

# **Response to Advance Care Directive 5 Year Review**

**24 May 2019**

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HCA acknowledges the Traditional Custodians of Country. We pay respect to Elders past and present, and recognise that their cultural heritage, beliefs and relationship to Country are important for sustaining health and wellbeing.

## Recommendations

1. Information and education about ACDs be more prevalent in the community including community information sessions, information available in a range of community services and centres
2. Primary Health practitioners supported to be more proactive in initiating early conversations with consumers about the benefits of completing an ACD
3. Examples of completed ACDs reflect varying circumstances (including people who choose to die at home)
4. The review and revision of the ACD Form and Kit be done in partnership with consumers using a codesign approach
5. Provide clear definitions and explanations about medicalised terms (such as diminished capacity) to better enable consumer to make clear decisions
6. Provide diverse examples of end of life circumstances and when to use an ACD, including for young people and acute care.
7. More space (both on the hard copy and a free text option in the online version) for each question
8. Wallet cards available at any chemist, GP clinic, newsagent etc
9. A community awareness campaign highlighting the purpose of the ACD in positively empowering people to make decisions and legal arrangements about their end of life are and other personal matters in the event they are unable to make the decisions at the time.
10. Greater education/information for 'authorised witnesses' to ensure they are appropriately skilled and prepared to witness ACDs and offer consumers clear information about the process.
11. Significant revision of the toolkit content and format to make it more user friendly, reduce text heaviness and highlight specific tips and key points.

## Introduction

The Minister for Health has initiated a review of the *Advance Care Directive Act 2013 (SA)* as part of a required five (5) years review.

This independent review is being undertaken by University of South Australia who is consulting with key stakeholders and the public to identify recommendations and findings about the effectiveness and operation of the Act as well as key areas of concern in the area of advance care planning to inform the Minister.

The Health Consumers Alliance of South Australia (HCASA) is the recognised voice of South Australian health consumers and a centre of excellence in consumer and community engagement and individual and systemic advocacy. Our Vision is Consumers at the centre of health in South Australia. We believe high performing health and community services support consumers to be self-determining and self-managing, so people can achieve what matters to them and respect and share decision-making at all levels: individual health care, services and policy.

To support this review, SA Health engaged Health Consumers Alliance of South Australia (HCASA) to provide consumer feedback on Advanced Care Directives. HCASA invited consumers, their family members, carers or friends who have lived experience of implementing an Advance Care Directive, either for themselves or for another person, have been appointed a Substitute Decision-Maker or have enacted an Advance Care Directive to attend a focus group and/or complete an online survey to support the response.

## Discussion

Experience using the Advance Care Directive (ACD) and Toolkit

### Consumer experience using an Advance Care Directive (ACD)

69% of respondents rated their experience of using an ACD as extremely good.

Consumers responded that they found the ACD generally easy to read however the Kit was far too wordy and was not an easy read given the pages were very text heavy. Consumers indicated that they felt most people would not read through the Kit and may find it difficult to navigate to relevant sections, particularly for people with low health literacy.

Respondents felt that the Form and Kit alone was not adequate for people considering completing an ACD and more education and information needed to be available to consumers and the community including

- Community information forums
- Information/resources made more readily available in community settings such as libraries, councils and community centred
- Health practitioners, particularly GPs, should be better educated to take a more proactive approach to openly initiating and facilitating discussions with

consumers/patients about the roles of ACDs, and how to complete them – including assisting them to complete key sections.

Respondents felt that the draft example of the ACD was helpful but suggested that a number of examples be provided that addressed the different circumstances people may be in when they decide to complete an ACD, including taking into account the environments people may choose (including their own home).

#### Recommendations:

1. Information and education about ACDs be more prevalent in the community including community information sessions, information available in a range of community services and centres
2. Primary Health practitioners supported to be more proactive in initiating early conversations with consumers about the benefits of completing an ACD
3. Examples of completed ACDs reflect varying circumstances (including people who choose to die at home)

#### How useful is the Advance Care Directive Form in supporting a discussion about your/ the other person's wishes?

75% of consumers rated the usefulness of using the ACD to support discussion about their wishes extremely good.

Consumers expressed that being able to initiate discussions/conversations helps to 'lift the burden' of end of life decisions and allows a person to live fully knowing they have made their wishes clear and have discussed this with the people close to them. Consumers stress the importance of their right to be self-determining in all aspects of their health and care management and no less, in their end of life decisions and how they experience they end of their life. Consumers responded that this right exists and must be respected and ensured whether in whatever circumstances the person is receiving care including residential aged care, hospital, palliative care services and home.

One respondent expressed that the ACD 'enforces ceilings of care'. They also expressed that completing an ACD allowed them to have good conversations and a structure for discussions about their wishes.

Some respondents felt that the current form and guide did not recognise or encouraging younger people to create an ACD and should be reviewed with young people to ensure it met their needs.

#### Is there enough information provided to help you make clear decisions about your/ the other person's wishes?

74% of respondents felt there was enough information provided to help them make clear decisions.

Respondents identified a number of key suggestions and recommendations to improve the information resources in the Kit so that consumers understanding of specific terminology used and the context of when to 'use' an ACD was clearer. Many consumers felt the ACD and Kit were, though not specified, focused on planning for end of life for older people. Consumers commented there is a lack of targeted information for a wide range of circumstances and situations, including young people. Providing examples of when it might be opportune for people to complete an ACD would be very helpful and better inform the broader community.

Consumers felt there was a need to clarify the definition of 'diminished capacity' explain it in clear lay terms, including in what circumstances an ACD would be recommended/used.

Consumers also felt it would be helpful to include a number of phrases or statements that they could use as a guide and as a trigger for them to consider. Whilst some individuals may prefer and feel confident in wording their end of life decisions about treatment, many felt that they were not confident in ensuring the language they used would be clear to clinicians making treatment decisions based on these statements and were concerned that their wishes could be 'overturned or overlooked' if not clear. Consumers are clear that dying is a normal part of life however consumers are not necessarily aware of what end of life treatment might be and therefore, unsure what to discuss in their ACD.

Consumers suggested that several general example statements could be included and/or information about what end of life treatment options might be so that consumers are able to clarify their wishes against each of these potential treatment options.

Consumers also commented on the practical reality that they may ask for or need support from another person to complete the ACD and therefore, statements such as Part 1 "You must fill in this Part" are not reasonable and can create confusion about who can complete the form.

One respondent suggested the following examples

*I do not wish to have any chest compressions (known as 'CPR') if my heart should stop, if the circumstances will not: improve my quality of life/ return to independent functioning in my daily life.*

*I wish to have the physical, spiritual care and management that will provide me a pain-free life even if the increasing amounts of those medications may hasten my death.*

*I only wish to have oral food and fluids until I no longer can safely take these by mouth. I do not wish to have any fluids of nutrition via artificial means, this includes by intravenous, sub-cutaneous, nasogastric (tube through my nose) or gastrostomy tube (tube through my abdomen into my stomach).*

*I wish to have the care and management that dignifies my life as it journeys towards its end. I do not want artificial means to prolong my death.*

#### Recommendations:

4. The review and revision of the ACD Form and Kit be done in partnership with consumers using a codesign approach.
5. Provide clear definitions and explanations about medicalised terms (such as diminished capacity) to better enable consumer to make clear decisions.

6. Provide diverse examples of end of life circumstances and when to use an ACD, including for young people and acute care.

### What improvements could be made to the Advance Care Directive Form?

Respondents commented that the amount of writing space available in each section was too limiting (as a hard copy document). Consumers also commented that the online version was cumbersome and did not allow easily allow for free text in each section.

Consumers made the following suggestions for improving the ACD Form;

#### Length of Form

- It is a great tool to ensure that consumers have actively prepared for the time that they may not be able to speak for themselves, and they have written down your wishes. However, it is a little too lengthy for most people. It can be intimidating as it looks very complicated to begin with.
- It is very long and there is a confusion between the legal and the personal decision making
- I found it very complex and I am a highly educated competent person. I found I needed to explain aspects of it to the Justice of the Peace I went to get it witnessed. I suspect it is very much like insurance... you don't know how good it really is until you need to use it!
- An option for people to include other key information such as any insurance or prepaid funeral details would be helpful
- More space provided for each question/ answer section

#### Wallet Card

- Many lawyers download the forms and are not aware of the wallet card. In my case I found, downloaded, cut, glued the faces together etc- this is a cumbersome process and the resulting card looks unprofessional and less credible than a purpose produced smart card. I tried to purchase a wallet card & was told I would have to purchase the whole kit as the cards are not sold separately.
- It would be helpful to provide options for people to get a copy of the Wallet card (without having to download and cut and paste).
- Wallet cards should be available at any chemist, GP clinic, newsagent etc so that anyone can ask for one and sign it and put it straight in their wallet or purse. They should be hard plastic (not unlike bus cards) that can be signed and written on and long lasting.

#### Recommendations

7. More space (both on the hard copy and a free text option in the online version) for each question.
8. Wallet cards available at any chemist, GP clinic, newsagent etc

## What has been your experience using the Advance Care Directive Toolkit?

Consumers found that although the information in the Toolkit was helpful and relevant, the information is very text heavy the format with two columns failed to highlight specific tips key points – *‘the words tend to run into each other’* and the information is *“not easy to digest because it is very wordy.”*

Some consumers commented that they felt better having someone assist them to complete it as the size of the document itself and the amount of information in the toolkit was very daunting. One consumer commented that they had the opportunity to have a social worker assist them but that this was not usually an option in the community.

Others commented that they would have appreciated assistance from their GP or Practice Nurse but that the time it takes to complete the form, and the depth of discussion required meant most GPs would not have the time to support this.

Others commented the most difficult part of the process was getting the ACD witnessed and verified copies made. A number of respondents commented that the “authorised witnesses” listed in the toolkit, require additional information about their role and access to additional training as some did not seem prepared to act as a witness and others commented that “as they had not been approached to witness an ACD before, they were not really sure what they needed to do”.

Consumers recognise the rationale for having a person independent of them to act as a witness. The fact however that the person’s treating health practitioner cannot be a witness as they are not ‘independent’ of the person, makes the process more difficult. Many consumers would reasonably and practically approach their health practitioner in the first instance.

Whilst many respondents raised issues with using the toolkit – most reflected how imperative it is for consumers to have control over their end of life decisions and the need for more community awareness and education about the role and function of ACDs, and greater assistance from health and community service providers to proactively inform, encourage and facilitate the community to complete one.

Consumers felt it was important to run community awareness campaigns focussing on role of an ACD in positively empowering of people to make decisions and legal arrangements about their end of life are and other personal matters in the event they are unable to make the decisions at the time.

## Recommendations

9. A community awareness campaign highlighting the purpose of the ACD in positively empowering people to make decisions and legal arrangements about their end of life are and other personal matters in the event they are unable to make the decisions at the time.
10. Greater education/information for ‘authorised witnesses’ to ensure they are appropriately skilled and prepared to witness ACDs and offer consumers clear information about the process.



### What improvements could be made to the Advance Care Directive Toolkit?

Consumers commonly responded that although they found the toolkit lengthy, they completed the form themselves, but felt it could have been an easier process if the content and format of the toolkit were reviewed and more user friendly.

Consumers also recognised that a person's end of life goals, wishes and circumstances may change over time and/or they may change their mind, and it is important to revisit the ACD from time to time to ensure that they are still happy with what they have written, and that their substitute decision makers are still who you want to act on their behalf.

Consumers made the following suggestions for improving the ACD Toolkit;

- Making it clear that people can add an addendum to their ACD (and can include more SDMs and other details).
- Whilst the information contained in the toolkit is important and helpful – it is difficult to wade through. There is a need to reduce the 'wordiness' of the toolkit and change the format to make it easier to navigate and find key points.
- The toolkit is too long and too much information all in together. Perhaps it could be broken into clear sections or a set of booklets – highlighting clear points

### Recommendations

11. Significant revision of the toolkit content and format to make it more user friendly, reduce text heaviness and highlight specific tips and key points.

### Experience Appointing/Being Appointed as a Substitute Decision Maker

#### If you appointed/or have been appointed as a Substitute Decision-Maker – how useful did you find the Substitute Decision-Maker Guidelines?

70% of respondents found the Substitute Decision Maker Guidelines very helpful to extremely helpful.

One consumer discussed the difficulty for SDMs in rural and remote areas where the person may be sent down to metropolitan services for palliative and/or end of life care. They outlined the importance of health and community services factoring in distance and raised the question of whether SDMs need to be physically present to make decisions and the difficulty of ensuring the person's wishes are met when the SDM is not physically present to assertively represent them.

Consumers outlined the need for health professionals to be clearer and more forthcoming in providing information about the types of treatments that would be futile and cause unnecessary harm to the person so that SDMs were better informed to make these important decisions. The role of SDM must be clearly understood and it must be made clear in the guidelines that the SDM represents the wishes of the person as outlined in their SCD (not what they (the SDM) thinks is best).

## What improvements could be made to the Substitute Decision-Maker Guidelines?

Commonly, consumers felt that although the Kit provides some information about what decisions may need to be made, this information needed to be clearer with more specific examples. Consumers recommended the review of the SDM guidelines to better clarify exactly when an SDM will need to make decisions and the legal responsibility/ capacity of the SDM to support people to make a more informed choice, such as providing examples of temporary loss of capacity (ie. delirium, anaesthetic, hallucinations etc).

One consumer felt there needed to be greater clarification about how many SDMs can be nominated – ie the Form allows for specific number, but it is noted that the Act does not limit the number or allowable SDMs.

### Recommendation

12. Clearer resources about the role of Substitute Decision Makers outlining specific examples of what decisions may need to be made and guidelines for decision-making.

## Have you/ or do you intend to upload your Advance Care Directive to you My Health Record?

50% of respondents said they have/or intend to upload the ACD to My Health Record. 10% of respondents said they would not upload their ACD to My Health Record and 10% said they do not have My Health Record.

Several consumers commented that they were comfortable with their family member/s or other SDMs having a copy of their ACD who would, if necessary, act on their behalf. They did not want their ACD to be part of their generic health information.

One consumer commented that they felt strongly that they would like to see Enduring Power of Attorney, ACD & Organ donation compulsory for all over 18 & ability to update & lodged with My Health Record or SA Health systems as often as needed.

Consumers commented that although uploading the ACD to My Health Record is a good option, this should not be the only place that ACDs should be logged including; Medicare, Medic alert, a separate register as not all people have MyHR, nationally accessible and lodging with a hospital or ambulance service.

One consumer provided the following experience.

*I have concerns about having an ACD that health services are not aware of at a critical time (eg ambulance staff). I would feel more comfortable 'lodging' a copy of my ACD with my GP and local health service (hospital)– to be added to EPAS & Homer issues. I attempted to do this, but the health service found the logistics of doing this too hard and they could not assist me. They told me I would have to lodge the form at each hospital. My E Health was available then. I am however still unsure whether uploading my ACD on My Health Record would enable availability at each hospital & I am aware than many people remain sceptical of My E Health security.*

## Experience enacting an Advance Care Directive and/or Substitute Decision Maker

### What was your experience with the health service in their response to the Advance Care Directive?

Consumers provided a range of positive and negative experiences with Advance Care Directives which emphasises the importance of health care professionals having sound understanding of the role and function of ACDs and SDMs

Consumer provided the following experiences in relation to enacting an ACD;

- I never had to enact the ACD, as doctors listened to siblings who had several conversations. There were informal document stating wishes, but no one asked for the ACD paperwork. Siblings were in tune with each other. It becomes sad when wishes aren't made clear.
- My lawyer has signed my ACT and my daughter is my SDN – we have had clear conversations about my wishes and she feels that she knows what I do and don't want. She is happy to represent my wishes.
- I was asked on a preadmission for hospital (surgery) if I had an ACD and to bring it with me. Although I ticked yes on the form, no one asked me for it when I was admitted or prior to my going into surgery
- I was asked for it when my parent went into an aged care facility. My parent has had several episodes when the facility has transferred them to hospital. I do not believe they have notified the hospital of the ACD – although they have recorded NFR on their records.
- I have had experience with a family member entering palliative care services for Palliative care. The service followed their wishes without the paperwork and without questions
- There is uncertainty by health care professionals. There are health care personnel who do not know the legislation and transitional conditions of the previous now known ACD, (Medical Agent, Enduring Power of Guardianship, Anticipatory Direction and the Common Law documents
- I had a very poor experience I had to speak up and be very assertive and persistent to remind the service that the person had an ACD and that they were required by law to follow it. - did not look for it. They had a copy but did not look for it at all.

### What was your experience with the health service in their response to your role/authority as a Substitute Decision-Maker?

Respondents provided the following experiences;

- Cardiac – I was not listened to because the doctor had a conversation with my mother and approved as her informed consent? She'd changed her mind and clarified her thoughts. How do you keep the SDM informed?

- I found that largely health care professionals do not understand the necessity to site the ACD- and that it is required to be confirmed by notary (or other authorised witness)
- I found that once the clinicians had seen the document and we had established the ground rules it was OK - I was listened to
- The rules behind the *Enduring Powers of Guardianship* are straight forward (lawyers will agree and do agree) and allow medical decisions to be made for the person suffering from dementia etc. This form/process has more to do with End of life and does not support for the living person who needs support
- Health professionals need to better understand that ACDs are equally applicable for young people as they are for older people (ie not only relevant when aging) and that they are important in acute care circumstances
- The ACD is only as good as the services understanding them, asking the right questions and supporting the process – they can otherwise be the most difficult barrier to ensuring the persons wishes and end of life experience is consistent with the person’s wishes.
- Appropriate mechanisms need to be in place to ensure health services implement ACDs appropriately and acknowledge and engage with the Substitute Decision Maker, to make the process easier for the person and their family/friend
- Health and community service providers (primary health, aged care facilities) need to be trained and skilled to support and encourage people to complete the ACD, as part of Patient Care and it can be activated when necessary
- People being asked to act as the SDM must be clear in their own minds that they feel they are able to act on behalf of the person. Sometimes the most likely person (eg a person’s children or partner) may not be able to make decisions when needed. Sister could not cope with the role of SDM and this made it very difficult.

### Has the Advance Care Directive helped to reinforce your role and authority as a Substitute Decision-Maker?

50% of respondents said the ACD helped to reinforce their role and authority as the Substitute Decision Maker

Consumers commented that knowing they had the paperwork (ACD) gave them confidence in their authority. Equally and most importantly, knowing the persons wishes and having had the opportunity to have clear discussions and work through and fully understand the persons wished, was both a relief and provides a level of confidence that they can fully represent them.

50% of respondents said that the ACD did not help to reinforce their role and authority as the Substitute Decision Maker

Consumers commented that endeavouring to act on the persons behalf in certain contexts and health services can be more challenging and the system itself is a barrier. One consumer commented that their experience in emergency services was extremely challenging as the clinicians challenged the ACD and the SDMs authority – the emergency care environment is positioned to act and therefore are very confronted by the ACD and its function.

Other consumers expressed the concern that the ACD is only as good as the person writing it and it can have poor or unclear statements that are open to interpretation. Completing an ACD therefore, requires the person to openly discuss it with their family, support network so that their knowledge of the persons wishes supplements and reinforces the document.

## **Conclusion**

HCASA supports end of life processes and resources that empower consumers to direct their own care, whenever possible and recognise that a person's needs, goals and wishes at the end of life may change over time.

HCASA recognises that whilst dying is a normal part of life, how individuals experience death and dying is paramount and their rights, needs, goals and wishes must be protected, respected and implemented.

HCASA emphasises the importance of ensuing health and community service providers and staff are adequately trained and skilled to provide high quality end of life care that is consistent with the needs, goals and wishes of the person and recognises that death and dying is a human experience not a medical treatment.

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