

# Dementia and Faith

## Bishop James Newcome

Dementia is no longer a subject that is forgotten, neglected or ignored. The statistics are startling.

- There are currently about 800,000 sufferers in the UK.
- By 2039 this will have risen to about 1.4 million.
- Up to one in four beds in UK hospitals are occupied by someone over 65 with dementia at any one time.
- The total cost to the NHS is more than for cancer, heart disease and stroke put together.

The government (and others) are alarmed—hence the former Prime Minister David Cameron’s national challenge to fight dementia, and the huge amount of research into the epidemiology, biochemistry and genetics of dementia disorders.

However, the spiritual dimension is frequently left out. On Monday I had a conversation with Professor June Andrews, author of the definitive book *Dementia: The one-stop guide*, and pointed out that though her book is excellent in every other way there is nothing in it about faith. So I was encouraged to find, and read, a book by a Methodist minister from New Zealand on this topic. The author’s name is Eileen Shamy, and the book is called *A Guide to the Spiritual Dimension of Care for People with Alzheimer’s Disease and Related Dementia*. Her main contention (with which I’m sure all of us agree) is that human beings are more than just ‘body, brain and breath’. She writes, ‘Healthcare which fails to include the spiritual dimension treats people as less than human.’ She points out that the word ‘spiritual’ actually embraces the essence of what it is to be human; to reject the spiritual dimension is ‘to shatter what should be whole and obscure what should be clear’.

So in this brief talk I want to reflect on both Shamy’s observations and my own experience by looking at four key themes which seem to me to be central to any considerations of dementia and faith:

1. Identity and personhood
2. Our value and worth as human beings
3. The fear induced by dementia both in those who have it and in those who care for them
4. The hope our Christian faith offers to us all

### 1. Identity and personhood

#### Identity

Dementia can lead to a loss of any sense of self and a loss of dignity—which means that a person’s identity can seem to be gradually stripped away. As the psalmist puts it, ‘Are your wonders known in the darkness, or your saving help in the land of forgetfulness?’ (Psalm 88:12, NRSV). But of course, for the Christian, our identity is ultimately found in Christ. We are who we are in his sight (as we were recently reminded by the Archbishop of Canterbury after his DNA test), which is why the concept of personhood is so very important.

#### Personhood

You may know the story of the nun with Alzheimer’s who asked her spiritual director, ‘What will happen if I forget God?’ Answer: ‘He will never forget you.’ And that is what ultimately matters, which is why it is so necessary to see people with dementia *not* as ex-people or ‘gone’, but as people like us who are still there.

Our personhood derives not from us but from God, and as his children we never lose our essential nature as human beings made in his image. For some people with dementia there is a loss of inhibition

caused by changes in the frontal lobe of the brain—which is often described as the ‘disintegration of personality’—but which might perhaps be the real person beginning to come through.

## 2. Value

We are all familiar with the way in which our 21<sup>st</sup>-century idols of materialism and consumerism value us according to what we can do. Our worth is seen in terms of activity and ability. But as W.H. Vanstone remarks in *The Stature of Waiting*, ‘Why is it that in the professed and public attitudes of today, the proper function of man is identified exclusively with his capacity for action, and that his human dignity is alleged to be preserved only to the extent that he acts, initiates and achieves?’

For the Christian, a person’s worth lies in the simple fact that he or she is infinitely precious to God regardless of productivity. Competence is not what makes us valuable to him, and we see that in the attitude of Jesus to vulnerable people—whom he valued but never patronised. Jean Vanier has recognised this more than most, and he says, ‘It is mutuality of need and weakness which builds community—and we are called not to independence but to interdependence.’

That’s why we need to affirm every person as loved by the one who created us all—which means including them in our worship, which is such an important resource for spiritual health and well-being. We need them as they need us—inconvenient and sometimes disruptive though that may be—and it is sometimes in those who seem most cruelly diminished by dementia that we come face to face with Jesus.

## 3. Fear

People with dementia have no signposts, which means that they can quickly lose the support of their community and become isolated. That quickly leads to fear—when what they most need is cognitive security, which comes when they can find some meaning in their experience. We can help to provide that, partly through the love and care we offer, but also through the eucharist, and through the familiarity of symbols and resources that have in the past sustained their spiritual health.

But of course fear isn’t confined to those with dementia. It affects the rest of us as well. Our fear of dementia is a sort of subset of our fear of death, and, as Shamy writes, we encounter in people with dementia ‘our own monstrous fears of loss and dependence’. If we’re not able to feel at ease with our own inevitable ageing and eventual death, we will never be able to relate properly to others on the basis of our common humanity. As the poet Robert Browning wrote in his poem ‘Rabbi Ben Ezra’:

*Our times are in His hand  
Who saith ‘A whole I planned,  
Youth shows but half; trust God: see all, nor be afraid!’*

## 4. Hope

People with dementia are not without spiritual awareness. In particular they pick up on and respond to nonverbal behaviour. Who we are (present to them) and how we are (peaceful and unhurried) can do as much as anything we say to reassure them that—in the great words of the apostle Paul—‘neither death nor life... nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord’ (Romans 8:38–39, NIV). Indeed, Paul himself knew what it was to be in prison, but still free. Once again, the eucharist can be of value here as a great sacrament of hope. Symbolic actions and rituals can help to rebuild and remember each person into ‘that place where he or she truly belongs’—in other words, the community of God’s people.

This is a reminder of the need carers also have for hope. They can so easily feel isolated, exhausted and forgotten—forced to live with (and never solve) a problem that only gets worse, not better. That’s why,

in the Church of England, we're planning a project called 'Caring for the Carers' (on which more in due course).

#### Conclusion

In the end, spiritual well-being is all about relationship—with God, ourselves, others and our environment—the sort of relationship that nurtures wholeness and reminds us that we are kept and loved by someone greater than ourselves who gives meaning and purpose to our lives. That applies to all of us, however old or young we are, and whether we have dementia or not.

Let me end with a little parable that Shamy quotes in her book, which I believe expresses much of what I have been trying to say about dementia and faith.

*Consider this true story, reported in the World Federation of Occupational Therapists Bulletin, 'Food for Thought—on Caring' (1985).*

*In a lecture to a class of graduate nurses the following case presentation was given:*

*The patient: white female. She neither speaks nor comprehends the spoken word. Sometimes she babbles incoherently for hours on end. She is disorientated about person, place and time. I have worked with her for six months but she still does not recognise me. She shows a complete disregard for physical appearance and makes no effort to assist in her own care. She must be fed, bathed and clothed by others. She is toothless so her food must be pureed. Her sleep pattern is erratic. Often she wakes in the middle of the night... Most of the time she is friendly and quite happy. Several times a day, however, she becomes quite agitated without apparent cause and screams loudly, until someone comes to comfort her.*

*After this presentation, the nurses were asked how they would feel about taking care of such a patient. Words such as 'frustrated', 'depressed' and 'annoyed' were used. The lecturer said he enjoyed the care of her and was greeted with disbelief. A picture of the patient was then passed around. It was of his six-month-old daughter.*