

Comfort care, peace and dignity at the end of life

Good end of life care is essential in dementia, but not always delivered. **Angela Liddament** explains her role as an advanced nurse practitioner in a Norfolk care village

The rising prevalence of dementia has drawn particular attention to the need for good end of life care. Both the Department of Health's End of Life Care Strategy (DH 2008) and the National Dementia Strategy (DH 2009) emphasised the importance of improving end-of-life care for people with one or more chronic long-term conditions, including dementia. The aim has been to bring it up to a level received by people with a cancer diagnosis.

Evidence shows that care provision has failed to meet the complex needs of the growing numbers of people living with dementia (Dempsey *et al* 2015). Furthermore, few people with dementia have access to palliative and hospice care (Ballard 2016). So, it is essential that good quality end-of-life care, whether in the community, hospital or care home, is made available (Bracegirdle 2012).

One of the problems is that, despite the availability of different prognostic indicators to aid clinicians in recognising when a patient is nearing the end of life, it can be particularly challenging in the case of dementia. It is another reason why this group often receives inadequate end of life care (Dempsey *et al* 2015).

The most used prognostic indicator in primary care is the Gold Standards Framework (GSF) Proactive Identification Guidance (PIG) (2016). This guidance has three triggers to suggest a person is nearing the end of life:

- the surprise question: "Would you be surprised if this person were to die over the next few months, years or days?"
- general indicators of decline
- specific clinical indicators related to certain conditions.

It remains unusual for a person with advanced dementia to be on a GSF register in primary care. Care homes, however, have improved considerably since the GSF in Care Homes (Badger *et al* 2007) and Six Steps (DH 2008) programmes emerged with the aim of educating both care staff and managers in awareness and development of better end-of-life care for their residents.

Notwithstanding this improvement, the social care funding crisis has led to a worrying trend in which residential placements are increasingly at a premium, resulting in more people with advanced dementia dying in hospital (Middleton-Green 2016).

The decision to move a loved one to a care home is often painful, a last resort and frequently seen by family, carers and friends as "failing" them. But this

feeling can be misplaced because a good care home should provide a nurturing, caring and supportive atmosphere for people with advanced dementia as they approach the end of life. Although care staff come and go, there will be some staff who are a consistent presence and offer continuity of care, ideally enabling a close bond to develop with resident, family and friends.

Bowthorpe Care Village opened in Norwich in early 2016 and, although not a new concept nationally, it was new to Norfolk. On a single site, which is part of a housing estate, there are 90 housing with care flats including 11 with "extra care" and six "bariatric" flats*, as well as a dementia unit with 80 residents. The dementia unit is a protected and locked environment with most residents covered by the deprivation of liberty safeguards (DoLS). It is seen as the best way, at this late stage of their dementia, to protect them from harm.

Although in a locked unit, residents are still encouraged, wherever possible, to participate in the day-to-day life of the village. Volunteers, carers and families are available to escort the residents to whichever activity they want to partake in. This includes a shop, hairdressers, restaurant, café, gardens and entertainment areas offering a wide range of planned activities.

Specialist palliative care

I am the advanced nurse practitioner (ANP) (DH 2010), on site Monday to Friday during office hours overseeing the medical care of all residents, with part-time support from a health care assistant and a GP visit twice weekly. Together with my ANP skills, I have extensive knowledge and experience in both palliative and end-of-life care.

Multidisciplinary team (MDT) meetings are held weekly, which include representation from local community nurses. We have a GSF register which is reviewed weekly and updated monthly using the PIG, ensuring that the best and most appropriate care is given. Information from the MDT meetings is then cascaded down to all care staff by team leaders, one of our priorities being to avoid unnecessary hospital admissions, especially for those residents at the end of life.

Both specialist and generalist palliative care are accessible for all from our community care service, in line with guidance from the National Institute for Health and Care Excellence (NICE 2011). There is a telephone helpline for advice from the specialist service, and community nurses are available for ➤



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*Accommodation for people who are severely overweight.

References

- Badger E, Thomas K, Clifford C (2007) Raising standards for elderly people dying in care homes. *European Journal of Palliative Care* 14, 238-241
- Ballard C (2010) Which activities are most engaging for people with dementia living in care homes. *Alzheimer's Society Research e-journal* (issue 11, December).
- Bracegirdle L-R (2012) A tormented death: end-of-life care for people with dementia. *British Journal of Nursing* 21(12) 723-727.
- Dempsey L, Dowling M, Larkin P, Murphy K (2015) The unmet palliative care needs of those dying with dementia. *International Journal of Palliative Nursing* 21(3) 126.
- Department of Health (2008) *End of Life Care Strategy*. London: DH.
- Department of Health (2009) *Living well with dementia: A National Dementia Strategy*. London: DH.
- Department of Health (2010) *Advanced Level Nursing: A Position Statement*. London: DH.
- Gold Standards Framework/Royal College of General Practitioners (2016) *The Gold Standards Framework Proactive Identification Guidance*. London: GSF/RCGP.
- Independent Review of the Liverpool Care Pathway (2013) *More Care, Less Pathway*. London: HM Government.
- Leadership Alliance for the Care of Dying People (LACDP) (2014) *One Chance to Get It Right: Improving people's experience of care in the last few days and hours of life*. London: Gateway.
- Mackey E, Dodd K (2011) Evaluation and effectiveness of pain recognition and management training for staff working in learning disability services. *British Journal of Learning Disabilities* 39(3) 243-251.
- Middleton-Green L, Chatterjee J, Russell S, Downs M (2016). *End-of-Life Care for People with Dementia*: ➤



A resident's memory box

➤ nursing support and symptom assessment as well as to provide equipment. Specialist and generalist services are 24-hour, so there is continuity even when I am not on duty. I ensure that medication and administration charts are in place for those residents the GP has agreed are at the end of life.

A resident with advanced dementia can have symptoms associated with the end of life for many months before death, such as being unable to mobilise without assistance, being chair or bed-bound, having double incontinence, variable verbal and non-verbal communication, loss of ability to swallow, reduced food and fluid intake and significant loss of weight, as well high risk of infection and pressure sores. So, it can be hard to know when care and treatment should change to “comfort care” – care oriented to the end of life – in accordance with the GSF.

Over the years I have developed my own approach to comfort care because it seems more sensitive to the needs of residents with advanced dementia. Dementia is a life-limiting terminal condition resulting in most of our residents being at least GSF “green”. In fact, approximately half of this group are actually at “amber”, indicating an increasing level of support and care as a resident passes from green to amber and eventually red as they near end of life.

However, because of the nature of advanced dementia and the difficulty of diagnosing when someone is truly at the end of life, I have introduced an extra “amber+” level for those residents for whom it is more appropriate to have comfort care only (led by the patient’s family).

Amber+ indicates that the resident has most end-of-life symptoms but is not actively dying. If the individual is having a sleepy day, they do not have to get up but are left to sleep either in bed or in a suitable recliner chair. If they show their inclinations by keeping their eyes or their mouth closed when food or fluid is offered, they are not forced to accept but care staff will perform mouth care, for example, and return later to try again. Staff will be aware that the resident is receiving comfort care only because they have a mayflower card in their memory box and a mayflower on their allocation sheet.

It is at this point that continuity of care from myself and care staff can be critical, as we are better able to recognise and respond to any distress, often knowing what simple actions will relieve agitation and whether medication is required to alleviate

Five priorities of care

When it is thought that a person may die within the next few days or hours:

1. This possibility is recognised and communicated clearly and appropriately to the resident and family: decisions are made and actions taken in accordance with the dying person’s needs and wishes. Needs and wishes are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with passion.

Source: LACDP 2014

symptoms. Amber+ residents are reviewed at least every two weeks by the GP as symptom management is the key to good end of life care.

Useful assessment tools

A person with advanced dementia is often unable to communicate their pain, nausea or any other discomfort they are feeling, yet there are several assessment tools that can be used to assess for pain and distress. The Abbey Pain Scale (National Council for Palliative Care 2012) is designed to assist in the assessment of pain in patients who are unable to clearly articulate their needs. It measures vocalisation, facial expression, change in body language, and behavioural, psychological and physical changes, and should be completed hourly initially. Once the patient appears comfortable, it can be completed every four hours for 24 hours to ensure the patient remains that way.

Alternatively, there is the Disability Distress Assessment Tool (Mackey & Dodd 2011). It is designed to describe the patient’s cues indicating that they are content, making it easier to identify distress cues by contrast. It is not a scoring tool but makes care staff more confident about their observation skills and their accuracy.

Medication

Not all people with advanced dementia will require medication at the end of life. Dying peacefully, in comfort and with dignity, may come after a period in which the resident has become more withdrawn and sleepy. This is especially so if they die “from” dementia. However, if, as often happens, a person dies “with” dementia from an acute illness such as pneumonia, end-of-life medication maybe needed to ease symptoms of

pain, agitation and excessive secretions.

Once I have identified a resident as being GSF amber+ and they are receiving comfort care, I will put in place anticipatory arrangements for medication together with an administration chart to ensure symptoms can be relieved if and when they occur. If it becomes clear that the dying person needs ongoing regular medication, I will set up a syringe driver for continuous delivery. At all times I liaise with the GP, who will be aware of the resident's condition and prognosis, and if a resident reaches the point of requiring continuous pain relief they are reclassified as GSF "red".

Communication is vital

Carers and family members of people with dementia often suffer significant levels of distress, burden and anticipatory or pre-death bereavement (Rahman 2017). Spouses, in particular, express feelings of loss in advance of their loved one's death. Memory loss and personality changes in advanced dementia, and the necessity of making decisions alone which used to be shared, all contribute to these feelings.

To help families (and care staff) understand comfort care, I have introduced a leaflet explaining what is happening and what to expect over the next few weeks. It has assisted families to understand the process their loved one is experiencing and what they can do to help. It also explains what symptoms may be experienced as life draws to a close.

Whether the resident is in the dementia or the housing with care unit, it is vital to remember to liaise with the GP and communicate with the resident and their family. It was because of communication issues that the Liverpool Care Pathway for the Dying (Watts 2013) was phased out and the *More Care, Less Pathway* review (Neuberger 2013) was published with recommendations leading to five priorities of care (see box). The point is to focus all care in the last hours of life on to the dying person (Leadership Alliance for the Care of Dying People 2014).

Having an advanced nurse practitioner permanently on site in the village to care the residents has been a successful model for those with dementia and those without. I am based in the village, all residents and families know of me and feel able to discuss concerns they have. If there is a complex issue I am unable to deal with, I can pass it on to the consultant. Consequently, there are very low admission rates to acute care, falls are monitored closely, medication is given and reviewed regularly, and palliative end-of-life care are of high quality.

A "good death" is desirable both for residents and for their families and carers. If their loved one has a good death, that is the best care we can offer the family. It gives them the chance of a peaceful end to their loved one's life, bereavement and a sense that everything has been done for their loved one. We only have one chance to get it right. ■

➤ *A Person-Centred Approach*. London: Jessica Kingsley Publishers. National Council for Palliative Care (NCPC) (2012) *How would I know? What can I do? How to help someone with dementia who is in pain or distress*. London: NCPC. National Institute for Health and Care Excellence (NICE) (2011) *Dementia: Supporting people with dementia and their*



The Alzheimer's Show 2018, Olympia London

PROMOTION: The Alzheimer's Show will be at Olympia London on Friday 8th and Saturday 9th June 2018. The two-day event is set to attract care professionals, family carers and those with an interest in learning more about dementia.

The show will feature a full conference programme across three theatres with leading professionals, industry experts and those living with dementia, Q&A's, panel sessions, practical activity workshops, advice clinics and a wide range of dementia and care exhibitors. The Alzheimer's Show is a valuable event for those working in the care sector wanting a better understanding of dementia, the challenges it can bring as well as providing access to fellow professionals and the latest and best information, products and services to help those living with dementia.

For further information and to book tickets visit www.alzheimersshow.co.uk. Tickets cost £15 online, £20 on the door.

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