



# A road to nowhere?

## Pastoral care in late-stage dementia

BY KATHRYN WRIGHT

### THE CHALLENGE OF DEMENTIA

The spectre of dementia is one that most people will encounter, be it in the diagnosis of a friend, family member, or as we face our own personal journey through it. Dementia is possibly the most feared of illnesses and is so often described as being a fate worse than death and for those of us in pastoral care the challenge is not just in how we are to provide that care but also in how we respond to the fear and despair that can threaten to overwhelm all involved. In order to be true agents of hope in these situations we need to understand why such intense fear arises, and how faith can help us to negotiate these fears.

In understanding the lens through which we view ourselves we come to see the profound impact our perspective has upon us, society, and those in failing health; we have often fallen back into Descartes' famous dictum "I think therefore I am" without realising the implications that flow from it. If rationality, the holding of a chronological narrative of self, and the ability to articulate become the foundational factors that we use to define a person as being truly human, then it is easy to see how a disease that inexorably erodes these qualities would evoke such fear. It would seem that in dementia we encounter the danger of losing our self, our dignity, autonomy, and value. Often these are the very things that

we define our humanity by. To care well here, and in fact to have the impetus to care at all, we need a much better story.

### RESPONDING TO THE THEOLOGICAL THEMES

#### SELF

Who am I when I can't remember the experiences that have formed me, the people who have loved me, or when I don't even know where I am. If my personality changes or my consciousness fades, am I still me? As dementia progresses many of the relationships that have such significance to us are altered, damaged, or lost, and this can lead to a real fear of that the very essence of who a person is can be lost. We know though, that both before this life and after it, God knows us, he knows who we are and there is nothing that can remove us from his knowing. We naturally undergo drastic changes throughout our lives, from conception through to adulthood and into old age, but throughout the entire journey I am always me, and you are always you. The fact is that in this life our 'self' will never find its fullest expression, it will always be in some way obscured, it is only in that final place that it shall be fully revealed. We can rest in the assurance that who we are is entirely secure, known by the Father, sustained by his Spirit, and redeemed in Christ.





Referred to in some places as the 'dissolving self' it's easy to see why this aspect of dementia is such a terrifying prospect and while our being able to bring hope and assurance can't remove the pain of watching a loved one in decline, it does bring a much-needed antidote to the fear and despair that can be so damaging.

### DIGNITY, AUTONOMY, VALUE

Is dignity lost as mind and body gradually fail? Our culture places huge value on independence and on productivity; the self-reliant and self-made person is often exalted as the pinnacle of who and what we can be. We will assess our neighbour, friend or co-worker as 'worth their weight in gold' generally as a reference to their productivity. We rightly recognise and praise hard work, someone who uses their skills to the full and whose contribution brings benefit to all, but is this balanced by recognising that individuals are unique in their capacities and capabilities, and that their worth is not measured by any of those things?

**"The LORD had his heart set on you and chose you, not because you were more numerous than all peoples, for you were the fewest of all peoples. But because the LORD loved you and kept the oath he swore to your ancestors, he brought you out with a strong hand and redeemed you from the place of slavery, from the power of Pharaoh king of Egypt." (Deuteronomy 7:7-8)**

Created in God's image our dignity and value are bestowed by him and intrinsic to our being; his love for his people is based upon who he is and not who we are or what we're able to do. It's a dangerous path to go down if we are to say that anyone's life is not worth living and as those in pastoral care, we have an opportunity to demonstrate the value of each and every person.

## ARE WE WALKING IN THE WILDERNESS?

### WHY DO WE CARE?

When considering pastoral care for those with dementia we may question its necessity and relevance. Why offer care to someone who may not recognise the visitor, remember the visit, or in some cases even know that there is a visitor? Wouldn't we be just as effective praying for them in our own churches and homes? Even looking at this from a purely practical level, engaging in discussions, activities, and religious practices has been shown to positively impact well-being and disease progression; just as the disease affects our relationships, so too relationships have an impact on the disease. We were made for community, and it should come as no surprise that our most holistic selves emerge from within that context. Loneliness becomes a significant challenge both for individuals with dementia and often also for their caregivers. Both those affected and those living with and caring for them can feel like modern day lepers as people once close gradually withdraw, sometimes due to communication difficulties, discomfort, shame, grief, and often a failure to understand why there would be any need to be present with someone no longer able to recognise them.

In our care we follow the example of Christ, coming alongside those who are unable to help themselves and who are often entirely unaware of the help that they need. Pastoral visitation becomes an enactment of our witness to the hope of resurrection and the kingdom of God. We must view those with dementia through a different lens, seeing them not as decaying individuals but beholding them as participants in God's kingdom, icons of his glory, and those within whom he is pleased to dwell. Despite the real suffering and difficulties





## References

Bryden, C. (2018), 'A Continuing Sense of Self in the Lived Experience of Dementia', *Journal of Religion, Spirituality & Aging*, 30, 279–290.

Post, S. (1995), *The Moral Challenge of Alzheimer Disease*, London: The John Hopkins University Press.

Swinton, John, (2012) *Dementia : Living in the Memories of God*, London: SCM Press.

associated with dementia, Christianity remains optimistic in the face of adversity, and pastoral care should be a reflection of that hope. Indeed, hope and suffering are intertwined in the message of Christ as he walked a path of suffering culminating in the seemingly hopeless sight of his crucifixion, yet his bodily resurrection and ascension manifested the future hope for believers.

God's faithfulness should manifest through his people and shown in our remembering of and caring for all, not merely as a learning experience or as an act of charity, but because it is intrinsic to who we are called to be. In our present actions we foreshadow what is to come.

## AN UNKNOWN PATH TO A KNOWN DESTINATION

When it comes to taking care of someone with dementia those of us who have primarily been trained to focus on change, emphasising growth in faith, healing and progression through the challenges of life will find our purpose being dramatically reoriented. If we approach the care of someone with dementia, especially in the later stages, with the mindset of healing and progress then we can feel at best like we are engaging in an uphill battle and at worst like it is a cruel exercise in futility. How can we aim for progress when we need to reintroduce ourselves not just at every meeting but multiple times throughout it? It can sometimes feel like we're wandering through a "wilderness" hoping to reach a place of rest ahead, but without any clear path to follow. Here it is where we find ourselves returning to those simplest of

pastoral skills. Here we find the depth of significance found in being rather than doing.

The truth is that we will never be able to understand the experience of the person with dementia, but we can still seek to come alongside them, to be present with them in their circumstances, loving them as the person they are becoming and in anticipation of the wholeness that is yet to come. It is no bad thing that this illness strips us back to the basics of care and reminds us that the power of being present with someone can never be underestimated. In our listening we show honour, in our singing we bring joy, in our patient and loving care we remind them and all watching that they are valued. As we reach out to hold a hand, we find ourselves reaching across time and space, physically connecting worlds that otherwise can appear to be completely sundered by the illness. As we return to rite and ritual, we see glimmers of past experiences emerge and we catch sight of times long gone but so deeply embedded in the person before us as the familiarity of word and cadence in the Lord's prayer, in psalms once often sung, light a spark of remembrance. Even in that final place of waiting as we hold vigil and prayer with those no longer aware or awake, we are witnesses to hope and to the journey yet to come. In our accompaniment we may not understand the journey, but we certainly know the destination.



## About the author

A church worker in Central Baptist Church, Dundee and member of ACC Pastoral Care UK, Kathryn specialises in pastoral care for the elderly and those with dementia. She is also currently a student with Highland Theological College and is in the final year of a BA in Theological Studies.