Palliative care for people with dementia

Palliative care services for those with dementia are patchy across the UK and could benefit from sharing best practice. Les Bright explores current practice and recent guidance.

Estimates of the numbers of care home residents with dementia vary, but it's clear that they make up a significant proportion of that population. What kind of care can they expect at the end of their lives? Palliative care services for people with dementia are not as well developed as for cancer sufferers and this means that patients in different areas of the country receive differing levels of care and support. However, partnerships are emerging and in some cases flourishing, which can help the sector improve.

Palliative care

Palliative care is defined as the active holistic care of patients with advanced progressive illness. Management of

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pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.

Special interest... and national interest

The National Council for Palliative Care (NCPC) has been undertaking a special project looking at policy and practice in dementia palliative care and aims to promote increased and better quality palliative and end of life care for people with dementia. The NCPC has produced a steady stream of accessible reports leading up to the publication of *Creative Partnerships:*

ORDER OF ST JOHN CARE TRUST

New care plan documentation recently introduced across the Trust has built on solid foundations of good practice. It includes references to advance care plans, especially important as the end of life approaches, where mental capacity is limited or variable, and to residents' religious and spiritual needs.

Each of the Trust's managers stressed the importance of working in partnership with colleagues from other services and residents' families. 'We've found that it's very important to stay in touch with district nurses and others who may have been very involved with residents until they move to our home,' said Plum Morgan who manages a home in Gloucestershire. This was echoed by her colleague Joy Warren, who manages another home, 'We have to make use of the resources out there and so we work really closely with community staff.'

Developing relationships with MacMillan nurses has proved particularly effective as they seem to be especially well placed to influence GPs, for instance, in relation to drugs they may be prescribing.

Managers have been encouraged to identify training courses, and Joy talked enthusiastically of a series of sessions which she and three colleagues – two care workers and a nurse – attended on end of life issues, organised by their local hospice. The trainers have subsequently acted as mentors offering advice and continuing support as she set about implementing the learning.

'Keeping people comfortable at this time means paying attention to pain relief. Even if someone is no longer able to communicate, staff who know them well will be able to pick up on facial expressions and will see when someone flinches or winces,' Plum said.

A resident may be beyond making choices but team working - drawing on the accumulated knowledge of professionals and family - can make such a difference.

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VALE HOUSE, NEAR OXFORD

The Botley Alzheimer's Home is a small not-for-profit organisation, set up nearly 20 years ago, by a pressure group which wanted to provide a better home for people with dementia than any of the options available locally at that time.

Vale House has 20 residents and as Tricia O'Leary, a nurse who manages the home explained, there are two distinct groups of people living there at any given time. People who were recently admitted due to problems in managing their difficult behaviour who need lots of attention in order to help them and their families through difficult times; and those in the more advanced stages of their illness who will, in keeping with the home's philosophy, live out the remainder of their life there. To ensure that is possible, and above all comfortable, the home draws on a wide range of expert help to augment the skills already in place across the team. Networking and partnership have been watchwords of the home's development and this means that they're able to tap into help across a wide range of disciplines as varied as nutritionists, dieticians, tissue viability nurses and Community Psychiatric Nurses. Recognising that residents' families need support too the team also includes a social worker with expertise in bereavement, capable of taking people through difficult times.

The key to this approach lies in acknowledging that the team is not expert in everything and can provide a better life - and ultimately death - for residents by being ready to seek advice and practical help where necessary. Care staff become expert with individual residents by working closely with them to understand their behaviour and the underlying patterns, and by encouraging families to share knowledge of a loved one's history.

Right now six or seven residents are still able to walk around, while a dozen or so are very frail and immobile and need assistance to eat. 'We want residents to live well until they die, and to be well fed and well hydrated so that they can be as comfortable as possible.' The key to this is, predictably, staff. By recruiting good people with potential and having an enlightened board of directors ready to invest in the team a good holistic service can be provided. 'Our attitude is to aim high.'

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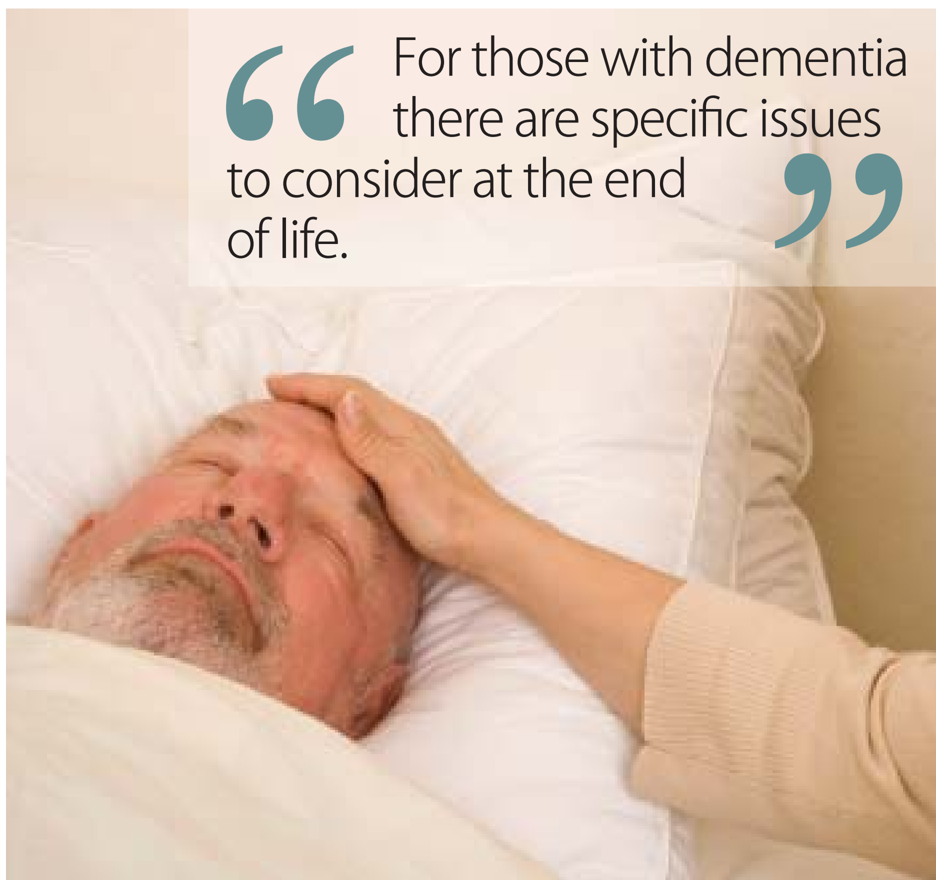
▶ *Improving Quality of Life at the End of Life for People with Dementia* launched at their conference in January 2008.

They have described the current position of palliative care for those with dementia as being fragmented and variable, and go on to suggest that the physical needs of many people are not met. If homes are falling down on that front then it is unlikely that they are doing any better in responding to the psychological, social and spiritual dimensions of their residents' lives.

But this is a good time to be identifying such deficiencies as the launch of the National Dementia Strategy in the summer of 2007 has led to increased professional attention being given to some critical issues. Continuing discussion of personalised care and ways of protecting and promoting dignity also provide opportunities to highlight scope for improvements to policies, procedures and practices, and to prioritise support for some very vulnerable people.

The implementation of the Mental Capacity Act 2005, in particular the provision for Lasting Powers of Attorney, now enables people to think and plan in advance beyond money matters. Expressing their wishes about health and welfare issues is yet another lever that will act to bring consideration of sensitive issues into conversations providers may have with new residents' families when they move into a home.



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Key messages

Death is a common feature of life in homes for older people. At any one time a number of residents may be in the end of life phase and so managers and staff should be as prepared for managing the events surrounding this as they are for other aspects of daily life.

For those with dementia there are specific issues to consider at the end of life.

According to the Alzheimer's Society life expectancy for a person with dementia can be difficult to predict. The disease can progress for up to around ten years and although it is a life-shortening illness those with it may die from another condition such as bronchopneumonia.

It's important to discuss the palliative care requirements of an individual with them, their family and carers to ensure that you address their needs and wishes. Collaborative working is vital if homes are to offer the best possible care. The list of potential collaborators is long and can include GPs, District Nurses, nutritionists, physiotherapists and relatives.

Good practice should be based around the fundamental principles of good care planning and be subject to regular review that aims to draw on the wishes of the resident and their carers and family members. **CMM**

HEART OF ENGLAND HOUSING AND CARE

This organisation, working in partnership with primary care services, managed to look after residents who were dying in its care homes. However, they recognised that as residents' situations worsened they were, in some cases, moved to hospital or a nursing home. This was disappointing for all parties who had hoped that they would be allowed to die at the home.

A pilot project was run with healthcare staff, looking at the next two deaths in each of two homes and what changes would be necessary to improve services for residents so that such late and distressing moves could be avoided. District nurses assisted and identified good practice issues that together contributed to a good end of life experience.

HoE has spread the learning from the pilot across all nine residential homes it runs so that in future more residents can live and die in comfort in their own home.

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For more information on the NCPC's project and publications please visit www.ncpc.org.uk