The challenges of end-of-life care in people with dementia

Dementia is one of the biggest health- and social care challenges facing our societies. The latest estimates say that there are 44 million people with dementia worldwide and 6.8 million in Europe, numbers that are set to double by 2050. In the UK alone, the cost is estimated at £26 billion a year. There has been a focus on timely diagnosis and early intervention and treatment, but recently interest has also been shown in another crucial aspect; end-of-life care. One third of people who die will have dementia.

In the UK, figures from the various government strategies cross-reference each other, and there is still a need for empirical research. We know that there is significantly increased mortality in people with dementia: the median survival time from diagnosis is just over four years — and only two years in people aged 90 or over. For people with dementia in care homes, survival is similar to that of people with metastatic breast cancer. People with dementia at the end of life have similar symptoms to those who are in the terminal stages of cancer.

One challenge is that dementia is often not perceived as a terminal illness; care-home staff looking after people with dementia tend to overestimate their life expectancy. As a result, there is often a significant delay instigating a palliative or end-of-life care approach. An added complication is the lack of mental capacity, almost universal in people in the final stages of dementia.

The five priorities for the care of the dying person, identified in One Chance to Get It Right, the landmark document published by the Leadership Alliance for the Care of Dying People in June 2014,1 all have resonance in relation to dementia.

- The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person’s needs and wishes. The particular challenge in the case of dementia is that, as noted above, the disease is often not seen as a terminal illness.
- Sensitive communication takes place between staff and the dying person. It is often wrongly assumed that people with advanced dementia cannot communicate. Even in advanced disease, communication is feasible – notably through non-verbal means – and essential.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care. People with advanced dementia should be involved in decision-making as much as their abilities allow them to be, but clearly carers and care workers have an essential role. What may be slightly different, compared with other illnesses, is that patients and carers often go through a much longer illness trajectory and adjustment to illness, which may affect decisions about treatment.
- The needs of family and others identified as important to the dying person are actively explored, respected and met as far as possible. This is crucial in dementia, because carers may have been involved for some time and will often experience a great deal of distress.
- 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 compassion. Carers of people with advanced dementia must be involved in this, as they know the person best. Behavioural changes, such as refusal of food or drink, may be manifestations of distress possibly caused by pain, and should not automatically be treated with sedative medication. The key here is compassionate, person-centred care. The issues around food and drink, and around spiritual needs are the same in all dying people, whether or not they have dementia.

End-of-life care planning in dementia should be taken more seriously. Patients should be encouraged to express their wishes in advance care plans. Relatives and carers, who often feel guilty and/or distressed, need to be better supported, including in bereavement, which can be complex due to the length and nature of the illness. The need for good end-of-life care in dementia should be better recognised and become a priority of service provision and research.

Reference