

## SUBMISSION TO THE

### Advance Care Directives Document Redesign Project

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#### Who is COTA SA?

COTA SA is an older people's movement run by, for and with older people. We represent the rights, interests and futures of more than 630,000 older South Australians. COTA SA reflects the diversity of modern ageing in terms of living arrangements, relationships, income, sexuality, culture, health, geography and aspirations. COTA SA connects with thousands of older people each year throughout SA. Our policy and advocacy are guided by the COTA SA Policy Council made up of older South Australians from a diverse range of backgrounds, along with a number of advisory groups. COTA SA's social enterprise, The Plug-in undertakes regular surveys with older South Australians in addition to its work facilitating access to older people for organisations, researchers and service providers. COTA SA is part of the COTA Federation with independent COTAs in each state and territory along with COTA Australia. The COTA Federation undertake regular State of the Older Nation surveys (2018 and 2021) to understand the views, life experiences and needs of Australians aged 50+.

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#### Acknowledgement of Country

*COTA SA acknowledges and respects Aboriginal people as the traditional custodians of the land of South Australia. We honour Aboriginal peoples' continuing connection to Country and recognise that their sovereignty was never ceded. We pay our respects to First Nations Elders past, present and emerging and extend that respect to all Aboriginal people.*

#### INTRODUCTION

COTA SA welcomes the opportunity to contribute to the Advance Care Directives Document Redesign Project.

We engage widely with older South Australians across the state, in person and via phone and email. The lived experiences of the diverse community of older South Australians shape our

policy and advocacy work. This feedback has been prepared in consultation with COTA SA's Policy Council and Rainbow Hub.

COTA SA is committed to the continuous improvement of the Advance Care Directives (ACD) so that it becomes the robust, respected and accessible system by which all South Australians can record their directions in the event that they are not able to make a decision for themselves. At the moment ACDs are completed by about 10% of older South Australians. Feedback to COTA SA is that many people don't know about ACDs, find them hard to use and discover they are not always triggered or respected as part of health care.

For many people an ACD is likely to be activated toward the end of life. Of about 13,000 deaths in SA each year, two thirds are people aged over 75.<sup>1</sup> It is therefore especially important that older people know about ACDs and have every opportunity to record their directions. Once recorded, it will also be important that ongoing education targeting health professionals and the community ensure they are respected and that they direct decision-making as intended.

We look forward to increased investment in promoting awareness and availability of ACDs and in providing support and coaching for people to complete their own directive. In the past COTA SA has been funded to roll out both individual support and group presentations to older people all over SA using trained peer education volunteers. It was a very effective and highly valued program and could quite quickly be reactivated and delivered at scale.

As a first step, improving the form and the guide will assist in ACDs becoming scalable across the population including for older South Australians. This feedback relates to the document redesign.

### **Overall Comments**

Both the form and guide are significantly improved on previous versions in terms of layout, readability and understandability.

The separation of the form from the guide makes each clearer and makes the form look much less intimidating.

We support the importance of continuing work to achieve a process, form and terminology which is consistent, familiar and useable throughout Australia.

We think the new form strikes the right balance between accessibility and formality.

We would like to see some Q&A added to the guide - we note for example that NSW expressly recognises an ACD made in another state or territory.

We think there should be a "how to" instruction video accessible and searchable online.

Many older people, even those who have an email address, are not comfortable to search and access online. Both the form and the guide must be available and useable in hard copy form as well as electronically.

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<sup>1</sup> <https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/age-at-death>

## The Guide

- P6 **What if I have other documents in place** - include here or elsewhere a reminder to make a regular time to review your ACD, eg birthday, tax time, annual health check.
- The stories are useful. Consider including an example of someone who does not know who their supporter could be because there is not someone to whom the person is close. For example for a forgotten Australian/care leaver.
- Are there opportunities to strengthen the quality of life emphasis?
- P9 refers the person to the Advance Care Directive website for “How to make certified copies” fact sheet – please note that many older people cannot access or search a website.
- It is worth noting somewhere that completion of the ACD may take time, many conversations and may involve lots of forward planning including to explain and to get the agreement of Substitute Decision Maker/s (SDM).
- It may be helpful to workshop or update the form with a palliative care nurse, in a multi staged process as it’s quite sensitive.
- Include ‘family of choice’ in definitions and text for example on p14.
- P15 Some suggested statements
  - Being independent of thought is important to me, even if I have to rely on others daily for physical care
  - Replace *I have spent my life in* with *I identify as part of* the gay and lesbian community and want to stay in contact with them, and replace *gay and lesbian community* with LGBTI+ community
- P16 Some suggested statements – is it helpful to give an idea of what is meant by *die with dignity*.
- P17 Some suggested statements – I will accept all health care and medical treatment that will improve my health and give me more time with *my family* [replace with or add *those close to me*]
- P35 include ‘pathway’ in the heading as it is referred to as that on the previous page.
- **For more information about** pp44-45 - It is unclear what the agencies listed here can do to help a person complete or challenge an ACD. We cannot see value in directing a person to an organisation unless they can assist. In addition, the list (including names of some organisations) would seem to be out of date.
- From a COTA SA point of view, we can and do support people to get the form and guide (including by posting them a copy) but we no longer have peer education funding to train staff or volunteers to assist a person to complete the form.