

# **MODELS OF DEMENTIA CARE: PERSON-CENTRED, PALLIATIVE AND SUPPORTIVE**

**A DISCUSSION PAPER FOR ALZHEIMER'S AUSTRALIA  
ON DEATH AND DEMENTIA**

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**TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA**  
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### **About Bupa Health Foundation:**

*Bupa Health Foundation helps build a healthier Australian community through its support of important health research, health education and other healthy living programs. Established as a charitable foundation in 2005, Bupa Health Foundation has partnered in more than 80 initiatives nationally, with a combined investment of around \$22 million, across its key focus areas: pain management, wellbeing, managing chronic disease, healthy ageing, empowering people about their health; and promoting affordable healthcare. For more information, please visit: [www.bupa.com.au/foundation](http://www.bupa.com.au/foundation)*

# FOREWORD

End of life care is a sensitive and complex topic. All too often, decisions regarding end of life care are made towards the end of the dementia journey at a time when the person living with dementia is often unable to relay their preferred care choices.

Dementia is a terminal illness, but the trajectory of the disease is different from other conditions such as cancer. The life expectancy of an individual with dementia is unpredictable and the disease can progress for ten years or more. Traditional approaches to terminal disease such as palliative care services are often not designed for the long trajectory or the complexity of issues that dementia raises around capacity and choice at end of life. Some consumers have been told that they are not eligible for palliative care services because the person was not 'dying quickly enough'.

Some of the most poignant stories I have heard during my time as President of Alzheimer's Australia have been about the difficulties of care at the end of life.

During our consultations on aged care reform in 2011, family carers told us they were racked with guilt because they had been unable to persuade staff to respect the documented wishes of the person with dementia. The result had been a painful and undignified death.

Family carers also feel that the provision of information about advance care directives is lacking. In cases where the person's wishes are not documented, family carers are left with questions as to what choices to make.

These issues add to the already considerable distress experienced by people living with dementia, carers and family members. If we are to avoid unnecessary trauma at end of life for the person and the family carer then frank and open discussions are needed much earlier.

The purpose of this paper is to generate discussion regarding how we care for people with dementia at the end of their lives. This paper sets out a new model of care underpinned by the principles of person centred care, palliative care and supportive care which will allow the person with dementia to live well and have control over decisions relating to their care.

I would like to thank Julian Hughes for his work on this publication and his willingness to undertake a public speaking tour for Alzheimer's Australia. I hope that the publication starts a much needed debate in Australia and causes us all to reflect on the importance of making our own wishes known.

I should also like to thank the Bupa Health Foundation for the funding that has made this publication and the speaking tour possible.



Ita Buttrose AO OBE  
President, Alzheimer's Australia



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# INTRODUCTION

The intention of this paper is to stimulate debate concerning how we should think about dementia as a condition at the end of life and how, therefore, we should plan and provide care for people with dementia and for their families. It considers questions of whether there is a need for dementia specific palliative care services and when discussions about end of life care should begin. It is about our models of care and how we put them into practice.

The document has five sections:

- 1 Some background issues will be raised and discussed;
- 2 The underlying philosophies of care will be articulated;
- 3 The components of supportive dementia care will be outlined;
- 4 How these might be incorporated into a care pathway will be shown;
- 5 The document will conclude with speculation on how the vision of supportive dementia care, which involves both person-centred and palliative approaches, might be achieved.

This document is not a systematic review, a manual or a guideline.<sup>1</sup> It does not present an actual care pathway.<sup>2</sup> It is an attempt to stimulate thought and debate about how it is best to provide care to people with dementia in connection with death and dying. It should be read in conjunction with the fuller document, *Wrestling with Dementia and Death*, produced by Alzheimer's Australia.

# THE BACKGROUND

Dementia is an umbrella term, which describes a syndrome (a collection of symptoms and signs) the most common cause of which is Alzheimer's disease; but it includes a large number of other conditions, the main types being vascular dementia, dementia with Lewy bodies and frontotemporal degeneration (Hughes 2011a). Many people with dementia have a mixture of these conditions.

Dementia becomes more likely as we grow older, so as the number of older people in a population increases it becomes more common. The prevalence of dementia

These statistics lead to two conceptual issues, which need to be considered as part of the background to further discussion. First, if the prevalence of dementia rises with age should it be regarded as part of normal ageing? Secondly, if the prevalence increases as we approach death, might this be one of the reasons for regarding dementia as a terminal condition?

## i. Normal ageing

There are good reasons to assert that dementia is not a part of normal ageing. The main reason is that most older

**Table 1 Rise in prevalence of dementia in Australia**

Age (in years)	Estimated or projected numbers of people with dementia in Australia		Projected increase between 2011 and 2050
	2012	2050	
65-74	57,200	108,700	90%
95+	14,200	98,300	592%
<b>Total for all ages</b>	<b>311,300</b>	<b>891,400</b>	<b>186%</b>

(i.e. the number of the people with the condition) is increasing throughout the world as a result of changing demographics. The Australian Institute for Health and Welfare (AIHW) has recently published updated figures on the prevalence of dementia in Australia (AIHW, 2012). Table 1 presents a small sample of the estimates and projections contained in the report. It shows that, although the numbers of people with dementia will increase across all ages over 65 years of age, the biggest percentage rise in the prevalence of dementia is accounted for by the rise in the number of people reaching the extremes of old age.

people do *not* develop dementia. So, for people over 80 years of age the prevalence of dementia is about 20%. But that means eight out of ten people over 80 will *not* have dementia. Individuals are at greater risk for a variety of diseases (such as cancer or heart disease) as they age, but these conditions are not considered normal ageing, instead they are considered diseases associated with older age. So, too, with dementia.

Nevertheless, cognitive abilities (memory and reasoning powers for instance) do decline as part of normal ageing and the biological changes which occur in the brains of people with dementia also occur in the brains of normal

older people. This does not mean that we can establish no standards of normality or abnormality. It is perfectly proper to decide that a certain degree of memory loss or certain behaviours are not normal. The worry, however, is that judgements which set too high a value on, for instance, retaining memory may *dis-value* the person with dementia and may even start to undervalue older people in general. Older people might start themselves to worry excessively about minor blemishes in terms of their cognitive function.

So, on the one hand, it is important to say that dementia is a disease, which may cause suffering to the person concerned and to those around. On the other hand, we must not stigmatize people with dementia; and we must not allow our worries about dementia and cognitive impairment to position all older people as, in some way, deficient or potentially so. How we think of people with dementia will affect how we treat them, individually and as a society (Hughes 2011b). People with dementia need help and, over time, they need increasing amounts of help. So do their carers. Individuals with dementia can be helped to live well – with the right approach, with understanding and in the right environment – and they should not be stigmatized (Nuffield Council on Bioethics 2009). To have dementia is to age in a certain way, with a particular disease, and any form of discrimination should be seen as such.

## ii. Dementia as a terminal condition

The second question concerned whether or not dementia should be regarded as a terminal condition. Most would agree that dementia is usually irreversible and that an individual will eventually die with dementia, and in many cases as a consequence of the disease. The difficulty with this terminology is that some may view the suggestion that dementia is a terminal disease as implying that a diagnosis of dementia means the end of a meaningful life. To talk about the condition being terminal seems, to some individuals, to be unhelpful and potentially at odds with a desire to assist people with dementia to live as full a life

as possible. To regard someone as ‘terminal’ could suggest that they do not warrant much active consideration.

In another light, however, to see dementia as a terminal condition, that is as one which inevitably will lead to death, can be helpful as it focuses attention on things that really matter and enables people and their families to make appropriate plans. It can also be regarded as a more honest perspective. Many people will die with, rather than from, dementia: many will die from heart problems or cancer for example. But if someone with dementia does not die from another condition, in the end the consequences of the dementia will bring about the person’s demise. This might be as a result of problems with swallowing causing pneumonia or it might be brought about simply by inanition.

Regarding dementia as a terminal condition can help clinicians and families to make realistic decisions about treatments. The focus should firmly be on quality of life. Unnecessary or burdensome interventions – investigations or treatments – should not be imposed on the person or his or her family. Meanwhile, the importance of living life to the full can be emphasized, rather than worrying about those things that cannot be changed. The motto of ‘life to years, not years to life’ becomes apposite from this perspective.

## Summary

The prevalence of dementia is increasing as the population ages. But this need not be regarded as a catastrophe. Longevity is, after all, a manifestation of our biological success (Kirkwood 1999). With the extra years we shall live will come different ways of ageing. The challenge is to make those extra years as good as possible. We can do this by focusing on how it is possible to live well with dementia, whilst still acknowledging the problems and suffering that it can cause. We can do this, too, by adopting a philosophy which encourages the right approach to people with dementia.

# PHILOSOPHY OF CARE

If we acknowledge that dementia is a terminal condition, then we must consider what might be the best approach to providing care and support to the person with dementia and their family. This section will consider three approaches to care: 1) person-centred care; 2) palliative care; 3) supportive care. It is important to note that these approaches to care are overlapping and contain many similar principles.

## Person-Centred Care

The predominant philosophy of care for people with dementia in recent years has been person-centred care (Kitwood 1997). Brooker (2007) has suggested the acronym VIPS to encapsulate the broader meaning of person-centred care: people with dementia and their carers must be **V**alued; they must be treated as **I**ndividuals; the **P**erspective of the person with dementia must inform our understanding; and the person's **S**ocial environment must be attended to because of the fundamental importance of relationships in sustaining personhood. Towards the end of his book, *Dementia Reconsidered*, Kitwood (who conceived the notion of person-centred care in dementia) suggested a new culture of care which:

'...brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasizes the fact that our existence is essentially social' (Kitwood 1997: p.135).

Person-centred care is underpinned by a philosophy of personhood, which Kitwood characterized as follows:

'It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood 1997: p.8).

The notion of person-centred care was born out of opposition to a narrow biomedical view ('the medical

model') and it is firmly based on a psychosocial and spiritual paradigm. As articulated by Kitwood, person-centred care places little emphasis on the medical management of patients.

Person-centred care promotes the rights and perspectives of the individual with dementia. This philosophy of care does not, however, specifically consider dementia as an end of life issue or provide guidance to clinicians or families on difficult decisions about medical treatments and withdrawal of medical interventions.

## Palliative Care

If dementia is a terminal condition, individuals with dementia should have access to a palliative approach from the time of diagnosis. Key aspects of palliative care relevant to dementia care can be summarized thus:

- Life is affirmed: people should be encouraged to live as well as they can even whilst accepting the inevitability of death, which should neither be hastened nor postponed;
- Distressing symptoms of whatever sort should be actively treated whilst maintaining quality of life;
- Care must be holistic: biological, psychological, social and spiritual, which necessarily means the family and significant friends must be included and care must extend to bereavement.

There are numerous parallels between person-centred care and the palliative care approach (Table 2) and theoretically one could take a person-centred approach to providing palliative care.

**Table 2 Comparison of psychological needs of people with dementia as highlighted in person-centred care and aspects of palliative care** (from Hughes 2006, Table 1.2)

<b>Psychological needs</b> (Kitwood 1997)	<b>World Health Organization definition of palliative care</b> (WHO 1990)	<b>Aspects of the palliative care approach</b> (Addington-Hall 1998)
Attachment	Support to person and family	Importance of sensitive communication
Comfort	Symptom control	Quality of life
Identity	Integration of psychological, social and spiritual	Whole person approach
Occupation	Affirmation of life	Respect for autonomy
Inclusion	Support to person and family	Care of person and family

There is much to commend the notion of palliative care in connection with dementia. With its roots in the hospice movement, aimed mainly at cancer, it has successfully combined a broad approach, which embraces complementary therapies, including an emphasis on spiritual care, alongside rigorous biomedical assessment and treatment. In this regard, it seems to provide a suitable breadth of vision for what we might wish to achieve for those with dementia. And yet, it raises concerns.

First, palliative care has developed mainly in connection with cancer care. Some families of people with dementia report that they are denied access to palliative care because the person with dementia is “not dying fast enough”. This raises the question of whether there is a need for a dementia-specific speciality within palliative care which could be designed to address both the longer course and unpredictable nature of the disease as well as ethical issues surrounding loss of capacity and proxy decision-making. At the same time, given that people may live with dementia for ten years or more, it must be considered whether the correct approach is long-term specialist palliative care or if there is just a need for a form of good dementia care, which incorporates a palliative care approach.

A second concern with a palliative approach is that people in the early stages of dementia neither wish to be told that they are dying nor that they are receiving palliative care. This becomes truer as people with milder forms of forgetfulness (i.e. mild cognitive impairment or MCI) present to health services. Whatever the good intentions of its proponents, some people incorrectly interpret palliative care as being entirely about dying and giving up. It sounds as if it is about care not cure, at a time people may still be hoping for the possibility of a cure.

Given that a person-centred approach does not provide sufficient guidance about end of life care and medical matters generally, and a palliative approach raises issues around the focus on end of life and seems designed for more time-limited illnesses, perhaps there is a need for a different approach to care for people with dementia.

## Supportive Care

An even broader notion has been mooted, namely that of supportive care, which involves:

‘... a full mixture of biomedical dementia care, with good quality, person-centred, psychosocial, and spiritual care under the umbrella of holistic palliative care throughout the course of the person’s experience of dementia, from diagnosis until death and, for families and close carers, beyond’ (Hughes *et al.* 2010: p.301).

The point about supportive care is that, not only does it extend across the complete time course of the condition, not only is it intended to be broad in the sense of biopsychosocial and spiritual, but – at a practical level – nothing is ruled out and everything should be ruled in. Based on a broad view of the person (Hughes 2001), individual complexity and difference should be embraced with enthusiasm and dedication in an effort to improve the lives of those with dementia and their carers. So, if we wish to use a broad model, which gives support throughout the illness including at the end of life, supportive care seems to provide an appropriate approach. It was, for instance, commended by the working party that produced *Dementia: Ethical Issues*. But they went on to say,

‘... the ‘label’ attached to care is less important than the beliefs and attitudes underpinning that label. If care is provided on the basis that the person with dementia is valued as a person and supported to ‘live well’ with dementia, within the context of their own family and other relationships, then the label becomes immaterial’ (Nuffield Council on Bioethics 2009; paragraph 3.10).

# THE COMPONENTS OF CARE

It would be good if we could now list the components of supportive care. We could then line up, as it were, what anyone might need so that we were ready to deal with all eventualities. In midwifery, for instance, a delivery pack contains all that the midwife might need for a normal delivery. Beyond the normal delivery there are the more complicated cases, but the components to deal with these cases can also be largely predicted. Interest in natural childbirth has added breadth to the components that might be required. Personal values and individual wishes make life more complex for those providing care. When we turn back to dementia care, however, individual differences in both preferences and in the symptoms of the disease will, arguably, have a much bigger influence on the patterns and requirements of care. Dementia is

more unpredictable than many medical conditions, in the sense that it is more various. This is for a raft of reasons reflecting the biological, psychological, social and spiritual complexity of dementia.

In fact, the underlying philosophy of supportive care suggests that, in dementia, it will not be possible to pin down in a precise manner what care or support might be required. This is not to say that we cannot list many of the likely components of care; but the idiosyncrasies of individual people with dementia and their carers mean that the types of care required will be singular. In Table 3 an attempt is made to set out some of the components of care within five broad domains.

It is inevitable that Table 3 is incomplete. The list of possible ethical issues alone could be extended to include situations that could not be easily predicted (Baldwin *et al.* 2004). New psychological approaches emerge; different medical conditions affect different people in a variety of ways; and so forth. There is much that can be done, as Table 3 shows, if only we grasp the opportunities and have the resolve to pursue the possibility that we might enable people with dementia to live and die well. Nonetheless, for the person with dementia and for his or her carers, a good deal of guidance is required if they are to be able to benefit from the rich possibilities of good quality supportive care.

**Table 3 List of components of supportive care for the person with dementia** (adapted from Hughes *et al.* 2010; Box 11.1, p.100)

Biological	Psychological	Social	Spiritual	Ethical and legal
Treatment based on genetic understanding of disease	Genetic counselling	Review of lifestyle factors	Acknowledging and supporting spirituality	Focus on personhood and person-centred care
Reduction of biological risk factors (e.g. cardiovascular)	Emotional support to person with dementia and carers, especially post-diagnosis	Environmental risk factors, including risks associated with behaviours such as 'wandering'	Help with maintenance of specific religious practices  Ethical issues	around giving the diagnosis  Early and appropriate
treatment of particular sub-type of dementia, e.g. with cholinesterase inhibitors or memantine or newer compounds	Support in maintenance of cognitive skills and memory remediation; cognitive stimulation	Community support (i.e. person-centred home care, day care, respite care)	Regard to overall quality of life	Medical decision-making in accordance with ethical principles (beneficence, non-maleficence, justice), e.g. treatment decisions
Medication optimization for (a) conditions associated with dementia, e.g. depression, hallucinations or other biological and psychological symptoms of dementia; and for (b) other non-related medical conditions, e.g. heart failure, renal disease, cancer, etc.	Psychological interventions: e.g. aromatherapy, doll therapy, exercise and activity therapy, music therapy, dance, art, reminiscence, validation or reality orientation, Snoezelen (i.e. multi-sensory therapy), etc. as well as needs-based behavioural interventions for behaviours that challenge	Individual care packages, perhaps involving personalized budgets with access to a variety of community (voluntary and state) services and facilities to provide support along with meaningful activities  Working through	and understanding the meaning of different aspects of a life (including suffering)	Advance care planning: statement of values, advance refusals of treatment, powers of attorney (for finance, property and welfare issues) or guardianship
Management of specific symptoms (e.g. pain, dysphagia, constipation, contractures, etc.)	Understanding of carer burden and need for practical carer support	Access to amenities and dementia-friendly events and premises, including dementia cafés	Namaste care <sup>4</sup>	End-of-life decisions including use of doctrine of double effect and doctrine of ordinary and extraordinary means
Falls reduction and maintenance of mobility	Provision of a therapeutic relationships	Choices around suitable accommodation and environments	Complementary therapies	Maintenance of dignity
Nutritional support, including dietary advice, supplements, spoon-feeding or artificial nutrition and hydration	Comfort and freedom from discomfort or distress	Aids for communication, including the provision of assistive technologies to support other aspects of day-to-day life	'Being with' the person as well as 'doing to' them	Issues around capacity and best interests
Good nursing techniques to maintain skin integrity	Maintenance of well-being	Anti-stigma campaigns for the public		Wills and management of finances
	Strategies for everyday living	Information and support for families		Maintenance of autonomy
	Provision of meaningful and pleasurable activities	Services specifically for younger people with dementia and for their families		Confidentiality
		Services for people with learning disabilities		Carers' responsibilities including the need to take over tasks
		Support for transport and assessments of driving abilities		Deciding on long-term care
		Services for people from ethnic minorities		Issues around sexuality (e.g. in long-term care settings)
		Services for people in remote areas		Allowing the person to take risks

# PATHWAYS OF CARE

From the time of diagnosis, if not before, the person with dementia, along with his or her friends and family, embarks on a journey. It has become increasingly common for health and social care staff to speak of care pathways.<sup>2</sup> But from what has been said above about the components of care, it should be obvious that there is going to be no single route which could be specified in advance. Practical care pathways, therefore, will have to provide frameworks of care, rather than detailed steps. For specific matters there will be well-trodden pathways. For example, a specific pathway can easily be constructed around the use of the cholinesterase inhibitors (i.e. the anti-dementia drugs donepezil, galantamine or rivastigmine). But even then, there will be elements of decision-making that cannot be easily pinned down in an algorithm. It is instructive to see why.

## **Values-based practice**

Algorithms depend on and work well with facts. If we know that the person with dementia is in pain – if this is a fact – then the next correct step is to give analgesia. The reason an algorithm cannot be used mechanically, however, is not solely because the facts are not known, but is also because of the pervasive nature of values in clinical practice. Values-based medicine (VBM) is the complement to evidence-based medicine (EBM) (Fulford 2004). The principles of VBM can be applied in all areas of health and social care as values-based practice (Woodbridge and Fulford 2004). For present purposes it is only necessary to focus on two aspects of VBM: first, that problems tend to emerge when there are diverse and conflicting values; secondly, that in settling disputes between values we should keep the views of the person concerned centre-stage.

To return to the case of pain, it may be difficult to establish that the person with advanced dementia is, in fact, in pain. This itself may require some form of value judgement. But say it is established that the person is in pain, there would then be a clear pathway to follow in terms of standard treatments of pain. This does not remove the necessity for value judgements. For instance, perhaps non-opioid analgesics have not proven sufficient; are the risks of adverse side effects from opioid drugs, such as sedation and constipation, justified in this particular patient? To see the pervasive role of values in practice, it is instructive to consider, albeit briefly, three situations, which can occur towards the end of life for people with dementia, to do with feeding, infections and place of care.

## Feeding

Swallowing problems can occur at various stages of dementia, but they become more problematic in more advanced dementia. Various protocols, guidelines or care pathways are available to guide practitioners and carers about what should be done. Many people feel that, despite worries about aspiration (i.e. food or associated secretions going into the lungs) causing pneumonia, it is better to continue to feed using food of an appropriate consistency with the person in an optimal position. This is on the grounds that feeding by mouth continues to provide human contact and because the evidence in favour of using artificial nutrition and hydration (i.e. by tubes inserted directly into the stomach via the nose or through the abdominal wall) in advanced dementia is not compelling (Sampson *et al.* 2009a). Nonetheless, there may be occasions when family or clinicians feel that artificial feeding should be pursued. Perhaps, for instance, it is felt the problem with swallowing is temporary and without intervention the individual will not have the strength to recover from the current illness. If the family believes that restoration of the previous level of functioning would have been what the person would have wanted, there may be a case for short-term use of artificial nutrition and hydration. This entails an important evaluative decision based on knowledge of the person's previous values, beliefs or wishes. The pathways to be followed can be set down in outline, but the individual course will be influenced by value judgements.

## Infections

There has long been evidence that antibiotics do not alter outcome when given to people with severe dementia (Fabiszewski *et al.* 1990). Conservative measures, such as antipyretics and tepid sponging have been found to be as effective as antibiotic medication for people with severe dementia. We also know, however, that pneumonias and other infections can cause significant discomfort (van der Steen *et al.* 2009). Furthermore, antibiotics can be used in a palliative way, without curative intent but simply to ease discomfort. So clinicians are faced by three choices: to use antibiotics because they think they will cure the patient, to use them simply to palliate, or to withhold them (which avoids their side effects) and use alternative conservative measures. Again, there are facts to consider, but also judgments of value, which will have to take into account the thoughts and feelings of those who know the person well. Any pathway would need to accommodate this sort of complexity, which reflects the mixture of facts and values.

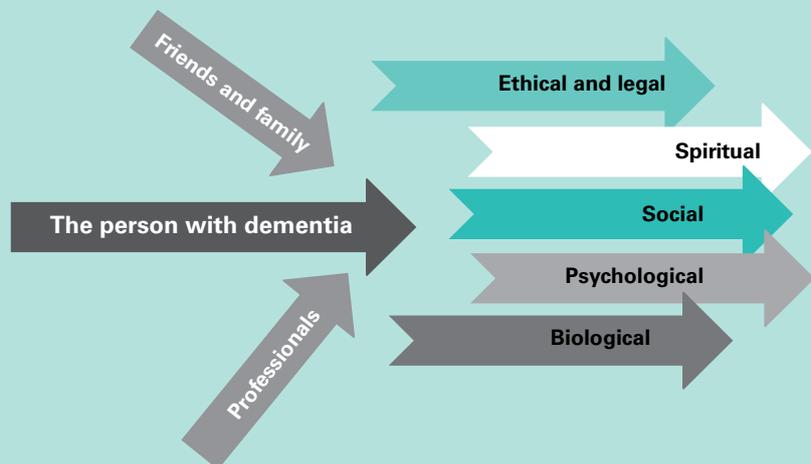
## Place of care

There is an emerging consensus that, when the person is in the most advanced stages of dementia, especially when they are in long-term institutional care, it is not generally in their best interests for them to be admitted to a hospital if their physical state deteriorates. The view is that the person should not be subjected to invasive investigations and treatments (including resuscitation) when these are likely to be ineffective and burdensome (Hughes 2010). There is good evidence that people with dementia do not do well in acute hospitals (their mortality is higher than for those without dementia), which raises the question as to why they are transferred from an environment in which they are known well to one which is disorienting and frightening (Sampson *et al.* 2009b). Nevertheless, there will be occasions when the judgement about a hospital admission will be enormously difficult. Again, this would be hard to pin down algorithmically because of the values at play: the prior wishes of the patient if known, his or her values, the feelings of the family (which may be conflicting), the instincts of the nursing staff in the care home (which may be conflicting), the skill and training of the staff, and the attitudes of the out-of-hours doctor seeing the patient perhaps for the first time.

## Pathways

It will not be possible, therefore, to establish a care pathway in any definitive fashion, even if it is possible to sketch the broad domains that make up supportive care. Instead, as indicated in Figure 1, the person will enter a terrain in which the outlines are known and within which there will be clearer routes, but these will depend on individual circumstances. The person with dementia does not (usually) set off on this journey alone, but is accompanied by friends and family to varying degrees. In addition, as depicted in Figure 1, there will be a variety of professionals who will be fellow travellers. What Figure 1 does not show is the extent to which friends, family and professionals may also come and go from the pathway, sometimes having more involvement and sometimes less.

**Figure 1 Overview of a care pathway**



Bearing in mind that Table 3, which set out possible components of supportive care, was itself inevitably incomplete – because of the nature of personhood (see Hughes 2011b) – each of the broad domains of the care pathway (i.e. biological, social, etc.) will include the set of relevant components for the particular individual. Thus, at some point it may be that behavioural and psychological symptoms of dementia (BPSD), such as agitation and aggression, become a problem. The appropriate route would be to seek expert advice on how to handle this sort of behaviour.<sup>5</sup> Care pathways for BPSD, which could be worked out in more detail for an individual, would tend to emphasize psychosocial, person-centred approaches.<sup>6</sup> But these might also include a spiritual aspect, if for instance it was found that religious music seemed to be soothing, where religious observances had always hitherto been a major part of the person's life. In addition, it might be that there are ethical and legal components of care to consider, if restraint is used or covert medication given. And the use of medication, which may occasionally be necessary, brings in biological components of care.

The complexity of care for an individual, which will often reflect the importance of diverse and conflicting values, and the need to place the person with dementia centre-stage, which were the aspects of VBM that seemed most relevant, suggest two final features of a dementia care pathway for discussion: first, the need for a key worker to provide continuity of care and, secondly, the relevance of advance care planning (ACP).

### **Key workers**

Supportive care depends on some form of continuity for the person with dementia and for his or her carers. The experience of care should be seamless rather than fragmented. It may well be that one person cannot provide the appropriate quality of care, through lack of experience or training, from the time of diagnosis to death and into bereavement. But transitions through different parts of a service, or from one service to another, must be handled well. Quality dementia care will

require detailed knowledge of the person, of his or her history, which may have biological, psychological, social and spiritual aspects. The pathway may also have legal and ethical pitfalls to be circumnavigated. So those who provide guidance will require detailed and dependable forms of communication. People with dementia and their carers, meanwhile, require a definite point of contact: someone who will be able to give them advice or direct them swiftly to the best source of advice.

### **Advance care planning (ACP)**

Values-based practice suggests that the values of the person most concerned by decisions should be given most weight. Given that in dementia a person's capacity or competence to make decisions gradually disappears, ACP seems sensible. It is a means of anticipating decisions, whether about finances, property, healthcare or general welfare. It can take various forms: statements of values, advance refusals of treatment or the appointment of attorneys or guardians. These different forms of ACP carry different legal weight in different jurisdictions. Because this seems to be a way to respect the person's previously expressed autonomous wishes, and because it is presumed that these wishes are most likely to align with the best interests of the person who now lacks decision-making capacity, governments have tended to encourage ACP for people with dementia.

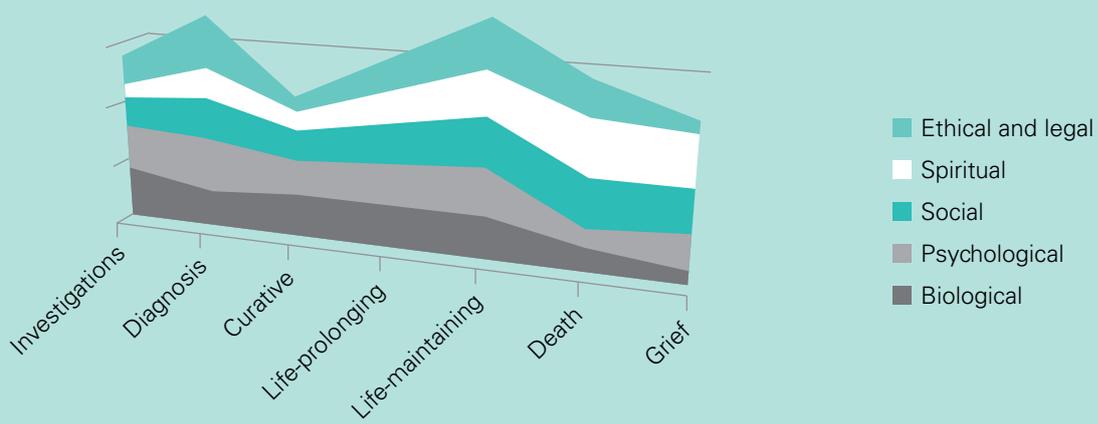
If, however, the earlier analogy with obstetric practice were pertinent, a further analogy might now be made between an advance care plan and a birth plan. The same presumptions come into play. For the most part a birth plan enables the person concerned to retain control of what happens. But there are unforeseen circumstances. In dementia the problem is that the variety of circumstances is much greater. At a simplistic level, we know that a pregnancy will last little more than nine months. Prognostication in dementia, even in severe dementia, is complex and lacking accuracy (Brown *et al.* 2012). So it is not possible to anticipate what the person's circumstances will be when they face death. Studies to

support the use of ACP in dementia are relatively few (Robinson *et al.* 2012a). Meanwhile, there are significant barriers to its use (Robinson *et al.* 2012b). These barriers may exist for very good reasons, reflecting inherent complexity, which therefore makes *precise* planning for end of life difficult. The complexity stems from the nature of personhood, the pervasive influence of values, the open-ended requirements and possibilities of supportive care and the varied ways in which dementia manifests itself in individuals.

If there are barriers to ACP, it is nevertheless a way to encourage communication and conversations about matters of high importance and provides an opportunity for the person with dementia to have an influence on their care pathway. ACP is a process rather than a one-off

event. In addition, it can be regarded as a type of 'working through' the diagnosis and its implications. Once again this stresses the importance of empathic support for the person and his or her relatives. If the on-going discussions are right, if they comprehend and accord with the individual's narrative, with all of his or her values, beliefs, wishes and needs, if they anticipate the difficulties that might arise and deal with them in ways that fully grasp the different aspects of personhood and components of supportive care, then the care pathway is more likely to be navigated so as to enable the person with dementia to live and to die well. This is an aspiration, but if realized it might produce the hypothetical pathway suggested by Figure 2, in which, at different times, different components from the various domains of supportive care have been used in varying amounts.

**Figure 2 Changing domains of supportive care** (adapted from Figure 32.1 Hughes *et al.* 2010)



# CONCLUSION

If this is the aspiration, how might it be achieved? Well, the components of supportive care, gestured at in Table 3, need to be available to be put into effect. The importance of key working and advance care planning, as articulated above, need to be realized. The key worker does not need to be a single person throughout the course of the condition, nor should ACP be one event. Instead, the experience of care has to be the experience of being supported. This will include relevant and timely conversations and communications with the person with dementia and with his or her carers. An example of how supportive care might be implemented and measured is outlined in Box 1. The use of Information Technology, although it would involve set-up costs, is intended both to reduce longer-term running costs and to ensure that plans can be readily available to staff and carers when required.

The aspirational aim will always be to maintain personhood and to enable the person to live well. When, then, it comes to dying, the aim should be for death to occur with dignity, without suffering or distress, it having been neither hastened nor postponed in keeping with the principles of palliative care.

What must be done? Changes are required at many different levels if the vision of person-centred, palliative and supportive dementia care is to be achieved.

- At the personal level, people with dementia, supported in solidarity by their family, friends, professional carers and community, must seek ways to live well (Nuffield Council on Bioethics 2009).
- At the personal level, professionals must embrace therapeutic optimism and rule out nothing if it might help the person with dementia to live life to the full (Small *et al.* 2007; p. 206).
- Professionals and families must also learn to accept that when investigations or treatments are ineffective or burdensome, they are not morally obligatory, even if it remains a moral imperative to provide comfort and dignity (Hughes 2010).
- Care homes must move from being institutions to become therapeutic communities (Small *et al.* 2007; p. 206).
- Voluntary organizations must encourage endeavours which support optimism and establish dementia-friendly communities and environments.<sup>7</sup>
- Public organizations and governments must create the foundations for supportive care throughout the course of dementia and must facilitate compassionate and effective health and social care, which takes account of the experiences and real narratives of people with dementia and their carers up to death and beyond.
- Society must embrace the possibilities of dementia, reject stigmatizing attitudes, support inclusion and look for ways in which dementia might be a source of joy even in the midst of decline (Greenblat 2012).

## Box 1 Implementing Supportive Care

### The Logistics

#### A key worker

The key worker can come from a variety of backgrounds. This may depend on local resources and arrangements.

The key worker in this model may be a care co-ordinator who does not actually provide day-to-day care, but oversees and co-ordinates the provision of care. Some of this function may be performed at a distance, using the internet or telephone.

The key worker, or care co-ordinator, may change with circumstances, but the imperative is that this is achieved through a seamless transfer of information.

The key worker will co-ordinate care via care planning, which will include advance care planning.

#### Care planning and advance care planning

There would be an individualized electronic care plan, which will include sections for immediate care planning and sections for advance care plans. The care plan would be constructed with the patient and his or her main or family carers. The key worker would be prompted by the programme to cover the important issues around care.

The care plan and advance care plan would be shared, with permission of the person concerned or his or her proxies, with all the relevant agencies (health, social care, voluntary organizations providing support, family, ambulance and paramedic services, primary and secondary care) if and when required. That is, with the right permissions, anyone involved in the person's care and requiring the information would be able to access the data at any time.

### Content of Care Plans

The care plan would run through a matrix of headings, with appropriate prompts to pursue particular issues, which might include the components of supportive care outlined in Table 3.

Care would be directed towards three domains: disease-directed, patient-directed and family-directed aspects of care would be identified under the headings of biological, psychological, social, spiritual, ethical and legal issues. Care priorities would be split up according to immediate care needs, intermediate care needs and long-term care needs, which would include advance care planning. This, in turn, could be split into sections: specific advance refusals of treatment, including advance refusals of cardiopulmonary resuscitation; powers of attorney, where proxy decision-making powers are specifically handed over to named individuals for specific areas, such as property and finance or welfare, which would cover both health decisions and decisions about where the person might live.

Finally, the care plan would include a section to record that objectives (agreed by those affected, i.e. to include family or professional caring staff) had been met when they were required to be met. Measurement would involve looking at particular aims, specified in advance, and completion of a simple Lickert scale (e.g. my/his pain was well controlled: strongly agree – agree – neutral – disagree – strongly disagree). Where there was variance and the aim had not been met, the reasons for this would be documented and new plans would be put in place.

# ENDNOTES

- 1** There are a number of reviews relevant to palliative care in dementia, e.g. Robinson *et al.* (2005), Hughes *et al.* (2007), Sampson (2010), van der Steen (2010). Professor Jenny Abbey also produced a useful Discussion Paper for Alzheimer's Australia (Abbey 2006). There exist a variety of guidelines for dementia care (e.g. NICE-SCIE 2006). Books which either act as manuals or provide guidelines specifically about end-of-life in relation to dementia include: Hughes (2006), Kelly and Innes (2010), Martin and Sabbagh (2011), Pace *et al.* (2011). A somewhat older text, which really helped to establish the importance of this field, is Volicer and Hurley (1998).
- 2** An example of potential care pathways for dementia is provided in *Dementia Services Pathways – An Essential Guide to Effective Service Planning*. This guide was developed by KPMG in Australia as part of the Dementia Initiative led by the Australian Government. It is available from: <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-dementia-services-pathways-2011-toc.htm> [accessed 18th November, 2012]. Further guidelines and care pathways can be found in Abbey *et al.* (2008). The National Institute for Health and Clinical Excellence (NICE) in the UK has also produced a care pathway for dementia available at: <http://pathways.nice.org.uk/pathways/dementia> [accessed 18th November, 2012].
- 3** For a description see Simard and Volicer (2010).
- 4** In Australia this could be from the Dementia Behaviour Management Advisory Service (DBMAS), who provide clinical support for people caring for someone with dementia demonstrating BPSD: <http://dbmas.org.au> [accessed 25th November, 2012].
- 5** In addition to information on the management of BPSD to be found in the sources referenced in Notes 2 and 5 above, the Alzheimer's Society in England, Wales and Northern Ireland (in partnership with the Dementia Action Alliance, the Department of Health, the Royal College of General Practitioners, the Royal College of Psychiatrists and the College of Mental Health Pharmacy) has produced a best practice guide; see Alzheimer's Society 2011.
- 6** The optimistic idea that dementia can be beaten by determined research efforts informs the campaign of Alzheimer's Australia. See: <http://campaign.fightdementia.org.au> [accessed 25th November, 2012]. The idea of encouraging inclusion and promoting quality of life has become a plank in the strategy of the Alzheimer's Society in England, Wales and Northern Ireland. See: [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1843](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1843) [accessed 25th November, 2012].

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