that in their present home some families make good care difficult, usually because they do not understand the disease: 'in their eyes the person has died already…(we are) keeping them safe, warm and fed' (H9a).

*Attitude of the family*

They felt that the times that care was not good in their home were often because of the attitude of the family. 'I think they think it is their mum being awkward … It is hard on the family as well but they always end up shouting when they come and say that they are not coming again' (H9c). Another carer explained the attitude of some families, 'I always think that they have lost their loved ones, ok they are not buried but they have lost them and are going through a grieving process… and then the resident says inappropriate things' (H7b).

*Use of medication*

This group was the only group that mentioned the use of medication. One said that families were very against its use, but she saw that,

> his behaviour is difficult without any form of medication… he is aggressive … (his daughter) is on the internet looking at side effects….but it's not to make our lives easier but to make their lives more enjoyable (H9a).

They believed that it was family not understanding that made things difficult for carers to offer good care appropriate to the person.

The reasons given for these examples given of when care did not work were mostly because of outside influences that staff could not control.

*Correlation with survey questionnaires*

These interviews are consistent with the results of the survey questionnaire where staff in group one homes were unwilling to give a 'best way' to care for people with dementia. They said that as it all depended on the person and how they might respond to any given situation. The staff interviewed were very aware that things did not always go to plan and that in the end they could walk away, but the resident could not, and that it was their responsibility to find the key to good care for that individual.

The survey in the second group of homes showed that many carers were confident that they knew what offered the best way to care. This was evident from the interviews as examples of good care were similar to homes in group one. However there were more examples of when care did not go well, which some carers attributed to staff not understanding or ignoring the needs of a particular resident. During the interview sessions I sensed some frustration from staff who were aware that some things could be done better. This was expressed through their engagement in the question and I noted that their replies in this section were often longer and more detailed.

The interviewees in group three frequently spoke of disruptive behaviour, or residents being aggressive being a problem that needed to be controlled. This fits the picture that emerged from the survey of staff, the majority of whom were concerned to keep the residents calm.

*Self-understanding of community*

From the survey and stories chosen by interviewees the picture that emerges is of communities concerned to offer individuals person-centred care that is flexible in order to meet the resident's needs. Staff wanted to get to know the person and through the relationship that developed believed they were more able to offer good care.

Reasons for this care not appearing to meet their standards varied with the length of time the home had been managed by MHA. Homes in the well-established group felt that they had failed in some way when the care was not good, and felt disheartened, while in the newly acquired homes not understanding or ignoring the needs of, the person were the most common reasons for care not being good. The newly opened homes found that behavioural problems and families' lack of understanding were the obstacles to good care.

This would seem to suggest that the Christian ethos of MHA offers a model of care for those with dementia that is concerned with the little things that make life special for them. This care is relationship based, where the staff look at the person not the problem. The care is such that 'taking a risk' is what one does because it is right for the person.

While this understanding of good care is highly developed in all the homes the awareness of how it can be put into action and what causes care not to work seems to develop through the experience of working within MHA.

This was summed up by one carer who said,

> whatever training you do in dementia is great, but every person is like me and you, you are different to me. You have to go with this. There are different ways of communicating with them. Once you get to know that person, you know the best way of communicating with them to get the best out of them (H3b).

This view will be further tested by looking at what staff understand to be the care MHA encourages and which 'value' from the Core Values Statement (cited earlier in the Methodology) supports that care.

### *Obligational*

Having discovered what staff understood as good care within their home this 'obligational' dimension offered a way to investigate how this is influenced by MHA.

The care that is offered in the home is a result of the training that MHA supports and the guiding principles behind the care offered is the ethos behind the core 'values' of the organisation. All staff received training for every aspect of their role, and to enable staff to be aware of the importance of the 'values' which encourage mutuality, training on the computer in 'Our Living Values' is provided.  But as with all training it is not just learning the facts but putting the new knowledge into practice that makes training successful.

Through this training module the participant gets to know life within an MHA home through the eyes of a new member of staff.  This is an interesting way of enabling staff to engage and identify with what could seem like a long list of 'must do's'.  The session ends with the filling in of a pledge card to remind the member of staff of the promise they have made to work in a way that will enhance the Values learnt. In some homes these pledge cards are pinned on a notice board to remind staff of what has been promised and how they can make a difference.

The survey results showed that training in person-centred dementia care had been completed by 90% of carers, but there were slight differences between the groups and these will be examined.

*Person-centred care*

Each interviewee in the first group said that the care MHA encouraged was 'person-centred' care and the way that 'person-centred' care was recognised was that it was about doing things *with* the resident not for them. 'Person-centred, not just about the activity staff but domestics. Some domestics give residents a cloth and let them polish. It's little things like that that make a difference' (H1b).

One carer said, in support of her comments that the organisation supported person-centred care, 'I have worked for other organisations and came to work for MHA 10 years ago and this is the only organisation I would come back to. It encourages quality care, spiritual care' (H1a).

A carer at the same home said,

> The care encourages as close to normal life as they could possibly lead. I've never known a home to do so many things or treat people with so much respect and dignity… it's so different here. The priorities are different (H1c).

The second group also emphasised person-centred care, 'that's what MHA teaches us' (H5a) and added comments about the individual being important: 'even though a person has dementia finding out what is their choice.. it does take an awful lot more time' (H4a), 'you have to find out the individual touches to care for their individual needs' (H4b).

The importance of the little things was mentioned by other staff, 'I think its lots of extra bits. Some organisations won't give you that, even charities look at the cost but it's something…that extra bit that we can say be proud of what the organisation is doing' (H3a).

The way that MHA offers care that is above what is required was also appreciated as was the spiritual care offered;

> I have worked for three other companies and MHA, for the spiritual side and therapy is fantastic, the other things they put in place,

seize the day, moments of wonder, the core values, the alternative therapies, no other company bothers with that (H2b),

And, 'if they want to do something the Company finds a way for them to do it' (H2c).

There were some staff in the second group who did not understand the question saying that 'I thought they supported all types of care from very early stages' (H5b), and when encouraged to think again continued, 'We wash and dress them help feed and medication, so its full on care here' (H5b). As we talked further it was clear that no training had yet been undertaken so the carer did not understand what I was asking, they were only conscious of what the care meant to the job saying that, 'we treat them as human beings and you don't belittle them, you don't treat them as a child because they are not children' (H5b). When asked where they had learnt that I was told they had watched other carers and learnt that way.

When another member of staff in that home was asked about what type of care MHA encouraged they said 'It's more centred on personal care, keeping people clean, fed and their environment clean' (H5c). As in the previous citation the carer first of all focussed on how the person looked before looking again at the person. Both these members of staff were quite new and lacked MHA training so had picked up some of the ethos that group one homes exhibited in the survey, but needed more time to pick up the culture of the organisation.

In this group more staff spoke about spiritual care, perhaps because they knew of my role within MHA, as I had to wear my name badge, so thought this was what I was looking for.

*Summary*
The type of care supported by MHA was understood to be 'person-centred' care but that what made it special was the attention to the little things and the spiritual care offered that made staff proud of the organisation.

Those in groups two and three had a much more varied idea of what type of care was encouraged by MHA, understanding that person-centred care was the ideal, but when asked to explain and say which of the values was important the person-centred approach did not hold together as firmly as the homes in group one. This was supported by the survey results which suggested that they were confident that they knew what the best way was to care, and the earlier interview question where they had many examples of when care did not go well.

*'Respect'*

One carer said: 'this is the only organisation I have worked for that places a lot of emphasis on core values and it's filtered through everything that we do' (H1a). Respect was the core value most often chosen by staff; 'respect every person. That underpins true person-centred care' (H1a). *S*he went on to give an example about training staff in the values where they had to look more deeply at what was important to the person, not just at what was presented.

Supporting their choice of the value 'respect' other carers said,

> Every single one of these ladies and gentlemen, even though they've got dementia, they are still their own person. They are different people' (H1c); 'they are a unique individual' (H2a); 'if you took away respect you would take away their individuality and you have to look for the person' (H2b); 'respect treats them as a whole person and encourages you to look again' (H2c).

Most in the group two homes chose the value respect, but also added dignity. One said, 'I think dementia is a cruelness and what they lose is their dignity' (H4a)', not only as personal appearance but as, 'forgetting that someone with dementia have lost their dignity; they don't know what they are doing, that they are not there' (H6b).

There are two different ways of looking at what dignity means; one concerned with the functional and one with rights and intention. An

interviewee in the group three homes linked the value 'we will care for each other' with the way care was offered, suggesting that, 'if you care for each other then respect comes' (H7a).

The value of spiritual care was also chosen and defined as that which: 'encompasses everything because I wouldn't classify it as religion only. It is everything around the person, what makes them tick, what makes them vulnerable, the happiness, the joy, the fulfilment' (H5a).

One carer who had only been in post for three weeks chose the spiritual care value as being important and said, 'I've never seen (it) incorporated in somebody's care… there are so many ways that someone can express without verbalising' (H7b), but after talking for a little while said that 'respecting people as a unique individual was the top one… how I treat you might not be the same as somebody else… because we are all unique'.

Another carer spoke of the flexibility that she found within the organisation: 'there are few rules and regulations apart from they can't go out onto the main road… they are all individual people... you have to try to understand them' (H7c).

This carer may not have known the phrase 'person-centred care', but she was showing she believed that to be at the heart of the care MHA encouraged.

In another home one carer had been so surprised by the flexibility of care she had

> …written an article published in Caring Matters about the ethos that we have about respecting them as unique individuals and respecting their needs and their wishes and with dementia. That's not always easy because they are not always able to give you that feedback... because where I was before they were all taken out of bed when it suited the staff, not when it suited the residents (H8a).

There seemed much surprise in this third group of homes that care could be flexible and fitted to the needs of the person and there was much more variety in the choice of values, but most ended that question by saying things like: 'and it's down to respect' (H8a), 'with respect comes everything' (H8c), and 'treating them with dignity would mean nothing if we don't respect them as a unique individual' (H9a).

It seemed that while talking they were thinking things through and coming to a conclusion that respect was the most important value as it affirmed their uniqueness.

*Correlation with survey questionnaires*

The importance of person-centred care, supported by MHA, was emphasised by all groups of staff. This is supported by both the survey and the earlier stories told to illustrate good care. 'Respect' was the value most chosen by staff as the one that underpinned their care and encouraged them to look again at the person.

**Tendency-need**

Browning's tendency-need dimension encourages the exploration of theories of human nature, so the interviews contained a question that asked about what the care MHA encouraged said about people with dementia.

The carers in group 1 were agreed that MHA supports care of people with dementia as individuals and people like us who need care. 'We put them at the top of the list… we value people as individuals' (H1a), 'individuals not just people with dementia' (H1b), or as 'people like ourselves… I don't think of them as any different to myself' (H1c).

Another carer said that 'we treat the person as a person without the illness but we are addressing the illness and trying to make the best of it for them' (H2b).

This idea of the person being there that somehow needed help to be themselves was also expressed: 'they are still a person even with their dementia' (H2c).

Those in group 2 homes also believed that MHA encourages staff to think of people with dementia as being 'like every other normal person… it doesn't mean that they can't do the things we do' (H4a), or that 'it doesn't mean that they should be treated any differently to anyone else' (H4b).

Another said that MHA showed that it valued people with dementia because in their home there used to be a 'lack of training, lack of knowledge, lack of everything' (H4a). This group were again more diverse but their answers supported the view that MHA shows that those with dementia are of value as people like everyone else.

Staff in group 3 homes spoke about person-centred care and supporting 'their values, their well-being and independence' ( H7a). 'How I treat you might not be the same as somebody else' (H7b) as the person is unique. 'We (MHA) have a very high respect for them and a need for a deeper understanding of each person as individual' (H7c).

Some carers found it difficult to put into words what the care MHA encourages says about what we think of them as people, so some told stories about how they care. 'Sometimes you come in at the end of the day and they look dishevelled but I think they have had a good day… they have been busy doing things that are nice' (H8c), while another said 'I think how I would have looked after my mum' (H8b).

Helping them to realise their potential and enabling them to be themselves seemed to be important and 'to be an individual in their own

right' (H9a). 'You shouldn't write them off because they have dementia…
recognise that they still have a life, just because they have dementia
doesn't mean their life has ended' (H9b).

All the homes supported the view that, through training offered and the
way that homes are resourced, MHA helps staff to understand that those
with dementia are people like us; unique individuals who need help to be
themselves and who are worthy of respect.

*Correlation with survey questionnaires*

The conviction that people with dementia are of value and so worth
spending time and money on is at odds with how care is often reported by
the media. The picture that emerged from the interviews, supported by
the survey, was of many staff trying their best in sometimes difficult
circumstances to offer appropriate care for a person who was like them
but needed help.

*View of the person*

In the survey the question that asked about good care being to enable
people to express their emotions scored very highly in all groups and that
would seem to support this view of the person as someone like us.
However the homes with less experience of MHA seemed to know the
'right' answers but although the interviews suggested that the person
came first the understanding of the best way of caring was often very
definite, which did not allow for the needs of the individual at that moment.
Those who believed that best care was to keep people clean and calm
seemed to support the view of the person being an empty shell, however
many in this group also scored highly on helping people to express their
emotions.

**Conclusion and more questions**

From investigating both the survey and interviews in the research I found that my views on how best care could be provided had changed. My understanding was that in dementia feelings and emotions are still there to enable the person to relate to the world, so I believed that the best way to care was so use Validation therapy, in which people are helped to express their feelings. However, staff in the first group of homes who competed the survey, showed me that my understanding had been too narrow and that at any moment any of the ways of caring from the survey could be the best way. What was important in care was to 'see' the person.

Staff who had spent many years working with other care providers expressed an appreciation for the way that MHA offers direction and support in the care of those with dementia. There was also a strong belief that the Christian ethos of MHA, as explored in previous chapters, made a difference to care as it encouraged a different way of looking at the person.

This research raises questions that are both practical care-based and theological.

• How can the values and the culture be handed on as MHA continues to expand?

• Person-centred care is accepted as the ideal, but what does it mean and how can it be practised?

• The spiritual aspect of care was seen as important in affirming the person. What does this mean for those offering care?

• 'Respect' was chosen as the value that was most important. What can this mean and what is it that they see in the person?

These questions will be explored in the next two chapters; the first looking at facets of care and the next investigating the possibility of a theology of

care using insights from both carers and those who have written about theology and personhood in dementia.

# Chapter 4: Mutuality and Respect

'When memory fails love takes its place' (Interview).

## Introduction

This research has emerged from personal experience within MHA and from an awareness that how the person with dementia is regarded will influence the care offered. I conducted surveys of staff in MHA dementia-care homes and interviewed individual staff members in these homes. Through questions and, more especially, through offering the opportunity to tell stories about the care they offer, I explored the values that underpin the culture of care which MHA offers those caring for people with dementia.

The fieldwork revealed unanimity among carers that I had not expected. One disclosure that, 'We will respect each person as a unique individual' was the core value chosen by almost all staff surveyed as being the most important value in terms of care for those with dementia, fits very closely with the value that was at the heart of MHA, that of 'mutuality'. It was this ethos of mutuality within MHA that is now understood in person-centred care. However alongside this consensus were the marked differences between the three groups of homes in their appreciation of the way that 'respect', defined earlier in this study as a looking again at the person, could be put into practice as they offer person-centred care. These themes will now be examined in more detail, beginning with a study of the context in which the care takes place. I will argue that the friendliness, respect and support for daily living that embodied MHA's ethos in the past is now written into the core values as 'respect'. And yet respect can be offered at a distance. In order to meet the needs of people with dementia it must be offered with friendliness and with support for daily living.

**A new perspective: reflection/respect**

Who we see when we meet someone with dementia is crucial to the care that can be offered. Staff offering good care said that, 'Whatever training you do in dementia is great, but every person is like me and you… you have to go with this' (H3b). Killick wrote of the importance of developing an ethos that supported equality of personhood 'rather than allowing declining mental capacities to divide humanity into those who are worthy or unworthy of full moral attention' (Killick 2004:145).

This is supported by my research which showed that in order to exercise this equality of care it was important to see the person with dementia as 'someone like me', not a different kind of being. This was something understood on an instinctive level by staff, since the core value that was chosen by almost all staff interviewed was that of respecting each person as a unique individual. And we are reminded that 'respect' derives from the Latin word *respectare*, which means 'look again' (Post 2005:224).

When the person with dementia is given the respect they deserve as a unique individual, staff use reflection and imagining as tools for offering appropriate care, 'not just caring. It's looking outside the boxes' (H3a). So looking again at the person and using all the skills and knowledge they have, and imagining behind the behaviour or lack of response to the person inside, offers a different perspective on care; one based on reflection and respect.

The proposition that carers' experiences of those with dementia should be reflected on and then used to inform the care offered, was the theme of the publishable article written for Part 1 of the D Prof (Goodall 2009). Carers and the chaplain worked with me to reflect on ways in which spiritual care could be offered, not just by the chaplain but by all staff. The model of care that was offered was that of relationship, reflection, and restoration which are built on the basis of respect for the person.

It has been noted earlier that all good care has its basis in relationship, with someone who knows and seeks to understand the person. But it is not enough to offer this without then reflecting on what is understood about the person as they truly are or as one staff member put it, 'what is behind the person' (H4b). Then the quality of care would be enhanced by repeating the cycle of reflection and action (Goodall 2009:181) as insights into the person influence care.

This model is similar to the idea of 'mutuality' - friendliness, respect and support - that was held in such affection by those who had connections with MHA in its early years.  In mutuality what makes it possible for the quality of care to move from just friendliness to a relationship that will offer the support needed is respect; a 'looking again' at the person.

**The culture of Mutuality**

I will begin by describing the history and culture of MHA as it was seen in earlier years through the offering of mutuality. The mission of MHA is 'to improve the quality of life of older people inspired by Christian concern' and the core values are a way of giving shape to these aims for those who offer care.

In the Strategic Plan 2010-2013, the guiding principles were reaffirmed as being those:

•      founded on love, compassion and respect

•      serving older people with a range of high quality care, accommodation and support services

•      focussed on nurturing a person's spiritual and physical well-being (MHA 2010:9)

MHA began more than 65 years ago with one home in Wallington, and with the blessing of the Methodist Conference the decision was made to have one home in each of the Districts of the Methodist Church. While this

was a worthy aim for a denomination that holds dear the idea of belonging to each other, connexionalism, it made the management of a national organisation more complex. If the homes had been grouped then it would have been easier for homes to learn from each other.

MHA to date has more than 100 projects (Appendix vi), some of which have belonged to the organisation from their beginning, some acquired from other organisations and some for which MHA has a management contract. With each expansion there has been a perception, voiced from long-term managers, some existing residents (Kellaher 2000), and from supporters of MHA within the church, that MHA is 'losing its soul' as they fear the strong Christian basis of MHA being eroded. The Christian values of MHA are cherished by those who work in or support the organisation, and they cannot see how values that have been embedded in homes over years can be passed on. The main concern is that the special nature of what was identified by Kellaher (2000) as 'mutuality' may be lost as MHA, under pressure from regulatory authorities to conform to certain standards, will become like all other care providers and lose its special qualities.

The challenge for staff is to make the values live in the way care is routinely offered. To enable this the guiding principles were developed into what MHA now understands as its core values, framed and displayed in a prominent position in each project, which are a reminder of the organisation's ethos and how it believes that care should be offered. Like other things that people see each day, these values can become so familiar that, like wallpaper, they are not seen.

My investigation into attitudes among staff in caring for those with dementia showed the culture to be unique to each home. It surprised me that there was not more variation in staff attitude within each home, and that staff who had only recently commenced work quickly complied with the way things were done and decisions made in their setting. Douglas, commenting on the way that decisions are made within institutions,

quotes Jaspers and Frazer: 'We have lost sight of the collective nature of attitudes… Recent developments in attitude research… have led to a complete individualisation of the study of attitudes' (Douglas 1986:82). Staff surveyed seemed to support the collective nature of attitudes as the results in individual staff groups were found to be less individual than I had expected and could therefore lead to changes being made by a few key staff influencing the culture of the home.

*Mutuality as an ideal*

The development of MHA was traced by Leonie Kellaher in her book *A choice well made*. She noted the involvement and ownership of many local Methodist churches as they were involved in 'raising money for the home or seeing 'their' home built' (Kellaher 2000:78). She also commented on the homes with their roots in the Christian religious belief and practice of the organisation and most residents. She found that the tradition of mutuality had been readily transposed into the residential setting and had contributed to the common culture which linked residents and staff. These Christian principles, seen in everyday exchanges between residents and staff, were fashioned into the explicit policies and principles of MHA with the aim being the 'maintenance of a good atmosphere through mutual respect among all parties and paying attention to individuality' (Kellaher 2000:79).

Mutuality, understood as the mix of friendliness, respect and support, was seen as the key to making the formal structure of the 'home' into a home as it permitted both individual and collective attachment which is the basis of good residential care (Kellaher 2000:83). This mutuality was seen as 'ordinary' but crucial. There is an assumption that no organisation has the right to try to shape the social interaction of individuals, but MHA 'has placed mutuality, in terms of good interrelationships in a good atmosphere at the top of the agenda' (Kellaher 2000:83). She noted that residents remarked on the mutuality they experienced 'and not least with trepidation that it may be in decline' (Kellaher 2000:82).

*The changing nature of MHA*

In writing about the special nature of management within Christian organisations, Tory writes that It is common for tensions to 'tend to rise as the organisation grows' (Torry 2005:119). Two developments contributed to this fear in the case of MHA where it was felt that the care it could offer was in decline. One was that the nature of care had had to change because of the growing demands of residents who were increasingly dependant, either physically or mentally. The other was the implementation of 'block contracts' to the local authority, which widened the outreach of MHA to include those of all faiths and none, many of whom did not have the common set of religious beliefs upon which it had been founded. These factors raised the possibility that the Christian values expressed through the mutuality that had been seen as so important to residents and staff might be lost, and the potential for changes to the values of the organisation 'away from the specifically religious goals of the organization's founders' (Torry 2005:119) had to be acknowledged.

One of the tensions organisations face is that they operate for survival in the secular world. Thus, 'regardless of how lofty and spiritual their mission statements are' (Furniss 1995:118) they can become operationally secular in character and the cost-benefit mentality can exert a dominant influence over '"life-world" values' (Furniss 1995:117). This led to a concern that the Christian values of MHA might be under threat because it needed to respond to the needs of the present age.

These strong Christian values had been esteemed within the organisation and were understood as the social glue that held the homes together. Dewing, writing about what enables care homes to be effective, suggests that it is the 'shared patterns of meaning, values and beliefs and expectations held by members of the organisation' (Dewing 2009:223). It was the importance of maintaining this idea of mutuality as a guiding feature of the home, that was now enshrined in the core values, that enabled the home to be more than an elder care facility. This was

recognised by majority of staff who took part in my research as what was important to hold MHA together. Yet surprisingly, with only one exception, they said that they were non-Christian, yet they believed that the Christian values of MHA helped them to offer better care for people. This was an important finding and the idea that the Christian values enable better care will be developed in the next chapter.

To those in the church, for whom MHA was seen as an almost sacred institution, this idea that it would change stirred up defences, with warnings that terrible things would happen. These ideas echoed Durkheim's doctrine of the sacred (Douglas 1986:113), and yet in order to meet the needs of the present age change had to happen and the world did not fracture. MHA now has a different relationship with the Methodist Church, as the Conference is no longer the Managing Trustee. This 'loosening of the bond' (Torry 2005:120), while maintaining a relationship with the Church, has released some tensions. The changed relationship has enabled the organisation to have the freedom to grow and develop into areas that might once have been seen as difficult, for example managing a Jewish care home and being involved in setting up a multi-faith home. And yet, perhaps because of the changes, the 'values' continue to be high priority.

In writing about how organisations think, Mary Douglas commented that 'the entrenching of an idea is a social process… based on common assent in some general grounding principle' (Douglas 1986:46). Common values that are 'shared by employees at all levels of the organisation' (Furniss 1995:117) are seen to contribute to a 'strong' culture which enables 'a standpoint enforced throughout the organisation by means of policy and procedure manuals' (Furniss 1995:117). It is the culture that develops in each home that 'directly influences the quality of life of the people who live and work there' (Dewing 2009:222).

*Handing on core values*

MHA's policy documents explain the ethos that informs the care offered, and each staff member is made aware of the values on which the care is based. But it is the day to day interaction that gives this ethos shape. While all this is sound it does rely on how staff comply with what is learnt during training and that they allow it to influence their conduct. When the day is busy the default position is to complete the tasks, then the way that they are done could be the first casualty. If the question, 'Why do you do it like this?' was asked the first response might be, 'Because we do'. This would go some way to understanding the consistency of attitude among staff in each home. However if time was given then the answer may reveal how the ethos of MHA is understood.

Having policies and procedures in place could lead to almost a rote learning where the reasoning is lost for, 'When institutions make classifications for us, we seem to lose some independence that we might conceivably have otherwise had' (Douglas 1986:91).

An organisation like MHA, which through its staff and residents is an expression of community, has corporate values that influence personal decision making, not just what is done but in the way things are done. One staff member reflected on having new staff in the home saying that,

> 'I don't think that they see the person as an individual to begin with, but once we have put our mark on them, then they do. It's not their fault because they are not used to looking outside the box when in fact there is an outside to the box' (H8b).

Staff are aware that they influence each other in the way that things are done in each home. Durkheim and Fleck taught that, 'each kind of community is a thought world, expressed in its own thought style…defining their experiences, and setting the poles of their moral understanding' (Douglas 1986:128). How we build institutions is by 'squeezing each other's ideas into a common shape' (Douglas 1986:91), which goes some way to understanding why the survey showed such a

consensus within each home and offers the possibility for influencing change.

**Respecting the person with dementia**

In many settings the priority of care for those with dementia has been to keep the person safe and secure, with little focus on what could give meaning or recognition of the person's identity. Staff recognising when care didn't work well said it was because they 'weren't respecting him. They weren't involving him in anything' (H8b). Kitwood writes that 'It is as if the presence of what used to be called 'organic mental disorder' places some kind of veto upon normal human encounter' (Kitwood, 1997:7). Care can be given without 'meeting' the recipient, but this is dangerous as it can lead to dehumanisation.  But if care-giving can involve meeting the other person then it 'protects, preserves and validates his or her personhood until the end of the dementia process' (Miesen 1997a:338).  If the person is met on a real and personal level then good care is enabled because of the 'bond between me and him '(H5b).

Staff can be resistant to this way of caring and tend to work as they have always done, some saying that, 'they are demented and that's what they are like' (H7b).   Much of human behaviour and action is routine: necessary so that we can then 'function effectively in situations that make multiple demands on us' (Somekh 2006:15).  This goes some way to explaining why people find it difficult to change as 'first people must be tempted out of their niches by new possibilities' (Douglas 1986:108), although through my fieldwork I discovered that 'a lot of staff left… they couldn't cope without the regimental' (H5b).

For those coming to work for MHA, in the well-established dementia-care homes, the possibilities of seeing people differently are there for them to observe and experience. They see experienced staff interact with residents who have a level of dementia that could make them difficult for society to accept. Innes writes that 'underlying beliefs about dementia

manifest themselves in ideas about cure and care' (2009:141). So the ideals on which care for people with dementia is given in MHA is that of person-centred care where the *person* not the *problem* is seen.

*The role of the carer*

Reflecting on this study I found that my own views on the role of the carer had been challenged by the insights offered by staff. I had previously focussed on the idea that feelings and emotions are not lost to people with dementia, and had so believed that the best way to care was to validate these feelings by affirming the emotion behind the words used.

However on evaluating the interviews I was surprised when staff refused to answer the survey questions that related to the best way to care. I realised that I had been missing the big picture by focussing on one aspect of the person. The reason given for not answering the questions was that the questions were not related to a particular person or situation, so they could not give an answer. The person with dementia could be at any stage of the journey on any day and so the crucial thing was, as these staff recognised, to understand where the person was at that moment and then seek to meet their needs. They are not left to struggle alone as the staff 'struggle with them in a joint effort of understanding' (Clarke, Hollands et al 1996:47), supporting their everyday living. This idea was summed up by one carer who said 'When memory fails love takes its place'.

In their study of long-term care, Henderson and Vesperi (1995) note that the way staff offer care enables residents to function, and that the 'initiating and translation role of staff…becomes crucial as residents experience a significant decline in their cognitive abilities'. (1995:215). As people with dementia become less able the quality and consistency of care offered becomes more important. In MHA homes staff are the vital link with the personhood of the resident and it is important to recognise that carers are the experts in their situation as 'personhood is created (or diminished) in social relationships' (Nolan et al. 2002:203).

The practice of person-centred care, which staff in the survey agreed was encouraged by the organisation, stands or falls on the quality of the care they offer especially as they initiate and translate communication. 'The resident may not be able to demonstrate such a connection: the care worker must act as an advocate or substitute' (Peace, Kellaher et al. 1997:121). But in order for the mutuality to be genuine this cannot be a one-way relationship with residents constantly on the receiving end. Mills suggests that being valuable and being valued are gifts that those with dementia are able to give as they 'can reciprocate and are able to encourage their own carers to experience well-being' (Mills 1997:25). Person-centred care cannot be offered at arms length as it requires staff to take a risk in first building a trusting relationship. It has been recognised that this model of 'making contact with the person is less safe but ultimately more life affirming and the … [carer] gains as much if not more than the person with dementia' (Nazarko 2002:48). One carer commented that since working for MHA in dementia care her daughter says that 'she has never known me as happy' (H7c). This idea of mutuality in care is supported by a staff member who said 'you try to make every day special for yourself and the resident' (H3c). This is the heart of mutuality; a giving and receiving that embodies respect for the person.

It has been recognised previously from the interviews that what makes for good care lies in 'knowing' the person, for it is the little things that make a difference to care and mark the difference between caring for a person with *dementia* and caring for the *person* with dementia. From my research, as evidenced in the previous chapter, it was the little things such as the ordinariness of a friendly greeting that brings a response; the singing of a song that the carer does not like, but which brings a smile to the person. It can also be seen in taking a risk which this knowing through friendship makes possible: allowing freedom to meander, while being there to support if needed; risking failure when others would play safe to save face. The risk is for the carer to trust what is imagined that the person wants and then to act on it. This imagining of the person is only

possible when there is knowledge that comes through a relationship that develops over time. Training may have been completed, but until this new view of the person is envisaged then the possibilities and the potential of the person with dementia will not be realised.

The 'living human document' (Asquith 1992) can only be read if the staff are open to the *person* with dementia. Staff interviewed spoke about 'being attached … I don't know why' (H5a), but that this enabled them to care for the person. This demands a new perspective on both the nature of care and the respect given to the person with dementia.

*The new culture of care*
Commenting on Kitwood's cultures of care Baldwin and Capstick note the differences between the old and new cultures of care. The <u>old</u> culture of care is one of 'domination, technique, evasion and buck-passing. While to enter the <u>new</u> culture is like coming home…[with] confidence in our power to know, discover, to give, to create, to love' (Baldwin and Capstick 2007:313). They suggest that a good care environment is where, 'those who have dementia are very much alive, responsive, relating to each other, making their presence felt;…The staff seem to enjoy what they are doing; they are satisfied, relaxed and free… there is vitality, energy, inspiration.' But they note that other environments can be created where, 'There is a sense of deadness, apathy, boredom, gloom and fear; most of those being cared for appear to have given up hope, their last resort being an occasional moan, or shout, or angry outburst. The staff are patronising, cynical, uninvolved, and even relating to each other largely in superficial ways' (Baldwin and Capstick 2007:306).

Those living with dementia need the mutuality for which MHA was esteemed and which was expressed in friendliness, respect and support, and the success in achieving this will be 'through a movement contrary to the shallow, technical and money-obsessed mentality of our times' (Baldwin and Capstick 2997:307). Good care does cost in training and support, but more than monetary costs it is the *way* that even the smallest

things are done in care that can enhance or diminish a person. The intention behind the action is what staff need to be aware of.

*The belief systems of carers*

Staff training emphasises person-centred care and, as well as face-to-face training, staff are expected to compete the el-box module called 'The person inside'. This programme emphasises the importance of seeing beyond behaviour and actions that could be distressing to try to understand what it is that the person is trying to communicate.

In my research I discovered that almost all those who took part in the survey had completed some form of training, and all agreed that the model of care MHA encouraged was person-centred. This said, it was then interesting in the survey to see how widely this was interpreted. In the previous chapter the data was examined alongside the transcripts and certain patterns of understanding were suggested. There were those carers who saw the residents as being disabled and so needing help, while other carers saw them as people whose lives had been lived so they could only find comfort in the past. There were also some carers who, despite person-centred training, seemed to believe that there was no longer a person there and believed that they could fulfil the person's needs by keeping them clean and calm. Innes, citing Gamma and Nolan, suggests that, 'The social theory of disability stressed the discrimination and barriers those with a disability faced within society: Disability is therefore an outcome of social attitudes and structures and the interaction between the person and environmental factors' (Innes 2009:137). What became clear was that, in order to see the *person,* staff had to use their imagination to see behind the presenting behaviour.

My fieldwork showed that, especially in the well-established homes, residents with dementia were recognised as individuals who happened to need care because of the dementia. What appears important is to know how to relate to the person. But to know something about the *person inside* seems to require an opening of ourselves to a 'not knowing' of the

other, and so allow for moments of freshness when a connection is made. Believing that the answers are already known can mean that the moment is lost and an 'us and them' relationship is established which, while it may be reassuring for staff who wish to remain in control, does little for the person with dementia except to disempower and marginalise: it does not enable the *person* to be encountered. My fieldwork showed that staff who seemed less willing to engage in the other's world blamed the person for being aggressive, their family for being difficult, or medication being wrong. These were all things that were outside influences and so out of the control of staff.

At its best, 'person-centred dementia care is about the recognition of the person ''inside'' the dementia' (Mackie 1994:21), not a focussing on the problems that are evident when, 'the word dementia conjures up images of mute people sitting in wheelchairs in nursing homes condemned to a life of nothingness, or even worse, images of aggressive persons who are feared and often restrained' (Touhy 2004:43-44).

What Touhy was advocating was an appreciation of the personhood of people with dementia that calls for care that looks beyond the disease to the person within.  By focusing on the person and not the problem of dementia it is possible to come alongside, allowing us to respond to the person's experience of the disease instead of trying to 'make it better' or pretend that it is not there. Mackie and Touhy agree that by recognising the person 'inside' or 'behind' the dementia it is then possible to develop relationships that nurture personhood.  Being present with them in the moment asks for a different way of 'seeing' the person (Meininger 2009), of having an appreciation of the gifts the person has and of the ways in which they now respond to the world, especially through the emotions which remain when memory fails.

In thinking about the emotional life of the self, Anderson quotes Oden in saying that 'Christian teaching has been less focussed on the after effects

than on the One who elicits and grounds these effects' (2003:12). The emotional life of the self has for some been something to mistrust, and so may explain the wish of some staff surveyed to keep people clean and calm. But it is often only through the emotions that those with dementia can be reached, as carers have described the effect of sharing a moment of laughter or tears with a resident.

In the New Testament there are many stories about who is lost or found, and who is 'whole'. Those with dementia are said by some to be lost to the disease, as wholeness is just seen in cognitive powers (Hudson 2004:95). However if those with dementia are seen and valued for themselves rather than pitied for what they have lost, then a relationship of support can be established because 'as cognition fades spirituality can flourish as a source of identity' (Dunn 2004:154). When trying to explain why she was able to offer care based on respect one carer suggested that 'Maybe my spirit was connecting to hers' (H5a). This is a care that goes beyond formal training and strategies and comes to the heart of good care that meets the person where they are.

*Communicating with the person*

In order to build relationships that enable respect to be put at the centre of care, staff need to discover ways to combat the isolation that the person with dementia can experience.

Staff offered different strategies for care, from ensuring they were clean and calm to understanding the emotions behind the words. But if care is to combat the social isolation that is dementia then communication must be at the centre.

Communication is about an understanding between people; the giving or exchanging of information, ideas or feelings, and is the foundation of all relationships and so central to human existence. Without it we are

diminished and life without communication, for example solitary confinement, is considered to be one of the hard forms of punishment. To offer care without any sound, because it is believed that there is no one there to communicate with, is likely to increase the person's confusion and cause distress.

Speech is usually thought of as the main way of communicating. But non-verbal modes convey as much of the sense as words. Armstrong and Reymbaut (Chapman 1996:5) suggest that only 7% of a message is conveyed by the actual words, and that the tone of voice, facial expression and gesture make up the remaining 93%. The key to good communication is active listening: giving attention to the person as well as to the words spoken. This is a challenge for those who offer care as it requires giving the whole of one's attention, loving attention, to the person. 'One has to respond sensitively to what is happening and pick up what is conveyed in a look, a squeeze of the hand, a closed fist or eyes filling up with tears. One has to listen to what is not said' (Ainsworth-Smith and Speck 1982:63).

From my data staff in some homes managed to make sense of what could be considered the bizarre communication of residents with dementia. And many carers agreed that it was they who enabled care as they built up a relationship with residents. One interviewee said that in order to show respect and build relationship she had to 'allow the person to express themselves and not make them feel they are being judged' (H1a). Carers feel a responsibility to understand what the person is trying to communicate. In these homes residents are not said to 'wander aimlessly' or 'babble without sense', although at times it may be difficult to work out where they are going or what they want to say. They are not left to struggle alone as the staff 'struggle with them in a joint effort of understanding' (Clarke, Hollands et al 1996:47), supporting their everyday living.

It is recognised that people respond to the attitudes of others, and that those with dementia are not 'dull' with little awareness of what is happening around them. Although the accepted way to speak of those with dementia and the condition they suffer has changed to a more positive one, carers' attitudes will continue to have an effect on the life of the person with dementia. Scrutton commented on the importance of the manner in which care is offered and suggests that carers should take some responsibility for behaviour that is sometimes described as 'challenging', or 'difficult'.

> Throughout the course of the dementing illness, the individual remains sensitive to the attitudes of those around him. He detects insincerity… Although the senile person may not be in sufficient control of his behaviour to act wilfully, he is able to respond to others' feelings and act out his frustration (Scrutton 1989:179).

What people most fear about dementia is that they will not be known or understood: that others will put their behaviour and language (or lack of it) down to their 'condition' and make little effort to engage with them. The fear the frustration of being alone and of not being understood is for many like a 'living death'. But in order for this enabling relationship to happen it is necessary for the culture of the home to be such that there is a 'safe place in which the person can be themselves and will not feel threatened' (Goodall & Reader 1992:145). This non-threatening space could offer the possibility of newness and change, while being held in a safety net through which they cannot fall and into which they can relax when they have exhausted themselves. This 'safe space' is necessary both for the person with dementia and for those caring for them as this type of care demands much of the carer in terms of openness and self-awareness.

Developing this mutuality in care enriches the work-life of staff so that coming to work is like a meeting with old friends. The benefit to staff of nurturing relationships has been recognised as then, 'caring can become an enriching experience, while in its absence it becomes a custodial affair' (Zogla 1999:1). And because of the importance of relationship it has been

suggested (Nolan et al. 2002) that 'person-centred care' should really be called 'relationship-based care', as people with dementia have to be 'understood in terms of relationship as that is the characteristic of all lives' (Hughes et al. 2005:5).

*Fostering relationships*

The ideal care for those with dementia is person-centred and based on relationship. This is supported both by my fieldwork and by research already conducted within MHA homes. It was the possibility that friendship might be lost that so distressed residents as MHA began to change.

When friends meet they often share laughter and the sound of laughter is often heard in homes that seem to have the most effective person-centred care. I noticed that in my fieldwork journal the atmosphere of the home had been noted, and there was a correlation between this lightness of relationship and the recorded effectiveness of care. Those who find communication very difficult will be seen to laugh along with others and will sometimes initiate the humour.

Humour can have a releasing and calming effect and Pattison says that he believes that humour can arise 'from the incongruities of life and it is appropriate for dealing with… frustrations' (Pattison 1988:176). 'Laughter is the shortest distance between two people' (Barton 2003:83) and as such is vital to relating to the person, especially someone with difficulties in communicating. A touch and a smile are proven ways of reaching the person: a coming alongside to share the experience of the moment.

The Wise Fool is used by Campbell (1981) as a model for good care that is, 'expert yet spontaneous; immediate and simple; loyal and vulnerable, and able to join in… laughter at itself and the world' (Pattison 1988:170). This laughter is not that of cruel humour which would laugh at those who are confused, but 'the laughter of delighted recognition and acceptance' (Pattison 1988:170).

One of the most important ways for an individual with dementia to find meaning in life is 'by encountering someone' (Bunkers 2004:63), and this is especially so with dementia as the world is mediated through the carer. To have someone alongside who has the skills to be aware when a connection is made, by recognising the 'little things' that are unique to that person, allows for the possibility of meaning to be found even if life for that person is severely restricted.

Each person's journey with dementia is different as the disease interacts with the individual's life and experience. While therapeutic interventions, such as reminiscence therapy, reality orientation, and validation therapy, have been developed to enable communication, the most effective interventions in the last twenty years support the belief that 'If there is one rule that can be applied consistently in dementia care, it is that there are no rules that can be applied universally' (Nolan et al. 2002:193) as care is best offered through the relationships that develop.

One of the most significant challenges to health and welfare systems over the coming years will be to provide care that offers quality of life to the person with dementia and their family (Nolan et al. 2002). This requires care that goes beyond maintenance of the person and focuses on the resident's abilities and interests, rather than what are seen as the deficits in the person.

The care of each person is unique to them as the carer discovers, and imagines, what enables that person's life to be worth living and so can bring a quality to their lives. My fieldwork showed me that there was no 'best way' to care: no one therapeutic intervention that will enable the person with dementia to live more fully. I learned that what is important is that the person is known and the possibilities for her imagined and then risked.

**Living in the moment**

The presenting face of those with dementia can be that they are lost, without a past or a future and often not seeming to know what the present is. If we regard those with dementia as being scarcely alive and so of little worth, and assume an absence of meaning in their lives, then this will affect the care that is offered. Those with dementia could be said to exhibit the characteristics of those who are in despair, i.e. 'with no hope, wandering, staring into space, showing no emotion, no interaction with others, a fragmentation of their personality – a lack of ego-integrity' (Ryecroft 1995:37). But on closer inspection good carers discover that this does not have to be the case.

Living in the moment requires staff to have a different perspective on life. The beginnings of dementia are characterised by fear and panic that everything is being stripped from them. But in my fieldwork staff were able to recognise good care that saw them able to connect to the person 'in the moment'. The idea that there could be another way to view dementia is counter-cultural in that it asks us to value another dimension of life in order to make sense of it. This will be developed in the following chapter as we explore how it might be possible to embody this ideal.

Maslow's hierarchy of needs offers the view that it is only when the lower needs are satisfied that the higher needs can be met (1970). He suggests that the basic needs for human life are: air, water, food, sleep, and sex. The absence of these brings discomfort so there is motivation towards satisfying these needs and only then can the quest for meaning and purpose begin. On the other hand Frankl (1979:33) suggests that the distinctions between higher and lower needs do not take into account the idea that when lower needs are not satisfied, a higher need such as the will to meaning may become even more urgent. 'Man's search for meaning is the primary motivation in his life and not a secondary rationalisation of instinctive drives' (Frankl 1992:105). He gives the example of those in German death camps during the Second World War

who were deprived of many basic needs, but found some purpose in life as they searched for their ultimate meaning. He describes this 'meaning' as 'a possibility embedded in reality' (Frankl 1979:38). Meaning is something that adds integrity to the person so that value is added to their life.

Frankl's description of how people searched for meaning in the death-camps in no way diminished the horror, or romanticised the experience (McFadden, Ingram & Baldauf 2000:71). Similarly to look for meaning in the life of someone with dementia does not make light of the pain that the condition causes to the person their family and friends. McFadden et al. use Frankl's words to define this meaning that is variable from person to person and from moment to moment. '"What matters is not the meaning of life in general but rather the specific meaning of a person's life at a given moment"… [and] in how to live each moment' (McFadden, Ingram & Baldauf 2000:72).

The idea of being present in the moment with the person with no agenda of our own means we have to focus our attention. This is 'respect' in action, a looking again at the person. Baarth wrote that this presence approach 'gains form and content from more or less incidental encounters, which over time grow into longstanding contact and trusting relationships' (Meinninger 2009:2). It is an open process that has no goal or plan except to get to know the person: to be alongside. This is in contrast to the interventionalist approach that knows what to do and wants to solve the problem.

The presence approach has at its starting point the relationship, with the primary object of 'being there' in the moment.  It is focussed on the life of the person as a whole, with all its joys and pains, with the aim of releasing the authentic expression of another's identity in all its variety.

*Finding identity through the spiritual*

MHA's supporting documents and core values affirm that spirituality is crucial to our care and that we are all on a spiritual journey. And that as staff seek to meet the human needs of the person they are also meeting the spiritual needs (Goodall 2009:173). Staff recording the life-history of the person is an important part of the entry into care and begins the building of relationship. Projects are resourced to accompany and support each person on their spiritual journey, especially so for those living with dementia, and each project has a chaplain, whose role is to be the focus for spirituality in that place: to build relationships and look to find ways to enhance that person's life.

The importance of searching for meaning in life, even in dementia, has been recognised and the question 'why?' asked by both onlookers and people with dementia themselves. Through reflecting on the experience of those who had suffered huge losses Frankl reasoned that 'He who has a *why* to live can cope with almost any *how*' (Frankl 1992:9).

Care of the whole person is more than care for the body alone. It demands of the carer openness and awareness of self that will enrich them as well as the one who is cared for. The importance of relationship in affirming the resident and the carer has been stressed because, 'Personal identity should be understood to be embedded in the purpose one has for one's life through how one relates and is therefore spiritual' (Webster 2005:5).

While there is anecdotal evidence of what can become important to those with dementia, it has been rare to hear this from the people themselves. However, as the ability to diagnose the disease at an earlier stage improves, there will be the potential to engage with what people themselves believe in respect of what is happening to them.

*The spiritual journey*

While staff chose as the most important value that of 'respect', seen throughout MHA's history as mutuality, some also added that respecting their spirituality was vital. 'I think this encompasses everything… it's everything around the person, what makes them tick. It touches life way back and the present time' (H5a). The modern human being is often described as someone able to invent herself. But with the onset of dementia this is no longer possible and people are not able to hide behind any self-created mask. Some might even see this journey into dementia as a journey into what is 'real' in life. While for some this may be appreciated as a 'spiritual journey' for others it could be seen as a robbing them of what made life worth living. 'What Frankl did not foresee was that it is possible to live apparently happily within the world of the false absolutes' (Lakeland 1997:10). The phrase often used of people with dementia that they are 'happy in their own little world'. By this what is meant is that dementia enables people to live contentedly in a world where nothing is 'true', but that this does not seem to bother them: nothing really matters.

However carers have commented that the journey into dementia could be a spiritual journey, as the material things of the world become of less value, and the person looks for new areas of meaning. Post and Whitehouse (1999) suggest that it should not be assumed that people with dementia cannot respond spiritually, and descriptions of what is of value as the disease progresses have been recorded. The following words were spoken to Cohen, a researcher, by a Jewish man diagnosed with Alzheimer's disease.

> Having Alzheimer's disease made me face ultimate realities, not my bank account. Alzheimer's disease transferred me from what I call the trivial plane to the spiritual or personal plane. I had to face the absolute horror of the 'A' word, and I began a dialogue with my existence, a dialogue with my life and my death (Snyder 2003:299).

This is far removed from the desolation that is expected, and often found, in many diagnosed with the disease. But for these people at least the possibility of another frame of reference has enabled them not to fall into despair, in fact to even value opportunities now open to them, and staff recognise that 'just because they have dementia doesn't mean their life has ended' (H9b). However the pain and trauma both for the person themselves and those around them must not be underestimated. While there are those who, perhaps because of their positive personality, can agree with the people quoted above, others will never find rest in the condition.

Christine Bryden has written eloquently of her journey into dementia and of the importance of spirituality to affirming her identity, saying that '… we live in the present, with a depth of spirituality and some tangled emotions rather than cognition, [which] means that you can connect with us at a deep level' (Bryden 2005:99), and that 'Spirituality can flourish as an important source of identity' (2005:150). Lawrence's experience as a practitioner led him to write that:

> At the core of the person with dementia, spiritual matters remain pervasively in the background. They offer potential pathways for connections amidst the fear and vagueness of what cannot be reached, spoken about, or validated by others who have no idea who the person **really** is inside or once was (Lawrence 2003:400).

**Conclusion**

My fieldwork supports the thesis that the type of care that will best provide for those with dementia is not a mechanical care, but a care rooted in respect and mutuality where care is offered, not by rote, but with a genuineness. This is possible when staff recognise that each person's journey into dementia is different, and that what is important is a search for meaning in the moment offered through respect and a loving relationship.

When asked about the best care, some staff said that 'it all depends'. They were able to reflect on where the person was at that moment and then discern the best type of care to offer. This reflexive process is continuous; leading from reflection to practice to reflection, and can transform the quality of life both for the person with dementia and the carer. Those carers who were already working this model of reflection/respect as they offered care thought that they were able to enjoy work more because it had more meaning and was less monotonous as they paid attention to the moment. The example of carers enjoying their work could also explain why carers new to MHA in the established homes, seeing the benefits to both carer and resident in this way of working, had adopted the practice themselves.

The example is given (Kennard 1983:22) of a therapeutic community where good practice died out because the organisation grew too big and because no training was given to establish new 'experts'. For as the original pioneers retired or moved on the practice died out. MHA puts extensive resources into training those offering care to those with dementia and, while it could seem extravagant, there is a model of best-practice care that has been developed and could be offered more widely to the care sector. This model of care requires a change in attitude from carers as it is based on the way that care is offered. It is centred on respect and then reflection, and the loving attention that is given to each person based on the ideals of mutuality and respect.

In the following chapter I will investigate the ideas of mutuality and respect from a theological perspective in order to explore how theology can:

- best inform the process of reflection as care is offered to those with dementia.
- truly enrich the value of respect
- help people articulate their deepest values

# Chapter 5: Caring for people with dementia:
# a sign of the kingdom

'Just because they have dementia it doesn't mean that their life ended …sometimes there is a glimpse of something…it could only be seconds' (interview).

**Introduction**

The fieldwork conducted within MHA dementia care homes has given me insights into what person-centred care can mean to carers, and the importance of MHA's core values, especially that of respect, to the care offered. This has enabled me to reflect on the care and respect that staff showed residents. The way they spoke about times when care worked well made it possible for me to begin to picture how theology might speak into this specific situation and offer some ideas that may in time form a fully worked out theology of care. I believe that there needs to be this first step to explore what theology can offer into the situation before that can happen.

The purpose of seeking to establish a robust theology for the care of those with dementia, and which I will seek to begin to address, is: to promote good care as an expression of the Christian life; to enhance the personhood of those who live with dementia and commend to others their capacity for mutuality; and to allow the wider Christian community to benefit from this revelation within God's created order.

Although the care of those with dementia within MHA, influenced by its Christian ethos, could be seen as an isolated example of good care, it may be that the way in which that care has developed is a sign of what is possible within the constraints of an organisation that has to survive in the real world but still wants to model Christian values. To speak of this in theological language could be to call this way of caring a 'sign of the Kingdom'. In a similar way Edmonds, in writing about care offered within

the L'Arche community, says that while it might 'not be a complete universal solution…it could be a *sign* of one' (2011:191).

Recognising the signs of the Kingdom is a theme that recurs within the Christian tradition. For example Christian Realism looks for a way of living in a fallen world with the anticipation of the Kingdom. Within the context of caring for those with dementia this demands an awareness and an openness to new possibilities, and an ability to see beyond the presenting problems of the disease: an anticipation of a future not quite in view.

Post reminds us that the root of our word respect, 'respectare' (2005:223) means to look again, and 'respect' was the core value that almost all staff in the survey chose as the most important of MHA's values. This 'looking again' at the person, not in dismay but with imaginative anticipation, an imafining of the possibilities for the person, has been shown to be the basis for good person-centred care. Staff agreed that the Christian values of MHA enabled good care, so in this chapter I will begin to uncover what it is about the ethos of MHA that supports a theology of person-centred care.

This 'living in the moment' with those who have dementia in order to establish a relationship that may enable the possibility of transformation or flourishing is counter-cultural and demands imagination based not on wishful thinking, but on the 'glimpse of something' (H8b) that is recognised.

The quotation used at the beginning of this chapter reminds us that staff understand that a person's life does not end with the onset of dementia, and because of their relationship with the person carers are able to glimpse responses that others might miss. Being present in the moment, which for many with dementia is all that is real, and imagining a different future for the person, one with the possibility of flourishing, is asking for a leap of imagination. But that is what carers do. They ask us to join with them in giving value to another dimension of life, other than the rational, in order to make sense of it.

However, before we can consider how theology can enable us to develop an ethos of care we need to look at what theologians understand by dementia and how it affects the person. I will also argue that an ethos of care needs a theology of what it means to be human.

**Dementia and theology**

Theology in the twentieth century saw a development in the study of the human condition, away from traditional theology which tended to focus on the nature of God and the life of the world to come and towards a model that is contextual. So theology has become more rooted in the day to day lived experience of people and what that experience can mean, rather than being abstract (Ballard 2007:65). This lived experience of God must amongst other things be 'politically aware and theologically courageous' (Campbell 2007:77); it is no longer enough to say that MHA's ethos is rooted in the Methodist Church. This theology must enable us to offer concrete proposals for the transformation of practice rather than applying what has already been learnt to a practical situation where it may or may not fit.

Practical theology offers an approach through which to discover theological insights of what God is doing in the world as human experience is 'the place where the Gospel is grounded, embodied, interpreted and lived out' (Swinton and Mowat 2006:5). Campbell writes that '*some* branch of theology must be concerned with matters that directly affect our human well-being' (2007:86), and suggests that practical theology is an 'exercise in creative imagination,… with all the ambiguity and inconclusiveness which this implies' (Campbell 2007:85). Goldsmith has written extensively from his experience of being alongside those with dementia and suggests that 'theology is being hammered out on the anvil of experience, and the churches are being asked if they have any Good News, any Gospel for these, the least of my brethren' (1999:135).

Until recently it has been academic disciplines other than theology that have reflected on spirituality and ageing (King 2004:124). Ageing and the problems associated with it had been left to the caring professions, and while theologians have wrestled with the poor and marginalised ageing was seen as a natural, if sometimes painful experience and so part of the general human condition. A new perspective on dementia care demands meaningful dialogue and a respect for inter-disciplinary insights into the condition.

I have suggested that dementia calls into question assumptions made about who we are as people and how we can relate to God; what suffering means; and, of ultimate importance to those who watch and wait and those who live with dementia, have asked if any hope can be spoken into this situation. Dementia calls into question our humanness and identity and, speaking from within a diagnosis of dementia, Bryden concedes that 'There is prolonged mental deterioration and no presumption of the existence of a cognitive person theologically… The "loss of memory entails loss of self"' (Bryden and MacKinlay 2003:71).

Dementia confronts us with sustained dying, reminds us of our common weakness and takes us to the limits of human power, and when faced with this it is theology that Keck (1996) suggests is able to speak into the situation. There has been a tendency to deny the depth of the questions raised by this disease and to ask questions of a God who is outside and above the situation and not in it (Kevern 2010b:3). For some there is only the vague hope that in God all will be well in the end. However our understanding of dementia and its effects has developed over the past few years and as a result the importance of dementia to theology has gradually been recognised and theologians have begun to develop ways to talk about it.

*Human identity*
The theme that continues to recur when thinking theologically about dementia is 'what does it means to be human'? Some carers would assert

that 'the person has gone' when they can no longer recognise any of the rational qualities that make a person. For while having the capacity to respond within a relationship implies personhood, some believe that we are only fully human when we make the decision to know ourselves in a relationship with God (Anderson 2003). So if a person is unable to make a conscious decision 'they cannot be described as living an authentically human existence' (Saunders 2002:11). They are then seen as an ex-person who only has a value in what has been their past. However my fieldwork confirmed my perception that the person, who can relate and respond, remains until the moment of death. But this requires a new way of thinking about dementia that was commented on by one interviewee who said 'it's those who have been in the industry a long time who have got set ways that probably are not going to be the most successful [in care]' (H3a).

Much of care is listening to inner promptings, or relying on a gut feeling that the person is still there – until it is proved otherwise. Theologians too have faced the despair and negativity that still surround the term dementia, and have tried to offer insights into what must still be possible as they reflect on the experience of caring for people with dementia and their value as human beings. Stuckey in his chapter titled 'The Divine is not absent in Alzheimer's disease', states the dilemma practitioners face and asserts that 'Alzheimer's can steal memories; it can steal personalities, it can steal bodily functioning, but it must not be allowed to steal the human spirit' (Stuckey 1995:75). We are reminded that through caring relationships there can be spiritual support that can remind people who they are and nurture their spiritual lives as they are connected within the life of the people of God. This reminds us that the person is not lost within dementia. But while it is an acceptance of the person as they are it does not seek to address questions about the nature of the person in their suffering or how they can relate to God.

Rather then concentrating on what the person is unable to do and be the suggestion is that the person with dementia is seen living with open trust

and by faith alone as, 'the life of dependency in dementia models faith as relationship, and could be seen as a more perfect way of being human' (Saunders 2002:17). It is this open and trusting nature that allows carers who are new to the person with dementia to make a meaningful relationship. But the person's response is likely to be inconsistent, and the carer needs to adapt her approach to the moment. It is this uncertainty that worries family and visitors who rely on continuity of the self.

*Dementia and the love of God*

This chaotic aspect of dementia has been a problem for theologians as well as for carers. From the writings of Aquinas who said that, 'the image of God is not found in the rational creature except in the mind' (Saunders 2002:8), the mind and more particularly rationality have been seen as the way humans share the divine likeness. Yet Alzheimer's seems to put into reversal the ordering process of creation and suggests a return to the chaos of the deep (Weaver 1986), but even so it is suggested that 'given the opportunities and some sympathetic help, people with dementia can still flourish as human beings, despite their incapacities' (Saunders 2002:7). However for those living in the light of the Gospel, Kevern suggests that the 'only safe way to analogize from *imago dei* to God is via Christ' (2010b:6). Through the work of Christ we take our place as God's children, no longer needing to earn our way to God through rationality. For if it is possible for carers to recognise and relate to a person with dementia even when they cannot enjoy rational conversations, how much more will God – who sees beyond the mind and into the heart – do so.

And yet Reformed Theology has at its centre the act of conversion in which the sinner finds a new relationship with God and so becomes authentically human. Rationality becomes important as there is a need to be aware of what God is doing. There is an emphasis on the unmerited grace of God, but that is balanced by the need for reason, as one has to be aware of our own sinfulness and our need of Christ and respond to the work of the cross. In conversation with an ordinand about people with dementia and what that could mean for their place within the love of God,

she suggested that because they were not able to confess their sin and accept Christ, they were outside God's love. If this is the case then dementia means death, both now and into the future (Saunders 2002:10), as the person is unable in any logical ways to confess their sins and accept Christ. This is a view held by many Christians who see both the inability to confess their sins or to ask for forgiveness as separation from the love of God. But this is not the lived experiences of care within MHA where dementia confronts us not only with the reality of human failings, but with the 'reality of human love and the unconditional love and acceptance of God' (Goldsmith 2004:192).

But the idea that the person has gone and there is no hope for what is left continues to be expressed. Keck expresses the concern of many families as, writing about his mother, he says 'it is hard for me to see how a person who has lost the capacity to speak, feed herself or go to the bathroom can be said to be experiencing or participating in the Kingdom of God' (Keck 1996:134). He continues with the suggestion that they are going to a better place and that 'part of dying well for someone is meditating faithfully on what will happen to them in the next life' (1996:149). It is as if the person is no longer living; the person has gone and we are just waiting for the body to catch up. What this says about their existence is that it is of little worth and our task is to remember for them the life in the world to come. For many who watch and wait this is the case. There is nothing positive, only a prolonged dying which reinforces the fear and desolation that there is around the whole subject of dementia, even within the church.

There are positive insights and some believe that there is a way forward and that the disorganisation of psychological processes, the chaos, in dementia does not really affect one's relationship with God, 'for this relationship extends through channels that transcend the experience of the body' (Weaver 1986:444). The breath of God, 'nephesh', that gives life to everyone confers a 'continuing relationship with God' (1986:446), and so as long as we have breath in us we can live within the love of God.

For Scriptures affirm that 'in Christ we already live in the end of time… the upholding and renewing power of God is active in this present space and time' (1986:453). Believing this offers an opportunity for the church to affirm them within the body of Christ, and offer good person-centred care by helping them to maintain their identity. And yet writing in response to a report by the Church of England in 1990 Saunders notes that 'Christian theology and the practice of the church...seem tacitly to exclude the person with dementia' (2002:3). This is easy to do when the most undemanding way to care is to keep those with dementia 'safe' and behind locked doors.

The chaos that many describe as a barrier to being within the love of God is therefore compounded by the reluctance to engage with those whose experience of life is different. This in turn limits both our understanding of the person and of the wideness of God's love.

*Searching for the positive*

The traditional/historical command to 'remember' in order to be within the Covenant love of God is not good news for those living with the ability to remember things less clearly, and not able to call things to mind without assistance. The scriptures emphasise that God is with us and that even in Sheol, the place of forgetfulness, God remembers us. Goldsmith offers the motif of 'remembered by God', which seems to encapsulate this 'Good News' for people with dementia as it 'stresses the basic truth that we are remembered by God long before and long after we make any recognisable response to God' (1999:131). He goes on to say that we are 'unconditionally accepted by God and unconditionally acceptable to God' (1999:131). This positive note emphasises that God's grace, love and mercy are not dependant on who we are or what we have done, but are there for us. God has taken all the initiatives, it is enough that the person just be as they are, this is prevenient grace. This would support the views of carers who believe that 'you have to treat every single person as an individual by respecting them', and that the individual can therefore still be found. From talking to carers I found that those with dementia tend to

assume that everyone knows them, so why would they not assume that God knows and loves them?

This is such a positive message that it could be that all that is needed is there, as 'nothing can separate us from the love of God' (Romans Ch. 8), so the understanding that all are enfolded within his love and remembered by him is a good starting point. But this could be seen as a holding operation on behalf of God for those whose suffering is great and who will find fulfilment in the next life. This God who remembers us 'comes at too high a theological cost as it leaves us *alone* in our struggle' (Kevern 2010a: 4). Some might say that respecting the person's past life, reminiscing with them and valuing who they were is enough, and that questions about the purpose and meaning of the pain suffered through dementia might be substituted with questions that enquire how we might respond to it.

It may be that the 'good news' within dementia is that is offers insight into the human condition. Some have so appreciated what dementia has taught them that they ask if we should always try to find ways to eliminate it as we have much to learn from people who live with the disease.

> I am not so sure that I would hope for a world without dementia, for in a world without dementia we would be without the ones we love who have taught us that remembering and planning and naming and knowing are not the key activities of human life, but rather that feeling and being and touching and singing have enormous riches and depths that we are often too busy to relish in our race to rationality (Killick and Allen 2001:62).

To see value in the person with dementia *because* they have something to teach us makes use of their experience of pain and distress and gives it a functional nature - for our benefit. We learn from them what is important. Goldsmith writes that although it requires humility and maturity, we 'realise that we can learn from them and recognise that we can still discern their humanity' (2004:202). Keck too suggests that we can learn

from those with dementia as, 'they' can teach us about the love of God, and 'lessons we learn from dementia about God's love, forgiveness and suffering apply to these people…and to us all' (1996:38). He declares that the lessons of Alzheimer's are 'painful for all initially, but not without purpose', for 'in seeing the mental chaos of Alzheimer's...we readily see ourselves' (Keck 1996:176) as each of us is disabled by The Fall.

Seeing those with dementia as a living example of the chaos caused by The Fall can deny them any hope for the present or the future. The person with dementia has become the means through which the caregiver 'may participate in the Kingdom of God even [especially!] as they confront the worst experiences of the full-time care for the demented' (Keck 1996:228). The one who suffers has become one who enables others to participate in grace, while not themselves a recipient of it.

These instances articulate one way of finding good news within dementia, and it does offer something positive within a difficult situation, but it is a very functional attitude as it is concerned with what they do for us and offers no good news for the person themselves. David Jenkins (2004:199) supports this view when he criticises the specialism of care for the elderly, which he says should be called 'care for people', as it must be recognised that we are fellow human beings together so negating the need for 'us' and 'them' categories.

To see dementia as something that is useful for us offers a very narrow and functional view. Jantzen argues against the suggestion that 'they' suffer that 'we' might learn from their suffering. She suggests that to see this as something that is useful for us is an obscenity (1998:260), and that this might well be applied to those living with dementia. She goes on to say that to find worth in the person, whatever their condition and simply for their own sake, is a defence against ways of understanding life that are inaccurate and damaging.

So we are left asking where is the 'good news', the hope, for the person with dementia now? What can theology offer to care-givers that will enhance an understanding of the respect they give to the person?

The ethos of MHA, based on the Christian principles of love and compassion, is rooted in the tradition of the Methodist Church, and in chapter one I outlined the way in which an understanding of the Methodist emphases of prevenient grace and social justice might offer a basis for care of those with dementia. In the following section I will explore how this theology underpins the care offered in MHA homes and argue that the concept of imaginative anticipation can add something to that care.

**Imaginative anticipation**

At the heart of my theological exploration of the values of mutuality and respect is Imaginative Anticipation. In the concept of Imaginative Anticipation the one offering care is able to build on what they understand of the person and, though respect and relationship, envisage a future that is not quite in view.

When faced with dementia the question often asked is, 'Why offer pastoral care to people who cannot speak, think rationally or even experience what we call self-consciousness?' (Meininger 2009:1). This would appear logical, especially to those who have already been excluded by society and sometimes their families. What Meininger suggests is a validation of the person by 'being present', because the theory of presence has important links with a prophetic-eschatological theology which 'asks us to look at human reality with different eyes' (2009:1).

The recently developed theory of presence approach to care takes as its starting point a caring relationship; a 'being there' for the other person (Meininger 2009:3) which aims to realise the authentic expression of the other person's identity as it is experienced in the here and now.

This theory of 'presence' was researched amongst poor neighbourhoods, amongst those who are 'socially redundant' (Baart 2002:5). But those who live with dementia could be seen in the same category since dementia can be recognised as a disease that affects social contact. Baart suggests that what is needed in coming alongside those who are disadvantaged is someone who can bring 'the faithful offering of themselves: being there, making themselves available' (2002:1). The focus of the meeting is not to give or share information, but to cultivate a caring relationship and what is needed are those who 'will not judge…by the language you use, who are free to share lesser and greater moments with you' (2002:5).

The 'presence approach' could make a difference to care because it is aimed at enabling the other person to express their authentic identity, as space and time are given for attentive listening and being. Meininger says that this approach presupposes a 'different way of seeing and therefore also implies a different way of being of the practitioner' (2009:4). This is a different way of seeing human reality that costs in the level of attention that needs to be given to the person, not simply to the task.

However what is missing is recognition of the power that offers new realities through the transformation of all creation. 'Christian faith implies the recognition that reality always can be viewed from a different perspective, the perspective of God and his promised Kingdom' (Meininger 2009:12). For those with dementia this way of thinking could lead to a shift in our understanding of what it means to be a person whose cognitive and rational abilities are being lost. To believe in this transforming could bestow a new dignity and appreciation of the person.

Grace Jantzen speaks of 'nothing less than a re-ordering of this world' (Joy 2009:33), one that is based in community and focussed on transformation from images of death to those of life. God is inviting humanity into a new future. In the same way and '[i]n the spirit of the Hebraic prophets, process theology sees hope for transformation emerging from healing relationships and healing communities' (Eppely

2011:91). This offers the possibility for MHA homes to be communities where people have the possibility of being transformed through their relationships with carers.

This is not to deny the absolute horror that can be dementia, and the danger is that it will be seen as viewing the disease through rose coloured glasses. Any bereavement is difficult, and offers a view of life that slices through our comfort, especially as the loss of continuity and connection that have held together the person's life is recognised. It is said that the sadness sometimes evident in those with dementia is them mourning their own death. However, with support people can come to an acceptance of loss, and so too is possible even within dementia. What is important is the quality of support and what is necessary is support that recognises the losses, but also looks for signs of a different kind of response that offers relating in another way.

*Imagining a future*

Jesus reinterpreted and embodied this prophetic preaching as he proclaimed the nearness of the Kingdom. 'In his liberating and joyful communion with excluded publicans and sinners as with his disciples, the Kingdom of God is realised and anticipated, prefigured and promised' (Meininger 2009:4). It is this 'eschatological kerygma' that enables a new imagination of reality that, once this has been glimpsed, cannot but help them to see themselves and others with different eyes (2009:5). Christian hope from the perspective of this prophetic-eschatology invites us to look at human reality with different eyes as a 'promised communion with God and our fellow human beings' (2009:1) is imagined. This attitude of attention he terms 'imaginative anticipation'. We cannot completely experience full communion with God and others in our world and so must anticipate this new reality, and we need to imagine as it is not something we already know but 'the fulfilment of a promise' (2009:5).

Meininger suggests that this can be brought about by a change of attitude that is embodied in a person. For those with dementia, as with all other

aspects of their life, this needs to be mediated through carers. What carers believe they are doing is summed up by one staff member, 'I don't think that we are doing anything particularly special. I can't put my finger on it' (H8a). And that is the point. It is not something particular. It is an attitude of care so special that it must pervade all aspects of care from eating to toileting to just being alongside.

This vision of the world enables the way the world, community and personal identity are viewed to all be connected to the promises of Jesus. Faith anticipates the fulfilment of a promise: that a person is becoming what God intended for them. Those whose human capabilities are not realised or diminished can pose a problem to this way of thinking, but within the practice of imaginative anticipation there is a wider framework for human existence. 'Imaginative anticipation is based on a 'not yet' that applies to everyone regardless of status or ability. All are equal in the sense that they are all on the receiving side of God's love' (Meininger 2009:7). It is the sharing, enduring and holding on together, the 'not yet' that is evident in our lives as we learn to communicate and relate to one another. This approach does not imply that suffering and disability are disregarded, but that they do not count in the way we interact with each other. 'It situates the confrontation with disability - both for the disabled person and the able-bodied person - in a framework that transcends human differences and the problems caused by them... without erasing them' (Meininger 2009:7). This enables people to relate in new ways, not as those who can and those who cannot, but as those who shall be.

This way of seeing someone does not anticipate a goal, but believes that the other person is fulfilling her promise. Within the practice of imaginative anticipation, 'realised or unrealised capacities lose their central significance, because these practices refer to a relational perspective that transcends…capabilities…that can be prognosticated or measured' (Meininger 2009:6) and is a framework that transcends human differences while affirming individuality.

It is understood that pastoral care should be based on sound evidence-based knowledge because this offers clear guidelines. But the eschatological promise, because it is something new and unthinkable, cannot do this. For carers within MHA this demands that 'respect' – looking again at the person – be taken seriously and that the work is encouraged, not just by reaching goals that are set but by using the imagination to wonder ...what if?…and offer new possibilities.

The metaphors we use give insight into what is believed (Jantzen 1998), and parables of the Kingdom start with 'the Kingdom of God is like…' suggesting a rethink of usual meanings in order to bring in new realities grounded in God's promise to bring Good News. For those with dementia the Good News uncovered through carers' own experience is found in mutuality and respect which is only possible as carers 'look again' at the person and take risks as they imagine what responses mean. For those who have a Christian faith, Kingdom values will make sense; for those with no faith then an understanding of the difference that a change in attitude can make to those with dementia could be enough to bring about an offering of care based on mutuality and respect. Perhaps this is why even staff who had no faith believed that the Christian values of MHA enabled them to offer better care.

However Meininger suggests that this 'presence approach' alone is not enough as 'the challenge is missing of any critical argument that has its source outside' (2009:10), and so what is offered ignores the possibility of renewal through God's promise. Presence theory recognises the importance of accepting uncertainty, but does not see that this can only be sustained by hope in eventual fulfilment (2009:10). It requires an attitude of 'fulfilled communion', which can imagine the person from 'the perspective of God and his promised Kingdom' (2009:12).

This re-imagining of the person enables new ways of being and acting, and of offering respect and full personhood to those who live with dementia and who are sometimes labelled as ex-people. Imaginative

anticipation that engages with the lived reality of the person 'requires a continuous renewal of our understanding of the Christian message, of ourselves, of others, and of the world we share with those others' (Meininger 2009:12).

**Personhood and future hope**

The Christian ethos of MHA is enshrined in its values, so having researched how staff demonstrate the values of mutuality and respect in their care, examined theological responses to dementia and suggested how the motif of imaginative anticipation might be used, I now move on to propose how a theology of care for those with dementia within MHA might be constructed.

What is required is a radical change in our perspective, both of those with dementia and how to care for them. 'Charity' is not enough (Edmonds 2011:25). What the Christian ethos adds is a respect for who the person is now, and who they are in the process of becoming, not simply for who they have been. One staff member described care as 'giving them the freedom of being able to develop' (H3a). This is the change in perspective: from trying to hold on to the past as the only thing that will give a person identity to learning from them who they are now and discovering with them who they will become.

As previously discussed, the identity of the one with dementia is often seen as resting not 'on what we know or remember of ourselves, but on being known by God' (Giddings 2010:3). But any real hope is in the future, as what happens during our lifetime is only part of the story, so the resurrection brings hope of a real transformation within the love of God. McDonald (2003) likens dementia to Holy Saturday, where the experience is a time of limbo and nothingness, but it can hold the joy of the present moment in which the eschatological restoration of the whole person can be anticipated.

McDonald offers a glimpse into resurrection life now as she explains that 'a trigger from the distant past casts shafts of future resurrection light into the present of advanced dementia' (2003:8). It is the possibility of the 'future resurrection light' being seen now that I wish to explore as a way of validating the present lived experience of the person with dementia. Killick quotes Debbie Everett who has written on the spiritual care of those with dementia, saying that they offer a fresh light that will 'lead us to re-evaluate human possibility' (2004:152).

The importance of the past is acknowledged as memories are held for them by others and those who have faith are promised new life in the Kingdom after death. But what of the time now? What possibilities are there for someone with dementia to experience life in the fullness of Christ now? I want to propose that the life lived with dementia need not be seen simply as one of decline, but of a journey into different possibilities into which God is speaking words of new life.

**Imaginative anticipation as a model for care**

*Becoming*

Those who observe people in the last stages of dementia often talk about the person having gone. Indeed some carers have said that the best way to treat them is just to keep them clean and calm; seeing them as 'ex-people' so needing little interaction. There is a recognition that the person with dementia can seem to disappear, but the question remains, 'where have they gone to? ...has their personality been destroyed or is it simply locked away'? (Goldsmith 1999:133). These questions ask us to think about who the real person is; the one then or the one now? Khalil Gibran asks us to consider children whose 'souls dwell in the house of tomorrow' (Goldsmith 1999:195), and hints that there is a sense of mystery, a not knowing, to what it must be like to be there.

This idea of mystery offers a more positive way of viewing life with dementia when cared for by someone committed to having respect for the person;

> Here I need not fear abandonment; I will be cared for no matter how strange and muddled and directionless I may appear. On this road my deepest yearnings are met through companionship, understanding and humour. Here I am known not only for what I am, but also for what I have been and who I may yet become (Hudson 2008:93).

Writing from within a diagnosis of dementia, Bryden asks us to 'be positive, to hope for a new life in the slow lane, as we reach for the stars together' (Bryden 2005:134). What a 'new life in the slow lane' might be like she does not tell us, but there is in this idea the possibility of something new happening. Dementia is most often seen as a journey into decline and death, so to speak of something new happening within the memory of God which holds past, present and future together, opens the way for a fresh approach.

This offers an innovative way of seeing the person with dementia: as someone who has a future as well as a life to lead now, and whose life is of value because it still has possibilities. It is a very different picture from the one of pain and despair that is usually associated with dementia. Goldsmith cites words by McKee that encouraged him to look again at those with dementia:

> If…there is a connection, and not a discontinuity, between the worlds of those with dementia and those without, and if there is the slightest possibility that a kernel of tranquillity persists at the heart of the chaos of dementia, then we… [have] denied their humanity… but also heightened the terror of their experience (Goldsmith 2004:201).

The idea of a 'kernel of tranquillity' at the heart of someone with dementia is attractive as it invites those who care to look for the something more

that could be there. It is the experience of some carers that there are those who are able to 'blossom and flourish' even in their dementia. In a later work Goldsmith develops this idea and asks if there can be a new beginning:

> 'Does the experience of dementia have to be one of unmitigated gloom and loss or can we discover nuggets of gold, little gems that will feed and nourish us into the future. It is important that carers… look out for little signs of hope: they are much needed in the journey through dementia' (Goldsmith 2008:131).

Our task, as those who care, is to recognise the signs of hope that may be visible, or may require imagination to see. Person-centred care is looking at the person: the person beyond the disease, to see who they are and who they are becoming.

'Human becoming' is a term used by Macquarrie who suggests that we should speak of not 'human being', as we are all in the process of becoming human as we discover and realise our potential. '"Becoming" suggests process, transition, incompleteness, movement from non-existence into existence (or the reverse)' (Macquarrie 1982:2). He writes that in order to understand human nature as something with movement it is necessary to go back to the root of the word from the Latin 'to be born': that which is emerging and taking shape, 'coming to be and always on the move… the realization of human nature as an emerging reality' (1982:3). This offers an understanding of the nature of being human as being as much about potential as of actuality. Traditional natural theology saw God in nature, in the created world. Macquarrie suggests that it is also possible to see God in what is unfinished; in the freedom and openness that allow for change and growth (1982:23).

A model of care from nursing offers an alternative to the bio-medical approach called the 'Human becoming theory' (Parse 1998), which has strong links to good person-centred care in which the quality of life is seen from the perspective of the person themselves. It is based on finding

meaning through the lived experience, and reaching out beyond the limits that the person sees as, 'While their outer appearance may well reflect chaos and loss, there may well be hidden depths to a person…which if the key can be found may reveal new and healing perspectives on their situation' (Swinton 2008:33). However what tends to happen in caring for those with dementia is that people look to see if either the person has managed to remain the same as she always has been, or that there is decline in the situation. Kevern suggests that we should look for 'signs among people with dementia of a continuing though changed self-expression' (2010a:248).

Change is possible, even in dementia, and Kevern invites us to consider the influence of the God who is 'elusive and intractable', and whose characteristics are 'creativity and flexibility' (2010a:249). The good news is that we are 'loved and accepted by God… through sheer grace' (2010a:210) by the God whose name was given to Moses and recorded as 'I am who I am'. But that can also be translated as 'I will be who I will be' which is much more dynamic. There is the possibility of God doing 'something more' (Swinton 2008:33), more than we can ever hope or think. But for people to recognise that someone with dementia is fully human, and also in the process of 'becoming', requires a leap of faith and imagination.

Seeing the person in this positive light would enable us to construct a different experience of dementia and enable the task of caring to begin in a more meaningful place,

> …a place where it is not assumed that the story of dementia is nothing but…loss and devastation, but…a fragmented human person who is held and sustained in their uniqueness by a God who has promised never to abandon them… Such a position is the foundation of Christian care (Swinton 2008: 34).

In learning to respect the person, and to 'look again' at who they are and who they are becoming that may not be quite visible, carers need the gift

of an imagination that can visualise the whole person loved and valued by God. To believe otherwise would be wrong as we would be 'posing a place in human experience which is beyond God's participation' (Kevern 2009b:417).

These ideas affirm the ethos of MHA and its adoption of person-centred care which accepts the reality of what could be an overwhelming diagnosis of dementia, but looks beyond, with different eyes, to the value of the person who deserves our respect.

*Flourishing*

The Christian church focuses on the act of salvation with its imagery of death and new life, and Jantzen asks why it is our death, as mortal beings, and not our birth, as natals, is that which preoccupies Western culture. She offers the image of 'flourishing' to shift us to a 'transformative imagery of natality' (Jantzen 1998:159). This idea of human flourishing is used as a model to describe the person blossoming as she has the potential to develop (1998:161).

As previously discussed metaphors can help us understand what gives our thinking foundation, and while the traditional idea of salvation carries with it the implication of rescue, the image of human flourishing and blossoming offers the potential of growth made possible from an 'inner dynamic of growth' (1998:160). This leads to a recognition of the divine as the 'horizon of our becoming' (998:275). Life then has the potential for new beginnings which can be anticipated and imagined.

While in theory the idea of 'flourishing' is appealing, if applied to the practice and care of those with dementia it would seem unlikely and it could be criticised as the wishful thinking of someone who cannot face the horror and desolation of dementia. However both my fieldwork and writers already cited have alluded to the possibility of flourishing. For example, 'giving them the freedom of being able to develop' (H3a), Goldsmith's 'little signs of hope' (2008:131), Hudson's, 'who I may yet become'

(2008:93), and Bryden's 'hope for a new life in the slow lane, as we reach for the stars together' (2005:134). In each example the writer is suggesting that there is something more that the person with dementia can aspire to, not through any intention of their own, but through the possibility of God's love still at work in their lives.

Writing from the experience of working alongside people with dementia and through this research I have been made aware of the unexpected ways in which people, even as they struggle with the effects of the disease, have exhibited 'little signs' of change in attitude and character that belie the dementia. Care that does not recognise the potential of the person was described by one staff member as like 'being a bit of a robot just doing what you have got to do' (H4b). But some staff did recognise in the resident the peace that seems to come, not from the chaos of dementia or the absence of 'anyone there', but from a still centre. This is situated knowledge (Graham 2007:111) in that it relates to specific circumstances. But when the possibility of flourishing is grasped by carers their awareness of the person can be changed as they see them being empowered by a community which 'nourishes and provides the rich web of relationships so necessary for flourishing' (Joy 2009:33).

What is needed is a theology that 'empowers and collaborates with individuals and groups of people with disabilities who struggle for justice in concrete situations… creating new ways of resisting the theological symbols that exclude and devalue us' (Eisland 1994:86).

*Change*
If a person is 'an individual substance of rational nature' (Cohen 1997:152) then those with dementia are rightly cared for as if their life was over as the disease strips them of the ability to reason. If however we see them a person still with the potential to become, then care needs to be developed in a different way as we begin to see them not as 'ex-people' but those whom God loves and with whom God works to bring them to fruition.

This is not an easy concept especially as the decline associated with dementia is evident, whereas recognising the potential that remains within the person demands imagination. But whilst we live we are in the process of changing, or have the possibility of change within us. Macquarrie suggests that 'human becoming' encompasses the idea of process and movement (1982:2), and human nature is seen as that which is in the process of taking shape (1982:3). This is about potential as much as about what we can actually see.

This is something that seems obvious as we grow and mature as humans, but then there comes a time when the person begins to experience losses as they journey towards death. However Browning writes, in his foreword to a book on practical theology and ageing, questioning what kind of people we should become as we age (Lyon 1985:10).  He suggests that age should not be a barrier to the potential for growth; not physical growth that cannot be sustained, but growth into the person we have the potential to be. To address the question posed by Macquarrie as to what quality of life differentiates human being from other beings, I would suggest that it is the potential for human flourishing that some might call the spirit at work within each person. In Part 1 of the D.Prof I wrote about using the 'fruits of the spirit' as a tool for evaluating the spiritual care of those with dementia (Goodall 2009), as these were understood as desirable, and observable, for the well-being of residents and acceptable as values by care staff of all faiths and none. However what I am proposing here takes this further as staff are invited to imagine a becoming that is out of their experience, but that will change the way that they see the person.

**Resources from Methodist emphases**

So far I have argued that the traditional model of salvation theology is not enough for those who have dementia, they who are understood as being unable to confess their sinful state and respond to the calling of the Saviour. They are however able to respond to the call of love and it is possible for others to nurture that gift within them but many carers 'do not

have the insight to see it' (H4c). Humans are referred to as being mortal, that is they are on the way towards death. But there is the possibility of new beginnings of 'birth and growth with room for the possibility of renewal, and in which further growth is always possible' (King 2004:135), and where there is the potential for people to 'flourish in spite of biological ageing' (King 2004:125).

I would argue that Wesleyan theology, on which the ethos of MHA is based, has something to offer to this in the doctrine of prevenient grace as discussed earlier in this study.

At a time when he was facing possible shipwreck, John Wesley was challenged by the faith of the Arminians on board. He was influenced by their assertion that 'Christ died …for all and every human being' (McGrath 2000:454). The work of salvation has already been completed by Christ. The doctrine of prevenient grace developed by Wesley was not something new. Augustine had explored the idea saying that God's grace is active in human lives before conversion. 'Grace "goes ahead" of humanity, preparing the human will for conversion' (McGrath 2000:433). Perhaps the good news for these with dementia is that God has already taken the initiative.

Wesley's theological writings were usually in response to a specific situation, often an attack on his preaching, and the purpose of theology was not in order to understand life, but 'for changing life: theology should help effect the love of God and neighbor' (Langford 1998b:35). And he resisted any division of theory and practice as he contextualised his message to meet people where they were (Logan 1998:122), and to affirm that 'God is *already* at work in our midst' (Runyon 1998:28).

As previously discussed, metaphors enable us to catch a glimpse of something that is difficult to grasp and Wesley uses '*therapeutic* metaphors, characteristic of the Eastern Fathers, indicating healing and renewing. Not just a release from the burden of sin but a restoration to

health' (Runyon 1998:29). Grace is not simply a one-off event, but a process involving 'the constant presence of the Spirit drawing the person into a relationship that will sustain and reinforce on the way' (1998:29). Here life is seen as participating in God, and recognising the 'inner dynamic of growth' (Jantzen 1998:160).

An 'inner dynamic of growth' seems unlikely in a care home. There is loss and decline of older age but there is also the God who suffers with us and offers us blessing:

> Hope is in a God who has not forgotten these… God's caring is seen here not in a …God who can do everything, but for some reason, known only to God, won't… Yet, there is a caring in the struggles with a body that has outlasted its mind, perhaps to provide as much lure as that enfeebled organism can respond to. There is a certain beauty in the struggle that God and each organism are engaged in to give even a limited sense of life to each experiencing moment within a nursing home (Lyon 1985:117).

What is missing from many care homes is this sense of hope. That at the end of life, with all its perceived and experienced indignities, the person is still of immense value and worth and that even, especially, in the darkest of times God is working within them. 'In Christ Jesus, God chooses all humanity for renewal in that destiny for which we were all created, to be the very image of God. And prevenient grace seeks to awaken every human being to that possibility' (Runyon 1998:42). This is the energy of God, to continually call all things into being with Salvation not as a past event but a future anticipation.

One strand of theology that came out of Methodism in the twentieth century which could have something to offer to the discussion is that of process thought. The idea of a God who is affected by what happens in the world, and who works through persuasion, not guilt, in ways that are appropriate for each person, is a theme that links the care of older people

with feminist, Methodist and process theology. 'In the spirit of John Wesley, process theology recognises the transforming presence of God's grace in every situation, prior to any effort on our part' (Eppely 2011:91).

Process thought was a product of its time, and was believed to have little to say to the present age. Recently however these ideas have been revisited by scholars including those from the Methodist tradition (Suchocki 2009) where process theology has been found to be helpful in relating to some contemporary situations (Townsend 2011:19) as it speaks positively into the problems of pain and disability as it 'maintains that in spite of the brokenness of life, we live in a grace-filled world. God is active in every moment of life, gently guiding the universe part and whole towards the possibility of greater complexity and beauty of experience' (Eppely 2011: 90).

Feminist scholars such as Grace Jantzen have recognised the influence of Whitehead, one of process theology's founders, as she writes of the 'continuous creative surge of the universe as the natality of the world, its emergence ever and again into new beginnings, new possibilities… The divine is not static but Becoming, not aloof but feeling and responsive' (1998:256). Linking the ideas of prevenient grace that calls us on from within, and process thought that is concerned with development, she writes that the 'divine incarnation… moves us into the future… [we] discern it by allowing scope for imagination' (1998:258). For although process thought does not answer the question as to what the future will be it does suggest a God who is at the heart, bringing all things together.

'Becoming' takes place in the creative response to what has happened in the past and it is 'in this becoming that something new comes into existence' (Suchocki 1986:9). She sees the creative response as relational and 'the rhythm of the universe … the mystery of the dance between past, present and future' (1986:21). For the one with dementia, who is often denied a future, this model offers an on-going relationship between past present and future, rather than existence now where only

the past has meaning. Whitehead describes how in process thought 'our own existence [is woven] tightly and unapologetically into the fabric of the cosmic process… [and] situates the whole… within the accommodating embrace of an ultimate meaningfulness' (Haught 2000:126). To find meaning within a life that seems to be devoid of such is to imagine another future. This model is not seen as a design but a 'promise'. God's plan is not a blueprint but an envisagement of what the cosmos might become. A design closes off the future and 'clips the wings of hope'. In the beginning, however, instead of design there lies 'the Vision' (Haught 2000:190).

These theological models offer a vision of a God who has already acted on our behalf through grace, prevenient grace, and who offers us the possibility of 'becoming' in whatever circumstances we find ourselves, through transforming love.

To engage with this in the practice of working with those with dementia is to demand a re-thinking of who it is that is seen: a respecting of the person so that the person behind the dementia is seen. The motif of imaginative anticipation offers the possibility for a positive future that is not quite in view: looking forward to life in God's Kingdom that is here – and yet not quite here.

**Practical implications**

Having examined the was that a theology of care for those with dementia can enhance the ethos of care I now suggest that there are practical implications for MHA homes, and for carers be they Christian or not. These would suggest that in order to care for the whole person a relationship needs to be built that can enable carers to re-imagine the person through respect and mutuality.

Carers who recounted stories about the care they offered recognised the importance of the relationship that was created.  When offering a picture

of what it was like to feed someone one carer said, 'Some of them eat while you talk. If you just feed them and not talk they sometimes don't eat… It's having a connection with people, not being a machine' (H5c). Good care is giving attention to and making a connection with the person

To those who find that they are on the edge of society, as they live with a disease that makes them increasingly reliant on others, care does 'not depend so much on the kind of food, but how it is offered and received' (Anderson 2003:106).  It is the building of relationship that is vital in order to enable the person to find meaning and make sense of life: not simply a keeping safe. There is something about meeting with another person that calls some to act as moral agents and 'fill the gaps in the person's identity' (Hughes et al. 2005:27) as they re-imagine the person. Disability has been described as denoting an unusual relationship with God, the person with disability being either 'divinely blessed or damned' (Edmonds 2011:19), depending on how they are viewed by others. This encourages the idea that disability is either caused by sin, or that suffering is a way of purifying the soul as 'the grace of God has to be achieved or earned' (Edmonds 2011:165) or could even be withheld. In caring for the vulnerable in a world where disability and dementia spoil the search for perfection, which appears to be at the heart of our society, the work of the L'Arche community is seen as a 'prophetic voice from the wilderness' (Edmonds 2011:179) as it focuses on the individual and the nurturing of loving relationships. In the same way carers in MHA's dementia-care homes seek to foster the message of compassion and loving inclusion through respect and mutuality.

Through relationship carers enable a sense of personal identity to be sustained. Desmond Tutu quotes a Zulu saying; 'a person is a person through others' (Hughes et al. 2005:26), and it is this relational nature of human beings that emerges in the relational shape of God in whose image all are created. Meaning is contextualized through relationship and is rooted in practice and in 'doings and sayings' (Hughes et al. 2005:21).

This appears to be reasonable, but meaning-making seems to rely on the ability to 'do and say'. It is as this public space breaks down with dementia, because of the 'loss of the "shared world space", that meaning-making becomes difficult' (Hughes et al. 2005:23). It requires an effort to affirm the other, especially when often there will be little or no response. Imagination is needed in order to recognize the possibilities of this way of relating.

*The cost of caring*

It has been said before in this study that this way of caring places demands on both the organisation and the carers, and it has been recognised that if employees are not supported, but left to do as they will, then probably the clients will be too (Kitwood 1998). But if employees are supported and encouraged they will take their sense of well-being into their day-to-day work. Sheila Cassidy, speaking from her experience within the hospice movement, says of the cost of this care that it is,

> …a lavishing of precious resources, our precious ointment, on the handicapped, the insane, the rejected and the dying that most clearly reveals the love of Christ in our times. It is this gratuitous caring, this unilateral declaration of love, which proclaims the gospel (Cassidy 1988:2).

Carers recognise when the person is no longer able to remember and can fall into what some call the 'plague of Alzheimer's disease' (Kipnes 1999), that 'it is then when memory fails, we let love take its place' (H2a), and that 'just because they have dementia it doesn't mean that their life has ended… sometimes there is a glimpse of something… it could only be seconds' (H8c). By allowing the person to be themselves and by responding to their changes with love, attention and imagination carers are recognising that there is more to the person than the presenting face. They may not recognise that they are using their imagination, but they are using their instincts to add value to the care they offer as this type of care is more caught than taught.

When imaginative and respectful care fails to happen then the person with dementia is treated as less than human, and they and their loved ones suffer because being human demands that they are afforded respect and dignity. A section of Matthew 25 has been re-written by a carer, to illustrate how both the positive and the negative aspects of care are observed and felt.

> For I was waiting for my meal while the care staff were quietly feeding others and you picked up a spoon to help me eat; I was thirsty - I had spilled the juice earlier - and you took the beaker and helped me to hold it to my mouth; I was a new resident, unknown to you, yet you smiled the smile of peace and acceptance... For I was hungry for love and you showed me nothing of Christ in your brief and cursory call; I was thirsty for recognition as a disabled but nevertheless a human being made in God's image, crying out incoherently, and you turned a deaf ear to me; I was unknown to you and you looked at me strangely with a look of disapproval (Appendix vii).

The Christian commitment to love and care for those who the world sees as almost worthless offers a firm foundation for good person-centred care, as, without the loving imagination to see behind the presenting condition, there is little to elicit compassion.

# Conclusion: Imaginative anticipation through respect and mutuality

Having investigated the basis of the ethos of MHA and researched the attitudes of staff I have proposed a theology of care for those with dementia which is grounded in respect, a looking again at the person to imagine what new thing God is doing in their lives.

The insights from both carers and theology suggest that there is something fresh that can be offered to dementia care within MHA which is affirming to the person with dementia and rewarding for the carer who recognises caring for people with dementia, observed in giving of respect and mutuality, as a sign of the Kingdom.

Practical theology has offered me a model for reflecting on and evaluating the situation in which I am placed in the light of my theological understanding which I believe enables the presence of Christ to be made real in every situation.

My context has been that of dementia care within an organisation (MHA) which has values grounded in the Methodist Church. The dementia care offered within the homes is based on Tom Kitwood's person-centred care approach, but this care has lacked an underpinning of theology.

While I understood that the relationship between carers and those with dementia was important, the carers have shown me that this type of relationship is one that enables them to notice the little things and to take risks both in what they offer of themselves and in the care they imagine for the resident. To be able to recognise that the resident is changing and that they are in the process of becoming can change the way that care is offered. No longer is care a test to see how much more has been forgotten, but a sharing of the journey within a relationship based on respect.

Theological considerations of dementia have emphasised the idea that even when we forget, God does not forget us and that even in the last stages of the disease there is the breath of life: the Spirit of God within, affirming that person as being of value to God. However some have been unable to accept the idea that when all reason is gone there is anything of value left, suggesting that we remember for them, while others have used dementia as a teaching aid asking what we can learn from it about the value of life as seen through those who have no option but to live as they do.

A model of being human which suggests a different way to imagine the person is that of not simply seeing life as degeneration, but as one with future possibilities: that we might 'flourish' through the grace that dwells within us. These ideas seem to find links within Methodist emphases as they are currently being expressed, which encourage us to see God's work as having been started and still continuing.

The care that is offered by those who truly respect the person is of a different quality to those who see their task being to manage and contain the person. It demands a leap of the imagination to see the person as someone who could 'flourish', rather than someone who is diminishing. Imaginative anticipation invites carers to look again at the person and respect, '*respectare'* (Post 2005:223), them as unique individuals being called into the fullness of Christ.  By developing an understanding of Meininger's model of prophetic eschatology the person can be imagined as whole and their eventual fulfilment within the Kingdom can be anticipated and care for those with dementia can be a sign of the Kingdom.

At the time of submission my research was making an impact within MHA as it was being used in informing the assimilation of a group of homes into the organisation.

This study has implications within MHA and the wider Christian community as it offers a model of care that does not have direct financial cost implications and could have an influence on both those in care homes and those living in their own homes who are visited by people from the church. The model of care is based on respect, a 'looking again' at the person, envisaging their potential and imagining what future God has for them.

My work within MHA offers an opportunity to influence care within each home as I am responsible for the training and mentoring of chaplains and producing a training module on dementia-care, as well as offering insights to the organisation through the chaplaincy and spirituality department. By encouraging the chaplains to embody the model of care in this study I hope to encourage person-centred care that has a more positive and respectful basis.

Further research could be developed in the following areas:

- To explore the attitudes of staff who responded positively to the Christian values of MHA offering better care, while stating that they were non-Christian.
- To explore how the needs of those residents who are less likeable, and so difficult to build a relationship with, are cared for.
- To investigate the process of a group of homes joining MHA and what influence that had on the care.

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# Appendix i

**Participant Information sheet and Consent form**

**<u>Research dissertation: Participant Information sheet</u>**

You are being invited to take part in a research study as part of a student project. Before you decide it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully and discuss it with others if you wish.

If there is anything that is not clear or if you would like more information then please ask me. My details are at the bottom of this sheet.

Take time to decide whether or not you wish to take part.

Thank you for reading this

**Who will conduct the research?**
The research will be conducted by Margaret Goodall under the supervision of Professor Elaine Graham, Department of Religion and Theology, University of Chester, Parkgate Road, Chester. CH1 4BJ.

**Title of the Research**
The title of the research is 'How does the Christian ethos of MHA offer a model of care for those with dementia.'

**The aim of the research**
The aim of the research is to look at the practice of care offered in MHA homes to those with dementia and to explore what influence the Christian ethos has.

**Why have I been chosen?**
You have been chosen because you work in one of MHA's dementia care homes.

**What would I be asked to do if I took part?**
You will be asked to complete a questionnaire that asks about your background and your experience of the care of those with dementia.
You could also be asked to take part in a longer interview on the same subject that will be recorded.
All this would take place within your usual working time.

 It is hoped that you will find sharing what you do in the home affirming of your role in caring for people with dementia within MHA.

**What happens to the data collected?**
The questionnaires will be analysed statistically to give a snapshot of care. The conversations will be recorded and then written up to provide rich stories through which to better understand the care in the homes and how it affects residents with dementia and those who care for them.


**How is confidentiality maintained?**
The homes will be given alphabetical names, eg home 'A',  and staff who take part will be anonymised. Great care will be given to make sure that, as far as possible, homes and staff are not able to be identified. If stories shared are home-specific then details may be changed to make them less identifiable.

**What happens if I do not want to take part or if I change my mind?**
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

**What is the duration of the research?**
The questionnaire should take about five minutes to complete, and the conversations may take up to 40 minutes.

**Where will the research be conducted?**
All research will take place either in your place of work, or by phone if after transcribing the conversation a follow up conversation is necessary.
The questionnaires will be competed in a central place in the home, and the conversation in a quiet place nominated by the home.

**Will the outcomes of the research be published?**
Feedback will be offered to each home on the completion of the research and a copy of analysis made available.  The final research will be published in my thesis for Chester University and may also be used my MHA.

**Contact for further information**
If you would like more information please contact me via my email

## Consent Form for Participants Taking Part in Student Research Projects

**Title of Project :**
'How does the Christian ethos of MHA offer a model of care for those with dementia.'

**Name of Researcher:** Margaret A Goodall
University of Chester Department of Religion and Theology

## Participant (volunteer)
Please read this and if you are happy to proceed then sign at the bottom of the page.

The researcher has given me my own copy of the information sheet which I have read and understood. The information sheet explains the nature of the research and what I would be asked to do as a participant.I understand that the research is for a student project and that the confidentiality of the information I provide will be safeguarded unless subject to any legal requirements. She has discussed the content of the information sheet with me and given me the opportunity to ask questions about it.

I agree to take part as a participant in this research and I understand that I am free to withdraw at any time without giving any reason, and without any detriment to myself.

**Signed**

**……………………………………………………………………….**

**Date ……………………….......**

**Family Name BLOCK LETTERS**

 **…………………………………………..**

**Other Names BLOCK LETTERS**

**…………………………………………….**

## Researcher

I, the researcher, confirm that I have discussed with the participant the contents of the information sheet.

**Signed**
**………………………………………………………………………**
**Date ……………………………..**

## Appendix ii

### Questionnaires

**Level 1 questions:**

Personal information:

1 How long have you worked as a carer of older people?
2 How long have you worked for MHA?
3 Have you completed any dementia care training?
4 If so what was it?

Circle the most appropriate from below to the following questions

5 I attend church
Often/ sometimes/ occasionally/ rarely/ never

6 I think that I am :
Very spiritual/fairly spiritual/ don't know/ not very spiritual/not spiritual at all

Care in the home:

7 We think that the best way to care for people with dementia is to keep them clean and calm
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

8 We think that the best way to care for people with dementia is to remind them of the past
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

9 We think that the best way to care for people with dementia is to remind them that they live in the present
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

10 We think that the best way to care for people with dementia is not to remind them that they live in the present
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

11 We think that the best way to care for people with dementia is to help them be in touch with their feelings
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

12 We think that the Christian values of MHA helps us to offer better care to people with dementia.
Strongly agree/agree/ uncertain/ disagree/ strongly disagree

## Appendix iii

**Interview schedule**

**Level 2 questions:**

Three participants from each home are to be interviewed, including the manager

1   Can you describe a time when caring for someone with dementia worked really well here?

2   What do you think made that happen?

3   Can you describe a time when caring for someone with dementia did not go well here?

4   What do you think made that happen?

5   What type of care for people with dementia do you think that MHA (and this home) encourages?

6   What do you think this says about our view of people with dementia?

7   (shown the MHA values statement)
  Which three of these most influence the care of people with dementia in this home?

8   Is there anything about what goes on here that helps or hinders your care of those with dementia?

9   Is there anything else that you would like to say about working with people with dementia?

**Appendix iv**

<u>**Research Question Rationale**</u>

**What do MHA and the home believe about the care of people with dementia?**

Which homes am I going to use?
3 of 3 types of MHA specialist dementia care homes:
3 well established homes that have been MHA from their opening.
3 recently acquired with management services provided by MHA in the last 5 years.
3 that are MHA new build.

**Level 1: survey questionnaires**

These will be on a printed sheet.
All staff on duty that day at the home will be given a sheet and asked to complete.

The questions will ask for information or have a 5 point scale:
Agree strongly: agree: not certain: disagree: strongly disagree

Qs. 1-6 are to gather personal information about their experience of dementia; their experience of MHA; and their spiritual/religious framework
Qs. 7-11 are to gather information about what they consider to be best practice in care for those with dementia.
Q. 12 is to ask if they think the Christian ethos of MHA makes a difference to care.

**Level 2: interview questions**

The manager and two other staff members chosen by the manager will be interviewed.

The questions will allow members of staff to share their experiences and tell stories that offer a think description of what happens in the home

Browning's five dimensions (1996:105) will be used to analyse the interviews.
This is how they relate to the research questions:

1.      Visional:  the use of particular narratives, stories and metaphors that Shape the self understanding of the community (Qs. 1& 3).

2.      Obligational: how the organisation operates given the above (Qs. 2, 4 & 7).

3.    Tendency-need: theories about our human nature and how they are worked out in practice (Q. 6).

4.    Environmental-social: constraints of the working environment (Q. 5).

5.    Rule-role: how the above are put into practice (Q.8).

**Appendix**
**v**              **Results from Survey Questionnaire**
   **On exel**

Appendix V

Research Questions:  Level 1

1 how long have you worked as a carer of older people?
2 how long have you worked for MHA
3 have you completed any dementia care training?
4 what was it?

   *circle the most appropriate to the following questions*
5 I attend church:
            often      sometimes       occasionally      rarely    never

6 I think that I am:
            very spiritual      fairly spiritual      not very spiritual       not spiritual at all

7 We think that the best way to care for people with dementia is to make sure they are clean and calm
            strongly agree     agree         uncertain      disagree      strongly disagree

8 We think that the best way to care for people with dementia is to remind them that they live in the past
            strongly agree     agree         uncertain      disagree      strongly disagree

9 We think that the best way to care for people with dementia is to remind them that they live in the present
            strongly agree     agree         uncertain      disagree      strongly disagree

10 We think that the best way to care for people with dementia is not to remind them that they live in the present
            strongly agree     agree         uncertain      disagree      strongly disagree

11 We think that the best way to care for people with dementia is to help them be in touch with their feelings
            strongly agree     agree         uncertain      disagree      strongly disagree

12 We think that the Christian values of MHA helps us to offer better care to people with dementia

strongly agree     agree          uncertain        disagree        strongly disagree

**Appendix VI**        **Results from Survey Questionnaire   Group 1 homes**

**MHA Homes by code letter**

| H1 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 0 | 0 | 1 | 6 | 3 | 10 |
| Q6 | 0 | 1 | 2 | 4 | 3 | 10 |
| Q7 | 0 | 2 | 7 | 0 | 1 | 10 |
| Q8 | 1 | 0 | 7 | 1 | 1 | 10 |
| Q9 | 0 | 2 | 6 | 2 | 0 | 10 |
| Q10 | 0 | 3 | 5 | 2 | 0 | 10 |
| Q11 | 4 | 5 | 1 | 0 | 0 | 10 |
| Q12 | 4 | 6 | 0 | 0 | 0 | 10 |

**Group 1: well established homes**

| Group 1 | 1 | 2 | 3 | 4 | 5 | Cohort |
|---------|---|---|---|---|---|--------|
| Q5 | 0 | 2 | 6 | 20 | 14 | 42 |
| Q6 | 1 | 15 | 7 | 13 | 6 | 42 |
| Q7 | 7 | 12 | 17 | 4 | 2 | 42 |
| Q8 | 1 | 1 | 21 | 5 | 14 | 42 |
| Q9 | 0 | 13 | 20 | 5 | 4 | 42 |
| Q10 | 0 | 9 | 21 | 8 | 4 | 42 |
| Q11 | 11 | 27 | 4 | 0 | 0 | 42 |
| Q12 | 12 | 24 | 1 | 4 | 1 | 42 |

| H2 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 0 | 0 | 3 | 5 | 4 | 12 |
| Q6 | 1 | 5 | 3 | 1 | 2 | 12 |
| Q7 | 1 | 2 | 7 | 1 | 1 | 12 |
| Q8 | 0 | 0 | 9 | 0 | 3 | 12 |
| Q9 | 0 | 4 | 7 | 0 | 1 | 12 |
| Q10 | 0 | 1 | 7 | 0 | 4 | 12 |
| Q11 | 3 | 9 | 0 | 0 | 0 | 12 |
| Q12 | 6 | 6 | 0 | 0 | 0 | 12 |

**Care experience**

| H1 | 1-5yrs | 5-10yrs | over 10 |
|----|--------|---------|---------|
| Q1 experience | 2 | 3 | 5 |
| Q2 MHA exp | 3 | 4 | 3 |
| H2 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 4 | 7 | 1 |
| A2 MHA exp | 8 | 2 | 2 |
| H3 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 6 | 3 | 11 |
| Q2 MHA exp | 9 | 10 | 1 |

| H3 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 0 | 2 | 2 | 9 | 7 | 20 |
| Q6 | 0 | 9 | 2 | 8 | 1 | 20 |
| Q7 | 6 | 8 | 3 | 3 | 0 | 20 |
| Q8 | 0 | 1 | 5 | 4 | 10 | 20 |
| Q9 | 0 | 7 | 7 | 3 | 3 | 20 |
| Q10 | 0 | 5 | 9 | 6 | 0 | 20 |
| Q11 | 4 | 13 | 3 | 0 | 0 | 20 |
| Q12 | 2 | 12 | 1 | 4 | 1 | 20 |

**Results from Survey Questionnaire**    **Group 2 homes**

**MHA Homes by code letter**    **Group 2:Recently Acquired Homes**

| H4 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 2 | 2 | 1 | 4 | 6 | 15 |
| Q6 | 2 | 4 | 4 | 3 | 2 | 15 |
| Q7 | 7 | 3 | 2 | 2 | 1 | 15 |
| Q8 | 0 | 0 | 2 | 11 | 2 | 15 |
| Q9 | 3 | 7 | 3 | 2 | 0 | 15 |
| Q10 | 0 | 0 | 5 | 8 | 2 | 15 |
| Q11 | 4 | 10 | 1 | 0 | 0 | 15 |
| Q12 | 1 | 8 | 3 | 3 | 0 | 15 |

| Group 2 | 1 | 2 | 3 | 4 | 5 | Cohort |
|---------|---|---|---|---|---|--------|
| Q5 | 7 | 4 | 3 | 6 | 10 | 30 |
| Q6 | 9 | 10 | 4 | 4 | 3 | 30 |
| Q7 | 12 | 8 | 3 | 5 | 2 | 30 |
| Q8 | 0 | 3 | 4 | 16 | 7 | 30 |
| Q9 | 3 | 8 | 6 | 11 | 2 | 30 |
| Q10 | 0 | 9 | 6 | 12 | 3 | 30 |
| Q11 | 8 | 20 | 2 | 0 | 0 | 30 |
| Q12 | 5 | 16 | 6 | 3 | 0 | 30 |

| H5 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 1 | 2 | 0 | 2 | 2 | 7 |
| Q6 | 2 | 3 | 0 | 1 | 1 | 7 |
| Q7 | 0 | 2 | 1 | 3 | 1 | 7 |
| Q8 | 0 | 1 | 1 | 1 | 4 | 7 |
| Q9 | 0 | 1 | 2 | 3 | 1 | 7 |
| Q10 | 0 | 3 | 1 | 2 | 1 | 7 |
| Q11 | 3 | 3 | 1 | 0 | 0 | 7 |
| Q12 | 3 | 2 | 2 | 0 | 0 | 7 |

**Care experience**

| H4 | 1-5yrs | 5-10yrs | over 10 |
|----|--------|---------|---------|
| Q1 Experience | 4 | 5 | 6 |
| Q2 MHA exp | 13 | 2 | 0 |
| H5 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 3 | 2 | 2 |
| Q2 MHA exp | 5 | 2 | 0 |
| H6 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 1 | 2 | 5 |
| Q2 MHA exp | 8 | 0 | 0 |

| H6 | 1 | 2 | 3 | 4 | 5 | Cohort |
|----|---|---|---|---|---|--------|
| Q5 | 4 | 0 | 2 | 0 | 2 | 8 |
| Q6 | 5 | 3 | 0 | 0 | 0 | 8 |
| Q7 | 5 | 3 | 0 | 0 | 0 | 8 |
| Q8 | 0 | 2 | 1 | 4 | 1 | 8 |
| Q9 | 0 | 0 | 1 | 6 | 1 | 8 |
| Q10 | 0 | 6 | 0 | 2 | 0 | 8 |
| Q11 | 1 | 7 | 0 | 0 | 0 | 8 |
| Q12 | 1 | 6 | 1 | 0 | 0 | 8 |

**Results from Survey Questionnaire**          **Group 3 homes**

| H7 | 1 | 2 | 3 | 4 | 5 | Cohort |
|---|---|---|---|---|---|---|
| Q5 | 1 | 9 | 4 | 4 | 2 | 20 |
| Q6 | 3 | 14 | 2 | 1 | 0 | 20 |
| Q7 | 7 | 3 | 4 | 5 | 1 | 20 |
| Q8 | 1 | 3 | 4 | 9 | 3 | 20 |
| Q9 | 2 | 7 | 1 | 8 | 2 | 20 |
| Q10 | 3 | 4 | 3 | 9 | 1 | 20 |
| Q11 | 10 | 9 | 0 | 1 | 0 | 20 |
| Q12 | 6 | 12 | 2 | 0 | 0 | 20 |

| Group 3:Recently Opened Homes | | | | | | |
|---|---|---|---|---|---|---|
| Group 3 | 1 | 2 | 3 | 4 | 5 | Cohort |
| Q5 | 3 | 13 | 5 | 13 | 11 | 45 |
| Q6 | 5 | 28 | 3 | 6 | 3 | 45 |
| Q7 | 13 | 13 | 6 | 10 | 3 | 45 |
| Q8 | 1 | 5 | 6 | 19 | 14 | 45 |
| Q9 | 4 | 14 | 7 | 14 | 6 | 45 |
| Q10 | 5 | 6 | 8 | 21 | 5 | 45 |
| Q11 | 25 | 16 | 1 | 2 | 1 | 45 |
| Q12 | 15 | 20 | 9 | 1 | 0 | 45 |

| H8 | 1 | 2 | 3 | 4 | 5 | Cohort |
|---|---|---|---|---|---|---|
| Q5 | 1 | 2 | 0 | 4 | 3 | 10 |
| Q6 | 0 | 7 | 1 | 2 | 0 | 10 |
| Q7 | 4 | 4 | 0 | 2 | 0 | 10 |
| Q8 | 0 | 2 | 0 | 3 | 5 | 10 |
| Q9 | 0 | 6 | 0 | 3 | 1 | 10 |
| Q10 | 0 | 1 | 1 | 6 | 2 | 10 |
| Q11 | 8 | 2 | 0 | 0 | 0 | 10 |
| Q12 | 6 | 2 | 2 | 0 | 0 | 10 |

| Care experience | | | |
|---|---|---|---|
| H7 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 11 | 3 | 3 |
| Q2 MHA exp | 18 | 1 | 1 |
| H8 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 4 | 3 | 3 |
| Q2 MHA exp | 10 | 0 | 0 |
| H9 | 1-5yrs | 5-10yrs | over 10 |
| Q1 Experience | 6 | 4 | 5 |
| Q2 MHA exp | 15 | 0 | 0 |

| H9 | 1 | 2 | 3 | 4 | 5 | Cohort |
|---|---|---|---|---|---|---|
| Q5 | 1 | 2 | 1 | 5 | 6 | 15 |
| Q6 | 2 | 7 | 0 | 3 | 3 | 15 |
| Q7 | 2 | 6 | 2 | 3 | 2 | 15 |
| Q8 | 0 | 0 | 2 | 7 | 6 | 15 |
| Q9 | 2 | 1 | 6 | 3 | 3 | 15 |
| Q10 | 2 | 1 | 4 | 6 | 2 | 15 |
| Q11 | 7 | 5 | 1 | 1 | 1 | 15 |
| Q12 | 3 | 6 | 5 | 1 | 0 | 15 |

I

**MHA's homes and schemes 2011**

| | | | | |
|---|---|---|---|---|
| SOU | Connell Court | 22 Weld Road | Southport | Merseyside |
| BRY | Epworth Grange | 1 Chirmside Street | Bury | Lancashire |
| MUS | The Meadow | Meadow Drive | Muswell Hill | London |
| MIL | Taransay Court | Liddesdale Square | Milton | Glasgow |
| BAN | West Court | 45 West Street | Banbury | Oxon |
| FOL | Grace Court | Grace Hill | Folkestone | Kent |
| SWI | Epworth Court | Bath Road | Swindon | Wilts |
| POO | Maidment Court | 47 Parkstone Road | Poole | Dorset |
| BAT | Stratton House | 16 Park Lane | Bath | North Somerset |
| MNO | Church Court | Church Lane | Midsomer Norton | Bath |
| MAR | Kingswood Park | Kingswood Road | March | Cambs |
| EXM | Moreton | 13 Drakes Avenue | Exmouth | Devon |
| MOA | Moor Allerton | Cranmer Close | Moor Allerton | Leeds |
| HUD | Bradley Court | 42 Keldregate | Huddersfield | Yorkshire |
| WIS | Edina Court | 55 Harecroft Road | Wisbech | Cambs |
| LYT | Starr Hills | Andsdell Road South | Lytham St Annes | Lancashire |
| SOU | Connell Court | 22 Weld Road | Southport | Merseyside |
| | Adlington House | Abbey Road | Rhos-on-Sea | Conwy |
| STO | Claybourne | Turnhurst Road | Chell | Stoke on Trent |
| FXG | Foxton Grange | 571 Gipsy Lane | Leicester | |
| LEI | Aigburth | 21 Manor Road | Oadby | Leicester |
| EPH | The Hawthorns | Naylor Crescent | Overpool | Ellesmere Port |
| NOR | Cromwell House | Cecil Road | Norwich | Norfolk |
| RUS | Rushden Park | 85 Melloway Road | Rushden | Northants |
| TYG | Ty Gwyn | 21-23 Stanwell Road | Penarth | South Glamorgan |
| WEQ | Weston /Queensway House | Weston Road | Stafford | Staffs |
| MHP | The Paddock | Meadow Drive | Muswell Hill | London |
| FAL | Langholme | Arwenack Avenue | Falmouth | Cornwall |
| HIU | Archers Court | Elmside Walk | Hitchin | Herts |
| CLA | Rowanberries | 3 Baldwin Lane | Clayton Heights | Bradford |
| HUD | Bradley Court | 42 Keldregate | Huddersfield | Yorkshire |
| LIN | Stones Place | Skellingthorpe Road | Lincoln | |

| | | | | |
|---|---|---|---|---|
| PEN | Morel Court | Raisdale Road | Penarth | South Glamorgan |
| DAV | Davids House | Pool Road | Harrow | Middlesex |
| BOT | Queens Court | 2 Downing Close | Bottisham | Cambs |
| PGN | Westbury Grange | Westbury Lane | Newport Pagnell | Bucks |
| HIT | Elmside | Elmside Walk | Hitchin | Herts |
| | Heald Farm Court | Sturgess Street | Newton Le Willows | St Helens |
| STH | Portland House | Clarence Street | Newton Le Willows | St Helens |
| BOG | Greenways | 227 Hawthorn Road | Bognor Regis | West Sussex |
| BOL | Beechville | 653 Chorley New Road | Lostock | Bolton |
| IPS | Norwood | 14 Park Road | Ipswich | Suffolk |
| ILK | Glen Rosa | 24 Grove Road | Ilkley | West Yorkshire |
| MUS | The Meadow | Meadow Drive | Muswell Hill | London |
| YAT | Derham Court | High Street | Yatton | Devon |
| AUC | Courtyard | New Trows Road | Lesmahagow | Lanarkshire |
| BOW | Handsworth | West Road | Bowdon | Altrincham |
| CLP | Ash Court | 155c Broomwood Road | Clapham | London |
| BOW | Handsworth | West Road | Bowdon | Altrincham |
| GLA | Willcox Close | Glastonbury | Bath | Somerset |
| HAR | Berwick Grange | 14 Wetherby Road | Harrogate | North Yorkshire |
| LIV | Fulwood Park | 19 Fulwood Park | Aigburth | Liverpool |
| BOT | Queens Court | 2 Downing Close | Bottisham | Cambs |
| LET | Trembaths | Talbot Way | Norton | Letchworth |
| BDF | Anjulita Court | Bramley Way | Bedford | |
| EXN | Exning Court | Cotton End Road | Exning | Suffolk |
| SAW | Orchard House | 191 High Street | Sawston | Cambs |
| SAX | Bircham House | High Street | Sawston | Cambs |
| STR | Cedar Lawn | Cedar Close | Welcombe Road | Stratford upon Avon |
| NEW | Pilgrims' Court | Eslington Terrace | Jesmond | Newcastle upon Tyne |
| ALH | Allesley Hall | Allesley Hall Drive | Allesley | Coventry |
| LEA | Homewood | 19 Kenilworth Road | Leamington Spa | Warwickshire |
| NUN | Aldersgate | Rose Lane | Nuneaton | Warwickshire |
| KEN | Kenbrook | 100 Forty Avenue | Wembley | Middlesex |
| LAW | Lawnfield House | Coverdale Road | Willesden | London |
| RIV | Riverview Lodge | Birchen Grove | Kingsbury | London |
| ABE | Hafan y Waun | Waun Fawr | | Aberystwyth |
| BRO | Brockworth House | Mill Lane | Brockworth | Gloucester |
| COV | Charnwood House | 77a Beake Avenue | Radford | Coventry |

| | | | |
|-----|---------------------|-----------------------|-------------------|-------------------------|
| | Ladyslaude Court | | | Bedford |
| EPM | Mayfields | Naylor Crescent | Overpool | Ellesmere Port |
| EPN | Naylor Court | Rossmore Rs West | | Ellesmere Port |
| CAR | The Homestead | 24 Flax Crescent | Carterton | Brize Norton, Oxfordshi |
| ARB | Gowan Park | Gowan Street | Arbroath | Angus |
| BLA | Pennystone Court | Handsworth Road | Blackpool | Lancashire |
| FOL | Grace Court | Grace Hill | Folkestone | Kent |
| RPL | Maple Leaf House | Kirk Close | Ripley | Derbyshire |
| COL | Coed Craig | Tan Y Bryn Road | Rhos on Sea | Colwyn Bay |
| LEE | Tranquility Court | 6 Tranquility Avenue | Crossgates | Leeds |
| WHO | Bridge Court | 43 Moathouse Lane West | Wolverhampton | |
| WLV | Waterside House | 41 Moathouse Lane West | Wolverhampton | |
| SHE | Southcroft | 33 Psalter Lane | Sheffield | |
| SHI | Hall Grange | Shirley Church Road | Shirley | Croydon |
| WAL | Ryelands | 15 Beddington Gardens | Wallington | Surrey |
| BAW | Walcot Court | Walcot Gate | Bath | |
| NOT | Queenswood | Cliffgrove Avenue | Beeston | Nottingham |
| OLD | Avonleigh Gardens | Clyde Street | Oldham | Lancashire |
| YOR | Field Court | Hempland Lane | Heworth | York |
| HCL | Hartcliffe | 15 Murford Avenue | Hartcliffe | Bristol |
| CRA | Harwood Court | Highburn | Cramlington | Northumberland |
| WOK | Woodbank | Holly Bank Road | Woking | Surrey |
| SCA | Priceholme | Givendale Road | Scarborough | North Yorks |
| HAT | Moorland House | Station Road | Hathersage | Hope Valley |
| LET | Trembaths | Talbot Way | Norton | Letchworth |
| GUI | Hinton Court | Union Street | Guisborough | Cleveland |
| DOR | Fairthorn | Dore | Sheffield | Yorkshire |
| AUG | Aughton Park | Aughton Park Drive | Aughton | Ormskirk |
| BUR | The Martins | Vinefields | Bury St Edmunds | Suffolk |
| AUC | Nethanvale | New Trows Road | Lesmahagow | Lanarkshire |
| HUL | Willersley House | 85 Main Street | Willerby | Hull |
| EKI | St Andrew's Court | Sycamore Crescent | Green Hills | East Kilbride |
| ABB | Abbey Park | Humber Road | Coventry | |
| AUC | Bankhouse | 62-64 Abbeygreen | Lesmahagow | Lanarkshire |
| HER | Herondale | 175 Yardley Green Rd | Birmingham | |
| KGF | Kingfisher House | 171 Yardley Green Rd | Birmingham | |

| BEX | Richmond | Collington Lane East | Bexhill-on-Sea | East Sussex |
| WHI | Bradbury Grange | 74 Canterbury Road | Whitstable | Whitstable |
| BAR | Norah Bellot Court | Vicarage Street | Barnstaple | North Devon |
| AUC | Lower Johnshill | New Trows Road | Lesmahagow | Lanarkshire |
| DOV | Alexandra House | Marine Parade | Dovercourt | Harwich |
| CHE | Callin Court | Grey Friars | Chester | |
| GRA | Wesley Court | 13 Royston Mains Place | Granton | Edinburgh |
| BHH | Briar Hill House | 51 Attlee Crescent | Rugeley | Staffs |
| SWD | Stanton Lodge | Kingsdown Road | Swindon | Wilts |
| SWN | Fitzwarren House | Kingsdown Rd | Swindon | Wiltshire |
| PNR | Woodlands | Bridge Lane | Penrith | Cumbria |
| WOL | Engelberg | Ash Hill | Compton | Wolverhampton |

**Appendix vii**

## 'A subversive re-writing of Matthew 25'

"When the Son of Man comes in his glory, and all the angels with him, he will sit on his throne in heavenly glory. All the nations will be gathered before him, and he will separate the people one from another as a shepherd separates the sheep from the goats. He will put the sheep on his right and the goats on his left.

"Then the King will say to those on his right, 'Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. *For I was waiting for my meal while the care staff were quietly feeding others and you picked up a spoon to help me eat; I was thirsty – I had spilled the juice earlier - and you took the beaker and helped me to hold it to my mouth; I was a new resident, unknown to you, yet you smiled the smile of peace and acceptance; I had pulled my skirt up above my knees and you helped me preserve my dignity by gently pulling it down and straightening it around my waist; I was shouting for help across the room and you came and touched my hand and blessed me; I felt I was in a prison – the locked doors, a final barrier to my freedom, and you came to reassure me that this was my home where others worked to help me, not their workplace where I was an inconvenient intrusion; I was confused and stressed and you played music to me, you read to me, you showed me pictures and laughed with me.'*
"Then the righteous will answer him, *'Lord, when did we see you in such a state of distress and respond in practical compassion?'*
"The King will reply, 'I tell you the truth, whatever you did for one of the least of these *broken people* of mine, you did for me.'
"Then he will say to those on his left, 'Depart from me, you who are cursed, into the eternal fire prepared for the devil and his angels. *For I was hungry for love and you showed me nothing of Christ in your brief and cursory call; I was thirsty for recognition as a disabled but nevertheless a human being made in God's image, crying out incoherently, and you turned a deaf ear to me; I was unknown to you and you looked at me strangely with a look of disapproval; I felt naked without any of the normal graces to cover my shame, yet you criticized me before others for being an objectionable old woman; I was sick in mind and soul but you gave me no comfort; I was imprisoned within my troubled imagination and you piously ignored me and failed to come and visit me. I was lonely and distressed, but you refused to comfort me, to use the gifts God had given to you for my benefit and the benefit of others – we, the poor in spirit.* [44]"They also will answer, 'Lord, when did we see you in such a state of distress and fail to respond in practical compassion?'*
[45]"He will reply, 'I tell you the truth, whatever you did not do for one of the least of these, you did not do for me.'

(A loving carer 2009)