Advance Care Directive Frequently Asked Questions

A clear path to care

Advance Care Directives

What can be included in an Advance Care Directive (ACD)?

An ACD is a legal document and can include a person's:

- future wishes and instructions for health care
- outcomes or interventions a person wishes to avoid
- specific refusals of health care (including medical treatment/life sustaining treatment) (binding provisions)
- values and what is important to them when others are making decisions on their behalf
- preferred living arrangements
- personal wishes.

It can also be used to appoint one or more Substitute Decision-Makers to make decisions on the person's behalf when they are unable to do so.

What does it mean to have a valid ACD?

A valid ACD is one which is signed by the person and witnessed by an authorised witness. You can rely on a valid ACD in good faith and have legal protection for doing so. You can be confident the person was competent when they completed the ACD unless you have evidence to suggest otherwise eg you knew the person at the time they wrote their ACD and you did not think they understood what they were doing, or you believed that someone was coercing that person to write one.

Who can witness an ACD?

A witness must be a member of the category of authorised witnesses as set out in the ACD Act (eg registered professionals, public servants with more than five years service, lawyers, Justices of the Peace, Ministers of religion) **and** must be **independent** of the person giving the ACD.

Being **independent** of the person means that the witness must not be:

- a person who may be a beneficiary, either directly or indirectly of the person's estate (usually a relative)
- a professional providing care either directly or indirectly to the person for example a doctor, nurse or aged care staff (or may be likely to provide care in the future eg GP in a country area)
- a person in a position of authority in a hospital or nursing home eg aged care manager or Director of Nursing/Medicine.

What do I do if the ACD only contains values and wishes and no Substitute Decision-Maker (SDM) appointment? When do I act on these?

When making clinical decisions, you should have regard to all the provisions set out in the ACD, and if reasonably practicable try and follow them. Clinical decisions (what treatments/care is offered) should be informed by what the person has stated is important to them when others are making decisions on their behalf, including outcomes or interventions they wish to avoid.

What are binding provisions?

A binding provision is a refusal of health care (including medical treatment and life sustaining measures). To be binding it must be relevant and applicable to the current circumstances as set out in the ACD.

Health practitioners must comply with a binding provision unless:

- There is reasonable evidence that the person had changed their mind, for example they have refused blood transfusions under all circumstances as a Jehovah's Witness (JW), however they are no longer a JW, but didn't update their ACD.
- It is an emergency **and** there is no time to consult the ACD/SDM or to work out the patient's condition to determine whether the provision applies.
- They have a conscientious objection to complying with an ACD. If this is the case they must hand over the care of the patient to another health practitioner in accordance with their professional Code of Conduct.

A refusal means that you do not have consent to provide the health care. To provide health care without the person's consent can be grounds for unprofessional conduct or assault and battery.

Who must follow a binding provision in an ACD?

Health practitioners[1] must comply with a binding provision in an ACD if there is no SDM appointed, or there is no time to contact a SDM if one is appointed.

If the ACD appoints a SDM, the SDM must follow the refusal in the ACD if they believe it is what the person would have done in the circumstances. They must therefore refuse the health care on the patient's behalf. The SDM stands in the patient's shoes and their consent/refusal is legally valid as if it was the person making their own decision.

Can I rely on a consent/refusal of health care in an ACD if relevant and applicable to the situation?

Yes, all health practitioners are protected from criminal and civil liability for complying with a person's ACD in good faith and without negligence.

Am I protected for complying with an ACD or SDM decision?

Yes, health practitioners, SDMs and others (eg social workers) are protected from criminal and civil liability for complying with an ACD in good faith and without negligence.

If the person has appointed one or more SDMs and the patient does not have capacity to make their own decision/s, their appointed SDMs are legally empowered to make decisions for them as if they had full decision-making capacity, eg standing in their shoes.

A person has appointed three SDMs, do I have to contact all three?

You only need to contact the first SDM you can reach (with health care decision-making powers). It is up to the SDM you reach to contact any other SDMs.

If there is more than one SDM how can they make decisions?

If the person has not specified in the ACD how they want SDMs to make decisions, they can make decisions either together or separately. This means that you can rely on the decision of the SDM you have made contact with.

What are my obligations in relation to SDMs?

If the patient is unable to make their own decision (consent to or refuse to consent) then you must seek consent for any treatment or health care from the SDM appointed under the ACD to make health care decisions.

What are SDM's obligations?

SDMs must make a decision they believe the person would have made in the circumstances. They are required to:

- comply with any relevant and applicable refusals of health care
- take into account any other wishes, values or instructions in the ACD
- seek to avoid outcomes or interventions the person wanted to avoid.

They can make all the lawful decisions the person could have made if they had full decision-making capacity. They cannot refuse:

- the natural provision of food and water by mouth or
- drugs to relieve pain or distress (eg palliative care).

Can an ACD be used to demand specific health care be provided?

No, if a person has specified particular health care they would accept, this is an indication of consent, if it is considered clinically appropriate to offer the health care. However there is no obligation on the health practitioner to provide the health care if it is not considered to be of benefit to the patient.

Does an ACD/SDM decision mean that patients are making clinical decisions and not doctors?

No, medical practitioners determine what treatment to offer, based on good medical practice and having regard to the patient's wishes and preferences. The ACD or SDM decision is simply either consent or refusal of consent to the treatment offered. It supports patient-centred decision-making by encouraging decision-makers to stand in the patient's shoes.

Unless it is an emergency **and** there is no time to consult the ACD/SDM or to work out the patient's condition, if a patient has refused particular health care or medical treatment which is applicable to the circumstances, then it cannot be provided. To do so would be to provide treatment without consent (which can be grounds for unprofessional conduct or assault and battery).

1 Health practitioners, as defined in the ACD Act, includes any health practitioner registered under the National Law, and also includes ambulance officers and paramedics

What if I am presented with an ACD (under ACD Act) and an Enduring Power of Guardianship (EPG) Medical Power of Attorney or Anticipatory Direction?

The ACD under the ACD Act would apply not the other document. If a person has completed an ACD (under the ACD Act) then that automatically revokes all previously made documents, including an Enduring Power of Guardianship, Medical Power of Attorney or Anticipatory Direction.

When does an ACD take effect?

An ACD takes effect, and decisions can be made under it (by the SDMs or health practitioners etc), when the person who gave the ACD has impaired decision-making capacity in relation to the decision. This may be temporary (eg in case of acute mental illness or fluctuating due to dementia) or permanent (eg advance stage of illness). See the Impaired Decision-Making Factsheet. It is no longer limited to the terminal phase of a terminal illness but can apply at any time the person's decision-making capacity is impaired. Assessing decision-making capacity is not a global assessment of whether the person has a diagnoses or impairment of the mind or brain and is unable to manage their own affairs.

Impaired decision-making capacity means that the person is unable to:

- understand the information given to them and the choices available to them (which must be presented to them in a way they should be able to understand including using an interpreter)
- understand the consequences of having the health care or not having the health care
- make a decision based on this information (or their own social, religious or moral grounds)
- retain the information, even if for a short time
- communicate the decision in some way eg verbally or with assistance.

Tools which can be used to assess decision-making capacity include the Darzins 6 step capacity assessment or the NSW Capacity Assessment Toolkit.

What do I do if it is not clear if the person has decision-making capacity?

Undertake a capacity assessment as per above. Or if there is disagreement contact the Office of the Public Advocate who can make a determination of the person's capacity. See the Impaired Decision-Making Factsheet

What does impaired decision-making capacity mean and how is it assessed? Are there tools I can use? Is it a medical assessment?

This is what you are looking for when you are assessing whether a person has the capacity to make medical, dental or health care decisions:

capacity = understanding the nature + effect of the proposed treatment (and the appropriate options) at the time the consent is required.

Does the person understand the nature and effect at the time that the medical or dental decision is required, not hours or days before or after it is made?

Does the person know the 'nature' of the treatment? That means, do they understand broadly and in simple language:

- what the medical or dental treatment is?
- what the procedure involves?
- why it is proposed?
- that there are other options? If choosing between options, the person must understand what each option is, what it involves, the effect of each option, and the risks and benefits.
- what it means if they don't have the treatment?

Does the person understand the 'effect' of the treatment? Are they aware, in simple terms, of the main benefits and risks of the treatment?
Does the person have the ability to indicate whether they want the treatment? Can they communicate any decision made, with assistance if necessary?
Has the person made the decision freely and voluntarily?

Also consider that a person has a right to refuse treatment. What most people would decide to do in the situation is irrelevant. Consider the following:

- Is refusal of treatment consistent with the person's views and values?
- Is this behaviour usual for the person?
- Has all the relevant information been given to the person in a way they can understand?

What do I do if there is a disagreement about decision/s under an ACD or by an SDM/Person Responsible?

If you have concerns about the decisions being made by the SDM or Persons Responsible (for example they are not following the ACD) you can seek advice from the Office of the Public Advocate or ask them to mediate the issue. As a last resort you can also apply to the Guardianship Board to hear and determine the dispute. In resolving all disputes, the wishes of the person who gave the ACD are of paramount importance, and not family members.

What do I do if a person has an Enduring Power of Guardianship, Medical Power of Attorney and Anticipatory Direction but not a new ACD?

These documents will continue to have legal effect as if made under the ACD Act, but they will still be limited to the terms set out in the ACD document itself. This means that you will be protected for relying on these documents in good faith. If a person has all three previous documents, they combine to become one ACD (under the ACD Act).

Any appointed Medical Agents and Enduring Guardians would become SDMs and are legally authorised to make decisions either together or separately. Any SDMs must follow the instructions in the Anticipatory Direction if the person is in the terminal phase of a terminal illness, or a persistent vegetative or minimally responsive state. If there is a dispute, then you can seek advice from the Office of the Public Advocate.

What do I do if a person has any of these previous documents (EPG, MPA and AntD) and an ACD (under the ACD Act)?

By completing an ACD (under the ACD Act) all other documents are automatically revoked. This means that the only one with legal force is a person's ACD.

What do I do if I have concerns that treatment decisions are being made which go against a person's wishes in their ACD?

You can raise this with the doctor in charge of the patient's care or senior management. You can also report your concerns anonymously to the Office of the Public Advocate. Other options include reporting your concerns to the relevant Health Practitioners' Tribunal or the Health and Community Services Complaints Commissioner.

For more information

SA Health
Policy and Commissioning Division
Email: policy&legislation@health.sa.gov.au
Subject line: Advance Care Directive