ADVANCE CARE PLANNING: Can on size fit all?

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)
- Vulnerable Voices Pilot Study

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

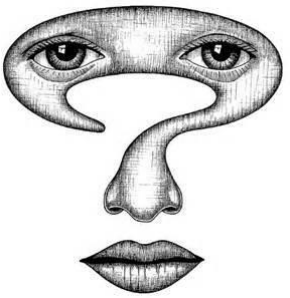
Guiding Principles

- 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 autonomy?



What is an advance care directive (ACD)?

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

Autonomy & the Framework

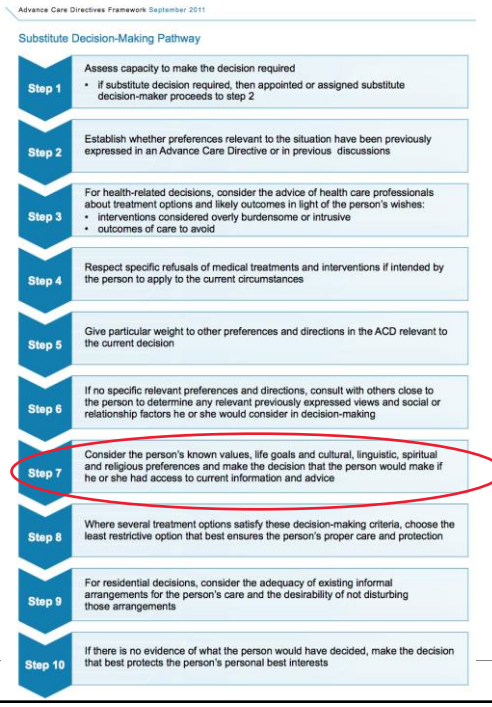
Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs and this specifically includes an exercise of autonomy by self-determined decisions, delegating decisions to others, making collaborative decision.

Autonomy is valued differently by different people depending upon their cultural, spiritual and religious beliefs or background. It should be recognised that as well as inter-cultural diversity there will also be intra-cultural diversity. Laws and policies should allow for autonomy to be exercised in a range of ways, including using an ACD to exercise self-determination, to formally delegate decisions to others, to ensure decisions are made collaboratively with or by the family, and a combination of these approaches.

Autonomy & the Framework

Given Australia's Indigenous heritage and increasingly multicultural population, it cannot be assumed that individual autonomy is the prevalent ethic in all communities or that normative western values and decision-making norms will apply to all families

However it must be recognised that ACDs are not appropriate for every person or every community, and that a person may choose not to complete an ACD. Nevertheless, legislation should not introduce barriers to Indigenous and multicultural families seeking to use ACDs; such families may need specific advice and support to complete ACDs if they choose to use them.



ADVANCE CARE PLANNING TOGETHER

The Framework in brief:

ADVANCE CARE PLANNING TOGETHER

- 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

An Act to:

- To protect health practitioners 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 as far as practicable and appropriate that health care accords with the expressed directions, wishes and values
- To ensure that the wishes and values are considered in dealing with the person's residential and accommodation arrangements and personal affairs
- To protect health practitioners and others giving effect to the directions wishes and values of a person who has given an ACD
- Provide mechanisms for disputes

s7 defines **impaired decision making**:

Not capable of understanding or retaining or using information or communicating decision

Importantly:

- Not incapable of understanding merely because not able to understand technical or trivial information
- Not able to retain merely because can only retain for a short time
- May fluctuate between being impaired and not
- Not impaired merely because a decision made results, or may result, in an adverse outcome

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

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

The current system:

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- Aged & Community Services SA&NT
- 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

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