Information for SA Health allied health staff on Advance Care Directives

The Advance Care Directives Act 2014 (ACD) made significant changes to the way that Advance Care Directives are managed and applied in South Australia. The Act creates new opportunities to redefine the role for Allied Health, and all staff, in supporting people to document their wishes, values and preference for their future health care, accommodation, personal matters and dying wishes.

This will ensure that health care teams are guided by consumer wishes and goals in the delivery of person-centred care, particularly when consumers are unable to guide staff themselves.

It must be remembered that it is a person's choice as to whether they complete an ACD or not. Staff can assist consumers by providing information to inform their choice.

Principles

Staff should be guided by the following principles:

1. An ACD enables a competent adult to make decisions about his or her future health care, residential and accommodation arrangements and personal affairs either by documenting their own wishes and instructions and/or through one or more Substitute Decision-Makers (SDM). It is a choice.

2. A competent adult can decide what constitutes quality of life for him or her and can express that in advance in an ACD.

3. An adult is presumed to have full decision-making capacity in respect of decisions about his or her health care, residential and accommodation arrangements and personal affairs unless there is evidence to the contrary (see SA Health factsheet What is impaired decision-making capacity and how is it assessed?).

4. An adult must be allowed to make their own decisions about their health care, residential and accommodation arrangements and personal affairs to the extent that they are able, and be supported to enable them to make such decisions for as long as they are able to (see SA Health factsheet Supporting a person to make a decision).

5. An adult can exercise their personal autonomy by making their own decisions, delegating decision making to others, making collaborative decisions within a family or community, or a combination of any of these, according to a person's culture, background, history, spiritual or religious beliefs.

6. A valid ACD (one that is signed by the person and witnessed by an independent authorised witness), and each SDM appointed under a valid ACD, has the same authority as the person had who gave the ACD when he or she had full decision-making capacity.

7. A decision made by a person on behalf of another in accordance with the Act:
   - must, as far as is reasonably practicable, reflect the decision that the person would have made in the circumstances (stand in the person's shoes); and
   - must, in the absence of any specific instructions or expressed views of the person, be consistent with the proper care of the person and the protection of his or her interests and well-being; and
   - must not, as far as is reasonably practicable, restrict the basic rights and freedoms of the person.

8. If a dispute arises in relation to an ACD or a decision being made under an ACD, the wishes (whether expressed or implied) of the person who gave the ACD are of paramount importance and should, insofar as is reasonably practicable, be given effect.
9. In determining the wishes of a person who gave an ACD in relation to a particular matter, the following should be considered:

- any past wishes expressed by the person in relation to the matter; and
- the person's values as displayed or expressed during the whole or any part of his or her life; and
- any other matter that is relevant in determining the wishes of the person in relation to the decision.

The following provides guidance for SA Health allied health staff about the type of support an SA Health employee may provide.

**To complete or not complete an ACD within a health service setting**

ACDs are preferably completed in the community, in a non-crisis situation, when the consumer and those close to the person can carefully consider the implications of completing an ACD or not, what it should contain and whether and whom to appoint SDMs.

However if a client of the health service has not been able to complete an ACD, but tells you as a health worker that they would like to have an ACD – what can you do?

It is important to understand that to be able to complete an ACD, the person must be able to understand what an ACD is, what it does, when it will be used, and it must be their own choice to complete one.

If a consumer requests support, and staffing workload permits, this can be provided within the health service setting as per local protocols and in accordance with this factsheet. It might be useful to suggest to the consumer that discussions with their significant others is an important part of the process.

If a witness is required it is suggested that an administrative officer (with over five years employment) who is not involved in the patients' health care (now or possibly in the future) should provide witnessing duties. See below section on witnessing.

**Witnessing an ACD**

**ACDs are only valid once they have been witnessed by an independent authorised person.**

- A valid ACD is one which is signed by the person and witnessed by an authorised independent witness (and SDMs appointments signed and accepted prior to witnessing).

- ACDs can be witnessed by a wide range of people including clinical and administrative staff working within SA Health (with over five years employment). Authorised witnesses include:
  - Justices of the Peace (JP)
  - lawyers
  - registered health practitioners including doctors, nurses, pharmacists, podiatrists, physiotherapists, some Aboriginal health workers, psychologists
  - credentialled non-registered health professionals including social workers, speech pathologists, exercise physiologists (with five or more years of government service)
  - registered professionals such as teachers and accountants
  - local, state or commonwealth government employees (with more than five years' service).


Even if your profession is on the list of witnesses, the Act requires that the witness be independent of the person who is writing the ACD. A witness cannot be:

- a person who has a direct or indirect interest in the estate of the person completing the ACD – for example a family member
- a person appointed as their SDM or
- their health practitioner (whether solely or as a member of a team)
- a person in a position of authority within a hospital, nursing home or similar facility.

If there is a chance you will be the person's health practitioner/social worker in the future you should not witness their ACD.

Some health workers believe that these provisions limit their ability to provide support to a person undertaking an ACD.
So… how else can a health worker be involved in supporting a client to consider and complete an ACD?

Raising awareness and providing information to consumers

An SA Health employee is able to answer questions from consumers about ACDs. However, you cannot direct someone to put one in place nor can you say specifically what types of things to write. Examples of some of the information which you can discuss with consumers include:

- situations where an ACD can be used eg when the person has impaired decision-making capacity in relation to the decision
- when an ACD takes effect eg when the person has impaired decision-making capacity in relation to the decision
- what a SDM is, the types of decisions they can make and how they must make these decisions (eg stand in the person's shoes)
- who can witness the document or where they can find a witness
- who will make decisions for the person if they cannot and they do not have an ACD and or any SDMs appointed
- examples of types of information which can be included eg future health care wishes, refusals of particular types of health care and when the refusal applies (called binding refusals if relevant to the situation), outcomes of care they wish to avoid, personal matters, residential and accommodation preferences
- the ACD DIY Kit and or online form and the availability of example statements to guide them in documenting their wishes
- the importance of discussing their wishes with those close to them to prevent problems down the track
- assisting to make or arrange certified copies
- guidance on how to make sure others know they have an ACD, where to keep the ACD once completed, who to give it to, to make sure it can be accessed when needed, including in an emergency
- where to buy or download the ACD form/DIY kit; website for online form
- where to get help with writing/witnessing their ACD or referring them to assistance within the service (if possible).

You can also provide them with a consumer brochure and or direct them to the website where they can find more information and or download the ACD form and or DIY kit themselves.

Scribing

As a health professional you are able to scribe on an ACD document on behalf of a consumer, particularly if they cannot write, are frail or have asked you for assistance to do this for them. The consumer should tell you what they want written and you can scribe word for word what they say. You should not provide any information that could be perceived as directive. Giving them a sample copy of the ACD DIY kit, or using this yourself, may help as a guide with them could help with this.

Certifying copies

Only certified copies of an ACD can be used within SA Health (that is certified copies only must be included in the person's medical record). Certifying a document is different from being a witness. Certification means that the person certifying the document is formally stating that the copy of the ACD is an identical copy of the original ACD document.

Anyone on the list of authorised witness can certify copies of the original ACD, and they do not have to be independent of the person making the ACD. This means that allied health staff can certify copies of a person's original ACD. See the SA Health factsheet How to Certify an Advance Care Directive for further information.

Allied health staff can also make certified copies for clients and arrange for the certified copy to be included in the person's medical record.

When decisions are needed - complying with or applying a person's ACD

Once an ACD has been completed, and signed by all parties and witnessed, what are your obligations?

If a consumer informs staff they have an ACD what must you do?

You must first request a certified copy of the ACD and arrange for it to be placed in the plastic sleeve in the alert section of the consumer's medical record. You can advise clerical staff to add it to the Alert, and update the relevant information (eg SDM contact details etc) on the patient administration system.

You should inform the consumer that without a certified copy staff may be unable to act on their wishes. If the consumer only has an original ACD, then you can arrange for certified copies to be made and follow the process as described above. (It may be useful to certify multiple copies at one time so the person can make sure any appointed SDMs, family, other health services etc).
Determining when the ACD applies or takes effect

Before others make decisions for the person, the person must be supported to make their own decisions for as long as they can. There are tips for staff on how to do this in the SA Health factsheet Supporting a person to make a decision.

For the ACD to apply (including for SDMs or Persons Responsible to make a substitute decision), the person must have impaired decision-making capacity in relation to the particular decision.

Under the law there is a presumption that a person is able to make their own decisions, unless there is evidence to the contrary.

To be able to make a health decision (to consent), the person must be able to:
1. Understand the information relevant to the decision, presented in a way that maximises their understanding.
   - Allied health staff could facilitate or assist a person to understand the information presented to them.
2. Be able to weigh up the risks and benefits.
   - Allied health staff could assist a person think through the options or implications of the decision.
3. Be able to retain the information even if only for a short time.
4. Communicate the decision, in any manner.
   - Allied health staff could assist a person communicate the decision eg using a letter board or other assistance.

Allied Health staff:
- could ensure the process is documented
- help the person understand the options available
- assist them to think through the issues
- support them to make their own decision
- liaise with the clinical/medical team
- assist in the decision-making capacity assessment
- bring in other family members/those close to the person to help communicate the options in ways the person understands or support them to make the decision
- ensure there is no coercion
- facilitate an interpreter or support person if needed.

If staff are concerned that an ACD may not be valid?

If you are concerned that an ACD may not be valid eg you believe that the person was not competent when they completed it, or you believe that there was coercion from family members, you can report your concerns to your manager.

If still in doubt, you can get advice from the Office of the Public Advocate on (08) 8342 8200.

If a SA Health employee believes an ACD is not being appropriately followed by either the SDM or health care professionals, what should they do?

It may that that the SDM or health practitioner is unaware of their obligations in relation to complying with the person's ACD. SDMs should be gently reminded that their role is to follow the person's wishes as expressed in the ACD, if relevant and applicable and to make a decision they believe the person themselves would have made in the same circumstances- to stand in the person's shoes.

In making decisions, SDMs/persons responsible must:
- try and make a decision they believe the person would have made (stand in the person's shoes)
- follow any relevant binding refusals of healthcare (healthcare the person did not want in specified circumstances or situations)
- be guided by any non-binding preferences and or values
- think about what matters to the person in how they live their life, what gives the person's life meaning
- cannot refuse the natural provision of food and water by mouth, or drugs to relieve pain or suffering eg palliative care.

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Health practitioners (which include all health practitioners registered under the National Law) are required to:

- seek consent from the person's appointed SDMs if the person does not have decision-making capacity in relation to the decision
- if no one appointed, or not able to be contacted, must comply with any relevant/applicable binding refusals of health care
- be guided in their clinical decision-making by any expressed values or wishes which the person expressed as important to them eg being able to recognise family/friends, live independently, make own decisions.
- must try and avoid outcomes the person indicated they wish to avoid
- must try and comply with non-binding preferences if it is reasonably practicable in the circumstances eg do not want to live in a nursing home.

Allied Health staff can:

- support SDMs and or persons responsible in making a substitute decision—stand in the person's shoes
- build capacity and knowledge among other staff members/clinicians about ACDs and their role/obligations etc
- assist with capacity assessment
- make sure the ACD is known about and included in care planning/team meetings/case discussions (SDMs involved too)
- liaise with significant others etc to ensure person's wishes are understood and are respected
- ensure a person's values/wishes etc considered in any decisions for future care/living arrangements
- ensure documentation included in handover/discharge arrangements.

If you have concerns, you should report these to the relevant management/supervisor and or seek advice from the Office of the Public Advocate (ph 8342 8200).