About 100,000 people with dementia die each year in the UK. It is exceptional for them to spend their last days in a hospice, and any involvement of formal palliative care services is still unusual. Despite the wish of most patients and their families that they should die in their own home, most people with dementia currently die in hospital, on acute wards, where staff are poorly trained to recognise and address their special needs.

In this issue, Sampson and colleagues [1] report a retrospective case note audit of older patients dying on an acute medical ward in a London hospital in 2002/2003. More than one in four had a diagnosis of dementia documented in the medical notes, and it seems likely that other cases were not recognised, as formal cognitive testing was not routine and the mean of the available abbreviated mental test scores in the ‘non-dementia’ patients was below the conventional cut-off. Whilst some invasive procedures, such as central venous lines and mechanical ventilation, were used infrequently in those with documented dementia, other interventions such as collection of arterial blood gases and use of nasogastric tubes and urinary catheters were more common in people with dementia than in those without. Most significantly, those with dementia were less likely to be referred to palliative care teams (9 versus 25%) and were prescribed fewer palliative medications (28 versus 51%).

That patients dying with dementia have significant health care needs, comparable with cancer patients, is now well established. Yet, their families typically describe poor advance-care planning and an inadequate level of symptom management, with distress associated with pain, pressure sores, constipation, restlessness and shortness of breath [2, 3]. A comparison of people dying with advanced dementia or terminal cancer in New York state’s nursing homes [4] found that those with dementia were more likely to experience burdensome interventions such as tube feeding (25%), laboratory tests (49%) and restraints (11%) and to have had poor advance-care planning. Before death, only 55% of demented residents had a do-not-resuscitate order and 1% had a do-not-hospitalise order. A prospective study of consecutive end-stage dementia patients dying in a general geriatric department of a tertiary hospital in Israel found that suffering increased during hospital stay, with nearly two-thirds dying with a ‘high’ level of suffering [5].

In the UK, the need for management and educational strategies to improve end-of-life care with advanced dementia has been the subject of recent government and professional interest [6, 7], and Hughes and colleagues [8] have called for the development of specialist palliative care teams for dementia. However, a systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia identified only two trials eligible for inclusion, both from North America and yielding equivocal evidence of benefit [9]. Regrettably, the authors comment that there is no sign that the number of empirical studies in this field is increasing.

As well as a growth in the evidence-base to guide service development, a number of barriers will need to be overcome if high-quality end-of-life care for people with dementia is to permeate clinical practice [10]. The common failure to recognise dementia as a terminal illness creates an immediate problem, and this is compounded by difficulties with accurately predicting prognosis. In the US nursing home study, only 1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 months at the time of admission, but 71% died within that period [4]. Difficulties with communication can lead to poor understanding of the wishes and needs of the person with dementia, and advance directives are rarely available to help with decision-making. Perhaps this may change with implementation of the new Mental Capacity Act. Clinical management may be hampered further by patients’ lack of co-operation and consent to assessment and treatment. Other ethical dilemmas abound, with frequent uncertainty around appropriate use of investigations, the place of antibiotics, best management of feeding difficulties and need for physical and pharmacological restraints.

Provision of care should not only go beyond merely symptom control, but encompass also patients’ psychological and spiritual needs, as well as consideration of the needs of their families who have often borne the burden of care for many years. It is necessary for all doctors and nurses responsible for clinical care of people with dementia to develop the necessary skills and knowledge to deliver optimal end-of-life care. The present situation where some palliative care teams refuse people with dementia—even those with concurrent cancer, and some physicians expect old-age psychiatry services to provide a takeaway service, even when patients with dementia are close to death—needs to change.

Tools to help with management in advanced dementia have been developed [11, 12] but are little used. Specific assessment and treatment protocols such as the Assessment of Discomfort in Dementia Protocol [13] or more general guidelines such as the Liverpool Care Pathway [14] can help to guide intervention. There is evidence that audit of symptom management in patients dying with dementia and development and implementation of multidisciplinary guidelines for the palliation of symptoms can have a positive impact.
This could easily be introduced into medical and geriatric departments without much need for extra resources.

More good-quality randomised controlled trials are necessary to determine the most appropriate interventions and most effective method of delivery of care. This might be a suitable activity for the new Dementias and Neurodegenerative Disease Research Network. Education about end-of-life care for people with non-malignant diseases such as dementia should have a much higher profile in general undergraduate and postgraduate teaching, and the focus of palliative medicine still needs to be broadened away from just terminal cancer care. Finally, policy makers and health commissioners need to be encouraged to continue to work with patient organisations and clinicians to develop and fund appropriate and cost-effective services for the large and growing number of people with dementia, so that the best quality of life is maintained from the time symptoms first develop right up to the moment of death.

References


