

Palliative Care for People with Dementia



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Based on papers presented at a Leveson Seminar

LEVESON PAPER NUMBER TWELVE

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Contents

Foreword	3
A Death Foretold: end-of-life care for people with dementia	4
<i>Dr Katherine Froggatt</i>	
Hope for Home: the terminal care of people with dementia at home	10
<i>Dr Adrian Treloar</i>	
The Long Goodbye: meeting the needs of a person in the last stages of dementia within a care home setting	16
<i>Revd Margaret Goodall</i>	
The Welcome Healer and the Narrow Daylight: dying in hospital	24
<i>Leslie Dinning</i>	

Foreword

This publication brings together four papers based on presentations at a Leveson Seminar on palliative care for people with dementia. This is a neglected field. It is widely accepted that those suffering from cancer, and other conditions where physical deterioration is to be expected and its course is to some extent predictable, receive palliative care. The same kind of care is not routinely offered to those living with dementia.

Four contributors address this issue from different perspectives.

Katherine Froggatt explores the difficulties involved in applying the concept of palliative care or end-of-life care to people living with dementia, who may have limited awareness of what is happening and for whom the dying process may extend over several years. These difficulties affect family and carers as well as the person with dementia. Part of the problem is the inability of those living with dementia to articulate what the experience is like for them. It is therefore desirable to address end-of-life issues soon after the onset of the condition but this needs to be done sensitively so that confronting the dying does not detract from the living that is still to be done.

Adrian Treloar, a consultant in old age psychiatry, considers the option of continuing to care for a person with dementia at home until the end. He does not suggest that this is possible for everyone but offers case studies where it has been done successfully and explores the conditions which are required to make it possible. These include a willingness to 'take on' the professionals who may require some convincing that this is the best option.

Margaret Goodall considers 'the long goodbye' of people in the last stages of dementia in the context of the care home. She draws on the work of psychologists who have investigated how people find meaning in life and discusses three 'therapies' in relation to this: Reminiscence Therapy, Reality Orientation and Validation Therapy. Her key assertion is that the search for meaning is the overriding spiritual need of people living with dementia as they approach the end of life and that there are techniques which can assist in this.

Leslie Dinning offers the view of a hospital chaplain. He sees his role as going on a journey with the person living with dementia, with the family and with the staff, all of whom need support. It is a journey in which the light is fading but it was not always like this. Light from the past can be brought to illuminate the present. As he says in one of his concluding key points, 'the chaplain is there to help to bring to mind all that the person was and still is in the context of family and community'.

None of these authors would claim to provide us with an 'answer' (let alone 'the' answer) to caring for those in the final stages of dementia. They do however offer us a wealth of insights from their differing perspectives and professional expertise to enable us to begin grappling with the issues. We are pleased to be able to bring their thoughts to a wider audience than those who were able to attend the seminar.

Alison Johnson
Leveson Centre Consultant

A Death Foretold: end-of-life care for people with dementia

Dr Katherine Froggatt

Dr Katherine Froggatt is a senior lecturer in the Department of Community, Ageing, Rehabilitation Education and Research in the School of Nursing and Midwifery at the University of Sheffield. In 2003 she studied end-of-life care in care homes in Australia and Canada as a Sir Winston Churchill Fellow.

Introduction

End-of-life care for people with dementia is a complex area that challenges us as a society and as individuals. This paper aims to give an overview of end-of-life care for people with dementia, through a consideration of both policy and practice initiatives which influence the care provision for people dying with dementia and their families. Knowledge of the broader policy context within which care provision is delivered sets the scene. This is contrasted with different roles played by the individuals directly affected by the end-of-life transitions of people with dementia. Palliative care specialises in the care of people who are dying from terminal illnesses other than dementia, so the relevance of palliative care for people with dementia is discussed. Finally, challenges present in the provision of care towards the end of life for people with dementia are presented.

Background

Dementia is present, in some form, in many people's lives in the United Kingdom. This is especially so for older people. It is estimated that 25% of people over 65 years old live with dementia (Hofman *et al* 1991). Other people in the population affected by dementia include people who live with someone with dementia, care for someone with dementia, either as family carers, professional carers or volunteers, or a wider group of people who may not be directly involved in care but know individuals and their families living with this condition.

Those people whom dementia affects are also likely to have to engage ultimately with dying

and death. The median length of survival from diagnosis of dementia to death is estimated to be 8 years (Hofman *et al* 1991). While this may be a longer time period than for some other conditions, dementia remains associated with death especially amongst older people. For the purpose of this paper end-of-life refers to any period of time towards the end of a person's life that can be identified, at least with hindsight, as leading to their death. For people with dementia this may mean months or years. End-of-life may be less clearly identifiable than with other terminal conditions, such as cancer, which have a more predictable and shorter pattern of progression.

The United Kingdom policy context

Within the United Kingdom, a range of policy initiatives have been introduced in recent years that promotes particular understandings of the ageing process and how this should be managed. These policy initiatives bring an emphasis on choice, independence and health as identified in *Building on the Best* (Department of Health 2003a). Within the care for older people field, rehabilitation and intermediate care for older people is encouraged in the *National Service Framework for Older People* (Department of Health 2001) and the *National Minimum Standards for Care Homes* (Department of Health 2003b). More specific initiatives in palliative care, for example the NICE *Guidance for Supportive and Palliative Care* (National Institute for Clinical Excellence 2004) and the *End-of-life Initiative* (Department of Health 2003c) also stress elements of choice and provision of care in people's own home as being a priority.

It is interesting to note that the older people policy initiatives contain only a limited focus on end-of-life care, and therefore the extent to which end-of-life issues can be fully addressed may be questioned. The placing of people with dementia in policy initiatives concerned with older people rather than long term neurological conditions also has implications for the specific needs of younger people with dementia. Their needs may not be adequately met because of this.

The individual perspective

Understanding the issues of dying with dementia can also be considered from a number of different individual perspectives. Three are described here: the individuals with dementia, family members of the person with dementia who are sometimes also carers and, thirdly, formal carers in health or social care. Whilst I consider these different groups of people separately, it is recognised that they are interrelated and share common attributes.

The person with dementia

People with dementia are not a homogeneous group. They are a diverse group of people with different demographic, social and illness characteristics that shape their experiences of living and dying with dementia (Cox and Cook 2002). As already indicated, the age of people with dementia can vary, and whilst the majority of people develop dementia in old age, there is a group of younger people who experience the onset of dementia earlier in their lives. Dementia as an illness is also not a unitary experience. People may have one of several types of dementia, each with its own manifestations and patterns, that further vary according to how advanced the disease is. Older people with dementia may also live with a number of other chronic or even acute conditions that also impact greatly upon their lives and may interact with the dementia. People's cultural and social background varies, and understandings of dementia may vary between different cultural and ethnic groups. The availability of social support from family and friends will influence an individual's experience of their illness, and this is also linked to their place of residence. An

individual living in their own home may experience life and their illness differently to someone who lives in a care home.

Overlaying the diversity of experience of dementia is diversity in the experience of dying. Cox and Cook (2002) have developed three scenarios to conceptualise dying with dementia. Firstly, people with dementia whose death can be attributed to a medical condition that is not related to the dementia. This might include a person with mild dementia, who develops cancer and then dies from cancer. Secondly, people with dementia may die with a complex mix of mental and physical problems where dementia is not the primary cause of death but interacts with the other conditions. Thirdly, people with dementia may die from complications arising from end-stage dementia.

There are limitations to what we know about people with dementia's experience of dying with dementia. There is some information available from family carers who have provided a retrospective view of the dying and death of their relative. Whilst there are obvious limitations to these accounts, in that they are proxy accounts and obtained after the event, they do provide some insight into what this period of time is like for the individual with dementia. Family carers describe a wide range of physical and psychological symptoms in the person with dementia observed by the relative. They include mental confusion, pain, urinary incontinence, low mood, constipation, loss of appetite, shortness of breath, pyrexia (Lloyd-Williams 1996; McCarthy *et al* 1997). A perspective of people with dementia can come from people earlier on in their illness. It is understandably a difficult issue to be faced – as one person put it:

I cannot live with all of my future life filling today's space. This would be way too heavy a load, and most likely destructive. (Raushi 2004)

Family carers

The family of the person with dementia are also a diverse group with differences arising from their demographic and social status as well as each family's particular characteristics. One

variation is in the age of the family members. Sometimes family carers are the same generation as the person with dementia (spouses, partners or siblings), sometimes the next generation down (children, nephews and nieces) or sometimes, for younger people with dementia, the carer may be a parent. Some family carers may also be living with their own particular health conditions that impact on their ability to care. They may also have to juggle other carer demands from different generations of the family such as young children.

The caring role may be shaped by the geographical distance from the person with dementia. The care given by a family member may be primary care, undertaking directly personal care tasks, or secondary care, visiting and supporting other family members doing the primary care. The caring roles adopted by different family members are affected by the emotional distance and type of relationships between family members; the dynamics may not be harmonious in relation to the person with dementia or within the wider family. The complexity of family life with divorce, deaths, remarriages, stepchildren, half siblings can mean that the negotiation around caring roles in the family is not always straightforward.

The experience of family carers of people with dementia has been well documented (Marriott 2003), but knowledge about the end-of-life period is more limited. An American study that talked with family carers of people with moderate to severe dementia about their decision-making identified a number of issues for the family carer. Decisions were made in the context of an extended period of emotional burden and guilt. Also the changes in condition of their relative were not generally recognised as being part of a trajectory of dying which therefore impacted on the types of decisions they made. Death when it came was seen as both a tragedy and a blessing (Forbes *et al* 2000).

Professional or formal carers

However much or little individual family members do of the care for the person with dementia at the end of life, professional carers

will be involved to different degrees. There is much diversity within this group particularly in terms of their background in care. Depending upon the place of residence of the person with dementia, he or she may receive care from people with a health care or with a social care background. Then again, these professionals may have a general care role or be specialists in dementia care or perhaps in palliative care.

The experience of these professionals in caring for people with dementia is similarly not well documented. Care work with older people is under-valued and is under-resourced in the care home sector (Davies and Seymour 2002). In palliative care the demands on staff caring for people who are dying is recognised (Aranda 2004). There is the potential for conflict between different care goals in the care for older people with dementia. Different professionals may work to different agendas; some seek a cure, others may focus on maximising the potential of the 'patient' through rehabilitation, and others prefer to emphasise the palliation of symptoms whether they be physical or behavioural. Careful communication and negotiation of these different approaches is required if the best interests of the person with dementia are to be met.

Care for people dying with dementia

In order to consider care provision for people dying with dementia, it is helpful to look at the distinct discipline of palliative care which has as its focus the care of people diagnosed with life limiting illnesses such as cancer. Palliative care has its origins in the hospice movement, of which the modern manifestations began in the 1950s with Dame Cicely Saunderson's establishment of St Christopher's Hospice in South London. This modern speciality has expanded from in-patient care to supporting people in hospitals, their own homes and care homes. It is currently diversifying to address the needs of people suffering not only from cancer but from a range of other life limiting illnesses including neurological, respiratory and cardiac conditions and now dementia. The goal of palliative care is defined as the achievement of the best quality of life for older people and families. This is

delivered in a number of ways through the active holistic care of people with advanced, progressive illness, the management of pain and other symptoms and the provision of psychological, social and spiritual support (National Institute for Clinical Excellence 2004).

Palliative care is divided into specialist and generalist provision. Specialist palliative care is provided by specialist palliative care professionals to meet complex needs (symptoms, psychosocial, bereavement) of people in all settings. Generalist palliative care is provided by generalist professionals to meet ongoing needs in all settings, but they may call upon specialist services to meet specific needs through consultancy services.

Another term increasingly used within the United Kingdom is that of end-of-life care although different understandings are attributed to this term. It may refer to the last few days and hours of life, or even the last few months of life, when an individual is known to be dying within a time period. Alternatively, it could be used to refer to a longer term transition over a period of maybe years. In Canada, the following definition is used to describe end-of-life care:

... an active, compassionate approach that treats, comforts and supports older adults who are living, or dying from, a progressive or chronic life threatening condition. (Ross *et al* 2000)

This definition captures the notion of a longer term transition that incorporates a movement from life to death. For people dying with dementia, a number of elements of this transition can be identified that require attention if we are to ensure appropriate care for people at this time in their lives. Three aspects are described here: living and losses, dying and death and bereavement (Froggatt 2004).

Living and losses

The onset of dementia leads to experiences of losses for the person with dementia and their family and friends around them. An older

person without dementia potentially faces a series of physical, social and emotional losses associated with an ageing body and changes that affect its ability to function as it used to. There may also be social and relational changes as family and friends themselves grow up, move away and even die. However, the person with dementia is likely to face further losses not only related to their ultimate physical death, but also associated with a social death as a person in the social world they inhabit (Sweeting and Gilhooly 1997). Increased need for care may increase the likelihood that a person with dementia will need to move into a care home in the later stages of the illness. The move into a care home is an important one. How this is managed sets a precedent for the relationships established and way in which future changes are handled. The losses associated with entry to a care home for an individual can include a move out of their own home, separation from a partner or spouse, the loss of nearby friends and neighbours and even an animal companion.

People's experiences of living in care homes are mixed. Where it is a positive experience, good relationships can be established between the person with dementia, their family members and the staff in the care home. It is experienced as a safe place to be. The length of time many residents live in a care home before they die creates the potential for establishing good relationships between care staff, residents and their families that is helpful when decisions are required about care choices.

Dying and death

As indicated above, there are a number of different ways in which the person with dementia may die (Cox and Cook 2002). The dying process experienced by many residents within care homes is very different from that experienced by patients cared for within a specialist palliative care context. The dying process for people with dementia is often uncertain and knowing when a person is dying is not always easy to determine.

This raises particular issues around decision-making with regard to end-of-life issues. The

increasing difficulties in communication experienced by people with dementia mean that work around decision-making that involves the person with dementia will have to be attended to much earlier in a person's illness journey than with some other conditions. Whilst family members can act as proxies for their relative, in some families it may not be a straightforward option as there may be a lack of clarity about who is responsible.

Also associated with the time period around the dying and death is a need to make a place for meaning-making and closure around a person's life. For a person with dementia, their active involvement in their dying may require earlier attention – before an individual is 'known' to be dying. Meaning-making may address spiritual needs and, especially in later stages, may draw on non-verbal activities and make use of symbol or familiar rituals.

Bereavement(s)

Whilst the person with dementia will be experiencing the bereavement that arises from their own forthcoming death, it is family members who are faced with the ongoing bereavement because the person they know and love is slowly deteriorating and losing physical and cognitive function over a long period of time (Seymour *et al* 2005). So too, professional carers may be facing bereavements as the person dies, but maybe with less legitimate space to acknowledge this.

Challenges around dying with dementia

From the issues laid out in this paper, a number of challenges can be identified in relation to seeking to meet the needs of people dying with dementia. Firstly there is a challenge to hold both living and dying together, not one at the expense of the other. An emphasis on healthy ageing and maximising the potential of older people may be helpful in many situations, at particular points in time. However, if we do not allow space for increasing frailty, infirmity and even death, which is the inevitable endpoint of ageing, then it becomes unhelpful. To go to the

other extreme of immediately associating a diagnosis of dementia with dying does not allow for the living that can still be experienced, and is equally unhelpful. We need to find ways of holding on to both living and dying.

Working with people living and dying with dementia occurs over a longer time frame than usually encountered in palliative care work. The needs of people with dementia may require us to undertake sensitive preparatory work earlier on in a person's illness than is normally done with other conditions such as cancer. If we are to honour and value the person with dementia, then we need to find ways that people with dementia, family members, professionals and volunteers can work with these difficult issues, at times when they are able and willing to do so. It is difficult to involve people with dementia in these processes early on in their illness, when death is not imminent, but the communication challenges present later on in the illness mean that this time is an important one. When verbal communication is less easy other forms of non-verbal or symbolic communication need to be found.

Finally, there is the challenge of working within and beyond the current system of resources. The financial resources for care, staffing and environments of care are unlikely to increase significantly in the near future. We need to seek imaginative ways to address needs both inside and beyond the existing systems of care. We should value, and seek to make our systems value, people with dementia as they live and die with this illness.

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Hope for Home: the terminal care of people with dementia at home

Dr Adrian Treloar

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Case examples

Grace, in her seventies, developed a multi-infarct dementia. She became very agitated, distressed and went into a nursing home. Within two weeks she had lost weight, was bruised, distressed and ended up sitting on a dementia assessment ward. She called out repeatedly numbers from 97 to 100. Sitting in a basket chair it was difficult to see what could be done to alleviate her distress or to care for her. Judicious use of anti-psychotics and antidepressants had some benefit and benzodiazepines were used as well. She didn't do that well but settled enough to go into a dementia specialist nursing home. There she lost weight, continued to be distressed and her husband could not bear to see her in such a way. He asked if he could take her home. The nurses and consultant all said they were very worried about this and thought it a bad idea. Her husband insisted and after discussion it was agreed that this could be tried. Wonderfully, Grace did well. In fact she lived at home for eight years. She gained weight and was happy in the care of her husband along with a small but loyal group of carers who supported her husband. For a lady

who was fully dependent and needed full nursing care including feeding, it was extraordinary to see her on trips out to shopping centres and her beloved golf club. Grace's long survival was, I think, attributable to the combination of good care with the fact that this was a multi-infarct dementia and not an Alzheimer's type dementia. Her dementia stabilised for quite some time and did not progress, explaining the unusually long length of time at home.

Others caring for those with dementia have had similar experiences, keeping their loved ones at home for between a couple of months and two to three years. Some went home from nursing homes. Overall, we have looked after 15 or so patients with such needs at home over the last five years in Bexley and Greenwich. With no dedicated funding and no formal service we are currently caring for eight such people in their homes.

One lady, surrounded by family in prayer had not responded for 48 hours to anything. She made a sign of the cross: the last sign of responsiveness she made in her life. She died peacefully that night. It felt almost inconceivable that the



Before ... and after discharge from nursing care



At home on Christmas Day, a fortnight before Grandma died

opportunity of family presence in such a way could have been achieved elsewhere.

Introduction

Very many people have the aspiration that when they die, they will die at home in the care of their loved ones. Of course this is not achieved in reality for all those who aspire to it. In cancer care large efforts have been made to develop community teams who will provide palliative care and advice on all aspects that patients need in order to stay at home. This work has been successful and well received by local communities and funded by charitable money.



By contrast the vast majority of people with dementia die in hospital or residential/nursing care. Few people with advanced and complex dementia die at home and few live at home in the months or years leading up to the end of their life. In part this may be because the demands of advanced dementia are not the same as the demands of cancer care. Increased levels of agitation, depression, psychoses and behaviour disturbance are all common features of severe dementia. The fact that people with severe dementia have poor mental capacity and poor understanding is an additional cause of complexity. Often enough, palliative care in other situations can be implemented at a time when the patient is mentally competent and able to understand and work with the things that are being proposed and done for them.

Despite these problems, it is now clear that care for advanced dementia at home is feasible. Experience in South East London has shown

that regular input at home with specialist medical and nursing advice and support has enabled people with advanced dementia, requiring 24-hour nursing and physical care, to be provided for at home up until the time of their death. Early results from qualitative research have shown that things were better as a result of care at home and that the success of such care requires a broad range of categories of support to make it successful.

Intrinsic carer factors

We think that it is necessary for carers to be relatively robust, determined to succeed and in



reasonable physical and mental health. Mental frailty in the key carer seems to be particularly problematic. The key carer will often be a spouse, but at other times may be a daughter or son or a friend. We have found that carers face obstructions in the work they do and at times have had to negotiate robustly with care managers, doctors, nurses and others. Many carers have had to purchase equipment which they found they could not get soon enough from statutory services. While in one sense at least this is quite unacceptable, it does seem to reflect the reality that this style of care is not well facilitated by statutory services. Each carer, however robust, requires the support of others.

Appliances

A wide range of appliances is needed. Hospital beds which can be raised and lowered and adjusted are almost universally required. Cushions which will raise pillows effectively are important and often not provided. Zimmer



frames, commodes, bath seats, wheelchairs, showers (or better wet rooms) and many other bits of equipment should be available when needed. Proper pressure relieving cushions for chairs are also needed.

Later on hoists are required. Standing hoists (when the patient is suspended from a single point) are obtainable from primary care trusts but many of our patients have also needed sitting hoists. So when hoists are needed for care at home they have to be available on time: if the carer can no longer lift their loved one, they will end up in care as a result. Carpet cleaners help too!



Space and people power

Some patients have been cared for in large Victorian homes with large families and lots of people. Others have been cared for in one-



bedroom maisonettes and small cottages. It is therefore possible to provide this style of care in a wide range of settings. An important principle is the willingness to alter the furniture of any setting. Space must be made to meet the primary need of bed, space for personal care, hoists and all the other bits of equipment required. Space for people to sit around a bed is also very useful. Sometimes the happiest moments for patients appear to be when two to three people are gathered around a bed where the patient can rest and where conversation about ordinary and normal things can continue.

Obstructions

Reluctant care managers, funding disputes, uncertainty about whether a person resides in the district where they own their home or with the family with whom they are staying, and many other factors have led to apparent obstruction to the provision of care at home. Often enough it may be that care managers, doctors and nurses are fearful that patients will come to harm as a result of being cared for at home. And yet dementia is a terminal illness: surely in such a circumstance it is right to take some risks to put in place a care structure that persons closest believe will make the quality of life better.

Care workers

Care workers rotas and working out what carers will do is crucial. It has been found that when carers are commissioned by statutory authorities there are sometimes problems with flexibility. A care plan gets written and care workers may be reluctant to work outside of that care plan or to vary what they do according to what is needed. Many of our carers have found that it is important to be substantially in control of the commissioning and designing of the care plan covering what gets done. This has been variously achieved by directly employing care workers and also it can be helped by direct payments. With direct payments the key carer is given money which they can spend themselves and directly to employ care workers. It certainly is the case, for example, that if someone has just been to the toilet and a care worker then turns up with



toileting on the care plan, then it is unnecessary to toilet the person again. Rather, other appropriate tasks should be substituted. Sadly it is often the case that if toileting is declined, care workers will leave without having done anything else.

Hospital and respite care

This is needed in some circumstances and sometimes is appropriate.

Money

The cost of doing this has been between £50 a week and £850 per week. We have once seen a package which cost more than £2000 a week but again in this circumstance there were thought to be considerable benefits for a patient who was not otherwise manageable in a continuing care setting. Certainly the weekly cost of care at home is, for the majority of people, lower than nursing home care. That the quality of life is better is perhaps a more compelling reason for promoting care at home. It is however heartening to know that such styles of care do not, generally, provide an additional cost pressure upon local health and social services.

Direct payments are useful. Continuing care money from primary care trusts should be available for complex management of dementia at home and has been provided for quite a number of patients.

Medication

Opiate analgesia is needed for some patients. It is not however frequently used and does not appear to be a mainstay of management of advanced dementia. Antidepressants are

frequently used: there is a very high rate of depression in patients with dementia. Anti-psychotics are also important. The high frequency of psychosis in dementia as well as the fact that behaviour problems in dementia are often driven by a psychosis which cannot be otherwise expressed should not be forgotten. The evidence base that distress and behaviour disturbance for some people with dementia responded to anti-psychotics is strong. These drugs do however cause side-effects (including stroke): the question therefore is whether or not the risk of side-effects outweighs the benefit accrued by effectively relieving the torment suffered by the patient. In a palliative care setting it must be acceptable to use drugs that can harm to alleviate severe distress which cannot otherwise be managed.

Antibiotics are important in some circumstances. Some antibiotics such as erythromycin and ampicillin are unpalatable and require larger volumes of liquid for about 20 doses. Others such as azithromycin only require four to six doses of low-volume medicine. This can be a real asset to dementia care when the patient is reluctant to take medicines. Similarly antidepressants and anti-psychotics which dissolve on the tongue can be very helpful. At times medicines may be put in foodstuffs (Treloar *et al* 2001). Anti-dementia drugs do not seem to be particularly useful. Memantine may help some of the behaviour disturbance.

Food and diet

Good food nicely presented regularly and often, cut up into small pieces is helpful. Dogged



persistence is also important: it may take a while for carers to get the hang of dietary support. A number of carers have found some particular 'secret weapons'. Guava juice is high in calories and it doesn't seem to be acidic. Thickened soups, peanut butter sandwiches, chocolate baby foods have all been found by some carers to be particularly helpful.

One particularly important point is to remember that people with advanced dementia often seem to have days when they don't particularly want to eat. Carers can be very worried about this: we often think that if someone does not eat three meals a day they are getting ill. We have found that if the patient does not want to eat and cannot be encouraged to do so without conflict and stress, it is often the best just to leave them be. If they don't eat one day they will often need a bit more the next day. Taking this approach may cause some trepidation because carers may feel they will die quicker from poor nutrition. In fact, we have generally found it is not the case. Patients have lived a considerable length of time after this approach has been taken.

Spiritual support

Perhaps the greatest spiritual need for patients is to feel loved and cared for by those whom they know and whom they value. Time spent sitting with a patient is important. It is essential to remember that no response from the patient does not mean that what has been said or done has not been felt. Many people who recover from episodes when they could not respond can recall and retell what was said and happened with surprising accuracy. We have seen patients very close to death suddenly show evidence that they are aware (perhaps by making a sign of the cross or saying prayers) and other patients suddenly come out with lucid comments at times



when they were not thought to be aware or hearing. The mere fact of being with someone having conversations with those around about day-to-day things is important and very positive for those with advanced dementia. Doing things at times of interaction is also important. Many people are not good at sitting doing and saying nothing. Feeding, personal care where possible and other activities are good things therefore for carers to do with their loved ones. Set prayers, reading from religious texts and so on may be helpful. Specific prayers appropriate for those who are dying may also be helpful – see http://www.catholicdoctors.org.uk/Miscellaneous/Prayers_for_the_dying.pdf

The need for specialist teams

We think that the complexities around the managing of complex and advanced dementia at home require a special approach. It is widely accepted that the Macmillan style approach of community team in supporting patients at home with cancer is right. Even though the components of care provided by Macmillan teams can normally be provided by others within their knowledge and competence base, it is well accepted that a specialist team does better. We believe that the same applies for dementia care. The challenges of managing complex and advanced dementia at home are significantly different from cancer care but the principle that a specialist team should co-ordinate services and the professionals is completely valid. We hope very much that we will see the creation of such teams and research into their effectiveness in the near future. A professional who is known to the patient and



carer, and who will visit and monitor proactively has been strongly identified as a requirement by our research. Reactive visiting by primary care staff and others at times of crisis is simply inadequate.

Conclusions

If it can be done, the terminal care of dementia at home is a good idea. It appears to be, for some, a better way for the patient. Dying people can continue to provide for those around them up to the moment of death. Perhaps at home with the family death is more human. Perhaps also bereavement is better.



Terminal care of dementia at home is not suitable for all and should not be considered as the only way. Residential and nursing care is needed for many people and there are times during an illness when people will require a different sort of care. We believe that it requires specialist teams although at the present time many are having to do this without any support of a co-ordinated nature.



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The Long Goodbye: meeting the needs of a person in the last stages of dementia within a care home setting

Revd Margaret Goodall

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Those coming to live in residential homes wish for 'a home for life'. With this comes the need for special care for those at the end of their life. For those with dementia this can be weeks, months or even years when it seems that the person has gone and we are waiting for the body to catch up. But taking the time to affirm the person as someone of value changes our approach to them and we see the person, not a job to be done.

Staff in care homes are asked to assess the person's physical, emotional and spiritual, needs. Physical needs can be straightforward and solutions can be offered to make the person comfortable. Emotional needs can be met through socialising and personal contact. But spiritual needs can be a puzzle unless we know of faith or church affiliation.

Neglect of the spiritual dimension

In their 1971 report the World Assembly on Ageing, sponsored by the United Nations, concluded that neglect of the spiritual dimension seriously impoverishes life and that confusional states may be greatly exacerbated by such neglect.

From working alongside care staff I have found that when there is awareness of spiritual needs, then the care reaches another level and can enable a good death for the person with dementia and their loved ones, so that they are able to affirm these words: 'I have fought the fight, I have run the race. I have kept the faith.' (2 Timothy 4:7)

Recently I have been involved in reviewing care plans for residents as there seemed to be

problems with the page titled 'Spiritual Care'. I was asked what else they could put as the same thing seemed to be written each time, for example 'attends church service'. Spiritual well-being does not only have to be evidenced in religious practice, but may arise from an awareness of meaning and purpose in life.

I am often asked why we bother, because it could be that to offer care to those with dementia is a waste of valuable resources on those who are not able to respond and who would not benefit. I am aware too that a great deal is expected of care staff and that they need support in order to be able to deliver the quality of care that we expect.

Spiritual needs of a dying person from a Christian perspective

There are some general 'needs' that may help us to offer spiritual care:

- The need for a God who is present. This is a God who loves and cares about the person and whose compassion can be imagined through images such as lying in the hand of God rather than in a bed, or talking with God under an oak tree in a green pasture, or feeling the touch of someone who cares. Any image that promotes warm feelings of love from God is important.
- The need for a sense of identity and meaning in life, of being connected spiritually with God and with all other living beings.
- The need for that which is spiritually familiar: prayers, hymns poems, and other forms that have provided comfort in the past.

- The need for relief from guilt as well as the giving and receiving of forgiveness so as to experience peace with God and others.
- The need to know that one's God is stronger than one's fear of death, an assurance that can be conveyed in part by an experience of caregiving so powerfully positive that the person can die in peace.
- The need to know that God will not punish someone who questions or is angry with him for the suffering, pain, and impending death that is experienced. This reaction is often a way for people to come to terms with the realisation that life is not fair and that their God and other spiritual people are with them on the journey through dying and that death does not mean failure and is not the enemy.
- The need to have a companion along the journey, a person who is sensitive to the dying person's needs and can be a loving, listening, and hugging presence as appropriate to the person.

Most of these are self evident, but how can we enable those who care to offer help with a sense of identity and meaning in life especially for those in the last stages of dementia?

Meaning

The idea that 'meaning' has to be found in order for a human to thrive is found in the writings of both Frankl and Erikson. Frankl writes that 'he who has a why to live can bear with almost any how' (Frankl 1992, 9). While he uses the axis of fulfilment (of meanings) and despair (Frankl 1979, 42), Erikson uses the axis of integrity (a sense of coherence and wisdom) and despair (Erikson 1982, 61) to describe this search for meaning. They both speak of 'hope' as that which comes from fulfilment (Frankl) and is born of integration (Erikson) and the absence of these for both writers is 'despair'. For those working with people with dementia the care offered must aim not just to contain such people so that no harm comes to them, but to find meaning and integrity in their lives to enable them to journey into a good death.

How can we enable those with dementia to find meaning?

Our present understanding of dementia is that it cannot be reversed and that, unless treated with drug therapy, the person will, over time, show deterioration in mental, and often physical, faculties. Dementia 'involves brain cell death so that if no other illness were to intervene, it would cause death' (Gidley and Shears 1988, 18), but not until 'the individual has lost his memory, his use of language, his ability to dress or feed himself and his personality' (Dippel 1996, 12). It strips away those human attributes that are valued most: the ability to think, to plan, to remember and to be an active part of society. A carer has written:

Memory holds the whole of our past life and experience. Its loss is greater than the loss of any of our senses. (Gibbons 1995, 3)

However, those who have dementia are still human beings and as such have been described as 'beings in the world', the world that for everyone must include 'reasons and meanings' (Frankl 1979, 52). To many the thought of being without a memory and failing senses can appear horrific. Frankl quotes Albert Camus who says, 'There is but one serious problem, and that is ... judging whether life is or is not worth living.' (Frankl 1979, 23) The presenting face of someone with dementia can be that they are lost, without a past or a future and often not seeming to know what the present is. Those with dementia could be said to exhibit the characteristics of those who are in despair, that is, with no hope (Ryecroft 1995, 37); wandering, staring into space, showing no emotion, no interaction with others, a fragmentation of their personality – a lack of ego-integrity. If we allow ourselves to assume an absence of reason or meaning in their lives, however, then that will affect the care that is offered.

Frankl and Erikson's work on meaning is such that it involves the whole of the person in striving towards integrity. Tom Kitwood was an advocate of alternative approaches to understanding dementia, recognising that 'the relationship between brain, mind and dementia remains obscure' (Harding and Palfrey 1997, 59). Post

mortem examination of those thought to have a greater degree of dementia may show less physical damage than in those whose dementia was 'slight'. This suggests that other factors contribute to the perceived dementia especially when 'experiential self', 'an integrated centre grounded in feeling and emotion', has not been well developed. It seems to make the person less able to adapt and make new neural pathways to compensate for the dementia.

Banyard contrasts this model of care that seeks to offer help towards integration with the biomedical model of care which asks us to look at people as if they were machines. This model suggests that if something goes wrong then we need to fix the machine. 'It looks for explanations in disordered cells rather than in psychological or social processes.' (Banyard 1999, 4) When applied to the treatment of dementia the approach is to 'manage' the disease by medication, the problem being the dementing person. For people living in the twentieth century this has some appeal as we know that some biomedical treatments produce dramatic results. Banyard (1999, 4) suggests that Western science has made a distinction between mind and body which encourages us to see people as split in two – a ghost and a biological machine. He says that this view can be comforting to people as they 'think that the original person is still there but trapped in a decaying body.' (Banyard 1999, 5) The thought that the person is blissfully unaware of this change in their being is also of comfort to those who look on, but this may be wishful thinking as the idea that they could be aware would be too painful. One lady recently said to me, 'I am not who I was, I am disintegrating.' For a carer this is a difficult situation. To be there to share the pain of another and to help them towards a meaning in the present, perhaps through the past, and find some hope for the future is an enormous task.

Banyard suggests a 'bio psychosocial model' (Banyard 1999, 6) which does not look for a single cause or effect, but looks at the connection between mental events and biological changes. Dementia is not a simple disease that can be diagnosed and treated. It is a complex process linking body, brain and the

idea of self and one of the challenges is to find some affirmation of their being in the world, some meaning rather than just existing.

If meaning cannot be found then this could call into question a person's humanity or 'beingness'. Erikson offers a model which describes the sequence of psychological stages throughout life. His stages define the main struggle within each stage and the psychological strengths that emerge from successful completion of the stage.

Infancy

Trust v mistrust: Hope

1–3 years

Autonomy v shame and doubt: Will

3–6 years

Initiative v guilt: Purpose

6–12 years

Industry v inferiority: Competence

12–18 years

Identity v role confusion: Fidelity

Early adulthood

Intimacy v isolation: Love

Middle age

Creativity v stagnation: Care

Old age

Integrity v despair: Wisdom

(Erikson 1982, 56–7)

Wulff (1991, 378) in writing about Erikson's eight stages says of 'Old age: Integrity versus despair' that, 'there is a quality of closure to a life of integrity, a sense of world order and spiritual meaning', an integrity that seems to convey 'wisdom' which Erikson defines as 'an informed and detached concern with life itself in the face of death itself' (Erikson 1982, 61).

It is this idea of 'integrity' rather than 'despair' that is the aim of each person as they come to the end of life. Erikson writes: 'Despair expresses the feeling that the time is now short, too short to attempt to start another life and try out alternative roads to integrity.' (Erikson 1981, 242) Integrity on the other hand is the acceptance of 'one's one and only life cycle' (1981, 241) as what is it because of the times one has lived through and that as such they are of value.

Much research is now taking place to develop pharmacological and gene therapy treatments to cure dementia or at least postpone deterioration but Kitwood, Buckland *et al* (1995, 34) showed that high levels of well-being could be observed in those with a whole range of cognitive impairment who were not on controlling medication and ‘... this challenges the views that dementing conditions require the use of psychoactive and tranquilizing medication.’

This suggests the use of psychological therapies in order to find meaning and connection with ‘self’ yet the idea of using ‘therapies’ at all with those with dementia is fraught with problems. There are those who would suggest that coping with dementia and living day to day is in itself enough to cope with. Maslow’s hierarchy of needs would lead us to believe that it is only when the lower needs are satisfied that the higher needs can be met (Maslow 1970). As lower needs are satisfied higher needs emerge.

Frankl on the other hand (Frankl 1979, 33) suggests that when lower needs are not satisfied, a higher need such as the will to meaning, may become even more urgent. He offers the example of those in the German death camps during the Second World War who were deprived of many basic needs, but continued to search for ultimate meaning in their lives. Frankl writes that ‘Man’s search for meaning is the primary motivation in his life and not a “secondary rationalization” of instinctual drives’ (Frankl 1992, 105).

Eric Erikson speaks of the need for a ‘sense of coherence and wholeness’ (Erikson 1982, 65). He says that wisdom ‘maintains and learns to convey the integrity of experience in spite of the decline of bodily and mental functions’ (Erikson 1986, 37). This search for meaning and wisdom, despite declining health, within the reality of the present situation of having dementia necessitates a non-medical care regime.

The three non-medical therapies that are in current usage in the care of those with dementia are Reminiscence Therapy (RT); Reality Orientation (RO); and Validation Therapy (VT). I will give an overview of each therapy,

supported by writers in each field, before looking at them in the light of ‘meaning’ as seen in the work of Frankl and Erikson.

Reminiscence Therapy (RT)

This therapy is usually used in a structured setting, either in groups or one-to-one, to encourage people to remember what happened in the past. However it is the ‘therapy’ most commonly used by those visiting as people feel on safe ground when talking about the past. The goal of this ‘remembering’ is to enable older people to identify significant people and events from their past that shaped their life and gave it meaning (Ronch and Joseph 2003, 240). It was originally developed for elderly people without dementia, and those who support its use claim that it provides ‘an opportunity to review and reorganise events in [their] life’. (Miller 1993, 127)

RT is popular with professionals such as psychologists and occupational therapists because it does not treat the resident as a ‘case’, but as an individual who has a history and who, with what remains of their brain function, can be helped to bring that history to mind. Memories help us to perceive ourselves as unique individuals with our own particular experiences, and ‘the recalling of past memories enables the person with dementia to remember, even for a short time, the person that they once were.’ (Goldsmith 1996, 95)

It has also been found that RT increased the degree of interaction between staff and patients outside any formal sessions, ‘enhancing the morale, attitudes and personal knowledge of their patients by care staff, with consequent improvements in the overall care that patients receive’ (Pulsford 1997, 707). This therapy has been found to have the added advantage that it seems to be enjoyed by both residents and carers, especially as it has the ‘self’ as its focus. It is a working through of a life that has been lived and so holds the key to the person.

Those who live with dementia need help with all aspects of life and the working through of memories is no different to any other part of their lives. Those who offer this help are in

some way helping the person to accept what their life has been, in all its variety, and to come to an acceptance that what has been has been; a working towards an integration of life rather than despair over what might have been.

In this respect those with dementia have much to teach those of us who are 'whole'. Frankl's system of 'logotherapy' – therapy through meaning – holds that 'having been is still a mode of being, perhaps even the safest mode' (Frankl 1979, 105) as the past cannot be taken from a person. Erikson (1982, 62) said that at the end the life cycle turns back on its beginnings. Hope can be born out of this integration, both for the person and those around them.

Just last week when visiting a family to arrange a funeral I met two brothers. They told me that they did not have a very easy or happy childhood because of their mother, and had, in latter years, become estranged from her. They spoke to me of their experience of their mother with dementia. She was, because of her upbringing, psychologically a needy child so could not offer the boys the mothering they might have expected. But as the dementia developed so their roles changed and the boys were able to offer her the mothering she had missed out on. As they spoke together of the past and allowed her to explore her memories they gained an insight into the mother they had not known and this enabled them to be reconciled to her. The dementia had been an opportunity for the mother to reconnect with her past and integrate all that had happened, and for the boys to share love for the first time.

The working through of memories had helped all three of them towards the closure of one life and when she died they were able to mourn the mother they had lost. They told me that their lives were richer as a result of the opportunities that dementia had given them to work through together the problems in the past and gain meaning from them.

Frankl writes that there is a 'healing force' in meaning and the brothers' experience of finding meaning with their mother while she had dementia are echoed in his words:

How happy we were that we could experience this close contact for those last few weeks, and how poor we would have been if ... [she] had died from a heart attack lasting a few seconds. (Frankl 1979, 21–2)

Reality Orientation (RO)

Reality Orientation originated in 1958 when Dr James Folson instituted a programme of activity for elderly patients in the Veterans Administration Hospital in Topeka, Kansas, USA. It was developed as a means of 'orientating a person to their environment by means of constant stimulation' (Miller 1993, 120). It is commonly understood as a means of stimulating unused neurological pathways in order to compensate for brain damage. Those who use RO support its use on the grounds that 'it improves the quality of life for dementia sufferers' (Miller 1993, 120) and enables carers and staff to provide a 'treatment package'.

The aim is to correct confused speech, reinforcing correct and appropriate usage of words, and to constantly remind the resident what their name is, where they are, what the current time is and what events are in the news. Inappropriate behaviour is also corrected, with correct behaviour prompted and encouraged.

Apart from direct interaction with the staff, RO can be seen in signs, using both words and symbols, which give a 'cue' to the resident to enable them to bring the meaning to mind. This is especially useful on the doors of toilets and in the use of information boards which can have the day, date, what the weather is like and what activities are planned for that day in the home. It is not so useful when everyday objects in the home are labelled or when words and actions are linked. The problem with this is that it can cause 'information overload' and so, instead of bringing meaning to a world that has become confused it can reinforce disconnection.

There are those who ask why we should bother to force reality on people with dementia as many of them seem content to sit and watch the world go by, if they are aware of the world at all. In fact forcing reality on to such people could

be said to be a form of cruelty. However if all people are recognised as being of value then there is a necessity to affirm their humanity in the time that they live.

The past is important as it is through our unique history that we become the people we are. But if the past only means something when still remembered ... 'it becomes a subjective misinterpretation of our ontology of time' (Frankl 1978, 106). There is a sense in which those who are encouraged to live in the past are hardly living as they are not aware of the present. There is a need for all people to find meaning in life as they are experiencing it. To those who would ask 'Why bother?' Frankl says, 'faced with life's transitoriness we may say that the future does not yet exist; the past does not exist any more; and the only thing that really exists is the present.' (Frankl 1978, 102) Erikson writes of the use of the pronoun 'I' as being a 'verbal assurance that each of us [is] in a centre of awareness in the centre of the universe ... in other words we are alive and aware of it.' (Erikson 1986, 52)

Reality Orientation needs to be used sensitively but has its place and is confirmed by the writings of Frankl and Erikson. One cannot change the place and time that is lived in, but one can be aware and find some meaning and integrity in the present moment. The 'sacrament of the present moment' is this idea in Christian thought. After all we only have one life and this moment is all that truly exists.

Frankl writes of the transitory nature of all that is and the 'present being the borderline between the unreality of the future and the eternal reality of the past' (Frankl 1978, 111). The past he sees as eternal because 'no one can blot out what has been' (Frankl 1978, 107). So, no part of life is seen as worthless or lacking in meaning.

Validation Therapy (VT)

This was developed by Naomi Feil in 1966 as a reaction to insensitive use of Reality Orientation. She had been working with disoriented elderly people, her job being to help them to face reality and relate to others in the group. She found that helping them to face

reality was unrealistic, and said that they 'withdrew or became increasingly hostile whenever I tried to orient them to an intolerable present reality' (Feil 1992, 9).

The ethos of Validation Therapy is that people must be listened to where they are and that there is little advantage in correcting people's language, when it has suffered as a result of dementia, while letting their feelings go unheard. Validation is used to empathise with another, to walk with them in their journey into dementia. Feil teaches that validating another's feelings builds trust which in turn brings safety and renews a sense of worth. To validate someone with dementia means to pick up their clues and help put their feelings into words.

The advantages of this therapy are that it acknowledges that the resident is a unique individual and that there is reason behind the often confused language and what could be seen as irrational or frightening behaviour. Wilder Penfield said:

When recent memory (short term memory) fails, very old humans restore the balance by retrieving early memories. When eyesight fails, they use the mind's eye to see. When hearing goes, they listen to sounds from the past. (Feil 1992, 12)

Those with dementia relive their past to restore their dignity, to remember a time when they were someone whom they recognised.

Feil (1992, 12) uses Erik Erikson's Theory of Life Stages and Tasks to explain how Validation can help with resolving the final stage of life. Erikson's theory is that there are tasks to be accomplished at each stage of life and that success in accomplishing a task at a certain age will depend on how well previous stages have been accomplished. 'Fears that were never faced in childhood reappear in disguise in old age.'

The task in old age according to Erikson's theory is to review life, to tie up living and to find inner strength which will lead to integrity. Failure to accomplish the task will lead to despair, the feeling that I might as well be dead.

Integrity in old age is the ability to use deep self-respect to heal the bruises that come with age. Without this self-acceptance, if no one can be trusted to love you, there is only despair. If despair is ignored then it can turn into depression; anger which is locked away.

But Feil suggests that there is a stage beyond 'Integrity versus despair', one of 'Resolution versus vegetation' (Feil 1992, 18). This stage belongs to the old-old. The task that is theirs to accomplish is to sort out the unresolved feelings of their past ready for their final move. She says that to die in peace is a deep human need. When people are told that they have only so much time to live it is often seen as the time to put things right so that, with issues resolved, they might die in peace.

Frankl writes of the importance of seeing the person as a human being of worth and value. Those with dementia are no different in that respect to all other human beings and need someone to listen to and to validate their feelings. If no one listens then they withdraw and vegetate, becoming one of the living dead who can be seen in many residential homes. It is through this human contact of someone listening to the meaning behind their words and actions that those with dementia are able to cope and find meaning.

However Stokes and Goudie maintain (1990, 183) that this form of therapy remains a relatively untried and unproven method of counselling in terms of both its underlying premises and principles of practice. They have taken the ideas behind Erikson's eighth stage of 'Integrity versus despair' further and what they suggest is 'resolution therapy' which they introduced in 1989. The underlying premise of this therapy is that in people suffering from an organic dementia, the disoriented messages received and the confused behaviour observed are likely to be attempts to make sense of what is happening now, or efforts to make their needs known which, if ignored, can result in people being labelled as difficult. They suggest the use of counselling skills so that carers can 'empathise with hidden meanings and feelings' (Stokes and Goudie 1990, 185) which lie behind confused

speech and actions. This is a therapeutic approach which reaches behind a person's memory to acknowledge their emotions as they struggle to cope with their situation. This idea is very similar to Feil's life stage of 'Resolution versus vegetation' from which she developed her Validation Therapy. Both these therapies look to find meaning behind the words used and both develop Erikson's work to offer therapy for those with cognitive difficulties.

Summing up

Having considered the range of therapies used in relation to the ideas offered by Frankl and Erikson I find that these writers' thoughts on 'meaning' support and validate the approach used to care for those with dementia. I also find that their ideas are being developed in such a way that they are even more suited to good dementia care.

Each person's situation is different and from the outside we can only guess the difficulty of coping with dementia but it need not be hopeless. Writing of his experience in a concentration camp during the Second World War, when everything was taken from them until they thought they could no longer exist, Frankl says 'a man can get used to anything, but do not ask us how' (Frankl 1992, 30). Frankl coped by trying to make sense of his situation and finding a meaning that would hold him.

Frankl sees the human search for meaning as the primary drive in life. Erikson's eight stages of life give us one way in which meaning is worked out in the different stages of life. For both writers this 'meaning' can give an integrity to the person such that value is added to life. This work of finding meaning can be fulfilled by the person herself, but for those with dementia the work has to be done with the help of others. Frankl's major contribution to the debate is 'logotherapy' – therapy through meaning – which is offered to those with dementia whenever the different therapies noted above are used as they all find their basis in the idea of the value of the individual.

These two writers offer much to the care of those with dementia: Erikson through his work

on the life cycle and the tasks of each stage of life and especially the last stage of 'Integrity versus despair' and Frankl who learned by personal experience the vital importance of finding meaning in life, for without that there is nothing.

We cannot answer the question 'Why?' especially when that refers to dementia. But we can, with careful attention, offer such care that meaning and integrity can be found and so enable the journey into a good death.

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The Welcome Healer and the Narrow Daylight: dying in hospital

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The spiritual care of people with severe dementia

The most profound and often asked question, 'Why?', is not answered by me. I am unable to answer it. This is about my journey of learning and sharing, of just being there, of listening and of giving support. It is written from the viewpoint of the whole person and it approaches spiritual and pastoral care holistically. It sees the sufferer as a whole person, even though he or she experiences many losses during the illness.

Starting points

Offering spiritual care to a person can mean many things. But when the person has severe dementia, do we somehow clip the spiritual and offer an excuse or platitude because he or she is slowly withdrawing from life and changing? 'He does not know.' 'She doesn't understand.' 'Why bother?' Such attitudes mask the fuller picture of the person's spirituality.

In the spiritual care of the sufferer of severe dementia, we must still see the whole person. This means that the chaplain has to get alongside and join in that person's journey and build up the picture. The chaplain meets sufferers when they are ill and probably have been for some time. It is now that we begin the journey with the person, the family and the staff and to engage with the sufferer's spirituality.

The theology of suffering is deep. It asks many searching questions but has no easy answers. Suffering caused by dementia can last a long time, causing carers and families to ask the

deepest questions. These questions are often directed with anger at God, at staff, at the chaplain or at anybody to hand.

Christians may find hope in the suffering, death and resurrection of Jesus and express it through their spirituality. But what of those people who profess to have no faith? Where is their hope?

This is not a theological quest for answers to suffering. It is a story of spirituality, of seeing the whole person even through suffering. It is a story about spiritual wholeness in the depths of suffering. It is a story about being there and viewing the daylight, even if it has become narrow. It is about listening to stories as the family remembers the past with all its joys and emotions. It is also about the present.

When the daylight narrows

The journey has begun. It is not a journey we would plan – it just happens. It can be a slow journey into a place where the full daylight has become narrow. It shines into the room but does not light it up as once it did. It is in the shadows of suffering that we have to find the spiritual.

In any spiritual journey, the daylight has never gone. It is all too easy to make the judgement that because someone has lost his or her speech or ability to recognise people or places, or because he or she presents him or herself in a very different way to how he or she used to, that person has lost everything. 'Why bother with spirituality?' I believe that the daylight, even though it is narrow, is still shining into the room of dementia. It gives hope.

Many people wait, not for a clear outcome but for a journey of uncertainty: uncertain where they are going or indeed where they may be taken. Life's transitional periods are characterised by uncertain change: the early years of parenthood, ill health, unemployment, retirement, redundancy, separation, divorce or bereavement. Donald Edie (1999) calls those in these states 'Saturday people'. They are people who, in a wide variety of circumstances, are learning the meaning of waiting during periods of sustained and wondering transition. As Edie says:

There is a long Saturday between the Friday of crucifixion and the Sunday of resurrection.

The pain and distress of those who suffer, the long watch and wait of carers and of their families as the daylight narrows – the long Saturday of dementia seems never-ending. In this situation, I must meet the spiritual needs of the person with dementia. In doing so, I must also meet the needs of the family. It is a time for the spiritual care to begin by seeing the whole person in full daylight.

From full daylight (the past)

My first encounter with the dementia sufferer is on his or her admission to the assessment or to the continuing care unit. I then begin to get to know the resident. The staff are wonderful at introducing me and giving me some background information. After getting to know the resident and meeting the family, I have the opportunity to join in their spiritual journey. A relationship of trust has to begin.

It is about listening to the person's past, where he or she was born, the joys of courtship, of marriage and of family life: children, grandchildren and great grandchildren. He or she may have served in the Second World War. I hear of working life and of retirement. Or, perhaps, I hear the anger of the spouse because the retirement years have been taken from the person by the illness. There are stories told of hobbies, of holidays, of favourite songs and music, of the shared good and bad times. The full daylight has brought much into their lives and it forms part of the spiritual story, which we all share to some degree.

Mrs A was cared for in a continuing care setting. Some time before the onset of dementia she had been the victim of a violent and unprovoked attack. Initially, she could be found on fine days out and about in the grounds with members of her family or with the staff. She responded to a wave and a smile. As time went on, Mrs A's condition deteriorated and became more challenging. Her family were regular visitors.

One day, when walking past her room, I saw Mrs A sitting on the floor with her husband. He looked upset, and I asked after them both. He was keen to tell me that it was their wedding anniversary. The occasion was both spiritual and emotional.

Mrs B visited her husband in the nursing home every day without fail, arriving mid-morning and leaving mid-afternoon. This was a way of life for her. On a fine day, she would take her husband out for a run in the car or take him in his wheelchair into the grounds or the surrounding streets, stopping for an ice-cream or just sitting and enjoying the weather.

Early on in my conversations with Mrs B, I learned that both she and her husband had been regular worshippers at their local church. My offer of bringing them both communion on a monthly basis was taken up. This was always an emotional time for Mrs B as she remembered the Sunday mornings going to church with her husband and their walks on a Sunday afternoon.

We always had communion in Mr B's room in the nursing home, surrounded by familiar photographs and ornaments. Mrs B always placed the communion wafer into her husband's mouth. As he deteriorated, because of his difficulty swallowing, Mrs B suggested that perhaps communion should stop. After a discussion, we decided to continue for a while longer with Mr B receiving only half of the communion wafer.

Some will tell how their spirituality has been expressed through a particular faith: their place of worship, the services they attended together, their involvement in different groups connected to their faith. Others will tell of how, as they grew older, they just drifted away from their faith. Still, they may remember its observances and traditions with affection.

All of this is very important for me in building up a picture of the person with dementia. It is that person's identity and spirituality.

The narrow daylight shines on the present

It is the glint of the narrow daylight shining through that makes the darkness and the dark places visible as the journey into dementia advances. The chaplain, in offering spiritual and pastoral support to the sufferer, has also to offer the same support to the family.

The majority of people suffering dementia will have been cared for in the early stages by their spouse at home. This involves the most intimate of tasks. On admission into the hospital, the carers' main role has been taken away. This brings a great sense of guilt: guilt that they are no longer at home, guilt that they can no longer care for their loved one, guilt that the most intimate of tasks in caring are now done by someone else.

With guilt comes anger. This can be directed towards the staff, who are now the carers. They may complain about anything and nothing, often becoming vocal about the way their partner is dressed, the food that is offered or the room being unsuitable. This is, I believe, the spirituality of emotion and feelings.

The chaplain is not immune from these emotions. God seems to take the blame:

He is a cruel God if he allows this to happen.
There is no God at all.
How can you believe in a loving God when he allows this to happen?
You would not let a dog suffer like this.

Others will put their whole trust in God, by faith and prayer and the support of the chaplain and their local church or faith group. This helps them through. For them it is not about questioning God. It is about letting God share the journey with them.

Spiritual and pastoral care has to be about letting the carers and families have time and space to be angry, to show emotion and to voice how it really is for them. Even the God of suffering, death and resurrection lets people have time and space to ask the deep and hurtful questions that dementia brings. If God did not allow people to do this, then where would we begin to find the theology of suffering? People will always need safe and confidential spaces. The chaplain, as a spiritual care-giver, has to offer this for all, including the staff.

It is important to make carers realise that they have not been shut out of their caring role. It has not been taken away from them. They are encouraged to visit regularly, even at mealtimes, when they can help. They can join in social events and take part in the carers' group. They remain involved by being consulted on the person's likes and dislikes, favourite food or clothing and how often the hairdresser should call. Personalising the room with pictures, photographs and ornaments and bringing in the person's favourite music and songs are all aids to remembering and creating a homely and friendly environment.

Again, I believe this is spiritual care performed as part of the overall care of the person.

The narrow daylight begins to fade

As dementia progresses, the changes in a person can be both frightening and dramatic. The changes in character, behaviour and communication can be very difficult for the family, as can the loss of recognition, the immobility and the weight loss. The person has journeyed from full daylight to narrow daylight and now the light is fading. This is not the person the family members have known all their lives:

I lost him when the illness began.

Some families have great difficulty in visiting because of the changes brought on by dementia. They may visit for a short time or the visits become increasingly infrequent. They become too emotional. Some families live too far away. The reaction of their neighbours and friends can be helpful or hurtful. Some will offer support, others will ask questions, such as 'Why do you go and visit so often when he doesn't even know you?' or 'Why don't you go and have a holiday? She won't miss you.' It is difficult for families to explain their need to be there for their loved ones.

The spirituality of love, care and devotion does not come to an end because a partner has developed dementia. Caring for someone with dementia is embracing the spirituality of life. It is remembering the past with the present. It is still seeing something of hope in the fading light. It is about sharing, joining in. It is the spirituality of wholeness.

This can be of some help and comfort at the end of a visit: travelling home alone, entering an empty house that is still full of memories, facing another night alone in fear of the telephone ringing – it might be the nursing home. Waking the next morning, it all begins again.

The narrow daylight shows the tears (end of life)

If we are viewing the dementia sufferer as a whole person and caring for his or her spiritual needs, we must also look at the spirituality that comes with the end of life.

The journey into dementia can last for many years. It is during this time that members of the sufferer's family have experienced many losses, many small bereavements. They have experienced the living deaths, such as the loss of recognition, of communication, of companionship. Perhaps the greatest loss of all is watching someone change from the person they have known and loved for years.

Yes, death comes to us all. When loved ones have watched someone slowly die over a long

period of time, his or her death is often seen as a blessed release. Death becomes the welcome healer, for it has brought the suffering to an end.

The spirituality of the whole person must also include the spirituality of end-of-life issues. Watching a loved one who has suffered from dementia for many years will often bring family members to a discussion of what to do at the end of the sufferer's life. It gives them the opportunity to plan the rite of passage. As a chaplain called to a bedside to offer prayers and support for the sufferers and their family, I often find myself drawn into these discussions. These are very spiritual moments for us all. Families and staff need time and space to talk and explore these issues.

Spirituality at the end of life is often expressed through religious belief. Prayers are asked because 'He used to go to church,' or 'She has always believed in God.' As a chaplain, I am only too happy to be available for residents and their families at this time. Conversations around death and the planning of the funeral are very profound for us all. God, faith and religion are discussed in depth. The words and prayers of the Christian burial or cremation service, for instance, can be important in our understanding of great suffering and in the search for meaning.

It is also possible for the partner of the sufferer of dementia to die first. Families may or may not want the resident told. Wanting the person with dementia to know his or her loved one has died demonstrates a positive attitude towards the illness and the sufferer's understanding of events. In my experience, many families wish to be inclusive in this way. Will the sufferer be able to attend the funeral service? If not, families have asked me to hold a service in the home after the funeral, the invitation being extended to the staff too. The service would normally contain the words of the funeral service and an explanation at each stage of the service. Family members read the messages of condolence from the cards and flowers are placed in the room.

I will remember Mrs C, a sufferer of dementia who attended her husband's funeral service –

she smiled gently throughout the whole service. Even though the daylight becomes narrow, it does bring with it a ray of sunshine in the most painful of moments.

The spiritual care of the whole person has to include the spirituality of death and dying. When a person has suffered for a long period of time with dementia, death is seen as the great healer – for death brings peace. A great sense of relief is often felt.

The planning of the funeral as a celebration and thanksgiving of life is also a very real part of the spiritual journey for the family. It is the last practical thing in which the family can participate. Has the spirituality of the deceased died as well? I believe not, as it lives on in the memories held.

Key points

The chaplain's role is to be with people who are suffering; to support them and their families and those who care for them.

Taking care of the whole person, which involves the multidisciplinary team, also means attending to his or her spiritual needs – a central plank in the philosophy of palliative care.

As part of the team, the chaplain is there to help to bring to mind all that the person was and still is in the context of family and community.

For some, spirituality is expressed through religious belief.

Religious acts of worship can help the individual with dementia to maintain and express his or her personhood and can comfort and support family and friends through bereavement.

Conclusion

The chaplain's role in the spiritual care of people with severe dementia is a varied role.

Spiritual care is offered at its best by nursing staff, clinicians, families and chaplains working together. I believe my role is 'being there'. It is being invited to share a very special spiritual journey.

The chaplain joins the journey when the daylight has become narrow. The chaplain's role is active and reactive. It means not just representing God in difficult situations; it also means trying to find God in the shadows when the full light has narrowed. The narrow daylight must never stop us seeing the whole person, for it is the spirituality of the whole person we are caring for.

The spirituality of those who care for the dying must be the spirituality of the companion, of the friend who walks alongside, helping, sharing and sometimes just sitting empty handed, when he would rather run away. It is the spirituality of presence, of being alongside, watchful, available, of being there. (Cassidy 1988)

This is what the spiritual caregiver is about: travelling the journey with the sufferer and his or her family and those who care for the person. We join the sufferer's spiritual journey. Let me end by reworking an old saying:

There in the grace of God go they.

The views expressed in this article are entirely personal and cannot be taken to reflect the opinions of the employing trust. Case examples are based on reality, but details have been changed or excluded to render the cases anonymous.

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