

Hopeful Care for People Dying with Dementia

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Commentary

Palliative care, when understood in its entirety, has hopeful connotations for those with a terminal illness, particularly at the end of their lives. When palliative care was first introduced, it only applied to people with cancer; it now encompasses people living with any incurable illness, including dementia [1].

Unfortunately, many health professionals, and much of the public, are not aware that dementia is an incurable disease of the brain which will end in death [2]. Furthermore, it is not generally understood that people dying with dementia have symptoms similar to those dying with cancer [3]. The result of this misunderstanding is that many people die without hope, their basic needs unmet.

When the needs of the person with dementia are not understood, the result can be unwanted hospitalization including intrusive treatments with no positive outcome. When aggressive, intrusive behaviour is interpreted as their 'worsening dementia' such patients are more likely to be prescribed ineffective and inappropriate psychoactive drugs rather than analgesia [4]. Their suffering is compounded by a lack of comprehensive pain assessment. A person dying with dementia is unlikely to have the capacity to indicate on a visual analogue scale the severity of their pain. A glance at their comorbidities, such as osteoarthritis, diabetes, Parkinson's disease and other musculo-skeletal problems should trigger the assumption that they are in pain.

Many papers have been written about the correlation of pain and dementia [5]: the essence of good pain management is one of the key foci of palliative care [6]. However, the other tenets of palliative care are too often overlooked. The person dying with dementia may also experience spiritual, social and psychological distress which they cannot articulate.

Families are often uninformed about the terminal nature of dementia and the benefits which can ensue from palliative care, exemplified by the last chapter of Joan's life.

Joan, aged 97, had been in the nursing home for eighteen months, no longer able to speak. Bedbound, incontinent, and totally dependent

for all aspects of her care, her eyes seemed to plead 'Won't somebody please help me?' Her family had been offered no counselling and were never invited to a care planning discussion. When a well-educated nurse suggested palliative care, the pervasive despair was replaced by hope. The new agenda included an Advance Care Plan incorporating Joan's previously expressed wish not to be hospitalized. Sensitive family discussion resulted in comprehensive documentation of Joan's spiritual, psychological and social needs. Her family were delighted to see her response when the priest visited, when her grandchildren sang to her, when headphones provided her favourite orchestral music, when her bed was wheeled into the sunshine, and when the bland nursing home food was replaced with her favourite sweet treats. Round-the-clock administration of a low dose opioid ensured her physical comfort.

The family had assumed Joan 'was no longer there'. Providing her with comprehensive palliative care assured the family that, even within the seemingly 'hopeless' context of dementia, hope could flourish. Not hope for a magic cure but hope kept alive by relief of distressing symptoms until she died.

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