

Dementia Care: Supporting A Plea for Personhood.

by Eric Stoddart

In many ways, dementia has become a dominant modern cultural image of becoming elderly. Intricately bound up with popular ideas about this condition are notions of hopelessness, loss, meaninglessness and perhaps most profoundly, the suggestion that the person is wholly lost to the illness; that all that is left is a shell of the person who used to reside within it. This paper attempts to offer a challenge to some of these stereotypical ideas by presenting a model of dementia care which focuses on the development of the personhood of the individual rather than the deficits which are brought about by the ravages of the condition. It will be shown that even in the midst of confusion, there stands a person made in God's image, and as such in need of love, understanding and the warmth of human relationship.

Personhood and Dementia

Contrary to common assumptions, people living with dementia do not only experience a significant loss in intellectual capacity and cognitive functioning. They also, and perhaps most profoundly, experience serious social and relational impairment, which blocks their passage to established sources of value such as occupation, meaningful conversation and 'normal' human conversation. This intellectual and social marginalization inevitably means that their personhood, i.e., what they are as unique human persons, comes under a serious threat. Their status as individuals with value, needs, rights and responsibilities is very easily neglected by those with whom they come into contact, whether these people are clinicians, chaplains, family or friends. There is little doubt that if you have a ward of 3040 people living with dementia and only six staff to look after them, then issues of personhood will inevitably take second place to the practicalities of every day living. Yet when you gaze into the eyes of someone living with dementia, as you feel them responding to your touch with a warmth that was previously hidden, you very soon become acutely aware that issues of personhood and effective care are inextricably interlinked.

Kitwood's Model of Personhood

One author who has written extensively within the area of dementia care is Tom Kitwood, a senior lecturer in psychology at the University of Bradford. In his contribution to *Dementia: Challenge and New Directions*, he states his belief that the biggest improvements for the quality of life of people who are living with dementia, has arisen not from medical breakthroughs but from the recognition of their personhood(1). Kitwood's model offers chaplains and healthcare workers a useful tool to enable them to reflect practically and

theologically on their practice and as theologian-practitioners, to begin to ask how they can effectively participate in the process of sustaining the personhood of people living with dementia.

Exclusion

Kitwood suggests that the general perception of 'primary degenerative dementia' in the 1980s was that it was 'a sentence to radical exclusion,' due to the fact that the person with dementia was considered not to exist socially(2). Consequently, although therapeutic intervention was offered, the condition was essentially allowed to take its, perceived inexorable, course. Any hope for improvement or management of the condition was perceived as lying primarily in further advances in biochemical research. Kitwood argues that this form of social exclusion was the inevitable outcome of a system of caring which failed to make appropriate recognition of the importance of the person in dementia care. In response to such exclusion, Kitwood pleads for a more substantial, and better articulated model of personhood which might overcome such misunderstandings and offer a more hopeful future for those living with dementia. He finds there to be a theoretical void in the social-psychological concept of personhood, with most research focusing on the intellectual and cognitive aspects of dementia. Kitwood's intention is to attempt to fill this void by drawing the emotional and relational aspects of dementia into the research equation.

Human Life as Co-humanity

Traditionally our understanding of what a human being is revolves around the idea that we are independent beings who are, more or less, understood as fundamentally separate from one another. However, there is another way in which we can explore what it means to be a human person. Ray Anderson captures the fundamental issue in his depiction of 'co-humanity' in which our humanity is determined by 'significant encounter' with another human (3). Following a similar line of thought, Emil Brunner recognises that, '[t]he individual as individual has no history. History consists in the fact that my existence is interwoven with the existence of others (4).' In other words, we only become the people we are as we enter into relationship with one another. Highlighting the importance of dialogue, Alistair McFadyen finds that, '[h]uman being in God's image signifies the human entrance into [a] relationship of active partnership by answering God's Word. Human being is not a static, unrelated substance, but a response to an external address(5).' It is in encountering one another that our history as a person is formed: one is only a father because of one's children, a wife because of one's husband, a lover be-

cause one is loved, and so forth. We are thus all relationally interconnected and dependant on one another for who and what we are and who and what we become. We respond to one another (not necessarily verbally) and in responding, together develop each other's personhood. What McFadyen is saying from a Christian perspective, is that this occurs because this is how we are in God's image. This is what human being is - it is an active process of dialogue with God, rather than the static concept of being a human.

From this it can be seen that we are all fundamentally responsible for developing the personhood of the other, a responsibility which is God-given.

The triune God [i.e. God who is Trinity] has created humankind as finite persons-in-relation who are called to acknowledge his creation by becoming the persons they are and by enabling the rest of creation to make its due response of praise(6).. Becoming persons ourselves is thus inextricably linked to enabling the rest of creation (which includes other people) to fulfil its calling. Keeping the linkage means recognising that part of my being a person is my enabling you to be a person.

In pastoral care it is common to appreciate this dual relationship between carer and cared-for. We might call it a binitarian conception. (i.e. as if there were only two Persons in God). A trinitarian conception however (i.e. our understanding of God as three persons: a community in His nature) pushes out the boundary to include carer, cared-for and others. It locks them together in the formation and sustaining of personhood. The 'others' may variously be family members, co-residents in a nursing home or the medical staff etc. Acts of exclusion (unconscious or deliberate) are, to the Christian, acts of sin against God's creation. With Kitwood we stand against exclusion and the, less obvious, failure to include.

Kitwood recognises people with dementia as being 'still capable of communicating their desires and feelings, and of living in a world of relationships(7).' He goes further and claims that these people remain able to experience 'some form of "personal growth"...even in the face of cognitive decline (8).' This is a substantial claim in the light of our tendency to understand personhood by asking what can this person do? Instead, this is asking what is this person *feeling*, and what is this person *being* in relationship to those around her? From a Christian perspective we absolve ourselves too easily by thinking that a person with dementia (a human-being-in-relationships) is mystically upheld in their relationship to God. As important as this aspect is to our proclamation of the Gospel ('though outwardly we are wasting away, yet inwardly we are being renewed day by day(9)') we cannot neglect our contribution to the personhood of someone with dementia. We (those without and those with dementia) offer

significant encounter and interweave our histories. We share a common nature, make an address to each other, and vitally, receive our summons to be human from God and from each other. Our response to the, oftentimes scrambled communication of someone who has dementia enhances or diminishes our personhood. When we rush off, or when we neglect the attempt to understand, not only do we diminish the personhood of the person we are facing, but we diminish ourselves and relinquish our God-given responsibility to affirm the personhood of the other.

Personal Growth

A person with dementia responds to people, to circumstances and to environments. For us to appreciate this as being engaged in personal growth, it is helpful if we borrow H. Richard Niebuhr's idea of 'social solidarity.' He understands human nature as being *response-able*. The more familiar word 'responsible' carries connotations of legal accountability on the basis of rational capability. Niebuhr's concept of being responseable, helps us to think in terms of what someone *can* do, rather than what they can no longer do. By response-ability, Niebuhr means that: (i) we respond to action upon us, (ii) our responses are the result of our interpretation of those actions, (iii) we anticipate that our responses will be met by the responses of other people (i.e. we are accountable to others), and (iv) in responding we recognise our social solidarity of continually forming society as we all respond to each other (10). I want to suggest, then, that personal growth exists, at least partly, within the realm of responsibility and that this remains true despite cognitive impairment.

As mentioned, a person with dementia responds to people, to circumstances and environments. This person interprets the question or event that faces them (but as their dementia advances this interpretation becomes different to that of other people). Their response is made in anticipation of a further response, but again, this becomes progressively more scrambled. Social solidarity is also taking place as an element of their response since society continues to be formed in their interactions with other people - even when their experiential world becomes so different. On this quadrilateral basis I would suggest that people with dementia remain responsible and can be assisted in being responseable.

It might of course be suggested that such a proposition makes little sense when I as a healthcare worker, am faced with a person who talks what I perceive to be 'nonsense' and who lives in a world quite discontinuous with my own. However, my own experience would lead me to believe that it is necessary to recognise that interpretation and anticipation are taking place and in this sense the person with dementia is making responses that are valid to them. Our responsibility becomes one of transla-

tion as we seek to understand what the person is actually saying, albeit with the wrong words, or even without using words at all. By assisting a person's response-ability we are helping them to make steps of personal growth.

Agenda for Dementia Care

Alongside his recommendations of physical reassurance from a known and trusted carer, the avoidance of over-concern with correcting a person's cognitive 'mistakes', and respectful pleasurable stimulation, Kitwood lists celebration and play as elements in assisting the development of the experiential self. These are not unrelated to reminiscing since attentive listening to stories of childhood holidays and children's antics celebrates the history of the person with dementia. However, when meeting a person in a ward or nursing home who is sitting as one of a number round the walls of a large room it is much harder to assist them in celebrating their history. The photographs and mementoes which one normally finds in a person's private dwelling can provide an easy route to conversation and reminiscence. Finding a patient at her bedside near her locker and pin-board filled with pictures can provide a much more stimulating pastoral encounter than in the anonymous Day Room. Is it an insurmountable difficulty to include personal mementoes around the chair in the Day Room where a patient spends so much of her day? Is their provision a greater difficulty than dealing with the current arguments over unofficially 'reserved' seats? Additionally, we have already seen the trinitarian understanding of being human in relation to others similarly engaged in being human. Perhaps we can push out the boundary still further to include an appreciation of the other parts of creation which are fulfilling God's intentions? In practical terms, the therapeutic value of domestic pets is already recognised in some children's wards. An even more fully trinitarian approach would be to actively encourage people with dementia to sustain their personhood through interaction with dogs, cats or birds which might be brought on visits. Is there, too, a role for chaplains facilitating the celebration of nature as God's creation through short trips for people into the countryside alongside the more traditional service of worship held indoors?

A New Understanding of Dementia Care

We can now summarise the challenges Kitwood's plea poses to Christian pastoral care. By so often

focusing the definition of humanity on the capacity to reason Christians are left struggling to support the personhood of people for whom this faculty is impaired. A turn towards concentrating on relational capability is vital so that there arises a reflexive model i.e., one which describes all of us in the process of development. In so doing the danger of paternalism and condescension can still arise. This exerts itself when a carer only understands himself or herself as being the bearer of Christ to the person requiring care. A more trinitarian understanding includes the dimension of commonality in human being yet preserves individual differences. In a still more direct sense the very personhood of the carer is determined by his or her response to the person with dementia. A failure to take time to listen, an over-eagerness to correct mistakes, to remove roles, and treat the person as irresponsible diminishes the carer's personhood as much as it does the person with dementia. Through both the practical steps outlined above and a clarification of our shared experience of being human pastoral carers have both the calling and the opportunity to sustain the personhood of people living with dementia.

Endnotes.

1. Tom Kitwood. 'Personhood, Dementia and Dementia Care' in S. Hunter (ed.), *Dementia: Challenges and New Directions*. Jessica Kingsley Publishers 1991. Research Highlights in Social Work 31.
2. Kitwood. 'Personhood.' p9. Italics added.
3. R. Anderson, *On Being Human - Essays in Theological Anthropology*. Eerdmans 1982. p54.
4. E. Brunner. *Man in Revolt: A Christian Anthropology*. Lutterworth Press 1939. p443.
5. S.A. I. McFadyen. *The Call to Personhood: A Christian Theory of the Individual in Social Relationships*. Cambridge University Press 1990. p19.
6. C. E. Gunton, *The Promise of Trinitarian Theology*. T. & T. Clark 1991. p120.
7. Kitwood, 'Personhood.' p 11.
8. Kitwood, 'Personhood.' p 11.
9. 2. Corinthians 4:16 (NIV)
10. H. R. Niebuhr. *The Responsible Self An Essay in Christian Moral Philosophy*. Harper & Row 1963. pp61-65

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