

See ME rather than my dementia – promoting Dignity and Personhood in Dementia

**A paper given at the Conference – ‘Dignity in Healthcare’
Anscombe Centre, Oxford, 18th June 2012**

‘Traditional’ and ‘Person-Centered’ approaches to Dementia

The speakers at this Conference, and in particular Daniel Sulmasy, pose an interesting challenge in addressing the care and support of people with advancing dementia. I would like to focus on ‘inflorescent’ dignity, pose the question of how we can enable someone with advancing dementia to ‘blossom, flourish, or thrive’.

Is this a contradiction as a person with advancing dementia gradually lose their physical and mental faculties ? Is it unrealistic to see dementia in these terms ? In the course of this brief presentation I would like to suggest that through understanding and meeting the ‘inner’ needs of someone with dementia, we may see small and in some cases even more substantial steps in both blossoming and thriving.

We need to begin by looking at ‘traditional’ and more person-centered ways of looking at the care and support of people with advancing dementia. In a traditional approach, the ‘self’ deteriorates as dementia attacks the mind. People retain the ‘form’ of social behaviour but their actions become meaningless. People with dementia are seen as ‘sufferers’ – perhaps in an effort to comfort those around them as well as society in general. They need to be ‘looked after’, rather than supported and empowered.

It is only relatively recently that we have been able to see the care and support of a person with dementia¹ in a relatively positive light. One of the key influences to the breakthrough in our thinking about dementia came about largely through the influence of Tom Kitwood who worked through the Bradford Dementia centre in the 1990’s in changing our perception in the way we see people with dementia.

While Carl Rogers had developed the approach to person centered care in the 1960’s through client centered counselling, it was Kitwood who developed the approach to the field of dementia care alongside other pioneers such as Naomi Feil who developed validation therapy during the 1990’s.² Social Role Valorisation, also played a part in encouraging an enlightened approach to dementia care.

¹ While this paper refers to ‘people with dementia’ it can be argued that as there are various types of dementia, it is more appropriate and person-centered to refer to ‘people with a dementia’.

² A remarkable example of Naomi Feil’s validation therapy in action can be seen on a you tube clip <http://www.youtube.com/watch?v=CrZXz10FcVM> in which Naomi Feil works with an elderly lady who has lost the power of speech to rediscover hymns of her childhood.

These approaches all had in common the experience of the person with dementia and their human rights as individuals and as citizens. In his seminal work, 'Dementia reconsidered – the person comes first'³ Kitwood described the influence as what he saw as 'malignant social psychology' – the influences such as disparagement and infantilisation which militate against an approach to care based on dignity and humanity. For Kitwood personhood has to be supported and maintained by the people close to the person with dementia.

The converse to the effects of malignant social psychology is positive person work, for example focusing on celebration, encouraging creativity, use of communication techniques such as validation, and giving pleasurable experiences.

Personhood

Kitwood coined the term 'personhood' to counter the stereotype of the person with dementia gradually losing their physical and mental functioning and their personality as dementia advances. The concept of personhood reinforces the image of the person with dementia as someone who is able to experience emotions, both positive and negative, as well as the ability to share these emotions to those who are able and willing to be present in what might be a bewildering and confusing situation.

There are clear implications of an approach based on personhood. We don't just see deficits and problems, instead we see the person as a whole. We see the person with dementia as a 'living person' rather than a 'living death'. A person with dementia is seen not just as an object of care, but as a source of wisdom and experience. Through the concept of personhood we can explore how we might promote inflorescent dignity.

Spirituality and Dementia

Like any other human being as age advances, the person with dementia needs to find a sense of meaning and purpose if they are to avoid a meaningless existence in their increasing frailty. As Viktor Frankl (1984) pointed out, 'it is a constitutive characteristic of being human that it always points, and is directed', to something other than itself... being human means to be open to the world, a world, that is, which is replete with other beings to encounter and with meanings to fulfil.'⁴

Paul Tournier, in reflecting on the state of increasing frailty, commented that the 'meaning of things is impossible to eradicate from the human heart'

³ Kitwood, T. 'Dementia Reconsidered – the person comes first': Open University Press, 1997

⁴ Frankl VE (1984) 'Man's Search for Meaning'. New York: Washington Square Press.

(p189).⁵ As Jung also put it so eloquently, 'We cannot live in the afternoon of life according to the programme of life's morning – for what was great in life's morning – money making, social existence, family and posterity, will be little at evening – whoever carries into the afternoon the law of the morning will pay for it with damage to his soul' (Jung, 1933).⁶

My own experience of the importance of personhood in dementia developed through an interest in spirituality and dementia. Some years ago as I made contact with patients in the dementia wards in the hospital for which I was responsible as Director of Older Peoples Services. I observed that even in advancing dementia, when some patients had lost the power of speech, they retained the power to remember familiar prayers and hymns. This led me to explore the ways in which an understanding of spiritual needs can promote dignity in the caring relationship.

Such an understanding of spiritual needs is particularly important as a person enters into what Elizabeth Mackinlay describes as the 'fourth age' of life.⁷ If the third age is that of being older and remaining independent, the fourth age is marked by increasing frailty and dependency.

Spirituality is of course not the same as religion. We may not necessarily have a religious faith, but we are all spiritual beings. As John Swinton has so eloquently put it: 'Spirituality is that aspect of human existence which gives it its 'humanness'. It concerns the structures of significance that give meaning and purpose to a person's life and helps them deal with the vicissitudes of existence. As such it includes such vital dimensions as the quest for meaning, purpose, self-transcending knowledge, meaningful relationships, love and commitment, as well as (for some) a sense of the holy among us.' (Swinton, 2001)⁸. Spirituality includes, as Mackinlay reminds us, an ability 'to live life to the full' in spite of increasing frailty.

As Swinton points out, people with dementia are often particularly open to intense spiritual moments, living as they do in the present moment. 'Enabling people to function within the spiritual dimension is a key which can unlock the person and reveal dimensions of personhood that appear lost until they are encountered in the stillness of the spiritual moment.

Personhood and the 'Other'

Kitwood also reminded us of the importance of 'the other'.

⁵ Tournier, P: 'Learning to Grow Old' SCM Press: London (1972)

⁶ Jung, C.G. (1933) Stages of Life. Collected Works, Vol. 8, Paragraphs 778, 784

⁷ Mackinlay, E: 'Spiritual Growth and Care in the Fourth Age of Life': Jessica Kingsley, London (2006)

⁸ Swinton, J and Pattison, S. 'Come all ye faithful', Health Service Journal 111(5786)24-25

'The 'other' is needed to offset degeneration and fragmentation. The more the dementia advances, the greater is the need for that 'person work' – we are needed to hold the fragments together' (Kitwood and Bredin, 1992)⁹

Kitwood went further in suggesting that people with dementia may well be more authentic and honest than those afflicted by the pressures of everyday life. The concept of personhood promotes a view of dignity in care based on respect and equality of the carer and the cared for.

In line with the principles of person-centred care we need to acknowledge the importance of other people in helping to preserve the personhood and identity of the person with advancing dementia. (Bano, Benbow and Read, 2011)¹⁰ Radden and Fordyce (2006)¹¹ point out the role of caregivers and others close to the person with dementia: 'Others must remember, reinforce, and reinscribe the identity of the person with dementia...we must preserve the person's identity as the person's own grasp on it weakens...'

It was no accident that Kitwood was influenced by some key philosophical influences. Buber's definition of an 'I-thou' relationship as compared to an 'I-It' relationship provided a powerful stimulus for seeing interaction with a person with dementia in a humanistic, person-centered way.¹² The I-thou relationship is a time when 'a deep realness in one meets a deep realness in the other' (Rogers, 1980)¹³ and is in contrast to the experiences of being ignored and demeaned in the context of an 'I-It' relationship.

As the 'other', can we enter into the world of a person with dementia / can we take part in the person's meaning making ? Can we move through the world with the person through changing situations which are annoying and frustrating and develop encounters which are meaningful?

⁹ Kitwood, T and Bredin, K: 'Towards a theory of dementia care: personhood and well-being', *Ageing and Society*, 12(3): 269-287 (1992)

¹⁰ Bano, B, Benbow, S., Read, K.; 'Dementia and Spirituality: a perfume always remembered' in Gilbert, P (ed) 'Spirituality and Mental Health' (Pavilion Publishers, Brighton) (2011)

¹¹ Radden, J. and Fordyce, J. Into the darkness: losing identity with dementia. In: Hughes, J., Louw, S, Sabat, S. *Dementia - Mind, meaning and the person*. Oxford: Oxford University Press. (2006)

¹² Buber, Martin: 'I and Thou' (Scribner, New York) (1958)

¹³ Rogers, C.R. 'A way of being' (Houghton Mifflin, Boston) (1980)

Dignity and Empowerment in Dementia Care

Other recent thinking on promotion of dignity in the care of people with dementia has focused on the notion of dignity as empowerment. The Nuffield Report on ethical issues in dementia¹⁴, published in 2009, reminds us of the ethical importance of constantly reflecting on ways in which we promote dignity to promote and uphold their value as a human being. The Department of Health Guidance published in 2010 on risk management in dementia 'Nothing Ventured, Nothing Gained'¹⁵ points to the need of a positive approach to risk management if we are to genuinely promote dignity and empowerment in people with dementia. The more recent concept of 'enablement' is also a way describing the need to promote autonomy rather than dependence in people with dementia.

My interest in this question deepened when I became involved both in a training as well as pastoral capacity in local residential and nursing homes as well as with the dementia ward in the local Mental Health Unit. In an environment marked by what appeared to be passivity and boredom, residents to whom I brought the Eucharist became engaged and connected. The 'power of the present moment' brought out a deep sense of the spiritual. As time progressed I was fortunate to be able to make a film 'Its still ME, Lord', commissioned by Caritas Social Action Network, on spirituality and dementia.¹⁶

Understanding the Spiritual Story

Care and support marked by dignity is about knowing about the life of the individual concerned. For this reason there has been a growing interest in the need to understand the 'spiritual story' of someone with advancing dementia if we are to truly understand their personhood. One of the helpful aspects of recent developments in care and support of people with dementia has been the development of life story work – an approach based on getting to know the 'inner self' – the achievements as well as the preferences of a person who may not be able to speak for themselves.

Spiritual assessment is often an extension of life story work – it involves a creative approach to getting to know a person, particularly when the power of speech is fading. Familiar objects, perhaps placed in a convenient 'memory box', are all part of understanding an individual spiritual journey. Promotion

¹⁴ Nuffield Council on Bioethics - 'Dementia – Ethical Issues' Cambridge Publishers, Cambridge (2009)

¹⁵ Department of Health: 'Nothing Ventured, Nothing Gained' (2010)

¹⁶ Caritas Social Action Network: 'Its still ME, Lord' – a DVD exploring spirituality and dementia (Caritas Social Action Network, London) (2009)

of choice, which is crucial to person-centered care, can be enhanced through enabling a person to choose their favourite hymns and prayers.

An understanding of spiritual needs is of course broader than purely religious needs. It is important to understand the 'inner self' and the ways in which a person might be able to connect with their 'inner self', for example through being encouraged to think about their favourite pastimes. It is encouraging that the use of the 'This is ME' tool¹⁷ is being developed in settings such as Acute Wards of General Hospitals, where the person with dementia can feel most disorientated.

Person-Centered Care Planning

Having understood the spiritual story, we must work out how this can be translated into the reality of everyday experience for the person with advancing dementia. It is unhelpful to have good intentions but fail to see that these have to be translated into actions which are carried out consistently by those responsible for care and support. Good care planning involves a focus on likes and dislikes, what is admired and liked about the person, and the ways in which a person would like to be addressed and supported. I have seen instances when a person is addressed in familiar terms by their first name when they might have preferred otherwise but have been unable to articulate this. Promotion of inflorescent dignity can be impeded by approaches based on familiarity and infantilisation.

In order to promote dignity for people with advancing dementia., we must be careful not to place spiritual care solely in the hands of ministers or chaplains. Each aspect of daily living has a spiritual component. Getting dressed and ready in the morning can be a mundane care task, or it can be enriched through enabling the person to pray if they wish to, to reflect on the day ahead, as well as giving time and space to express their innermost thoughts.

It is also important to pay close attention to communication skills to promote dignity in a person with advancing dementia. A person with advancing dementia may take up to five times longer to absorb a message and may only understand the first and last words of a sentence. While communication may have to be slower, it should never be condescending or conducted in a that looks down on the person.

Spirituality can and should be embedded into seemingly simple care routines. The act of washing is closely connected with religious rituals of purity and cleansing. Preparing for the day, or going to bed in the evening can, with the right support, be a meaningful spiritual experience. Meal times as well as the opportunity to mark religious feasts through celebratory meals are especially significant as is attention to dietary and cultural needs. In order to emphasise

¹⁷ 'This is ME': available through www.alzheimers.org.uk

the importance of spirituality in the everyday life of a care setting I am currently facilitating a number of workshops for staff in residential homes titled 'My Spiritual Home' in which we discuss how spiritual aspects can be embedded into the care routines of the home.

'The Power of Presence' – Meeting spiritual needs as dementia advances

The well known author and columnist Daniel O'Leary speaks movingly of the 'power of presence' in promoting dignity.

*'The role of your body in revealing Presence is central; the graciousness of your eyes – windows out and windows in; the touch of your hands – extensions of your heart; your body – the dignity of composure; your body betrays the inner state of your soul; the dignity of your voice, a radiance from your physical presence, a reverence for the Presence of the other. Then you release a healing Presence in the other.'*¹⁸

With a focus on understanding and meeting spiritual needs, the personality of the person with dementia – their inner self- comes alive and they are no longer seen as a person who is a passive being in an armchair in the lounge of a residential home – instead they become seen as someone whose personality is still very much intact. Perhaps this is what Teilhard de Chardin might have had in mind when he referred to 'the divinisation of our passivities'.¹⁹

We may need to find other ways of communication when the power of speech begins to fail. Symbols and familiar objects become increasingly important at this time. The use of 'spiritual memory boxes' can enhance a sense of identity and personhood as physical and mental faculties fail.

Moira was a 90 year old resident in a specialist dementia care unit. She was approaching the end of her life and was unable to speak or take in food or drink. After some time in her room I realised that it would not be possible to have a conversation with her. Having spent some time in prayer with her I turned on the television when 'Songs of Praise' was showing. Her mouth began to move slightly as familiar hymns were sung on the programme.

¹⁸ O'Leary, Daniel. From a talk given at the Conference: 'The Journey of Hope – Catholic Chaplaincy in Mental Health Services' - Liverpool, March 2012. Available on: <http://www.welcomemeasiam.org.uk/the-journey-of-hope-conference-03-2012.html>

¹⁹ De Chardin, Teilhard: Le milieu divin : an essay on the interior life : Fontana, London (1964)

The multiple forms of a spiritual journey

If we are truly to respect and enhance the dignity of a person with dementia, we need to be alert to the many forms which a spiritual journey can take. Such a journey is not always marked by a religious faith, or even by a confident faith – it can be marked by feelings of guilt and unworthiness that a person may have difficulty in rationalising. It can be equally marked by a sense that God has let them down. Our role is often not to promote false reassurances but to be with a person as they journey through these difficult feelings. At the same time we need to be alert to the fact that spiritual needs have to be addressed in flexible ways as dementia advances.

Martha, who was born and brought up in Italy, has Alzheimers Disease and is in her early 90's. She has been a resident in a care home for the last two years.. She has difficulty in remembering visitors and is increasingly disorientated her verbal powers are failing. Each Sunday she receives Communion. As words become more difficult to express she takes the Crucifix into her hands and kisses the foot of the Cross. While she has difficulty in understanding some of the liturgy, she enjoys praying the Our Father and Hail Mary in her native Italian.

Spiritual Needs of those whose lives are touched by dementia

The spiritual needs of those close to the person with dementia are equally important. For many family members and caregivers, complex feelings of guilt, anger, mixed with love, come to the fore. David Keck has commented on the range of emotions which arise for those close to the person with dementia. He asks: How can we speak of 'dignity' in the physical and mental decline which characterises dementia? How can there be any beauty in the world as the fragmentation of the personality of the loved one progresses? Can the beauty of God's glory and creation be found and affirmed in the cognitive and physical decline of dementia? How can we plan a funeral which will recognise the worth and achievements of our beloved parent?²⁰

For those close to a person in the advancing stages of dementia, diminishment needs to be put in the context of a person whose life story needs to be seen in the context of lifetime of achievement and fulfilment. As a person with dementia loses their sense of reality, visual and other memories are needed to remind them – and even more importantly, their loved ones, of the person that they have been and will continue to be.

'Giving back – the 'gift' of dementia.

²⁰ Keck, D. 'Forgetting Whose We Are: Alzheimers Disease and the Love of God': Abingdon Press, Nashville (1996)

Can dementia ever be a gift ? Or is such an assertion an aberration ? Can a person with advancing dementia bestow dignity on those involved in their care and support ? My pastoral experience over the last few years has led me to believe that this is very possible. Sometimes the person I am ministering to has spontaneously prayed for myself and my family and suggested that I need to slow down and stop rushing around ! We can become the person who is ministered to as well as ministering. Rosalie Hudson (2008) has written movingly of this connection:

'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 of Trinitarian love we are welcomed as partners; we are drawn into the fellowship of the Father, Son and Spirit, even when we have forgotten the steps – dementia reminds us of our own frailty'.²¹

Rather than being seen as 'carers' or 'ministers' we become equal partners in a spiritual quest. As Kevern (2010) points out, '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'.²²

Conclusion

Dementia need not be seen as a living death. It is open to all of us involved in the care and support of people with advancing dementia to show how through a focus on promoting personhood through the prism of spirituality even as mental and physical faculties decline, we can enable a person with dementia to 'live life to the full' and enjoy times of flourishing and thriving.

Ben Bano
June 2012

²¹ Hudson, Rosalie: *Disabled or Enabled; Ethical Issues in Dementia Care* in: Mackinlay, E (ed): *Ageing, Disability and Spirituality*: Jessica Kingley, London (2008)

²² Kevern, Peter – 'What sort of God is to be found in dementia' ? *Theology*, May/June 2010 Vol CXIII No 873 (p 177)

