

## section 2.6.3: End stage dementia

### General description of disease and progression

Dementia is a chronic, progressive degenerative disease with resultant loss of intellectual functions and memory and inability to manage activities of daily life. Dementia has over 150 known causes but most commonly is due to Alzheimer's disease or multiple small strokes. Dementia is more common after 65 years of age, but younger people can be affected. Dementia is incurable, progressive and life shortening<sup>1</sup>:

- caused by atrophy of essential cerebral structures and permanent loss of neurones
- average length of a dementing illness is 8-10 years
- death most commonly caused by a life-threatening infection
- dying process may be evidenced by a "turning from the outside world and withdrawing into the internal self"<sup>2</sup>
- may be accompanied by loss of appetite, loss of energy, cardiovascular changes and other physiological signs of dying

### Potential problems

- communication difficulties:
  - inability of the patient to report symptoms
  - end of life care complicated by the patient's inability to be involved in decision-making with the weight of this task falling to other family members or caregivers
- progressive inability to function, increasing dependence on caregivers for all activities of daily living
  - potential for falls and decubitus ulcers
  - patient may be resistive to having personal care provided
  - personal care may include single or double incontinence
- challenging behaviours or symptoms including:
  - delusions, hallucinations, depression, agitation, aggression, vocalisations
  - wandering or pacing
- caregiver challenges
  - the loss of the "person" is likely to have occurred years prior to the dying process
  - family may be burdened with the inability to deal with unresolved issues
  - high input caregiving may span many years

### Specific considerations for end stage disease

- effective management of pain and discomfort, observation for behaviours which indicate pain or distress which may include restlessness, vocalisations, unwillingness to move, aggression, changes to vital signs or altered facial expression<sup>3</sup> and a long term plan for management
- providing for safety without undue restraint and minimizing external stimuli
- maintenance of dignity and emotional wellbeing

- taking time to explain the patient's expected course of disease and decline to family members including:
  - withdrawal from daily activities, lack of interest in food with subsequent decisions regarding nutrition and hydration
  - assisting them to understand that these changes are integral parts of disease progression and ultimately the dying process
- support for family taking into account the likely "rollercoaster ride" with multiple occurrences of infections, the struggle to retain of the uniqueness of the individual and the burden of decision-making<sup>4</sup>
- **encouraging the use of formal advance directives as soon as possible after diagnosis**, in this way plans include the person with dementia while they can play a part in decision making processes<sup>5</sup>

## references

---

<sup>1</sup> Alzheimer's Association Vic – Dementia Explained – see [www.betterhealthvic.gov.au](http://www.betterhealthvic.gov.au)

<sup>2</sup> McCracken A & Gerdson L (1991) Sharing the legacy; Hospice care principles for terminally ill elders. *Journal of Gerontological Nursing* 17(12), 4-8.

<sup>3</sup> See Section 2- *Relevant assessment tools* for Abbey Pain Scale.

<sup>4</sup> Smith S (2001) Dementia in Treatment of End-stage Non-Cancer Diagnoses. Hospice and Palliative Care Nurses Association, Pittsburgh, PA.

<sup>5</sup> Decision making in advance: Reducing barriers and improving access to advance directives for people with dementia (2006) Alzheimer's Australia Discussion Paper.