

# Relinquishing or taking control? Community perspectives on barriers and opportunities in advance care planning

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## Abstract

**Objective.** This paper reports on the experiences and perspectives of community members in relation to advance healthcare directives and enduring power of attorney, including the factors that encourage or discourage engagement in advance care planning (ACP).

**Methods.** A qualitative methodology was used involving 26 in-depth telephone interviews with community members (mean age 66 years). The aims of the interview question were to gain an understanding of: (1) motivations for engaging in ACP; (2) barriers that prevent people from engaging in ACP; and (3) suggestions for promoting ACP.

**Results.** The findings suggest that: (1) community members lack knowledge about ACP; (2) forms appear inaccessible and complex; (3) community members avoid ACP due to fear, mistrust and concerns over control; and (4) there are misperceptions regarding the relevance of ACP based on age and health.

**Conclusions.** There is unnecessary fear, avoidance and mistrust around ACP activities, largely resulting from misinformation. There is an undoubted need for greater education and support to be offered to individuals and their families regarding ACP, its benefits and its limitations.

**What is known about the topic?** There is a lack of awareness about ACP in Australia, which is compounded by issues in the accessibility of ACP information, forms and support in completing the often complex documentation. Further, studies have indicated health practitioners tend to avoid assisting patients with ACP decision making and formalisation of their wishes for health care should they lose testamentary capacity.

**What does this paper add?** This paper contributes further understanding of the experiences and perceptions of people, particularly older Australians, in relation to ACP, including the motivating and discouraging factors for people in the uptake of advance healthcare directives and enduring power of attorney. People felt discomfort and mistrust about ACP, and lacked understanding of its relevance regardless of age or health status. Those who had engaged in ACP, prompted by family members or experiences in, or witnessing, ill health, felt a sense of security in having formalised their wishes.

**What are the implications for practitioners?** It is now clear that people require improved provision of information and support around ACP-related activities. This support may best be offered by practitioners such as nurses and social workers who are knowledgeable regarding ACP and skilled in counselling. Without discussion of death and dying, and the role of ACP, people will continue to feel a mistrust and avoidance towards formalising their healthcare wishes in advance.

**Additional keywords:** advance directive, aging, community, death and dying, decision making, end-of-life issues, enduring power of attorney.

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## Introduction

Advance care planning (ACP), which can include the appointment of an enduring power of attorney (EPoA) for personal and health matters and completion of an advance healthcare directive (AHD), comes with many challenges. Many people in Australia are unaware of their right to appoint an EPoA for personal and health matters<sup>1</sup> or experience feelings of discomfort, sadness and resentment, among other things, when confronted with ACP when in a residential care setting.<sup>2,3</sup> This is compounded by a perceived lack of easy-to-understand information<sup>4</sup> and varying terminology, legislation and documentation used across Australian states and territories. For example, an EPoA for personal and health matters in Queensland is variously called a substitute decision maker, enduring guardian or medical agent in other jurisdictions. AHDs and EPoAs for personal and health matters are not well understood by Australian healthcare practitioners.<sup>1,5,6</sup> Practitioners find it difficult to discuss end-of-life decisions with patients,<sup>9,10</sup> many experiencing a lack of confidence or knowledge.<sup>11</sup> Some practitioners do not view ACP as part of their role<sup>1</sup> or lack the time, skills and willingness to assist patients.<sup>1,5</sup> Literature from the US suggests that many people cannot see the relevance of ACP to their own lives<sup>9,10</sup> and they prefer not to think about declining health and dying.<sup>11</sup> However, despite 'social and personal taboos about discussing the dying process' in Australia,<sup>5</sup> many older Australians are interested in finding out more about ACP and are actively seeking information in this area (L. Crowe, V. Quinn, L. Chenoweth, S. Kularatna, J. Boddy, A. Wheeler, unpubl. data).

Although there is limited literature, particularly in Australia, focused on community member experiences and perceptions regarding ACP, recommendations have included a 'life in order' program for community members<sup>1</sup> and training for health professionals to assist them to work effectively with patients and their families to retain appropriate control in end-of-life care.<sup>6,12,13</sup> Involving families can be important given caregivers may override or misinterpret the healthcare consumer's wishes when there is no AHD in place. People in the US who have engaged in ACP, often with the support of a social worker,<sup>14,15</sup> report feeling more comfortable that they have addressed concerns about living in a burdensome state<sup>16</sup> and believe AHDs ensure them a sense of control and way of protecting their families from excessive burden.<sup>17</sup> However, few people in south-east Queensland (and possibly Australia) have undertaken any form of ACP.<sup>18</sup> Consequently, the present study sought to examine the views of community members about this topic.

## Methods

This qualitative research is part of a broader study on ACP in Queensland, Australia. Thus, the Queensland terminology related to ACP is used herein (in particular, 'EPoA for personal and health matters' is the term used to describe substitute decision makers in Queensland). Stage 1 of this research examined practitioner perspectives on ACP, whereas Stage 2 focused on the perspectives of community members. This article presents findings from Stage 2, the community member perspectives and experiences in relation to ACP. The study was granted ethics approval from the Griffith University and Queensland Health Ethics Committees.

## Data collection

In-depth telephone-based interviews were conducted with 26 community members using a snowball sampling technique. The 26 participants were recruited from community support groups and social clubs in the Gold Coast area. The interviewees consisted of 17 female and 9 male participants, with a mean age of 66 years. The interviews were between 30 and 40 min in duration, and a structured interview schedule ensured consistency across interview questions. The aims of the interview questions were to gain an understanding of: (1) motivations for engaging in ACP; (2) barriers that prevent people from engaging in ACP; and (3) suggestions for promoting ACP.

## Data analysis

Each interview was audiorecorded and data transcribed. Transcripts were initially subjected to an open reading to elicit preliminary themes, issues and concepts. Transcripts were then coded using NVivo software (QSR International Pty Ltd, Melbourne, Australia). The inductive thematic coding process was comprehensive, with constant checking of the reliability of the coded themes. Initial themes, clustered during analysis, were recorded and checked for consistency of interpretation among the members of the research team. Subsequent waves of coding involved developing deeper levels of understanding by categorisation of earlier codes into overarching themes and elucidation of relationships between themes. To ensure validity and rigour, peer checking (with the wider research team) was conducted to ensure the researcher's interpretations were true to the data.<sup>19</sup>

## Results

Of the 26 participants in the study, 15 had appointed an EPoA for personal and health matters and four had completed an AHD. These numbers are higher than the general population.<sup>18</sup> This may be due to the older age group of participants and their involvement in support groups and social clubs in which information on health and well being is commonly delivered to members.

### Lack of knowledge

Participants spoke of a lack of knowledge of ACP as the major contributing factor in the limited uptake of EPoAs for personal and health matters and AHDs. A participant described this as a common case of 'simply not knowing, simply being unaware, and can't be bothered' (#25, male, 68 years). Another explained the confusion that exists around ACP forms:

What happens with these forms, what do you actually do?  
(#8, male, 68 years)

Several participants disclosed they were oblivious to AHDs before participating in the interview, with statements including 'I've never heard of them' (#17, male, 75 years), 'I don't know what that means' (#1, female, age unknown) and 'I didn't know it existed' (#19, female, 71 years). This is compounded by a lack of easily accessible information:

Where does the man in the street get this information from? A lot of people go through life and have never heard of it. (#2, female, 65 years)

The issue of misinformation was also raised and it was suggested that some people may be deterred by the false belief that a solicitor is required for the completion of an AHD. Similarly, financial disincentives were repeatedly raised, with a participant stating:

The expense I think is a big thing, having to see a lawyer and that sort of thing, I think people find it too expensive. (#8, male, 68 years)

This statement is concerning given it is not necessary to involve a solicitor in completing an EPoA for personal and health matters or an AHD.

There appeared to be a lack of understanding around the implementation of AHDs, with a participant expressing concern regarding their use:

I guess it can take your wishes too far. If you say 'please don't resuscitate me', that could be a dangerous statement to make because you actually might have the potential to survive there. (#12, female, 66 years)

This quote raises concerns about the level of misunderstanding that exists around ACP. The participant may not realise an AHD should be developed with considered medical advice that clearly and accurately articulates a person's wishes. She may also not realise that medical staff can override an AHD when there is evidence to suggest that to follow the AHD would be inconsistent with good medical practice.

### *Inaccessibility*

A key barrier to engaging in ACP was perceived by participants to be the inaccessibility of the forms required in the process, particularly the AHD. The complexity and length of the form was clearly a significant disincentive and hurdle for people considering formalising their end-of-life wishes.

It's an incredibly complex form. . . It goes pages and pages. I think there needs to be more information about it, but also the pros and the cons for it really. (#12, female, 66 years)

This is further compounded by a lack of available support when completing the often complex paperwork:

Because it's not something I can just flick open a telephone book and ring someone or an organisation to get it done, I haven't done it. (#26, female, 64 years)

In addition, access to a close and trusted person capable of upholding one's wishes should they lose capacity is potentially a significant hurdle for people wishing to engage in ACP, and compounded by issues of geography, limited social support and family conflict. For example, one participant stated:

I've got no family living close by or anything like that so it's very difficult to have someone to do that. (#11, male, 70 years)

The experiences of these participants highlight the importance not only of family being in close proximity, but also the role of social support:

I have over the time approached good friends of mine, and asked them if they would consider, without putting any pressure on them, but they sort of declined on that one . . . from my own immediate family the circumstances there prevent anyone taking on that role. (#9, male, 62 years)

### *Experience of ill health*

Experience of trauma, diagnosis of ill health or decline in health with age was perceived to play an influential role in ACP, with participants expressing their belief that an AHD was often only made relevant in these circumstances.

I think it depends on their diagnosis really. If you're somebody who has strokes quite frequently, and each one is worse, I could see that there would be good reason to think about it at that stage. (#12, female, 66 years)

One participant expressed his intention to defer the appointment of an EPoA for personal and health matters until such a time that he could see his mortality more clearly:

I would be a bit reticent about [EPoA appointment]. I'd need to be in a position to foresee my demise. Six months or something like that, then I would make a definite plan. (#17, male, 75 years)

### *Family*

Family was seen as a driving factor behind ACP. For instance, following cancer treatment, it was family who encouraged and supported the completion of an AHD for one participant:

Actually it was family, my sister and brother in law that suggested I do one. (#4, female, 51 years)

This was also the case in relation to the appointment of an EPoA for personal and health matters, with a participant's daughter being most influential:

The main reason really was our daughter had done one and so she'd been on our back about doing it. (#8, male, 68 years).

ACP was used to 'relieve them [family] of any pressure at that time [during end-of-life]' (#15, female, 63 years) by having an AHD in place. Another participant commented:

I don't want my daughter to have the worry of making that decision [about life support]. I just don't want that burden on her. I would rather make the choice than her, and then she can follow my wishes. (#21, female, 69 years)

### *Age*

Some participants communicated their belief that AHDs were limited in usefulness for younger people. One participant suggested his reasons for not having completed an AHD previously was 'just being too young' (#8, male, 68 years); similarly, another participant, despite being 66 years of age, stated 'I see it really as a tool for older people' (#12, female,

66 years). It was clear that awareness of the importance of AHDs and EPoAs for personal and health matters increases with one's age:

...you reach retirement age you realise you're mortal, and sooner or later you could be in a position where you can't make your own decisions. When I found out about the advance health directive, I thought that's exactly what I want. So I went ahead and printed it out, had it filled out, saw a doctor, got it witnessed, and I'm in business. (#16, female, 71 years)

### Avoidance

There appeared to be a commonly held sense of discomfort with the topic of ACP among participants, leading to people preferring to 'put-off' ACP. Participants summarised several likely factors in people's avoidance of ACP, including 'ignorance, indifference' (#25, male, 68 years) and that people 'just don't want to know about it' (#10, male, 68 years). One participant spoke of having organised a will and a funeral, but that she would 'have to get around to' (#23, female, 70 years) thinking about ACP. Other participants blamed a busy lifestyle and unhelpful attitudes as likely reasons for the common avoidance of ACP:

I haven't had time to think about it, it's something I've known about but haven't done anything about it. (#6, female, 76 years)

### Fear and mistrust

Many spoke of fear as a central factor behind not considering end-of-life treatment options and engaging in ACP:

You don't put anything in place because you're afraid that by doing so is actually going to tempt fate in a way, and so you just pretend it's not there, it's just not happening. (#24, female, 56 years)

While ACP is not always associated with end-of-life treatment, because people may lose cognitive capacity well before the end of their life, it posed concerns for people. Participants perceived ACP, and appointment of an EPoA for personal and health matters, may result in a loss of autonomy and self-determination:

...it's hard to hand responsibility over to somebody else [an EPoA], for things that impact so greatly on your life. (#15, female, 63 years)

A common concern of 'not trusting people and fear of what somebody might do' (#3, female, 61 years) was repeatedly raised. Alternatively, fear and mistrust around the potential consequences of not appointing an EPoA for personal and health matters were viewed as motivating factors:

It was the fear factor from the EPoA side that I thought 'Oh my God, I don't want that to happen so I'd better do this'. (#3, female, 61 years)

### Security

For those who had engaged in ACP, an AHD was described as offering a 'sense of trust and safety' (#5, female, 61 years). People described the positivity they felt about the appointment of an EPoA for personal and health matters, particularly someone 'that you trust, and someone who knows you personally and knows what you would want' (#16, female, 71 years). This was considered important across the lifespan:

...just in case you have an accident, or a stroke or something, and lose your testamentary capacity. . . I don't think it necessarily pertains to elderly people. (#12, female, 66 years)

Conversely, a participant disclosed his concern regarding his inability to appoint an EPoA for financial, personal and health matters:

I feel, not having one, you feel a sense of insecurity. . . I think I'm getting to a stage in life where an EPoA is probably the answer for myself that I can hand everything over, feel more at peace about things. (#9, male, 62 years)

### Discussion

A lack of knowledge of ACP was perceived as the major contributing factor in the limited uptake of EPoAs for personal and health matters and AHDs, with several participants disclosing they were oblivious to AHDs before participating in the study. This supports previous research findings that indicate a lack of awareness of the concept of ACP and its relevance.<sup>1,9,10</sup> This lack of awareness is compounded by misinformation and misconceptions regarding ACP and the perceived inaccessibility of ACP forms, particularly the AHD.<sup>4</sup> The complexity and length of the forms is likely to be a significant factor in preventing people from completing the formal process, particularly as support with the process is limited or difficult to access. The appointment of an EPoA for personal and health matters can be further complicated when an appropriate and trusted person is not available.

Similar to the findings of Fried *et al.*<sup>11</sup> in the US, the present study indicates people believe others are uncomfortable with facing the topic of one's inevitable deterioration in health and death and are, at times, themselves hesitant to face their own mortality. This was frequently presented in the present study, with many participants expressing fear regarding death and dying, and facing one's mortality; this can be considered a key factor discouraging people from considering end-of-life treatment options and engaging in ACP.

Jeong *et al.*<sup>2</sup> identified that people in residential care settings described a range of emotions when first considering ACP, including 'guilt, discomfort, denial, sad, difficult, awful, cruel, burdensome, abusive, confronting and resentful'. Although participants in the present study did not comment on these emotions, perhaps because they were living in the community with many experiencing reasonable health, they did identify a level of mistrust among people in relation to ACP processes. Community members' fear and mistrust was also associated with the perception, albeit a possible misperception, of ACP as entailing a



'relinquishing of control' over health care decision making and the possible loss of autonomy and self-determination.

Personal experience of trauma, diagnosis of ill health or decline in health with age were perceived to increase people's sense of relevancy of ACP and this can prompt people to consider and complete an AHD and EPoA for personal and health matters while they are still living in the community. Such motivation to engage with ACP could be harnessed with enhanced support and guidance from healthcare practitioners to address issues of inaccessibility relating to ACP.<sup>4</sup> Indeed, the involvement of social workers in this way has previously been shown to increase ACP engagement.<sup>14,15</sup>

The desire to protect family members from excessive burden was found to be a driving factor behind ACP-related activities, and this relates to previous findings regarding the impetus behind AHD completion.<sup>17</sup> However, the present study also revealed the support and encouragement of one's family holds a key role in ACP-related actions, and suggests education and support of family members should be a priority. Furthering the support for ACP, the present study also indicates that people who have engaged in ACP feel a sense of security, described as a feeling of trust and safety, particularly in relation to having an AHD.

## Conclusion

The barriers to ACP found in the present study and in previous research repeatedly point to the need for enhanced education around ACP, what it does and does not cover and how to access and complete the necessary documentation. The present study particularly illustrates the need to better inform people of the broader relevance of ACP for all adults, not merely those who are aging or experiencing chronic ill health, as suggested by participants. Education will need to incorporate some of the motivating factors learned from people who have engaged in ACP; for instance, using real-life case studies to illustrate potential consequences and relevancy. By doing so, it may be possible to widen the narrow 'window of opportunity'<sup>4</sup> in which ACP uptake is more likely. Such education needs to ensure that participants can make an informed decision about the benefits or not of participating in ACP.

Complementary to increased community education regarding ACP, there is an undoubted need for greater support to be offered to individuals and their families regarding ACP and its benefits and limitations. A certain level of discomfort, fear and denial exists around death and dying, and these discussions are often avoided at the personal and professional level. The role of healthcare practitioners should be, in part, to promote discussion on these topics. Without discussion, people maintain unnecessary fear, avoidance and mistrust, as well as a lack of knowledge and information. It seems appropriate that social work and nursing staff equipped with counselling skills and knowledge of ACP would be well placed to have these discussions regarding the formalising of peoples' wishes well in advance.

## Competing interests

None declared.

## Acknowledgements

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## References

- 1 Brown M, Jarrad S. Putting the powers in place: barriers for people with memory loss in planning for the future. *J Law Med* 2008; 15: 530–7.
- 2 Jeong SY, Higgins I, McMillan M. Experiences with advance care planning: older people and family members' perspective. *Int J Older People Nurs* 2011; 6: 176–86. doi:10.1111/j.1748-3743.2009.00201.x
- 3 Jeong SY, McMillan M, Higgins I. Gerotranscendence: The phenomenon of advance care planning. *J Religion Spirit Aging* 2012; 24: 146–63. doi:10.1080/15528030.2012.632712
- 4 Boddy J, Chenoweth L, McLennan V, Daly M. It's just too hard!: Healthcare practitioner perspectives on barriers to advanced care planning. *Aust J Primary Health* 2012; 19: 38–45. doi:10.1071/PY11070
- 5 Scott IA, Mitchell GK, Reymond EJ, Daly MP. Difficult but necessary conversations: the case for advance care planning. *Med J Aust* 2013; 199: 662–6. doi:10.5694/mja13.10158
- 6 Squires B, Barr F. The development of advance care directives in New South Wales. *Aust J Ageing* 2005; 24(Suppl.): S30–S35. doi:10.1111/j.1741-6612.2005.00097.x
- 7 Brown M, Grbich C, Maddocks I, Parker D, Roe P, Willis E. Documenting end-of-life decisions in residential aged care facilities in South Australia. *Aust N Z J Public Health* 2005; 29: 85–90. doi:10.1111/j.1467-842X.2005.tb00754.x
- 8 Mitchell G. End-of-life care for patients with cancer. *Aust Fam Physician* 2014; 43: 514–19.
- 9 Schickedanz A, Schillinger D, Landefeld S, Knight S, Williams BA, Sudore RL. A clinical framework for improving the advance care planning process: start with patients' self-identified barriers. *J Am Geriatr Soc* 2009; 57: 31–9. doi:10.1111/j.1532-5415.2008.02093.x
- 10 Sudore RL, Schickedanz A, Landefeld S, Williams BA, Lindquist K, Pantilat S, Schillinger D. Engagement in multiple steps of the advance care planning process: a descriptive study of diverse older adults. *J Am Geriatrics* 2008; 56: 1006–13. doi:10.1111/j.1532-5415.2008.01701.x
- 11 Fried TR, Bullock K, Iannone L, O'Leary JR. Understanding advance care planning as a process of health behaviour change. *J Am Geriatr Soc* 2009; 57: 1547–55. doi:10.1111/j.1532-5415.2009.02396.x
- 12 Cartwright C. End-of-life decision making: practical and ethical issues for health professionals. *Australas J Ageing* 2000; 19: 57–62. doi:10.1111/j.1741-6612.2000.tb00145.x
- 13 Mitchell G, Nicolson C, McDonald K, Bucetti A. Enhancing palliative care in Australia: the residential aged care setting. *Aust J Primary Health* 2011; 17: 95–101. doi:10.1071/PY10054
- 14 Johnson YM. The bioethical underpinnings of advance directives. *Ethics Soc Welf* 2009; 3: 32–53. doi:10.1080/17496530802481730
- 15 Johnson YM, Stadel VL. Completion of advance directives: do social work preadmission interviews make a difference? *Res Soc Work Pract* 2007; 17: 686–96. doi:10.1177/1049731506299011
- 16 Simon J, Murray A, Raffin S. Facilitated advance care planning: what is the patient experience? *J Palliat Care* 2008; 24: 256–87.
- 17 Martin DK, Emanuel LL, Singer PA. Planning for the end of life. *Lancet* 2000; 356: 1672–6. doi:10.1016/S0140-6736(00)03168-8
- 18 Milligan E, Hamilton P. The prevalence and use of advance health directives (AHD's) in promoting patient autonomy at end-of-life. In: Proceedings of the Gold Coast Health and Medical Research Conference; 2–3 December 2010; Gold Coast. 2010. Available from: [http://www.griffith.edu.au/\\_data/assets/pdf\\_file/0010/264295/2010-GCHMRC-book-FINAL.pdf](http://www.griffith.edu.au/_data/assets/pdf_file/0010/264295/2010-GCHMRC-book-FINAL.pdf) [verified 18 April 2012].
- 19 Denzin NK, Lincoln YS. The Sage handbook of qualitative research, 4th edn. Thousand Oaks: Sage Publications; 2011.