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### Forgetting Whose We Are

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# Forgetting Whose We Are: Theological Reflections on Personhood, Faith and Dementia

John Swinton, PhD

**ABSTRACT.** Because our culture so values rationality and productivity, observers easily characterize the life of the person with dementia in the bleakest terms because it lacks sociocultural worth. The experience of the person with irreversible and progressive dementia is clearly tragic, but it need not be interpreted as half empty rather than half full.<sup>1</sup> doi:10.1300/J095v11n01\_04 [Article copies available for a fee from *The Haworth Document Delivery Service*: 1-800- HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2007 by *The Haworth Press, Inc.* All rights reserved.]

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God looks through the tangles and confusions to our hearts to see what He Himself wrote there.

—*Jesus Christ*<sup>2</sup>

Dementia is a challenging and painful condition. It is challenging to our relationship, to our sense of security in the world and to our deeply

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held understandings of what it means to be a person and to lead lives which are good and fulfilling. It is painful because it causes a breach in our relationships that can, at times, appear unbridgeable and unbearable. But, dementia is challenging and painful not only because of the biological consequences of the deterioration of the brain and the relational difficulties that this initiates. It is painful because experiencing such deterioration within the types of societies that we have created in the Western world, societies which function according to the political and philosophical assumptions of liberalism, means that dementia takes on a shape and a meaning which is deeply disheartening. In liberal societies that venerate the primacy of reason, rationality, cognitive ability, independence, and the capacity for self-advocacy the experience of dementia stands as a challenge to our most basic aspirations. To be a person within liberal society is to be an autonomous, rational individual. Personhood is thus defined precisely by those aspects of experience that people with dementia lose as their condition progresses. To have dementia is to cease to be a person . . . or so our cultural assumptions would imply. It is little wonder, as Stephen Post points out in the epigraph to this paper, that the experience of the person with dementia is interpreted as half empty rather than half full! There is a real sense in which dementia is a cultural as well as a biological illness.

And yet, those of us who spend time with people who are experiencing dementia, know that this cannot be the case. It is difficult . . . sometimes painful. But as we relate, as we love, as we struggle to hold onto one another in the midst of the storms of dementia, we know intuitively that there is something more; that the person before us is of worth, is valued, *is* a person. We may not be able to articulate why it is that we feel this way, and indeed there are times when we struggle to feel this way! But still we reach out in hope and faith. What our culture tells us is truth needn't be so.

In this paper I will argue that to represent personhood and dementia in the ways that our society often does is to misunderstand at a fundamental level what it means to be human and to live humanly. Persons are not defined by what they *do* but by what they *are*, or perhaps better, as David Keck puts it, by *whose* they are.<sup>3</sup> The paper develops a practical theological critique of contemporary notions of personhood as they relate to the experience of dementia and argues for a revised understanding centred in God's commitment to human beings which is not defined by doing but by being with and for the other. In distinction from certain other models of personhood the paper will argue for the fullness of the personhood of people with dementia in all circum-

stances, thus opening up the possibility of developing forms of caring practices which move beyond culturally constructed assumptions about what dementia is assumed to be, towards models of care that take seriously the possibility that there is always something more if we take the time, slow down and look for it.

Let me begin with a story, my story.

### *A NARRATIVE OF SADNESS*

I remember the first time I walked on to a “dementia ward.” I was 18 and it was the first day of my psychiatric nurse training. I had no idea what was going to happen. The only thing I was certain about was that I didn’t want to be there. The place was busy, noisy, and it stank of urine and faeces. “Bodies” were wandering all around me; strange, lost souls with no apparent goal, just wandering; sometimes whispering to themselves, sometimes shouting to others who seemed to remind them of something or someone hidden deep within their past. I felt as though I was drowning in a terrifying sea of babbling, dishevelled, “crazy people.” I had never been on a ward before . . . any ward never mind this one! This was an initiation by fire. At first I sought solace in the television room. Perhaps if I sat very quietly and watched television they would leave me alone and I could finish up my shift and slip home before they noticed I was gone! But it was not to be. I was only 10 minutes in the door when the charge nurse ordered me to go and change an elderly man who had been incontinent. So, I and a nursing assistant took this gentleman into the open, public toilet to change him. As we wrestled with him to get his trousers off, the smell of faeces almost overpowering us, other patients wandered past, staring blankly at us as if we were not really there. It was like a scene from Bedlam!

And that day set the pattern for the rest of my time in that ward. A daily round of routine, wherein warehoused “non-persons” were given the basics of care within a context which seemed to assume that whoever these people might have been, they are no longer worthy of more than basic care and minimal respect. And yet, as I began to get to know Chrissie and Charlie and Derek and all the other persons who lived out their final days within that hopeless context, I began to see things differently. I began to realise that these people were not “lost souls,” they were people; people with long and fascinating histories who had contributed greatly to the world. Certainly they had lost a lot. In a real sense they had forgotten who and whose they were. Yet, there was much that

they still retained. They still laughed and cried; they still enjoyed the warmth of human contact; they were still—if you were prepared to come close, listen and take the time to engage—easily recognisable as valuable people with unique personalities. They still told stories which made no sense within their present context, but which provided echoes and resonances of lives lived well. The longer I worked with people whose life experience included dementia, the more I realised that the act of forgetting may not be the sole domain of the dementia sufferer. It seemed to me more that it was the system and sometimes, those of us who sought to offer care within that system, who frequently “forgot” people’s status as unique persons created to be in meaningful loving relationships with others and with God.

### *Moving on?*

Some 20 years later I found myself returning to the same ward, but in a new role as a hospital chaplain. Much had changed. The attitudes and routines were considerably less rigid, more compassionate and thoughtful. At one level the system appeared to be beginning to see people with dementia as significant persons in need of care, love, recognition, and sometimes protection. And yet, as I began to spend time with people with dementia and talk to carers it was clear that the ways in which services were set up, the lack of time that professional carers had to spend with people, the shortage of staff and the general expectation of the institution led to it still being very easy to “forget” the personhood of people experiencing dementia. The temptation to leave people sitting for hours in front of the television set in the common room watching daytime TV programs and children’s cartoons until the next mealtime or changing time came around, still loomed heavily on the horizon. Some of the structures had certainly changed and some of the practices carried out by individuals were excellent, but the subtle shadow of warehousing and the not so subtle demands of caring for profit raised the awkward question of precisely what kind of commodity people with dementia were assumed to be. Why is it that we seem to struggle to remember and hold on to the personhood of people with dementia and to provide models of care and support that reflect this?

Before we move on to try and answer this question, it will be helpful to begin by looking at what dementia is from a biological perspective and how widespread this condition is within the population. I write this paper from my own location in the United Kingdom, but I am aware that the issues I raise have implications throughout the western world.

## *The Demographics of Dementia in the United Kingdom*

According to the Alzheimer's Society,<sup>4</sup> dementia currently affects over 750,000 people within the United Kingdom, approximately 18,000 of whom are under the age of 65. Dementia affects one person in 20 over the age of 65 and one person in five over the age of 80. It is clear that the number of people suffering from dementia is steadily increasing and it is estimated that by 2010 there will be about 870,000 people experiencing this condition in the UK. This is expected to rise to over 1.8 million people with dementia by 2050. Worldwide there are around 18 million people who experience dementia. This being so, it is clear that the life experiences of people with dementia are of growing importance for both church and world.

## *The Biology of Dementia*

As a medical condition, dementia can be defined as a clinical state which is characterised by a catastrophic loss of function in multiple cognitive domains.

Diagnostic features include Memory impairment and at least one of the following: Aphasia, apraxia, agnosia, disturbances in executive functioning. In addition, the cognitive impairments must be severe enough to cause impairment in social and occupational functioning. Importantly, the decline must represent a decline from a previously higher level of functioning. Finally, the diagnosis of dementia should NOT be made if the cognitive deficits occur exclusively during the course of a delirium.<sup>5</sup>

At this basic level the story of dementia is narrated through the perspective of biomedicine and is conceived primarily as a narrative of pathology and loss. And of course dementia is indeed a narrative of profound loss for both sufferers and for those who care for them. This cannot and must not be underplayed. The issue that will occupy this paper is whether or not this is the only story that can be told about the experience of dementia.

Important as these diagnostic and demographic concerns are, we need to be careful that they do not deflect us from important aspects of the experience of dementia. It is easy to forget that dementia is a deeply personal and meaningful event within a person's life before it becomes a diagnosis. *No two people experience their dementia in the same way.* This is not a merely pedantic point. Diagnoses provide a formal structure which enables doctors to translate the personal experience of the sufferer into a form of professional discourse that will facilitate the utilisation of

the doctor's professional knowledge and skills in a way that, hopefully, will move a person from a state of disease to a state of health (or at least to alleviate their suffering in a meaningful way). However, important as diagnoses may be, they do not (or at least should not) comprehensively define the nature of the experience of the diseased person. They can tell us *some* things about dementia, but they cannot tell us other things. I would suggest that one of the errors that has been made in seeking to understand people experiencing dementia is that we have allowed the diagnosis and the diagnostic characteristics to determine the way in which we conceptualise and act towards the person who receives them.

### ***Dementia and Culture***

I previously suggested that dementia is a cultural as well as a biological illness. It will be worthwhile reflecting on this suggestion a little further. Dementia is a complicated human experience which has important biological interpersonal aspects. It is also a condition that, as has been suggested, is deeply impacted on by the type of culture within which it is experienced. The influence of culture on perceptions of dementia comes to the fore when one begins to reflect on the question of what it means to be a person and whether or not the consequences of dementia actually de-personalise the sufferer, that is, make them non-persons. A good example of this is found in the work of the Australian ethicist Peter Singer. Singer argues from liberal presuppositions that the central tenets of personhood reside in the human ability for "self-awareness, self-control, a sense of the future, a sense of the past, the capacity to relate to others, concern for others, communication and curiosity."<sup>6</sup> Singer's understanding of the moral capacities required for full personhood are drawn from the definition of personhood offered by the philosopher John Locke's definition in the *Essay Concerning Human Understanding*: A person is "a thinking intelligent being that has reason and reflection and can consider itself as itself."<sup>7</sup> For current purposes it will be helpful to draw attention to two aspects of Singer's definition:

1. Its liberal assumptions.
2. Its emphasis on *function* as definitive of personhood.

According to these understandings, human beings do not find their worth in what they *are* in and of themselves, but rather by what they are capable of *doing*, or what they *don't* or *can't* do. The essence of personhood resides in and is determined by such human functions as memory, reason, self-consciousness autonomy, and self-advocacy. It is

not enough for someone simply to be human. To be a person one needs to be able to carry out particular functions without which the morally protective label of “person” cannot be ascribed.

Of course, the attributes highlighted by Singer are precisely the attributes which the condition of dementia takes away from the sufferer. This leads to Singer is being able to advocate and argue strongly for the involuntary killing of people with dementia on the grounds that they are no longer persons.<sup>8</sup> This leaves us with the rather odd situation wherein human beings can be persons for 60, 70, 80 years, and live under the protection of this particular notion of personhood, only to find themselves living out their final years as non-persons who suddenly (or gradually) become less worthy of moral attention and protection. In the light of the demographics presented previously, this offers a bleak future for a large section of the population who will inevitably encounter dementia and in so doing, lose their status as persons.

We will return to the notion of personhood later as we move on. Here it will be enough to highlight the fact that models of personhood based on individual functionality and liberal assumptions will inevitably exclude people with dementia (and those with other stable or deteriorative cognitive disabilities), from the moral responsibility and protection of society. Post sums up this debate over the personhood of people with dementia thus:

There is a persistent bias against the profoundly forgetful that is especially profound in modern philosophical definitions of personhood. Only “persons” narrowly defined, it is often argued, have moral standing. Human beings with significant cognitive disabilities would have little or no moral status under such a system. The philosophers of this “hypercognitive” personhood seem to state that if we do not wear the persona dictated by their intellectualist leanings, we count less or not at all under the protective principles of non-maleficence and beneficence.<sup>9</sup>

Such discussions place people with dementia in a very tenuous position. As Stanley Rudman puts it, “It is clear that the emphasis on rationality easily leads to diminished concern for certain human beings such as infants . . . and the senile, groups of people who have, under the influence of both Christian and humanistic considerations, been given special consideration.”<sup>10</sup> The liberal worldview and its functional assumptions, when accepted uncritically, poses a significant threat to people with dementia.

If we are to offer a plausible alternative to such assumptions, it is necessary to begin with a basic question: *Is the person lost when they*

*encounter dementia?* Seeking to respond to this evocative question will provide an avenue into vital areas that are necessary for our understanding of what successful ageing might mean in the context of dementia.

### ***IS THE PERSON LOST TO DEMENTIA?***

One of the most important and influential myths which surrounds dementia is the assumption that the person with dementia is somehow lost to the disease process. In the eyes of many, the individual is perceived as “dead and gone”; somehow, it is assumed that the person who used to be there has been destroyed by the ravages of the disease process. What is left behind is nothing more than a shell of the person that used to be. This perspective is typified in the type of functionalist discussion put forward by Singer and Locke. In this view, the assumption is that the *real* person (defined by their ability to function at a cognitive level that is determined quantitatively and functionally), is stripped away, leaving only a shell or a shadow where once there was a person; the body is there but in a real sense the *true* person has departed. Dementia is assumed to “de-soul” the person,<sup>11</sup> to strip them of that which is essential for meaningful personhood. When this happens it becomes easy for us to begin to disregard people with dementia by shutting them away (either psychologically or physically), and offering modes of care which are deeply de-personalising and dispiriting. (e.g., leaving people to sit for endless hours with little or no stimulation and to farm out such “caring services” to individuals and conglomerates who view them primarily as commodities rather than persons).

But is there another way in which we can understand dementia and personhood? A way which will retain a person’s dignity and sense of self worth (in the eyes of self and others) and which might hold the potential to provide perspectives which could enable good and faithful living in spite of the ravages of this condition? Is there another way in which we might tell the story of dementia?

### ***RETHINKING DEMENTIA: FROM “INEVITABLE PATHOLOGY” TO PERSON-IN-RELATION***

Let us begin to answer these questions by exploring critically the suggestion embodied within the “natural history” narrative of dementia that

the primary story that can be told about this life experience is one of inevitable decline and loss. In developing an alternative narrative, it will be helpful to begin by examining the work of the English psychologist Tom Kitwood. Throughout his writings Kitwood consistently argues against the suggestion that dementia can only be framed negatively in terms of a “natural history” of pathology and loss. While acknowledging the very real loss that people with dementia encounter, Kitwood presents an important counter-argument, suggesting that dementia should be reframed in terms of what people with dementia *are* and *can* do rather than what they are not and cannot do. He calls for the recognition of another story that can be told about dementia within which people with dementia can be recognised as full persons who have lost much, but who nonetheless deserve respect in every dimension of their lives. Kitwood argues that, given the appropriate social, relational and spiritual context, it is possible for people with dementia to live lives which are considerably more hopeful than the biomedical narrative might suggest. Central to Kitwood’s position is the suggestion that while dementia may be organic in origin, the actual life experiences of people living with this condition are not as determined by fading neurological activity as is commonly assumed.

Kitwood is particularly interested in the interface between medicine, culture and experience, and the way that these things come together to create a particular experience and understanding of dementia. In line with some of the points made above, he argues that our understanding of dementia has been constructed by a cluster of discourses, of which the dominant one is grounded in medical science.<sup>12</sup> Within this interpretative framework, the person is totally subsumed to their neurological condition, even to the point where, linguistically, they are frequently referred to as “dead.” The possibility that the person may remain, despite the ravages of their condition, is often not even considered. The reason for this Kitwood suggests, is that dementia has become so medicalised that other ways of interpreting and understanding the person’s condition are almost totally subsumed to the power of the medical interpretation.

Throughout the many debates on the causes and treatments of senile dementia and indeed in much of the literature on dementia care, certain questions are very rarely asked. Who is the dementia sufferer? What is the experience of dementing really like? How can those who have a dementing illness be enabled to remain persons in the full sense? That they are experiencing subjects, with cognitions, intentions, desires, emotions, there can be no doubt. In the dominant

discourse, however, and in some of the subordinate discourses also, dementia sufferers are present largely as an absence. Those who are recognizable as persons are the carers. The dementia sufferers themselves are not; rather, they are defined out of the world of persons, even to the extent of it being claimed, almost literally, that those in the later stages are already dead.<sup>13</sup>

Whilst not using the same conceptual language, Kitwood here indicates the tensions between the natural and the social history of dementia and the negative consequences that occur when either one is given priority over the other. Due to the power of the medical interpretation of dementia, (the natural history) the *person* behind the diagnostic label, (their social history) has been “lost” from the debate about what dementia is, and what constitutes effective dementia care.<sup>14</sup>

### *Returning to the Question of Personhood*

Kitwood offers an alternative definition of personhood which challenges functional understandings in important ways. He defines personhood not in terms of functionality, but in terms of relationship. “It is a standing or status that is bestowed upon one human being by others, in the context of relationships and social being. It implies recognition, respect and trust.”<sup>15</sup> In this understanding, personhood is not a personal attribute and it does not relate to the presence or absence of a particular function. Personhood is the product of a particular type of relational encounter. To be a person requires one to be in a particular form of relationship with another person who is willing to bestow you with recognition, respect and trust. Personhood is not an individual achievement. It is a gift of community. This position is quite a significant shift away from liberal individualistic perspectives on personhood and its focus on the significance of intellect, reason, individuality and autonomy. Rather than conceiving of human beings as isolated, individual monads who in a sense, both create and own their personhood, in Kitwood’s perspective, community comes first; individuals emerge from and are shaped by the types of relationships that occur as they participate in some form of community.

### **PERSONS-IN-RELATION**

This idea that we are persons-in-relation is the critical position that is taken up by the Scottish philosopher John Macmurray. Macmurray developed his understanding of personhood in opposition to mode of

understanding human beings that is implicit in Descartes dictum *cogito ergo sum* (I think therefore I am), a formulation of the essence of humanness which is profoundly cognitive. Rather than focusing primarily on intellect and reason, Macmurray draws our attention to the significance and indeed the primacy of action. He puts forward a model of the Self as defined by its ability to act; by its agency, rather than primarily its ability to think or function at a cognitive level. In Macmurray's schema, thought is a component of human experience which is to be perceived as subordinate to or a subordinate component of human agency, action and behaviour.<sup>16</sup> It is in action that we encounter the world and it is in action that we discover who we are as persons. Ray Anderson offers a useful summary of some of the central aspects of Macmurray's thinking as they relate to the current discussion:

The self as agent cannot exist in a personal sense in isolation; action will be impossible in the complete sense because apart from the Other, who is also an agent, there will be no "resistance" to the self of the kind necessary to produce a personal act. Without resistance, which Macmurray defines as the core of tactual perception, the self as agent cannot experience itself, because there will be no 'other' than self to constitute a limiting factor to the movement of the self. The opposition, which comes in the form of that which is Other than the self, constitutes the unity of the experience of the self as Agent.<sup>17</sup>

As Macmurray himself puts it: "The distinction of Self and Other is the awareness of both; and the experience of both is the fact that their opposition is a practical and not a theoretical opposition."<sup>18</sup>

Important here is the suggestion that tactile resistance is essential for the development of the self. The Self does not develop through internal rational reflection alone, but requires and indeed demands the tactile experiences of human relationships and community. It is as we relate to and act upon others that the individual self emerges. As Price correctly highlights, in Macmurray's thinking:

Emotional and intellectual development is essentially communal and physical from the earliest of infancy. The mind is not in a box as Descartes conceived it, but develops in dynamic bodily interaction between self and other.<sup>19</sup>

An example from neurology will help to make the strength of this point clearer. Neurologist Sir John Eccles offers a particularly illuminating case study which helpfully illustrates the necessity of human relationships in the development of personhood.

A child, Genie, was deprived of all World 3 influences by her psychotic father.<sup>20</sup> She was penned in isolation in a small attic of his house in Los Angeles, never spoken to, and minimally serviced from the age of 20 months up to 13 years, 8 months. On release from this terrible deprivation she was of course a human being, but not a human person . . . Since then, with dedicated help by Dr. Susan Curtiss, she has been slowly climbing up that ladder to personhood. The linguistic deprivation seriously damaged her left hemisphere, but the right hemisphere stands in for a much depleted language performance. Yet, despite this terribly delayed immersion in World 3, Genie has become a human person with self-consciousness, emotions, and excellent performances in manual dexterity and visual recognition. We can recognise the necessity of World 3 for the development of the human person. The brain is built by genetic instructions (that is, by nature), but development of human personhood is dependent on World 3 environment (that is, Nurture<sup>21</sup>).

While, in the light of the previous discussion we may not completely agree with Eccles criteria for personhood, his key point remains apposite: Emotional and intellectual development is essentially communal and physical from the earliest stages of infancy. Relationships have neurological as well as psychological and spiritual significance.

### *Something More?*

The significance of such a relational perspective on neural development for our understanding of dementia is brought into focus from a slightly different perspective in Kitwood's understanding that the development of the brain is epigenetic rather than fixed and linear. Kitwood hypothesises that the brain functions on three levels.<sup>22</sup> At the first level we have the structural condition of the brain that is established over the lifetime of the individual. This level of brain functioning is open to the rigors of time and disease processes, and is inevitably deteriorating throughout a person's life. It is degeneration within the physical structure of the brain that causes the process of dementing.

The second level is hypothetical. “It is the highest level of mental functioning that is possible when a person’s brain is in a particular structural state . . . the upper limits to mental functioning are set by the structural state of the brain.”<sup>23</sup>

The third level comprises the *actual* mental functioning of the person. Kitwood points out that the actual functioning of all people is considerably lower than their potential functioning. None of us ever achieves maximum brain function. Consequently the human brain has a depth of reserve functioning that is rarely if ever used.

Such a schema has important implications for the ways in which we choose to care for people with dementia:

First, if Kitwood’s hypothesis is correct, there is no necessary correlation between level one and level three. We cannot realistically hope to understand and define dementia simply by exploring level one. Indeed, to attempt to do so is a serious error which can have significant negative impact on people experiencing dementia. However, as Kitwood points out, “This error is made repeatedly, and the findings of medical science are called in as a testimony to its truth.”<sup>24</sup>

Second, and importantly for current purposes, if we accept that there may well be regions of the person’s brain that remain undeveloped despite the ravages of dementia, this opens up space to explore ways in which the person’s brain functioning may be enhanced or diminished through nonneurological interventions such as the provision of particular types of contexts and environments within which a person’s spiritual and relational needs are prioritised.<sup>25</sup>

### *Rementia*

Kitwood’s hypothesis is not without a degree of empirical foundation. In his work he provides tantalising evidence to suggest that given an appropriate social, relational and spiritual environment, a degree of *rementing* can take place. In particular, Sixmith and colleagues in a study of “homely homes” where the care was of a very high quality found:

Clear examples of ‘rementing,’ or measurable recovery of powers that had apparently been lost; a degree of cognitive decline often ensued, but it was far slower than that which had been typically expected when people with dementia are in long term care.<sup>26</sup>

In the light of this, Kitwood, throughout his work, calls for a movement away from the medicalisation of dementia towards a model which takes seriously the wholeness and inherent relationality of persons and the significance of the natural interconnectivity of body, mind and soul. Such a focus encourages us to develop an alternative narrative that focuses on such things as personhood, interpersonal relationships, and spirituality.<sup>27</sup> In developing the beginnings of such a discourse it will be helpful to return to the thinking of John Macmurray.

### ***PERSONS-IN-RELATION***

In the second book which emerged from his 1953 Gifford lectures, Macmurray, building on his theory of action began to develop a model of persons as inherently communal—*Persons-in-relation*. In this volume Macmurray strengthens his critique of Cartesian individualism by providing a conceptual basis for understanding human beings as by definition persons-in-relationship:

The idea of an isolated agent is self-contradictory. Any agent is necessarily in relation to the Other. Apart from this essential relation he does not exist. But, further, the Other in this constitutive relation must itself be personal. Persons therefore, are constituted by their mutual relation to one another. “I” exist only as one element in the complex “You and I.” We have to discover how this ultimate fact can be adequately thought, that is to say, symbolized in reflection.<sup>28</sup>

For Macmurray, as for Kitwood, personhood emerges from relationship; community is the place from where individuality emerges. It is as “I” relate to “you” that I discover who I am and what it means to be human. *I am because we are; we relate therefore I am!*

Macmurray’s perspective, in like-manner to Kitwood’s is helpful for our developing understanding of the experiences of people with dementia. It not only challenges the types of cultural assumptions about individuality and functionality that we explored previously, it also seriously challenges assumptions about how we should conceptualise and respond to persons who have dementia. If human beings are persons-in-relation, then our personhood is not determined by anything within ourselves, but rather by that which lies between us. “Because the self is basically an agent who acts, personhood can only exist when there is a community of acting agents who intentionally relate out of love.”<sup>29</sup> We become

who we are as we relate to others. It is in the relational space that lies between “You” and “I” that I, for better or for worse, discover who I am and how I should or can inhabit the world. Neurological damage alone is not enough to threaten our personhood. It may alter the types of relationship we have. It may make us have to work very hard to sustain the reality of the personhood of the person with dementia. Nevertheless, the fact that a person has brain damage does not in itself prevent them from being a fully human person-in-relationship. Other people may prevent me from being a person, but the physical state of my brain cannot achieve such a task. In contrast to functionalist understandings of personhood, it is not defined by what someone has or does not have. Rather personhood relates to who someone is in relation to others.

### ***Rethinking Personhood***

This perspective moves us away from approaches to personhood that are based primarily on autonomy, self-determination, and cognitive capacities, towards a perspective which offers a strong place for the significance of relationships, emotions, feelings and non-cognitive experiences. Perhaps most importantly, the emerging relational understanding of personhood avoids the functionalist assumption that some people are to be considered human and others are not. This perspective assumes that to be human is to be a person.

## ***A THEOLOGY OF DEMENTIA CARE***

Important as Macmurray and Kitwood’s positions are for current purposes, they are not without their problems, primary amongst them being the lack of the transcendent in their understanding of relationality. If personhood is determined by human relationships-in-community alone, what happens to those who do not have access to such meaningful personal relationships? What happens to those whom others refuse to recognise as persons and who are deprived of the opportunity to attain meaningful personal relationships? (The outcast, the lonely, the forgotten, the hermit, those who have forgotten who they are relating to.) Do they cease to be persons? In order to grasp the significance of Kitwood and Macmurray’s perspectives and its significance for Christian care of people with dementia, we need to introduce a theological element which, while taking seriously the significance of human relationships, reaches beyond their limitations and anchors personhood in that which is in, yet beyond human relationships and community.

### ***God, Trinity and Human Relationality***

In my book *From Bedlam to Shalom* I argued for a relational conception of the human being based on Trinitarian theology.<sup>30</sup> There I made a case for human relationality to be viewed as analogous with Divine relationality; the inherently relational nature of human beings emerges from the and reflects the nature and relational shape of the God in whose image they are created; a Trinitarian God who is Himself constituted by relationships. In this understanding God, understood as Divine Trinity is defined in social terms, as a perichoretic community of love; God the Father, God the Son and God the Holy Spirit, inextricably interlinked in an eternal community of loving relationship.<sup>31</sup> The concept of perichoresis indicates both distinction and complete unity or communion; a co-existence of each member with the other. Such a conception of God as Trinity suggests a divine community of three fully personal and fully divine individuals, unified by their common divinity, that is, by the possession by each of the whole divine essence. Within such a context love is directed towards human beings, but primarily and archetypically towards the other persons of the trinity. God is therefore: “He who has His being in personal, loving, dynamic relations of communion.<sup>32</sup> Within such a conception of God the creation of humanity—whose inherent relationality is a direct product of being made in the image of this Trinitarian God—is understood as the product of the overspill of this divine perichoretic love. Thus it can be seen that human beings are created *from* and *in* loving relationships, *for* loving relationships. Love is the essence of God’s nature; God *is* love.<sup>33</sup> The relational nature of human personhood is thus seen to be analogous to Divine personhood. It is God’s willingness to enter into personal relationships with human beings which sustains and ensures their personhood, quite apart from human relationships which can be transient and changeable.

### ***A CHRISTOLOGICAL PERSPECTIVE***

Here I would like to build on this understanding by focusing on an important Christological perspective which is vital for understanding (1) the way in which God remains with us and for us even when we can no longer cognitively be with and for God, and (2) How those who follow the Trinitarian God who *is* love can understand themselves in relation to people with dementia. In order to achieve this, I will draw on the thinking of the German theologian Dietrich Bonhoeffer. A thoughtful

and creative reflection on Bonhoeffer's Christology as it relates to the experiences of people with dementia will provide a vital foundation for dementia care. Central to the argument that will be developed here is the suggestion that God remains with us and for us even when we cannot grasp the significance of that relationship with our cognitive senses. If God is with and for the person with dementia, then those who claim to follow God are called to be with and for the person with dementia in quite particular ways.

### *God with Us and for Us*

In his Christology lectures Bonhoeffer offers a challenging perspective on the nature of Christ and the type of relationship that God offers to human beings. He suggests that:

Christ is Christ not as Christ in himself, but in relation to me. His being Christ is his being *pro me*. This being *pro me* is in turn not meant to be understood as an effect which emanates from him, or as an accident; it is meant to be understood as the essence, as the being of the person himself. This personal nucleus itself is the *pro me*. That Christ is *pro me* is not an historical or ontical statement, but an ontological one. That is, Christ can never be thought of in his being in himself, but only in his relationship to me. That in turn means that Christ can only be conceived of existentially, viz. in the community . . . It is not only useless to meditate on a Christ in himself, but even Godless.<sup>34</sup>

This passage encapsulates something of the essence of Bonhoeffer's Christology. If we are to understand Christ we must understand the relationship of Christ to human beings; *the very being of Christ is his being-for-humanity*. Bonhoeffer suggests that it is impossible to reflect on Christ-in-Christ's-self without reflecting on his relationships to humanity. In Christ in a very real sense, God creates a space within God's self for human beings. God opens up God's very being to incorporate human beings in such a way that it is not possible to understand Christ without recognising his relatedness to and desire to relate to human beings. As Rasmussen puts it, "Christ can be thought of only in relational terms. 'Being-there-with-and-for-us' is the manner of his existence and presence. . . . Christ exists '*as community*.'<sup>35</sup> Indeed, in Bonhoeffer

perspective, to reflect on Christ without reflecting on his relatedness to human beings is a Godless act.

This relatedness is not theoretical, nor does it relate only to the historical Jesus. Christ's relatedness to human beings is active and contemporary. God is *pro me* in the present as well as in the past. "The humanity is taken up into the Trinity not since eternity, but from now to all eternity." God is with us and for us now in a way that is unchangeable. Christ is the one who is for others; his sociality towards and for human beings is ontological. As Jenson puts it, "This *new* thing of and in God (that it is new is clear from the fact that this is "from *now* to eternity" is an extension of God's identity to include humanity."<sup>36</sup>

Bonhoeffer views the human self as analogous to this inherent relatedness of Christ.<sup>37</sup> The human self is inherently social, formed, as has been suggested in this paper, in self-other relationships. In like manner to the suggestion that Christ can only be understood as Christ-in-community, so also human beings can only be understood as they relate with one another and with God. The human person is created to be with and for others and with God in a way that is analogous to the way in which Christ is with and for human beings.

### *Creating Space for the Other*

This Christological perspective has at least two important implications for the ways in which we frame the care of people with dementia. First, if in Christ, God has opened up his very being in relationship to human beings, there is nothing that can change that transformative fact; not neurological deterioration, not forgetting who and whose we are, nothing. God remains with and for the person with dementia even when the person can no longer be with and for God, at least in a cognitive sense. The significance and personhood of the person with dementia is safeguarded and sustained within the very being of God quite apart from the relationships a person may or may not encounter at a temporal level. We might forget God, but God will not and indeed cannot forget us. When we can no longer minister to God and to others, the God who is with us and for us will minister to us in our hour of need.

This point can be well made if we reflect creatively on one of Bonhoeffer's poems,<sup>38</sup> "*Christians and others*":

All go to God in their distress,  
Seek help and pray for bread and happiness,

Deliverance from pain, guilt and death.  
All do, Christians and others.

All go to God in His distress,  
Find him poor, reviled without shelter or bread,  
Watch him tormented by sin, weakness and death.  
Christians stand by God in His agony.

God goes to all in their distress,  
Satisfies body and soul with His bread,  
Dies, crucified for all, Christians and others  
And both alike forgiving.

Like all poetry there are many ways in which one might interpret this poem.<sup>39</sup> Here we will use the experience of dementia as a lens through which we might interpret or perhaps better re-contextualise Bonhoeffer's words. Verse 1 informs us of the various ways that, through our lifetime both Christians and non-Christians minister to God.<sup>40</sup> Verse 2 narrows the focus to the ways in which Christians minister towards and stand in solidarity with God for the sake of the Kingdom. The idea of ministering to God is interesting. Indeed we might define discipleship as a process of ministering to God through acts of worship, prayer and so forth, and through our attitude of being with and for the other in all of the various states through which we encounter life. To be a follower of Christ-who-is-for-others is to lead lives which are open to ministering towards the other, including the Ultimate other-God. Many people encountering dementia have spent most or all of their lives ministering to God in discipleship and acts of care towards God and one another.

But verse 3 takes us to another place. Here we find an interesting resonance with John 21: 18-19: Jesus said, "Feed my sheep. I tell you the truth, when you were younger you dressed yourself and went where you wanted; but when you are old you will stretch out your hands, and someone else will dress you and lead you where you do not want to go." Jesus is of course prophesying Peter's eventual death. However, his words have a deep resonance with the experience of dementia and the contextual meaning of the third verse of Bonhoeffer's poem. When it is no longer possible for us to minister to God in the ways that we once did; when we can no longer even remember who God is or what God has done for us in Christ, God comes to us and ministers to us in our weakness. God remembers us even when we can no longer remember God. This coming-to-us-in-our-weakness should not be perceived in terms of a reward for good service.<sup>41</sup> It is an act of Graceful friendship,<sup>42</sup> the inevitable

outcome of Christ being *pro me* in ways that cannot be destroyed by the ravages of time or disease.

God's coming to us in our weakness, His remembering us when all seems to have been forgotten is an inevitable outcome of his essential nature as Christ-for-us. Christ's *pro me*, his unending friendship, carries us and sustains our personhood even when we can no longer minister to him. Our ministry towards God is not forgotten; our friendship with God is sustained even when we have forgotten what it means to be God's friend. Bonhoeffer's insightful poem read through the lens of the experience of dementia reminds us of the importance of recognising the sustaining hope that we do not only minister towards God, we are also ministered to by God in our hour of need. The onset of dementia creates precisely such an hour.

### MARY'S STORY

A story will help us understand and begin to see how we might embody these important theological reflections. Margaret Hutchison, a nurse, tells the following story of her experience with a woman who has developing dementia.

An elderly lady suffering from dementia, paced the corridors of the nursing home restlessly—repeating over and over, just one word. The staff were disconcerted, but no one seemed quite sure how to calm her and put her mind at rest. In fact they were at a loss to understand the reason for her distress. The word she repeated over and over again was God—and that was all she said. One day a nurse got alongside her and walked with her up and down the corridors until eventually in a flash of inspiration she asked the lady, “Are you afraid that you will forget God?” Yes, Yes! she replied emphatically. The nurse was then able to say to her, “You know even if you should forget God, He will not forget you. He has promised that.” For this lady who was forgetting many things, and was aware of it, that assurance was what she needed to hear. She immediately became more peaceful, and that particular behaviour ceased. She was responding positively to care which extended beyond the needs of body and mind—care of the human spirit.<sup>43</sup>

This woman's revelation about the sustaining love of God which reaches beyond memory and the ability to reciprocate cognitively is

crucial. Human beings are indeed persons-in-relation. Whom we become is, in a very real sense profoundly shaped by those we encounter. But, ultimately our identity as persons and our hopes and possibilities for the future is determined and sustained by God who, in Christ is with us and for us even, and perhaps particularly in our darkest hours of need. Even when all of our faculties are taken from us, we remain persons-in-relation through God's continuing desire to relate to us, to minister to us, to be with us and for us now and for evermore. This is an inevitable and beautiful consequence of being made in the image of a Trinitarian God's who is *pro me*.

### ***LOVING GOD AND THE MEANING OF LIFE***

All of this suggests that the task of dementia care is first and foremost to sustain and facilitate meaningful personal relationships, ultimately with God, but penultimately through other human beings. Iozzio puts this point well when she observes that "the summum bonum of human flourishing towards which human beings are called . . . [is to be] . . . related intimately with the triune God."<sup>44</sup> It is this theological dynamic which defines both happiness and success in the whole of life and no less so in the context of the experience of dementia. Theologically and anthropologically understood good dementia care has to do with enabling persons to remain in relationship with God and with one another despite the ravages of the condition. Care that is truly care must be shaped and bounded by this fundamental presupposition. In concluding this paper we will briefly reflect on how this might work itself out within the practices of the church.

#### ***Personhood as an Act of Faith***

This paper has offered an argument for the personhood of people with dementia to be perceived as real and ever-present even in the midst of the experience of severe dementia. Kitwood's hypothesis on the epigenetic development of the brain suggests that we simply do not and cannot know the cognitive level that people are working at or indeed have the potential to function at. While their outer appearance may well reflect chaos and loss, there may well be hidden depths to a person's experience which, if the key can only be found, may reveal new and healing perspectives on their situation. Thus whilst a person's situation may

appear to be hopeless, in reality there always remains the possibility of “something more.”

None of this is intended to minimise the very real pain experienced by people whose loved ones face the outworking of this condition. While we may not want to argue that personhood is lost to the illness, there is no question that often the person-as-we-once-knew-them encounters radical changes. Iozzio, reflecting on her own families experiences with her father who had Alzheimer’s disease captures something of the deep loss that accompanies dementia for all concerned:

Lovers, once intimately attuned to each other’s rhythms, find themselves negotiating life’s blessings and curses with a stranger. Children, having managed adult relationships with their parents, find themselves in reversed roles mothering or fathering them. Sisters and brothers, after fiercely asserting their uniqueness, find themselves holding desperately to the old familiar. Not suspecting the moment when I am no longer recognizable to my lover, parent, brother, friend, I am caught off guard by their unknowing. How do I remain faithful to them when they question, because of my Alzheimer’s dementia, who I am?<sup>45</sup>

To retain a sense that the person before us is fully a person when such profound changes are occurring is not an easy task for caregiver, be they professional or lay. To recognise people as fully human when they have forgotten who they are, who you are and to whom they ultimately belong requires more than psychological reframing; it requires an act of *faith*. The writer to the Hebrews describes faith thus: “Now faith is being sure of what we hope for and certain of what we do not see.” In order for us to hold on to the personhood and the full humanity of someone who appears to have been stripped of both, we need to be sure of what we hope for and certain of what we do not see. We need to develop a faith that is based on the theological certainties highlighted in this paper and supported by the types of philosophical and psychological insights which assure us that our faith is not in vain. When this happens, Christians can begin to construct a different story around the experience of dementia and begin their task of caring at a different place; a place where it is not assumed that the story of dementia is *nothing but* a natural history of loss and devastation, but is rather a narrative of a fragmented human *person* who is held and sustained in their uniqueness by a God who has promised never to abandon them;<sup>46</sup> a unique individual who requires the offer (but not the imposition) of relationships that can affirm her in

her personhood and in her relationship with God. This theological dynamic allows us in faith to grasp (sometimes with great difficulty) the truth that the person before us may have changed in quite profound ways, but that they nonetheless remain persons loved by God and in need of friendship and love. Such a position is the foundation of Christian care and a key to facilitating successful ageing.

### ***Re-Membering and Remembering***

As in faith, the person experiencing dementia is held and sustained within the affirming boundaries of human and divine relationships, they are *re-membered*. To re-member something is to bring back together that which has been fragmented. To re-member a person with dementia is to offer them the kind of relational environment which mirrors God's loving, remembrance and unchanging embrace and in so doing, draws back together the wholeness of the person whose life has been fragmented by the experience of dementia. Such a relationship both *re-members* the person and *remembers* for them. As Iozzio puts it:

As long as my father lives, the work of my brothers/my aunts and uncles, my cousins, my husband and me is to *remember* for him. We work to put him back together, to *re-place* him in our relationships, to *remember* his sense of self. Even as he continues to lose his sense of self, which has been bound up in relationality to my mother and our family these many years, we are to remind him of his place among and with us. Even as the dementia of [Alzheimer's disease] causes him to not know us we are to know him. And even as he barely resembles the man he used to be—commanding, decisive, large—he is still husband, father, brother-in-law, and uncle to us. Fidelity asks this much of us, that we remain with him even as he fails to remember us, abandonment is not an option.<sup>47</sup>

What can be said of fidelity can also be said of faith: *Abandonment is not an option.*

### ***Faith-in-Community***

Such faith requires a community of persons-in-relation to sustain it. The church community; the Body of Christ is precisely the context required to develop and sustain such faith and the “practices of remembrance” which emerge from it. Dementia is a profoundly stressful experience for the person who is experiencing it (particularly in the

early stages); but is also so for those who seek to offer care and support. The alienation, sense of loss and crushing sense of loneliness and responsibility felt by carers cannot be underestimated. Often carers are left to struggle on alone. Such situations can stretch faith and the ability to re-member and remember to its utmost limits. Acts of faith and remembrance require relationships of deep love and support. We have argued that, in Christ, God has related a space within God's self for humanity. As beings made in the image of that same God, we are also called to open up a space within ourselves and within our lives for the other. If we are to take seriously and embody this revelation, we must recognise that the care of the person with dementia (and of those who offer care to them) is not simply the responsibility of the individual's family and close kin. Such care belongs to the whole Body of Christ. If this is so, then the burden of care cannot lie simply with discrete individuals quite apart from the responsibilities of the Christian community. Nor can it simply lie with "secular" caring services. The care of Christians with dementia is a responsibility of the whole Christian community and not just those who are "directly involved." This basic theological understanding needs to be factored in strongly to any caring or respite strategy that church communities embark upon. If, through the gifts of recognition, friendship, acceptance, support, and hospitality, churches can offer committed support, encouragement, and solidarity with caregivers and people experiencing dementia, then the possibility of the church community opening up a genuine and unchanging space for the person with dementia and their family becomes a real possibility.

### CONCLUSION

These closing reflections on the implications of the understanding of dementia developed in this paper are only pointers towards many ways in which the church can embark upon its ministry of faith and remembrance with people living with dementia.<sup>48</sup>

Perhaps the key thing that we should take away from the discussion presented in this paper is the importance of subjectivity for epistemology: It is necessary to come closer to people with Alzheimer's disease to overcome hypercognitive acculturation and unduly negativized stereotypes.<sup>49</sup> It is only as in faith, we come close to the person whose life is being affected by dementia that we can begin to see that there may be "something more" than we first thought. In coming close and reflecting

on that experience in the ways that we have done in this paper, we receive the gift of a deep revelation of a God who relates and remembers and who creates human beings with the primary purpose of relating and remembering. When we come close and listen to God in the midst of the deep fear that we will be forgotten; that dementia will take away the main purpose of our lives and our only source of true happiness, we do well to remember the words of Jesus to the criminal on the cross who shouted: "Jesus, remember me when you begin ruling as king!" Then Jesus said to him, "Listen! What I say is true: Today you will be with me in Paradise!"<sup>50</sup> The truth of these words is the source of our hope and our joy. We will *not* be forgotten.

## NOTES

1. Post, S.G. (1995). *The Moral Challenge of Alzheimer Disease* (1st ed.), The Johns Hopkins University Press, p. 15.
2. I am grateful to my friend and colleague Donald Meston, assistant chaplain at Aberdeen's Cornhill Hospital for this quotation. Source unknown.
3. Keck, David. (1996) *Forgetting whose we are: Alzheimer's Disease and the love of God*. Nashville: Abingdon Press.
4. Alzheimer's Society. <http://www.alzheimers.org.uk/> (Accessed 3/10/06).
5. <http://penta.ufrgs.br/edu/telelab/3/dementia.htm> (Accessed 3/10/06).
6. Singer, Peter. (1993) *Practical Ethics*. (2nd ed.). New York: Cambridge.
7. Locke, J. (1964) *An essay concerning human understanding* (1690). Wozzley AD, ed. Glasgow: William Collins/Fount, p. 211.
8. Singer, Peter. *Practical Ethics*, p. 192.
9. Post, Stephen. "God and Alzheimer's A neurological reflection on religious experience, self, and soul." <http://www.parkridgecenter.org/Page482.html> (Accessed 3/10/06).
10. Rudman, Stanley. (1997), *Concepts of Persons and Christian Ethics*, Cambridge University Press, pp. 47-48.
11. Sacks, O.W. (1985) *The Man Who Mistook His Wife for a Hat*. London: Duckworth. Ch. 2.
12. Kitwood, Tom. (1995) 'Toward the Reconstruction of an Organic Mental Disorder.' In Alan Radley, *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*, London: Routledge.  
Tom Kitwood. "Personhood, Dementia and Dementia Care" in S. Hunter (ed.), *Dementia: Challenges and New Directions*. Jessica Kingsley Publishers 1997. Research Highlights in Social Work 31.
13. Kitwood in Radley, Allan. (1995) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. Taylor and Francis, p. 153.
14. Swinton, John. (2000) *Resurrecting the Person: Friendship and the care of people with severe mental health problems*. Nashville: Abingdon Press.
15. Kitwood, Tom. (1997) *Dementia Reconsidered: The person comes first*. Milton Keynes: Open University Press, p. 8.

16. Macmurray, John. (1991) *The Self as Agent*. Humanity Books.
17. Anderson, Ray S. (1975) *Historical Transcendence and the Reality of God: A Christological Critique* Grand Rapids: Eerdmans, p. 194.
18. Macmurray. *The Self as Agent*, p. 109.
19. Price. 'Community and theology in the life of Ray Anderson.' In Todd H. Spiedell. (Ed) (2002) *Essays in Celebration of Ray S. Anderson: On Being Christian . . . and Human*. Origen: Wipf and Stock Publishers, p. 25.
20. Eccles here is using Karl Poppers' representational model of human neurological evolution. According to this model, the human brain evolved in three stages. (Worlds) World 1 is the world of physical objects and states, including human brains. World 2 is the whole world of physical subjective experiences or states of consciousness, i.e. perception, thinking, emotions, memories, imagination, etc. World 3 is the world of knowledge in the objective sense, i.e., the whole man-made world of culture including language. According to Eccles and Popper, It is in the interplay between World two and World one that a person develops a sense of self and a conscious place in the universe. Persons create world 3 experiences by using world 2 experiences. World 3 experiences in turn affect world 2 experiences in a continuing dialectical process which constitutes cultural and active human evolution. Eccles Op. Cit. pages 72-74. (Passive evolution is an opportunistic process whereby an organism seeks to adapt to a particular environment in an attempt simply to survive. Active evolution demands a higher level of consciousness, and occurs when an organism, primarily human beings, seeks out particular ways of living and places to live in according to personal, self-conscious values and purposes. Eccles argues that it is primarily in this second sense that human evolution continues in the present.)
21. Eccles, John C. (1989) *Evolution of the Brain: Creation of the Self*. London: Routledge. pp. 221-222.
22. Kitwood *Dementia Reconsidered*. p. 151.
23. Kitwood *Dementia Reconsidered*. p. 151.
24. Kitwood *Dementia Reconsidered*. p.152.
25. Kitwood *Dementia Reconsidered*. p. 152.
26. Kitwood *Dementia Reconsidered*. p. 62.
27. Kitwood *Dementia Reconsidered*. p. 55.
28. Macmurray, J. (1961) *Persons in Relation*. London: Faber and Faber. p. 24.
29. Anderson, *Historical Transcendence*, p. 248.
30. Swinton, John. (2000) *From Bedlam to Shalom: Towards a practical theology of human nature, Interpersonal relationships and mental health care*. New York: Peter Lang.
31. This concept of perichoresis is developed by Jurgen Moltmann as it pertains to the personhood of God within the Trinity in: *The Trinity and the Kingdom of God: The Doctrine of God*. (1993) London: SCM Press Ltd. Pp. 174 ff, and as it applies to God's relationship with His creation in his: *God in Creation: An Ecological Doctrine of Creation*. (1985) London: SCM Press Ltd.
32. Feenstra, Ray S., & Plantinga, C. (1989) *Trinity, Incarnation and Atonement: Philosophical and Theological Essays*. Indiana: Notre Dame Press, p. 27.
33. 1 John 4:8.
34. Bonhoeffer, Dietrich. *Christ the Center 1978 [1966]*. trans. John Bowden from the German *Christologie* (in *Gesammelte Schriften III*, 166-242). New York: Harper & Row. Abbreviated CC, pp. 47-48.
35. Bonhoeffer. *Christ the Centre*, p. 216.

36. Jenson notes that “He [God] does not change who he is because he is insufficient; he extends himself freely and lovingly to include humanity in his own glory.” In John de Gracy (ed.), (1996) *The Cambridge Companion to Dietrich Bonhoeffer* Cambridge: Cambridge University Press, p. 152.

37. Bonhoeffer, Dietrich. *Sanctorum Communio: A Theological Study of the Sociology of the Church* (1998) DBW Vol. 1. Translated by Reinhard Krauss and Nancy Lukens. Edited by Clifford Green. Minneapolis: Augsburg Fortress.

38. Robertson, Edwin. *Dietrich Bonhoeffer's Prison Poems*. (1999) Grand Rapids: Zondervan, p. 51.

39. Robertson, Edwin. *Dietrich Bonhoeffer's Prison Poems*. Robertson relates it to Jesus being ministered in his agony by Mary and John. We might also reflect on it in the light of Matthew 25 and Jesus suggestion that when we minister to the poor, the broken and the outcast, we are actually ministering to him. Again we might reflect on Jesus' experience in Gethsemane and the significance of being available to God in this way.

40. Matthew 5:45. “He causes his sun to rise on the evil and the good, and sends rain on the righteous and the unrighteous.”

41. Although hope and faith in Christ inevitably brings rewards, one of which is the knowledge that God will never leave nor forsake us.

42. John 15:15. “I no longer call you servants, because a servant does not know his master's business. Instead, I have called you friends, for everything that I learned from my Father I have made known to you.”

43. Hutchison, Margaret G. “Unity and Diversity in Spiritual Care.” Paper originally presented at the Sydney University Nursing Society First Annual Conference for Undergraduate Nursing Students in NSW, September 1997.

44. Iozzio, M.J. (2005) “The writing on the wall ... Alzheimer's disease: A daughter's look at mom's faithful care of dad.” In *Journal of Religion, Disability and Health*. Vol.9 No. 2 pp. 49-74. Page 57.

45. M.J. Iozzio. “The writing on the wall . . . Alzheimer's disease,” p. 51.

46. Romans 8:39. “Neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord.”

47. p. 64 (*italics added*).

48. Elsewhere I have explored the significance of the sacraments, liturgy and worship for the process of re-membering and resurrecting the personhood of people with dementia Swinton *Resurrecting the Person*.

49. Post. *The Moral Challenge of Alzheimer's*, p. 17.

50. Luke 23:43.

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