



A Clear Path to Care

Part 2

The New *Advance Care Directive* and changes to third party consent

Main concepts



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This presentation will:

Discuss the following:

- How individuals can appoint SDMs or document values and wishes on an ACD
- Binding refusals
- Non binding requests
- Substitute decision making
- The legal hierarchy for consenting when a patient has impaired decision-making capacity
- New protections for health practitioners
- That there is no requirement to provide treatment which will not benefit the dying patient



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The Form

Appointing a Substitute Decision Maker (SDM):

- Person can document the appointment of one or more SDMs here (Part 2a)
- Do not have to appoint SDM- can leave blank
- SDM can be appointed to make all or specific decisions (healthcare, residential, personal – Part 2b)
- A health practitioner must seek consent from an SDM (appointed to make health care decisions) for any treatment or health care
- The SDM can make lawful decisions as if they are the person – they legally “become the person”
- The SDM must:
 - Make a decision they believe the person would have made i.e. as “if in their shoes”
 - Refer to documented wishes or values
 - Comply with relevant refusals of health care
 - Seek to avoid outcomes or interventions the person would have wanted to avoid

Advance Care Directive Form

By completing this Advance Care Directive you can choose to:

1. Appoint one or more Substitute Decision-Makers and/or
2. Write down your values and wishes to guide decisions about your future health care, living arrangements and other personal matters and/or
3. Write down healthcare you do not want in particular circumstances.

Part 1
You must fill in this Part.

Part 1: Personal details

Name: _____
(Full name of person giving Advance Care Directive)

Date of birth: ____/____/____

Part 2a
Only fill in this Part if you want to appoint one or more Substitute Decision-Makers.

Part 2a: Appointing Substitute Decision-Makers

I appoint: _____
(Name of appointed Substitute Decision-Maker)

Ph: _____ ☎ Date of birth: ____/____/____

I, _____
(Name of appointed Substitute Decision-Maker)

am over 18 years old, and I understand and accept my role and the responsibilities of being a Substitute Decision-Maker as set out in the Substitute Decision-Maker Guidelines.

Signed: _____ Date: ____/____/____
(Signature of appointed Substitute Decision-Maker)

AND

I appoint: _____
(Name of appointed Substitute Decision-Maker)

Ph: _____ ☎ Date of birth: ____/____/____

I, _____
(Name of appointed Substitute Decision-Maker)

am over 18 years old, and I understand and accept my role and the responsibilities of being a Substitute Decision-Maker as set out in the Substitute Decision-Maker Guidelines.

Signed: _____ Date: ____/____/____
(Signature of appointed Substitute Decision-Maker)

Your initial Witness initial

Part 2a
(continued over page)

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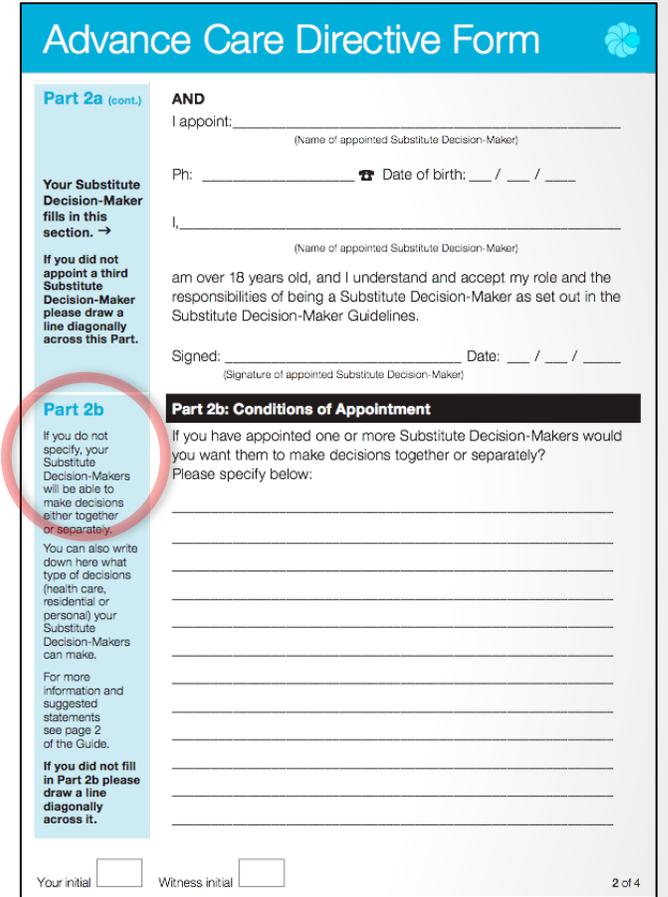
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The Form

Part 2b Conditions of Appointment

- One or several SDMs can be appointed
- SDMs can be appointed to act individually or together

Important: Health practitioners only have to contact the first SDM that can be reached - it is then up to that SDM to contact any other SDMs



The image shows a page from an 'Advance Care Directive Form'. The page is titled 'Advance Care Directive Form' at the top. It is divided into two main sections: 'Part 2a (cont.)' and 'Part 2b: Conditions of Appointment'. 'Part 2a' includes fields for appointing a Substitute Decision-Maker (SDM), including their name, phone number, date of birth, and signature. 'Part 2b' asks the user to specify if they want one or more SDMs to make decisions together or separately, and provides a space for them to write down what type of decisions (health care, residential or personal) the SDMs can make. There are also fields for 'Your initial' and 'Witness initial' at the bottom. A red circle highlights the 'Part 2b' section header and the instructions for specifying decision-making preferences.

Part 2a (cont.)

Your Substitute Decision-Maker fills in this section. →

If you did not appoint a third Substitute Decision-Maker please draw a line diagonally across this Part.

Part 2b

If you do not specify, your Substitute Decision-Makers will be able to make decisions either together or separately.

You can also write down here what type of decisions (health care, residential or personal) your Substitute Decision-Makers can make.

For more information and suggested statements see page 2 of the Guide.

If you did not fill in Part 2b please draw a line diagonally across it.

Part 2b: Conditions of Appointment

If you have appointed one or more Substitute Decision-Makers would you want them to make decisions together or separately? Please specify below:

Your initial Witness initial

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The Form

Refusals of Health Care

- The person can document binding refusals here
- These must be complied with if the refusal was meant to apply in the relevant situation
- BUT there are new protections for health practitioners to act against a binding refusal in emergency and uncertain/urgent situations where a SDM or Person Responsible is not available

The image shows a screenshot of the 'Advance Care Directive Form' for South Australia, specifically Part 3. The form is titled 'Part 3: What is important to me - my values and wishes:'. It contains instructions for the user to write down what is important to them, including health care they want, where they wish to live, and other personal arrangements. There are several horizontal lines provided for writing. A red box highlights a section where the user can make binding refusals of health care, with a note that if they do, they must state when and in what circumstances it will apply. At the bottom, there are fields for 'Your initial' and 'Witness initial', and a page number '3 of 4'.

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The Form

Witnessing and Interpreter Statements

- The form must be witnessed and initialled on each page by the individual and the witness
- There is an interpreter statement
- Any copies of the ACD must be certified

Advance Care Directive Form

Part 4: Giving my Advance Care Directive

Part 4
You must sign this form in front of an independent witness.

Only an independent authorised witness can sign your Advance Care Directive
Information for witnesses is included with this form.

I, _____
(Full name of person giving this Advance Care Directive)

do hereby give this Advance Care Directive of my own free will.

I certify that I was given the Advance Care Directive Information Statement and that I understand the information contained in the Statement.

Signed: _____ Date: ____/____/____
(Signature of the person giving this Advance Care Directive)

Witness statement

I, _____ certify that:
(Full name of Witness)

I gave: _____
(Full name of person giving this Advance Care Directive)

the Advance Care Directive Information Statement.

In my opinion he/she appeared to understand the information and explanation given and did not appear to be acting under any form of duress or coercion.

He/She signed this Advance Care Directive in my presence.

Ph: _____
(Occupation of Witness)

Signed: _____ Date: ____/____/____
(Signature of Witness)

Part 5: Interpreter statement

Part 5
Do not complete this Part unless an Interpreter was used.
If you did not use an Interpreter please draw a line diagonally across this Part.

I, _____ certify that:
(Full name of Interpreter)

The Advance Care Directive Information Statement was given through me to _____
(name of person giving Advance Care Directive)

In my opinion he/she appeared to understand the information given.

The information recorded in this Advance Care Directive form accurately reproduces in English the original information and instructions of the person.

Ph: _____

Signed: _____ Date: ____/____/____
(Signature of Interpreter)

Form approved by the Minister for Health pursuant to the Advance Care Directives Act 2013 (SA)

Your initial Witness initial

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The effect of the legal changes

Obligations of a health practitioner

- 1) If a Substitute Decision Maker is appointed – must seek consent
- 2) Must follow relevant binding refusals of health care
- 3) Should be guided by any non binding advisory instructions
- 4) Must try and seek to avoid outcomes or interventions the person wanted to avoid
- 5) In the absence of an ACD (an SDM or instructions)- need to seek consent for treatment from a “Person Responsible”
- 6) For unresolved disputes- a new dispute resolution process – Public Advocate and then the Guardianship Board



The effect of the legal changes

New Protections

- A Health Practitioner:
 - can rely on an ACD (and/or the decision of a SDM) in good faith and without negligence
 - protected if they act in good faith and without negligence even if they misinterpret an ACD
 - cannot be made to breach their professional code/standards
 - can refuse to comply with an instruction of an ACD on conscientious grounds (but should hand over care)

In addition:

- An Advance Care Directive cannot be used to demand treatment which is:
 - illegal,
 - aid in euthanasia or assisted a suicide
 - a refusal of mandatory treatment (e.g. under the *Mental Health Act 2009*)



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But what is the real impact of the Advance Care Directives Act 2013 and changes to the Consent Act on clinical decision-making?

Better law because it emphasises patient autonomy, but balanced with protections that align with good practice...

Aligns with Standard 2 – Partnering with Consumers



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Major changes...

- In regard to every situation where a patient has impaired decision-making capacity and a decision needs to be made requiring consent
- Clarifies decisions involving withdrawal of treatment
- Not just at end-of-life, but for patients with mental illness, dementia, delirium, under anaesthesia, etc.
- Not because it's complex, but because from July 1st 2014, it changes laws that give greater clarity for health practitioners in making clinical decisions for their patients





These changes...

- 1) Make it clear what patient autonomy is, and the pathway that must be taken to apply it
- 2) Provide new important protections for health practitioners





Making it clear what patient autonomy is, and the pathway that must be taken to apply it

- What patient autonomy is:
 - The overriding principle for everyone – SDMs Persons Responsible and Health Practitioners – is to **act as if they are in the patient’s shoes – and to decide as they would have done**
- We must not apply our own values, what we want, or even what even we think might be “best” for the patient
- The pathway that must be taken to apply patient autonomy:
 - Single ACD form with SDMs and/or wishes
 - Single set of legal rules- with a **clear legal pathway (or “road”) or legal hierarchy when obtaining consent; and a clear dispute resolution process**



Consider this common case

Profile: Dorothy

- 88 year old woman
- Full mobility, lives alone and mainly independent except for a weekly cleaning service. She has as good quality of life and enjoys gardening in particular

Presentation:

- Develops pneumonia with dehydration and acute delirium
- Assessed that she would require IV fluids and antibiotics to recover
- Does not have decision-making capacity

Situation:

- She has an ACD with one SDM appointed and vague documented wishes about not wanting to live if she had brain damage

What would you do and what treatment would you provide?



Did you “stand in her shoes”?

- Were you applying your values, best practice, best interests, protocol?
- And if you provided treatment (e.g.) IV – did you seek the consent of the SDM?



The Legal Hierarchy

The legal hierarchy of who can consent (and refuse to consent) for a person with impaired decision-making capacity:

- 1) A Substitute Decision-Maker if one is appointed on an individual's ACD
- 2) If no SDM is appointed, relevant Instructions or Wishes documented in an ACD
- 3) If there is no ACD – a Person Responsible has legal authority

A Person Responsible is (in the following order):

- Guardian appointed by the Guardianship Board/Tribunal
- Prescribed relative with a close and continuing relationship available and willing to make the decision (spouse/domestic partner, adult related by blood or marriage, person related by adoption, Aboriginal or Torres Strait Islander kinship/marriage)
- Close friend available and willing to make the decision

If none, then:

- Someone charged with day to day care and well-being of patient (e.g. a Director of Nursing in aged care)
- Guardianship Board/Tribunal (last resort)

But just a reminder - if an individual has capacity, you must talk to them first to get consent - this is something that is often forgotten



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In Summary, the Legal Hierarchy is:

- 1) Substitute Decision Maker appointed on an ACD
 - 2) Wishes and instructions documented on an ACD
- If none of the above:
- 3) Person Responsible



Key Protections for health practitioners

- 1) Protected for complying with an ACD in good faith (ACD Act, s41)
- 2) A protection to act (Consent Act, S13(1a))
 - against a binding refusal in an emergency and uncertain/urgent situation, and
 - SDM or Person Responsible is not available, and
 - has reason to believe that the binding refusal was not meant to apply in the circumstances
- 3) A new protection (Consent Act, S17(2))
 - no longer a requirement to provide, and the ability to withdraw, treatment
 - which a doctor does not think is of benefit to a patient
 - in the terminal phase of a terminal illness, persistent vegetative state or minimally responsive state



The existing problem

s17 (2) of the Consent to Medical Treatment and Palliative Care Act 1995

17(2) A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision, is, in the absence of an express direction by the patient or the patient's representative to the contrary, under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state.



Amendment of section 17 (2)

The care of people who are dying:

- A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of the patient under the medical practitioner's supervision:
 - (a) is under no duty to use, or to continue to use, life sustaining measures in treating the patient if the effect of doing so would be merely to prolong life in a moribund state without any real prospect of recovery or in a persistent vegetative state (whether or not the patient or the patient's representative has requested that such measures be used or continued); and
 - (b) must, if the patient or the patient's representative so directs, withdraw life sustaining measures from the patient.



A Doctor's Professional Standards:

AHPRA Medical Board of Australia Good Medical Practice: A Code of Conduct for Doctors in Australia (March 2014)

3.12.3 Understanding the limits of medicine in prolonging life and recognising when efforts to prolong life may not benefit the patient.

3.12.4 Understanding that you do not have a duty to try to prolong life at all cost. However, you do have a duty to know when not to initiate and when to cease attempts at prolonging life, while ensuring that your patients receive appropriate relief from distress.



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AHPRA Nursing and Midwifery Board of Australia National competency standards for the registered nurse

2.3 Practises in a way that acknowledges the dignity, culture, values, beliefs and rights of individuals/groups:

- demonstrates respect for individual/group common and legal rights in relation to health care
- identifies and adheres to strategies to promote and protect individual/group rights
- considers individual/group preferences when providing care
- clarifies individual/group requests to change and/or refuse care with relevant members of the health care team



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Summary

ACD and Consent Part 2

- Individuals can appoint SDMs or document values and wishes on an ACD
- Binding refusals must be complied with if relevant
- Non binding requests should be complied with if reasonably practicable
- Everyone- SDMs, persons responsible and health practitioners must act as if “in the patient's shoes” and decide as they would have done and are protected under the law for doing so
- There is a clear legal hierarchy to consenting when a patient lacks capacity- SDMs, documented wishes and values, Persons Responsible
- There are new protections- particularly in acting in emergency urgent/uncertain situations
- There is no requirement to provide treatment which will not benefit the patient

