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Advance Care planning in Australia: aspirational or practical?

Investigating the inclusion of vulnerable populations in Advance Care Planning: Developing complex and sensitive public policy, APP1133407

Partnership Project

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seek LIGHT



- National Framework
- South Australian Legislation (Advance Care Directives Act 2013 (SA)

Background to the project



Improving Care at the End of Life: Our Roles and Responsibilities

 Only 17% of physicians believed that most of the time, doctors know the patients' preference for end-of-life care, and

 Approximately 1/3 indicated that they had observed, at least once a week, treatment being provided to patients that was inconsistent with the patients' wishes.

Let's talk about death and dying....









The National Framework

Guiding Principles



- Greater use of advance care planning will assist the community to recognise the limits of modern medicine and the role of health-promoting palliative care
- Mutual recognition of Advance Care Directives across all states and territories will be facilitated through harmonisation of formats and terminology
- Growing numbers of Australians will contemplate their future potential loss of decision-making capacity, and will appreciate the benefits of planning where and how they will live and be cared for, and of communicating their future life and care choices in advance.
- Advance Care Directives will be well established across Australia as a means of ensuring that a person's preferences can be known and respected after the loss of decision-making capacity

Guiding Principles



- Decisions by substitute decision-makers chosen and appointed under Advance Care Directives will be respected and will reflect the preferences of the person
- Advance Care Directives will be readily recognised and acted upon with confidence by health and aged care professionals, and will be part of routine practice in health, institutional and aged care settings
- Clinical care and treatment plans written by health care professionals will be consistent with the person's expressed values and preferred outcomes of care as recorded in the Advance Care Directive

In short:



- realistic end of life objectives,
- · engagement with the process of advance care planning,
- consistency,
- authority and,
- the recognition of preferences and values

What is an advance care directive (ACD) AVANCE CARE PLANNING TOGETHER

ACDs can record a person's values, life goals and preferred outcomes, or directions about care and treatment refusals and can formally appoint a SDM – or a combination of these

The Framework in brief:



- It is aspirational
- Aimed at simplicity, consistency and clarity
- Empowering individuals
- Emphasising autonomy recognises that it is a culturally sensitive concept, and
- Is values based in its language





Advance Care Directives Act 2013 (SA)

Second Reading Speech:



- Indicated that there will now be a single form as opposed to a variety of different forms and types of decision makers,
- The new Act would make it easier to complete and apply advance care directives
- Individuals will now be able to express their views and preferences
- The forms and guidelines would all be written in simple, lay person's language – this would, he suggested, assist those for whom English is a second language and Aboriginal and Torres Strait Islanders

Second Reading Speech:



- Fluctuating capacity will be recognised under the Act
- And he explained that the Bill (now Act) is underpinned by set of over-arching principles:
 - Rights-based approach
 - Flexible requirements
 - Values and goals of care as opposed to specific treatments
- Highlighted that the only binding provisions are those that are a refusal of treatment
- And patients cannot demand a specific form of care

An Act to:



- To <u>protect health practitioners</u> and others giving effect to the directions wishes and values of a person who has given an ACT
- Enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs
- Express wishes and values in respect to above
- Allow future decisions to be made by another person on their behalf
- Ensure <u>as far as practicable and appropriate</u> that health care accords with the expressed directions, wishes and values
- To ensure that the wishes and values are <u>considered in dealing</u> with the person's residential and accommodation arrangements and personal affairs
- To <u>protect health practitioners</u> and others giving effect to the directions wishes and values of a person who has given an ACD

Provide mechanisms for disputes



Health practitioner cannot be compelled to provide particular health care (s6)

Whilst a person can indicate his or her wishes in respect of the health care he or she wishes to receive, ultimately the question of what form of health care should be provided to a patient is a matter for the health practitioner to decide (however, a person is entitled to refuse health care of any kind, or to require it to be stopped, including health care that saves or prolongs his or her life).

s9: Objects include

• to enable competent adults to express their wishes and values in respect of health care, residential and accommodation arrangements and personal affairs, including by specifying outcomes or interventions that they wish to avoid;

s10 Principles

The following principles must be taken into account in connection with the administration, operation and enforcement of this Act (including, to avoid doubt, the resolution of disputes under Part 7):

- an advance care directive enables a competent adult to **make** decisions about his or her future health care, residential and accommodation arrangements and personal affairs either by stating their own wishes and instructions or through 1 or more substitute decision-makers;
- (b) a competent adult **can decide what constitutes quality of life** for him or her and can express that in advance in an advance care directive;
- a person is, in the absence of evidence or a law of the State to the contrary, to be **presumed to have full decision-making capacity** in respect of decisions about his or her health care, residential and accommodation arrangements and personal affairs;

s10 Principles (cont)

Sets out principles that a substitute decision-maker must follow and highlights that decision must reflect, values and wishes of the person

Binding and Non-Binding Provisions



s19 Binding and non-binding provisions

Refusal of particular health care will be a binding provision

This means that directions about living arrangements etc are non-binding, and of course there is no ability to demand treatment

Substitute Decision-Maker (SDM)



s23 Powers of SDMs:

- Health care
- Residential and accommodation arrangements
- Personal affairs

NOTE:

Even if it is written in the ACD the SDM cannot refuse the administration of drugs to relieve pain or distress; the natural provision of food and liquids by mouth

The Reality:



- A procedural Act
- Specific guidelines for witnesses
- "Simple English Guides" are far from simple at 74 pages

Best described as:

A well intentioned but unworkable document



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- Alzheimer's SA
- Law Society SA
- Modbury Hospital Foundation
- Multicultural Communities Council SA
- Northern Adelaide Local Health Network
- Northern Community Health Foundation
- Northern Health Network
- Palliative Care SA
- SA Health

