Northumbria Research Link

End-of-life care and dementia

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Introduction

In the UK, research continues to confirm that people with certain chronic illnesses, such as chronic lung disease and cardiac failure, represent the 'disadvantaged dying' compared to those with terminal cancer.[1,2] But what is the situation for people dying with advanced dementia and what is the experience of their carers? Practical guidance for clinicians is scarce. In Standard 7 of the National Service Framework for Older People,[3] which covers mental health, there is mention neither of how care should be provided nor of how patient choice should be ensured for people with dementia at the end of life. In the UK, 5% of the population aged 65 and over and 20% of those aged 80 and over have dementia[4]; similar prevalence figures are found in the USA.[5] Current predictions suggest that the number of people with dementia will increase by 40% by 2026 and will double by 2050.[3] The increased demand for end-of-life care for people with dementia will be associated with major social and economic costs,[6,7] but what is the current standard of such care? How can the quality be improved? And how should future services be configured to cope with this increasing need? In this paper,

we review current knowledge around end-of-life care in dementia, discuss the clinical challenges and ethical dilemmas presented to carers, consider the difficulties in delivering such care and suggest practical approaches to improve the quality of such care.

End-of-life care for people with dementia – current evidence

In the UK, over 40% of people with dementia die in the community[8,9]: 9% at home, 25% in nursing homes, and 56% in hospital.[9] However, dementia as a cause of death is underestimated, with one-third of death certificates of people with dementia failing to state this as a cause of death.[10] Hospice use by people with dementia is minimal[8,11]: less than 2% of people in hospice care in the UK have a primary diagnosis of dementia.[8] In the USA this figure is marginally higher at 7%,[11] but the vast majority of people with dementia will die in nursing homes.[12,19]

Most of the recent research examining the quality of end-of-life care for people with dementia originates from the USA.[14,16] In a retrospective cohort study, comparing the care received in the last year of life in nursing homes by people who died with dementia ($n = 1609$) with those who died from terminal cancer ($n = 883$), the former received sub-optimal care in several areas. The study demonstrated: an increased use of

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non-palliative interventions in people with dementia (for example, 25% were tube-fed compared to 5% of people with cancer); inadequate treatment of some symptoms; and a lack of advance-care planning (for example, the records of 55% of people with dementia recorded a 'do not resuscitate' statement compared to 86% of people with cancer).[15] A parallel study, exploring the end-of-life care received by people with advanced dementia in nursing homes compared to those who continued to live at home with support from home-care services, also found less than optimal care in both settings.[14] The evidence on end-of-life care in hospital settings in the USA is equally concerning: in one study over 60% of people with dementia admitted to a geriatric ward died with high levels of suffering.[16] A UK-based study, which explored carers' perspectives as a proxy measure to represent the end-of-life experiences of people with advanced dementia, revealed a high incidence of untreated symptoms in people with dementia, which persisted for longer than in patients with cancer.[8] In addition, people with dementia and their families required more input from health and social services than people with terminal cancer.[8] Although the provision of end-of-life care in nursing homes in the UK has been studied in some depth,[17–19] specific research focused on the end-of-life experiences of people with dementia in such settings is lacking. So why do people with advanced dementia and their families continue to receive poor quality care at the final stage of life? In the next section we discuss the difficulties professional carers face in providing high quality end-of-life care in dementia.

Difficulties in the provision of high quality end-of-life care in dementia

These include: communication issues; a failure to recognize dementia as a terminal illness; specific management issues including challenging clinical and ethical dilemmas; addressing carer needs; and organizational factors relating to the present delivery of health and community care in the UK.

Communication issues

Patients and relatives may not be aware of the exact diagnosis of dementia, making discussion and negotiation around end-of-ife care issues difficult from an early stage.[20] There is extensive variation in the rate of disclosure of a diagnosis of dementia, with carers informed more frequently of the diagnosis than people with the illness.[20] Euphemistic terms were more commonly used in disclosing the diagnosis to people with dementia than to their carers.[21] Despite their considerable training in communication skills, between 28% and 42% of general practitioners reported difficulty in disclosing a diagnosis of dementia.[21,22]

As dementia progresses, a person's cognitive and communication abilities decline and it becomes harder for both lay and professional carers to ascertain accurately the wishes and needs of the person with dementia.[23] For those with dementia in nursing homes, information and observations from staff are often invaluable, but a high staff turnover may lead to unreliable reports and misinterpretation of the significance of symptoms,[24] with the creation of a 'malignant social environment'.[25] In addition, when a person with dementia leaves their home to live in a nursing home in the UK, they may have to change their general practitioner,[24] severing this potentially therapeutic relationship.[26]

Failure to recognize dementia as a terminal illness

Identifying dementia as a progressive illness would allow those with dementia and their carers to consider palliative-care approaches more readily and at an earlier stage.[27,28] Although, theoretically, experts consider the advanced stages of dementia to meet palliative-care criteria,[29] practically, both professional and lay carers appear to have difficulty with this concept.[15] On nursing-home admission, only 1% of people with advanced dementia were perceived by staff as having a life expectancy of less than six months, yet 71% died within that period.[15] The National Centre for Health Statistics did not include Alzheimer's disease as a cause of death until 1994.[30] Much of this difficulty is related both to the protracted length of time from confirmation of a diagnosis of dementia to death, currently quoted as between four to nine years,[31–32] and to the problems clinicians have in identifying the point at which care becomes palliative, which arguably could be from the point of diagnosis.[33]

Specific prognostic markers for advanced dementia, focused on a life expectancy of six months, have been developed in the USA in order

Table 1. *Medical problems in advanced dementia*[23]

Neurocognitive
- Progressive worsening of memory and other cognitive deficits
- Increasing confusion and disorientation with specific behavioural changes (apathy, aggression and agitation)
- Progressive worsening of speech leading to an inability to communicate

Functional
- Loss of mobility, becoming eventually bed-bound
- Loss of capacity for self-care, eventually becoming totally dependent

Nutritional
- Progressive loss of appetite, loss of capacity to swallow and inability to feed independently
- Increasing risk of aspiration

Complications
- Bladder and bowel incontinence
- Fever and infections (pneumonia, urinary tract)
- Pressure sores

to inform hospice admission criteria.[34] The guidance is based on scales which have attempted to classify the progression of dementia into stages, for example, the Global Deterioration Scale,[35] and the Functional Assessment Staging (FAST) Scale.[36] For a person with dementia to qualify for hospice admission, they must be at or beyond FAST Stage 7, i.e. they have lost the capacity for mobility and self-care, have no meaningful communication and are incontinent of bladder and bowel function.[36] Although such scales are not entirely accurate, they have been shown to predict a six-month mortality of approximately 60%.[37]

Clinical challenges in end-of-life care for people with dementia

Routine clinical care

The advanced stages of dementia are associated with a consistent range of medical problems (see Table 1).[23] For example, mental confusion occurs in 83%, urinary incontinence in 72%, pain in 64%,[8] swallowing problems in 72% and malnutrition in 50%.[38]

Antibiotic treatment of intercurrent infections is less effective in dementia[39] because several risk factors (e.g. an inability to report symptoms, decreased immune responses to infections and loss of ability to ambulate) make infections an unavoidable consequence of advanced dementia. Non-randomized studies also indicate that antibiotic treatment is not necessary to maintain comfort during an intercurrent infection.[40] Nutritional problems in dementia include weight loss, food refusal and difficulties chewing and swallowing.[41] Food refusal may be managed by diet modification and by administration of antidepressants[42] or dronabinol (which is not available in the UK).[43] Chewing difficulties and choking may be minimized by modifications of diet texture. Aspiration resulting from choking may be prevented by ACE inhibitors[44] and amantadine.[45] Tube-feeding does not prevent aspiration or provide other benefits.[46] It poses a burden for the person with dementia[47] and deprives them of the enjoyment of taste and interaction with caregivers during feeding. Even if tube-feeding is initiated, it can be converted to natural feeding.[48]

Decreased life expectancy[49] makes inadvisable the use of preventive interventions that have only long-term consequences, such as restricted diets, and intensive treatment of chronic conditions such as hypertension. Aphasia leads to an inability to report symptoms of diseases,[50] but also symptoms caused by over-treatment or distress induced by medical procedures. Some medical procedures routinely performed for cognitively intact individuals may not be appropriate for individuals with advanced dementia. Cardio-pulmonary resuscitation (CPR) is not indicated because of the low probability of survival and great burden imposed by the procedure.[51] Even in a hospital, CPR is three times less likely to be successful in patients with dementia than in patients who are cognitively intact, and the success rate is almost as low as in metastatic cancer.[52] Transfer to a hospital

for treatment of intercurrent infections may not be indicated because treatment in a nursing home has a better outcome.[53,54]

Management of distress and pain

As dementia progresses, the loss of cognitive and communication abilities makes the assessment of distress in a person with dementia a complex issue. 'Distress' can have a variety of causes: pain; delirium; depression; agitation or psychosis; social isolation; immobility or drug-related side-effects.[55] The consequences of pain are far reaching, affecting sleep, mobility, immunity[56] and mental state,[57,58] yet it is currently notoriously under-diagnosed and inadequately treated,[56,59–61] for example, patients with severe dementia received less opioid analgesia post-hip fracture than their cognitively intact peers.[61]

The experience and expression of pain in dementia is attracting interest, with attempts to link it to the neuropathological characteristics of illness subtypes. Central to this, is the degree to which medial and lateral pain systems are affected. In Alzheimer's disease damage to the medial pain system predominates. This plays a pivotal role in the motivational-affective processing of pain, and translates clinically into reduced pain intensity and increased tolerance.[61,62] The relative preservation of pain thresholds has also been observed in Alzheimer's disease.[61] These factors have implications for the clinical utility of some observational pain scales.

Recognizing pain can be difficult in patients with communication difficulties.[63] Self-report is not feasible, and identification rests with carers.[8] Recent years have seen the emergence of pain tools, which have sought to tackle problems of under-recognition and under-documentation in this group. The PAINAD, (Pain Assessment in Advanced Dementia)[64] derived from the DS-DAT (Discomfort in Dementia of Alzheimer's Type), has five items – breathing, negative vocalization, facial expressions, body language and consolability. When compared with two visual analogue scales, PAINAD was effective in assessing pain but the study was limited in its sample size.[64] The NOPPAIN (Non-Communicative Patient's Pain Assessment Instrument) was designed for use by nursing assistants at times of intervention.[65] The tool was deemed valid but the study was again

limited by sample size. A novel component of the ADD (Assessment of Discomfort in Dementia) is its stepwise inclusion of pharmacological and non-pharmacological interventions.[56] The Abbey Pain Scale borrows its design from previous tools and, therefore, features indicators and prompts with established validity: it appears to be valid, well-received by users and easily completed.[66]

In the treatment of pain in dementia, non-drug treatments (e.g. massage, TENS, aromatherapy. etc.) should also be included in the therapeutic options, but robust evidence for their use is lacking.[67] The World Health Organization's (WHO) analgesic ladder has been adopted in some settings.[68] It recommends the timely administration of analgesia, starting with non-opioids and working progressively to strong opioids, until the patient is pain-free. 'Adjuvant' treatments are also employed, such as tricyclic antidepressants and anticonvulsants.[69] Although tools to assess pain in dementia[56,64,66] and guidance on pain management[68] exist, the unacceptably high number of people suffering[16,70] clearly indicates the need for further research and interdisciplinary collaboration.[60]

Behavioural and psychological symptoms in dementia (BPSD)

Ninety per cent of people develop behavioural and psychological symptoms in dementia (BPSD).[71] The management of BPSD is challenging, with two-thirds of general practitioners and 50% of hospice staff[37] lacking confidence in this area. More than 80% of people with dementia residing in care facilities have behavioural or psychiatric symptoms,[72] with symptoms of agitation (including aggression and restlessness) occurring in over half. The frequency of these symptoms, the distress that they can cause,[73] the potential risk to other residents and the burden upon carers[74] have made the treatment of these symptoms a high clinical priority. Theoretically, non-pharmacological interventions are recommended before pharmacological methods.[75]

A wide range of the former exist, such as electronic tagging and tracking devices, behavioural approaches (e.g. reality-orientation), distraction therapies (e.g. exercise, music therapy), alternative therapies (e.g. homeopathy), environmental modifications and subjective barriers, but

evidence on their effectiveness is scanty.[76,77] Also, the high levels of staff turnover,[78] the absence of an appropriate skill-mix and staff shortages in most care-facility settings has rendered the systematic application of non-pharmacological management techniques unfeasible. This has led to an increased imperative to utilize drug treatments, but unfortunately with an inadequate evidence-base to inform clinical practice.

Neuroleptic drugs are the most widely-used pharmacological therapy used to treat BPSD and are prescribed in up to 60% of people with dementia in nursing homes,[72,79] often for prolonged periods, with a median duration of prescription in excess of one year.[72] Whilst there is clear evidence of benefit across more than 20 randomized placebo controlled trials (20% advantage over placebo) over periods of six to 12 weeks,[80] the placebo response rate is very high ($>40\%$) and the overall benefit in terms of quality of life has not been evaluated. Of even greater concern considering the patterns of prescribing in clinical practice, the evidence of longer-term efficacy is far less clear, with only one placebo-controlled trial of greater than 12 weeks, which showed no benefit with neuroleptic treatment,[81] and a number of randomized controlled-withdrawal trials suggesting no significant exacerbation of neuropsychiatric symptoms when long-term prescriptions of neuroleptics are discontinued.[82–84] In addition to established side-effects such as parkinsonism and drowsiness, there are serious risks potentially associated with neuroleptic drugs. These include a threefold increased risk of stroke/cerebrovascular events,[85] an almost twofold increased mortality,[86] oedema, falls and reduced quality of life,[87] and accelerated cognitive decline.[81,88] People with dementia residing in nursing homes are a very frail and vulnerable group of people, with an average life expectancy of only two years.[89] It is therefore a source of major concern that this widespread use of neuroleptic treatments may increase the likelihood of serious detrimental outcomes, including death, and impair the quality of life of these individuals.

End-of-life care experiences for families of people with dementia

The experience of families who care for people with dementia has been likened by some to 'coping with a living death'.[90] A number of models have been outlined to describe the caregiving trajectory in dementia,[91–98] with Lindgren applying the term 'caregiver career'.[95] This encompasses three distinct but overlapping stages: an Encounter Stage (the diagnosis and loss of previous life-patterns), an Enduring Stage (managing extensive care-routines and social isolation) and, finally, an Exit Stage (the relinquishment of caregiving through the death of the spouse or their admission into care).[95] Sweeting and Gilhooly, either independently[99] or jointly,[100,101] pioneered the application of the constructs of 'anticipatory grief' and 'social death' to the process of caregiving and dementia. Whatever term is used, carers generally consider the person's death as 'a relief'[102,105] in contrast to the general literature on bereavement.[106,108]

Such families face particular stresses in comparison to other caregiving groups[109,110] and experience greater detrimental effects in terms of physical and mental health and social isolation.[7] A variety of interventions have been developed to help, such as support groups,[111,112] training programs,[113] family-based psychosocial interventions[114–116] and specialist community care,[117,118] each with different outcomes and levels of efficacy at various stages of the caregiving trajectory.[119,120] In general, carers of people with advanced dementia require more emotional support and respite care prior to the person's death than afterwards,[121] and the more social support they receive pre-bereavement, the better adjusted they are post-bereavement.[122–124]

There are a number of areas concerning family carers of people with dementia which require more exploration, e.g. end-of-life decision-making, especially for family carers with relatives in residential care,[125,126] the adequate preparation of family carers for their loved one's death[122–124] and measuring quality of life at the end of life.[127,128] Shock and devastation amongst carers following the death of the person with dementia is associated with a lack of foresight.[129] Appropriate information and intervention strategies should be provided throughout the caregiving trajectory, so that the terminal phase is demystified and feared a little less. The introduction of Admiral nurses, with specialist knowledge and experience in dementia care and carer support,[130] may provide an opportunity to address this, although initial results show little difference in both carer and patient outcomes, whether carers receive support from this service or existing community mental health teams.[131]

Ethical issues at the end of life

The unique aspect of ethical issues in dementia relates to the increasing and unavoidable need for others to take decisions for the person with dementia. The question is, what justifies these decisions? In many cases, they are justified by reference to the evidence for the effectiveness of the particular action. But in most cases the decisions are difficult precisely because they involve clinical and ethical aspects, for example, those involving artificial nutrition and hydration (ANH) in dementia.[132] From a meta-analysis showing that artificial feeding did not achieve its objectives, Gillick argued against the use of percutaneous endoscopic gastrostomy (PEG) feeding.[133] Such arguments are justified by the ethical principles of beneficence and non-maleficence.[134] Subsequently Gillick considered the use of ANH at different stages in the person's dementia.[135] These decisions are difficult because they rely on there being a clear distinction between the person whose condition will lead to death at some stage and the person who is already moribund. In a condition such as dementia, deciding how close to death a person is may not always be straightforward. In addition, such decisions do not solely depend on medical matters as they affect the individual, since they also involve families. Research suggests that the simple application of the principles of medical ethics with respect to ANH decisions is not always helpful.[136] In an ethnographic study in Holland, the wishes of the family were found to be important in making these decisions, but so too were the medical condition of the patient and judgements about quality of life.[137] These factors were more important than living wills and policy agreements.

Such studies show a mixture of clinical and ethical issues coming together in connection with difficult decisions. The range of decisions in the later stages of dementia that raise ethical issues is too broad to be surveyed in detail,[138,139] but the brief discussion of ANH already points towards the importance of autonomy and how death comes about. It has been recognized for some time that autonomy is a complicated notion.[140] It seems to rely on an atomistic view of people as rational and discrete individuals, rather than as interrelated and interconnected, dependent selves, embedded in a history and context.[141] A fuller view of autonomy supports and is supported by a broader view of the person with dementia.[142] This conception of the person helps to justify (and ought to encourage) the greater willingness to involve families in decisions concerning death and dying.[143] It is, after all, part of the holism of the palliative-care approach that family carers ought to be involved in decisions, especially in dementia.[144]

It is not always clear how to ascertain the person's autonomous wishes. Legislation in various countries supports the use of advance directives, but advance directives are not always easy to interpret in concrete situations.[146] Where the person's views are not definitively known, carers are required to act in his or her best interests and the advance directive might then help as a guide to what might be best. But the determination of what is best for someone should be broad-based, recognizing the continuities in terms of dependence, and the character and body that go to make up the self.[146] It is certainly relevant to note that the person with dementia can be encouraged, even in the severer stages of the disease, to participate in decisions.[147] The person's awareness or lack of awareness (and, therefore, his or her ability to participate in decision-making) may be a function of the social environment.[148]

The end of life in severe dementia raises further difficult ethical considerations. For instance, the issue of withholding or withdrawing treatment is again one that has to be decided on both clinical and ethical grounds. It is possible that predictors will be found to suggest when antibiotic therapy should be used and when it should be withheld in people with severe dementia.[149] However, there is still an ethical decision to be made about how hard to treat the person. The distinction between ordinary and extraordinary means, when this is understood in terms of the burdens imposed by the particular treatment against the likelihood of benefits accruing to the person concerned, has traditionally been found useful.[159] It would still require an evaluative judgement to decide when treatments were burdensome in this way.

Values theory and practice provide a way to approach the conflicts that arise when judgements are based on conflicting values.[151] The key is to try to place the values of the person concerned centre stage, but to give space to the values of others. People's decisions cannot be presumed. In a study of 52 older people in nursing homes in Australia, who were given a hypothetical case of someone with recurrent aspiration pneumonias and severe dementia, most of the participants

(61.5%, p < 0.1) preferred the idea of hospital admission and 73.1% (p < 0.001) said they would choose antibiotic treatment.[152] Negotiating these ethical dilemmas requires practical wisdom on the part of the clinician. Practical wisdom is the sort of virtue or disposition commended by virtue ethicists as a way of dealing with moral dilemmas that arise at the end of life.[153] But the virtues are acquired through experience and practice. Virtue ethics stress what we *become* by doing or not doing certain things. It requires that weight is put on the value of caring itself, as an activity that demonstrates human flourishing. From this point of view, palliative care (with its acceptance of death) seems more appropriate for people with severe dementia than the thought that their lives should be ended by either active or passive euthanasia.[154,155] In any event, the ubiquity of clinico-ethical decisions at the end of life in dementia calls out for specialized knowledge and skill.

Improving end-of-life care for people with dementia – adopting a palliative-care approach

The World Health Organization recently stated that 'every person with a progressive illness has a right to palliative care'.[156] The continuing inequities in terminal care between people with cancer and other chronic illnesses has led to an impetus in the UK to extend the provision of palliative care to people with non-malignant disease.[157] Both professional carers and lay carers of people with dementia favor a palliative-care approach in advanced dementia,[158,159] however, there is currently little evidence for the efficacy of a palliative-care model in dementia compared to traditional care, although the research base is poor.[160] Palliative care is defined as 'the active total care of patients and families by a multi-professional team when the patient's disease is no longer responsive to curative treatment'.[161] The concept of palliative care incorporates both a general 'palliative-care approach', to promote both physical and psychological well-being from all professional carers involved, and the provision of specialist palliative-care services from hospice-based palliative-care teams.[162]

In the USA, a palliative-care approach has been adopted in some areas for people with dementia and specialist units akin to hospices have been established.[163,164] When the provision of palliative care in a dementia special care unit (DSCU) was compared to traditional long-term care units, the DSCU was both more effective clinically and economically than traditional care, with more evidence of advanced-care planning, less invasive care and lower average three-month costs in the DSCU.[164] However, examples of such specialist care are rare, with only a small number of people with dementia accessing hospice care.[8,11]

Nevertheless, would a specialist hospice approach for end-of-life care for people with dementia be appropriate in the UK? Nearly half the people with dementia in the UK will die in nursing homes,[8] and transferring people in the late stages of dementia from what has become their 'home', may be more detrimental to their quality of life than beneficial.[24] In addition, the provision of end-of-life care for people with dementia in the USA is affected by different factors, for example, financial reimbursements to physicians for 'hospitalized' patients exceed those for nursing home visits.[27] Such factors heavily influence how future care is planned.

Priorities for education and service organization

Despite the limited evidence-base,[160] it would seem that palliative care represents an important and sensible alternative to conventional care in the advanced stages of dementia.[17,158,159] However, professional carers appear to experience difficulties in adopting a general palliative-care approach in dementia.[15] So how can we overcome existing barriers[27] and ensure that such an approach is promoted in advanced dementia and that people with dementia receive high quality end-of-life care?

Having acknowledged the communication difficulties that exist for carers in talking to people with dementia, we need to understand why it is so difficult for professionals to use the word 'dementia' explicitly, and how this process can be achieved in a sensitive and person-centred way.[20] Training packages already exist for helping professionals improve their individual skills in consultations where communication difficulties exist.[165,166] For if the diagnosis were empathetically discussed at an early stage, it would enable people with dementia to express their wishes when they were mentally capable. This might encourage the use of advance statements to help carers deliver more person-centred care in the advanced stages of the disease.[24]

Currently only 11% of people dying with dementia have made a living will.[15]

In contrast to cancer care,[167,168] there is currently little practical guidance on the provision of end-of-life care in dementia.[3] Care pathways have been developed to transfer the specialist palliative care received in hospices at the end of life into other care settings.[167,168] The Liverpool Care Pathway (LCP)[168] and the Gold Standards Framework (GSF)[168] have been shown to support measurable improvements in the quality of end-of-life care and are recommended by NICE.[169] Such models however are limited to care in the last few days of life and their development is grounded in a cancer-care model. The principle of developing a similar care pathway for advanced dementia care might produce similar demonstrable improvements in quality, improve education and facilitate more integrated care.[168,170] In the USA, the Palliative Excellence in Alzheimer Care Efforts (PEACE) program was developed to integrate a palliative-care approach into dementia care.[171] It incorporates advance planning, patient-centred care, family support and a palliative-care focus from the diagnosis of dementia. Initial results have shown adequate pain control and appropriate attention paid to patient wishes, and choice in location of death.[171]

Professionals working in the community need access to specialist expertise to provide end-of-life care in dementia.[172] Unfortunately, the Audit Commission found that specialist support for managing people with advanced dementia was not available at all in 40% of all areas of the UK,[172] and even dementia-care specialists lack confidence in providing palliative care.[173] A multidisciplinary approach is therefore required, with a wide range of specialities, for example, old age psychiatry, palliative care, speech therapy, primary and community care, specialist nursing and carer support (for example, Admiral nurses).[130] Such expertise is readily available but it is not currently organized in a co-ordinated and integrated way for dementia care.[24] The creation of a community-based team specializing in the management of advanced dementia, and including such expertise, would facilitate more integrated care and allow specialist advice to be provided, regardless of where a person with dementia was living.[24] Such teams could be directly accessed by any professional carer including nursing-home staff.[19] Another possibility for the provision of more seamless care could be through the national extension of the Admiral

nursing service.[130] Although further evidence is required of its effectiveness,[131] such a service could provide opportunities similar to the introduction of McMillan nurses for cancer care i.e. a key source of specialist help for both primary and secondary care professionals.

In addition to improving general palliative care, the evidence for the effectiveness of a specialist hospice service for people with dementia is limited,[164] especially in the UK. However, existing NHS continuing-care beds could provide the opportunity to develop such a specialist unit, which could act as a base for the advanced dementia-care team and provide a source of inpatient beds, should specialist care be required.[33] In conclusion, it would appear that much needs to be done to improve the quality of dying for people with dementia, both in the provision of specialist palliative-care services and in the facilitation of a general palliative-care approach. From a review of current evidence, it would seem that people dying with dementia do truly represent the 'disadvantaged dying'.

References

1 Murray S, Boyd K, Kendall M, Worth A, Benton T. Dying of lung cancer or cardiac failure; prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002; **325**: 929–32.

2 McKinley R, Stokes T, Exley C, Field D. Care of people dying with malignant and cardiorespiratory disease in general practice. *Br J Gen Pract* 2004; **54**: 909–14.

3 Department of Health. *National Service Framework for Older People*. London: Department of Health, HMSO, 2001.

4 Medical Research Council Cognitive Function and Ageing Study (MRC CFAS). Cognitive function and dementia in six areas of England and Wales: the distribution of MMSE and prevalence of GMS organicity level in the MRC CFAS Study. *Psychol Med* 1998; **28**: 319–35.

5 Evans DA, Funkenstein HH, Albert MS, *et al.* Disease in a community population of older persons: higher than previously reported. *JAMA* 1989; **262**: 2551–56.

6 Brodaty H, Green A. Family carers for people with dementia. In: O'Brien J, Ames D, Burns A eds. *Dementia*, third edition. London: Hodder Arnold Health Sciences, 2005: 193–205.

7 Ory M, Hoffman III RR, Yee J, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and

non-dementia caregivers. *Gerontologist* 1999; **39**: 177–85.

8 McCarthy M, Addington-Hall J, Altmann D. The experience of dying with dementia: a retrospective study. *Int J Geriatr Psychiatry* 1997; **12**: 404–09.

9 Kay D, Forster D, Newens A. Long-term survival, place of death, death certification in clinically diagnosed pre-senile dementia in Northern England. *Br J Psychiatry* 2000; **177**: 156–62.

10 Burns A, Jacoby R, Luthert P, Levy R. Cause of death in Alzheimer's Disease. *Age Ageing* 1990; **19**: 341–44.

11 National Hospice and Palliative Care Organisation. NHPCO facts and figures on hospice and palliative care. Available at: http://www.nhpco.org; Accessed July 2005.

12 Sloane PD, Zimmerman S, Hanson L, Mitchell CM, Riedel-Leo C, Cutis-Buie V. End-of-life care in assisted living and related residential-care settings: comparison with nursing homes. *J Am Geriatr Soc* 2003; **51**: 1587–94.

13 Volicer L, Hurley AC, Blasi ZV. Characteristics of dementia end-of-life care across settings. *Am J Hosp Palliat Care* 2003; **20**: 191–200.

14 Mitchell S, Morris J, Park P, Fries B. Terminal care for persons with advanced dementia in the nursing home and home care setting. *J Palliat Med* 2004; **7**: 808–16.

15 Mitchell S, Kiely D, Hamel M. Dying with advanced dementia in the nursing home. *Arch Intern Med* 2004; **164**: 321–26.

16 Aminoff B, Adunsky A. Dying dementia patients: too much suffering, too little palliation. *Am J Alzheimers Dis Other Dement* 2004; **19**: 243–47.

17 Field D, Froggatt K. Issues for palliative care in nursing and residential homes. In: Samson Katz J, Peace S eds. *End of life in care homes – a palliative-care approach*. Oxford: Oxford University Press; 2003.

18 Froggatt K. Palliative care and nursing homes: where next? *Palliat Med* 2001; **15**: 42–48.

19 Froggatt K, Poole K, Hoult L. The provision of palliative care in nursing homes and residential care homes: a survey of clinical nurse specialist work. *Palliat Med* 2002; **16**: 481–87.

20 Bamford C, Lamont S, Eccles M, Robinson L, May C, Bond J. Disclosing a diagnosis of dementia: a systematic review. *Int J Geriatr Psychiatry* 2004; **19**: 151–69.

21 Downs M, Clibbens R, Rae C, Cook A, Woods R. What do general practitioners tell people with dementia and their families about the condition? A survey of experiences in Scotland. *Dementia* 2002; **1**: 47–58.

22 Illiffe S, Eden A, Downs M, Rae C. The diagnosis and management of dementia in primary care: development, implementation and evaluation of a national training programme. *Aging Ment Health* 1999; **3**: 129–35.

23 Shuster J. Palliative care for advanced dementia. *Clin Geriatr Med* 2000; **16**: 373–86.

24 Hughes JC, Robinson L. General practice perspectives: coordinating end-of-life care. *Nurs Resid Care* 2004; **6**: 601–04.

25 Kitwood T. *Dementia reconsidered: the person comes first*. Buckingham: Open University Press, 1997.

26 Balint M. *The doctor, his patient and the illness*. Edinburgh: Churchill Livingstone, 2000.

27 Sachs G, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med* 2004; **19**: 1057–63.

28 Hughes JC, Hedley K, Harris D. The practice and philosophy of palliative care in dementia. *Nurs Res Care* 2004; **6**: 27–30.

29 Ryan D. The first international conference on the palliative care of the elderly. *J Palliat Care* 1989; **5**: 40–42.

30 National Center for Health Statistics. Highlights of a new report from the National Center for Health Statistics (NCHS): *Mortality trends for Alzheimer's disease*. 2003.

31 Walsh JS, Welch HG, Larson EB. Survival of outpatients with Alzheimer-type dementia. *Ann Intern Med* 1990; **113**: 429–34.

32 Wolfson C, Wolfson DB, Asgharian M, *et al*. A re-evaluation of the duration of survival after the onset of dementia. *N Engl J Med* 2001; **344**: 1111–16.

33 Hughes J, Robinson L, Volicer L. Palliative care in dementia. *BMJ* 2005; **330**: 57–58.

34 National Hospice Organization Medical Guidelines Task Force. *Medical guidelines for determining prognosis in selected non-cancer diseases*. Arlington, VA: National Hospice Organization; 1995.

35 Reisberg B, Fetris SH, DeLean MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychology* 1982; **139**: 113–39.

36 Reisberg B. Functional Assessment Staging (FAST). *Psychopharm Bull* 1988; **24**: 653–59.

37 Hanrahan P, Luchins DJ. Access to hospice programs in end-stage dementia: a national survey of hospice programs. *J Am Geriatr Soc* 1995; **43**: 56–59.

38 Luchins D, Hanrahan P, Murphy K. Criteria for enrolling dementia patients in hospices. *J Am Geriatr Soc* 1997; **45**: 1054–59.

39 Fabiszewski KJ, Volicer B, Volicer L. Effect of antibiotic treatment on outcome of fevers in institutionalized Alzheimer patients. *JAMA* 1990; **263**: 3168–72.

40 Van der Steen JT, Ooms ME, Van der Wal G, Ribbe MW. Pneumonia: the demented patient's best friend? Discomfort after starting or withholding antibiotic treatment. *J Am Geriatr Soc* 2002; **50**: 1681–88.

41 Morris J, Volicer L. Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutr Clin Care* 2001; **4**: 148–55.

42 Volicer L, Rheaume Y, Cyr D. Treatment of depression in advanced Alzheimer's disease using sertraline. *J Geriatr Psychiatry Neurol* 1994; **7**: 227–29.

43 Volicer L, Stelly M, Morris J, McLaughlin J, Volicer BJ. Effects of dronabinol on anorexia and disturbed behavior in patients with Alzheimer's disease. *J Geriatr Psychiatry* 1997; **12**: 913–19.

44 Sekizawa K, Matsui T, Nakagawa T, Nakayama K, Sasaki H. ACE inhibitors and pneumonia. *Lancet* 1998; **352**: 1069.

45 Nakagawa T, Wada H, Sekizawa K, Arai H, Sasaki H. Amantadine and pneumonia. *Lancet* 1999; **353**: 1157.

46 Finucane TE, Christmas C, Travis K. Tube-feeding in patients with advanced dementia: a review of the evidence. *J Am Med Assoc* 1999; **282**: 1365–70.

47 Morrison RS, Ahronheim JC, Morrison GR, *et al.* Pain and discomfort associated with common hospital procedures and experiences. *J Pain Symptom Manage* 1998; **15**: 91–101.

48 Volicer L, Rheaume Y, Riley ME, Karner J, Glennon M. Discontinuation of tube- feeding in patients with dementia of the Alzheimer type. *Am J Alzheimer's Care* 1990; **5**: 22–25.

49 Kelman HR, Thomas C, Kennedy GJ, Cheng J. Cognitive impairment and mortality in older community residents. *Am J Public Health* 1994; **84**: 1255–60.

50 McCormick WC, Kukull WA, Van Belle G, Bowen JD, Teri L, Larson EB. Symptom patterns and comorbidity in the early stages of Alzheimer's disease. *J Am Geriatr Soc* 1994; **42**: 517–21.

51 Zweig SC. Cardiopulmonary resuscitation and do-not-resuscitate orders in the nursing home. *Arch Fam Med* 1997; **6**: 424–29.

52 Ebell MH, Becker LA, Barry HC, Hagen M. Survival after in-hospital cardiopulmonary resuscitation. A meta-analysis. *J Gen Intern Med* 1998; **13**: 805–816.

53 Fried TR, Gillick MR, Lipsitz LA. Whether to transfer? Factors associated with hospitalization and outcome of elderly long-term care patients with pneumonia. *J Gen Intern Med* 1995; **10**: 246–50.

54 Thompson RS, Hall NK, Szpiech M, Reisenberg LA. Treatments and outcomes of nursing-home-acquired pneumonia. *J Am Board Fam Pract* 1997; **10**: 82–87.

55 Regnard C, Huntley ME. Managing the physical symptoms of dying. Part 1. *Nurs Resid Care* 2004; **6**: 130–34.

56 Kovach C, Noonan P, Muchka S, Weissman D. Use of the assessment of discomfort in dementia protocol. *Appl Nurs Res* 2001; **14**: 193–200.

57 Cipher D, Clifford P. Dementia, pain, depression, behavioural disturbances and ADL: towards a comprehensive conceptualisation of quality of life in long-term care. *Int J Geriatr Psychiatry* 2004; **19**: 741–48.

58 Harkins S. Geriatric pain: pain perceptions in the old. *Clin Geriatr Med* 1996; **12**: 435–59.

59 Marzinski L. The tragedy of dementia: clinically assessing pain in the confused non-verbal elderly. *J Gerontol Nurs* 1991; **17**: 25–28.

60 Frampton M. Experience assessment and management of pain in people with dementia. *Age Ageing* 2003; **32**: 248–51.

61 Scherder E, Oosterman J, Swaab D, *et al.* Recent developments in pain in dementia. *BMJ* 2005; **330**: 461–64.

62 Scherder E, Sergeant J, Swabb D. Pain-processing in dementia and its relation to neuropathology. *Lancet Neurol* 2003; **2**: 677–86.

63 Regnard C, Mathews D, Gibson L, Clark C, Watson B. Assessing distress in people with severe communication problems: Piloting the Northgate DisDAT. *Int J Palliat Nurs* 2003; **9**: 173–76.

64 Warde V, Hurley A, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. *J Am Med Dir Assoc* 2003; **4**: 9–15.

65 Snow A, Weber J, O'Malley K, *et al.* NOPPAIN: A nursing-assistant-administered pain-assessment instrument for use in dementia. *Dement Geriatr Cogn Disord* 2004; **17**: 240–46.

66 Abbey J, Piller N, De Bellis A, *et al.* The Abbey Pain Scale: a 1-minute numerical indicator for people with end-stage dementia. *Int J Palliat Nurs* 2004; **10**: 6–13.

67 Cameron M, Lonergan E, Lee H. Transcutaneous electrical nerve stimulation (TENS) for dementia. In: *Cochrane Data Syst Rev*, 2003.

68 Web reference: www.who.int/cancer/palliative/painladder/en/print.html.

69 Web reference: www.whocancerpain.wisc.edu/eng/15_2/essenhal.html.

70 Closs S, Barr B, Briggs M, Cash K, Seers K. *Pain assessment in nursing home residents with varying degrees of cognitive impairment*. The Mental Health Foundation, 2002.

71 Lloyd-Williams M. An audit of palliative care in dementia. *Eur J Cancer Care* 1996; **5**: 53–55.

72 Margallo-Lana M, Swann A, O'Brien J, *et al*. Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *Int J Geriatr Psychiatry* 2001; **16**: 39–44.

73 Gilley D, Whalen M, Wilson R, Bennett D. Hallucinations and associated factors in Alzheimer's disease. *J Neuropsychiatry Clin Neurosci* 1991; **3**: 371–376.

74 Donaldson C, Tarrier N, Burns A. Determinants of carer stress in Alzheimer's disease. *Int J Geriatr Psychiatry* 1998; **13**: 248–256.

75 Howard R, Ballard C, O'Brien J, Burns A, Dementia. Guidelines for the management of agitation in dementia. *Int J Geriatr Psychiatry* 2001; **16**: 714–17.

76 Price J, Hermans D, Grimley Evans J. Subjective barriers to prevent wandering of cognitively impaired people. In: *The Cochrane Library*. Issue 1. Chichester, UK: John Wiley & Sons, 2004.

77 Robinson L, Hutchings D, Corner L, *et al*. Wandering in dementia: a systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health Technol Assess*, 2006 (in press).

78 Margallo-Lana M, Reichelt K, Hayes P, *et al*. Longitudinal comparison of depression, coping, and turnover among NHS and private-sector staff caring for people with dementia. *BMJ* 2001; **322**: 769–70.

79 McGrath A, Jackson G. Survey of neuroleptic prescribing in residents of nursing homes in Glasgow. *BMJ* 1996; **312**: 611–12.

80 Ballard C, O'Brien J. Treating behavioural and psychological signs in Alzheimer's disease: the evidence for current pharmacological treatments is not strong. *BMJ* 1999; **319**: 138–39.

81 Ballard C, Margallo-Lana M, Juszczak E, *et al*. Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: randomised double-blind placebo-controlled trial. *BMJ* 2005; **330**: 874.

82 Bridges-Parlet S, Knopman D, Steffes S. Withdrawal of neuroleptic medications from institutionalized dementia patients: results of a double-blind, baseline-treatment-controlled pilot study. *J Geriatr Psychiatry Neurol* 1997; **10**: 119–26.

83 Cohen-Mansfield J, Lipson S, Werner P, Billig N, Taylor L, Woosley R. Withdrawal of haloperidol, thioridazine, and lorazepam in the nursing home: a controlled, double-blind study. *Arch Intern Med* 1999; **159**: 1733–40.

84 Ballard C, Thomas A, Fossey J, *et al*. A 3-month, randomized, placebo-controlled, neuroleptic-discontinuation study in 100 people with dementia: the neuropsychiatric inventory median cut-off is a predictor of clinical outcome. *J Clin Psychiatry* 2004; **65**: 114–19.

85 Committee on Safety of Medicines (CSM). *Atypical antipsychotic drugs and stroke*: Committee on Safety of Medicines; 2004, 9 March 2004.

86 Food and Drug Administration Public Health Advisory. *Deaths with antipsychotics in elderly patients with behavioral disturbances*. US Food and Drug Administration, FDA Public Health Advisory, Centre for Drug Evaluation and Research; 2005.

87 Ballard C, O'Brien J, James I, *et al*. Quality of life for people with dementia living in residential and nursing-home care: the impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs. *Int Psychogeriatr* 2001; **13**: 93–106.

88 McShane R, Keene J, Gedling K, Fairburn C, Jacoby R, Hope T. Do neuroleptic drugs hasten cognitive decline in dementia? Prospective study with necropsy follow-up. *BMJ* 1997; **314**: 2662–70.

89 Cohen-Mansfield J, Marx M, Lipson S, Werner P. Predictors of mortality in nursing-home residents. *J Clin Epidemiol* 1999; **52**: 273–80.

90 Woods RT. *Alzheimer's disease: coping with a living death*. London: Souvenir Press, 1989.

91 Aneshensel C, Pearlin L, Mullan J, Zarit S, Whitlatch C. *Profiles in caregiving: the unexpected career*. San Diego: Academic Press, 1995.

92 Willoughby J, Keating N. Being in control: the process of caring for a relative with Alzheimer's disease. *Qual Health Res* 1991; **1**: 27–50.

93 Wilson H. Family caregivers: the experience of Alzheimer's disease. *Appl Nurs Res* 1989; **2**: 40–45.

94 Teusink J, Mahler S. Helping families cope with Alzheimer's disease. *Hosp Community Psychiatry* 1984; **35**: 152–56.

95 Lindgren C. The caregiver career. *J Nurs Scholar* 1993; **25**: 214–19.

96 Motenko A. The frustrations, gratifications and well-being of dementia caregivers. *Gerontologist* 1989; **29**: 166–72.

97   Nolan M, Grant G, Keady J. *Understanding family care: a multidimensional model of caring and coping*. Milton Keynes, Buckinghamshire: Open University Press, 1996.

98   Cohen C, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002; **17**: 184–88.

99   Sweeting H. Caring for a relative with dementia: anticipatory grief and social death. *Bull Br Soc Geront* 1991; **16**: 6–11.

100 Sweeting H, Gilhooly M. Anticipatory grief: a review. *Soc Sci Med* 1990; **30**: 1073–1080.

101 Sweeting H. Dying and dementia. In: Cox S, Gilhooly M, McLennan I eds. *Dying and dementia*. Stirling: Dementia Services Development Centre, 1997.

102 Davis R. *My journey into Alzheimer's disease*. Amersham-on-the-Hill, Buckinghamshire: Scripture Press, 1989.

103 Williams O J K, Nolan M. Younger-onset Alzheimer's disease: learning from the experience of one spouse-carer. *J Clin Nurs* 1995; **4**: 31–36.

104 Bayley J. *Iris: a memoir of Iris Murdoch*. London: Duckworth, 1998.

105 McColgan G, Valentine J, Downs M. Concluding narratives of a career with dementia: accounts of Iris Murdoch at her death. *Ageing Soc* 2000; **20**: 97–109.

106 Bass D, Bowman K. The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death. *Gerontologist* 1990; **30**: 35–41.

107 Bass D, Bowman K, Noelkar L. The influence of caregiving and bereavement-support on adjustment to an older relative's death. *Gerontologist* 1991; **31**: 32–41.

108 Parkes C. Bereavement and mental health in the elderly. *Rev Clin Gerontol* 1992; **2**: 45–51.

109 Clark P, King K. Comparison of family caregivers; stroke survivors vs. persons with Alzheimer's disease. *J Gerontol Nurs* 2003; **29**: 45–530.

110 Briggs K, Askham J. *The needs of people with dementia and those who care for them*. London: Alzheimer's Society, 1999.

111 Knight B, Lutzky S, Macofsky-Urban F. A meta-analytic review of interventions for caregiver distress: recommendations for future research. *Gerontologist* 1993; **33**: 240–48.

112 Dellasega C. Coping with caregiving: stress management for caregivers of the elderly. *J Psychosoc Nurs* 1990; **28**: 15–22.

113 Brodaty H, Gresham M, Luscombe G. The Prince Henry Hospital Dementia Caregivers' Training Programme. *Int J Geriatr Psychiatry* 1997; **12**: 183–92.

114 Pusey H, Richards D. A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging Ment Health* 2001; **5**: 107–19.

115 Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist* 2002; **42**: 356–72.

116 Carradice A, Beail N, Shankland M. Interventions with family caregivers for people with dementia: efficacy problems and potential solution. *J Psychiatr Ment Health Nurs* 2003; **10**: 307–15.

117 Challis D, von Abendorff R, Brown P, Chesterman J. Care-management and dementia: an evaluation of the Lewisham Intensive Case Management Scheme. In: HunterSE ed. *Dementia: challenges and new directions*. London: Jessica Kingsley Publishers, Ltd. 1997, 139–64.

118 Keady J, Clarke C, Adams T eds. *Community mental-health nursing and dementia care: practice perspectives*. Maidenhead: Open University Press; 2003.

119 Corbin J, Strauss ASF. *Unending work and care: managing chronic illness at home*. San Francisco CA: Jossey Bass, 1988.

120 Rolland J. A conceptual model of chronic and life-threatening illness and its impact on families. In: CS Chilman, EW Nunally, FM Cox. eds. *Chronic illness and disabilities*. Beverly Hills, CA: Sage, 1988: 17–68.

121 Albinsson L, Strang P. Differences in supporting families of dementia patients and cancer patients: a palliative perspective. *Palliat Med* 2003; **17**: 359–67.

122 Mullan J. The bereaved caregiver: a prospective study of changes in well-being. *Gerontologist* 1992; **32**: 673–83.

123 Almberg B, Grafström M, Winblad B. Caregivers of relatives with dementia: experiences encompassing social support and bereavement. *Aging Ment Health* 2000; **4**: 82–89.

124 Schulz R, Mendelsohn A, Haley W, *et al.* End-of -life care and the effects of bereavement of family caregivers of persons with dementia. *N Eng J Med* 2003; **349**: 1936–42.

125 Forbes S, Bern-Klug M, Gessert C. End-of-life decision-making for nursing home residents with dementia. *J Nurs Scholar* 2000; **32**: 251–58.

126 Bonjean J, Bonjean D. Working with the family. In: CR Kovach ed. *Late-stage dementia care: a basic guide*. London: Taylor and Francis, 1997: 171–87.

127 Albinsson L, Strang P. A palliative approach to existential issues and death in end-stage dementia care. *J Palliat Care* 2002; **18**: 168–74.

128 Teno J, Landrum K, Lynn J. Defining and measuring outcomes in end-stage dementia. *Alzheimer's Dis Assoc Dis* 1997; **11**: 25–29.

129 Collins C, Liken M, King S, Kokinakis C. Loss and grief among family caregivers of relatives with dementia. *Qual Health Res* 1993; **3**: 236–53.

130 Greenwood M, Walsh K. Supporting carers in their own right. *J Dement Care* 1995; **3**: 14–16.

131 Woods R, Wills W, Higginson I, Hobbins J, Whitby M. Support in the community for people with dementia and their carers: a comparative outcome study of specialist mental-health service interventions. *Int J Geriatr Psychiatry* 2003; **18**: 298–307.

132 Wasson K, Tate H, Hayes C. Food refusal and dysphagia in older people with dementia: ethical and practical issues. *Int J Palliat Nurs* 2001; **7**: 465–71.

133 Gillick M. Rethinking the role of tube-feeding in patients with advanced dementia. *N Engl J Med* 2000; **342**: 206–10.

134 Beauchamp T, Childress J. *Principles of biomedical ethics*, fifth edition. New York: Oxford University Press, 2001.

135 Gillick M. Artificial nutrition and hydration in the patient with advanced dementia: is withholding treatment compatible with traditional Judaism? *J Med Ethics* 2001; **27**: 12–15.

136 Eggenberger S, Nelms T. Artificial hydration and nutrition in advanced Alzheimer's disease: facilitating family decision-making. *J Clin Nurs* 2004; **13**: 661–67.

137 The A, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. *BMJ* 2002; **325**(7376): 1326.

138 Hughes JC, Dove P. The ethics of end-of-life decisions in severe dementia. In: Hughes J ed. *Palliative care in severe dementia*. London: Quay Books, 2006: 45–54.

139 Purtilo R, ten Have H eds. *Ethical foundations of palliative care for Alzheimer's disease*. Baltimore: Johns Hopkins University Press, 2004.

140 Collopy B. Autonomy in long-term care: some crucial distinctions. *Gerontologist* 1988; **28** (suppl): 10–17.

141 Agich G. *Dependence and autonomy in old age: an ethical framework for long-term care*. Cambridge: Cambridge University Press, 2003.

142 Hughes J. Views of the person with dementia. *J Med Ethics* 2001; **27**: 86–91.

143 Chan H. Sharing death and dying: advance directives, autonomy and the family. *Bioethics* 2004; **18**: 87–103.

144 Hedley K, Hughes J. Aspects of holistic terminal care in severe dementia. *Nurs Resident Care* 2004; **6**: 82–85.

145 van Delden J. The unfeasibility of requests for euthanasia in advance directives. *J Med Ethics* 2004; **30**: 447–52.

146 Gedge E. Collective moral imagination: making decisions for persons with dementia. *J Med Philos* 2004; **29**: 435–50.

147 Sabat S. *The experience of Alzheimer's disease: life through a tangled veil*. Oxford and Malden, MA: Blackwell, 2001.

148 Woods B, Pratt R. Awareness in dementia: ethical and legal issues in relation to people with dementia. *Aging Ment Health* 2005; **9**: 423–29.

149 van der Steen J, Ooms M, van der Wal G, Ribbe M. Withholding or starting antibiotic treatment in patients with dementia and pneumonia: prediction of mortality with physicians' judgment of illness severity and with specific prognostic models. *Med Decis Making* 2005; **25**: 210–21.

150 Jeffery P. *Going against the stream: ethical aspects of ageing and care*. Leominster, Gracewing, and Collegeville (Minnesota): The Liturgical Press, 2001.

151 Fulford K. Facts/Values. Ten principles of values-based medicine. In: Radden J ed. *The philosophy of psychiatry: a companion*. Oxford: Oxford University Press, 2004: 205–234.

152 Low J, Chan D, Hung W, Chye R. Treatment of recurrent aspiration pneumonia in end-stage dementia: preferences and choices of a group of elderly nursing-home residents. *Intern Med J* 2003; **33**: 345–49.

153 Hughes JC, Louw SJ. End-of-life decisions. In: Burns A, O'Brien J, Ames D eds. *Dementia*, third edition London: Hodder Arnold Health Sciences, 2005: 241–45.

154 Hughes J, Dove P. The ethics of end-of-life decisions in severe dementia. *Nurs Resident Care* 2004; **6**: 240–43.

155 Post S. *The moral challenge of Alzheimer disease: ethical issues from diagnosis to dying*, second edition. Baltimore: The Johns Hopkins University Press, 2000.

156 World Health Organisation. *Better palliative care for older people*. Copenhagen: World Health Organisation, 2004.

157 House of Commons Health Committee. *Palliative care*. London.

158 Luchins DJ, Hanrahan P. What is appropriate health care for end-stage dementia? *J Am Geriatr Soc* 1993; **41**: 25–30.

159 Hanrahan P, Luchins D, Murphy K. Palliative care for patients with dementia. In: Addington-Hall J, Higginson I eds. *Palliative care for non-cancer patients*. Oxford: Oxford University Press, 2001.

160 Sampson E, Ritchie C, Lai R, Raven P, Blanchard M. A systematic review of the scientific evidence for the efficacy of a palliative-care approach in dementia. *Int Psychogeriatr* 2005; **17**: 31–40.

161 World Health Organisation. *Cancer pain relief and palliative care*. Technical Report Series 804. Geneva: World Health Organisation; 1990. Report No.804.

162 National Council for Hospice and Specialist Palliative Care Services. *Specialist palliative care: a statement of definitions*. London: National Council for Hospice and Specialist Palliative Care Services, 1995.

163 Volicer L, Rheaume Y, Brown J. Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. *JAMA* 1986; **256**: 2210–13.

164 Volicer L, Collard A, Hurley A, Bishop C, Kern D, Kanon S. Impact of special care units for patients with advanced Alzheimer's disease on patient discomfort and costs. *J Am Geriatr Soc* 1994; **42**: 597–603.

165 Kai JE ed. *Valuing diversity: a resource for effective health care of ethnically diverse communities*. London: Royal College of General Practitioners, 1999.

166 Kai J, Spencer J, Wilkes M, Gill P. Learning to value ethnic diversity – what, why and how? *Med Educ* 1999; **33**: 616–23.

167 Ellershaw J, Foster A, Murphy D, Shea T, Overill S. Developing an integrated pathway for the dying patient. *Eur J Palliat Care* 1997; **4**: 203–07.

168 Thomas K. *Caring for the dying at home. Companions on a journey*. Oxford: Radcliffe Medical Press, 2003.

169 National Institute of Health and Clinical Excellence. *Improving supportive and palliative care for adults with cancer*. In: http://www.nice.org.uk; Accessed 15th August 2005.

170 Ellershaw J, Wilkinson S. *Care of the dying. A pathway to excellence*. Oxford: Oxford University Press, 2003.

171 Shega JW, Levin A, Houghan GW, *et al*. Palliative excellence in Alzheimer care efforts (PEACE): a program description. *J Palliat Med* 2003; **6**: 315–20.

172 Audit Commission. *Forget-me-not*. London: Audit Commission; 2002.

173 Evers MM, Purohit D, Perl D, Khan K, Martin DB. Palliative care and aggressive end-of-life care for patients with dementia. *Psychiatr Serv* 2002; **5395**: 609–61.