

End of Life Care for People with Dementia

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Context

- Better living conditions/health care have led to increased longevity – this is a success story, and it has rightly been celebrated as such.
- In addition, rapid technological development has allowed people who would have previously died to be kept alive for long periods of time, often through the use of such things as ventilators and PEG tubes.
- *But*
- These successes have led to practical, legal & ethical issues, in particular around end-of-life care and extending the dying process, including for the increasing numbers of people with dementia.

Community Concerns in Terminal Illness: Rank Order

FACTORS	Q1	Q2	NT
Loss of Mental Faculties	1	1	1
Loss of Control	2	2	2
Loss of Independence	*	3	3
Burden on Family	*	4	4
Loss of Dignity	4	5	5
Leaving Loved Ones	5	*	6
Protracted Dying	*	*	7
Extreme /Physical Pain	3	6	8
Death Itself	9	9	10/10

After a Diagnosis of Dementia

Advance Planning for Expected Changes

- A diagnosis of dementia for one of your patients/clients may cause a range of emotions for them and/or their carers, including grief, disbelief, anger, shock or even relief.
- Knowing the diagnosis at an early stage allows time for setting up good supports and planning for expected changes as the disease progresses.
- The person with dementia can participate in the planning process and ensure that his/her wishes for end-of-life care are known and documented.

Advance Care Planning

Is a process that allows a person to make and communicate – in advance – decisions about their health care and treatment for a future time when they have lost capacity. (Addresses first two concerns).

Ideally it involves a discussion between the person, their health care provider and their carer/ family/ friends, about their values, beliefs and views about end-of-life care.

For it to be fully effective it also needs to include recording those decisions.

When Does a Person Have Capacity to Make A Decision (inc. write an AD, appoint a MA or an EG?)

- Person is presumed to have capacity unless proven otherwise (a diagnosis of dementia does not immediately mean the person has lost capacity).
- Person must understand *the nature* and *the effect* of the decision to be made – (case study).
 - Complete and sign the document without any coercion, pressure, or influence by others.
- Person must be able to communicate their decision in some way - not necessarily by speaking or writing - body language may be adequate, e.g. nodding/ shaking head (case study).

Incapacity is Not:

- Ignorance
- Eccentricity, cultural diversity or having different ethical views
- Communication failure
- Having a diagnosis of dementia; depends on level
 - Mild (usually would still have capacity)
 - Moderate (may have fluctuating capacity)
 - Severe (usually would not have capacity but may still indicate when they don't want something – like a PEG tube!)
- Bad decisions
- Disagreeing with doctor or nurse

Carers

- A major stress among carers of people with dementia is not knowing what is the right thing to do and being afraid of doing the wrong thing.
- Some of the stress can be relieved with appropriate advance care planning.
- People with mild-moderate dementia should be supported to complete an ACD and to appoint a SDM.
- People with advanced dementia – who have not made substitute-decision making arrangements – may need to rely on the legally authorised person responsible (close relative, friend or carer) to make health and lifestyle decisions on their behalf (Substitute Judgement, not Best Interests).

End-of-Life Decisions: What does the law allow?

- Refusal of treatment: a person may refuse any treatment, even life-saving treatment if they have the capacity to do so, or through an Advance Care Directive, or via a SDM/PR.
- Refusal of CPR: <20% of people who have a cardiac arrest in hospital survive to discharge and of those who do, many are left in a worse condition than previously. For older, very ill patients it is about 5%
- Refusal of artificial provision of food or fluids: (i.e., through a tube). Person themselves can also refuse “natural” provision of food or fluid, but SDM/PR cannot do so.
- Refusal of antibiotics: The use of antibiotics does not necessarily improve the comfort of patients with advanced dementia (but may be required to reduce fever).

What does the law allow? - 2

- Right to Adequate Pain Relief
 - Every person (competent or not) has the right to adequate control of pain and other symptoms, even at the risk of hastening death.
 - People with dementia are often denied adequate pain relief.
- Terminal or Palliative Sedation
 - Use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, including anxiety, when other attempts at relief have failed. Includes withholding or withdrawing artificial nutrition/ hydration.

(Note: Neither of these are euthanasia)

Confusion About what is/is not Euthanasia

- Many problems stem from confusion over what is, or is not, euthanasia. This leads to:
 - Inadequate pain management
 - Inappropriate use of medical technology
 - Fear among health professionals of legal consequences of care provision
 - Poor doctor-patient communication
 - Disillusioned patients/families/carers

Common Beliefs

- Some commonly held beliefs are that euthanasia includes:
 - (a) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life; or
 - (b) respecting a patient's right to refuse further treatment; or
 - (c) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient

None of these is euthanasia

Definitions of Euthanasia

- The World Medical Association defines euthanasia as: the deliberate ending of a person's life at his or her request, using drugs to accelerate death.
- Definition used in studies in Qld, NT, NSW & Europe:
 - Euthanasia is a deliberate act intended to cause the death of the patient, at that patient's request, for what he or she sees as being in his/her best interests (i.e. Active Voluntary Euthanasia – AVE).

Giving Pain Relief Which May Also Shorten the Patient's Life

- Often referred to as "the doctrine of double effect" - primary intention is to relieve pain, secondary, unintentional effect may be the hastening of the person's death.
- Accepted by most religious and medical groups, including those who strongly oppose euthanasia.
- Not giving adequate pain treatment when needed may shorten life: patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated.

Withholding/Withdrawing Futile Life-Supports Systems

- Used to be called "passive euthanasia"; general agreement that that term is unhelpful - it can lead to the inappropriate continued use of invasive technology.
- Often it is not prolonging life, it is merely prolonging the dying process.
- Removal of futile treatment is good medical practice. However, no definition of futility in law; generally agreed, when burden outweighs benefits – but “burden” and “benefit” should be from patient’s viewpoint.

Palliative Care for People with Dementia.

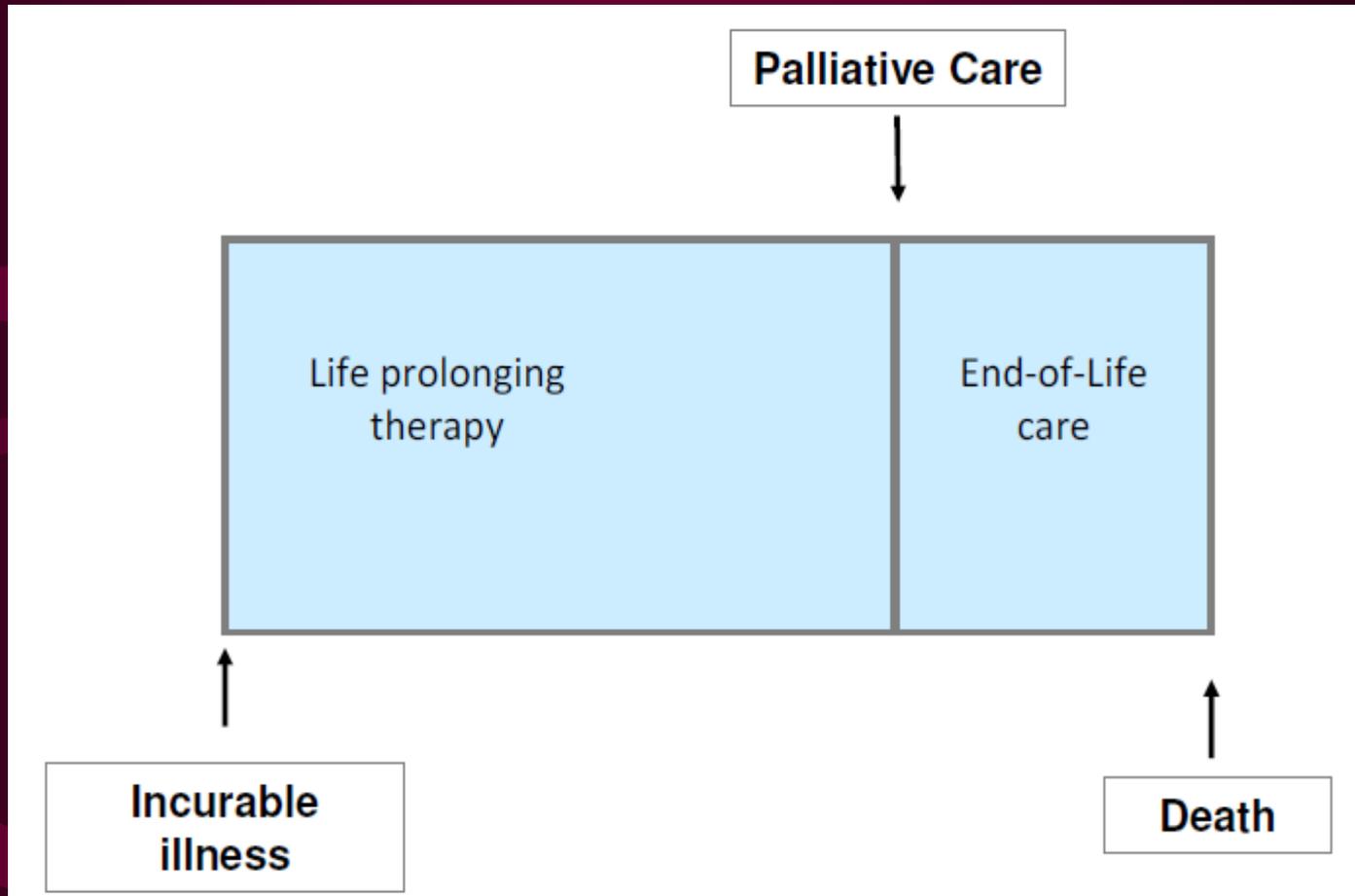
- Palliative Care Principles apply as equally to a person with dementia as they do to someone whose terminal illness is cancer or COPD or other diseases.
- A “palliative approach to care” can be provided by primary care services and practitioners, including in residential and community care.
- Specialist palliative care, provided by palliative care physicians and/or specialist palliative care nurses, may be required for adequate management of complex or severe symptoms, including – for people with dementia – confusion and aggression.

Palliative Care for People with Dementia -2

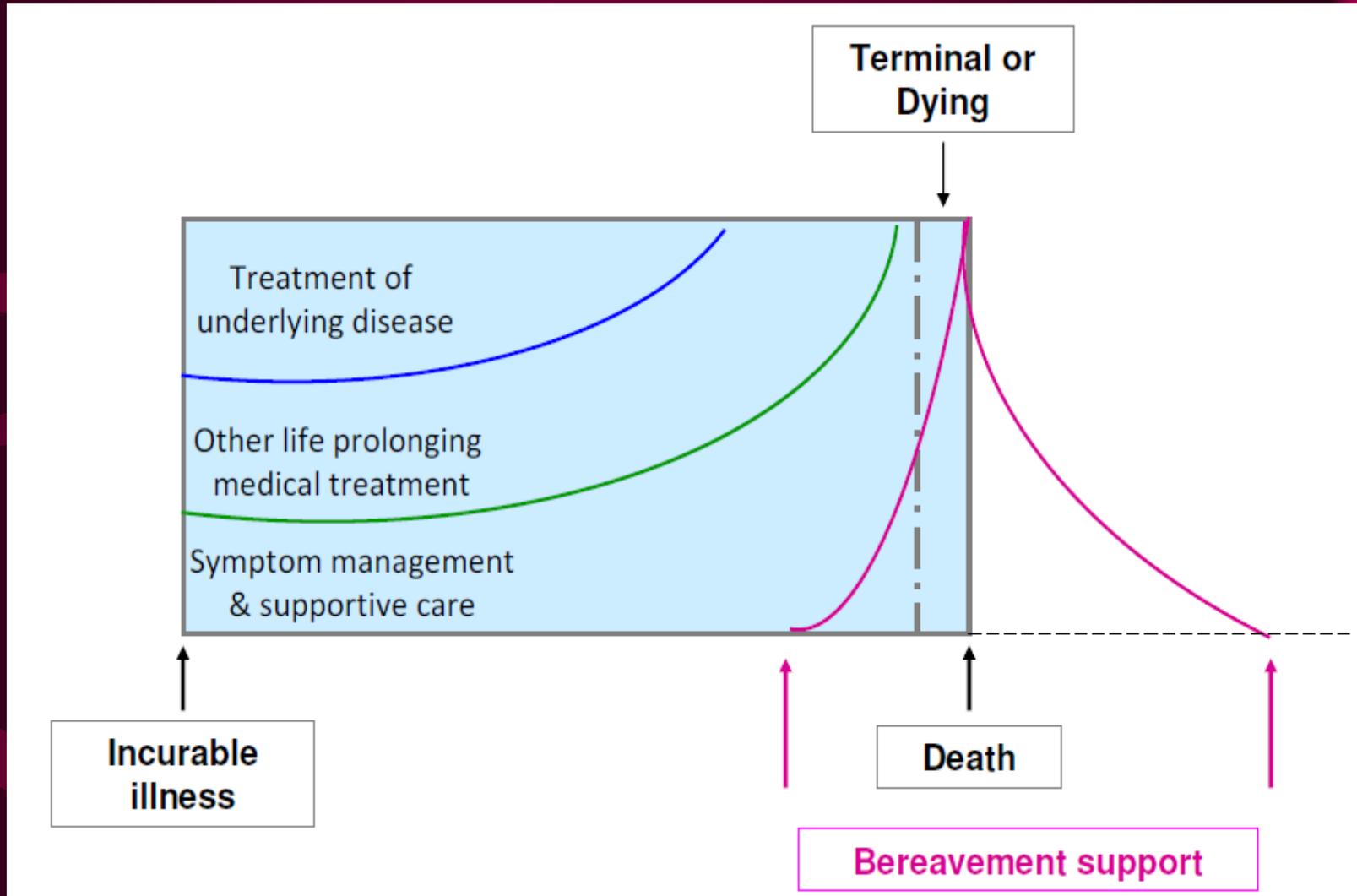
- PC Aust. (2005): Standards underpinned by core values including:
 - *dignity* of the person with dementia and his/her family is maintained;
 - work with the person's *strengths and limitations*;
 - act with *compassion*;
 - demonstrate *respect*; and
 - be *accountable*

Palliative Care - The OLD

(Thanks to Dr Barbara Hayes, Northern Health, Victoria)



Palliative Care: The NEW



Palliative Care Provision in Residential Care: What are the Challenges?

- Lack of RNs to give medication such as morphine & to carry out medical orders of the palliative care physician (including if pain relief is ordered *prn*, using clinical judgement to know when it is needed); (Not AIN/PC)
- 1 RN for 60 residents: may have to transfer to hospital!!
- Need for discussion with patient/family by RN or P/C physician who know them, ahead of emergency; should not be done by agency nurse in the middle of the night!
- Residents need support/assistance to complete Advance Care Directives when they are in a stable condition.
- Medical orders need to be drawn up in advance to translate ACDs for compliance by RNs, Locum GPs

Palliative Care Provision in Residential Care: What are the Challenges? - 2

- Have plans in place to deal with pain relief, nausea, shortness of breath, delirium/agitation;
- Order medications in advance to deal with above – don't wait until you need them; they may not be readily available in your community pharmacies. (Same for community care)
- For all above: RACF staff training is required, including:
 - What palliative care is: not just pain & symptom control – includes physical, psychosocial, spiritual & bereavement care;
 - What is/is not euthanasia: adequate pain relief, even if it hastens death, is not;
 - Artificial Nutrition/Hydration – can increase suffering & deprive resident of peaceful death;
 - (For residents with dementia) – how to assess capacity
 - How to ask the right questions at the right time

Palliative Care Provision in Community Care

- Can be less restrictive than in RACF: family members can be taught to administer pain medication (e.g., RN can put in “butterfly” & leave loaded syringes of medication in the ‘fridge, so carer does not need to draw them up)
- But: providing palliative care at home depends on having good family support – for 23/24 hrs/day the RN will not be there – need instructions, “what to do if...”
- Need to provide right equipment for patient’s condition;
- Service providers need to know how to access specialist palliative care services in your area if staff are providing a palliative approach to care.
- Essential that family carer has access to a palliative care professional to provide advice by phone, even at 3am!
- Also, some patients do not have family to care for them

Palliative Care Provision in Community Care - 2

- Medical treatment orders need to be developed, in clear simple terms that carer can follow, so e.g., they don't panic and call the ambulance – need instructions to call the palliative care team;
- MTOs also need to authorise nurse to legally give medication, with doses specified & possibly frequency & route of administration
- Letter from palliative care specialist or team in case ambulance is required, which states (e.g.,) “No CPR, intubation or other life-sustaining treatment – For comfort care only”; letter could also state that patient is in the condition specified in the ACD (and now lacks capacity), so the ACD should be followed

Audience Discussion

- Discuss in pairs/group
 - Are you comfortable discussing death & dying with your patients/clients/residents & their carers/families?
 - Have you discussed with any of your patients/clients/residents & their carers/families the option of writing an ACD/appointing a SDM?
 - Have you discussed with your own family members/ friends the option of writing an ACD/appointing a SDM – including for yourself?
 - If you have a patient/client/resident who has been diagnosed with dementia, how do you (or would you) start the discussion around Advance Care Planning? When?

Healthy Ageing: Healthy Dying

- An ageing world population brings many challenges – including the imperative to protect our most vulnerable older people
- When older people and people with dementia not only live well but also die well, we can claim success!

Thank You