

The background features abstract, overlapping geometric shapes in various shades of green, ranging from light lime to dark forest green. The shapes are primarily triangles and polygons, creating a dynamic, layered effect. The overall composition is clean and modern, with the text centered against a white background.

# A review of the Do-it-yourself Advance Care Directive in South Australia

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# Questions

- ▶ What led to the *Advance Care Directive Act 2013 (SA)*?
- ▶ What did it offer?
- ▶ What have been the lessons learned over the past five years?

# The history

- ▶ In 1995 the *Guardianship and Administration Act 1993* was implemented, giving the provision of an Enduring Power of Guardianship.
- ▶ The *Consent to Medical Treatment and Palliative Care Act 1995* gave provisions of a Medical Power of Attorney and an Anticipatory Direction.
- ▶ There was recognised confusion and complexity with the different provisions in two Acts (along with the existing Enduring Power of Attorney for finances.)

# Revising the legislative framework

- ▶ The Advance Care Directives Review Committee task - to design a legislative framework that took into account:
  - ▶ a changing social and medical environment
  - ▶ escalating public expectations
- ▶ *'a simpler, more consistent and accessible system of advance directives that will ensure the proper protection of citizens whose capacity becomes compromised and increase people's capacity to direct ...where and how they want to live and what treatment they want offered when unable to speak for themselves'*

# Advance Care Directives Act 2013

'to enable competent adults to give directions about their future health care, residential and accommodation arrangements and personal affairs'

- Bestow future decision making to another person
- Give written instructions concerning key decisions for a time if incapable of making their own decisions:
  - ✓ wishes and preferences for care and accommodation
  - ✓ binding provisions in the refusal of health care

# Principles support autonomy

- ▶ To make decisions about future health, residential and accommodation arrangements, personal affairs
- ▶ Decide what constitutes quality of life and express that in advance
- ▶ To make their own decisions to the extent able, and be supported to make such decisions as long as can
- ▶ Exercise autonomy through self-determined, delegated or collaborative decisions

## Authority of the substitute decision-maker

- ▶ the substitute decision maker has the same authority as the person who gave the advance care directive
- ▶ Legal duties:
  - as far as practical reflect the decision the person would have made
  - in the absence of instruction be consistent with the proper care of the person
  - must not as far as is reasonably practical, restrict the basic rights and freedoms of the person

# The advance care directive

The person making the advance care directive be:

- ▶ Be competent, and the directive be made without coercion
- ▶ validated by independent witnessing

That the person and their agents appointed:

- ▶ understand the context of the powers
- ▶ the choices available to them
- ▶ the consequences of completing the form

Protections provided eg dispute resolution, revocations

# Do-it-yourself

- ▶ Written to apply for any period of lost or diminished capacity, rest of life *and* end of life
- ▶ To encourage instructions to be outcome based
- ▶ To allow for recording of personal values and preferences

## Binding instructions

- ▶ That medical or legal advice not be required to be valid
- ▶ Encouraged to seek advice regarding future refusals and consents to treatment

# Implementation

- ▶ Developing a kit with a form eg simply written, use of scenarios and examples
- ▶ The forms are accessible eg hard copy, website

The community is educated as to their use

- ▶ General public education campaign
- ▶ Ongoing education by Legal Services, Public Advocate

# A case study: making an ACD

A volunteer program in a regional area in South Australia – recognition that members of the community would require information and support

- ▶ Public seminars regarding ACD's
- ▶ One-to-one support regarding how to complete the form
- ▶ Linked to a JP service for witnessing and certification

460 people have used the volunteer support program

# Evaluation of program

Interviews with:

- program instigator
- program volunteers
- Justices of the Peace
- members of the community

Evaluators: Sue Jarrad and Margaret Brown

## Some initial findings:

- education and promotion
- a trigger
- access to the kit
- understanding the principles and duties
- having the conversation with family members
- completing the form
- witnessing, certification and distribution

# Community education

- ▶ The importance of understanding what it offers
- ▶ Knowing the legal duties for existing Powers eg Enduring Power of Guardian
- ▶ Greater media presence required eg TV ad

## Barriers

'there doesn't seem a pressing medical need at present'

'when I looked through it I thought -I don't have time for this now'

# The trigger

People often require an event to initiate making an ACD:

- ▶ 'our GP told us to get one'
- ▶ 'It's a matter of getting around to it'
- ▶ 'our daughter cracks the whip'
- ▶ in hospital with a triple bypass 'hurried us up a bit'

## Access

- ▶ Knowing where to get the information kit

## Steps to making an ACD

- ▶ understanding the principles and duties
- ▶ having the conversation with family members

'our children are not near us- we need to take it with us and discuss it with them'

'we've encountered a bit of a demarcation dispute between our daughters...we are having to rethink who our substitute decision makers will be'

# Completing and distributing the form

- ▶ Filling out the form

  - ‘It took me ages. I found so many suggestions of what to write, doubling up, I’d put it aside and leave it for a while’

  - ‘a bit confused at the start’

- ▶ Assistance made it easier:

  - ‘found it helpful when we were a bit lost’

- ▶ Witnessing, certification and distribution

  - understanding about the original form, making copies

  - where to keep and distribute the form

# Learnings

An ambitious schedule:

- ▶ new legislation, new lexicon, new duties
- ▶ limited resources for community education

Limitations of do-it-yourself advance care directives

- ▶ of selecting and guiding substitute decision makers
- ▶ of making binding instructions without full knowledge

# The legislated review

- ▶ Getting the form right- future revisions
- ▶ Further community education
- ▶ Providing more assistance to complete an ACD
- ▶ Reviewing witnessing arrangements
- ▶ Very little data to show overall uptake

The review is an opportunity to take stock

- ▶ *a formal assessment with the intention of instituting change if necessary'*

Thank you

Sue Jarrad