

Care and Caregiving for a Person with Dementia - making meaning of a changed life

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for the Anglican Diocese of Canberra and Goulburn*

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The purpose of this paper: is not intended to provide direct advice for carers on how to perform their role. Rather it seeks from the point of view of one carer, to shed light on the nature and challenges of that role and to suggest ways of 're-envisioning' the role from burden to 'an intentional, mutual spiritual path.' What must also be said is that this path is personal and varied, drawing as each from different personal histories and Christian traditions.

Introduction: The relationship between people living with dementia and their carers, (especially those who are family members) is inescapably dialogical and mutually affecting, requiring continuing efforts of understanding, interpretation & adaptations, especially on the part of the carer.

With reference to the inherent power relations that are at play in pastoral care with those living with dementia, I had previously highlighted the need for vigilance in such situations. As Stephen Pickard pointed out, even as we thankfully recognise what we can learn from our sisters and brothers, 'Ministry to the disabled can all too easily become a curved ball; it becomes a means to our (own) betterment,'¹ and we might add, to our own virtue signalling.

The balance of 'power relations' in caring for the dementia diagnosed, especially by a family member, is of a different kind. Here the needs of the latter are often highlighted and for good reason, they set the agenda. Here, as most writings on caring also

¹ Stephen Pickard, 'Being a disability-inclusive Church', unpublished paper.

highlight, the needs of the carer must also be taken into account for the relationship to be sustainable².

How this is interpreted, negotiated and played out, as well as incorporated into the life of faith is a subject that is can be quite specific to the situation but which requires, nevertheless, much wisdom, learning and periodic re-setting.

First and foremost, for the caregiver/recipient relationship to work well at the practical level, the carer needs reliable knowledge and understanding to guide and inform **their** thoughts, judgements and actions. An area of knowledge that is essential for the carer at a primary level concerns the nature of dementia itself, specifically as it applies to the person in her care but, just as importantly is an appreciation of what it means to live with the condition & what is its likely prognosis and progression. All these are relevant to how the carer interprets the needs, behaviour and the condition of the person in their care.

Then, perhaps even more fundamentally is the question of how, and to what extent dementia has changed the person, in view of the loss (great or small) of capacities that are evident. *To what extent is this the person they once were? In fact, **are they still persons?*** Opinions on these questions are more diverse and even controversial as they reflect the question of how we conceive of persons in the first place.

This question of the identity of the person living with dementia is crucially relevant to how they are treated by others and, as we will see in the pioneering work of Tom Kitwood,³ and John Swinton⁴, it

² Jane Marie Thibault & Richard L Morgan, *No Act of Love Is Ever Wasted: The Spirituality of Caring for Persons with Dementia* (Nashville: Upper Room Books, 2009), pp. 32-33

³ Tom Kitwood, *Dementia Re-considered: The Person Comes First* (Buckingham: Open University Press, 1997).

⁴ John Swinton, *Dementia: Living in the Memories of God* (Grand Rapids: Eerdmans, 2012).

is also directly relevant to the nature and quality of the care that is their due.

For caring and carers, there is therefore a clear need to understand the condition *on its own terms* not only regarding, as noted above: a) the nature of dementia in its various forms; b) the lived experience of those with dementia; c) the progress of this degenerative condition; but also crucially, d) theologically adequate views of dementia and personhood. These discussions will form the first section of the paper.

As a carer, I discovered, later than I would have liked, the practical and existential importance of adequate knowledge in all these areas for judgements and for interpretations that are fair and well-informed.

The first part of this paper will begin with the need for understanding dementia in relation to those areas listed above, beginning with medical data significant for the work of caring and ending with an argument to re-examine our assumptions on personhood and the bearing these have on relationships and care. But as more recent literature have pointed out, the medical model alone is insufficient for proper and worthy care of the dementia diagnosed & as TS Eliot famously and more poetically warned, “Where is the wisdom we have lost in knowledge; where is the knowledge we have lost in information?”⁵

The sections that follow will also feature *the wisdom that is needed for the unique demands of caring for a family member*, especially in the context of Christian faith and the spiritual path.

I. Understanding the condition on its own terms

a) the nature of dementia in its various forms ⁶

⁵ TS Eliot, *The Rock* (London: Faber & Faber, 1934).

⁶ The Dementia Australia website is a useful introductory source on the nature of this medical condition. <https://www.dementia.org.au/>

b) the lived experience of those with dementia: challenges & impediments:⁷

- the need to process thousands of pieces of new information which they encounter every day
- the increasing loss of short-term memory
- a life that is lived in the past or in an 'eternal now': when, for example, people met two minutes before are not remembered; the 10 steps from the bedroom to the lounge cannot be retraced without help...
- memories become more and more distant and childhood is relived – sometimes carers are mistaken for parents and sons and daughters are not recognised
- severely compromised memory and processing abilities produce disorientation in time and place, misperception and problems sequencing actions correctly.
- coping with a world when so many normal interpretative cues are unavailable is exhausting and stressful and the environment becomes increasingly bewildering.
- maintaining any kind of function takes enormous effort; there is deterioration in a person's fine motor skills, balance, speech, bladder and bowel control

⁷ Saunders presents an insightful and sensitive account of the experience of dementia, especially the challenges and struggles it presents. See his 'Dementia: Pastoral Theology and Pastoral Care, (Cambridge: Grove Books, 2002), pp. 5-6.

See also Malcolm Goldsmith, 'The Experience of Dementia' in Chapter 4, *In a Strange Land... People with Dementia and the Local Church* (Southwell & Edinburgh: 4M Publications, 2004) for his discussion and recommended sources on the question.

For a clear, accessible and personal theological discussion regarding the lived experience of persons living with dementia, I also **recommend a conversation** between John Swinton and Curtis Chang on The Good Faith Podcast, 'Dementia: Living in the Memories of God' on

<https://www.youtube.com/watch?v=JLTBsf3rhNs>

- depression, aggression, anxiety, paranoia, disinhibited behaviour, lack of interest in self-care and confabulation (the invention of narratives to make sense of reality as it is (mis) perceived), are common reactions to the stresses experienced
- Diana Freil McGowan expresses in a book describing the course of her own dementia, that life “had become an improvisational theatre, and I was left to ad lib my way through it.”⁸

c) progress & prognosis⁹

While the medical diagnosis of dementia is based on symptoms common to many people, it is a mistake to assume that all people with dementia suffer in the same way and have the same needs because the experience of the illness is highly individual.

The progress varies depending on:

- personality & life history
- ethnicity
- environment
- the speed of neurological wasting;
- the areas of the brain it affects
- the ability of the sufferer to compensate for consequent losses
- the extent to which he or she is supported & the web of relationships in their life
- the environment in which they live

⁸ Diana Freil McGowan, *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's*, Mainsail Press: Cambridge, 1994, p. 75.

⁹ Saunders, 'Dementia', pp. 8-12.; See also Goldsmith, 'The Experience of Dementia', pp. 56-69.

The factors above are again instructive for the carer for the judgements they make and the ways they progressively tailor care to the one they care for.

d) Personhood: conceptions of the self and communication

It is important to be aware that the language we use to describe the condition of dementia and the accompanying behaviour can often reveal assumptions which need to be questioned. James Saunders maintains, for example,

- that the low priority given to persons with dementia in the area of church pastoral care reflects the disturbing perception that dementia has rendered them non-persons simply because of the generally accepted assumption that rationality (expressed in language and in the ability to order and plan one's life) is a prerequisite of humanity.¹⁰
- For this reason, the humanity of people with dementia has often been denied by a philosophical obsession with rationality which has, in turn also influenced models of how we come to faith and even of engaging in relationships. As a result, the writings we find are, in Saunders' words, 'stuffed full of the language of thinking, reasoning, and analysing'¹¹ which further marginalise those with dementia.
- Furthermore, these assumptions are reinforced by a medical model reflected in statements such as that dementia renders a person 'progressively different and less able as they lose the ability to retain new information or recall previous memories, even of close relatives, together with loss of cognitive ability and changes to social behaviour'.¹² This 'slipping away' idea of personhood

¹⁰ Saunders, 'Dementia', p. 9.

¹¹ Saunders, 'Dementia', pp. 8-12.

¹² WHO, 1997.

presents a challenging question to theology: *does dementia erase the person?*¹³

Supporting the limitations of this ‘standard paradigm’ of dementia, theologian John Swinton¹⁴ argues that when our expectations of the dementia-diagnosed are constrained by narrow ‘standard’ definitions, we fail to recognise **the person** who is dementia-diagnosed & we misinterpret their intentions and actions by those narrow expectations regarding the person they have become.

Well-known pioneer in the field of dementia care & critic of this ‘standard paradigm’ of dementia, Tom Kitwood¹⁵, warned against the focus on the loss and decay that is allowed to define the person by the disease. He argued instead that the wellbeing of the person with dementia will also be affected by the quality of the care they receive.

Kitwood laid out what compassionate caring entails and the priorities for understanding a person’s condition. For example, he recommended that all behaviours (even “problem” ones) should be viewed as an attempt at communication relating to need. Instead of labelling the behaviour as “challenging”, Kitwood believed it is up to the caregiver to *interpret* these expressive behaviours and figure out ways of meeting their need.

An example that is relevant to Kitwood’s claim is the progressive effect of dementia on the person’s use of language in which the loss of capacity for clarity and nuance could unwittingly be interpreted as rudeness and dominance. But on the basis of his view of personhood and Kitwood’s observations above, we can be

¹³ Christopher Collins, “Re-imagining dementia: seeing ourselves more fully in the dementia-diagnosed”, *Holiness. The Journal of Wesley House Cambridge*, Vol 3 (2017) Issue 1 (Holiness & Pastoral Relationships): pp.57-69.

¹⁴ Swinton, *Dementia: Living in the Memories of God*, p. 39.

¹⁵ Tom Kitwood, *Dementia Re-considered: The Person Comes First* (Buckingham: Open University Press, 1997).

confident that meaningful communication is possible with the dementia diagnosed.¹⁶

For Kitwood, communication involves more than the giving of instructions because it includes *relationship as an end in itself*. Under the influence of Jewish philosopher, Martin Buber's I-Thou model of the self¹⁷, Kitwood maintained that personhood is formed in personal encounter when the other is recognised as worthy of respect and worth spending time with.

As Swinton explains, 'human beings are persons-in-relation. Personhood is primarily a relational concept... it is not capacities that count... The thing that makes a human being a person is his/her relationships... The task of care providers is to learn to look at persons with dementia differently --- as relational beings whose personhood is sustained in and through the relationships that people choose to have with them.'¹⁸

This has direct implications for communication & for care of those with dementia. It follows that when in the company of those living dementia, we must 'listen' in anticipation and remain open to varieties of communication and ways of communicating.¹⁹ As will be further illustrated later, how we think of the person with dementia has a direct and significant effect on how we interpret their behaviour and how we communicate with them, especially when the dementia is in an advanced state.

Much is often required of the imaginativeness and resourcefulness of carers, as well as great sensitivity, patience and humility on their part. In 'Spirituality tin, tool boxes & teddy bears,' Anne Ranse²⁰

¹⁶ Malcolm Goldsmith, 'The Experience of Dementia', p. 85

¹⁷ Martin Buber, *I and Thou* (Edinburgh: Clark, 1937).

¹⁸ Swinton, op cit, p.139.

¹⁹ Goldsmith, op cit, p. 89

²⁰ Anne Ranse, 'Spirituality Tin, Tool Boxes, and Teddy Bears: Tools for pastoral ministry with older people, isolated and housebound', from Anne Ranse & Don Jamieson, from *When I am Old: A Guide to Pastoral Ministry with the Frail, Isolated Older People*, published with the support of Anglicare, 2014.

shares the idea of the use of objects to spark conversation with the elderly on her pastoral visits to nursing homes.

The idea replicates what the character from Mem Fox's 1984 classic²¹ learns about the nature of memory. When the young boy, Wilfred Gordon McDonald Partridge who lived next door to a nursing home finds out that his special friend, Nancy Alison Delacourt Cooper is losing her memory, he sets out to find what a memory is.

Inspired by the characterisation of memory as 'warm, from a long time ago, something that can make you cry or laugh and that is precious, like gold', Ranse uses the idea of a spirituality box that is full of objects able to evoke memories and forgotten emotion to spark conversation with the elderly on her pastoral visits.

She tells a story that shows how the evocative power of a fluffy soft toy lamb helped to spark memories and create trust over a continuing relationship. The man's spiritual hunger finally led him to participate in the chapel services at the home, including communion. She continues:

'Ministry continued with this man until the day he died, relationships were built with his family and he was buried from the chapel of the Good Shepherd at the Nursing Home where we sang his favourite hymn, 'The Lord is my shepherd.'

The spirituality tin has brought comfort, connection, reconciliation and life with Christ for this man. It raised his spirits, stirred his soul and gave him hope'²²

On the other hand, carers could have experiences that are less affirming for both parties. As noted earlier, with dementia is loss of vocabulary and nuanced language which together with the frustration with such losses, give rise to language that could sound demanding, unfeeling and rude.

²¹ Mem Fox, *Wilfred Gordon McDonald Partridge* (New York: Kane Miller, 1985).

²² Ranse, 'Spirituality Tin, Tool Boxes, and Teddy Bears'.

When addressed in these ways, the carer is presented with the tension between understanding the other and maintaining self-respect and even self-care. While they empathise with the frustration the other feels and understands the loss of capabilities for nuance and kindness²³, they are also entitled to respect and consideration.

Such moments highlight *the dance between love of the other and care of self* which is a challenge often articulated in carers' groups²⁴, and not only in the area of communication but also in relation to the demands of care as a whole.

While situations vary for carers, carers' groups are among the most productive places to make sense of the experience of care and to build resilience within it. When trust has been built up within the group, carers can share the range of challenges and emotions they experience and when there is attentive listening, interspersed with humour, they can feel less alone and more empowered in their role.

Prior to further discussion on this side of caring, we will hone in on the unique demands of caring for a family member (& include in this group, caring for a close friend)

II. Carers & caring: the unique demands of caring for a family member

a) 'Strangers to themselves and to others'²⁵

The one afflicted with dementia, can be so overwhelmed that he or she loses sight of who they are. As Swinton explains, the affliction is such that they 'struggle to exist ... feeling that their true selves are

²³ As Saunders puts it, 'the sophisticated public face we all present to the world is high-maintenance and demands energies and capabilities which someone struggling to keep going does not have available', Saunders, op cit, p.6.

²⁴ Refer, for example, to opportunities offered Dementia Australia: <https://www.dementia.org.au/>; & Carers, ACT: <https://www.carersact.org.au/>

²⁵ Swinton's phrase, in *Dementia: Living in the Memories of God*, p. 266

fading away.’²⁶ The identities of both parties, including that of the carer, change imperceptibly.

The reality of these struggles present unique challenges to the carer who is also a family member. The lived experience of, and prognosis for the condition are such that for the carer, their role, as Swinton describes it, ‘subsume every other role and every other possibility for their lives. The affliction becomes all that they are... All parties involved – carers and cared for - becomes strangers to themselves and to others... The affliction of dementia makes strangers of ourselves and the ones we love.’²⁷

The sense of overwhelm is seen in the exclamations of carers below:

What has happened to my life?: ‘Broken hearts and tired lives’²⁸

1. ‘This is not the way it was supposed to be!’ blurted an anguished middle-aged woman ... Marian, daughter ... (of mother recently) diagnosed with Alzheimer’s disease. ... I was supposed to enjoy my retirement. But I’m spending all my time taking my mother to her medical appointments. I’m here today to pick up a prescription for a new memory pill. There’s just no time for me; I feel trapped, and I’m burning fast. My own doctor told me that caregivers often die before the person they’re caring for. Is this what I have to look forward to? ... It wouldn’t be so bad if she could get better, but she just gets worse. She’s really not the mother I’ve always known; it’s as though a demanding stranger has invaded her body. Caring for her seems like such a waste of time of time & effort – I wish she would just die.’

Then Marian wailed, ‘I feel so guilty admitting all of this to you – she is my mother, after all! I haven’t had anyone to talk to, no one who has any inkling of what my life is like now!... You and

²⁶ *Dementia: Living in the Memories of God*, p. 266

²⁷ *Dementia: Living in the Memories of God*, pp.266-7.

²⁸ Experiences documented in Jane Marie Thibault & Richard L Morgan, *No Act of Love Is Ever Wasted: The Spirituality of Caring for Persons with Dementia* (Nashville: Upper Room Books, 2009), pp.29-30.

all my mother's friends from church must think I am cold hearted for not taking her into my own home, but we have no room!"

2. 'I am furious with God for letting this happen to my husband! He's been such a good man, devoted to our church. God is just not present in this situation – and neither are those church members my husband served.' (a church member "" and one of Morgan's spiritual directees)

What can we deduce from the above exclamations from carers? What toll do they bear in the role? Where are the struggles for carers?²⁹ It is clear that the challenges they face are as emotional as they are spiritual, involving:

- changes in the one diagnosed with dementia involving the loss of aspects of the person they once knew, **as well as** the mutuality and relationship that had been developed over time;
- the shock of a new life that neither party had 'signed up for'
- the loss of the freedom, autonomy & choices that the carer previously enjoyed, including projects and pursuits, & in the case of couples, their previously joint pursuits
- the demands of close care require both commitment and continual learning on the job
- life becomes more home bound and routine

²⁹ Refer to data in Appendix - 'Impact of Caring on Carers' Wellbeing'. I am indebted to Dalanglin Dkhar for this excerpt from her PhD exegesis entitled, 'Interpreting the carer story in *Unconditional* – a social impact film'. *Unconditional* (2024) shines a light on four long-term carers and uses their lived experience to advocate for carers and bring awareness and recognition to this invisible community. (<https://unconditionalfilm.com.au/>)

- the continual vigilance that is required in the role, especially when the person they care for cannot always communicate their needs.
- fatigue and at times, the sense of inadequacy in the role
- carer's guilt and self-judgement which is commonly reported. It is not surprising for carers to feel they haven't done enough on the one hand, and at the same time, resenting that there is so much still to do, and then feeling disappointed with themselves for the negative emotions they experience
- the anxiety that this could be prolonged or that he/she may become incapable of the role
- the search for meaning, including spiritual meaning in the midst of a new and unidentified role

b) What then, do caregivers need?

While Richard Morgan has a point that, 'All caregivers have two basic needs: (1) to be affirmed that their caregiving is not in vain, and (2) to be reassured that the lives of those they care for are not being lived in vain,³⁰, the reported experiences above reveal that these "basic needs" do not do justice to the emotional complexity of carers' experience which comes with the mix of grief, exhaustion, aloneness, self-pity, futility, guilt, and even disappointment with the church and with God himself!

It is important therefore to unpack this complexity, and in the context of Christian faith, to ask: *how do we understand the unique challenges experienced by carers of a family member with dementia from the point of view of the carer's faith journey?*

How then can carers see the situation and the one they care for in a way that is worthy of both parties? (described as 'a tsunami that ultimately wipes away all self-knowledge through God's eyes?')³¹

³⁰ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p.28.

³¹ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 30. [discussion goes to 33 & 34]

c) making meaning of the changed life:

In their very direct and practical approach, Thibault & Morgan begin realistically with the acknowledgement that the caregiving/receiving situation they find themselves involves a 'drastic and unwanted change of (their) life plans' which is 'never a desired path', and that the lack of conversation and literature available demonstrate that it is not yet 'a well-recognised, intentional path to God that is recognised & supported by institutional religions'³²

For this reason, sober realism is required. The meaning of that changed life will, as Thibault & Morgan observe, be shaped by the degenerative condition of dementia, whatever the prognosis. Very practically, it will also be shaped by the patterned way of life for both parties, a life that is largely dictated by routine and the limitations of their situation, with far less room than (ever) before in their lives for variation and enterprise.

This changed life requires submission to the circumstance for both parties in the face of loss and death. Unsurprisingly, Thibault & Morgan note that the sacrifice this elicits is for Christians, an ultimate response to Jesus' command to "love one another as I have loved you".

Yet, this is not the whole reality for the Christian conception of the life of faith and the 'love and truth of Jesus'³³ which consistently reminds us that God's grace is prevenient and sufficient to changed circumstances such as these. It is in this spirit that Thibault & Morgan 're-envision caregiving from burden to an intentional, mutual spiritual path.'³⁴

While those 4 words need unpacking, it is clear that in this discussion, we are entering into the realm of the carer's interiority and spiritual journey.

³² Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 68.

³³ See Task Force ToR.

³⁴ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 68.

d) 'an intentional, mutual spiritual path.'

To do justice to this serious endeavour, we need first to attend to the words 'intentional' and 'mutual'.

Being sole carer to someone living with dementia presents a challenge to faith for the kinds of reasons noted above. Loving care requires a steadfast intention to meet the needs of the loved one to the best of their ability.

Again, with realism, Thibault & Morgan acknowledge that this presents a test to carers at a few levels: it tests, for example, whether they can love unselfishly and unconditionally, 'Knowing that no act of love was ever wasted.' The experience of loving a person with dementia is a 'unique, mutual spiritual path' precisely because the act of loving without any expectation of return, 'changes us, stretches us, transforms us. It teaches us to love as Christ loves'³⁵

But in what sense is it a 'mutual' spiritual path?

As Thibault & Morgan explain that in the process, carers 'learn to love generously, without constraint, without praise or thanks, sometimes despite a slap in the face.'³⁶ But that love can only become mutual when it is balanced & accompanied by wise self-care on the part of the carer. Here, wisdom is required because there are traps to self-giving love. For when care is the habit of unending and unnecessary sacrifice, genuine love for the other is then no longer sustainable, and care can become nothing more than thankless drudgery.

To use CS Lewis' terminology, it becomes 'need love' parading as 'gift love'. In his classic, *The Four Loves*³⁷, the fictional Mrs Fidget personifies this self-gratifying love because all her acts of giving direct attention back to herself and burdened her recipients with the obligation to show gratitude for her sacrificial displays.

³⁵ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 32

³⁶ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 33.

³⁷ CS Lewis, *The Four Loves*, (New York: Mariner Books, 2012), pp. 48-51.

An intentional spiritual path of loving our neighbour must be respectful to the recipient and not oblige them with indebtedness. The path is mutual when love is free and unaffected, and unlike Mrs Fidget's actions, are unobtrusive and unself-conscious.³⁸

As Thibault & Morgan add, sustainable love 'does not ask for martyrdom', Mrs Fidget style. It may even require us to 'say no to a person's demands when they are not in his or her interest or when what that person asks is beyond our physical, mental, or financial capacity to provide.' 'This is when love becomes "tough love"'³⁹

This is a picture of mature & healthy love of self and the other and the path to its practice is indeed part of any spiritual journey. But boundaries are often more difficult to set than giving in to Mrs Fidget style martyrdom. And it requires a *steady heart* to get there, a freedom from guilt, from fear of what others think and negative reactions from the one in their care. *Who is equal to this self-forgetful freedom? Who is equal to this healthy love?*

It is therefore no wonder that we are being led by these and other authors⁴⁰ into a contemplative journey of self-knowledge. As Thibault & Morgan put it, we need "Soul-Quiet" in this work of love. But they wisely begin with some down to earth, centring advice by reminding carers that caregiving does not have to be perfect. That the daily acts of care are often, quite naturally, routine acts of will but are, nevertheless, self-giving acts of love. Carers also need to know that *they* can be the presence of Christ to their loved one and their presence is as important as any task they actually do for them. Finally and importantly caregivers are

³⁸ Matthew 25 is the paradigm of acts of unwitting goodness and **self-forgetful** love.

³⁹ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p.33

⁴⁰ See also Swinton, chapter 9: 'Becoming Friends of Time: Learning to Live in the Present Moment', in Swinton, *Dementia: Living in the Memories of God* see especially pp. 227-241.

reminded that they too, are God's beloved and the subjects of his continual care.⁴¹

e) The path of "Soul-Quiet"⁴²

Thibault & Morgan use this term to describe any practice of centring the self in the presence of God to find freedom in their souls. While they recognise that some carers may already have a regular practice that works for them, their recommended practice of living in the present moment is particularly needful when the following carer responses to frustrations commonly occur: of *Responding* to the frustration of the present situation by comparing it with what has been and what could have been; *Responding* to the frustration with the physical confinement of their circumstances by escaping into an imaginary life elsewhere; and, *Responding* to the frustration of endless tasks by taking on more tasks and responsibilities than they can manage, i.e. by multi-tasking.

Thomas Merton, the Trappist monk from the Abbey of Gethsemani in Kentucky taught a practice of facing *such instances of unwelcome reality* that he called: "Now Here This"⁴³.

Practicing Now recognises that the only moment I have is *this* moment. It is wise to be present to it. Taking refuge in remembering past good times or imagining a better future are fantasies that create a sense of loss and even of resentment. It is therefore wise to pay attention to *this* moment. "Now" reminds me to be present to it

Practicing Here reminds us to be in this place and nowhere else. In my life as a carer, I am at times tempted to escape into a different life, such as my life before I was a carer. 'Here' reminds me to place my consciousness in my present physical space. 'What it looks like,

⁴¹ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 85.

⁴² Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 89.

⁴³ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 89.

feels, smells, sounds, and even tastes like.”⁴⁴ ‘Here’ reminds me to be here in my present location.

Practicing This reminds me to avoid multitasking. This may be a particular tendency for carers who feel that time is scarce and insufficient for what needs to be achieved. While this may look like efficiency, the reality is that when we multitask, we can become even more stressed. ‘This’ reminds us to place my whole consciousness in the present task.

Thibault & Morgan acknowledge that a practice of this kind can sound completely counter-intuitive in the thick of caregiving but, importantly, they add: ‘This technique seems to *expand the understanding of time*, creating serenity in a stressful life.’⁴⁵

As seen above, the frustrations that come with caring are often *framed by how time, as well as place are imagined* – in terms, for example, of an ideal past or future; or as a better and more ideal place, or when time is felt as being in short supply. (how often have I complained about being ‘time poor!’) All these forms of ‘escape’ are normal but they can often only incur further stress on top of a demanding role.

While Thibault & Morgan do not develop what they mean by ‘expanding the understanding of time’, it is significant that John Swinton ends his classic work on Dementia⁴⁶ with a discussion on the relationship between spirituality and time as well as the crucial need to understand how our relationship to time *shapes the quality of the moments we experience*. Indeed, while that is well-known from our everyday experience, it is highlighted for carers how significantly our relationship to time reveal our understanding of *what is worthwhile for our engagement & who is of value*.

⁴⁴ Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 89.

⁴⁵ Heading used in Thibault & Morgan, *No Act of Love Is Ever Wasted*, p. 90.

⁴⁶ Swinton, *Dementia Living in the Memories of God*.

f) **'Becoming a Friend of Time': learning to live in the present moment'**⁴⁷

Redeeming the Time: the sacrament of the present moment

A contemplative practice like, 'Now, Here, This' shows that we can have some agency over how we experience the moments in our lives. Contemplative practices in general also reveal to us that exercising such agency is not easy and goes against the grain of how time has framed our responses. This is particularly the case with what is termed 'clock time.'

From his experience as a psychiatric nurse, theologian John Swinton recognised the tension between the recognised virtue of being efficient and busy doing things for his patients and the less recognised virtue of being *present* with them. This too, is the caregiver's dilemma.⁴⁸

While it would be unrealistic to run our lives without the clock, it is important to understand how it imposes on the quality of human relationships. With its measurable units, the clock imposes a uniformity and sameness over our natural experience of time. This produces a negative tension between 'clock time' & 'lived time' – it 'being the place where all of us really reside'.⁴⁹

When we prioritise clock time over lived time, we see that the inclination for intimacy is denied, together with the richness and depth of human emotion. In her observation of American aged care homes Athena McLean notes that those that are ruled by

⁴⁷ Swinton, *Dementia Living in the Memories of God* chapter 9, pp.227-257. This chapter is a valuable source of insight into levels of engagement with those living with dementia. At a more profound level, it opens up a new understanding on the mystery of human communication and the power of presence in our relationships.

⁴⁸ However, while there are insights from Swinton that are relevant for caregivers, practically, a clear distinction needs to be made between them & caring professionals. The former does not 'clock off' and for that reason, need to wisely manage their time.

⁴⁹ Swinton, *Dementia Living in the Memories of God*, p. 233.

clock time 'cannot adequately handle the dilemmas of the human condition' or allow 'fallibility, lamentation and the tragedy of life to be fully embraced.'⁵⁰ Clearly, such time is 'fallen' and needs to be redeemed.⁵¹

As Swinton explains, our time needs to be sanctified in God's service, not by endless scheduled activities but by enjoying it as 'the existential space within which we learn to love and care for one another' & to be present to the other'⁵².

Drawing on the theology and practice of 'L'Arche' founder, Jean Vanier that we need to re-think time & slow down in the way we relate to people with intellectual disabilities, theologian Stanley Hauerwas extends this advice to the realm of dementia:

'To become a friend with someone with Alzheimer's, I think, is exactly the kind of challenge that it means to become a friend of time. We forget that our most precious gift for others is presence; just being present... When there is not a lot to do other than to be present, you find out ... what it means to be a friend of time.'⁵³

Being present with someone with dementia, especially if they are unable to reward us immediately with the communication we normally expect, is an expression of love which as Swinton puts it, involves our saying to the other: "It is good that you exist; it's good that you are in this world."⁵⁴

⁵⁰ Athena McClean, 'Dementia Care as a Moral Enterprise: A Call for a Return to the Sanctity of Lived Time', *Alzheimer's Care Today* 8, no. 4. (October-December 2007), p. 368, quoted in Swinton, *Dementia Living in the Memories of God* p. 234.

⁵¹ Swinton, *Dementia Living in the Memories of God*, p. 232.

⁵² Swinton, *Dementia: Living in the Memories of God*, p. 252.

⁵³ Stanley Hauerwas, *There is a Bridge*, DVD, quoted in Swinton, *Dementia: Living in the Memories of God*, p. 229.

⁵⁴ Swinton, *Dementia: Living in the Memories of God*, p.230.

Swinton offers several moving examples of transformative experiences when ‘wilful love’⁵⁵ listens, and gives the benefit of the doubt to ‘a fleeting look, a noise that most would consider to be meaningless’. In such interactions, any power relation is wilfully given up by the carer and the ‘sacrament of the present moment’ creates a mutual ministry between the parties when one spirit ministers to another: ‘Soul to soul, nephesh to nephesh’⁵⁶ even when no words are spoken.

These experiences are spiritually profound, but for Swinton, they also yield insights on spirituality and the nature of personhood. When Mary, with limited vision and no speech but makes sounds, can share in, and honour the silence of a Quaker meeting⁵⁷ or when one with advanced Alzheimer’s can come out of a fog for a moment to wake her husband with, “Darling, I just want to thank you for all you’re doing for me,”⁵⁸ before falling back into a fog, we begin to understand spirituality and the self in a rich light, that spirituality is not simply a feeling that is within Mary, it is also a *sharing* in an atmosphere that is beyond her, ‘the feelings, emotions, and the mood of the meeting’⁵⁹ in which she participates. In other words, Mary’s experience reminds us that spirituality is a *corporate* event that is greatly dependent on the *presence of others*.

The completely unexpected declaration of gratitude to her husband from the woman with advanced Alzheimer’s adds richly to our understanding of selfhood, discussed earlier. For a manifestation of this kind cannot be grasped by biological explanations, by an appeal to ‘residual memory’, nor by dualistic ideas of the self – that it is a dichotomy of body and mind/subjectivity. Rather, as Swinton contends, such moments of sporadic lucidity suggest that body and subject are not separate

⁵⁵ Swinton’s phrase, in *Dementia: Living in the Memories of God*, p.242.

⁵⁶ Swinton, *Dementia: Living in the Memories of God*, p.236.

⁵⁷ Swinton, *Dementia: Living in the Memories of God*, p.239.

⁵⁸ Swinton, *Dementia: Living in the Memories of God*, p.243.

⁵⁹ Swinton, *Dementia: Living in the Memories of God*, p.39.

but *unified*, such that being embodied affects the nature of subjectivity, and subjectivity in turn is *remembered* in the body.

Indeed, our example indicates that the self does not reside in some inner, phantom world that dementia has destroyed, but it is also evident in *physical expressions called to remembrance* by the body. In other words, Mary's participation in the silence and the woman's declaration to her husband are expressions of their persons that show their *purposive relation* towards another, allowing for fellowship and **communion**.⁶⁰

The experiences above are also a compelling reminder to us not to forget those who seem absent to us but who clearly desire fellowship and communion. These profound moments in 'sacramental' time are indeed gifts for carers and care providers. In closing, however, we return to the non-professional carer, who does not 'clock off' and who, in their day-to-day care, inhabits the 'time' of routine care to enquire: *how can that be filled with faith, hope and love?*

ii) Lift up your hearts: 'the drama of Eucharistic Time'⁶¹

The daily routine of care with its hits and misses, ups and downs and re-sets occasioned by lessons learnt in the process requires wise management for the carer. As with institutional settings, clock time is a necessary aid to prudent planning, to seeing ahead, anticipating difficulties, circumstances and reactions. After all, we need to make lists and reminders for day to day care.

How then can this daily lived time with its humble, repetitive tasks, be blessed with meaning, faith and hope? How can this daily round

⁶⁰ Swinton's application of philosopher, Merleau-Ponty's view of the self (**in which the body is itself a kind of consciousness & a kind of subjectivity**) to these instances, reminds us that our theories of the self, whichever one we assume, are highly relevant to how we interpret the behaviour of those with advanced dementia. See Swinton, *Dementia: Living in the Memories of God*, pp. 244-247.

⁶¹ The phrase is from David Ford, *The Shape of Living* (London: Fount, 1997), p.134.

be 're-envisioned' from burden to 'an intentional, mutual spiritual path' for both parties – carer and recipient?

From day to day, carers find that their 'management' of time only goes so far. They find, perhaps as never before, that they are subject to events, decisions and constraints that are outside their control. The exhortation not to be anxious, to live in the present moment requires particular patience, practising that attitude to time 'which trusts that there is a "right time" that is worth waiting for.'⁶²

Patience requires trust in a heavenly Father who knows what we need, a 'God of abundance' who is richly active through what is happening. Contemplative practices like Merton's "Now, Here, This" encourage us to lean into the work before us, 'always watching for God's way through them, bringing good out of them'⁶³ Time is not empty, even when it feels thin of meaning, for God is redeeming the time.

If spirituality is indeed a corporate event that depends greatly on the presence of others, the capacity to trust God and to wait on him is naturally grown within the community of faith. Here, the weekly living out of the church year reminds us of that most fundamental truth, that 'Our time is God's time'⁶⁴ and each of us, including those with dementia, participate in that drama of God's time.

The climax of that drama, is of course, Easter, when we celebrate the life, death and resurrection of Jesus and in our regular celebration of the Eucharist, we identify with the drama afresh and 'see our own lives in its light'. As we meet the "real presence" of Jesus Christ, at each celebration, we remember that "His is the face before whom we are living now"⁶⁵ Our weekly celebrations,

⁶² Ford, *The Shape of Living*, p. 132.

⁶³ Ford, *The Shape of Living*, p. 132.

⁶⁴ Ford, *The Shape of Living*, p. 134.

⁶⁵ Ford, *The Shape of Living*, p. 135.

year after year can transform our sense of time, past, present and future and we learn to see our own lives in its light.⁶⁶

For the carer and the cared for, the church year becomes their 'temporal home' which through the great acts of the drama of the Bible, stories and through saints' days (and we must add, with the emotional honesty of the psalms), remind us that that we are all held by God and our lives are part of the present continuation of that drama.

How then, can the community of faith speak such reminders to our carers and to those with dementia in their charge?

How can the community build that bridge to those with dementia with the love and truth of Jesus?

How can the church show those with dementia that they live in the memories of God and are held by their sisters and brothers of faith?

As Swinton puts it: 'To be present with and for people with dementia and to fellowship and worship with them is to remember them well and to act accordingly. It is to hold them in their identities as people remembered by God and by the community of God's friends.'⁶⁷

How can the communities of faith lift our hearts with Easter hope?

At the beginning of the Eucharistic prayer, we have this familiar call to all to draw near to God's love and mercy:

The Lord be with you

And also with you

Lift up your hearts

We lift them to the Lord.

Amen.

⁶⁶ I am indebted to David Ford for these rich thoughts on 'Eucharistic time', in *The Shape of Living*, pp. 134-135.

⁶⁷ Swinton, *Dementia Living in the Memories of God*, p. 251.