

**Planning for the End of Life
for People with Dementia:
Presentation to Alzheimer's Australia
(Western Australia)**

Professor Colleen Cartwright, Director
ASLaRC Aged Services Unit
Health and Wellbeing Research Cluster
Southern Cross University

Adjunct Professor, UNSW Medical Faculty
Rural Clinical School

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.

Fears and Concerns in the General Community

Carers' Stories - 1

- Loved one “left hooked up to machines until the very end. We couldn’t even get close enough to give him a hug and say goodbye”.
- “Mum always said she wouldn’t want to be resuscitated if her heart stopped, but they wouldn’t listen”.
- (Daughter). “She said that the medical staff were running through her room ‘like a gravy train’. She didn’t know most of the time what they were there for or what they were doing... they usually just said something like ‘Now we’re just taking you down to test you for (whatever)’ ... They never asked her permission”.

Fears and Concerns in the General Community

Carers' Stories - 2

- (Husband – who felt that the specialist just could not accept “defeat”). “Because of (X – specialist) they were still trying to cure her but it was not any point. They were doing everything. Everyone was making out that this was going to be the answer, when they knew damn well it wasn’t”.
- (Wife) “First of all he was stubborn when he was in hospital; he wouldn’t eat - he was just starving himself. They couldn’t get him to eat ... so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn’t want it”.

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 you or someone you care for may cause a range of emotions, 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 their wishes for end-of-life care are known and documented.

Legislative Basis for Advance Planning in Western Australia

*Acts Amendment
(Consent to Medical
Treatment) Act*

2008

*Guardianship and
Administration Act*

1990



Planning Ahead – Legal Mechanisms

- Advance Planning helps to address fears and concerns in relation to:

Financial Mechanisms

- Enduring Power of Attorney.
- Family Agreements (Written agreements give greater certainty).

Health/Personal Care Mechanisms

- Advance Health Directives.
- Enduring Power of Guardianship.
- Person Responsible.
- Discussion with Health Care Provider/Noted in File.

Advance Care Planning

Is a process that allows you to make and communicate – in advance – decisions about your health care (including your medical and dental treatment) for a future time when you have lost capacity e.g. treatment wanted or not wanted under specific conditions.

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

It also includes recording your health-care decisions.

Advance Directives

- An Advance Directive - referred to as an Advance Health Directive in WA:
 - Is a written document, allowing a person to make their wishes for future health care known.
 - Extends the current right of a competent person to refuse treatment to a future time when they may not be competent.
 - Is NOT a form of euthanasia, as it only allows actions which a person could legally consent to for themselves if they were competent to speak.
 - Only comes into effect when the person making it loses decision-making capacity.

Benefits of Advance Directives

- Gives control back to patient.
- Ensures patient's wishes are known - patient's own words.
- Assists health care provider with decision-making.
- Relieves family stress at time of trauma.
- Gives security in relation to future events (allows person to live well now by taking away fear of end stage of life).

Barriers to Use of Advance Directives

Barrier	Cty %	HPs %
Don't know how to	61	88
Don't know enough about them	60	91
Prefer to leave decision to doctor	37	63
Don't like to think about end-of-life issues	33	75
Prefer to leave decision to family	29	69

Enduring Power of Guardianship -1

- A competent person aged 18 or over can appoint an Enduring Guardian (EG) to make personal & lifestyle decisions and/or decisions about medical and dental treatment on their behalf, in case they lose the capacity to make own decisions.
- A person can choose whoever they like to be their EG so long as that person is competent and accepts the appointment.
- EG:
 - Must be at least 18 years old.
 - Is usually a trusted relative or friend.

Enduring Power of Guardianship - 2

- A person can appoint more than 1 EG.
- If more than 1 EG is appointed they must act jointly. (Note: Can also appoint a substitute EG – an appointee - in case the original EG dies or becomes incapacitated).
- EG must agree to the appointment, should understand the appointor's wishes and be prepared to carry them out.
 - Appointment must be in writing, in approved form.
 - Form must be signed by appointor, EG and 2 witnesses (1 must be authorised witness* e.g. solicitor, JP (*list of non-fee-charging witnesses available). The witnesses must sign in the presence of the appointor and in the presence of each other.
 - Certified copies of form.

What if there is no AHD or EG?

- ‘Person Responsible’ is the first reasonably available (and culturally appropriate) adult of full legal capacity, willing to make treatment decisions, of the following:
 - A spouse or de facto (includes same-sex partners).
 - Adult son or daughter.
 - Parent.
 - Sibling.
 - A (non-professional) carer.
 - A person with a close personal relationship.

(May not be the person the patient would have chosen to make their decisions). **NOTE: Not necessarily Next-of-Kin.**

Note: For a person in a residential aged care facility, (nursing home), the “carer” is not a staff member at the facility. Usually it would be whoever was the carer before the person went to the facility.

When Does a Person Have Capacity to Make A Decision (inc. write an AHD; appoint an EG)?

- Person is competent unless proved 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).
- 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
- Bad decisions
- Disagreeing with health care provider

Priority for Decision-Making for Treatment Decisions in WA

- Advance Health Directive
- Enduring Guardian
- Guardian appointed by the State Administration Tribunal
- Person Responsible
- If none of the above apply an application may be required to the State Administration Tribunal for the appointment of a guardian

Where Should an AHD be Kept?

- Copy in GP file.
- Copy with Enduring Guardian.
- Copy accessible at home
- On admission to hospital or residential aged care facility, copy should be placed in patient record, to be available for subsequent admissions/guide care plans.
- (Old lady – in plastic sleeve, “blue-tacked” to fridge).
- Use wallet card.

End-of-Life Decisions

What does the law allow? - 1

- Refusal of treatment
- This is a legal and moral right possessed by every competent person, under both common law and, in some States/ Territories, under statute law relating to assault; also the right of a non-competent person who expressed their wishes in an Advance Health Directive or to their Enduring Guardian.
- A person may refuse any treatment, even if doing so will result in their death.

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.

End-of-Life Decisions

What does the law allow? - 2

- Refusal of artificial provision of food or fluids
 - Continuing with artificial nutrition and hydration in a person with advanced dementia can increase their suffering and prevent a peaceful death.
- 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).

End-of-Life Decisions

What does the law allow? - 3

- Pain control
 - 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.
- The Abbey Pain Scale is recommended for assessing pain in someone with dementia.

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.

End-of-Life Decisions

What does the law allow? - 4

- Resuscitation

- Not for Resuscitation or No Cardiopulmonary Resuscitation is the most common order that is given in relation to withholding a specific treatment.

- Terminal sedation

- Refers to use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering (therefore supports ethical principal of beneficence), including anxiety, when other attempts at relief have failed.
- Includes withholding or withdrawing artificial nutrition/hydration.

Palliative Care

- A palliative approach to care can be implemented very early after a diagnosis of dementia.
- Where possible establishing a relationship with the palliative care team early in the disease will assist efforts to monitor the patient's progress and to know when additional support is needed.
- Palliative care can be provided in the home, in the hospital or a hospice or in a residential aged care facility – emphasis is on quality of life, dignity and comfort.

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 AHD or to appoint an Enduring Guardian.
- People with advanced dementia – who have not made substitute-decision making arrangements – may need to rely on Person Responsible (spouse, carer, or other person with close relationship) to make a decision in their best interests but PR will not necessarily have the knowledge of what the person wants to occur.

What Else Needs to be Done?

- Educate people with dementia and their carers/families; and empower them to ensure that their forms are recorded and wishes respected.
- Educate GPs, hospital staff, residential aged care providers, other health care and community care providers.
- Know what documents exist, where to get them, how to complete them.
- Know the law and be prepared to advocate on behalf of your relative/client/patient.

Available Resources

Office of the Public Advocate

- EPG guide and kit (both contain EPG form) – in print and online
- Information sheets – in print and online
- AHD/EPG brochure – in print and online
- Sample completed forms - online
- Telephone Advisory Service
- (1300 858 455)

Further information

- Enduring Powers of Guardianship:
 - ✓ I: www.publicadvocate.wa.gov.au
 - ✓ E: opa@justice.wa.gov.au
 - ✓ Telephone Advisory Service: 1300 858 455
 - ✓ TTY: 1300 859 955
- Advance Health Directives:
 - ✓ I: www.health.wa.gov.au/advancehealthdirective
 - ✓ E: chiefmedicalofficer@health.wa.gov.au
 - ✓ T: (08) 9222 2300

Contacts

– ASLaRC Aged Services Unit

<http://aslarc.scu.edu.au>

– Alzheimer's Australia

www.alzheimers.org.au

– The National Dementia Helpline

1800 100 500

Acknowledgments

Alzheimer's Australia National Consumer
Advisory Committee

All staff and volunteers

My senior research officer Dr. Sonya Brownie