"Blossoming Spirits": Communication Despite Dementia

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Introduction

We define ourselves as *homo sapiens* – persons who are intelligent and able to reason. However if we develop severe dementia, and are eventually considered 'out of our mind', then must we be relegated to some sub-category of the species? Is our identity and personhood then lost?

Or can skilled communication help to affirm a vulnerable elderly person's very being? The premise of this paper is that through communication, relationship can and should be established despite the very real barriers of severe dementia. The image of God, as described in Genesis 1:27, affirms the worth and dignity of *every* individual person, so human selfhood does not cease when faculties gradually deteriorate and rational abilities are lost. No matter how degenerative illness may change us physically or mentally, God is active within us.

However fleeting any human interaction may seem, the act of communicating and being in relationship with 'one of the least of these my brethren' (Matt 25:41) has significant theological implications for the personhood of the elderly individual, as well as for the communicator. Personhood is seen, both in the Hebrew Scripture as well as the New Testament (e.g. Romans 8:29) as God's gift, to be enjoyed both in relation with him and our fellow human beings.

Christians are commanded to love one another even when there seems little reward. We are asked in John 15:12 to love others as he loved us, and Christ ministered amongst the most marginalised. John Swinton, who writes from both a nursing and a theological background, reminds us that 'We can only understand what it means to love and be loved if we first experience love, and we can only understand what it means to

be accepted by God if we are first accepted by his people.'[1] Surely this refers to both parties in this special communication: both affirming the worth of the elderly person and acknowledging its demands on the communicator.

Approaches to dementia

Communicating with people with dementia does present significant barriers, to family, carer and pastoral visitor alike. A key symptom of dementia is memory loss, especially for recent events, and as the illness develops, so might persistent confusion and changes in behaviour and personality, often including paranoia and social withdrawal. Along with a loss of reasoning ability and various language difficulties, which directly impede self-expression and understanding, it is not hard to understand how frightening and potentially very isolating a diagnosis of dementia can be.

Alan Jacques estimates the likelihood of dementia occurring in a person aged over eighty to be one in four or five. The number of those elderly is rising rapidly, the majority of them are female and this terminal illness can affect individuals for up to fifteen years.[2] NHS researchers point out that 5% of people aged seventy to eighty in Scotland are affected by dementia, and amongst the over eighties, this rises to 20%.[3] Many of those people are church members.

The traditional bio-medical model of dementia treatment provides objective and valuable treatment, but this approach may focus on the symptoms and the disease, rather than the individual. So we have Fontana and Smith's phrase 'unbecoming of self'[4] describing the expected unravelling of awareness until no mental function was apparent. In their opinion, although remnants of instinctive social behaviour may remain, eventually 'where once there was a unique individual there is but emptiness.'

However, much progress has been made in the area of dementia care over the last fifteen years. A person-centred approach was pioneered in the 1990s by Tom Kitwood, working with the Bradford Dementia

Group, who proposed that it could be communication difficulties which give the impression of unawareness in a person with dementia.[5] Malcolm Goldsmith also writes on the listening and communication skills required for pastoral care, but within a theological framework. He emphasises that it is 'not acceptable to write off a person's ability to communicate just because we find it difficult to comprehend what they are trying to say to us',[6] and uses Kitwood's expression to emphasise that deliberately considering 'the PERSON with dementia,' rather than 'the person with DEMENTIA' is 'a seemingly small difference with considerable repercussions.'[7]

In the Old Testament there is a community memory which sustains individuals through hard times, which is particularly clearly described in Isaiah 40–55, in the 'strange land' of the Babylonian exile. The strength of the Hebrew community enabled it to realise that Yahweh was still accessible, that 'His song could still be sung' no matter how frightening the circumstances. The experience of dementia sufferers may be similar, and they too rely on their family in Christ to sustain their identities. We were created to live in community: in companionship we can all represent the unconditional love of God, binding together the disparate pieces of the Body of Christ.[8]

Yet Robert Davis writes in his autobiographical account of knowing Christians 'who simply cannot handle being around someone who is mentally and emotionally impaired.'[9] These attitudes do not fit with the Church as an inclusive community, and Swinton too cites examples of similar attitudes towards intellectually disabled people from both clergy and nursing staff.[10] The perpetrators in his examples justified their discriminatory behaviours because they believed intellectual capacity and meaningful participation to be prerequisites of religious faith. Such attitudes display exclusivity far from the open acceptance demonstrated by Christ in his ministry.

However, the effort required of pastoral visitor, family member or carer, in such specialised communication is considerable, and we may often feel that any connection was temporary. It is humbling and hard to remember that we inadequate people may act as agents of God,

that we can choose to reflect his concern and care for us to others in some limited way, trusting in the action of the Holy Spirit. To affirm a person with severe dementia as a unique individual who is valued by God, the communicator has to commit to nurturing that person's relationship with others in community, and with God. This we are told to do in Mark 12:30–31: 'You shall love the Lord your God with all your heart … You shall love your neighbour as yourself.'

In communication with people with severe dementia

We should never assume anyone with dementia is unable to understand, for this is a self-fulfilling prophecy. Nor should we ignore or merely 'manage' behaviours and verbalisations, but can try to interpret them as attempts to communicate.[11] Crucially, we must see every person with dementia as an individual to acknowledge his/her story and to affirm some continuity from past to present in their identity. Be wary of any 'elderly and confused' stereotyping, for if we can know or learn something of a person's individual life history, we can 'hold memories' for an individual who has lost much of their own memory.

Although this has time implications for communicators, just asking a carer or relative where an elderly person spent her childhood or what job or life experience was important to them before their illness, can prove an invaluable memory jogger in conversation. Using life story, 'conversational remembering'[12] allows the older person to contribute, and the communicator to reconnect and reaffirm in a subsequent conversation. In dementia, long term memory is often easier to access, and careful listening to a rambling childhood memory, though it may take a while, clearly signals the importance of the individual and his/her past.

Thus the communicator is clearly reminded that each individual has a 'self-story' to tell, and is indeed still a significant, though isolated, 'real person.' In affirming and accompanying them, we can enable them to feel that their story too, no matter how unusually it may be expressed, is also valued as part of a much greater framework. It is so important for elderly, home-bound and confused folk to have a sense

of being valued by the united Body: their decades of life experience are now constricted to one space, to which they no longer hold a key.

Each photograph in Tom Kitwood's inspiring book, *Dementia Reconsidered,*[13] shows an elderly person interacting with at least one other person. But the everyday 'equality' of a communicative exchange cannot be expected.[14] Kitwood's image is one of a tennis match between an experienced coach (the communicator) and a beginner (the person with dementia). The conversation must be structured in such a way as to give the beginner the best possible chance of responding.

Any words used should be clear, unambiguous and literal: metaphorical or abstract concepts should be avoided and very theological language is of limited use. So the words of worship, unless it is very familiar liturgy, should be 'earthed', made tangible if possible through by symbol or example.[15] A visitor should clearly identify him/herself, and their connection with the elderly person, both verbally and non-verbally. You might bring a small cross, wear a clerical collar, or leave something (a card, the church magazine) which can allow carers to reinforce your visit afterwards.

People with dementia may need considerably longer than usual to process information, or to respond to a question. This delayed reaction time, combined with a non-expressive face, can lead a visitor to assume incomprehension, and to go on to another point too quickly. This decrease in facial expression, on which we rely for so many non-verbal clues, makes conversation less rewarding: interacting despite this 'flat' effect requires skill and effort.

Hoffman and Platt speak very convincingly about how eye contact encourages relational communication: 'as one looks into their eyes, and they look back, the eye contact may help one feel that some awareness is truly there … we felt the connection on a deep level.'[16] Alternatively, if a lengthy avoidance of eye contact is detected, the person's unwillingness to communicate with you must be respected. In any interaction with a vulnerable person, the individual rights of that person must be prioritised.

Different individuals, with different dementing conditions, can show various patterns of language deterioration. This ranges from those who know what they want to say, but cannot utter the correct words, to forms of communication where there is little mutual verbal understanding. So the channel of non-verbal communication becomes even more important when the verbal channel is partially blocked by disability.

There is evidence that non-verbal comprehension may be amongst the longest preserved abilities in dementia,[17] and person-centred care tries to interpret behaviours which seem meaningless and sometimes problematic. Repetitive and sometimes anti-social behaviours, like biting, can be interpreted as trying quite literally to 'make a mark' as other modes of self-expression fragment. The importance of 'embodied' behaviour for and in those with dementia should never be underestimated.

So a calm manner and tone, and a friendly facial expression on the part of the communicator are very valuable, particularly if the elderly person demonstrates anger, grief and volatile mood-change with little inhibition. It is hard to wait patiently while the other may be struggling to find words we would rather not hear: lack of social convention means that the briefest of encounters can be unexpectedly raw. But particularly if our conversation partner is demonstrating distress, the communicator is required to hold that distress, and to transmit security and acceptance.

This is hard, for one of the least acknowledged challenges in communicating despite dementia may be the strength of the pastoral carer's own (often subconscious) feeling, about being in what is for many of us a fearful situation. We may see and hear distressing behaviours, we may be trying to converse despite intermittent and seemingly random movement and shouting: it is hardly surprising that many communicators feel anxious themselves.

Yet we are required to be 'fully present' to the person we are interacting with: this involves both very active listening and considerable self-

awareness. Such 'being' with a person can often be very hard: many of us find the 'doing to' mode easier and that the impulse to fill the risky gaps with banal chatter is difficult to resist. But silently and wordlessly offering the costly gift of attention, your companionship to a confused person, is beyond price. Representing the Body of Christ, we must not 'neglect the poor or ignore their suffering'[18] but take the risk of making ourselves vulnerable, and assist the confused elderly to sense that they are not alone.

Kitwood[19] writes helpfully of the ways in which people with dementia relate, highlighting the possibility of intensely felt emotion and lack of inhibition. As communication channels become more limited, features of personality may become more exaggerated, and he suggests treating the response of the person with dementia as though it were a foreign language, as if every attempt at communication might be some form of allusive or metaphorical meaning, rather than literal sense.[20]

So obstacles to communication must not be allowed to undermine vulnerable elderly folk. The individual may have lost nearly all of their ability to communicate, but they are still human beings; still, perhaps especially, persons who are cherished by their Creator. Denying anyone the right to feel valued as a unique individual, or to have their story acknowledged, constitutes oppression and denies the *imago Dei* in her or him. People with dementia may indeed be likened to *gerim*,[21] the 'resident aliens' of the Hebrew Bible, sojourners on a long and rough road into the unknown. They need reassurance (as we all do) that wherever we go, we cannot move beyond God's love. Psalm 139 reminds us that even 'If I make my bed in Sheol, Thou art there … even the darkness is not dark to Thee.'

They are trying … and so must we

In affirming those with dementia, there should be no implication of a wholly active-passive communication model. Our interaction is never as one-sided as it may seem to an observer and the potential benefits of such communication are usually shared. There will be give and take in this specialised communication, and the communicator may

receive in unexpected ways, if not in straightforward mutual exchange. Goldsmith lists several variations of 'awareness' in dementia,[22] with gradual loss overall, as part of a fluctuating pattern, as the most common. This gives rise to these sudden and inexplicable moments of clarity and understanding which occur haphazardly, but are often profoundly moving.[23]

The hard work of communicating with elderly confused people can resonate with different biblical images. Matt 25:36 speaks of prisoners: powerless, naked, marginalised. Thus elderly folk with severe dementia represent Christ on earth: 'I was sick and you visited me, I was in prison, and you came to me.' Stephen Post refers to people with dementia as 'the marginalized forgetful,' believing that 'persons who lack certain empowering cognitive capacities are not nonpersons: rather, they have become the weakest amongst us and, due to their needfulness, are worthy of care.'[24] Surely he implies *most* worthy: it is hard not to see Jesus' positive discrimination in favour of the weakest (1 Cor 12:20 ff) as applying to these disenfranchised people.

W. H. Vanstone talks of Jesus being 'handed over' to his fate, feeling in his vulnerability that even God had abandoned him. After all the activity of his life, and Mark's gospel particularly gives a sense of the urgency of Jesus' ministry on earth from the garden of Gethsemane onwards, 'He is there as the recipient, the object, of what is done.'[25] In dementia too, a person is often 'handed over' to his or her inescapable fate. Coping with indignity and dependency, this situation is a lonely and a long-drawn-out wait for people and their families, so Vanstone's emphasis on the dignity in 'the stature of waiting' is significant.

It was important for the incarnate Christ to be 'handed over'[26] to waiting, and facilitating communication to honour the 'person-in-waiting' could perhaps be seen as a supportive strand in this human phase of waiting. As Christ incarnate anticipated his death passively, so must these elderly members of his Body, dependent for many years on others for care: 'from the Christian viewpoint, it (waiting) is never … a condition of diminished human dignity.'[27]

Vanstone movingly describes a friend of his,[28] who lost his powers of expression to multiple handicap. He concludes that visitors received an 'indelible impression' that their friend's dignity, his enfleshed personhood, was in no way diminished, 'but rather, if that were possible, enlarged. … how can it be that man may bear, in passion no less than in action, the image of that impassable God of whom Christianity has for so long spoken?'[29]

We could particularly note here (although the author does not) the importance of Vanstone's continued interaction with his terminally ill friend, and Vanstone's efforts to understand the significance of the waiting. Human warmth and interest are critical to a person who feels threatened and helpless: Christ Himself, in the passivity of his passion, was denied this.

The differences between the cognitive abilities of those with and those without dementia are all too real, but from Israelite times, the *gerim* were protected in law: 'as you are, so shall the sojourner be before the Lord.'[30] They were still held in community, as the frail elderly should remain in the community of the present-day Church. This seems an apt image of elderly people with dementia, given God's bias to the poor and weak members.[31]

In the confused and isolated depths of dementia, rather than let any elderly person feel or believe that God has forgotten them at the end of their lives, we must offer as much meaningful human contact and communication as we can. Public vulnerability, physical dependence on others, acceptance of adversity often with grace: significantly, these aspects of life with dementia can represent an embodied reflection of Jesus in his Passion.[32]

Conclusions

The challenges and costs of such pastoral accompanying should not be underestimated. There is always a gap between theological concepts and the time-consuming and potentially stressful reality of 'being alongside' an elderly person with severe dementia, and it is hardly

surprising that most people find this responsibility hard and distressing. But a capacity to be open to others, however difficult communication might be, reflects the two key commandments of being in relationship with the creator God, and with others.

As frail people ourselves, we must 'own' our feelings and be aware enough to reflect upon them creatively. However, 'entering into the community of the dispossessed'[33] requires certain gifts and skills, and not everyone may feel themselves able to do this.[34] A more widespread sharing of expertise is urgently required among pastoral and ministry teams. Specific listening and communication skills are essential for the relational nature of ministry within our ever-increasing elderly communities, and resources must be prioritised for the underpinning of pastoral training and supervision.

People with dementia should not be lumped together under the 'home-bound elderly' section of any pastoral care team's visiting responsibilities: every elderly person is an individual, with a unique life's experience to be valued and affirmed in the church community. Belonging to such a transformative whole can bring hope and some peace, even in dementia.

Dementia sufferers are not some indeterminate sub-group of humanity. Each is named by him, and we are commanded to stand by the weakest, and most hidden, in our community. Those whose cognitive capacities deteriorate are not non-persons, but are the most worthy of care. [35]

The dynamic of such demanding communication with these disenfranchised people represents a ministry of presence, as we practise Jesus' positive discrimination in favour of the weakest.[36] As representatives of the Body of Christ, we can use communication skills to affirm that person, and to reflect, as best human beings can, the value which our Creator sees in us all. We are loved as we are, because God, through grace, chooses so to do. Communication, even simple acceptance and reassurance, can connect a fragmented existence to something holy, here and now. As the Body of Christ on earth now, his

love can be made known through us; and we will encounter that love reflected back from our sisters and brothers.

An adaptation of Romans 8:37–8 might read:

> For there is nothing in death nor life … nor things present, nor things to come … nor severe dementia nor cognitive deterioration nor even vegetative coma, nor anything else in all creation will be able to separate us from the love of God in Jesus Christ our Lord.

When another person's sense of memory and identity becomes confused, then other faithful hearers and speakers of the Word must sustain them in communication. For our faith has relationship and inclusion at its heart.

'You shine the sun of your listening upon me, and
Our spirits blossom.'[37]

1 John Swinton, "Friendship in Community: Creating a Space for Love," in *Spiritual Dimensions of Pastoral Care: Practical Theology in a Multidisciplinary Context* (eds. D. Willows and J. Swinton; London, Philadelphia: Jessica Kingsley, 2000), 104.

2 Alan Jacques, *Understanding Dementia* (2nd ed.; Edinburgh: Churchill Livingstone, 1992).

3 NHS Health Scotland, *Coping With Dementia: A Practical Handbook for Carers* (Edinburgh, Glasgow: Health Scotland, 2006), 9.

4 Andrea Fontana and Ronald W. Smith, 'Alzheimer's Disease Victims: the "Unbecoming" of Self and the Normalization of Competence,' *Sociological Perspectives* 32 (1989): 35–46.

5 Tom Kitwood and Kathleen Bredin, "Towards a Theory of Dementia Care: Personhood and Well-Being," *Ageing and Society* 12 (1992): 285.

6 Malcolm Goldsmith, *Hearing the Voice of People with Dementia: Opportunities and Obstacles* (London: Jessica Kingsley Publishers, 1996), 52.

7 Malcolm Goldsmith, *In a Strange Land …: People with Dementia and the Local Church* (Southwell: 4M Publications, 2004), 17. Goldsmith is an Episcopalian priest and former researcher at the Dementia Services Development Centre at the University of Stirling.

8 The interdependence of the disparate is fundamental to the Pauline idea of the Body of Christ, as exemplified in 1 Cor 13.

9 Robert Davis, *My Journey Into Alzheimer's Disease* (Amersham-on-the-Hill: Scripture Press, 1989), 57.

10 Swinton, "Friendship in Community," 102–103.

11 Goldsmith, *In a Strange Land*, 42–3.

12 Ellen B. Ryan, Lori S. Martin, and Amanda Beaman, "Communication Strategies to Promote Spiritual Well-Being Among People with Dementia," *Journal of Pastoral Care and Counseling* 59 (2005): 50.

13 Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham: Open University Press, 1997).

14 Many useful suggestions to enable such communication are offered in Malcolm Goldsmith's books, and practical tips for carers are available from the NHS Scotland handbook referred to at n. 3 above.

15 Much valuable work around worship for those with dementia is available. See Goldsmith, *In a Strange Land,* ch. 11.

16 Stephanie B. Hoffman and Constance A. Platt, *Comforting the Confused: Strategies for Managing Dementia* (2nd ed.; New York: Springer Publishing Company, 2000), 48.

17 Ryan, Martin and Beaman, "Communication Strategies," 45.

18 Ps 22:24.

19 Kitwood, *Dementia Reconsidered*, 5. Kitwood and Bredin between 1987 and 1995 developed the Dementia Care Mapping System, an observational tool widely used in person-centred dementia care.

20 Kitwood, *Dementia Reconsidered*, 76 ff.

21 David Lieber, entry for 'stranger' in *Encyclopaedia Judaica*, vol. 15 (Jerusalem: Keter Publishing House, 1971), 419.

[22] Goldsmith, *Hearing the Voice of People with Dementia*, 32 ff.

[23] For example, I said the Lord's Prayer with a seriously ill lady who had shown little response for weeks. As I left some moments later, she loudly and clearly responded with 'Amen'. Similar occurrences are common enough to remind you never to assume that awareness is completely absent.

[24] Stephen G. Post, "Dementia: Inclusive Moral Standing," in *Aging, Death and the Quest for Immortality* (eds. C. B. Mitchell, R. D. Orr, and S. A. Sallady; Grand Rapids, Cambridge: Eerdmans, 2004), 90.

[25] W. H. Vanstone, *The Stature of Waiting* (London: Darton, Longman and Todd, 1982), 20.

[26] Vanstone, *The Stature of Waiting*, 32, points out that this emphasis is noticeable in the gospels of both Mark and John.

[27] Vanstone, *The Stature of Waiting*, 109.

[28] Vanstone, *The Stature of Waiting*, 67–8.

[29] Vanstone, *The Stature of Waiting*, 68.

[30] Numbers 15:15–16 emphasises the vulnerable yet protected status of such 'protected strangers'.

[31] Exodus 23:12 and 22:21.

[32] Vanstone's emphasis on the significance of waiting underpins this analogy, although this book is not specifically about dementia. But his premise corrects the attitude that, to be of value, a person must be active and achieve.

[33] Goldsmith, *In a Strange Land*, 202.

[34] Perhaps the most important is the belief that communication with a person with severe dementia is not only possible but absolutely vital.

[35] Stephen Post, amongst others, expresses this view of inclusive and moral solidarity, see Post, "Dementia: Inclusive Moral Standing," 90–92.

[36] See Paul in 1 Cor 20 ff.

[37] Ellen B. Ryan's poem "Garden Blossoms" is the introduction and conclusion to Ryan, Martin and Beaman, "Communication Strategies".