

# Seeing the person beyond the dementia: do people with dementia have spiritual needs?

Text of a talk given in Medway by Alison Johnson, 23 January 2008  
(<http://www.levesoncentre.org.uk>)

## Introduction

My passion resulting from working with Tom Kitwood, being Secretary and editor of CCOA Dementia group and working with MHA and then freelance

Alison Delapage

*'I think the work you are doing is vital to the well being of people with dementia. The more I hear about the wide range of quality of care, the more I find that the element missing in poor quality care is the 'spiritual' one - **spiritual in the widest possible sense as pertaining to all that meets the deeper human needs of people as opposed to just their physical well being and entertainment/occupation.***

Similarly Murna Downs of the Bradford Dementia Group

*Our society values cognitive skills - knowing, naming etc - and has little respect for the emotional world. People with dementia can help us remember that **being and touching and holding and laughing are as important as remembering and naming and planning.***

So this is my topic - the importance of being and touching and holding and laughing - we might call spiritual needs or maybe simply **human** needs.

Government at last has taken this on board - caring for people with dementia in a **holistic way and taking account of their spiritual needs** has become a significant theme.

- NSF for Older People Standard Seven, 'Treatment of dementia always involves at all stages emphasising the unique qualities of the individual with dementia and recognising **their personal and social needs**'

- NSF Standard Two, ‘Service users and their carers should be able to expect procedures ... to meet any particular needs and preferences relating to gender, personal appearance, communication, diet, race or culture, and **religious and spiritual beliefs.**’
- *Your Guide to the NHS* (2001) states, ‘NHS staff will respect your privacy and dignity. They will be sensitive to, and respect, your **religious, spiritual** and cultural needs at all times’
- National Minimum Standard 11.1 in Care Homes for Older people states ‘Care and comfort are given to service users who are dying...and **their spiritual needs**, rites and functions observed’.

But what do we mean by ‘taking account of spiritual needs’? and do older people with dementia still have these needs? Individuals have **differing ideas about the meaning of spirituality.** Let me state categorically at once that by ‘spiritual’ needs I do NOT necessarily mean religious needs. Meeting spiritual needs is not simply a matter of providing opportunities for religious observance, although that may be an important element for those who have a specific faith.

My belief:

- everyone irrespective of their faith has spiritual needs
- spiritual and religious needs are not necessarily the same
- attention to spiritual needs requires us to take account of a person’s culture, including their religious allegiance where relevant
- a person’s spirituality is linked to their sense of identity (Tom Kitwood’s personhood) and the need for this linkage is nowhere more urgent than in those with dementia, whose personhood is so often denied in current practice. People with dementia are already likely to be a disadvantaged group – often old, certainly vulnerable and frequently confused. To ignore their spiritual needs increases still further that social exclusion.

I see spirituality it as the way in which an individual responds to and makes sense of the raw experience of life - for instance moments of delight and sorrow, understanding and bewilderment, hope and despair. These can be interpreted within or without a religious framework. We all need :

- to feel valued and affirmed
- to love and be loved
- to hope in something in this life and beyond
- to have faith and trust in someone or something
- to know peace, security and tranquillity.

People in the later stages of life often seek to come to terms with their sometimes painful past, their diminished present and their uncertain future and the questions they ask do not depend upon whether they are religious or not - and I believe that people with dementia have the same needs as any other older person.

Meeting the spiritual needs of older people is **not an optional extra** but is crucial if the aims of holistic and person-centred care are to be met. For many, but certainly not for all, this spirituality may come from a relationship with God but we must never ever believe that those without adherence to a particular faith do not have spiritual needs. Nor must we think that meeting spiritual needs simply means arranging for pastoral visits from the vicar or minister or taking services from time to time in care homes. It is not just a job for religious professionals or an extra burden for carers but is central to ensuring the well being of older people with dementia and ensuring that they have continuing meaning and purpose in their lives.

The key question is : how, whilst paying attention to the physical, mental and emotional needs of the person with dementia can we incorporate the further dimension of spirituality?

In essence therefore seeing the person behind the dementia and paying attention to their spiritual needs requires us to focus on human feelings and relationships and at every point asking the question what does the way I treat this person say about how I feel about them and their value and how will it make them feel?

**So we first need to make sure that we see the person behind the dementia.**

Personhood - person-centred care is actually the second standard of the NSF - 'To ensure that older people are treated as individuals and they receive appropriate and timely packages of care which **meet their needs as individuals...**' This is easier if they are a relative or friend as we already know them. But how often do people speak of 'the death that leaves the body behind' and imply that the person they knew and loved has gone somewhere and is no longer there? I am convinced that the person is still there, it is the channels of communication that are erratic. This is illustrated by the story of the elderly couple and the hospital consultant.

But what of those we care for professionally? They are people not a category of person. All are different individuals with different spiritual needs. They may not be able to tell us who they are but we need to know. It is important to produce life story books, photographs and memory boxes (containing items of importance to the individual and who they are) because through them we can re-engage with their lives. We should all be making a memory box now!

An example of how knowing a person's life story can transform their care:

- Old Mrs Brown
- A confused old lady lives in a home for people with dementia. The staff are impatient with her because she 'gets in the way' when they are trying to make beds. But she was trained as a nurse and a perceptive care assistant asks her to help with making beds. And she does it - envelope corners and all!
- And what of the people who interfere in the staff office? Maybe they used to work in an office and are looking for a sense of purpose again. Perhaps the home of the future will have a residents' office equipped with PCs!

So remembering what I've just said that we need to ask the questions 'what does the way I treat this person say about how I feel about them and their value and how will it make them feel?' let's look at a typical **day in the life of a person with dementia** and see how at each stage in our interaction with them we can respond to their needs bearing in mind the person behind the dementia and their individual spiritual needs. Illustrate this mainly from residential care because that is my area of experience but just as relevant for anyone who meets spiritual needs.

### **Waking up**

Many of us have had the unpleasant experience of being woken up in hospital by a rattling trolley, loud voices and totally impersonal approach and we all know that being woken rudely by the telephone or the postman at the door can put us in a bad mood for the day. A gentle good morning, the turning on of a soft light and a cup of tea placed by the bed, the pulling of curtains and comment on the weather and maybe turning on of a radio with a favourite station - all these actions say 'it's nice to see you this morning' and make the person with dementia feel valued.

Laraine's example of the very disturbed lady who was impossible to get up and dressed in the morning. Care assistant noticed Bible and suggested she read something from the Bible before she started the day. The lady said at the end of the reading 'that was nice' and was in a happier and calmer frame of mind than ever before. Again know the person.

### **Toileting**

We've all heard horror stories of older people with dementia being left tied to toilet seats or sitting in their own excrement and hopefully such instances are now rare. But we can still forget that individuals still need privacy, time and a pleasant clean environment - how many cognitively intact people find it difficult to use public loos? I still think one's own toilet in a care home is essential - so often the attitude is if they need help why do they need their own toilet. The walk to the toilet can be a chance to look out of the window, chat or even singing a song!

### **Personal hygiene**

We all know that for their physical health, a person with dementia who is unable to bath or shower independently requires regular washing to ensure personal hygiene. But so often bathing older people is seen as a chore to be done as quickly as possible and often whilst conversing with a friend.

We need to ensure that they are given a choice of bath or shower, a choice of time of day and regularity and the privacy of a pleasant, warm and domestic-style bathroom. For all of us a bath can be more than simply a place to get clean. The relaxation of a leisurely bath can be a balm for the soul and for a resident may be a peaceful oasis in a communal setting and an opportunity to share deeper conversation with a trusted member of the care staff. As a resident in a Christian home commented :

*Staffing is such a problem there is very little chance for talking with staff and having a bath is almost the only opportunity for talking to a carer. I'm sure it is recognised that more time should be given to this if possible.*

Aromatherapy, hair dressing, massage, nail care, foot care - all help to make people feel valued and good about themselves

### **Dressing**

Our individuality and well being is often very dependent on what we are wearing. The old culture of dementia care saw random ill fitting clothes and the attitude that any garments would do for any resident. Even at home, carers were under the impression that the person with dementia no longer had any idea of what they looked like so it didn't really matter. To

see the person behind the dementia, we must ensure that we still allow for choice. Not infinite choice but rather would you like to wear the red dress or the green dress today? Ladies who've always worn jewellery still want to wear it. Men who wore ties still want to wear them - and not a blue tie with a green shirt. And how good it makes you feel when the person helping you dress compliments you on how you look.

A carer reported 'I remarked 'I really like what you're wearing today. It's lovely isn't it? This brought about a smile, and a vigorous and proud smoothing of the dress' Barbara Pointon's pictures of her husband illustrate this so well.

### **Mealtimes**

It goes without saying - or should do - that people with dementia continue with the same likes and dislikes with regard to food. Never think it doesn't matter what you give people to eat and how attractively this is presented. But think too of the nourishment of the spirit we all experience through sharing meals with friends, engaging in conversation or celebrating special occasions. Celebration of big 0 birthdays and wedding anniversaries is very important. In some care homes guests are welcomed at meals by arrangement but staff and residents only eat together at special times like Christmas. Could more homes encourage staff and residents to share meals together and at the invitation of residents welcome families and friends from the community to eat in the dining room?

### **Daily living**

We've looked at what might be called personal maintenance tasks but what about daily living itself? People with dementia still need to participate in life. They need a sense of community and belonging and many older people, especially those who live alone and/or are housebound have lost this and become very isolated. This is even more the case for older people with dementia. Often their so-called independent living in their own home has been reduced to life in one room with total dependence on visits from relatives, friends or professional carers to attend to their every need. I sometimes wonder whether this state of being is actually as desirable as is often suggested. John Gatward describes it as '**a virtual institution created by inflexible care packages available to people in their own homes**'. Dare I say that the move into sheltered housing or a care home might not be a loss of living in the community but rather as a move into community and an end to isolation - a community consisting of other older people, of staff, of relatives and hopefully of members of the community local to the home.

So what features might we encourage in the daily life of people with dementia? Not sitting all day snoozing and gazing into space (although remember that there is a place for this too!)

- **A continuing role** - a deep rooted spiritual need which we all share is that need to be needed, to continue to see meaning and purpose in life and not to feel useless or put out to grass. Even those with dementia can still have a role. An elderly minister at Westbury although living with dementia continued to see himself as having a pastoral role - and was treated with respect for this by the staff. Residents in care homes and at home may still be able to lay the table, clear away the crockery, help wash up, make the bed, fluff up the pillows or draw back the curtains. Simple tasks like these encourage conversation, help to maintain manual skills, and create a feeling of satisfaction in a job well done. But most important of all, this sort of activity gives a continuing sense of role and purpose. How much better and more normal it is to go into the living room of a home and see some residents helping with meal preparation, others folding clothes ready to be aired, others looking at the paper or knitting rather than doing nothing - or dare I say it playing carpet bowls!
- **Opportunities for conversation** - A young researcher Claire Surr observed in an article 'For many people with dementia conversation is like gold dust.' and to this we might add one-to-one attention. Once called 'gossip therapy' or 'a gathering spot for companionship'. The work of John Killick demonstrates the amazing capacity of people with dementia to talk and he has written down poems which are incredibly illuminating
- **Opportunities for just being** - Many older people with dementia just want someone simply to come alongside them, maybe hold their hand and to show love and respect and unconditional love. A chaplain 'When I realised that there were many ways to be with my residents beyond words, the fear of being with them diminished and I came to value them as the full human beings that they are' Care staff need to understand that sometimes 'just being with' is work!
- **Opportunities for laughter and celebration** - we've already spoken of the importance of celebrating birthdays and other special occasions. And how about videos and photographs to remind people later of what happened? I think many older people with dementia are starved of opportunities for sharing in laughter. Note that we're talking about laughing with them not laughing at them. For many joking and teasing and singing and banter can still be enjoyable.
- **Opportunities for joy, wonder, awe and uplift** - it is possible to appreciate the wonders of nature without attributing that to God as creator. Chosen special music, a walk through autumn leaves, a visit from a baby or a pet, all these can bring about spiritual moments.

The list is endless and if in a day you can string together enough joyful moments the person with dementia will have had a good day at the end. Never dismiss anything as pointless because 'they won't remember' The sacrament of the present moment. People with dementia remember the feeling even if they don't remember what engendered that feeling. We can learn from them and they can give to us. How to live in the moment in silence and sometimes in confusion and chaos. How to wonder at a drop of water falling down a pane of glass.

- **Opportunities for religious practice** - if that is their choice. in our anxiety not to equate spiritual needs with religious needs we mustn't forget that for many older people with dementia their religion was an important part of their lives and still continues to be. For them time needs to be set apart for worship and prayer. The repetitive nature of ritual gives familiarity and reliability and also offers the benefits of companionship and a sense of belonging. Some important considerations might be the use of symbols (candle, bible, a cross) of appropriate music and hymns, prayers and Bible readings. Amazing experiences of recall and recognition in those who seemed far away. Example of a minister who mentioned Messiah and a previously comatose resident looked up and then smiled and recognised a feeble attempt to sing something from Messiah. (see leaflet Worship for people with dementia)

### **Bedtime**

Again we all have our bedtime rituals. Need to know how the person with dementia normally goes to bed. Do they like a drink? Do they like music as they settle down to sleep? A home manager used to visit each resident at bedtime and say 'May God remember you and bless you'

### **Conclusion**

We are all part of an ever increasing network of people who are dedicated to putting forward at every opportunity the view that older people with dementia need holistic attention, that is attention that gives due respect not only to the physical, mental and emotional needs of every individual but also to their spiritual needs.

People with dementia have suffered multiple losses but as Helen Keller points out in a short poem, they are still themselves inside and must be treated and valued for who they are. She uses the word 'soul' but we could equally use the word personhood:

*They took away what should have been my eyes (but I remembered Milton's Paradise)*

*They took away what should have been my ears (Beethoven came and wiped away my tears)*

*They took away what should have been my tongue (But I had talked with God when I was young)*

*He would not let them take away my soul – possessing that, I still possess the whole.*

A quotation from a book by Sheila Cassidy *Sharing the darkness: the spirituality of caring* (Darton, Longman and Todd 1988) sums up what I feel about older people with dementia and our vocation to care for their spiritual needs. For me this is a Christian imperative, but I think all of you can probably identify with her sentiments:

*It is the lavishing of precious resources, our precious ointment, on the handicapped, those with mental illness, the rejected and the dying that most clearly reveals the love of Christ in our times. It is this gratuitous caring, this unilateral declaration of love which proclaims the gospel more powerfully than bishops and theologians... It is a particular form of (Christian) madness which seeks out the broken ones, people with dementia, the handicapped and the dying and places before their astonished eyes a banquet normally reserved for the whole and the productive.*

May this be our mission today.

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