A note from the CEO

We need to improve Care for people with Dementia at the end-of-life

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Article:

End-of-life Care for people living with **dementia** demands compassion, expertise and a truly multidisciplinary approach and it has become a major national and international priority for healthcare policy and research. As the leading cause of death in the UK, dementia Care at life's end must meet the highest standards. This article highlights critical areas for improvement; an essential read for all professionals and families involved.

By **2040** it is estimated that **220,000** people with dementia will die each year in England and Wales (**Etkind et al. 2017**). Most will spend their final days in **Care Home**, **Nursing Home** and **Assisted Livings** or hospitals, often with multiple chronic conditions alongside dementia; making comprehensive, multidisciplinary Care vital.

"A palliative care approach in dementia must include the adequate treatment of distress." (**Sampson et al. 2020**). There is widespread recognition that Care for people with dementia at the end of life must improve **Key areas** for **change** include:

- **Advance Care Planning**: Engaging people with dementia early to share their wishes and preferences.
- **Early Palliative Integration:** Introducing palliative care sooner in the dementia pathway.
- **Clear clinical guidance**: Supporting clinicians who deliver end-of-life care to this population.

One frequently overlooked element is recognising and managing distress in all its forms, which is essential to maximise comfort and wellbeing. For many years, distress in advanced dementia was seen as an inevitable "universal symptom" of a damaged brain. We now understand that distress signals unmet needs; physical (pain, hunger, thirst), emotional (anxiety, depression, restlessness), social or spiritual (need for connection), and cultural or existential. When these needs are ignored, people with dementia can exhibit behaviours like shouting or aggression, further complicating care.

Research shows clinicians' understanding of distress varies widely, leading to significant undertreatment. People with dementia at life's end often receive inadequate pain relief and are less likely than others to be prescribed palliative medications (**Yorganci & Sleeman, 2023**). Conversely, overtreatment; such as inappropriate antipsychotic prescribing without proper assessment remains a concern.

A true palliative approach requires a holistic, structured assessment before any intervention. Dementia-specific tools are emerging to aid this process. IPOS-Dem, for example, is a quick, comprehensive measure that identifies palliative needs in dementia, covering both disease-specific and comorbid concerns. Studies show its use enhances observation, care planning, provision, and team communication (**Ellis-Smith et al. 2018**).

Equally important is supporting staff who care for distressed patients. Working with distress can be frightening and disempowering; regular training and mentorship are essential.

Specialist dementia nurses (often called Admiral Nurses) play a vital role in training and supporting colleagues. In addition, the Palliative, End of Life Care and Dementia ECHO; a collaboration between Hospice Organisation Anonymised and Dementia Charity Anonymised; offers clinicians opportunities to build confidence and skills. Reducing distress in people dying with dementia will improve the experience for patients, families and care teams alike.

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