

# Seeing patients with dementia through to the end of life

Death with dementia accounts for 1 in 3 deaths in an average general practice. End of life, and death with dementia may be complicated by distress, which is difficult to interpret and resolve. A positive, proactive approach using palliative care principles helps the patient, their family, and professional carers. General practitioners attending nursing homes is the best method for coordinating this work. Support should be available from local services for old-age psychiatry and palliative care.

**David Jolley\*** Consultant Psychiatrist, Personal Social Services Research Unit, Manchester University, Dover Street, Manchester M13 9PL, UK.

**Julian Hughes** Consultant Psychiatrist, North Tyneside General Hospital, Rake Lane, North Shields NE29 8NH, and Institute for Ageing and Health, Newcastle University, Claremont Road, Newcastle upon Tyne NE1 7RU, UK.

**Ian Greaves** General Practitioner, Gnosall Health Centre, Gnosall ST20 0GP, UK.

**Alice Jordan** Training and Research Fellow and Specialist Registrar in Palliative Medicine, North Tyneside General Hospital, Rake Lane, North Shields NE29 8NH, UK.

**Elizabeth Sampson** MRC Research Fellow, Department of Mental Health Sciences, Royal Free and University College Medical School, Hampstead Campus, Rowland Hill Street, London NW3 2PF, UK.

\*email david.jolley@manchester.ac.uk

As more people in the UK expect to survive into their 80s and beyond, their chance of experiencing some months or years of life with dementia and dying with dementia has increased substantially. One in three deaths in an average general practice will be an individual who has dementia.<sup>1</sup> Many deaths among people with dementia are indistinguishable from general deaths of older people—ie, an acute illness or trauma results in either death in the community, or admission to a general hospital for assessment, investigation, and treatment. In such cases, there is sadness at the end of life, but no added problem.

For some people, however, life sustained into the severe stages of dementia can be troubled.<sup>2</sup> Their last weeks or months of life may be marked by increased physical dependency, falls, incontinence, debility, and the emergence of behavioural changes such as agitation, aggression, or vocal distress.

Although almost everyone would like to stay in their own home to die, the reality is that most will die somewhere else: 76% of one cohort of patients with dementia, who had been identified while living in their own homes, had moved into some form of institution before their death. On average, such patients spent 18 months of their final, 8–9 dementia-dominated years in an institution.<sup>3</sup> The quality of care received by people with dementia in nursing homes, psychiatric wards, or general hospital is often less than optimum, both at the end of life and in the preceding months.

## Box 1: Key points

- The chance of an individual experiencing some months or years of life with dementia and dying with dementia has increased substantially
- For some people, life sustained into the severe stages of dementia can be troubled
- The quality of care received by people with dementia in nursing homes, psychiatric wards or general hospitals is often less than optimum
- Using a palliative care approach is key. The primary objectives are to avoid or reduce distress rather than to extend life
- The appropriate and adequate use of symptomatic treatments: heat or cold massage, physiotherapy, gentle exercise, pressure relief, aromatherapy, non-opiate analgesics, mild opiate analgesics, or stronger opiate analgesics is essential good practice
- Medication is part of this doctoring—working with the individual, the care-staff, family, and spiritual leader, as well as other residents of the care establishment is essential to gain an understanding of what this death means to them, and to play a part in their addressing this death in a satisfactory and positive way during the process of dying and in the time ahead

Maintenance of bodily health, muscle mass, and strength, and avoidance of contractures and immobility needs skilled encouragement and exercise which might best be overseen by a physiotherapist. However, such care is not easy to supply with the available workforce. Maintaining

skin integrity requires scrupulous attention to nutrition, pressure areas, and posture. Loss of continence and the ever-present threat of constipation add to the prospect of discomfort and pain, or the emergence of intercurrent toxic states. If these are to be avoided, they have to be countered by sustained vigilance and sensitive, disciplined attention from carers. Homeostasis, which previously guaranteed internally moderated stability, is destroyed by the advance of dementia.

The natural appetites of thirst and hunger are dulled and depend on externally imposed routines to function at all, and awareness of hazard is muted. Thus, maintaining sufficient intake of food and drink becomes a struggle and will be further compromised if mastication and swallow are lost or disorganised. This is a worrying and even frightening situation for professional carers and family, although patients may be oblivious and untroubled.

The urge to do something—ask for help, seek transfer to hospital, make use of mechanical devices such as nasogastric tubes or PEG-feeds—may be strong. The experience of their use in this situation is interpreted differently in different countries and cultures. In the UK the predominant view is that these mechanical approaches are not helpful, can be distressing, and can induce additional health problems. They carry risks of both morbidity and mortality rather than guarantees of greater quality or length of life.

Reduced mobility, shallow breathing, and impaired immune response increase the risk of infections in people with advanced dementia. Pneumonia is the most common cause of death in these patients. The appropriate identification of infections and treatment, if indicated, is clearly good practice and can reduce symptoms such as cough, fever, and toxicity. However, attempts to maintain life in the face of overwhelming infection is not recommended because, although life may be marginally extended, the patient might develop distressing symptoms, debility, and decubitus ulcers.

## Palliative care

---

Using a palliative care approach is key. The primary objectives are to avoid or reduce distress rather than to extend life. Evidence suggests that palliative interventions are often rewarded by longer life than might be achieved by apparently curative therapies.<sup>4</sup> When patients are distressed in the last stages of dementia, their ability to identify and describe the focus and nature of their feelings is often lost or confused. Careful examination and thought is required to seek possible causes and to correct them as far as is possible. Beyond this, appropriate and adequate use of symptomatic

treatments: heat or cold massage, physiotherapy, gentle exercise, pressure relief, aromatherapy, non-opiate analgesics, mild opiate analgesics, or stronger opiate analgesics is essential good practice. Patients cannot ask for what they need, so doctors have to anticipate their needs and prescribe accordingly. Checklists exist to help in the identification of pain in dementia,<sup>5</sup> but these still require clinical judgement. And, even in the presence of recognised pain, people with dementia are not given analgesics in equivalent quantities to those administered without dementia.<sup>6</sup> This problem may be a consequence of symptom modification or of difficulties communicating symptoms in dementia.<sup>7</sup> However, concerns exist that appropriate prescribing is withheld because of fear of misunderstanding or the misrepresentation that medication was given with an intention to shorten life—rather than to alleviate suffering.<sup>8</sup> Such scruples are virtually unknown in the palliative care of cognitively intact patients dying with cancers.

Medication is part of this doctoring—work with the individual, the care-staff, family, and spiritual leader, as well as other residents of the care establishment is essential to gain understanding of what this death means to them. Physicians also play a part in addressing death in a satisfactory and positive way both during the process of dying and in the time ahead. These are tasks that demand time, wisdom, and experience. Ultimately doctors must be prepared to be experts in management of death, so that it can be accepted with confidence and respect.

## Hospital versus hospice care

Relocation of patients to places of supposed greater expertise, usually for maintenance of life, rather than best care of its ending, might satisfy fears that we did all that we could. But, such actions rarely add to the comfort and reassurance of the dying person. They may not be welcomed by a community devoted to resuscitation and staffed by people who have known little or nothing of this muddled and frail old person, their family, or their recent history.<sup>8</sup> Arguments are being developed for specialised palliative-care services for people with dementia working from the model that is successful for cancer and other terminal illnesses.<sup>9</sup> However, no infrastructure of charities exists, such as underpins hospices, that might accept such a role nationally for dementia. The removal of long-stay or end-of-life care from most NHS mental health services has denied staff the opportunity to gain and practise expertise in providing this facility.

For the most part, the hospice work is done in private-sector nursing homes and the doctoring comes from general practitioners. General practitioners must

take a positive and proactive interest in patients who have dementia. Many patients enrol at a practice late in the disease, having been placed in a nursing home from elsewhere, and so doctors lack the long-term involvement and mutual knowledge that otherwise develops between practitioners, older patients, and their families. A big effort is, therefore, required from all parties if optimum preparations for the last phase of life and final parting are to be accomplished. This time will be well spent, and may reduce distress and trauma. The primary-care team should expect support throughout from a local old-age psychiatry service, perhaps complemented by advice from the local palliative-care service in specific situations.

National policy has shown increasing interest in end-of-life care in dementia. The *Gold Standards Framework*<sup>9</sup> has been adapted for use within nursing homes, the National Council for Palliative Care is carrying out a UK-wide information-gathering exercise for all local services attempting to improve end-of-life care for dementia, and the National Audit Office has backed the guidelines issued by NICE and the Social Care Institute for Excellence calling for a palliative care approach for people with dementia. Much remains to be learned by all partners; hence, audit and research strategies should be included as essential components of routine work. Participants will be rewarded by mutual education and, hopefully, progressive improvements in the quality of care and experience for patients, families, and front-line staff.

### We have no conflict of interest.

### References

1. Davies E, Higginson I (eds). Better palliative care for older people. WHO Europe, 2004. [www.euro.who.int/document/E82933.pdf](http://www.euro.who.int/document/E82933.pdf) (accessed 20 Aug 2008).
2. Hughes JC, Jolley DJ, Jordan A, Sampson EL. Palliative care in dementia: issues and evidence. *Adv Psychiatr Treat* 2007; **13**: 251–60
3. Keane J, Hope T, Fairburn CG, Jacoby R. Death and dementia. *Int J Geriatr Psychiatr* 2001; **16**: 969–74
4. Tripodo V, De Vito E. Management of dyspnoea in advanced motor neurone disease. *Curr Opin Supp Palliat Care* 2008; **2**: 173–79
4. Zwakhalen S, Hamers J, Abu-Saad H, Berger M. Pain in elderly people with severe dementia: a systematic review of behavioural pain assessment tools. *BMC Geriatrics* 2006; **6**: 3
5. Closs SJ, Barr B, Briggs M. Cognitive status and analgesic provision in nursing home residents. *Br J Gen Pract* 2004; **54**: 919–21
6. Scherder EJ, Sergeant JA, Swaab DF. Pain processing in dementia and its relation to neuropathology. *Lancet Neurol* 2003; **2**: 677–86
7. Sampson EL, Gould V, Lee D, Blanchard M. Differences in care received by patients with and without dementia who died during acute hospital admission: a retrospective case note study. *Age Ageing* 2006; **35**: 187–89
8. Hughes JC, Robinson L, Volicer L. Specialist palliative care in dementia. *BMJ* 2005; **330**: 57–58
9. The Gold Standards Framework in care homes. [http://www.goldstandardsframework.nhs.uk/care\\_homes.php](http://www.goldstandardsframework.nhs.uk/care_homes.php) (accessed 20 Aug 2008)