

## THE SILENT GRACE OF DEMENTIA

*Tentative faith-comments around the mystery of those with dementia. What do we see, as family and carers when we look at someone with dementia?*

As dementia advances there is an urgent need for 'person-work', for a care-filled reverence in this fragile world of the soul. A spirituality around dementia has to do with not denying to people their humanness, their sense of identity, of being their own person. Friends and carers are called to be, in a sense, the memory for the person, to hold the fragments of a life together, a life to be seen, perhaps, in the light of past courageous enterprise and creative achievement. That intensely alive person, the glory of God, as St Irenaeus put it, is still alive inside, though not always recognisable as such.

Getting to know as much as possible about the life, passions, interests of the person concerned, is, as you well know, a primary and utterly necessary step. That is why, as a person with dementia loses their sense of reality, then visual and other memories are needed to remind them – and even more importantly, their loved ones, of the person that they have been and, in some context, will continue to be: (-eg a person's spiritual story: preparing their spiritual boxes of memories in good time: 'This is your Life' collection - pictures of key events, wedding photos, childhood photos, symbols, church, rosaries, hymns, rituals, prayers: the 'themed' and decorated room of the '30, 40s, 50's with posters, music . . .)

We often reflect, as we did here last year, on the divine seed, the divine image, within us at birth and baptism. God's initial dream within us may *seem* to have been eclipsed when our mind no longer functions as it should, but it is never completely lost. Nor does it ever die. We need to reach into a deeper place, a different context to say and believe these things. For God there is no final drought, no lasting famine, no season without a harvest.

One essential fact to remember is that people are more than their mind and memory. Too often the mind over-reaches itself and tries to dominate the body and the soul. Most of us believe that we *are* our thinking, that it is the mind that makes us human. (*That, in fact, is one of the reasons for our depressions and inner distress.*) But we are all infinitely bigger than our

minds. There is a richer, deeper self beyond memory, beyond mental commentaries about present and future.

A robust faith believes in something deeper than ‘thinking’ in all dementia sufferers - a precious place that is unreachable by anything that happens to them, no matter how severe, a kind of virgin soul that is impervious to the vicissitudes of human experience. Thomas Merton writes of ‘the secret beauty of their hearts where neither sin nor desire nor self-awareness can reach, the core of their reality, the person that each one is in God’s eyes.’

*‘To you she looks imperfect. But to me she is flawless. She will never destroy . . . she will remind you every day that I am who I am, and that the smallest dust speck in darkest space does not fall out of my hand. My ways are not your ways. She is my sign to you. Treasure her.’ (Morris West)*

### The work of the Carer: Re-menting, re-minding, re-memembering

In his book *Person to Person* Tom Kitwood holds that in dementia, identity remains intact, because others hold it in place; thoughts may have disappeared but there are still interpersonal processes; feelings are expressed and meet a response. A spirituality within dementia must be around the deeper, connected presence of the divine in everyone, beyond the normal ways we relate. The carer needs to be aware of this mystery and to be sensitised into it by reflection, sharing and prayer.

Beyond our minds there is a connection that links our souls, our spirits. People need their carers to keep their human/spiritual essence alive, God’s human soul that is enlivened in and by each other. Christine Bryden who was diagnosed with dementia at 46 said, ‘I need you to minister to me; to sing and pray and play for (in my place/stead) me, to remember (since I cannot do it anymore) for me.’

Christine, a top civil servant and single mother of 3, was diagnosed at the beginning of dementia in 1995, at the age of 46. ‘My journey’, she wrote, ‘is to the inner self; to the reflection in the divine within. This is what gives me an abiding sense of meaning as I travel the journey from diagnosis to death.’ She’s now 63. (Books by Christine: *Who will I be when I die?: Dancing with Dementia*. Jessica Kingsley Pub.)

To repeat, at the heart of the phenomenon of dementia is the loss of one's personhood and identity. When the condition sets in there is a gradual erosion of a conscious sense of self, of all that gives a person the self-awareness necessary for living with others. It is in their relationships that people recognise themselves as autonomous and authentic; as a source of wisdom and experience rather than as an object of care. How do we empower them beyond 'caring for' them, as 'validation-therapy' or life-story work, for instance, tries to do?

Because the condition of dementia takes away the future and dissolves the immediate past, there is no alternative to 'Being in the Now' in real time. A new level of authenticity, of living by subtraction, has to become the norm. This grace of living in 'the sacrament of the present moment' is something we all strive after in our own lives - the greatest grace for avoiding anxiety, fear and unhappiness.

In his valuable website ([www.welcomemeasiam.org.uk](http://www.welcomemeasiam.org.uk)) Ben Bano urges carers to remember and reinforce this sacred selfhood of people with dementia. So much will depend on the carers' own inner spiritual understanding of the body/soul interdependence; they need every help to deepen and enrich their own spiritual life, their own vision and wisdom, their presence and power to relate at profound levels. In a sense, this depth of understanding is necessary for all who serve others.

Staying true to the principles of Incarnation, it is through the senses that the inner shrine is reached. They are the thresholds to the soul. The graciousness of the carer's eyes – windows out and windows in; the touch of the friend's hands – extensions of the heart; the dignity of the helper's composure - the body betrays the inner state of the soul; the dignity of the carer's voice, the radiance from her physical presence, the real reverence for the mystery of the other. Embodied love is the sacrament of invisible grace that somehow touches the fretful, demented mind and, beyond all our explanations, works silent wonders. (*Why is human presence so powerful? – because of Incarnation when the power of God's human presence was revealed.*)

All of this ministry is the Gospel fully lived, but often with no thanks for it, no reward, no pay-back – just an inspired lavishing of loving and devoted

attention. Writer and missionary Sheila Cassidy calls it the extravagant and compassionate outpouring of ‘our precious ointment’ on those marginalised and isolated. To see the other through the eyes of God, the carer must be faithful to her inner work. It takes a lot of personal transformation to become an unconditionally loving presence that transcends even the invisible walls of dementia.

### How does faith help us?

It is only with the sacramental vision of Christianity that we can see the divine hand in all fading and dying. By sacramental vision I mean that faith-way of seeing things in which God is recognised at the very heart of everything and of everyone. God is totally present at all stages of development and diminishment, as fully incarnate in the dying autumn poppy as in the ravishing rose of summer, as totally present in the person enduring the dark night of the mind as in the cerebral brilliance of a Thomas Aquinas. It was, in fact, this very saint and scholar who believed that beneath the surface of earthly dimness, diminishment and dying there is always a shimmering of divine light and beauty.

We now speak of a hidden dignity in the physical and mental decline which characterises dementia, a rare spiritual quality, a gain out of loss, as the fragmentation of the personality of the loved one progresses. In her book *Touch the Spirit: Connecting to the Inner World of Dementia*, Dr Deborah Forrest uses the term ‘dementia consciousness’ to describe the inner awareness of the person with dementia, the person alive inside, the enduring presence of the human spirit, the life-force, the soul-force that is shifting away from the head towards the inner soul. This, she says, opens new channels for communication. Something of God’s essence can somehow be revealed and affirmed in the cognitive and physical decline of dementia.

Incarnation and baptism graces all of us with a real priesthood whereby we consecrate each other. ‘Carers’ or ‘helpers’ become equal partners in a spiritual quest. Peter Kevern suggests a more empowering way of seeing the relationship between dementia patients, those around them, and God’s presence. In his *What sort of God is to be found in Dementia?* he asks, ‘If we are all in God’s image, then the world is not divisible into patients and carers

in any stable way – the dividing line of these constituencies runs through each of us’.

Pauline, a friend, ministers daily to Siobhan who is in the last stages of dementia. ‘Even though her mind has left her, I have nothing to give her,’ Pauline told me. ‘But in her embrace I know I am loved by God. For me she is the living presence of the divine. When I leave her I feel I am a better person, as though I had been in a sacred place.’

Beyond being objects of compassion or subjects of benevolence, dementia sufferers can be perceived as gift, a window that reveals a more profound truth, a face of God. We must often work very hard indeed to see through that dark glass. Theological ethicist Stanley Hauerwas, calling on the deepest implications of Incarnation, suggests that God somehow *becomes* dementia in solidarity with the dementing person, to guarantee their authentic humanity and divinity.

Maybe, then, the seeming loss and emptiness of dementia is a purifying preparation for what the eye has not seen or the ear heard – but first for death. After all, everything must begin to fade away, die in us, for the new dawn to break over us. In his daily meditation Richard Rohr OFM recently wrote, ‘But we fear nothingness. That is why we fear death which, of course, feels like nothingness. Death is a shocking realisation that everything I thought was me, everything I held on to so desperately, was finally nothing. (cf Kathleen Dowling Singh’s book ‘The Grace in Dying: How we are Transformed Spiritually as we Die’. The nothingness we fear so much is, in fact, the treasure and freedom that we long for, which is revealed in the joy of the Risen Christ. We long for the space where there is nothing to prove and nothing to protect, where I am who I am, in the mind and heart of God. And that is more than enough’.

In her *Disabled or Enabled; Ethical Issues in Dementia Care*, Rosalie Hudson has written, ‘Perhaps the person with dementia – freed from all pretension, totally incapable of spiritual self-examination – might be an icon of God’s grace to us . . . in the divine dance (*perichoresis*) of Trinitarian love we are all welcomed as partners; we are drawn into the space of the Father, Son and Spirit, even when we have forgotten the steps . . .’

