

SEEING THE PERSON BEYOND THE DEMENTIA



Papers presented at a Leveson Seminar

LEVESON PAPER NUMBER EIGHT

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Leveson Paper Number Eight

Seeing the Person beyond the Dementia

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Foreword

The papers published here are all based on presentations given at a seminar held at the Leveson Centre in March 2004. The aim of this event was to consider how those involved with people living with dementia could continue to see the person rather than the disease and thus be able to respond to his or her spiritual needs. The Leveson Centre hopes to develop an understanding of spirituality as an important but often neglected dimension in the lives of older people in general and in particular those who live with dementia.

In the first paper, John Killick draws on his work at the Stirling Dementia Services Development Centre to show how it is possible to establish and maintain meaningful relationships with people living with dementia. He suggests that this is not merely possible but actually rewarding and that we may even be able to learn from people with dementia because they have a particular kind of consciousness which is largely denied to the rest of us. He illustrates this with moving poems from people with the condition whom he has interviewed.

Gaynor Hammond then looks at the role of reminiscence in helping older people with dementia retain their personhood. As we go through life we all build up a personal history with a mixture of joys and pleasures which help to make us the people we are. Gaynor describes how Faith in Elderly People Leeds developed the idea of the Memory Box which contains people's personal mementos which can then be used as memory cues to open up 'windows of recognition' and help them to retain their identity.

Finally Sally Knocker examines the needs of older people with dementia suggesting that time, attention, human contact, conversation, a friendly smile are some of the most important gifts we can offer. She looks at the work of Tom Kitwood in this area and concludes that this should be an important ministry for churches.

Alison M Johnson
Centre Consultant

Touching the Strings at the Centre of my Heart: Learning love from people with dementia

John Killick

John Killick is currently Associate Research Fellow in Communication through the Arts at the Stirling Dementia Services Development Centre. He was formerly writer in residence for Westminster Health Care and is author of You are Words, Openings and Communication and Care of People with Dementia (with Kate Allan).

Not much more than a decade ago the whole future for people with dementia looked bleak indeed. The Medical Model held sway, and since doctors and scientists didn't know what caused the condition, how to predict who might get it and who might not, and there was no cure in sight, they threw up their hands intellectually and looked the other way. Here is a typical definition:

As a result of a degenerative process in the brain, nerve cells become gradually incapable of communicating with one another. The disintegration of the brain tissue leads to a breaking of the communication lines which anchor a person in his own time and environment. His mind goes adrift. Communication with other people and even his own body becomes disturbed. There is total dislocation. The patient slowly but inevitably regresses to the functional level of an ailing, helpless newborn baby. (Souren and Franssen 1994)

Some threw up their hands emotionally too:

There is this grotesque thing in the corner ... an uncollected corpse that the undertaker cruelly forgot to take away. (Miller 1990)

Unfortunately the perpetrator of that second quote also happened to be President of the Alzheimer's Disease Society at the time!

Then along came Tom Kitwood of Bradford University to turn the whole scene on its head. He proposed to replace the old formula:

person with DEMENTIA

by:

PERSON with dementia

This changes the perspective dramatically. Instead of looking at the disease as dominating the person we see the person first and the condition second, as one would with cancer or TB. The problem with dementia, of course, and the reason why that had not been proposed before, is that it attacks cognitive

capacity, as many other diseases do not, and therefore was thought to impair the very sense of self by which we distinguish and value the human. Many family carers still speak of their loved one as having 'gone away', but this may be a misperception caused by the communication difficulties which are a common characteristic of the condition. Similarly the 'challenging behaviours' which many people with dementia are supposed to exhibit may be the natural consequence of the misunderstanding and resulting mistreatment of the person by those around them. This is the Psychosocial Model of Dementia which Kitwood expounded, and it led to the concept of 'Person-Centred Care', where everyone is to be treated as an individual despite the severity of the symptoms exhibited.

This is, of course, a counsel of perfection, and Kitwood acknowledged that it posed an uncommon challenge for those called upon to face it:

As we discover the person who has dementia we also discover something of ourselves. For what we ultimately have to offer is not technical expertise but ordinary faculties raised to a higher level: our power to feel, to give, to stand in the shoes (or sit in the chair) of another. (Kitwood 1993)

The crucial phrase here is 'ordinary faculties raised to a higher level'. Therein lies the problem: how many people can achieve that degree of empathy, and how do you learn to exercise it? Faith Gibson in an important article raises the same dilemma, but answers it in a way which makes plain that once one realises that communication is possible there is really no alternative but to engage with it:

We must employ whatever power we have in the world of dementia care for this purpose (risking person-centred communication). We must use our present knowledge, our skills and feelings, to communicate. We are morally obliged to continue working in extending our limited understanding, developing our embryonic skills, and taming our deep anxieties. (Gibson 1999)

One of the barriers to empowering persons with dementia is the value our society places on intellectual capacity. Most of our institutions (notably our education system) enshrine reason as the moving force of society, and financial rewards come to those who can harness it to provide for people's needs in the most efficient manner. Stephen Post, an American ethicist, has coined the term 'hypercognitive culture' for the shrine at which we worship:

We live in a culture that is the child of rationalism and capitalism, so clarity of mind and economic productivity determine the value of a human life ... Rather than allowing declining mental capacities to divide humanity into those who are worthy or unworthy of full moral attention, it is better to develop an ethics based on the essential unity of human beings and on an assertion of equality despite unlikeness of mind. (Post 1994)

Children and older people miss out on this scale of values, but we are prepared to put faith and resources in the way of the former because of what they may become. The latter have outlived their usefulness, and people with dementia are the bottom of the pile because they are potentially a drain upon the national budget and time and money spent on them are not going to be recouped in any way.

Into this negative scenario I want to introduce some tentative suggestions of what people with dementia may have to offer us which may have been overlooked. First of all there is emotional honesty. Although it is undoubtedly true that many of those with the condition are caught out and left floundering by our emphasis on cause and effect and our insistence on the importance of maintaining the chain of memory, their ability to live intensely in the present seems to be something special from which we could learn. This gives a particular resonance to new relationships, but it also means that our motives are quite keenly put on trial. Quite often in communicating with individuals I have felt that I am being observed, tested and somehow found wanting. It is uncomfortable to be put in this position but also productively challenging. In a remarkable paragraph Debbie Everett, a hospital chaplain in Canada, has identified this aspect of communication as follows:

People with dementia are magic mirrors where I have seen my human condition, and have repudiated the commonly held societal values of power and prestige that are unreal and shallow. Because people with dementia have their egos stripped from them, their unconscious comes very close to the surface. They in turn show us the masks behind which we hide our authentic personhood from the world. (Everett 1996)

Another aspect closely allied to integrity which I can identify is that of spiritual awareness. In some this can seem a striving for grace; in others it is as if this quality has been vouchsafed to them almost because of a lack of effort, as a kind of gift for humility. An example of the former would be the following poem dictated to me by a man who always conveyed the impression of being very much concerned about such matters:

to see what is beautiful
to hear what is beautiful
they don't know what is beautiful –

all these young people
good men, nice boys, fine chaps –
they are too busy to see

it'll be a good bit longer
before *you* see
what you want to see

but they don't want to see
what in some queer way
they are anxious to see

we see it very rarely
but the difference is
we are trying to see!

(Killick and Cordonnier 2001)

When I asked for a title for the piece he suggested 'Glimpses'. The next poem was dictated by a man who had never previously revealed to me feelings of this nature, though he did have moments of quiet reflection, usually quickly superseded by episodes of boisterous humour. On this occasion he had appeared asleep, when he suddenly opened his eyes, asked me if I had my notebook with me, and unhesitatingly spoke the following words:

In the skies up high
with the clouds below you –
that's where I'd like to be.

With the birds,
the little sparrows,
but I'll remain a man.

It's an attraction,
it's the spaces
that we can't reach.

I was up there one day
and got the sensation
I didn't want to come down.

I'd rather be
a creature of the air
than of the earth.

(Killick and Cordonnier 2001)

When I asked this man for a title he replied scornfully "The Blue Far Yonder" of course,' as if no other would do. The first poem is more mysterious, the second simpler, at least on the surface. What they both have in common is a sense of reaching out, a visionary quality, which I find distinctive and moving.

One day I was in a nursing home lounge and noticed a lady in the corner of the room who was quietly singing to herself. It was a low sweet sound. I asked the staff if this was unusual. 'No, she does it all the time. She's the happiest

soul on the Unit,' one of them said, and the others concurred. When I had made contact with the lady, and gained her permission to listen closely to her words this was what I wrote down:

I don't know what to do
I want to go home
I can sit here but
I don't seem happy any more
I don't know what to do
I want to but
I can't any more
I want to lay
I don't know when it will be
I want so let me have it
Don't make it so hard for me
O World, I don't know what to do
I want to see my sunset good
I want it as it was promised
I'm waiting for the hour
I want to see my sunset good

(Benson and Killick 2002)

There are two striking aspects of this text. Firstly, the complete mismatch between the impression of the lady's singing and the message contained in the words. This 'happiest soul on the Unit' was in fact longing for death, and the message this conveys to care staff could not be starker: unless they pay attention to the minutiae of communication they are never going to come close to understanding the states of mind of those they are looking after. Secondly, though the feelings expressed are largely negative the lady does have expectations that death when it comes will bring her spiritual release: 'I want to see my sunset good' shows faith in an ultimately positive resolution of life's journey.

I return to the largest of all the big issues posed by dementia: what the condition does to the person. Here are two answers, both given by individuals with Alzheimer's Disease. In her book *Who Will I Be When I Die?* the Australian Christine Boden writes:

The unique essence of 'me' is at my core, and this is what will remain with me at the end. I will be perhaps more truly 'me' than I have ever been. (Boden 1997)

And the American Barb Noon says this in her poem 'Burning Bright':

Sometimes I picture myself
like a candle.

I used to be a candle about eight feet tall –
burning bright.
Now, every day I lose
a little bit of me.

Someday the candle will be
very small.
but the flame will be
just as bright.

(Noon 2003)

At Stirling University we have produced books, packs and videos to encourage the use of the arts with people with dementia. There is a video titled *Responding to Music* and in one of the interactions the man with dementia says to the musician: 'You have touched the strings at the very centre of my heart.' (Mullan and Killick 2001) I truly believe that people with dementia have the capacity to do that for us if we can only stifle our anxieties, lose some of our self-consciousness, and let love accomplish its amazing transformations.

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Rediscovering the Person through Sharing Memories

Gaynor Hammond

Gaynor Hammond is a member of the Christian Council on Ageing Dementia Group and a trained nurse who has been project worker for the Faith in Elderly People, Leeds Dementia Project since 1998. Her particular interests are the spiritual needs of people with dementia, reminiscence and the Memory Box.

Many people have found reminiscence a very useful tool for helping to open up those windows of recognition with people whose memories have been lost. I was on my way to do some reminiscence work with one of my local day centres. I had plenty of time to spare and decided to call at the hairdresser's for a trim. When I arrived he asked me if I would like a colour – it wouldn't take long and he was anxious that his trainee, who had been learning to colour hair, got some experience. I was in a charitable mood that day so I agreed. I am a natural blond but need a little help these days to keep it that way so what could go wrong? He then asked me if I would give her free rein in choice of colour, assuring me that she had a good eye for this and he wanted to encourage her. This girl was seventeen! Warning bells started to ring but again I was assured that, if I didn't like it, it would wash out. I relaxed and let her loose. The result was Belisha beacon yellow. I couldn't believe what I had let her do and I was now due to go to the day centre so had no time to do anything about it. My only consolation was that I was working with people with dementia so they probably wouldn't notice!

I walked into the room. People had begun to arrive and were sitting in a semicircle staring vacantly into space. Some were confused and disorientated by the journey from home.

I began to converse with them, helping them through reality orientation to connect with where they were. 'Hello,' I said breezily. 'Welcome to the day centre. It's Wednesday morning. My name is Gaynor and I am here to do some memory work with you. We are going to ...' 'My hair used to be that colour.' A voice from the corner brought me up sharply. Oh no, my hair! 'You'll never believe what I did,' and I began to relate the whole story of letting a seventeen-year-old loose on my hair, ending with the words, 'I must have been mad!' How insensitive can you get. I had just said I must have been mad to a group of people with dementia. With my head in my hands I was mentally writing out my resignation. I was clearly unfit for this job.

As I looked up everyone was laughing and one by one they started to relate their own hair disaster stories and we spent the next hour laughing till we ached. No one walking into that room would have suspected that anyone there was suffering from dementia. That became our reminiscence session for the day. And if you are really serious about this work then I recommend that you go straight to the hairdresser's and ask for Belisha beacon yellow!

What I want to describe to you is the Memory Box. There is a wonderful book (Fox 1987) about a little boy called Wilfrid Gordon McDonald Partridge and his search for the meaning of 'memory'. In his search he asks five of his friends, who are all much older than him, to explain the word 'memory'. These are the answers they gave:

Something warm
Something from long ago
Something that makes you cry
Something that makes you laugh
Something as precious as gold.

One question, five answers and, yes, memory is all of those things. If only there was a way of wrapping up all those precious, sad, funny, warm and golden moments and putting them in a box to keep for ever, to unpack and re-live once again, whenever we wanted – now that would be a gift worth having.

Studies have shown that the attitude of carers towards a person can be radically altered by some knowledge of the person's life history. The experience of Age Exchange and writers on reminiscence, notably Faith Gibson, confirm this view.

So if general reminiscence is so valuable how much more would personal reminiscence be? That is why we at Faith in Elderly People, Leeds looked at the idea of capturing people's personal reminiscences through creating a personal Memory Box.

Everything we have done in life, the places we have lived and the people we have encountered have had some effect or influence on us and helped to make us the people we are. As we go through life we build up a personal history with a mixture of joys and pleasures. This Memory Box would contain a collection of personal mementoes to use as memory cues to open up those 'windows of recognition' and therefore help the person to retain their identity.

The best way I can explain the Memory Box is to show you mine.

Here is a stone and a seashell collected from Blackpool beach. I was born and brought up in Blackpool so it is a very special place to me. I have photographs of me in Blackpool, me on a donkey, me swimming in the sea. Perhaps I had luminous hair then – Sellafield nuclear power station being just round the corner!

Though photos are good and need to be included, the shell and pebble are tactile, tangible reminders of glorious days spent on the beach. Whenever I show this to older people, particularly those with dementia it is amazing how many lift the shell up to their ear, to listen to the sea!

My working days were spent as a nurse. Here I have my frill cap, belt and badges. The uniform was very important to me as it was to all of us. We were

very proud of it and the nurses of that era rebelled when we had to trade it in for something more practical. I can remember clearly the day the hospital where I was working closed down and I had to move to one of the large NHS hospitals. They gave me a pair of pyjamas to wear. It was awful and, even worse, when I arrived on the ward almost all the nurses had piercing everywhere! Would I have to do that to fit in? I think it was then I decided my nursing days were over.

But uniform is very important. A practice nurse goes to visit an elderly couple to make sure they are managing all right. The husband cares for his wife with dementia. She is what is often termed 'pleasantly confused' which in effect means she sits there most of the day and does nothing and she causes no trouble. Except when the practice nurse visits. Then she comes alive. The uniform of navy blue dress and belt with buckle and badges sparks memories of when she was a nurse and once more she is back in her role. The husband is sent off to make tea. It has to be brought in on a tray with cups and saucers. 'Sister' is invited to sit down and tales of patients and work are told for the next half hour. Such is the power of memory triggers.

I have a baby-grow in my box; this was worn by my eldest son who is now twenty-six. He is not happy that I have kept it so I dare not tell him of all the booties, matinee coats and other garments that I have kept. But this baby-grow is symbolic of all the children that have enriched my life.

Hobbies are important. In my box I have a paint palette, brush and two small paintings. I love water colour painting. Hopefully, if you have to look after me, you will just need to produce paper and paints and you can keep me quiet and out of trouble for hours.

In her book (Shamy 2003), Eileen Shamy spoke about her mother who had dementia. Her mother loved to crochet and even in the late stages of dementia she would spend many fulfilling hours employed in this hobby. That is until the day she lost her crochet hook. It had only fallen under her chair and she had a spare in her bedside table, but the nurses were always too busy to look and eventually it got forgotten. When her daughter Eileen went to visit she was distraught to find that her mother had been robbed of the skill which had given her so much pleasure. All for the few minutes it would have taken to find her hook!

I keep a lipstick in my box. This is because make-up is important to me. It is a part of my routine. I get up, take a shower, get dressed then put my make-up on. The lipstick is there to remind anyone who might be looking after me that I don't want to appear in public without my make-up!

We have a wonderful psychiatrist who is very sensitive to people's needs and always looks at their spiritual needs and person-centred care before prescribing pills. One day she was sent for by a nursing home who asked her to prescribe some sedative for a resident who was presenting challenging behaviour. In

other words she wouldn't go down to breakfast and was thumping any nurse who tried to make her. When the doctor arrived she immediately noticed that the lady, who was usually heavily made up, had no make-up on so she asked why. She was told that the lady's daughter took it all away because she was looking like a clown! The doctor prescribed more make-up and a nurse was sent to the chemist to replenish her stock. Once made up the lady went down to breakfast with no trouble, happy because that spiritual need had been recognised.

I have many other things in my box but finally I will show you my Bible. I am a Christian and for me my faith infiltrates every part of my life. So bible reading, prayer and fellowship of other Christians is important to me. I was working in a nursing home and one of the residents had been a Methodist local preacher. He now had dementia and one of the ways the disease affected him was that he shouted and swore a lot – much to the dismay of his family and care workers. But instead of affirming him, the fact that he had been a lay preacher was used against him. He was asked on a regular basis, 'Is this how ministers carry on?' One morning I offered to get him up. When I approached him I introduced myself, told him it was morning and suggested he might like to get up. He told me to go away – or words to that effect! I ignored this but said to him, 'I hear you were a lay preacher, I am a Christian too, shall we start the day with prayer?' He said, 'I'd like that.' A sentence without swearing! So I took his prayer book out of his drawer and read one of the Psalms. He recited it with me, not needing to look at the prayer book for he knew the words. He had probably started his day with prayer and bible reading for years so this was ministering to his spirituality and it was a precious moment for us both as we worshipped together. I then got him out of bed and washed and dressed him without the usual struggle but in a peaceful state of mind and spirit.

I spoke to the nurses later and suggested that they read a Psalm from the Bible with him before they started to get him up. One said it would take too long – even though it took two of them much longer to get him up than it had taken one of me. Another said she didn't believe the Bible. I did point out to her that I had seen her reading the *Sun* newspaper to a resident and she couldn't surely believe in that but it didn't stop her doing it.

I hope that describing my Memory Box has encouraged you to engage with people through reminiscence and to help them develop their own Memory Box as a means of maintaining their own identity.

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Reaching the Parts that Matter: Connecting with the whole person through activities

Sally Knocker

Sally Knocker works part time for NAPA, the National Association for Providers of Activities for Older People as the 'Growing with Age' National Project Manager. She is also a freelance dementia specialist trainer and writer and has recently edited and written The Alzheimer's Society Book of Activities.

This paper is written with my two hats, one as project manager for 'Growing with Age', a NAPA (National Association for Providers of Activities for Older People) project which is exploring the extent to which residents in care homes and sheltered housing can be more closely integrated with the life of the wider community, which of course includes the church community. The other 'hat' I wear is as a specialist in the area of dementia care over the last twelve years and with a particular passion for promoting activities.

The focus of this paper is to explore a little what we think people with dementia might need and to touch on what members of faith communities might offer individuals as part of a wider definition of pastoral care.

Some time ago I saw in *The Guardian* a 'Clare in the community' cartoon by Harry Venning. It shows 'Clare' visiting an old lady sitting in her chair in a residential home. 'Crikey, Nan!' she says. 'Look at the time! Sorry I've gone on, but it's been such a long time since my last visit, and I had so much to tell you!' 'Don't you dare apologise!' says the old lady. 'I get so few visitors here in the Home that I love to hear about you, that lovely boyfriend Brian, little Megan, naughty Ross the Dog and all those clients that keep you so busy. But I agree, it has been a long time since your last visit ... because I'm not your Nan. She's in the room next door.'

This cartoon makes a very significant point to me about what people living in care homes badly need. Most residents are not asking for lots of different group activities like quizzes, games or arts and crafts. Very few of us choose to spend large amounts of our time in large groupings in fact. Most of us live in couples or small families or alone. It is therefore not very surprising that what most older people long for is more *one-to-one time* and companionship. Time, attention, human contact, conversation, a friendly smile – these are the most important gifts we can offer people who feel isolated and possibly cut off from the home and community to which they belonged before they came to live in a care home. To me, this is an even more important ministry than churches offering opportunities for services for worship and communion to people in care homes.

I turn now more specifically to what people with dementia might need from those who support them Two short anecdotes of people with dementia with

whom I have worked help illustrate the kinds of things that liven up people's lives depending on their personality, background and interests.

A complaint to make

I was visiting a care home when Gwen called me over to speak to her. She said, 'I have a complaint to make about this place.' I looked suitably concerned and sat down with her, suggesting that she might like me to go and find the manager to discuss the matter too. 'Oh it's really very simple,' she said. Gwen bent towards me and said in hushed tones: 'There just aren't enough *men* in here!'

She was absolutely right of course. All the residents at that time happened to be women and there were no male care workers. Gwen had always been a woman who loved men's company and she immediately perked up as soon as she heard a man's voice. Not really a lot to ask?

A breath of fresh air

I decided to take an elderly woman with dementia out for a walk in the park. I deliberately chose one of the most frail residents of a nursing home, Mrs Hamble, whose verbal communication was now very impaired and who did not participate in any group activities. Her key worker warned me that she would almost certainly sleep throughout the whole trip as this was what she tended to do these days. It was a beautiful sunny autumn day, and I suddenly had an impulse to run through the leaves in the park. When I did this, Mrs Hamble opened her eyes and at first looked rather bemused at the sight of me running and laughing through the leaves. She then started to laugh herself and it was as if her face was transformed into someone 50 years younger. She called out 'Run! Run!' and 'Again!' when I paused for breath, and was delighted when I caught a large falling leaf from a tree and handed it to her. We then went to a small children's playground, full of colour and laughter and action. Mrs Hamble was totally engaged and alert during the whole experience, putting her hand out to the small children and clapping as they came down to the bottom of the slide. Both the parents and the children responded very warmly and naturally to her and did not seem to need many words to communicate.

Neither of these 'entertainments' cost a penny, but they had a transforming impact on Mrs Hamble's well-being and did require an investment in terms of one-to-one time spent with this resident for about two hours in total.

The first point to make then is that what people with dementia often need is much the same as what all of us need from life.

Normal everyday experiences

We can take many of these things for granted but getting milk out of the fridge for a cup of tea, travelling in a car or a bus, watching children playing as the above example showed, experiencing the changes in weather or enjoying the spring blossom and hearing the birds sing can all enrich our lives and can sometimes be sadly lacking for people living in institutional settings.

Variety in the day and not feeling bored

We all know that sitting for a whole day, at a series of seminars for example, looking in the same direction and passively listening to speakers is not the most comfortable thing to do and it is hard to keep your concentration and interest. The old saying 'variety is the spice of life' is particularly true for older people with dementia whose days will be much improved by not just sitting, but moving around, watching and doing different things, enjoying a range of things with which to engage.

To feel loved and needed

This is such a simple but important thing and yet for many older people whose families are perhaps not so close at hand and who are no longer working, it is hard to feel that you still have a role which is valued in the world. Helping people to continue to feel needed can be done in such simple ways. I recently took a range of wedding hats and outfits into a care home and spent a very enjoyable half an hour consulting a small group of residents about which they felt suited me best for a wedding I was going to attend! I got some very forthright comments and some interesting discussions about fashion and social etiquette at weddings ensued. But the most significant aspect of this activity was possibly that I was giving a message to those involved that I still respected their opinion; they *mattered to me* and I wanted to *hear* what *they had to say*.

Conversation and company

This is one of the most precious activities of all and one where the churches can surely have a precious resource in terms of the members of the congregation who can offer this friendship and fellowship.

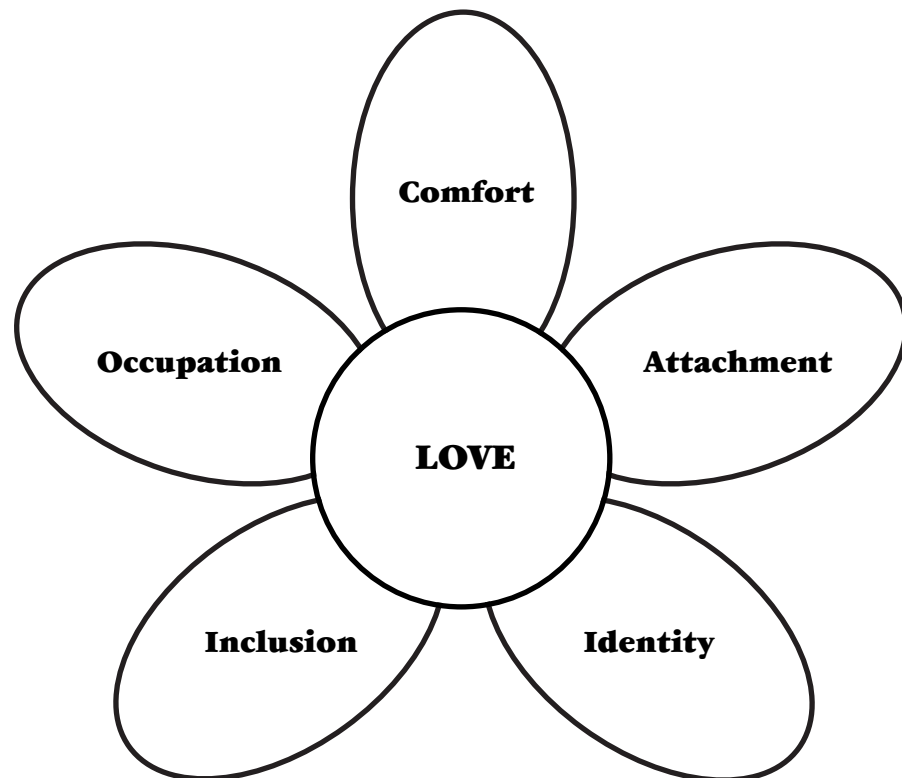
Treats and fun to spice up life

All too often in care homes, all the fun is concentrated at Christmas time when everyone is inundated (and probably fairly exhausted) with festivities, good food, jolly music and so on. Why not bring aspects of these things more into everyday life – a chocolate or a nice drink or the fun of singing can make any day feel special!

When looking at the whole area of activities, I think it is also helpful to consider what people's deeper psychological needs might be and how

engaging with activities can help us connect with the whole person. 'Doing' to many people is synonymous with being alive, making something happen and leaving their mark on the world. However what does meeting a 'person's psychological needs' really mean? What actually are these needs?

The psychologist Tom Kitwood has described a cluster of needs, which overlap, coming together in the central need for love. The fulfilment of one of these needs will, to some extent, involve the fulfilment of the others as they are closely interrelated.



After Tom Kitwood (1997) *Dementia Reconsidered – the person comes first* (Open University Press)

We will look at each of these psychological needs in turn with a particular emphasis on how they might relate to a person engaged in an activity.

The need for COMFORT

The word comfort carries meanings of tenderness, closeness and the soothing of pain or sorrow. To provide comfort to another person is to provide a kind of warmth and strength, which might support them at a time of need. In a very real sense a person who has dementia is likely to be experiencing loss and change and to be in need of these qualities.

There are many activities which might bring comfort to a person, particularly those which involve contact with others, for example receiving a hug from a child, holding someone's hand or possibly stroking a dog. Soaking in a warm

bubble bath or having a gentle hand massage may all also be comforting for some. Others might derive comfort from participation in a religious ritual or looking at the photograph of a loved one.

The need for ATTACHMENT

In the field of child psychology there is a considerable body of theory which considers the importance of specific bonds of attachment for a young baby or child, given the vulnerability and uncertainty which is implicit in growing up and discovering the world. In a different but comparable way, a person with dementia might also be experiencing considerable uncertainty and new 'strange' situations and so the need for the sense of safety and security that attachment can bring can be very heightened.

The attachments which people with dementia develop might not always be with particular people. It is quite common for a person's attachment needs to be expressed in terms of a quite intense preoccupation with a particular item like a handbag or keys or a piece of clothing. It might be very important, for example, for a person to be able to sort through their handbag as a regular activity to reinforce a sense of security and control over their life, and for that handbag to never be far out of sight.

The need for IDENTITY

All of us will have different ways of describing our identity. For some people we may well define ourselves first in relation to our roles with others, for example 'I am a mother,' or 'I am a wife.' Others may place greater emphasis on their race, nationality, religion or sexuality: 'I am Christian,' 'I am Nigerian,' 'I am gay.' For others their sense of identity is strongly linked to the job that they do – 'I'm a builder,' 'I'm a lawyer' – or the interests that they have – 'I love art,' 'I enjoy walking.' To know who one is as a unique individual gives a sense of continuity with our past and a 'story' or picture to present to others about what it is that matters to us.

It becomes especially important to respect a person's identity in the face of cognitive impairment. It is vital that we know enough about a person's life history to help hold their sense of identity if and when an individual's memory is failing. This is why things like developing a Memory Box as Gaynor has vividly described or life history books or photo albums are so important.

The need for INCLUSION

Human beings are traditionally social animals who tend to live and work more in group situations or communities rather than operate in isolation. People with dementia continue to have this need to 'belong' in a group, yet can often find themselves feeling isolated even in a crowd. It is this need which is the central focus of the 'Growing with Age' project which seeks to include residents in homes within the wider community. Churches too can do a great deal to ensure

a philosophy of inclusion in the way they welcome and support people with dementia, not just on Sundays, but in other aspects of the church community.

The need for OCCUPATION

This psychological need is the one that relates most obviously to involvement in activity. To be occupied means to be involved in the process of life in a way that is personally significant and which draws on a person's abilities and powers. A person might be occupied in the company of others, or in solitude, in obvious action, in reflection or in relaxation. What is important is that in whatever it is they are involved, they feel some sense of engagement and satisfaction rather than boredom or apathy.

Many of the ways in which people are most commonly occupied in daily life become less accessible to older people in care settings, for example tidying up your house, going out to a shop, or choosing to put your feet up and read a newspaper. Sometimes a person with dementia will seek out ways of being occupied by walking about a great deal or picking objects up or playing continuously with an item of clothing.

The skill of a care worker is to know when this kind of activity is an expression of boredom or frustration or when a person seems happily absorbed in this occupation. If the person does seem positively occupied, it is most important that a person is not disrupted or that the behaviour is not falsely labelled as either problematic or without meaning.

It might be argued that all these psychological needs relate to and connect with an individual's spiritual well-being. The definition of 'spiritual well-being' offered in Leveson Paper Six – 'moments of awe and wonder', 'experiences of life which transport one beyond the mundane' and 'relationships with others that give meaning and purpose in life' – offer us an invitation to find simple activities which bring people these possibilities.

I can think of a number of examples of where these 'moments', 'experiences' and 'relationships' have been discovered: an afternoon spent 'wedding watching' sitting on a bench near a church on a sunny Saturday afternoon, enjoying the colours, laughter and sense of occasion of an event which reminded onlookers of their own special day. Another memory I have is of spending over half an hour with an older woman saying the Rosary whilst she was sitting on the loo. (I'm sure God didn't mind as it provided her with some comfort!) Another memory is of reading aloud from a crossword puzzle book at the bedside of a man with dementia who had hardly spoken for months. When I said, 'Bird of prey – five letters', a clear voice emerged from the frail figure with the closed eyes in bed, 'Eagle!' Let us never make assumptions about what people with dementia can and cannot do. By giving the gift of time and helping people to feel occupied, included, respected and loved, the church has a very special ministry to offer those who have dementia.

I would like to end with the vision of the 'Growing with Age' project and invite you to help contribute to making this vision a reality in future:

Imagine a world where the local residential home or sheltered housing scheme was the hub of community activity in an area, with doors open to a wealth of interesting experiences inside and outside the home – a place that people enjoy visiting rather than dread that they might end up there.

Note

Parts of this paper have been drawn from previous publications by Sally Knocker: *The Alzheimer's Society Book of Activities*, The Alzheimer's Society, 2002 and an article for *Signpost* Volume 8 Number 3, February 2004, 6–8.

A number of other publications about people living with dementia are available from the Leveson Centre:

Dementia: Improving Quality of Life Papers presented at a Leveson seminar by Kate Read, Jill Phillips, Margaret Anne Tibbs and Alison Johnson. £5.00 (Leveson Paper 6)

Older People, Faith and Dementia: twenty-four practical talks for use in care homes, Chris Crosskey (published in partnership with Church Army), 2004, £6.00

A Good Death Papers presented at a Leveson seminar, 2003. Includes a paper 'Achieving a good death in dementia' by Beatrice Godwin. £5.00 (Leveson Paper 4)

Please send orders to the address on the inside front cover with a cheque payable to The Foundation of Lady Katherine Leveson. Prices include postage and packing.