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"We need to improve care for people with dementia at the end of life"

Standfirst: With holistic and structured assessment and better management, distress does not have to be an inevitable part of dying with dementia

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End-of-life care for people with dementia has become a major national and international priority for healthcare policy and research. Dementia is the leading cause of death in the UK and it is estimated that by 2040, 220,000 people with dementia will die each year in England and Wales (Etkind et al 2017). People with dementia often do not die in their own homes; most will come to the end of their life in care homes or hospitals, meaning that their care at the end of their lives is everyone's business. Given that most people will have multiple chronic health conditions alongside their dementia, a multidisciplinary approach is vital.

There is widespread recognition that we need to improve care for people with dementia at the end of life (Sampson, 2020). A number of key areas for change have been identified including engaging people with dementia in advance care planning to empower people to share their wishes and preferences; integrating palliative care earlier into the dementia care pathway; and creating clear guidance and support for clinicians who are delivering end-of-life care for people with dementia.

One area that is frequently overlooked is the importance of recognising and managing distress in all its forms, which is essential to maximise comfort and wellbeing. For many years distress was regarded as an inevitable part of the terminal phase of dementia; a 'universal symptom' arising from a damaged brain. However, we now understand that if someone with dementia is distressed it is because they are trying to communicate something they are unable to express. People with dementia can struggle to make their needs understood and clinicians often lack the time, confidence and skill to listen.

When needs are poorly recognised, assessed or go unmet, people with dementia may become distressed, resulting in behaviours that staff find challenging such as aggression, shouting or screaming. These needs might include physical needs (such as pain, difficulty swallowing resulting in hunger and thirst); emotional needs (such as anxiety, depression and apathy, which might intensity physical symptoms such as vomiting, restlessness and sleep disturbances); as well as spiritual or existential needs (such as a need for connection); and cultural and social needs.

Research demonstrates that the way clinicians understand and respond to distress in dementia varies significantly and depends, in part, on where they work. There is significant evidence of the undertreatment of people with dementia at the end of their lives – people with dementia often receive inadequate pain management and are less likely than people without dementia to be prescribed palliative medications (Yorganci and Sleeman, 2023).

Conversely, there are also concerns about the overtreatment of people with dementia; for example, concerns have been repeatedly raised about the inappropriate prescription of antipsychotic medication, including at the end of their life, in acute hospitals. Unease has also been raised in that too often distress is wrongly assumed to be solely the result of pain and that strong opioids might be used without a clear assessment of needs.

A palliative care approach in dementia must include the adequate treatment of distress, which will rely on a holistic and structured assessment of a person's needs before starting any non-pharmacological or pharmacological interventions. Targeted assessment measures designed specifically for people with dementia are emerging and need to be embedded as part of routine assessments. One example is the IPOS-Dem – a quick and easy-to-use, comprehensive measure that helps to identify palliative care needs, including dementia-specific concerns and those common in people with multiple chronic health conditions. Research demonstrates that using the IPOS-Dem helped clinicians to improve their observation and awareness, care planning and care provision, and it facilitated communication and collaboration (Ellis-Smith et al, 2018).

Alongside this, it is essential that the challenge of providing care to people who are distressed is recognised. Working with people who are distressed can be frightening and disempowering. It is vital that all staff can seek support and training. Admiral Nurses are well placed as specialist dementia nurses to facilitate training and to offer support to colleagues. Another source of support open to all is the Palliative, End of life care and Dementia ECHO – a joint venture by Hospice UK and Dementia UK that brings together clinicians who want to build their skills and confidence in supporting people dying with dementia.

Reducing the distress experienced by people dying with dementia will improve the experiences of people with dementia, their families and clinicians.

References

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Resource: Hospice UK – Join an ECHO network https://www.hospiceuk.org/innovation-hub/support-for-your-role/networks-communities/project-echo/join-echo-network#:~:text=Palliative%2C%20End%20of%20life%20care%20and%20Dementia%20ECHO,network%20is%20a%20joint%20venture%20with%20Dementia%20UK.

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