



## **DEMENTIA: IMPROVING QUALITY OF LIFE**

**including papers presented at a Leveson Seminar**

**LEVESON PAPER NUMBER SIX**

Leveson Paper Number Six

# **Dementia: Improving Quality of Life**

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Including papers presented at a Leveson Seminar

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## Foreword

The majority of the papers collected here were presented at a Leveson Centre seminar held on 25 February 2003. In the first paper Kate Read, Director of Dementia Plus, gives an overview of the nature of dementia, the ways it manifests itself and in particular looks at how an understanding of the person can make a difference to the quality of care. Jill Phillips who until recently was home manager of one of MHA Care Group's specialist home for people living with dementia then provides practical hands-on examples of this approach.

A substantive paper by Margaret Anne Tibbs is based on the research she carried out at MHA Care Group as part of a Bradford Dementia Group team which resulted in the report *A Special Kind of Care*. In it she considers the important issue of communication with people with dementia and explores ways in which faith survives or fails to survive under this assault on the self.

The collection concludes with a previously unpublished paper by Alison Johnson, the Centre Consultant, which was originally presented at a *Journal of Dementia* conference in Warwick in 2000. Based on her Winston Churchill Fellowship in Australia, where she looked at good practice in dementia care, she paints a picture of living and working together in care homes where residents, staff, relatives and members of the wider community together live life to the full and come to the beginning of each day with eager anticipation and to the end of the day with a sense of achievement and satisfaction. The publication concludes with a bibliography suggesting further reading in the field of dementia and spirituality.

*James Woodward*  
*Centre Director*

## What Is Dementia?

**Kate Read**

*Kate Read is Executive Director of Dementia Plus, the Dementia Services Development Centre for the West Midlands.*

Dementia is a condition very strongly associated with late life and in particular people aged over 80. Whilst approximately 1% of people over 65 suffer from dementia the likelihood rises as people age with 24% of people over 85 having dementia. But in working with older people it is important to remember that the converse is true: 99% of people over 65 do *not* have dementia and even in the very oldest cohorts over three quarters do not have a dementia.

But what is dementia? In 1982 the Royal College of Physicians defined it thus:

The acquired global impairment of higher cortical functions including memory, the capacity to solve the problems of day to day living, the performance of learned perceptuo-motor skills, the correct use of social skills and the control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive.

So it is something that usually affects memory, in particular of recent events. Do not assume people remember nothing; often important earlier memories are retained. It can affect intellect. New learning is difficult, thinking may be slower and judgement less good but good signage and prompts can help. Mood can be affected. Some people can become anxious, depressed or agitated; likewise some people's behaviour changes and a previously mild mannered person can become angry or behave with uncharacteristic disinhibition *but* good care and attention to the person's well-being helps.

However it must be emphasised that no two people experience dementia in quite the same way – it is a very individual experience. Also the experience changes for the person over time so it is important to keep a watching brief and respond as their needs change. Carers and supporters should be aware that the person's memory and skills can fluctuate from day to day. A familiar example is that of carers who tell of frustrating times trying to dress someone who has always been able to dress themselves but one day loses a step in the process and can no longer do it – but then later in the week can dress themselves again perfectly. Carers who do not understand dementia can find themselves wondering if the person was trying to wind them up! They were not; it is a facet of the way dementia manifests itself that these variations can occur.

Generally the pattern of dementia over several years is one of declining cognition, emotions and behaviours which carers can find increasingly challenging alongside increased physical difficulties.

What is it that makes us the people we are? I believe that the experiences throughout our lifetime are fundamental in making us into the people we have become. The early memories: first pet, mum bringing brother or sister back from hospital, our first day at school, first star, first detention (or worse), first pay cheque, first boyfriend, subsequent boyfriends, getting married, illness, bereavement. All these and many many more memories have formed us. Part of our memory and our ability to recall these images contributes to our sense of self, including both the wonderful and the sad moments.

I picture my memory as hundreds of windows, through which I can look back to these moments. Many of them interconnect, leading me on or back to other moments or people remembered. But what happens when the view through one of those windows is blank. In truth we all have those moments – often when we are stressed or tired, worrying about something or just not concentrating. The face is familiar but the name has gone temporarily. This is *not* dementia, but merely a natural reaction to the pace of life.

But what of the occasion when your husband asks you to post a letter and when you get home again you cannot even remember he asked you – the letter is still there in the bag! More worryingly even when it is there in front of you, you do not recognise it and are still adamant you have *never* seen it before. If that becomes a regular pattern it is certainly worth seeking advice. Most people who develop dementia or who live with someone with dementia will say that it was not the first incident that alerted them but the repeated pattern of difficulties.

And certainly experienced practitioners will be looking for that pattern, the history of memory problems developing rather than a single incident. However please note that if there is a sudden decline over a matter of a day or two then medical help should be sought as a priority because a rapid onset of memory problems can often be an indication of physical illness, for example severe infection which can be treated and needs to be treated. The treatment will then alleviate the memory problems too.

One of the facets of memory that we all use most of the time is the power of association. Try to remember quickly a list of random letters, for example:

GFMS    SDNO    CZPA    PVTE    VRXI    AQBM

Most people find that challenging. But if given the following list of the same number of letters most people can remember them more easily:

REME    PDSA    WRAF    WABC    BRMB    RSPB

Why is that? The key lies with association. The second list is easier to remember because the letters are meaningful – most people know of PDSA as the Peoples Dispensary for Sick Animals, so the letters are meaningful and once the link is

made they are easier to remember. Indeed some people remember by making a further link and visualise a sick pet or similar to reinforce the memory.

The difficulties start arising when it is not one or two blank windows out of the hundreds of memories or knowledge. The real problems start when, because one window is blank, there is no link to the next window and so over a period of time a whole wall of your memory, which was full of images, becomes filled with holes and the final picture can look increasingly blank and therefore bleak.

But this is where good care really comes into its own. If what is happening in the present links to a surviving memory which is positive then the person is more likely to be relaxed and content. If many windows are blank and the present activity is unpleasant or connecting back to a worry or negative experience the person is far more likely to be anxious or even angry and frustrated. Recognising these cues, acknowledging them and working with them to try to achieve the optimum well being for the person is one of the fundamentals to person-centred care.

Even a person with advanced dementia will have times of insight and understanding. John Killick in *Communication and the Care of People with Dementia* relates some of his conversations with a lady named Alice who was living in a nursing home. Although her dementia was considerable she had insight into what was happening to her and could express it with great dignity and poetry:

The brilliance of my brain has slipped away when I wasn't looking.

Conversations with Alice also provide a salutary reminder of the impact of poor care practice. In particular Alice's plea below emphasises the interplay of dementia and poor practice, which together can close many of the windows in a person's memory. This then insidiously takes away from them the facets of their history and experience which makes them the individual personality they are.

Are you a person who could swing it for me with the authorities? I want you to ask them a question for me: Would they please give me back my personality?

Good care practice can do much to address this and this is one of our challenges.

## Reference

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Killick, John and Allan, Kate (2001) *Communication and the Care of People with Dementia* (Open University Press).

## The Mayfields Approach

### Jill Phillips

*Jill Phillips was formerly manager of Mayfields, MHA Care Group's specialist home for people living with dementia.*

I am a Registered Manager of a 45-bedded home for people living with dementia. The residents that live at Mayfields are from the age of 65 years upwards.

Mayfields is a purpose-built residential home for people with dementia and was opened in spring 1997. The ethos of the home is to recognise each resident as a unique individual and to provide an approach to care which fulfils their emotional, spiritual, social and physical needs. Our priority is to give individual care within a calm and relaxed atmosphere. The emphasis is always on doing things *with* residents rather than *for* them.

Mayfields has beautiful gardens and the residents can go out of any door or any patio door and walk freely. They can go out of Greenacres Lounge, have a little walk and enter into Rosebank Lounge or Bluebell Court or vice versa. They have so much freedom – there is approximately one and a half miles of secure gardens to walk through.

Anyone coming to live at Mayfields has an in-depth assessment carried out, not just at Mayfields but also at their home. The family and friends work very closely with the team to ensure lots of information is given to us to make sure that transition of their loved one goes as smoothly as possible. Having information about their lifestyle can make such a difference – from what their occupation used to be to how they like their drinks served – in a mug or a china teacup and saucer. Little points mean so much. Mayfields is their home and we need information about their daily lifestyle, not what is happening now with the onset of dementia, but how they used to live in their individual environment.

The staff at Mayfields have ongoing training about dementia. This includes the whole staff team and all the volunteers, relatives and friends. This has proved so successful – they all feel part of the home.

Spirituality is so important in this type of environment. We all express our spirituality in different ways, by music, quiet time, prayer, touch and sound.

There are so many stories I could tell, but this one is very close to my heart. A gentleman came to the home in an emergency situation. He was very quiet, withdrawn and lost within himself. We tried continuously to talk to him and encourage him to communicate, but alas – no joy. This gentleman would walk sideways, raise his arms and stretch them out frequently. We could not find out why he was performing these movements. We spoke with the family who lived away, we read books, but no explanation could be offered.



During this time Mayfields was having a new extension built and this gentleman continually walked down to this area. Contractors, including decorators, were in the home daily. One day I was walking along the corridor where this gentleman was going through this routine and a young seventeen-year-old trainee said to me, 'You know what he's doing don't you?' My reply was of course, 'No! I wish I did.' The young man said that the gentleman was 'sizing up the walls'. I was amazed that a young man could see this and that is what is so important. He did not see the dementia, he saw an elderly gentleman, but most importantly he saw him as an individual. The next day the trainee came in with a little box with compartments in, and inside was a paintbrush, a wooden roller, a ruler and a pencil. The trainee and the gentleman built up a lovely relationship. At long last it was wonderful to be able to communicate with him.

Taking time to listen, but also to hear is paramount in caring with people living with dementia. Spending quality time walking in the gardens, sitting in their rooms or just one of the quiet lounges makes the person feel they belong. Photograph albums and talking tapes of their loved ones is helpful. Some residents have an individual tape made of sounds they recognise from home, for example their doorbell, radio, church bells ringing, a dog barking, alarm clock and the telephone ringing.

It is my responsibility as a Registered Home Manager to make clear exactly what is expected of the staff team. For example it is not just their role to address each resident's physical needs, but to respond to their emotional and spiritual needs. This is person-centred care. For me it means that I must prepare to offer the whole staff team a deeper level of support if they are to care through their empathy, energy and creativity. I must address their emotional needs as a whole team and as individuals to ensure they will not switch off or burn themselves out. Therefore I as a manager adopt a person-centred approach to the staff team at Mayfields. This is supported locally and organisationally.

# Who Is It That Can Tell Me Who I Am? Communication, Faith and People with Dementia

Margaret Anne Tibbs

*Margaret Anne Tibbs is a social worker and currently freelance trainer and consultant in dementia. She is the author of Social Work and Dementia (2001).*

## Introduction

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This quotation from *King Lear* by Shakespeare was used by Archbishop Rowan Williams in a televised interview – and when I heard the question asked in this form I realised that it encapsulated what I hope to say in this paper.

I shall be attempting to explore areas of identity and spirituality in the light of my experiences in the research project 'A New Picture of Care' on which I worked from 1998 to 2001.

Shakespeare, writing nearly 400 years ago, was clearly familiar with dementia. He puts the following words into the mouth of Lear, (Act 4, Scene 7)

I am a very foolish fond old man,  
Fourscore and upward, not an hour more nor less;  
And, to deal plainly,  
I fear I am not in my perfect mind.  
Methinks I should know you, and know this man;  
Yet I am doubtful ....

Shakespeare is describing what we now, subscribing to the prevailing medical discourse of dementia, describe as the disease process of dementia. In his day such mental decline appears to be associated with the fact that Lear is very old.

So – if I have dementia and ask 'Who is it that can tell me who I am?' (Act1, Scene 4) the answer has to be those who are looking after me. Those who will stand with me, who will care for me through my problems in communicating, through my frustrations, my episodes of agonising awareness of what I have lost, my rages and my tears, the times when I withdraw within my own head in protest at the unforgiving world in which I find myself.

Our sense of our own identity is one of the aspects of our humanity which is seriously undermined by dementia. This is because it depends on memory which is one of the early casualties of the neurological damage. We need to be able to remember our own story and the story of the significant people in our lives. It is these stories which tell us who we are. Without memory and a sense of who we are, we are living in a place which undermines our very humanity.

As Lear says (Act 2, Scene 4):

... we are not ourselves  
When nature, being oppressed, commands the mind  
To suffer with the body.

If we can no longer remember our own story we are dependent upon other people to hold on to it for us. This depends on other people caring enough about us and having enough time and skill to tell our own story back to us. What are our chances of us finding such people?

Our sense of our identity is strongly linked to our ability to communicate with language. Sadly, this is also eroded by dementia. As the precise and accurate words we use to convey what we mean are lost, we start to rely more on metaphor and poetic imagery. Later still we resort more and more to non-verbal communication and eventually our primary means of communication is our behaviour – actions speak louder than words. Just as we depend on other people to hold our identity for us, we also depend upon others to have enough time and be sufficiently motivated to decode our fractured and fragmented language. We depend on others to decipher our code.

There is a Zulu proverb which means, ‘A person becomes a person through other people’ – ‘Umuntu ukumuntu ngybanye abantu’. In other words, we only develop and maintain our status as human beings through relationships with other human beings. If we develop dementia we are in grave danger of becoming non-persons – partly because the fading sense of who we are becomes increasingly difficult to communicate to other people. We can reach a place where we are totally dependent upon other people taking the time and trouble to find out how to sustain our well-being. We will no longer be able to sustain it for ourselves.

If we are honest we have to admit that many people do not find it easy to engage with people with dementia at any level other than the most superficial. This applies to many family members as well as those who care for them in a professional capacity.

People who are very disturbed and tormented, whose behaviour is chaotic and apparently meaningless, frighten us. This apparent meaninglessness is very disturbing. Those who fail to respond to us are equally disturbing to most people. The lack of any interaction – the absence of clear evidence whether the person is awake or asleep is hard to handle. ‘Is there any point?’ we ask ourselves.

These deep anxieties collude with the prevailing shortage of the resources of money and staff in care homes to condone our failure to engage with people with dementia on a personal level. This collusion gives respectability to our neglect. It makes it seem all right to ignore these fellow human beings on the grounds that ‘they are in a world of their own’ and to say that ‘they don’t know what’s happening to them – therefore it doesn’t really matter if we ignore them’.

Since the research project finished I have been working as a trainer. In the past two years I have worked with care staff from many different settings in many different places, providing training in person-centred care. In every training session I meet some individuals who are not only willing but anxious to learn new caring techniques and who express a powerful desire to ‘make a difference’ to people’s lives. They are aware that they do not know enough. They are looking for answers, reasons, wanting to understand puzzling behaviour, looking for new ways to try and help. These people often feel very validated when they are given a narrative which fits their own experience.

The narrative of person-centred dementia care was, as we all know, first written down by Tom Kitwood in the early 1990s. He developed it from his work as a Rogerian psychologist with other client groups. It was the first time, since 1907 when the medical narrative of dementia appeared with the describing of Alzheimer’s disease, that we had an alternative narrative (Shenk 2002). We have seen that in Shakespeare’s day dementia was not regarded as a disease.

Of course, many people were already providing person-centred care, following their own instinctive response to the need of other people, but it was Kitwood who gave us the narrative (Kitwood 1990).

Now – ten years later – the challenge is to achieve a critical mass of care staff so that isolated examples of good practice can become the mainstream. The present state of affairs has been described by several people, for example Packer (2000). People have generally learned to ‘talk the talk’ – even the policy makers (who generally trail far behind the practitioners.) The *National Service Framework for Older People* (2001) has Standard Two devoted to person-centred care. The National Care Standards Commission is beginning to insist that care homes and home care agencies deliver person-centred care.

But how do we make it happen? How do we learn to ‘walk the walk’ as well as ‘talking the talk’? How do we help people who want to work with those with dementia to overcome the deep seated resistance to engaging them at a truly personal level?

If we are going to stop people with dementia being treated as non-persons we have to learn how to do this. ‘A person becomes a person through other people.’ Individual care workers in the field often realise that their innate common-sense approach is inadequate for dementia care. But this is all they have to bring to the job, in the absence of proper training. Families also hope for and expect to find more than physical care when they place their relatives in long-term care homes. Many search long and hard for homes that can provide more.

I am firmly on the side of those who believe that person-centred care can be achieved – even within the present budgetary constraints. To me this is not just a practical but also a spiritual issue. Treating people as people rather than

objects is a profoundly important spiritual task. My work on ‘The New Picture of Care’ research project has added further conviction to my belief.

## **The study**

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### **1 Brief history of the project**

The project was designed originally by Professor Tom Kitwood and started in January 1998. A team of three part-time researchers from Bradford Dementia Group started work – Errollyn Bruce, Claire Surr and myself. Kitwood had approached Methodist Homes for the Aged (as it was then known) and obtained funding from them to carry out a three-year longitudinal study in their homes. He did this because he viewed Methodist Homes as an organisation which was committed to the idea of providing person-centred care.

Quality of life in institutions has been an enduring issue. Specific interest in the fate of older people in long-term care was kindled by Townsend’s (1962) groundbreaking study exposing the poor quality of life experienced by older people in care homes. This has remained a cause for concern, but it is only in the past ten years that people with dementia have been included in this agenda. Once deemed beyond well-being and quality of life, there is now good evidence that like all of us, people with dementia need dignity, purpose and control (Bruce *et al* 2002).

### **2 Aims of the project**

- To look for evidence of well-being among the residents in the study.
- To identify factors associated with the maintenance of well-being; and risk factors for poor long-term outcomes.
- To contribute to our understanding of how the care environment affects well-being.

### **3 Participants**

At the end of the preliminary work we had a sample of 93 people living in ten different Methodist Homes, located in different parts of England and Wales. They were mostly very old. The average age was 84. The age range was 59 to 98 with relatively few residents under 80.

The dementia of the people ranged through mild and moderate to severe. The range of MMSE scores was from 0 to 20 with an average of nine. The test was used before the study started to select the subjects and at regular intervals thereafter. The Activities of Daily Living was variable – with an average of 31 on the Bristol ADL Scale (possible maximum on the scale is 55). The range was from 12 to 55.

## 4 Methods of study

Residents were divided into groups of five. In the specialist homes there were three groups of five. In the homes with wings there was one group of five and in the mixed homes there was one group of five.

Staff in the selected homes were asked to complete a well-being profile and make brief notes about well-being for each person every month.

We (the research team) were in the homes for two days each visit, including an overnight stay.

At the end of each visit, field notes were typed up. Taped conversations with residents were transcribed and all the numerical data was entered into the computer for analysis.

Case reviews for each resident were carried out at the end of the 24 months of data collection. This entailed reading all the field notes and transcripts of interviews with residents and staff. We also looked at the scores and ratings for all the measures for each resident. We tried to work out which factors had been most influential on the person's well-being.

## 5 Well-being

A central concept in the study was that of well-being. This is regarded as an outcome of the delivery of person-centred care. When all the quantitative and qualitative data had been collected residents were allocated to one of three well-being groups – high, medium or low. Residents were assessed by care staff and researchers separately. We found a high degree of agreement – 83% between the two sets of assessments. Graphs were made of each person's well-being so that we could observe patterns over time. The majority of residents showed signs for well-being for 60% or more of the time during the study period:

High	44.5%
Medium	45.5%
Two groups combined	90.0%
Low	10.0%. This was a very small number of individuals.

Comparisons were made between the different groups on all the transcripts of interview which we looked at.

## 6 Mindsets

Field notes and conversation transcripts were coded for the mindsets which act as the underpinnings of well-being. (Mindsets were adapted from the 'Global States' developed by Kitwood and Bredin.)

The mindsets are:

- Identity
- Sense of Control
- Hope
- Social confidence

Where people had high well-being it was much easier to spot evidence of the mindsets and it was generally more difficult in those with low well-being.

For this paper I propose to concentrate only on Identity and Hope.

## **Findings of the study**

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### **Well-being and Identity**

People showed strong signs of identity by presenting themselves positively and being keen to talk about themselves. They made an impact on others by talking about past experiences. They were aware of their own place in the world. They expressed feelings about their relationships and social position and opinions about beliefs and feelings. These showed that people were in touch with what they felt to be important, both good and bad. Expressing opinions shows an expectation that someone will take notice of what you say. Sharing your negative feelings suggests an assumption that your feelings will count. We did not assume that well-being had to be associated with people who are always happy and jolly. Nobody is happy all the time. It is more complex than that.

### **Well-being and Hope**

Hope was defined by Kitwood and Bredin as ‘a confidence that some security will remain even when so many things are changing, both outside and within’ and ‘a sense that the future will, in some way, be good’. We kept to that broad definition.

Two areas of life seemed to be crucial in maintaining hope. These are finding comfort and security despite everything and finding meaning in life and acceptance of death.

Hope clearly has a spiritual connotation although most of the research team felt that it was important to separate this from faith (Bruce *et al* 2002). For the factors which we found were associated with well-being and those which we found to be threats to well-being see the Appendix.

### **The context of care**

We identified three factors which helped to form the context within which care was provided.

## **1 A special atmosphere**

This is very important, though elusive to define. We identified that it came from the Christian atmosphere. Several families who were not Christians had chosen Methodist Homes because of this. Relatives who had visited many homes looking for the right place often commented on the fact that there was something special about them. Some comments from relatives were:

Love and care that goes far beyond legal requirements.

What really matters is that it is loving (from the daughter of a resident who had been a life-long communist).

Outstanding kindness of the staff, their patience and affection.

## **2 A non-punishing place**

All the homes – but particularly the specialist homes and those with specialist wings – created an undemanding environment. By this we meant one that relieves anxiety for people with dementia from many of the demands that are likely to cause anxiety or put them at risk. Many residents sense that things like organising meals, paying bills, laundry, mail and gardening were being taken care of in the home. Apart from a few critical fellow residents, the people around were generally accepting of the typical disabilities of dementia. They did not expect clear speech, coherence, speed, agility and so on, and did not put people under pressure to meet normal standards. More importantly, they did not make people feel less fully human on account of their disabilities.

For many residents the homes were much less punishing than the outside world and this was significant in helping them to maintain a sense of being a competent, valuable member of a community with much to offer. Several families commented that their relatives had become less agitated and distressed since coming into care, something that the staff were aware of too.

## **3 A clear value system**

It was interesting to note that the clear Christian value system was valued by most families, whether they came from the same tradition or not. The idea that right and wrong is important fitted with the outlook of the residents. Questions of meaning are of great interest to people reaching the end of life. They are definitely on the agenda of Methodist Homes.

There is a strong sense of community in the homes – which is probably characteristic of Methodism. Both residents and staff expect to join in activities if they are able. There was a clear sense, sometimes expressed in interviews, that one should make the effort to join in if others had made the effort to organise



something. There is also a recognition that the group should try to accommodate the needs of individuals as well as for individuals to fit in with the group.

These underpinnings seem to provide a good back-drop for work which helps people to hold on to the meanings which have been an anchor in their life, whatever they are. We found that, on the whole, the atmosphere in the homes was inclusive.

These three underpinnings are definitely supportive of person-centred care and likely to support well-being. The distinction between the spiritual and the religious was very important to those who designed the research. It was felt by Methodist Homes that they made a feature of good spiritual care – each home having its own dedicated chaplain, in-house services on Sundays, mid-week prayer and hymn singing groups as well as regular volunteers from the church.

The question was asked by the researchers whether religious care was actually being confused with spiritual care and whether some people could feel excluded by it. However it seemed to me that while this was an issue for the research team, it was not really an issue for the people we were studying. In fact they would not have related to our attempts to separate the two. Most of the people in the study had spent their whole lives within a particular faith tradition – Christianity. The branch of it within which they lived was Methodism. It was part of the air they breathed and they would no more question its truths than they would doubt their own existence.

I came across a definition of spiritual well-being by Eileen Shamy which seemed to put into words what I want to say. The idea was also reflected back to me clearly in conversations with some of the residents in the study. In *More than Body, Brain and Breath* she said:

Spiritual well-being is an affirmation of life in a relationship with God, self, community and the environment, that nurtures and celebrates wholeness. It is the strong sense that I am ‘kept’ and ‘held’ by Someone greater than myself who ‘keeps’ the whole of creation, giving it life and purpose. It is the certain knowledge that I am part of meaning and purpose. (Shamy 1997)

### **The role of faith**

Finding meaning in life has long been identified as an important characteristic in survivors of extreme situations. There is no doubt that dementia may be classed as an extreme situation. Methodist Homes give a context of meaning which is familiar to many residents, particularly relevant to those for whom religious activities maintain continuity with their past religious involvement. Singing the old hymns, hearing familiar words, marking familiar landmarks throughout the church’s year help many residents to feel they are in a good place, even if it is not home. Even for those who did not belong to this faith

tradition, they were familiar to people of the oldest generation from their school days when everyone attended Christian school assemblies.

There was little doubt that the Christian environment encouraged reflectiveness, connectedness and meaning to life, attributes which are generally accepted as some of the secular or non-religious attributes of spirituality.

### *A Special Kind of Care*

The final report of the research was published in November 2002. The title is intended to position the report clearly within the current political debate about the funding of long-term care (nursing care in England, Wales and Scotland being free at present while personal care has to be paid for in England and Wales, though free in Scotland). At present far more people with dementia are being cared for in residential care homes than nursing homes.

We wanted to give a clear message that, while people with dementia do not usually need nursing care, they definitely need more than mainstream residential care. They need staff who have received additional specialist training and a higher ratio of staff to residents than those without dementia.

The report can be downloaded from the MHA Care Group website at [www.mha.org.uk](http://www.mha.org.uk) or purchased through MHA Care Group, Epworth House, Stuart Street, Derby, DE1 2EQ, Tel: 01332 296200.

What is implied by 'A Special Kind of Care'? The Report emphasises:

- an understanding of the particular disabilities and experiences of dementia;
- avoiding malignant social psychology;
- communication;
- interpretation;
- empowerment;
- help with grieving and emotional turmoil;
- making good use of life history;
- making use of external sources of support;
- spiritual care.

Some of the implications for practice arising from the study:

- We need to provide people with dementia with opportunities for sustained conversation, where they can talk about themselves and their experiences.
- People with dementia need us to acknowledge and encourage their attempts to seek meaning as they try to make sense of their experiences. It is clear that they are making strenuous efforts to sustain their own well-being and these need to be supported.

- Staff who are caring for people with low well-being, who seem to be overwhelmed by negative experiences, need a great deal of support.

## Personal challenges

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It seems to me that as a person of faith, nurtured in the Western Protestant tradition, there are certain questions which, working with dementia, I must face. The traditional teaching of the Church, from the early Christian fathers and St Thomas Aquinas onwards down the centuries, was that ‘God’s grace is a gift which is only possible to a rational being’.

The Reformation theologians reframed these ideas but still assumed that rationality must be present, when they said that ‘the person must be aware of their sinfulness and need for Christ in order to enjoy a relationship of trust and obedience with Him’ (Saunders 2002). Even now we still ‘find it difficult to move beyond the vocabulary of reason, for thinking, reading, reflecting and communicating – words and ideas – lie at the heart of so much Christian life’ (Saunders 2002). This has posed particular problems to those who minister to people with dementia whose ability to think, read, reflect and communicate becomes progressively impaired.

An alternative narrative came in the early years of the twentieth century from theologians Karl Barth and Martin Buber who developed theologies in which relationship rather than reason was understood as the cornerstone of being human. The ‘I-Thou’ relationship they called it – or - ‘Umuntu ukumuntu ngybanye abantu’ – ‘a person becomes a person through other people’.

It is interesting that the idea of the ‘I-Thou’ relationship was a strong influence on Tom Kitwood’s definition of the ‘person-centred approach to dementia care’. It is still included in the course material for the BDG Certificate of Education in Dementia Studies.

This theology gives me an alternative to the statements which are so often made by family carers – ‘the person I love died long ago’; ‘all that is left of the person is an empty shell’; ‘dementia is the death which leaves the body behind’ – in other words ‘the disaster view of dementia’.

I have to believe that there is purpose and meaning in life in order to go on. I’m with Anne Frank when she wrote in her diary, ‘It is utterly impossible for me to build my life on a foundation of chaos, suffering and death’ (Anne Frank, cited by Shamy 1997)

The ‘New Picture of Care’ research provided me with clear evidence – in the form of transcripts of recorded conversations with people in the study and observations made about them by the staff – that their humanity is still intact. I have no doubt at all that I was engaging, sometimes at a deep level, as one human being with another human being. It made no difference that the other

person had virtually no short-term memory and that their language skills were impaired. I know that we met – soul to soul.

Initially it was not easy to do this. We had concerns and questions about our own abilities. Firstly, would the people be prepared to talk to us? Clearly they would not remember us as we would only be visiting them at three month intervals. So what cues could we give them to assist the process? What would we do if they had nothing at all to say to us? We learned how to do this – by trial and error – and I am so grateful that we did. Having these conversations is an experience for which I shall always be grateful.

To quote Eileen Shamy again, 'I know that one of the sweetest, most normalising experiences any of us can have is that of sharing joy ... briefly we had entered each other's world, each with a crowd of associated memories' (Shamy 1997).

To conclude I should like to let a few of the people I talked to speak for themselves. Their names have been changed.

### **Miss Mills**

I asked her (on my third visit), 'Miss Mills, do you pray?' 'Oh yes,' she said. 'Now that's something I couldn't do without. That is ... that's always been part of my life. I had grandparents who were great ... church members and I ... they took me to church when I was small and I've always carried on. And that's been part of my life and that's that.' So I said, 'It's part of who you are isn't it?' and she said, 'Really, yes. If people only realised that, it does become part of your own life ... I was taken to school, to church, when I was much too young to understand, but I suppose we absorb it.'

Later, she said, 'It's good to have a laugh isn't it? ... We live on laughter ... when you think about it ... we live a tremendous amount on laughter ... there you are. We've got to live on something so it might as well be laughter.' Later I asked her, 'So you have no worries about the future?' and she said, 'Oh no, no ... I've been taken care of all this time and it will continue. It's nice to feel so safe.'

Miss Mills was 93. She also had very poor short term memory but seemed to be happy doing very little. Her MMSE score was consistently 18. When I asked her if she looked back over her long life she said, 'Yes I suppose I ...well it's ... I mean I don't gloat over it, if you know what I mean but I ... er ... I do. If something reminds me of it, I either laugh or wonder what in the world was happening at that particular time ... for that to happen.' I asked her, 'Are you still learning?' She said, 'I suppose so. If something happens I think ... Ooh I don't think I've ever had that happen to me before. Which is learning.' 'And coming to live in a place like this?' 'I've never, ever experienced anything like it ... but I'm very happy because you're learning something new.' Not a bad thing to feel when you're 93.

## **Jim Phillips**

An excellent example of good spiritual and religious care was given to a man referred to as Jim Phillips in the report. Jim had a long career in the regular army and retired with the rank of Major. He had also been a lifelong active member of the Church of Scotland and became a Sessions Clerk of the church on retirement. His cognitive impairment was too advanced for recorded conversation after the first visit when he told me that the home's dog was actually his dog and that he looked after him, remarking, 'Actually Paddy is a lot less trouble than anyone else as far as I can see because he keeps quiet. Fairly quiet ... and he's a terribly nice dog.' (The fact that Paddy was actually a bitch with another name was never an issue for anyone and Jim continued to think of her as his own). He had brought up the children of two marriages – he was widowed twice, and obviously had a very strong need to look after and cherish the ladies – in the most gentlemanlike manner.

It was the chaplain of the specialist dementia home where he lived, who has made a particular study of ministry to people with dementia, who realised that Jim had special needs. He was not accepting the dementia-adapted act of worship in the home and never joined in when it was held. The chaplain (Revd Margaret Goodall) felt that Jim probably didn't even recognise that it was a religious service. So she arranged for a volunteer from the Methodist church in the local town to come every Sunday to collect Jim and take him to church.

I observed Jim at monthly intervals throughout the two years of the data collection and he was always moving around the home, escorting someone or hovering, unable to concentrate on anything for more than a few minutes. He only sat down when he was really tired. According to the daily records at the home it was regularly reported that he enjoyed the service and was always peaceful and calm afterwards.

Knowing, from observation, how hard it was for Jim to sit still for any length of time, I found this behaviour really difficult to explain. Therefore I asked the volunteer who took him to church about these visits. He assured me that Jim did sit through the service which lasted well over an hour, including quite a long sermon. He joined in a lot of the hymns and prayers which he knew by heart and very much enjoyed the social time afterwards. I concluded that this weekly experience must be reinforcing his sense of connection with his Lord and his faith as well as with the wider community and gave him an extra sense of peace which enabled him to relax. It was definitely instrumental in maintaining his well-being.

## **Sister Janet**

'I suppose I'm too old darling. I'm really getting very old now ... and you can't stop it ... you go on and on and there's nothing you can do to stop it' – Sister Janet and King Lear. She was 97 at the time, virtually blind and only able to

walk with a frame guided by a care assistant. But she still wanted to be doing things for other people. 'I'm not used to this dull sort of existence,' she said, 'I'm bored. Yes. I've had a good life and I'm bored now ... you've got to have some sort of ... when I say job, I don't mean a paid job, you've got to have some purpose, something definite that you're doing ... and you don't need money necessarily.' In fact, the reasons for her lack of activity were related to her physical disabilities rather than her dementia.

On another visit she was very fed up, but was able to describe her feelings about her mental state very accurately. 'I don't feel as though I'm me at all. I feel as though I'm some queer creature who's come to earth here but who, I don't know. I don't know myself' (seventh visit). That seems to me to be a vivid description of the confusion caused by dementia ... 'I hate this way of not knowing what to do next.'

On another occasion when we were discussing what it was like living with other people all the time she said, 'Living with other people doesn't make you feel less lonely, it makes you feel more lonely ... if they're not people who belong to you.' Her moods changed of course and on other occasions she was very protective of the home and told me how she felt loved and cared for by the staff.

On my second visit I asked her, 'Do you feel at peace and ready to depart?' and she said, 'I don't think about it. You just go on going on. At least that's what I do ... why should I [speculate about the future]? I'm quite happy here and I'll be happy to go when the time comes.' When I said, 'You've always been a great believer haven't you?' she said, 'Oh yes!! That's something different.'

She had virtually no short term memory (her MMSE score was between 12 and 14). She would drink her favourite cup of black coffee and almost as soon as it was finished would ask for another, saying she had not had a drink for ages. But she was still able to put into words the nuances of her feelings.

She was something of a hero in the Methodist church having been one of the first deaconesses who went to work in the 'mission field' (the Caribbean). She was awarded the MBE. for this work. By the time I met her she had absolutely no recollection or interest in that fact. Her chaplain said, 'She has worked extremely hard all her life. She is completely imbued with the Protestant work ethic and is bewildered to find herself in a situation where there is nothing she can do.' Her key worker – a young man of African descent – told me, 'She is a most special person to me and I love her.'

I think that says it all. It answers the question of King Lear with which we began. 'Who is it that can tell me who I am?' It is people like him who can say, 'She is a most special person ... and I love her.'

## References

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- Bruce, Errollyn, Surr, Claire and Tibbs, Margaret Anne (2002) *A Special Kind of Care* (MHA Care Group).
- Department of Health (2001) *National Service Framework for Older People* (Department of Health).
- Kitwood, T (1990) 'The dialectics of dementia: with particular reference to Alzheimer's Disease', *Ageing and Society* 10, 177–96.
- Kitwood, T and Bredin K (1992) 'Towards a theory of dementia care; personhood and well-being', *Ageing and Society* 12, 269-87.
- Packer, T (2000) 'Does person-centred care exist?' *Journal of Dementia Care* May/June, 19–21.
- Saunders, James (2002) *Dementia – Pastoral Theology and Pastoral Care* (Grove Books).
- Shakespeare, William (2001) *Arden Shakespeare: King Lear*, third series edited by R A Foakes (Thomson Learning).
- Shamy, Eileen (1997) *More than Body, Brain and Breath* (ColCom Press).
- Shenk, David (2001) *The Forgetting – Understanding Alzheimer's: a biography of a disease* (HarperCollins).
- Townsend, P (1962) *The Last Refuge. A survey of Residential Institutions and Homes for the Aged in England and Wales* (Routledge and Kegan Paul).

## Appendix

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The following factors were identified in *A Special Kind of Care*.

### **1 Factors associated with high well-being**

As a group, compared to those with moderate or low well-being, they

- were less disabled;
- had lower levels of cognitive impairment;
- were more independent in activities of daily living;
- had better language and better communication skills (we made a clear distinction between the two);
- were ealthier than others;
- showed fewer signs of depression;
- had few problems with bowels or skin;
- had fewer problems with incontinence or mobility;
- were more active physically and socially.

All these factors are obviously associated with better physical health and less advanced cognitive impairment and might easily be predicted.

However, there were other factors which were more surprising. The group who showed high well-being also

- had better relationships with their families;
- had more supporters who were making strenuous efforts to meet their needs;
- seemed to cope better when faced with cognitive decline and/or a change in their abilities;
- participated in a greater range of activities on a regular basis;
- were more sociable and had more friendships with specific people;
- spent a lot of time moving about the home;
- had more favourable relationships;
- were getting more than average amounts of time from the staff;
- were more likely to be seen as popular or seen as characters;
- were less likely to have their emotional needs overlooked by the staff;
- were less likely to have no visitors at all;
- were less likely to have inappropriate support from people unable to understand their dementia.

## **2 Factors associated with threats to well-being**

- Accumulated losses and emotional turmoil.
- The experience of dementia and the disabilities it brings.
- Changed relationships.
- Living in community in long-term care.
- Having to accept help with personal care.
- Ill-health and physical decline.
- Depression.
- Sedative medication.
- Negative life events



# Living and Working Together

Alison M Johnson

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## Introduction

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A good home for people with dementia is one where residents, staff, relatives and members of the wider community together live life to the full in, as far as possible, exactly the same way that we all live out our normal lives. We must never lose sight of the fact that people with dementia are primarily people and that a good care home should be primarily home. How can we then ensure that, in the words of Professor Faith Gibson, our residents continue to feel ‘fully paid up members of the human race’ coming to the beginning of each day with eager anticipation and to the end of the day with a sense of achievement and satisfaction?

In an earlier presentation at a *Journal of Dementia Care* conference, I developed the idea that activities of daily living were equally as important to the maintenance of well-being as the more traditional activities programmes favoured in many care homes, where residents are expected to take part in bingo, carpet bowls and collage making. This view was shared by the author of a recent article in *Community Care* which looked at life in sheltered housing in Holland. He made this comment about the vibrant life he observed within the complex:

It’s not down to bingo and Christmas parties. Residents seemed livelier because there were **things to do as a matter of course**, rather than social events just added on.

‘Things to do as a matter of course.’ This surely is the key to a fulfilling life in a care home for people with dementia. Activities don’t have to be structured, they are not a means of passing time, or keeping residents occupied, they are the stuff of life itself. Activity means everything we do, because everything has the potential to be therapeutic. Our task is to provide opportunities for our residents to continue to live and work in such a way that their personhood is affirmed and they can feel fulfilled. In this way we will be able to care for them in a rounded and holistic way paying attention to their physical, mental, emotional and spiritual needs.

Activities are therefore too important to leave to one profession or one individual activities organiser. It must become the responsibility of every single member of the staff – and that includes those who clean or garden or cook meals. In Australia the so-called diversional therapists did run activities themselves but were seen primarily as facilitators rather than as people who ‘took the residents off over there away from everything and kept them busy doing something’. They also had an important role in educating staff and providing guidance on how to incorporate activities into everyday care provision.

## Life story

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The place to begin in this approach to activities is where we must always begin – with the individual resident. To understand the needs of the person with dementia we must know as much as possible about his or her life and work. Was Mrs Jones a housewife or did she go out to work? Did Mr Briggs live in India at one stage of his life? What happened to Mr Brown in the war? Have we ever studied the framed certificate on Mr Anderson's wall? An attempt to find answers to these questions and to get to know as much as we can about every other aspect of our residents' lives will help us to understand the person now – especially as people with dementia are often living in an earlier period of their lives.

A good home will encourage residents and their families to develop a life story book which includes information, photographs and other memorabilia which help to capture memories. The *Journal of Dementia Care* has published *A Pocket Book of Memories* for this purpose. Another idea developed by Faith in Elderly People, Leeds is a *Memory Box* which contains meaningful memory joggers, personal items and photos. Both book and box can help provide answers to some of our questions about our residents, but are also invaluable for reflection on past times, for sharing with other residents or visitors and for using with new staff to introduce the residents to them. In addition our care plans should closely document likes and dislikes and personal preferences.

## Living and working

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How then can we develop the life and work of our home to take account of the individual needs of our residents? It would of course be easier if there were enough staff or volunteers for one-to-one attention. Failing this, we need to look at the daily routine and see how residents could be involved in the various components of daily living – personal maintenance, work, recreation, physical activity, social interaction and spiritual development.

### Personal maintenance

We begin with what Faith Gibson calls personal maintenance. An important aspect of life for us all is caring for oneself – getting washed and dressed, bathing, eating meals, washing our hair and so on. Staff members can brush a resident's hair roughly dragging out the tangles or can brush with care almost like a massage. Similarly smoothing hand cream into arthritic hands can be done in a perfunctory way or be a blessing to someone who misses the closeness of the affectionate touch of a caring relative.

Most of our residents will need help with bathing or showering. This activity helps to ensure personal hygiene, but for all of us a bath can be much more than simply a place to get clean. Staff can ensure that residents 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. 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. And afterwards the choice of clothes to wear, the rediscovery of forgotten garments and the opportunity of reminiscing about them make an everyday task a pleasurable activity.

Similarly we all have to eat and drink to ensure that we have sufficient nutrition and fluid to maintain life. But having a meal is so much more than eating or drinking. For older people with dementia who live in a care home, it can be a significant event in a day when not very much may be happening! Engaging in the familiar social ritual of a meal not only triggers past memory but provides a milepost in the day.

It is important again to ensure choice of menu, allowing for individual likes and dislikes (we don't lose these because we have dementia!). We can still allow flexibility in timing and location – a late meal for a resident who has had a visitor or breakfast in bed for those who don't choose company early in the day. But think too of the nourishment of the spirit we all experience through sharing meals with friends, engaging in conversation or celebrating special occasions. Might it be possible from time to time to encourage staff and residents to share meals together and welcome families and friends from the community to eat in the dining room?

And what of the end of the day? Our bed is so much more than simply a place to get a good night's sleep ready for the next day. Many of us look forward to bedtime as an opportunity to unwind, relax, escape from our families, read, watch television, have an intimate conversation with a parent or spouse or a time to think or pray. What about some calming music or relaxing massage for a resident at bedtime? And does someone say 'goodnight and sleep well' to each of them?

## **Work**

### **In the home**

Having cared for our physical needs, most of us spend a large part of the day in productive activity, otherwise known as work. For many of our female residents, this activity was centred in the home. In the survey carried out by the Centre for Policy on Ageing as a part of the consultation for *Fit for the Future*, a resident remarks:

I like to help the staff around the place and wash up. I don't want to give up. I've always liked being busy.

This comment applies equally to residents with dementia, many of whom believe that they still have household responsibilities. A continuing role with

domestic tasks has numerous benefits for our residents – it builds confidence and self esteem, maintains skills, makes them feel useful and valued and provides continued social interaction – the opposite from the boredom, apathy and futility of life which so many people experience in care homes.

Many of us who have visited dementia care facilities in Australia have come back with enduring memories of homes where the kitchen was the centre of the life and work of the home. Often a part of the main lounge and dining area, it was accessible to residents who were able to help as much as they wished with, for example, potato peeling, sandwich making or washing up. Through in the dining room residents laid the tables and cleared away afterwards. The smell of cooking permeated the home. Life seemed normal, the atmosphere peaceful and close relationships between staff and residents developed through shared activity.

There are many reasons why we may not feel able to replicate this here – for example staff roles, regulation and design. However MHA Care Group has attempted to do so by providing a kitchen as part of the lounge in its purpose-built dementia care homes.

At Mayfields, Ellesmere Port, which was commended by the Audit Commission, a group of residents regularly makes cakes. This involves much discussion and reminiscence about recipes, suitable ingredients and their packaging, types of scales and preferences for gas or electric cookers. The cake making itself brings back memories of the feel and the texture of the ingredients and the smell of the cakes cooking in the kitchen adjoining the lounge speaks of home. And what pleasure there is in having something to share with other residents and staff or to sell at the regular coffee morning.

Another area of the work of the home where residents may well like to be involved is in the laundry. Washing at least some of their clothes, pegging them out in the garden and folding aired garments and replacing them in drawers are all comforting tasks that remind residents of home, of normality and of continuing role, and give satisfaction in a task achieved. In Australia I saw a happy group polishing their cherished silver ornaments and reminiscing on their origin and meaning to them. Similarly many residents much prefer to dust their own rooms rather than have a domestic sweep in and carry out the task rapidly but without love and care.

Many of our residents spent a lifetime caring for children and husbands. In Australia I saw many examples of residents who believed they still had family responsibilities and who were comforted and affirmed by caring for a doll. Whilst some are concerned about infantilising and undermining the dignity of a resident who plays with a doll or teddy bear, others point to examples of adults with all their mental powers who take a bear to bed! We must never dismiss any activity out of hand without looking carefully at its benefits to the individual resident.

In the same way a resident who had always had a pet found solace in the companionship of a toy dog. He was a perfect companion, gave meaning and purpose to life and provided a topic of conversation with staff and visitors. If you've spent all your life caring for an animal, why must you stop when living in a care home?

Men also need opportunities to be involved in work around the home. This may be domestic tasks but for this generation of men it is more likely to be DIY or gardening. Every Australian man has his shed in the garden where he likes to potter and most homes included at least one. Several had chicken runs and most supplied an outside toilet too! Many residents were involved in gardening, including some who grew vegetables for the kitchen. At a day centre in Sydney the men with dementia daily swept up the leaves, just as they would have done at home. In Tasmania I saw a car in the grounds so that those who could no longer drive could continue to polish and care for a vehicle.

### **Outside the home**

And what of those whose work took them outside the home? We often find residents are anxious to go out after breakfast and it is clear that for many this is linked with a feeling that there is work to be done. It is important therefore that we find out about the working lives of each individual resident and then seek to provide some sort of opportunity for continuing involvement in that sort of activity.

In a home south of Brisbane I saw a room set aside as an office for the use of residents. A desk was available with paper, pens, staplers, hole punches and all the other impedimenta which surrounds those who work in offices. A number of men and women used this office from time to time and felt at home and reassured by this familiar environment. In another home, an engineer tinkered happily in the courtyard with a large and greasy machine and in yet another I was told of a nursing sister who had always worked at night. She slept during the day and shared the life of the home at night with the night staff!

It is important that in these and all our work activities we ensure that as far as possible residents will not experience failure. As well as helping to maintain cognitive and other skills such work must be achievable. Thus Mrs Howard may well still be able to wash her blouse by hand – but is unlikely to recall how to operate the washing machine. Mr Brown can remember how to plant leeks but may not be able to start the motor mower or be safe operating it.

Thus, engaging in familiar work activity, even if sometimes simulated, can allow a resident a sense of continuing value, purpose and fulfilment – which no amount of sitting around or carpet bowls can achieve!

### **Recreation**

However life is of course more than work, and we all need recreation. Often this is the only activity found in a care home. But when we most enjoy relaxation is

when we have chosen it or when we find time to relax after our work. The late Revd Fred Pratt Green, when a resident at the Methodist home in Norwich, captured this most tellingly in a poem about life in a care home which concludes:

Doing nothing, I observe,  
is only boring  
when there is nothing to do.  
Today I want to do nothing  
because of things  
I am supposed to want to do.

Our residents need to have the choice of taking part in activities or declining to do so and opting to watch or to retire to their rooms. Table games, arts and crafts, quizzes and puzzles can all be enjoyed by people with dementia and we must never underestimate latent abilities, or the possibility of learning new activities in old age. A lady who has never sewn in her life is now at the age of 84 finding enormous pleasure in making a cross stitch hassock for the parish church. A carer tells of how her Mum who never used to sing now sings often and with gusto. Another resident rediscovered the pleasure of knitting with the patient assistance of a friend.

We can often stimulate memory by showing videos of old films, looking at old magazines, reading aloud or reciting poetry. Often if we begin a poem, old song or nursery rhyme, the pattern and orderly sequence of sounds enables someone else to continue right to the end. I was greatly moved when visiting a home in Toowoomba to meet an elderly lady who was able to say little but who, in response to my request, played *Walzing Matilda* on the piano. In another home, a lady sang beautifully to the pleasure of her friends – and the visiting English lady. Those of us with a faith can bear witness to the joy of residents, sometimes with severe dementia, who are nevertheless able to join in the Lord's Prayer or the 23rd Psalm. Such skills and memories are there dormant in so many residents, if only we can find the key to unlock them.

Recreation can of course also be passive rather than active but is nevertheless an important part of life. A specialist Snoezelen room is a bonus. Equipped with soft textures, gently moving light, relaxed sound, warmth and pleasant smells it can be a joy to residents and staff alike. But there are numerous other ways that residents can enjoy relaxation through the use of massage and aromatherapy as part of the getting up or going to bed routine and light and music and other forms of sensory stimulation can be provided in any lounge or resident's room. Such stimuli often seem to by-pass the blocks to communication which have developed in the brain.

### **Physical activity**

Physical activity is also a very important part of life. Although people with dementia may lack the memory or drive to exercise we can still make opportunities for this

during the day. For the more fit there may be continued delight in walking in the garden or to the shops, preferably with the companionship of a valued member of staff. Some may still be able to swim. For others physical activity may be confined to a slow walk to the dining room on the arm of a member of staff. Don't be tempted to use a wheelchair just for the sake of speed.

Keep-fit is not just an important way of mobilising arthritic joints and improving overall fitness but can provide a wonderful combination of music and movement and refreshment for both body and spirit. Singing along with the familiar tunes and the general fun and banter that goes with exercise can often make this activity a highlight of the week – and it can easily be adapted for those who need to remain seated. Many people with dementia are agitated or wander, and these energies can often be effectively channelled into exercise of some sort.

### **Social interaction**

We have already several times touched on a vital further area of important activity for all human beings. This is the basic need for continuing social interaction. We have seen how mealtimes are an opportunity for this, we have looked at working together in the home through shared domestic activity, we have seen how much better a walk can be enjoyed when accompanied by a friend or member of staff and what pleasure can be gained from a shared keep-fit session.

So often in the past, people with dementia were dehumanised and staff believed that they were an empty shell without need for social interaction. People with dementia lived together in a home but in the deepest sense were profoundly alone. Those who carry out Dementia Care Mapping often discover very little social interaction for those with dementia who are quiet and cause no trouble.

How then can social interaction be encouraged in a care home? Staff often feel that they must always be 'doing things for' residents rather than 'being with' them. But often the two activities can be combined. How about a care assistant ironing whilst talking to a resident? Or having a chat or laugh whilst washing up or folding laundry?

Each resident needs to feel part of the community and to experience tenderness, closeness and the soothing of pain and distress. The reassurance of attachments to care staff or to other residents will help them to function well, to feel part of the shared life of a group and to enjoy activities through which they can continue to express themselves.

However staff need also to be clear that just being with a resident is an activity in itself. Residents in care homes frequently complain that the staff don't have time to talk. And staff have the same complaint. An experienced social worker is quoted as saying:

There's just no time any more for the job to be meaningful and I miss that.

She had no time to sit and be, sit and talk, with the people she was in contact with day to day.

Staff need the ability to listen, accept and understand. An Australian nursing home manager writes of the happy relationship she nurtures between staff and residents where:

It is great to see nurses sit and chat with the group without feeling pushed to be busy bees. A discussion about local events or a child's illness or a recipe can go on for 20 minutes. The staff member has to be prepared to 'waste the time'.

An unachievable dream or an important contribution to a positive and caring environment?

### **Spiritual development**

And finally what of the spiritual development of people with dementia? We must be clear that spirituality transcends the purely religious and can be discerned in moments of awe and wonder, in experiences of life which transport one beyond the mundane and in relationships with others that give meaning and purpose to life. For many, but certainly not for all, this spirituality may come from a relationship with God but we must never believe that those without adherence to a particular faith do not have spiritual needs or are not spiritually aware.

We have already identified ways in which, through relationships and social interaction in the home, we can respond to this spiritual dimension of life. We have also looked at how a doll or soft toy can bring comfort and a sense of being needed. In many homes, the presence of a dog or cat, a fish tank or aviary can give enormous pleasure. A pet offers constant interest and stimulus – stroking and patting it and talking to it and about it with other residents and visitors. The Pat-a-Dog scheme will supply visiting dogs for homes unable to cope with their own, and sometimes a staff member is delighted to bring his or her own dog to work.

We need only look outside the window to nurture a continuing sense of wonder in our residents. I still remember the Australian home in Queensland where residents and staff were closely observing a bird which had nested in the courtyard and was raising her family there. The bird family had even become a regular part of the daily record! We can all share the beauty of a rainbow or frost on the trees, the swelling buds in spring or the colour of the autumn leaves.

In conclusion, every small intentional act of kindness can be seen as an activity and should be valued as such. We must never dismiss anything we do with residents as pointless because our residents will forget. People with dementia



will recall the emotion of joy, respect, wonder or security even if they cannot remember what they have been doing or why.

If we are able through our life and work in the community we call home to draw together enough joyful and meaningful activities and interactions, our residents with dementia will come to the end of the day with the feeling of satisfaction and well-being which is the right of every person.

## References

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- Bell, Virginia (1997) 'Carer support is cost-effective', *Journal of Dementia Care* Nov/Dec, 11.
- Benn, Melissa (2000) 'Talking a good game', *Community Care* 19 March, 14.
- Broughton, Michael and Johnson, Alison (1998) 'Activity and community involvement' in *The care assistant's guide to working with people with dementia* (Hawker).
- Department of Health (1999) *Fit for the Future* (Department of Health).
- Garratt, Sally (ed) (1995) *Rethinking Dementia* (Melbourne Ausmed Publications).
- Green, Fred Pratt (1991) *The Last Lap* (Stainer and Bell).
- Johnson, Alison (1998) 'All play and no work', *Journal of Dementia Care* Nov/Dec, 25-7.
- Sheppard, Linda and Rusted, Jennifer (1999) *A Pocket Book of Memories* (Hawker).
- Marshall, Mary (1996) *I can't place this place at all* (Venture Press).
- Phillips, Meic (2000) 'Let's go Dutch', *Community Care* 10 Feb, 26.

## **Spiritual Needs of People Living with Dementia**

### **A Resource List**

#### **Resources available from:**

- \* CCOA Publications, Chaplaincy Centre, St Nicholas' Hospital, Gosforth, Newcastle upon Tyne, NE3 3XT.
- † Lynn Fox, MHA Care Group, Epworth House, Stuart Street, Derby, DE1 2EQ.
- ‡ CCOA Publications, 19 Eldred Road, Liverpool, L16 8NZ.
- ⌘ FiEP, Gaynor Hammond, 29 Silverdale Avenue, Guiseley, Yorks, LS20 8BD.
- § DSDC Stirling, Iris Murdoch Building, University of Stirling, Stirling, FK9 4LA.

#### **Books**

- \* Allen, Brian (ed) (2002) *Religious Practice and People with Dementia* (CCOA).
- † Bruce, Errollyn, Surr, Claire and Tibbs, Margaret Anne (2002) *A Special Kind of Care: improving well-being in people living with dementia* (MHA Care Group).
- † CCOA (2002) *Living with Dementia: resources from Christian organisations* (CCOA and Methodist Homes).
- † CCOA (2001) *Visiting People with Dementia* (CCOA and Methodist Homes).
- † CCOA (2001) *Worship for People with Dementia* (CCOA and Methodist Homes).
- ‡ Froggatt, Alison and Shamy, Eileen (revised edn 1998) *Dementia: a Christian perspective* (CCOA Occasional Paper No 5).  
Froggatt, Alison and Moffitt, Laraine (1997) 'Spiritual Needs and Religious Practice in Dementia Care' in Mary Marshall (ed) *State of the Art in Dementia Care* (CPA).
- ‡ Goldsmith, Malcolm (1998) *Dementia, Ethics and the Glory of God* (CCOA Occasional Paper No 11).
- ⌘ Hammond, Gaynor (2002) *The Friendship Club* (Faith in Elderly People).  
Higgins, Patricia (2003) 'Holding a Religious Service for People with Dementia', *Journal of Dementia Care* 11(3).  
Killick, John and Allen, Kate (2001) *Communication and the Care of People with Dementia* (Open University Press).  
Moffitt, Laraine (1996) 'Helping to Re-create a Personal Sacred Space', *Journal of Dementia Care* 4(3).
- § Murphy, Charles J (1997) *Dementia Care and the Churches: involving people and premises* (Dementia Services Development Centre, Stirling).
- § Shamy, Eileen (1993) *Spiritual Needs of People with Dementia* (Dementia Services Development Centre, Stirling).  
Shamy, Eileen (2003) *A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementia* (previously published in New Zealand as *More than Body, Brain and Breath*) (Jessica Kingsley).
- ‡ Treetops, J (1996) *Holy, Holy, Holy: the church's ministry for people with dementia: suggestions for action* (Faith in Elderly People).

## Videos

- \* *Is Anyone There* – training video pack. A 20-minute video with accompanying booklets exploring what we understand by the terms spirituality and dementia, includes real care situations and sequences of worship (CCOA Dementia Project).
- † *A Mind to Care* – a video about dementia (MHA).
- † *Nourishing the Inner Being* – produced for MHA Care Group by TVA Care Limited as part of their ‘Learning to Care’ series. The video is inspired by the Model of Spiritual Care devised by former Senior Chaplain of MHA Care Group, Revd Albert Jewell (MHA).
- † *The Person not the Problem* – originally performed as a play, this specially commissioned work has now been produced as a video. Complete with notes to provoke and guide questions, it helps both individuals and groups confront some of the issues that dementia raises (MHA).