WHERE IS THE PERSON WITH DEMENTIA?

- A THEOLOGICAL REFLECTION

by

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A dissertation submitted to
The University of Birmingham
for the Degree of
MASTER OF ARTS

The Queen’s Foundation
for Ecumenical Theological Education
September 2008
Abstract

This dissertation presents a dialogue between the literature on dementia and personhood, and arises out of the writer’s theological reflections on experiences of dementia in his own family and in encounters during his pastoral ministry. The effects of dementia, both on the person living with the condition, and on his or her family are discussed, with particular reference to difficulties in communication and loss of memory. Over-reliance on the organic model of dementia care is critiqued in the light of a person-centred and personhood-respecting approach.

An inquiry is made into ‘what it means to be a person’ from philosophical and theological approaches, including the inheritance of thought within the Judeo-Christian tradition. It is concluded that being a person derives from being made in the image of God (who has been made known in and through Jesus Christ) and being made for relationship with God.

Conclusions are presented concerning a person’s ‘interior world;’ the dominance of words over the experience of Christ is critiqued; some implications for the Church in determining its priorities for pastoral care and the urgent need for the Church to show God’s love to people living with dementia, and those who care for them is emphasised.

Dedication

I dedicate this present work to the memory of my grandfathers, Lawrence Frape and Frederick Waters, and to my father Ronald Waters, all of whom travelled into the ‘strange land’ which is dementia.

Acknowledgements

I wish to acknowledge the encouragement and guidance I have received from my supervisor, the Revd Dr. James Woodward; also the contribution from staff at the Queen’s Foundation for Ecumenical Theological Education, Birmingham. I thank Dr. David Smart for his critique (from the perspective of a medical doctor) of an earlier draft of the dissertation and alerting me to various possibilities in the discussion. My thanks go to Pam Shannon for giving me the opportunity to see person-centred dementia care in action. My thinking has been enriched by meeting adults with severe mental impairment, and those who care for them who attend our Church luncheon club.

I am grateful to my vicar, Canon David Bird, my staff colleagues and many members of the congregation at St. Giles Church, Northampton for bearing much of my ministry work-load during my study time.

I thank those in my congregation who have given freely of their time to share their experiences of dementia. The insights and challenges I experience through visiting older members of my congregation, for whom the question, ‘Where is the person with dementia,’ arises daily have been invaluable in shaping my thinking.

I thank my wife Louise for her patience and love throughout the process of researching and writing this dissertation.
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BIBLIOGRAPHY
INTRODUCTION

1.1.1 The scope of the dissertation
This work emerges from my personal experience and ministry context as an ordained Anglican minister employed to lead the ministry of his local Church with older people. I recognise that to have broadened the inquiry to include the attitudes of people who do not profess faith in Christ, or who are followers of other religions would have enriched the discussion, and to have recorded the attitudes of a scientifically reliable sample of people - family members and professionals - who care for those living with dementia would have strengthened the research aspects of the study. Similarly, it is recognised that there are significant differences between the types of dementia and how they cause personality change, however I felt this discussion was beyond the scope of the present work.

1.1.2 Approach to the topic
I rely on the theological foundations of belief in the creator God who has been made known in and through Jesus Christ; the principle of the trustworthiness of the Bible as the ultimate reference point for all our discussions. I address the question, ‘Where is the person with dementia,’ - and to do this I make use of my reflections on the experience of caring for members of my family living with dementia, and pastoral encounters in my ministry. This is a work of applied theology, so insights from ancient and more recent sources of theology on the nature of what it means to be a person have informed and shaped the debate. These ‘primary sources’ have been accessed through reading summaries in several theological dictionaries, but I recognise that to have read these works ‘first hand’ would have been desirable. Throughout the work, I have attempted to use the issues which have arisen in my reflections to engage with psychological and other perspectives on dementia in the literature. My reading of more descriptive literature on dementia and its diagnosis has clarified my thinking on the topic.

1.2 STORIES:

1.2.1 How we remember a person
Our memories of people are partial, are subject to interpretation and reinterpretation - if we have judged that a person was kind and loving, we interpret his or her actions in the light of this overarching 'sense' of them as a person. Frankly, we attempt to perceive from the outside what we can only really guess at – the inner workings of a person’s mind. At one level we tend to retain information about more easily observable phenomena – for some subjects this may be by appearance or words which have been spoken, but at heart we tell and remember stories most of all and can remember the pattern of someone’s life through the medium of their life- narrative. Recorded ‘facts’ such as employment record, educational history and life-events provide milestones for our memories, but more importantly, though perhaps more subtly, we have an interpretative framework around which we ‘hang’ our recollections. In recalling the stories of my grandfathers and my father, I am acutely aware of the partial nature of my own memories; I am the first to recognise that I am ‘remembering at a distance,’ and have conflated my parents’ and other people’s reflections with my own. There are many things I never knew about my grandfathers and my father, but I have focussed in this present work on matters which are, I feel, germane to the discussion of the mental and physical diminishment which accompanies dementias.
1.2.2 My Grandpa – my mother’s father

Lawrence Frape was born in 1892, the youngest of eight surviving children, and worked for over 50 years at the same company, English Electric in Stafford. He served as a sergeant in the trenches of Northern France and Belgium during the First World War, fought at the battle of the Somme, and very nearly died following a poison gas attack. This kind and gentle man never told the story of how he had been awarded the Military Medal, but spoke only of his deep admiration of the selflessness of the Pacifists he encountered who served in the trenches as unarmed medical personnel. Tragically and perhaps typically for families of that generation, one of his brothers died in the conflict and another was severely wounded.

My grandfather eventually became senior test engineer at English Electric, a manufacturer of electricity generation and distribution equipment, which was used around the world: my grandfather travelled to Canada and Portugal to oversee and test the installation of hydroelectricity generation plant. He could perform calculations to many decimal points accuracy using his slide rule in one hand whilst holding the telephone in the other. In the Second World War he was an ARP (air-raid) warden. Following his retirement from English Electric he enjoyed travelling with my grandmother.

But this was not the grandfather I remember. To me, he always seemed vague, and needed time to search for the right word. I have early recollections of him as an increasingly stooped man who seemed very clever but assumed a much higher mathematical and scientific ability in me than was reasonable for a primary school child! He taught me how to draw perfect freehand circles and was the one who found me when I got lost in a department store in Brighton, but he didn’t seem to connect with my brother and me in the same way as my grandmother did with us. I think my own father realised things weren’t right when he discovered that Grandpa had tried to rewire his garage with thin bell wire, rather than the proper cable, and when Grandpa struggled to understand the function of the buttons on the new radio we had purchased for him. I felt upset and annoyed that an electrical engineer should have been brought to this level of humiliating incompetence by what was termed in the 1970’s ‘senile dementia’. I remember Grandpa seemed happiest when he was doing the washing up, but I recall his need to rewash the plates and cups (a feature of dementia I now know is called perseveration). A hernia operation exacerbated the decline so he became a shrunken shadow of his former self both physically and mentally - we suspected the effects of the anaesthetic and a lack of oxygen. My Grandpa became more and more determined, and sometimes went off on his own and couldn’t find his way back home causing great distress to those around him.

My aunt and uncle and my parents took it in turns to have my grandparents come and stay, when my Grandmother could no longer care for my grandfather alone. I was easily embarrassed as a young teenager, so my discomfort was heightened by my grandfather’s difficulties. When my friend Richard came round and teased me about why we had large labels on all the doors in our house with ‘kitchen’, ‘bathroom’, ‘bedroom’ etc. written on them, I made a joke, and tried to be cool about it. I wish I had had the courage to say the truth that my grandfather just needed a bit of help finding his way around.1 I felt hot with discomfort when people stared at me as I held my grandfather’s hand in West Malling High School.

1 Tom Smith emphasises the need to improve the person’s environment by, ‘Making familiar and necessary things speak to them.’ Tom Smith Living with Alzheimer’s Disease (London, Sheldon Press, 2000) p 88.
Street just to give him reassurance, and stop him wandering off – how I wish I had confronted those who stared and confidently explained that my grandfather was like a little child who needed to know he was loved and cared for.

It first dawned on me that Grandpa no longer remembered who the family members were when I heard him complaining about the ‘hotel staff’ (that is my brother and me) to the ‘hotel manager’ (my father). Shortly after that he no longer recognised my mother, and cruellest of all he objected to the presence of ‘that woman in my room’ (that is, my grandmother, his wife of nearly 60 years.) My Grandpa wasn’t drifting away, he was paddling furiously!

At the end of his life, I just remember the ‘shell’ of the man who resembled my Grandpa, but who wasn’t. My mother asked our neighbour Alys, a Christian, ‘Where do you think my father has gone?’ Alys didn’t give an answer, but I wanted an answer. My mother’s question, and Alys’s silence have stayed with me for the last 30 years.

1.2.3 My Grandad – my father’s father

Frederick Waters died 18 years ago – he had Parkinson’s disease, a form of dementia and his physical and mental capacity was severely diminished. He just sat in his chair and gradually drifted away. I watched the decay of the life that that once was and I heard ghastly echoes of what my other grandfather had endured over a decade before. My strong reaction (now as an adult) made me realise how deeply my other grandfather’s dementia had impacted on my young life. Selfishly, I’m afraid, I was worried that my father would become like his father, and that too I would follow suit.

Around the time of my paternal grandfather’s death I recall seeing on a television documentary the scanner image of a demented brain, and what was revealed under the microscope after death. I was struck in particular by the gaping fluid-filled spaces where brain tissue had once been and separately, what seemed like tangled knots under the microscope. In those moments, when I saw the physical changes wrought by dementia, I admit I felt a tremendous sense of relief: I now had a scientific explanation for my grandfathers’ aberrant behaviour. The correlation between the changes in the structure of the brain and dementia was in fact tremendously releasing, and I found that I could forgive the aggressive defiance shown by one grandfather and the pitiable docility of the other at the end of their lives. The deterioration they had both suffered was obviously the consequence of the destruction of substantial areas in their brains – they were not being awkward on purpose! It was plain to me that the organ responsible for producing the chemical and electrical impulses which

2 ‘Consequently, the cognitive deterioration that dementia causes means that the person with dementia will, at some stage in their illness, begin to react to the world around them as if it were a new, foreign, unrecognised world, peopled by strange, unfamiliar beings.’ Richard Cheston & Michael Bender Understanding Dementia: the man with the worried eyes (London and Philadelphia: Jessica Kingsley, 1999) p. 141

I recall here what my grandfather ‘lost’ as his dementia progressed: recognition of family members; memory of place and objects; knowledge of the date and time; ability to remember the connection between objects; lack of understanding where different rooms were; inability to express or communicate needs, difficulties; changes in emotional states – anger, frustration, aggression; loss of constraint – leading to socially unacceptable behaviour; changes in temperament and responsiveness to outside stimuli; changes in behaviour patterns; loss of ability in physical, artistic, creative, ability to consider abstract thoughts or concepts; erosion of the ability to communicate; loss of verbal and mental reasoning.
govern temperament, behaviour, communication and control of the body had ‘malfunctioned’ in the cases of my grandfathers. The reader will deduce that my current thinking is to value additional insights to the ‘organic,’ model of understanding dementia, as helpful as it was for me at the time in understanding what had happened to my grandfathers.

1.2.4 My Father

My father worked in the electronics industry from the earliest days of semiconductors devices; he loved making things out of wood, was a skilled watercolourist and draughtsman, and produced witty cartoons full of exquisite detail. He had a phenomenal memory for facts and figures, and wrote in an elegant copperplate. Near the end of his life he couldn’t remember my daughter’s name, and could barely write his own. He had been diagnosed with progressive supra-nuclear palsy: brain scans revealed infarcts which correlated with the step-wise deterioration of his mental and physical ability. I was deeply distressed – I had always relied on him for advice, but now he often spoke nonsense. I deeply regret that I argued with my dad, using the logic and commonsense he had so gently imparted to me, telling him in no uncertain terms his delusions were just not true. My training as a Christian pastor should have led me to listen properly to him, and give him the reassurance he needed, but my own feelings of despair got in the way - the problem was not just his but mine as well. Our mutual incapacity produced a destructive resonance. In the literature I note the pain of daughters who are like their mothers, and sons who are like their fathers, all tinged with the fear that we might one day be like our parents:

‘One of the areas of behaviour that people find difficult is getting old and dying. We are frightened of ceasing to exist. Ceasing to exist whilst still alive is even more painful to contemplate. Yet it is the term ‘living death’ that Woods (1989) used so evocatively to describe dementia. Our society puts great emphasis on thinking quickly and effectively. People who cannot do this frighten us, perhaps because one day we might be like them. So people with dementia certainly do things that we find hard to handle.’

On reflection I was trying to haul my father back from disappearing over the horizon into dementia. The literature contains many accounts of the distress dementia causes to family members, and the difficulty family members have in dealing with the changes the condition brings about. Whilst staying in Sevenoaks hospital, my father had fallen and broken his collarbone – it was obvious that the staff had neglected him. The senior nurse dismissed my polite inquiry into how this could have happened, saying, ‘People like that don’t know what they are doing.’ I found this deeply hurtful, and I felt powerless to challenge her because my father was so vulnerable - I didn’t want her or her colleagues to bully my dad. I also felt angry that my father’s diminishment made the nurse devalue him as a person - in I wish I had asked the nurse what on earth she was thinking of when she said, ‘People like that,’ – why couldn’t she stop and see who my father was, or rather who he had been? My father died six months later, having just moved into a private care home. I felt his death was a merciful release from the worst that dementia could inflict upon him.

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3 Richard Cheston & Michael Bender Understanding Dementia: the man with the worried eyes (London and Philadelphia: Jessica Kingsley, 1999) p 49.
This dissertation has been prompted by my desire to engage theologically as I ask ‘Where is the person with dementia?’ I want to work on behalf of ‘people like that’ so they are afforded the full dignity of the human individual. The Church of Christ is called to minister with and among people living with dementia with confidence in a loving God.

1.3 THE ‘STRANGE’ LAND OF DEMENTIA

1.3.1 The history of the study of dementia

Standard accounts of the history of investigations into dementia start with the work of Alois Alzheimer in 1906. Alzheimer is credited with correlating the presence of plaques and fibrous tangles in the brain of a patient diagnosed with pre-senile dementia at the age of 51 (and who died at 55) – although these features had been already been identified as early as the 1880s in other brain tissue specimens and were considered highly likely to be associated with dementia. A century ago the new technology (inspecting prepared brain tissue samples under the microscope –the science and art of histology) drove the hypothesis that plaques and tangles were responsible for dementia. Cheston and Bender however dispute a simplistic interpretation of Alzheimer’s work. They argue that selective observations, which disregarded brain atrophy in Alzheimer’s original specimen led to the history of the domination of the model of cellular damage in the brain over other approaches. Cheston and Bender also point out that the absence of detailed description of the condition and background of the patient’s life seriously impaired the validity of the original diagnosis and its contributory causes. Apart from a revival of interest in the 1960s which came with new scanning techniques, until fairly recently the study of people with dementia has been something of a neglected discipline limited to attending to physical care needs. It is important to note that the classification of the dementias is highly complex: Not only are there are at least one hundred different types of

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4 From Fish, Sharon (text adapted for the UK by Susan Cuthbert) Alzheimer’s: Caring for your loved one, caring for yourself (Oxford: Lion 1991) p 66 Alzheimer’s discovery: tissue lying inside the cell bodies or nuclei of neurons exhibited an abnormally high number of fine nerve fibres or filaments twisted around each other – neurofibrillary tangles. Also unusually high numbers of fibrous plaques located between brain cells, composed of degenerating terminal dendrites or burned-out nerve endings that surrounded fibrous waste products of amyloid protein. Senile or neuritic plaques.

5 Richard Cheston and Michael Bender dispute the validity of the conclusions made in the early years of the 20th Century concerning the causality of Alzheimer’s disease – miliary foci or plaques and neurofibrils. The patient, Frau Auguste D. on whom the original ‘defining case’ for Alzheimer’s had been made had two things wrong with her brain: brain atrophy due to atherosclerosis (thickening of the artery walls) as well as plaques and abnormal fibrils. Further histological investigation shortly after Alzheimer on the same brain tissue samples chose to ignore the evidence from atherosclerotic causes. Understanding Dementia. 1999 pp 22-40.

6 Tom Smith, Living with Alzheimer’s Disease (London, Sheldon Press, 2000), p 85: Alzheimer’s accounts for two-thirds of all cases of dementia in N America and Europe. Non-Alzheimer’s dementias include: vascular dementias (1 in 5 of people of European origin) multi-infarct dementia – sudden, progress is step-like, with plateaus: medical and or surgical treatments can often eliminate the likelihood of further stroke activity if the confusion is related to vascular disease; diffuse Lewy body disease (second most common); fronto-temporal dementia (including Pick’s disease) – patients keep their memory until late in the illness – it is characterised by: apathy and irritability, misplaced jocularity and cheerfulness, loss of normal tact and manners, loss of concern about the feelings of others, lack of normal judgement, no insight into their problems, repetition of jokes or anecdotes and increased sex drive: fronto-temporal dementia starts younger than Alzheimer’s, and 1 in 5 cases is inherited.
dementia, but confusingly the designation DAT (Dementia of the Alzheimer’s Type) has been broadened to encompass a wider category of presentations of the disease to raise its profile. Whilst there it may have been the case in the past that Alzheimer’s was over-diagnosed by both physicians and carers, a recent Leveson Centre bulletin contended that only 30% of people with dementia receive a diagnosis.

1.3.2 The terrain of dementia

John Bayley, whose wife the novelist Iris Murdoch died with dementia is not alone in using the metaphor of the person with dementia being on a voyage into an unknown place. Maggie Steber, writes of her mother’s ‘melancholic voyage of memory loss,’ and the writer and minister Malcolm Goldsmith refers to the ‘strange land’ of dementia. Whilst dementias are generally progressive, the symptoms may reach a plateau for some time, or abilities may be regained, if only for a brief time. What is clear from the literature is that the effects of dementia depend upon the individual. Tom Kitwood’s controversial and radical suggestion that remenia is possible has added another complexity to the strange land which is dementia. In seeking to describe the terrain of this ‘strange land’ I cannot overstate the case that the effects of dementia are not the same for every person living with the disease: the events of the person’s life experiences interact with and inform the person’s response to the disease. A

Other dementias: alcohol-induced; after head injury; linked to Parkinson’s disease; linked to AIDS; Creuzfeld-Jakob disease; Huntington’s chorea, amyotrophic lateral sclerosis, multiple sclerosis and others (there are more than 100 types in the literature).

More recently the main motivating factor in promoting Alzheimer’s it could be argued, has been to obtain research grants. It has been necessary to increase the public profile of the disease to do this. Alzheimer’s is probably over diagnosed by family members and clinicians (bearing I mind the sense of relief it might bring). As a person whose family has been affected by dementia (and progressive supra-nuclear disease) the writer is of two minds in this. I am grateful for the increased debate and the raised profile, and the research funding this might provide. However the history and progress of how dementia is treated and perceived is far more complex. For a number of reasons, the term Alzheimer’s disease (or Disease of the Alzheimer’s Type, DAT) is now used to encompass a much wider variety of dementias – and is the diagnosis given in a majority of cases. It might be argued that it is in the interest of people with dementia for the Alzheimer’s Society, or the Alzheimer’s Research Trust to urge for public funding for research into dementia by establishing the large number of people who are or who will probably be affected by dementia. To increase the public awareness of dementias is laudable, but the route by which Alzheimer’s has come to dominate the headlines is based neither on the best science nor on the most transparent of criteria.

Sharon Fish Alzheimer’s: Caring for your loved one, caring for yourself (Oxford: Lion 1991) p22

Leveson Link News Update, (Temple Balsall: The Leveson Centre, June 2008)

‘She is not sailing into the dark. The voyage is over, under the dark escort of Alzheimer’s, she has arrived somewhere. So have I.’ John Bayley Iris, Quoted in Tom Smith Living with Alzheimer’s Disease (London, Sheldon Press, 2000)

Maggie Steber, ‘When Memory Ends,’ National Geographic November 2007, p56.

Malcolm Goldsmith, In a Strange Land…: People with Dementia and the Local Church (Southwell, Notts: 4M Publications , 2004)

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person living with dementia is so much more than a diseased brain.\textsuperscript{13} we are alongside a person with a past (and a future!) not a sufferer with a set of symptoms. The fine detail of dementia is beyond the scope of this dissertation but it must be said that the differences between the types of dementia are important and the intention here is not to crudely lump together all dementias into one category. What has gone on before in the person’s life is the story of what was held in their memory. The memory itself may have been erased, but the attitudes, patterns of behaviour and what has gone on in the person’s life, have all interacted together to shape the person we have in front of us. Kitwood\textsuperscript{14} argued that the behaviour of the person with dementia is not meaningless, and should not be ignored. Life-story and social and emotional background is entirely relevant, and the interaction between the carers and the person with dementia holds the key to hastening or slowing the progress of the disease.

1.3.3 Diagnosis of exclusion

When all other possible causes of the symptoms have been eliminated from the inquiry, dementia may be diagnosed. The correct diagnosis is essential to best helping the person who is living with the disease. There are more than 50 different disorders\textsuperscript{15} whose symptoms can mimic those of dementia – some chronic and incurable, whilst others can be treated, reversed or cured completely. Many have nothing to do with the brain at all in relation to cause.\textsuperscript{16} Depression mimics dementia, but a simple working distinction is that a person who is unwilling to carry out tasks might well be suffering from depression whilst a person who is unable to carry out tasks might have dementia.\textsuperscript{17} Another difference between other disorders is that there can be a reduction in the severity of the symptoms of the disease and a degree of recovery of the mental / cognitive capacity. From the purely organic model (based as it is on an hypothesis of irreversible loss of, or damage to, brain tissue, this is not true in Alzheimer’s – in which the downward decline is described as being unrelenting. It should be noted that psychological interventions may produce some degree of improvement, and case-by-case descriptions do not necessarily support a downward trajectory of decline in individual cases, but only of the whole sample of patients. However, dementia remains incurable, ‘You cannot apply the assess-treat-cure model, which is borrowed from medicine, to dementia, because you cannot cure dementia.’\textsuperscript{18}

We have considerable insights into the process by which the brain stores and translates experience into memories, manages the life of a person. The correlation with the structures, chemical and electrical activity of the brain with certain function is better understood than ever before, but the fact remains that dementia is an incurable disease.

\textsuperscript{13} Kitwood emphasises this point repeatedly. Tom Kitwood, Dementia Reconsidered (1997).

\textsuperscript{14} Kitwood Dementia Reconsidered (1997)

\textsuperscript{15} Delerium and depression – pseudodementias; dehydration, urinary tract infection, malnutrition, drugs – build up and toxicity.

\textsuperscript{16} Sharon Fish Alzheimer’s (1991), p 23

\textsuperscript{17} Richard Cheston & Michael Bender Understanding Dementia: the man with the worried eyes (London and Philadelphia: Jessica Kingsley, 1999) p 34

\textsuperscript{18} Cheston and Bender Understanding Dementia(1999) p 101.
This might seem a hopeless scenario – it would appear from investigations into neuroscience that humans simply do not regenerate new neurons. When we meet a person with dementia they seem like a computer disc case containing a damaged computer disc whose data cannot be retrieved or is corrupt – we can read the label with what should be there, or was there, but we, as outside observers cannot get hold of the information which was once stored. Medically this can easily lead to quiet despair at best or ‘therapeutic nihilism’ (Kitwood’s term) at worst. In this dissertation I aim to rediscover the hope that person living with dementia has not been lost.

There may yet be a cure for dementia, but that is for future generations to discover. A decade ago Tom Kitwood, Richard Cheston and Michael Bender argued adamantly for the balance to swing away from the predominance of the organic or ‘medical’ model of dementia towards the psychological person-centred approach to the disease. Kitwood’s argument was that a person’s capacity might actually improve following psychological intervention, hence rementia. When loosed from the constraints of the diseased brain model (in which such recovery is theoretically impossible) there is still hope that some capacities can be retained for longer and improvements made. Globally, across the whole population of dementia sufferers there will inevitably be a decline (this is a function of statistical variation), but for the individual person (and this is a key point) decline is not unrelentingly downwards. By recovering sight of the person in dementia, rather than just seeing a series of losses and diminishment, we have hope that the person has not disappeared, is known by God and held in God’s hands for eternity.

1.3.4 Loss of abilities
Dementia brings with it the loss of physical abilities - and mars the ability to perceive and process information - leading to unsafe behaviour, such as forgetting to switch off the cooker: ‘Alzheimer’s disease is a chronic, progressive, irreversible brain disorder or dementia for which there is no definable cause, no definitive treatment and, to date, no foreseeable cure. Dementia is a multifaceted decline of intellectual functions of sufficient severity to interfere with an individual’s activities of daily living, career, social relationships and social activities. Dementia involves personality changes, loss of memory and judgement, and difficulty with abstract thinking and orientation.’

The transfer of information is impaired so that the capacity to properly identify genuinely threatening phenomena affects the response of the person living with dementia, who may as a consequence have a very high level of stress, which in turn produces psychological disturbance.

1.3.5 Loss of relationships
Dementia is a disease which destroys relationships, and wipes away experience and interconnectedness with other people and cuts across our deeply ingrained models of how social interaction operates. We, the carers, the onlookers, the ones outside the dementia feel a change or loss of the relationship we once enjoyed with the person who has dementia. When visiting care homes for people with dementia, I have been struck by the sense that. ‘Here are people who once were.’ I also sense I am receiving a reminder about my own possible future

Fish Alzheimer’s (1991), p 19
and that I might become like them one day, though I’d rather not. By suggesting that the person with dementia has ‘disappeared,’ because that is what the experience can seem like to the carers, is to limit the definition of personhood to the quality and level of interpersonal interaction the carer experiences, rather than the intrinsic, God-given worth that is being a person.

Whilst the person with dementia objectively has a series of losses, which in themselves produce a set of difficulties for everyday living, I argue that the difficulty experienced by those who care is a major problem.

The challenge we have in answering the question, ‘Where is the person with dementia?’ is that we as observers are by definition outside the interior world of the person with dementia. We may deduce that we no longer share the intellectual apparatus of person-to-person communication: that is open to God alone and the person. There is a sense that ‘eternity’ is gradually advancing into the inner world of the person with dementia, where the ‘things of earth grow strangely dim’ and the things of God outweigh other considerations.

1.3.6 Communication disability

Dementia carers often describe a sense of bereavement, implying that the person appears to have departed before death. ‘What is experienced by people with dementia is an impaired relationship between their brain and everything around them.’ In all the discussion, what emerges is the crucial nature of communication between the person with dementia and the carer, as the former loses the ability to either perceive or express wishes, preferences, complaint or praise, the dignity of the person with dementia comes under threat. The demands on the carer are considerable, and may increase daily: the former level of trust (which it is argued is an essential part of human interactions) comes under threat as the person with dementia perceives benevolent and caring actions as threatening in the context of a bewildering and frightening world with fewer and fewer memories to act as fixed points to sustain relationships. The person living with dementia may be very fearful, and communicate that in a socially inappropriate way.

Kitwood states, ‘The greatest need of people with dementia is to be treated with respect, as paid-up members of the human race rather than diseased brains,’ and uses the term ‘Malignant social psychology’ to describe those aspects of the social world which impair

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21 Mary Marshall quoted in Tom Smith Living with Alzheimer’s Disease 2000 p 88:

22 ‘The brain is only half the story. Dementia is all about people trying to communicate and trying to cope. Fear – not knowing where the toilet is – this can overpower all other social interactions.’ ‘Aggressive and unpleasant behaviour may become the only channel of communication remaining to the person with dementia in the presence of a highly stressed life. [We must] listen to the emotion behind the confused words.’ Tom Smith, Living with Alzheimer’s Disease (London, Sheldon Press, 2000), p88

23 Kitwood quoted in Cheston and Bender Understanding Dementia (1999) p44

Deciding that Alzheimer’s disease ‘exists’ because it is in the DSM (Diagnostic and Statistical Manual of Mental Disorders) does not clarify what happens to people when they lose their skills and abilities or the dialectical relationship that exists between the individual and their social context (Kitwood 1988, 1990a, Kitwood and Bredin 1992; Harding and Palfrey 1997)

24 Kitwood, 1990a quoted in Cheston and Bender Understanding Dementia p 48.
the personhood of the person with dementia through our lack of trying to understand what a person living with dementia wants to communicate either through neglect or inappropriate response of carers to the person living with dementia.

This is not the place to criticise hard-pressed nursing staff in residential or nursing homes, or exhausted family members trying to care for people with dementia. The prescribing of drugs, for example anti-psychotic drugs, or sedatives might not be primarily for the benefit of the person living with dementia, but to make the person more compliant, or less disturbing than disturbed. I argue that there is a deeply medicalised model of care in the West into which we are inculcated from an early age. For example the parents of a small child who is unable to sleep, because of fever, give medicine to take the pain away. The child has relief from pain, but the parents also got some sleep. In the case of fever it may prolong the infection to take medicine, because the fever is a mechanism of the body to fight infection, when reassurance and improvement in physical comfort would be more effective at bringing the infection to an end. Hence, by analogy, we may be complicit in reinforcing the solely organic model of understanding dementia, and missing a pathway to improving the life of the person with dementia by ‘sedating’ a dementia patient, rather than listening to what the person is trying to communicate about his or her needs, and by not dealing with their underlying distress. The ‘seeing the person with dementia’ approach is fortunately gaining ground. Studies into personhood and dementia now abound, with research institutes spawning worldwide. This, we have to agree, is a positive situation. The whole ‘dementia studies’ debate is a multifaceted and complex one. What I urge here is that the spiritual dimension (no, it’s more than a dimension) is not ignored. In a first aid scenario, the ‘spiritual aspect’ can get lost in the rush. We are not dealing with a first aid scenario, but a long-term situation.

1.3.7 The prevalence, significance and challenges of dementia

Dementia poses huge socioeconomic challenges. We do not know how we will find the money, time and trained people to care for people living with dementia in the next decades. Researchers have called the increasing prevalence of dementia sufferers a ‘rising tide,’ and Tom Kitwood, one of the foremost writers in the field, stated over a decade ago that ‘Dementia may prove to be the most significant epidemiological feature of the late 20th century.’

By virtue of the changing demographics of the population in the developed world the number of people diagnosed with dementia is increasing markedly, and the proportion of the population with dementia is increasing apace. It is beyond the scope of this work to analyze population trends, but people are living longer than their parents and grandparents did, and a decline or stagnation of the birth rate is a factor in the developed world. Whilst the prevalence of dementia is mercifully low in younger age groups, it increases markedly with age: nearly 30 percent of all those in the 85 plus age group have dementia. At present, some 700,000


26 ‘One out of every three of us may have an older relative diagnosed with Alzheimer’s.’ ‘No matter how bizarre or bewildering their behaviour, they are still precious people carefully designed in the likeness of their creator. As carers we have daily opportunities to fan the flames of their hearts and spirits as we care for them in love.’ Sharon Fish Alzheimer’s: Caring for your loved one, caring for yourself (Oxford: Lion 1991) p20, 22.

people are affected by dementia in the UK, and that is projected to double within the next 30 years.\textsuperscript{28} This doubling of cases will be mainly attributable to the rapid increase in the proportion of people in the population who will live beyond 85 years of age. It is difficult to estimate the prevalence of dementia world-wide because of differences in establishing a diagnosis, but roughly five million Americans have Alzheimer’s disease.\textsuperscript{29}

The economic and social impact of an ageing population with dementia on the world will grow as the population of the developed world lives longer. As the West struggles to find qualified care staff to care for its older people in general (and those living with dementia in particular) residential and nursing care homes employ care staff from the Indian subcontinent, Africa and South East Asia and Eastern Europe. In my experience these members of staff are gifted and caring, and in the UK we benefit from their work with older people, but the impact on the medical and healthcare facilities in their home countries must be deleterious: it feels as if we in the West are ‘mining’ the resources of the developing world entirely for our own benefit, much as we did in colonial days.

Dementia produces a tension between recognising the rights of the person, but dealing appropriately with the diminishment of the person’s capacity for sound judgement. Quite apart from the distress to other family members and issues of individual safety this diminishment causes, there is the potential for wide scale disruption - there have been cases of leaders of countries who have started to suffer with dementia and who have clung onto positions of power with catastrophic consequences.\textsuperscript{30} We may recognise that the leader was still a person, but not the same as the one who was first elected.

Dementia offers one of the greatest challenges of the 21\textsuperscript{st} Century. The Church must respond and offer hope to those who are living with dementia and those who care for them.

\textsuperscript{28} Rebecca Woods, chief executive of the Alzheimer’s Research Trust, quoted in ‘Warning on drugs for Alzheimer’s patients in nursing homes,’ The Guardian Tuesday April 1, 2008.

\textsuperscript{29} Joshua Foer, ‘Memory’ National Geographic November 2007, p 54

\textsuperscript{30} Lord David Owen, a physician and former British Foreign Secretary charts the impact on world history of certain leaders whose mental and physical incapacity (from various causes) led to terrible decisions or a vacuum of leadership. Harold Wilson, former Prime Minister, resigned for an honourable reason - he had been diagnosed with dementia, and recognised his judgement was impaired. Wilson knew he was different because he could not remember or assimilate all the information with which he was presented. This capacity had been one of his greatest strengths, and Wilson recognised he had lost what it took to do his job. His namesake, Woodrow Wilson, the U.S. President clung onto power despite suffering a series of strokes which produced dementia. After WWI Wilson failed to drive through legislation to enable the U.S. to become a member of the League of Nations, which it is argued, was a major contributory factor in the circumstances which led to WWII. Citizens who had voted for Wilson would have had every right to question that the same person, was in power as the man they had elected. David Owen, CH, The Rt. Hon. Lord ‘Diseased, demented, depressed: serious illness in Heads of State’ Q J Med 2003; 96: 325-336, (2003)
1.4 INTRODUCTION TO THE THEOLOGICAL THEMES EXPLORED IN THE DISCUSSION

1.4.1 Distress in the person living with dementia

The person living with dementia may themselves have an intense experience of grief, which cannot be helped long-term, because their loss of memory does not permit the integration of the grieving process which would enable them to ‘move on’ in their grief. Hence a person living with dementia may be experiencing a permanent level of underlying stress. Not surprisingly, stressful situations can both mimic and magnify the symptoms of dementia: assessing a patient can produce stress, which may exacerbate their difficulties. Becoming the subject of investigation or questioning, and being put inside a scanner, for instance, would make matters worse for the person living with dementia.\(^{31}\)

1.4.2 The grief of family members

In frustration or grief we may say to ourselves, ‘She’s ga-ga,’ ‘She’s gone,’ statements which imply the person living with dementia has ‘disappeared’. The grief of bereavement is suffered in advance of the death of the person with dementia. I return to the question: does the real problem with dementia lie in our inability as carers to cope with the destruction of all that substantiated our relationship with the person living with dementia?

1.4.3 Second Childhood

My younger daughter’s birth two and a half years ago coincided with the opportunity to start this investigation into dementia. I have been astonished by the parallels which have come to light naturally with the process of a person entering into dementia, but in reverse-time: I have watched my daughter’s development from being completely dependent on those around her as a newborn infant through to becoming a potty-trained child who can communicate her needs and take some control over her environment - a gradual transition from needing reassurance to responding to reasoning.\(^{32}\) An infant’s development - gaining mobility, speech, perception, understanding of place and surroundings is mirrored in the descent into dementia. What has struck me is how my daughter’s community – her family, friends and neighbours have felt at ease in every stage. At no point has anyone thought my daughter was not a person - she has been welcomed into families in the street and at Church. She even has a special room provided (the crèche!) where she can enjoy the company of like-minded individuals and do her own thing when singing songs and listening to talks gets a bit too much for her. Maybe

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\(^{31}\) I had the experience recently of being lost in an unfamiliar place. I knew I was in the right side of the City because of the style of the houses and the feel of the area. I had no map, did not know the landmarks, only the name of the road I was trying to find. Becoming stressed, I remembered the names of a couple of key places near to my destination. So I headed for the one I recognised, and eventually got there. To be honest I was a bit fearful. The stress I experienced prevented me from thinking straight and recalling the information necessary to get me there – I was too embarrassed to ask for help. Incorrectly identifying my location -a few wrong turns and a slightly distressed frame of mind increased my fearfulness. Imagine I thought, having dementia and being in a never-ending state of flux in one’s mind - having a reduced capacity to remember things, partial or no recognition of either surroundings or the other people.

one day the same tolerance and welcome with be shown in Churches towards people living with dementia. But we need to be careful here, are we happy that an adult living with dementia is thought of as being child-like? And how are we, who once were the children of those who live with dementia to treat our parents, who have now become like a child?

The response of the Church, as an individual living with dementia loses the capacity to communicate and to participate in Church activities can be to neglect the continuing need for pastoral care of the person. For a person living with dementia the capacity to process thoughts more complex than, ‘Am I safe? Or where am I?’ disappears. If the Church community fails to visit the person living with dementia, then they feel abandoned by God.

1.4.4 Articulation of beliefs

Having been brought up in the Christian faith to ‘profess with my lips and practise in my life,’ I remain convinced about the value of word, prayer and sacrament, service, proclamation and participation in Christian discipleship, but now I am seeking a way of more effectively practising pastoral care among people with dementia.

It is not that I feel the particular mode of teaching and profession of the Christian faith which appeals to and relies upon the ability to read and understand, to articulate thoughts, and which requires attendance and active participation in Church, giving assent to creeds and doctrines is somehow lacking, but when the channels of communication and the basis of relationship have been eroded by dementia there must be another way of ministering God’s grace (and being ministered to) with people living with dementia.

Why do we allow so much of our teaching and profession of the Christian faith to rely on the articulation of that faith? Western Christianity is both very cognitive and very activity-based. The traditional measures of faith development and ‘conversion’ are less likely to be seen in the lives of older people, especially those with dementia, so do we need to discover another way of discipleship? Is it a naive hope that ‘eternity takes over’ as a person is lost in dementia?

1.4.5 Where is God?

Dementia is a cruel and unrelenting disease. How is this suffering of ‘older saints’ consistent with a loving God? My own reflections on dementia have prompted me to ask many questions of God. This dissertation is offered as my contribution to the debate as I join with the relatives and friends of those who have dementia in searching for meaning in dementia. I argue that it is vital for the Church to engage with the impact of dementia. The challenge is two-fold: first to provide pastoral care for Church members living with dementia, their families and other carers, and second in the mission of the Church to a broken world. The hope offered by the Christian gospel extends to all of God’s creation – even the darkest and most desperate situations. So caring for the carers and witnessing to the weary is part of the Church’s mission with older people.

33 “Alzheimer’s Disease progresses slowly and continuously, leading to declining functional capacities over time but without specific markers of decline. Functional deterioration occurs in approximately the opposite sequence to the gains made early in childhood neurological development”. Smyer and Qualls (1999) p142
1.5 A CRITIQUE OF THE MEDICAL-PSYCHIATRIC-ORGANIC MODEL

1.5.1 Progress in Western healthcare

The Western healthcare model is of progress in medicine. The medical or organic view of dementia, based as it is on structural change and biochemistry is a welcome conversation partner in this theological reflection, but its voice should not dominate the discussion: I emphasize that the art of caring for a person living with dementia involves looking beyond the medical model. The difficulties faced by a person may be attributable to structural changes in his or her brain, but the brain is both extraordinarily capable and extraordinarily fragile. The organic approach is helpful when it gives insights, but is harmful when it inhibits the potential of the person living with dementia in the eyes of the medical profession. Sole use of the organic model creates a problem in that it encourages one to think that nothing can be done to help the sufferer, leading to the conclusion that it is only possible to alleviate or reduce the troubling symptoms, and manage the physical well-being of the person with dementia. The basis of this conclusion is that it is impossible to repair or replace damaged brain tissue and restore the brain’s original functionality.

1.5.2 Drug therapies

There is much to learn from the medical model: whilst drug therapy has usually been prescribed in the past to manage the symptoms of the condition rather than to actually treat it, newer drugs are being developed. National Institute for Clinical Excellence (NICE) guidelines published in November 2006 describe the efficacy of drugs to change or delay the progress of dementia in moderate cases of dementia. The debate rages – some drugs (such as vasodilators) have serious, even life-threatening side-effects, and antipsychotic treatments are applied to control behaviour, but the hope remains that a ‘cure’ will be found for dementia. I join with writers such as Kitwood, Cheston and Bender in arguing that the organic model is not an adequate approach to dementia when it is used alone - the psychological and psychiatric must be held together in our thinking.

Factors affecting the rate of decline

There has been research into factors which might slow down or speed up dementia, such as educational background and profession. Some evidence points to ‘well-exercised brains’ (possessed by people who are highly interactive and people-orientated, highly skilled, or whose work involves complex manual operations) coping better with dementia than less-well exercised brains. The evidence is however not conclusive, and there is the difficulty of isolating factors in the research groups, as family background, financial situation, nutrition, working in skilled employment with the hands or by thinking are all interlinked. Cheston and Bender argue against the sole use of the organic (the damage to the brain), psychiatric or stages of decline model of dementia, and make a strong case for the inclusion of psychological insights, and Kitwood argued over a decade ago for the person-centred approach to dementia care.36

34 The evidence is for all to see: the eradication of certain diseases, improvements in diagnostic technology and advancing surgical techniques.
35 Cheston and Bender Understanding Dementia p 47
36 In fact Kitwood proposed a far wider-reaching change to the very culture of care, and denounced the historic roots of the present climate of caring for the elderly in general and those with dementia in particular, based as
1.5.3 **Being treated as a person**

The sufferer is treated as less of a person, and may not even be allowed to hear the diagnosis, because he or she is deemed not to have the necessary mental apparatus to process the fact that he or she has dementia. The person living with dementia, who has this important piece of information withheld from them continues in a downward spiral of confusion and despair, is denied one means of understanding who they are and what they are doing. Along with Kitwood, Cheston and Bender argue that functionality can and does improve through the careful application of care for the whole person. The psychological approach yields the positive result of considering the sufferer as a person, rather than a collection of losses due to the disease. The subjective experience of the person with dementia comes more to the fore in the discussion. It is to be hoped that he or she is then more likely to be treated as an individual. The 2006 *NICE* Guidelines on dementia emphasise the importance of the person-centred approach in caring for the whole person.

1.5.5 **Psychological Perspectives**

Recent debate has been characterised by a move away from solely considering the organic nature (i.e. mainly in terms of the observable features brain) of the disease called dementia to encompass a much wider description from psychiatric or medical as well as psychological perspectives. Kitwood’s suggestion that a certain level of ‘*rementia*’ was possible has proved to be controversial, and is widely discussed. The concept of ‘*rementia*’ cuts across the ‘therapeutic nihilism’ of an over-medicalised view of dementia. The overwhelming thrust of Kitwood’s argument was to say that more can and could be done for people with dementia – and that the personhood of the sufferer would be better respected. Tom Smith, whilst not wholly espousing the concept of ‘*rementia*,’ argues for focussing on ‘the remaining competence of people with dementia and not on their failing abilities. Everyone has potential that needs to be realized.’

1.5.6 **Cellular damage or inadequate care?**

Kitwood raised a crucial question in the debate as to whether ‘some, at least, of the symptoms that are commonly found in dementia might be due more to a failure of understanding and care than to a structural failure of the brain.’ Whilst damage to certain specific areas of the brain may produce certain losses or difficulties, the reverse is not always

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37 Accounts of other family members, rather than the person, hearing the diagnosis are common in the literature.

38 The Stirling University Centre in Scotland employed a poet John Killick, who worked on communication through art with dementia sufferers. There is evidence that paintings, sculptures, photographs, embroidery and poems enhance the sense of wellbeing of those with dementia - the arts are a great vehicle for self-expression, whether it is banging a drum painting a picture or creating a poem!


40 Kitwood, *Dementia Reconsidered* (1997)
the case: the presence of difficulties or certain behaviours is not conclusive proof that the respective areas of the brain have been damaged. Also as we have discussed earlier, other conditions may mimic the symptoms of dementia. For too long we have concentrated on the cellular-damage model rather than the inadequacies of the care system.

1.5.7 Life stories and the psychosomatic unity of a person

A person’s life story too is relevant and has been drawn into the debate along with aspects of a psychological approach. For too long there has been an unequal tug-of-war between the medical and the psychological aspects of caring for individuals with dementia. It is desirable that members of the medical profession are involved in the care of those with dementia, but they should not, it is argued maintain their unique elite status and deny the value of insights from other perspectives. The care of people with dementia cannot be limited to a purely organic model it must consider the psychosomatic unity of the person. We need to see the person primarily, not the brain damage and the loss of capacity.

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41 The existing dominant organic framework of equating specific brain damage to specific losses in the individual would appear to be inadequate. The advances in scanning technologies may lead us further down the path of perhaps mistakenly correlating every change in a person’s abilities with changes in brain structure.
WHAT IT MEANS TO BE A PERSON

2.1 What It Means To Be A Person – Philosophical Approaches

In seeking to explore our understanding of ‘what it means to be a person,’ we may approach the question along three different philosophical lines of inquiry. To briefly summarize:

2.1.1 Rational: ‘I think therefore I am.’ (Descartes, 1596-1650).

This perspective argues in terms of the capacity a person has for autonomous, rational individual thought and is the foundational principle for humanism. Christians would dispute the argument formulated in Plato’s Protagoras that ‘man is the measure of all things.’

2.1.2 Spiritual: ‘I am known by God, therefore I am.’

This perspective considers a person’s relationship with God and how that person can both know God and be known by God, who has been made known through his Son, Jesus Christ. Brueggemann’s analysis of the Old Testament establishes that ‘The spiritual aspect of humanity is axiomatic in historical, legal, liturgical and prophetic texts. Wisdom literature gives a more detached and autonomous portrayal (it is atomistic and appeals more to human wisdom). But ‘The fear of the Lord is the beginning of wisdom.’ Relationship with God lies at the heart of Job and Ecclesiastes. McGrath records that up to the time of the Pelagian Controversy of the early fifth century there was more or less general agreement in the church’s view of human nature. Along similar lines, Crowder, inferring from the absence of anthropological dogma in the first centuries also concludes that the patristic era writers had a shared understanding of the nature of humankind, whilst hotly disputing the nature of Christ. Nothing similar to the Council of Chalcedon which brought to an end a century of Christological controversy exists concerning the nature of what it means to be a person.

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42 Descartes’ axiom, ‘I think therefore I am,’ arose as a consequence of his experiment to eliminate all external stimuli, and all external reference points, including God. Whilst philosophically intriguing, the experiment could not in truth eliminate God from the equation, for it was God who made Descartes.


44 Spirituality is not self-enlightenment, but enlightenment from beyond ourselves and our own experience, from the everlasting God, who has been made known in and through God’s Son Jesus Christ who was, and is and is to come. Whether an individual acknowledges this or not, it remains the truth. However, this writer is prepared to listen to the perspective of individuals who do not believe in God, whose understanding of ‘spiritual,’ might be recognition that there is something greater than themselves, something greater indeed than human culture and society, what some secular organisations, such as Alcoholics Anonymous, have termed a ‘higher power.’


However Crowder records that the earliest writers made a ‘sustained and searching reflection on the nature and destiny of human beings’. It is plain that the Christian vision of what it meant to be a person was inseparable from other doctrines. Individuals are identified and understood as such through their relationship to God. Crowder notes that for Clement of Alexandria (c.150- c.215) knowledge of self and knowledge of God are very closely connected with one another; for Aquinas (c.1225-74) – ‘Sacred doctrine is not concerned with God and the creatures equally. It is concerned with God fundamentally, and with the creatures in so far as they relate to God as their beginning or end.’ (STI q. 1 a.3); for Luther, ‘God is the name of the ultimate context in which and to which they [people] are responsive;’ and for Calvin and his predecessors there was no constructing a theological interpretation of what it is to be a person independently from doctrines of creation and redemption (Calvin’s discussion was based on the sense that knowledge of God and of ourselves may be mutually connected: in other words we discuss the knowledge of God first, then ourselves afterwards). In the New Testament a person is understood in terms of his or her relationship with God – first, all have sinned and fallen short of the glory of God. The person must take the step of repentance as an individual, because it is the one and only God who justifies freely by God’s grace through the redemption that came by Jesus Christ (Rom 3:23).

2.1.3 Relational: ‘I am known by other people, therefore I am.’

This perspective argues that it is in relationship with other people that we are truly persons. The sense of interrelatedness between human beings – in other words being in community with each other - reveals a third strategy in the search for what it means to be a person. What is evident above all in this third approach is the crucial nature of communication and the various modes of articulation of this desire for community which provides the ‘glue’ for human relationships.

What it Means to be a Person – Streams of Thought in the Judaeo-Christian Tradition:

In the development of the concept of what it means to be a human person, these streams of thought can be identified in the Judaeo-Christian tradition:

2.1.4 A person is a psychosomatic and holistic unity

We may gauge from the laws of purification in the Old Testament that a person’s body is the person, hence in Hebrew thought there is no reason or evidence to make a distinction between mind and body (or mind, body and spirit). In the Old Testament the human person is a

48 Quoted in Colin Crowder, ‘Humanity,’ 2000 p 313


50 See Leviticus 5:3, 7:20, 11:25, 14:19, 21:1; Numbers 5:2, 19:11-16 (Scripture References obtained using NIV and NRSV concordances and NIV Cross-reference system compiled and Edited by John R. Kohlenberger III and Edward W. Goodrick).

51 Mind, reason – nous. The mind is that which (one step back from the outside observer) is foundational to a person’s self-awareness and is discerned by an observer primarily through communication with other people. The expression of a person’s thoughts is mediated or hindered via an array of social, cultural linguistic, religious and other ‘channels, filters and barriers’. The relationship between the participants and the capacity
psychosomatic unity – material ‘body’ and immaterial ‘soul’ are not distinguished. To be a human person is a lived psychosomatic experience so it is declared, ‘The non-physical cannot exist without the physical.’ Humans are living beings and their intentionality of action accompanies their ‘livingness.’ Interestingly the Hebrew word ‘Nepesh’ which used in Genesis 9:5, can also be used to indicate inner desires – see Leviticus 4:2). ‘Ruach’ often means ‘breath’ but can indicate non-physical attributes such as ability and thought.

2.1.5 A person may be described by their divided (three-fold or two-fold) nature

a) In the early Eastern Christian tradition the theory of a trichotomous division of a human person into three spheres or levels, was developed by Origen (and subsequent writers). In this scheme the body was the animal-like lowest level was akin to ‘beasthood,’ the soul was the middle level (of the ordinary) and the uppermost level was spirit as divine. This three-decker hypothesis drew on the contrast between the earthly and the spiritual recorded in Paul’s theology of the resurrection body which is recorded in 1 Corinthians chapter 15.

b) In traditional Christianity the view of a dichotomous division into the physical and non-physical body and soul can be discerned. Following Plato’s thinking, the soul provides movement for the body, which is the abode of the pre-existent soul. The body is mortal as distinct from the immortal soul. For the stoics, the soul is the ‘animating principle’ of the body. This approach was reconciled by Irenaeus who declared that humans are made spiritual by the pouring out of the Spirit.

2.2 DISCUSSION: PSYCHOSOMATIC HOLISM VERSUS PLATONIC DUALISM

Hebraic, holistic thought may be seen in contrast to Platonic dualism which has tended to dominate traditional Christian thinking, which (though in continuation with the Old Testament and Judaism) took on much of the Greek tradition. People are to be distinguished from animals as well as from God and other higher beings, such as angels, but the New

of each person to understand the other, the cognitive abilities of each is key to the communication of the activities of the mind. Technology permits the observer to detect the electrical and chemical activity of the brain associated with the certain workings of the mind, and the correlation of voluntary and involuntary actions with different parts of the brain is fairly well established.


53 Body – soma. That which is concrete and directly observable; it displays the characteristics of life: growth, response, reproductive capacity, feeding and respiration. These biological characteristics are shared with other creatures. If the body is devalued in comparison with the soul one needs to be aware of the hazard of the gnostic heresy which argued that the body, along with the world, was that from which a person’s inner self must be set free.

54 Soul – psyche. At the point of death the soul is freed from the body. The soul continues beyond death. We may draw on Paul’s theology (who merely kill the body but cannot kill the soul). The soul is known in relationship with God.


Testament writers use the Greek division into soul (psyche) and body (soma) in a different way: they are not speaking about different parts of the individual, but are using the terms as different ways to speak of different parts of the entire, unified, integrated person. It is stressed that a human being is a psychosomatic unity in life, while an immaterial element continues after death. Human existence is a bodily experience – in other words, we live in our bodies. ‘Person does not mean “essence or “nature” but the actual unique reality of a spiritual being, an undivided whole existing independently and not interchangeably with any other. This reality is the reality of a being which belongs to itself and is therefore its own end in itself. It is the concrete form taken by the freedom of a spiritual being, on which is based its inviolable dignity.’

2.3 PERSONHOOD AND GOD

2.3.1 Personhood - in relation to God and in relation to God’s community

Brueggemann establishes the overarching theme of the Old Testament that Israel is God’s community, living together in fellowship with him. Being cut off from that community is a punishment for sin (Leviticus 7:20), and exclusion from the community is the ultimate sanction. ‘Humanness is conceived only in relation to Yahweh – fundamental characteristics are seen only in this relationship: obedience, discernment and trust; complaint, petition and thanksgiving; praise and hope.’

The centrality of community within the Church, along with the relationship of the individual with God is reflected in P.S. Johnston’s statement: ‘…The focus has shifted from the person to the community, with less emphasis on the physionomy and psychology of individuals and more on the relatedness of humanity. However, given the richness of human life and of biblical witness, these perspectives should be seen as complementary rather than competing.’

What I am edging towards is an understanding of a person in relationship with God. This is not to exclude the importance of human relationships in defining the ‘grid references’ for our lives. Indeed it is most often in human relationships we experience the love of God – it is argued that in Christian community God’s love is made known within that community and to those who would not count themselves yet as members of that community.

2.3.2 Personhood - made in the image of God

God blesses humans in Genesis 1: 26-27. The creation of people precedes God’s declaration that creation is ‘very good.’ People are created by God, but are distinct in being made in God’s image. ‘The image of God is clearly foundational to the biblical concept of humanness.’

57 Walter Taylor ‘Humanity’, p 321
58 Muller and Halder ‘Person: Concept,’ Sacramantum Mundi, 1969 vol. 4 p 404.
59 Walter Brueggemann Theology of the Old Testament 1997, p 450
60 Johnston (2000) p 564
61 Walter Brueggemann Theology of the Old Testament p 450
Crehan, summarising Origen’s understanding of 2 Corinthians 3: 18 establishes that ‘the image of is God [in humans] is marred by sin; those who have the Lord ever before the eyes of their mind mirror forth the glory of God. If the mind is occupied in recalling, knowing and loving God it is much more in the image of the Trinity than if it is doing anything else.’

Bridger delineates the traditional analyses of humanity i) being made in the image of God; ii) of conscience and iii) reason, but argues these are ‘atomistic.. conceptual abstractions …’ which do not reflect the processes through which individuals and communities develop through ‘social interaction and historical development.’

2.3.3 Personhood – insights from the Trinity

The concept of body, mind and consciousness (or soul or spirit) finds parallels with a theology of the Trinity. Bridger emphasizes that the entire Godhead is involved in humanity’s creation: ‘The Imago dei is fundamentally Trinitarian in outworking and concept. Human beings are made in the image of God the Holy Trinity. The narrative centre of the human story is Christ and it is he who gives it theological continuity.’ ‘Reason and conscience marks out humans as distinctive bearers of the imago dei.’ Whilst I struggle to find parallels which fully satisfy in respect of the present inquiry, reflection on the Trinity is a fruitful exercise: in a sense the body is likened to Christ incarnate, the mind relates to God the Father, and consciousness is likened to the activity of the Holy Spirit.

Bridger goes on to quote James Orr (1844-1913): ‘The image of God … is a mental and moral image. It is to be sought for in the fact that man is a person – a spiritual, self-conscious being; and in the attributes of that personality his rationality and capacity for moral life including in the latter knowledge of moral law, self-determining freedom, and social affections…’

Bridger’s summary identifies Irenaeus, Clement of Alexandria, Athanasius, Augustine and Aquinas among the “substantialists” whose arguments are based on an emphasis on reason and the mind. This starting point may have resulted in a dualism in which the mind or spirit came to be viewed as superior to the body (though Augustine in fact argued against body-soul dualism). The operation of conscience was understood as an inner faculty, informed by reason and revelation, which informs the will.

On the other hand Bridger denotes Luther and Calvin, Barth and Brunner as “relationalists” drawing on the Trinitarian insight of a three-fold ‘being in communion’ established by God between humanity and himself, between human beings one to another and between human beings and the created world. ‘The image of God … is to be understood as a relationship within which man sometimes stands, whenever like a mirror he obediently reflects God’s will in his life and actions’. Rahner states:

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64 James Orr, God’s image in Man, p 56-57, quoted in Francis W. Bridger, 1995, pp 21-27

‘Man (sic) is a being who is referred to “God”, whose self-understanding must be based on God and point towards him… where man has not grasped this reference or where he has freely rejected it, he has lost sight of himself, of his essence as a whole, of what distinguishes him from an intramundane thing.’

2.3.4 Personhood - through attaining the likeness of God

Taylor delineates the argument that all people are as yet unfinished, because they have been under the power of sin, but the relationship has been restored through Christ’s saving work on the cross:

‘Rather, the anthropos [man] is always understood in terms of the relationship with God. In relationship to God there is a dual perspective on who humanity is and who humanity is to become.’

2.3.5 Personhood - the capacity of human beings for the ‘divinizing grace of the incarnation’ (though this disputed in these terms by Protestant Theology).

Augustine’s term (often used by John Wesley) Prevenient Grace expresses the sense that God’s grace has been active in a person before conversion.

2.3.6 Personhood - ‘created by God and saved through Christ’

‘What is distinctive about the Christian vision of humanity, therefore, is not that it posits the existence of an additional entity, the soul, not recognised by other anthropologies, but that it posits the existence of an additional relation—a relation to God, as creator and redeemer— which encompasses all the other relations which define us as individuals. The insistence that the {person\textsuperscript{70}} is an ‘embodied soul’ or an ‘ensouled body,’ and not a soul somehow occupying a body, is now not just the conclusion of arguments…’

2.3.7 Personhood – determined by an individual’s behaviour

‘Morality is the becoming what one ought to be, a person’ – a progress to the ‘full harmony of human nature.’

a) in Medieval thinking, wrongdoing inserted a flaw in this harmony, which meant that an individual who stole or committed murder did not become a person.


67 Walter Taylor ‘Humanity’, 1992, p 321. Taylor continues, ‘In the present the anthropos is sinful (Synoptics) and enslaved under the power of sin (Paul and John). The individual person and humanity as a whole are weak, mortal, and sinful (Matt 16:23; Rom 1: 18-3:20; 1 Cor 1: 25.) The relationship of humanity to God has been changed in the Christ event. (Romans 3:21-26,; Ephesians 2: 1-22; 1 Peter 1: 18-2:10).’

68 Joseph Crehan, ‘Man,’ 1971 p 231-3

69 Juan Alfaro, ‘Nature- The Theological Concept,’ Sacramantum Mundi 1969 vol. 4 1969 p 175

70 I have used ‘person’ here in place of Crowder’s term, ‘human being’

71 Colin Crowder, ‘Humanity,’ 2000 p 313
b) in Christian morality – if you do not submit your mind to God, you will not become the person God intends you to be.

2.4 “WHAT IT MEANS TO BE A PERSON” IN DIALOGUE WITH THE PRESENT INQUIRY INTO DEMENTIA:

2.4.1 The importance of communication

If a person no longer has the ability to communicate, or has lost the power of speech, or has lost the capacity they once had to have an independent life and to perceive abstract concepts, does this mean that they are no longer a person?

For carers, the difficulties in communicating with the person living with dementia recasts the nature of the relationship, and requires skilful readjustment on their part to maintain communication. These difficulties may lead to the destruction of the relationship as the lines of communication have collapsed. A person finds his or her affirmation, mutual care and support in community and in relationship with other persons. The human capacity to show love, to receive and respond with love demonstrates God’s love to others. The role of the carer is to maintain a loving presence or contact with the person who is no longer capable of the normal modes of communication. Just ‘being there’ may be enough, though I have wrestled with this point, as my personal experience provides conflicting evidence: I sat for hours besides the hospital bed of my father when he was unconscious and in intensive care following life-saving surgery on an aortic aneurism. When my father recovered enough to come home, he had absolutely no recollection or perception that I had been there beside his hospital bed – yet I had been there praying for him. Was I there for his sake or mine? I would argue that my presence had been significant, and did matter to him, although my father was unaware of it. Later, as he entered into dementia I and others held my father’s memories for him, although again this is an unscientific conclusion.
CONCLUSIONS

3.1 WHAT IT MEANS TO BE A PERSON

3.1.1 Made in the image of God

Whilst people possess biological functions which are to be found in animals – such as respiration, feeding, growth, movement response and reproductive capacity, people are also made in the image of God. We learn from scripture that this is what distinguishes humanity from the rest of God’s creatures, and it is through being in relationship with God that a person find his or her meaning, and knows his or her ultimate worth.

3.1.2 Challenges in pastoral care

To argue that a person living with dementia is a person first and foremost because he or she is known by God and second is in relationship with other people presents both hope and difficulty in the debate. The first criterion is difficult to determine – the relationship with God aspect: a person observing the person with dementia cannot know what has gone on between that person and God. We hope that God sees into a person’s heart and truly knows what is going on in within the person.

3.1.3 The temporality and fragility of human nature

Changes in the second aspect, in regard to the relationships with other people are something of which we can be acutely aware. The loss of relationship is agony for the carer, and may be the cause of continuing distress to the person with dementia themselves. We are ‘fearfully and wonderfully’ made, but we do not live for ever here on the earth, and our lives are a process of growth, maturity, decline and decay. A problem in one part of our bodies produces problems elsewhere.

3.1.4 A person is a psychosomatic unity

I conclude that we are a psychosomatic unity – mind, body and spirit. The person’s subjective experience is interwoven with and into all of their lives. In a sense the organic model of dementia releases the person with dementia from responsibility. The response of the Church to those who isolate themselves from others through a shutdown in communication can be censure. If the Christian community takes seriously the message of Jesus’ parable of the lost sheep (Luke 15: 1-8/Matthew 18:12-14), where those safe in community are left to care for themselves, and the one who is missing is sought out, then we will seek out those who are lonely and have become separated from ‘the flock.’ If a person is impaired through missing a hand, he or she is not in the normal state of affairs accused of some moral weakness or psychological instability because he or she cannot perform the same functions as a person with two hands. Whilst he or she may become disabled through the environment, adaptations

72 I find many parallels in the story of the film Away From Her. Aubrey, who had been involved in financial irregularities before his illness has already been ‘let off the hook’ from owing money to his employer because of his dementia. The screenplay encourages us to release Fiona, who falls in love with Aubrey, from moral responsibility because she has ‘forgotten’ her husband of 45 years.
can and should be made to reduce the disability. When a person is diagnosed with cancer, with some exceptions, the patient is not normally considered to be morally wrong because he or she suffers from the disease. The striking feature of dementia is that the nature of the person’s personality can change so markedly – the network of shared memories, recollections, the capacity to relate to and interact with others and the ability to recognise even family members can be lost.

3.2 APPLICATION: THE CHURCH’S PRACTICAL RESPONSE TO PEOPLE LIVING WITH DEMENTIA

3.2.1 Changes in temperament leading to judgement by the carer

A deeply distressing outcome of dementia can be the change in temperament - a person with dementia, who in his or her previous life never let a swear word issue from their lips, or was gentle, chaste and respectful, might start to use foul language, become violently aggressive or engage in sexually inappropriate behaviour. Disorientation, aggression, over-sexualised actions, bad language are not uncommon, but the progress of the dementia is not common to all – many people with advanced memory loss will retain all if not most of their social graces. The carer may make a judgement that the person with dementia is not behaving in a moral way (attacking another person out of the context of self-defence, being abusive) which may seem like a moral retreat, or even a retreat from personhood, but the problem remains that the person can disappear behind bizarre and aberrant behaviour.

3.2.2 The fruits of the spirit – behaviour and belief

We would not want to deny the importance of consideration, courtesy, gentleness and so on in the conduct of human relationships – and of course many of these are culturally conditioned rather than universally accepted principles for the conduct of human affairs. When these markers of ‘civilised behaviour’ go, because of the ravages of dementia, the family can feel that the person has been lost to them, and even worse, he or she has ‘lost their faith’. This discussion interacts with the debate about how a person’s behaviour reflects their beliefs. Certain behaviour may seem to deny the profession of faith made earlier in the person’s life, yet here, the organic model may allow us to ‘excuse’ the person’s behaviour, if we see that the part of the brain which controls behaviour or which inhibits offensive behaviour is no longer functioning. It is a remarkable person who would not react in an aggressive manner when under threat or suffering from extreme stress.

Intriguingly, sometimes the relatives of those diagnosed with dementia have expressed a sense of relief upon hearing the diagnosis. At last they know what was ‘wrong’ with mum/dad/aunty/uncle/granddad. I ask the question, does a diagnosis of dementia release that person from personal responsibility for the consequences of their actions? Perhaps that had better be rephrased – for the consequences will be there nonetheless, it is their culpability we are addressing here. Inevitably we are dealing with legal language, and I suppose the legal framework or basis of sin-judgement-and redemption.

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73 Hitchins (2007)
3.2.3 A critique of the dominance of words over the experience of Christ

Profession of Christian faith, in my Christian experience, most often relies on the verbal articulating of that faith, and thence acting in a manner consistent with such a profession of faith. It can be argued that Christian faith need not be articulated for it to be sincere - though the benefits of confessing faith in Jesus Christ are two-fold: a) this articulation helps the speaker clarify his or her thoughts and position (which evokes the teachers’ maxim, ‘Expression deepens impression’), and b) will assist other persons present to enter into a better understanding of the viewpoint of the Christian.

3.2.4 Relationship with God

In conversation with a person with dementia, for ease of argument, two scenarios emerge: a) The person, who earlier in their life made a profession of faith, and then who, because of the losses of cognitive ability caused by dementia is no longer able to articulate that faith to another person, b) The person who begins to seek after God, but then begins to lose the ability to understand rational thought and to converse with another person at the level of abstract thought. I would argue that an experience of Christ transcends the capacity to verbalise that experience. Christian maturity is understanding the wisdom of God revealed by the spirit (1 Corinthians 2:6-16), ‘attaining to the whole measure of the fullness of Christ’ (Ephesians 4:13) following Christian rules for holy living (Colossians 3: 1-17). Words are vital for those who understand them,

‘Yet too often, Christians – and here we mean especially Protestant Christians – have allowed our worship to be shaped by the very presumptions of rationality and productivity that are regnant in the wider culture. Many Protestant services are so dominated by words that those who are mentally incapacitated are unable to participate. Further, the physical and social spaces of worship often powerfully communicate to persons that only the mentally and physically able ought to attend.’

Whilst an infant is denied certain rights of the adult, he or she does not have commensurable responsibilities. It is argued unambiguously here that all infants are persons. By the same logic, each individual, in whatever state of physical or mental capacity or incapacity is still a person.

3.2.5 Body and soul

The organ of thought, the organ of the mind is the brain. I argue that when it malfunctions, this does not cause a loss of the transcendent relationship of the person with the creator God. The erosion of the capacity to express oneself in terms which are understandable to other people does not accurately indicate the state of affairs of the relationship of the person who has with dementia with God. I believe we can challenge this notion of reliance on articulation in order to be assured of salvation.

The division into mind, body and spirit whilst technically obsolete permits a certain 
understanding of the difficulties which come from living with dementia. The danger is of 
veering towards a purely mechanical understanding of the human person, who it is proclaimed 
is a psychosomatic unity. We indwell our bodies, the body gives opportunity for the free will 
of the person to act out or communicate the inner dialogue. When the body malfunctions, the 
whole is affected. When the brain malfunctions, it can appear that the person is lost – but that 
is not the case. And herein lies a paradox: the body, though it is integral to who we are is but 
the shell in which we live, a fragile, temporal shell.

When a Christian minister conducts a funeral service, it is the funeral of a person. It is argued 
that this is distinct from the role of the undertakers, who arrange for the burial of a body, or 
for a body to be cremated. We do not speak of ‘burying a person’ - this would imply that the 
person was still living! Thus death brings with it a separation of ‘the person’ from the body. 
Separating the human person for the sake of argument into ‘body and soul’ or ‘body, mind and 
soul’ may assist the discussion up to a certain point, but does not accurately reflect the 
‘psychosomatic unity’ which is the human person: one lives in one’s body; one’s thoughts are 
generated within the brain, (which is part of the body) and the actions of one’s body are under 
the direction of the brain. In dementia the cognitive impairment and physical debilitation of 
disease join forces to produce a distortion and destruction of the observable characteristics 
which made the person who they once were.

A major conclusion of this investigation into dementia is that the personhood of the individual 
who has been diagnosed with dementia is paramount. The basis of this personhood lies not in 
their own merits, their social graces, their role or status in society, but in their being made in 
the image of God, and of being in relationship with God. This connection is stronger than any 
other – first comes the belief, then the behaviour. Being in Christ and in relationship with God 
is not through personal merit but is made possible through the blood of Jesus Christ shed on 
the cross at Calvary.

This discussion is helpful up to a point, but there is an increasing sense of revulsion at 
atomising or reducing human life to the purely functional level. What about the aesthetic or 
creative aspects of human life – these do not disappear.

The spiritual is not an add-on aspect, it is the most important, because the spirit endures 
beyond death. But the Easter faith believes in life before death too. The comfort, assurance 
and above all hope of the Christian faith should not be hidden away. Jesus has the words of 
eternal life, and offers life in all its abundance now.

3.2.6 The Interior world

The conclusion the writer is edging towards is this: an interior world exists where a person 
does his or her ‘business with God.’ Other people have no unmediated access to this interior 
world – there can only be insight via from thoughts translated into the words of the person 
and the actions undertaken after reflection. Because the person-to-person channels of 
communication have been marred in dementia, the carer or observer can only glimpse what is 
going on. The role of the carer or indeed the pastor is to remind and refresh the memory of the 
person to think on God, to give comfort and assurance so that the remaining ability for 
rational thought turns to contemplation of the love of God – made known in and through Jesus 
Christ – rather on the fearful and negative topics which understandably will predominate in
the mind of a person who through cognitive incapacity has either no past, or a fleeting and out of date past, a frustrating novel present and an unimaginable future. Research tentatively shows that by exercising cognitive abilities a person might retain those abilities further after the onset of dementia. Similarly giving opportunity for a Christian person to exercise his or her spiritual gifts may help that person continue to draw comfort from the scriptures, from hymns and songs, and the presence of other Christians.

3.2.7 The Eucharist

In the course of my ministry have taken communion (by extension) to people living with dementia. I have reflected at each occasions that the person living with dementia has responded differently than if they were simply eating, drinking or taking their medicine. There has been a tangible sense of the presence of Christ in the Eucharist, a remembering, a sense of recognition from the person living with dementia that something is happening out of the ordinary. The conventions of pastoral care are deeply challenged by dementia. We must keep on caring, keep on speaking words of comfort and love, keep on respecting the individual living with dementia as a person. Whilst the social graces, which oil ‘normal’ conversation have gone, and our prayers and presence may seem futile, they are not.

3.2.8 Appealing to other senses

I conclude that in the celebration of the Eucharist the phenomena of worship had been remembered at a deep level in the minds of the people living with dementia that their significance could be recalled, when other, more transient, recent memories have come and gone. I argue that the smell and taste of bread and wine in the context of the Eucharist had patterned and impressed themselves almost indelibly upon their memory, when their own ability to articulate their beliefs have gone. The ability to recognise signs, symbols and phenomena of worship – such the significance of the cross, a candle, and the Eucharist are somehow retained at a different level within the person living with dementia.

Dementia sufferers are social beings – as are all people! As the process of the diagnosis is being made, the sufferer faces a series of investigations which undermine their personhood and tend to make made them feel worse about themselves. This damaging collusion between medical science and the patient’s condition is anti-therapeutic.

3.2.9 Prophetic proclamation of the Gospel

The Church is called to be prophetic – to proclaim the gospel into people’s lives in the power of the Holy Spirit. This is manifestly counter-cultural: the ‘spirit of the age’ tells us that visiting and caring for people living with dementia is futile, because the channels of communication have gone. In response to this lie, the Church must hold onto the truth, without compromise, that people are made in the image of God and are made for relationship with God.

The Church must confront the consumer-mentality of the developed world, which bases a person’s worth on his or her ability to be productive. We need to guard against this criterion contaminating what the Church stands for, and to question our ‘standard measures’ of Christian growth and maturity (such as increased attendance, changes in behaviour, accountability, active rather than passive participation, baptism and confirmation), which will
not be found amongst people living with dementia. I emphasize that part of the Church’s calling is to affirm the spiritual nature of the person living with dementia. By visiting and continuing to minister amongst people living with dementia the Church proclaims that a person living with dementia is made in God’s image and made for relationship with God. By continuing to share our lives with people living with dementia, we will encounter Christ in each other. The Church, by identifying with the most vulnerable people in society will show God’s love to this broken world. The friends and relatives of those living with dementia will also meet with Jesus in those encounters, discover fresh hope and be open to God’s love and grace to come into their own lives.

If Kitwood\textsuperscript{75} can argue convincingly from the perspective of anthropology and evolutionary theory, that the burden of the task of caring for people with dementia should be ‘upon the community as a whole and not a few hard-pressed individuals,’ how much more should the Christian Church, as God’s community follow its calling to minister with people with dementia?

The challenge posed by dementia is an opportunity for the church to act with loving action towards those who are weakest and without a voice in society. Our good words will seem hollow without action. The challenge of dementia is that it flies in the face of the humanist lie – we are worthy because of our productivity and our capacity for abstract thought. Treating a ‘dementia sufferer’ as a person is not an abstract activity, but one which is grounded in loving, practical action. The voice of the voiceless must be heard. The church must ‘care for the carers,’ whether those carers are unpaid family members or people employed in the task of caring for those living with dementia. Jesus’ words, recorded in Matthew 25: 35 made it plain that we are to reach out to people who are vulnerable and in need.

3.2.10 The body and mind may not be intact, but the person is intact and spiritual life continues

Finally I have the sense that ‘people like that,’ who are living with dementia are on a journey, and on this journey eternity has begun to take over and the concerns for complex things has diminished – they are known, because Christ is known. Dementia challenges our thinking as it cuts across our simplistic notions, and questions our questions, and tears apart our reliance upon the rational to describe the transcendent nature of our relationship with God. As we minister with ‘people like that’ in Christ’s name, we demonstrate Jesus’ love by our attitudes and actions, and give reassurance that the loving arms of Jesus surround the person with dementia. We join with the person in proclaiming:

\begin{quote}
‘Loving Shepherd of thy sheep,
keep thy lamb in safety keep,
nothing can thy power withstand,
none can pluck me from thy hand
\end{quote}

\textsuperscript{75} Kitwood 2007 p 41
Loving Saviour, thou didst give
thine own life that we might live,
and the hands outstretched to bless,
bear the cruel nails’ impress

I would praise thee every day,
gladly all thy will obey,
like thy blessed ones above
happy in thy precious love

Loving Shepherd, ever near,
teach us all thy voice to hear,
suffer not our steps to stray
from the straight and narrow way.

Where thou ledest I would go,
walking in thy steps below,
till before my Father's throne
I shall know as I am known.⁷⁶

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⁷⁶ Jane E. Leeson *Loving Shepherd of Thy Sheep* (1842, altered) Hymns Ancient and Modern New Standard. This hymn has been a favourite of mine since childhood. The picture of Jesus holding the lamb was suggested by a moving chapter in Robert Davis *My Journey into Alzheimer’s Disease* (1989)pp 128-9
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