

## 8 Planning for the rest-of-life, not end-of-life

### Reframing advance care planning for people with dementia

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#### Background

Advance care planning (ACP) began in the United States in the 1970s and in Australia in the 1980s. It was a response to developments in medical technologies occurring from the 1960s when ‘it often became difficult to distinguish saving life from prolonging suffering and death’ (Sabatino 2010: 213). ACP developed out of a concern that people were receiving treatment at the end-of-life that they may not have wanted if they had been able to make their own decisions.

Historically, ACP has been aimed at extending personal autonomy, and has placed much attention on the process of completing Advance Care Directives (ACD) in which people document what it is they want or do not want for a time in the future should they be unable to make their own decisions. Most deaths in western countries occur in hospital (Broad *et al.* 2013) and medical interventions have the potential to extend the dying process while undermining dignity and the provision of comfort (Squires and Barr 2005). Hence the medical profession has been a dominant and important voice in discussions about ACP, perhaps contributing to a tendency to focus on documented ACPs, and decision-making about end-of-life medical care.

This has also meant that, in Australia where hospitals are the responsibility of State and Territory governments, a variety of approaches and legislative provisions for ACP have developed (Carter *et al.* 2016). To address this, Australia’s Health Ministers recognised the need for a national policy framework, *A National Framework for Advance Care Directives* endorsed by the Australian Health Ministers’ Advisory Council in 2010 (Australian Health Ministers’ Advisory Council 2011). The terminology used in this chapter is based on this document, and we start by outlining what is meant by advance care planning, an advance care plan, an advanced care directive and a substitute decision-maker.

**Advance care planning (ACP):** ACP is the process of planning for future health and personal care (including lifestyle issues) where the person’s values, beliefs and preferences are made known so they can guide decision-making at a

future time when that person cannot make or communicate his or her decisions. ACP may be completed in a structured process with a trained professional or may occur in an informal family setting. It can include both formal and informal conversations, but does not, as we explain, always result in the recording of a person's preferences.

**Advance care plan:** Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made on a person's behalf and should be prepared from the person's perspective to guide decisions about care. There are many ways of recording an advance care plan including oral and written versions. They may be made by, with or for the person. A person with diminished competence may complete an advance care plan or be assisted to complete one. A preferred decision-maker in an advance care plan is not a statutory appointment.

**Advance care directive (ACD):** An ACD is one way of formally recording an advance care plan. An ACD is one type of written advance care plan and is recognised by common law or authorised by legislation and is signed by a competent adult. An ACD can describe a person's wishes regarding their future care and can appoint a substitute decision-maker.

**Substitute decision-maker (SDM):** SDM is a term used to describe the person who is appointed or identified by law as the person able to make decisions on behalf of a person whose decision-making capacity is impaired. In this context it is used regarding the person being able to make health, medical, residential and other personal decisions. Depending on the state this person may be also termed the Enduring Attorney (Health), Enduring Guardian or Person Responsible.

The medical model of ACP, developed out of the hospital system, is characterised by a focus on the individual, and discussion is limited to medical treatment decisions and the advance documentation of a person's consent or refusal of these treatments. This approach faces a number of challenges to being adopted more broadly across the community. Major difficulties identified include a reluctance by many older people and families to discuss end-of-life issues (Rhee *et al.* 2012; Scott *et al.* 2013; Sinclair *et al.* 2014), cultural perspectives that do not align with the ideals of ACP (Shanley *et al.* 2009; Connolly *et al.* 2012; Kwak *et al.* 2014) and individuals not seeing the relevance of ACP (Schickedanz *et al.* 2009; Sinclair *et al.* 2013; Sinclair *et al.* 2014). In addition, health professionals often lack the confidence, understanding and time to discuss ACP (Shanley *et al.* 2009; Rhee *et al.* 2012; Poppe *et al.* 2013; Van der Steen *et al.* 2014). They may also be concerned that discussions about end-of-life care may erode the person's hope (Houben *et al.* 2014).

The challenges of ACP are even greater for people with dementia, given the need to develop plans well ahead of time and to review these as the illness progresses. Unfortunately, for most people, ACP is often left until it is too late for people with dementia to either initiate or be involved in these discussions (Shanley *et al.* 2009; Dening *et al.* 2011; Robinson *et al.* 2012; Poppe *et al.* 2013). Medical personnel often express concerns about the legal status of ACDs completed by people with dementia (De Boer *et al.* 2010). This means that

people with dementia and other forms of cognitive decline experience barriers to ensuring their wishes are respected.

The reliability and clinical clarity of ACDs are likely to be strengthened when the ACD is discussed – or at least raised – at the time of diagnosis, or at first contact with support services. There also needs to be a pathway agreed as to how it can be reviewed regularly, ensuring it is relevant to current clinical circumstances (Carter *et al.* 2016).

Given these barriers, and the narrow focus on end-of-life decisions, it is unsurprising that awareness of ACP is low (Dickinson *et al.* 2013; Houben *et al.* 2014) and the take-up of ACDs even lower (Lewis *et al.* 2015; Sinclair *et al.* 2016). This is accentuated for those from culturally and linguistically diverse communities in which ACDs may be less culturally acceptable due to different approaches to decision-making and personal autonomy (Jeong *et al.* 2015). Additionally, in cultural contexts in which dementia is not well understood (Low *et al.* 2010; Boughtwood *et al.* 2011), dementia is more likely to be diagnosed later (Boise 2014), which in turn may reduce the opportunity for that person to participate in ACP due to the impact on cognitive capacity over time.

However, despite these challenges, there are many benefits in undertaking ACP as early as possible, for individuals, carers (informal and formal) and families of people with dementia. The benefits include improved quality of life, decreased stress and anxiety (Shanley *et al.* 2009; Rhee *et al.* 2012; Poppe *et al.* 2013; Van der Steen *et al.* 2014) and increased adherence to previously expressed wishes (Livingston *et al.* 2013). In addition, ACP assists those who will be called on to make decisions (Rhee *et al.* 2012; Shanley *et al.* 2009; Poppe *et al.* 2013; Van der Steen *et al.* 2014).

The increasing numbers of people living with dementia make it imperative that effort is made to increase early take-up of ACP for those living with this condition. In Australia, dementia is now the leading cause of disability burden for those aged 65 years or more (Australian Institute of Health and Welfare 2012) and is identified as the second leading cause of all deaths (Australian Bureau of Statistics 2015). People with dementia will make up an increasing proportion of the users of health and community care services and having an ACP in place is likely to improve outcomes. For example, when people with dementia are admitted to hospital, impairments in communication and perception, together with the change in environment and routine can cause significant distress and result in longer stays and poorer outcomes (Samaras *et al.* 2010; Sampson 2010; Australian Institute of Health and Welfare 2013), but with an ACP greater guidance for staff is likely and even the potential for hospital admission can be reduced.

## **The study**

Recognising the potential significant benefits of ACP for people with dementia and their carers, we undertook research to identify how to increase uptake of ACP among people with dementia. The study was funded by the Cognitive

Decline Partnership Centre and guided by an expert advisory committee. Consumers were instrumental in confirming the need for this work, and the fourth author (Williams) is a consumer representative from Dementia Australia who was on the advisory committee and also gathered and provided the perspectives of interested consumers over the course of the study.

The study sought to better understand which interventions are effective to support ACP for people with dementia by seeking the views and experience of experts and stakeholders. Participants were recruited by approaching a wide range of organisations and individuals with interest or expertise in ACP, for example, organisations representing the interests of people with dementia and carers, general practitioners and physicians who were regarded as leaders in the field of ACP, nurses and allied health workers who assisted people to complete ACP, academics who had written on the subject and government officials involved in the development and promotion of ACP. A purposive sampling framework was used to ensure participants came from a wide range of community, health and aged care settings, from consumer groups and from the different states and territories of Australia given the differing legislative and policy approaches.

Interviews were conducted over the telephone. There were 82 participants across 67 separate interviews. Most interviews were one-to-one, however, 12 organisations involved two or three participants as part of the teleconference. Of the participants, 16 came from primary care, including eight general practitioners (GPs), three practice nurses and five from primary healthcare networks; 11 came from aged care, both residential and community care; 11 from acute care; ten from ACP services operated under the auspices of hospitals in some states; eight from palliative care; eight from consumer organisations, including six from specialist dementia organisations; six from the field of geriatrics/gerontology; and six from government (including ACP policy areas and public advocates). In addition, there were three consumers (a person with dementia and two carers), two from legal areas and one from an ambulance service with involvement in ACP.

The interviews were conducted by the first (Yapp) and third (Kelly) authors. The semi-structured interviews were based on questions informed by the literature and explored barriers and enablers for ACP, and any differences in approach that were required if someone had dementia. Participants had an opportunity to ask questions and make statements regarding issues they felt were important but had not been covered. Interview length ranged from 30 to 80 minutes, with most taking 45–50 minutes. Informants from different health and aged care sectors continued to be recruited until no new themes emerged from the interviews from that particular sector.

All interviews were audio recorded and transcribed verbatim, and the transcripts were provided to participants to allow for corrections or clarifications if they wished. Around 30 per cent of the transcripts were modified by participants, primarily to clarify spoken comments into a clearer written form. Three of the interviewees made more substantial changes, providing additional information.

The transcripts were then coded using a template analysis method (King 1998), utilising NVivo (v.10) software (QSR International). In this thematic analysis, coding was based initially on an agreed structure informed by the literature, with a focus on barriers and enablers to ACP and the difference that dementia made. The themes were adapted and refined through a process of discussion by the authors Yapp and Kelly as new themes emerged from the data. The first three transcripts were dual coded independently by these authors, and differences were discussed to arrive at a common understanding. This was repeated for a further two transcripts until consistency was achieved. Authors Yapp and Kelly went through each interview at least once, and confirmed the emerging themes, with the assistance of the advisory committee.

The interviews provided a wealth of information about ACP generally. There were a number of themes, however, that are particularly relevant for people living with dementia or other forms of cognitive decline. These findings relate to the impact that the disease process has on the target group's ability to engage in ACP, their potential needs in the future and how they and their carers are treated in the health and aged care system.

## **Findings**

The main findings of this study in relation to ACP were that, for people with dementia: engagement with ACP needs to occur as early as possible, prior to significant loss of cognitive capacity, and that additional support may be required for continued involvement in decision-making; positive approaches focusing on how the person wishes to make the most of their life, rather than a narrow focus on medical interventions at the end-of-life are likely to be more successful; conversations, and the relationships underpinning these, are of primary importance (rather than a focus on completion of paperwork); and the appointment of a trusted SDM who knows the person with dementia well is crucial. These findings are elaborated further below, with any important differences in the setting or background of the informants highlighted.

### ***Undertake ACP early to maximise meaningful participation of the person with dementia***

A number of informants from all settings identified the need to undertake ACP early for those with dementia, at a time when the ability to plan ahead was still relatively unimpaired. Informants from residential aged care settings in particular highlighted that ACP is often left too late in order for people with dementia to be meaningfully involved. This was attributed, in part, to a lack of understanding of the progressive nature of dementia. Informants from aged care, specialist dementia services and those with expertise in geriatrics/gerontology were particularly likely to raise aspects highlighting the difficulties cognitive changes had in reducing the ability to engage in ACP such as discussions about future scenarios, and to consider more abstract concepts.

The biggest difference [in ACP for people with dementia] is that we have a more limited window of catching these people. So making sure that people are introduced [to ACP] and have the opportunity to have those discussions very early on in their illness when they can still participate [is important].

(Primary care)

Specific issues to do with changes in cognition and dementia illness can change how easy it is for them [people with dementia] to engage in formalised and systemic advance care practices and also how easy it is for us as healthcare [professionals] to recognise that that's in fact what's happening.

(Palliative care)

Many of the respondents in primary care, palliative care, acute care and residential aged care settings indicated that ACP discussions often occurred with family, as the person with dementia already had reduced decision-making capacity. Encouraging ACP discussions at or soon after diagnosis of dementia, particularly in the absence of widespread take-up of ACP in the general population, is needed for people with dementia to have a greater voice into the future.

***The person with dementia is often excluded unnecessarily from decision-making***

Although family involvement in decision-making can be helpful, particularly where the family or carers know and respect the views of the person with dementia, this can also have less positive outcomes. A number of informants from acute care, aged care and primary care indicated that decision-making too often relies on family decision-making to the exclusion of the person with dementia. This is not necessarily due to impaired ability. Informants indicated this was often because staff opted for an 'easier' approach, due to time pressures or lack of skills in supporting the person with dementia being involved. There were a few informants from a range of settings who spoke passionately about perceived poor outcomes due to the person with dementia's views being ignored or not sought and this was attributed to erroneous assumptions and the stigma surrounding dementia.

In particular for people with cognitive impairment I'd have to say they tend to default to the family. I've seen so many times when doctors and nurses don't even bother addressing or even looking at the person themselves just because they've got a cognitive impairment. They don't talk to the person, they talk to the family.

(Acute care)

There were some respondents, however, who indicated that people with dementia could be involved in decision-making, even very late in the disease process. These informants were from backgrounds where they had good

knowledge of dementia: ‘I think that persons with dementia always have a role to play in informing us in things related to their advance care planning, even to the point of people with very severe disease’ (palliative care). The lack of knowledge of dementia and how people can be supported to mitigate many of the impacts excludes people from being involved in making their own decisions. It also leads to a need to consider how ACP is approached if the cognitive challenges of dementia are to be overcome.

***Medical approaches focused on documenting wishes in respect of end-of-life limit engagement for the person with dementia***

An important component of the study was to look at the model of ACP informants were using, to determine whether there was a particular type that people with dementia were more readily able to engage with. A large proportion of respondents used a form of ACP that primarily focused on end-of-life medical issues, particularly in acute and primary care. This approach reflects the future decisions that may need to be made in these settings.

Many informants from all settings raised a number of concerns about a medical approach to ACP, particularly for people with dementia. These concerns were around focusing only on end-of-life medical interventions, completion of paperwork and the lack of certainty that still remained when decisions needed to be made. Although these issues may be relevant for all, they were particularly problematic for people with dementia. The main aspects informants raised about the traditional medical approach to ACP for people with dementia, with indicative quotes, are outlined below.

*Problems identified in the focus on end-of-life medical interventions*

Informants, particularly from aged care, ACP services and specialist dementia services, indicated that deciding what medical interventions may or may not be wanted is difficult without a clear understanding of the diagnosis and prognosis, which is often the case with dementia. In addition, informants from specialised dementia services indicated that where there is a diagnosis, the person may be in denial regarding their condition: ‘Only 50 per cent of people ever get their diagnosis of dementia and in general practice we’re only just getting our heads around that and it can be at more advanced stages that they’re getting diagnosed’ (GP, primary care).

Understanding abstract concepts related to medical interventions was raised by some participants with expertise in dementia as a particular challenge for those with dementia. In addition, there can be difficulty imagining a future self. Informants indicated that the impact of dementia on a person’s ability to plan, understand/have insight and make decisions means that the likelihood of engaging with ACP will decrease as the condition progresses. Those from aged care indicated there was often a lack of understanding of what the potential medical interventions meant.



By the time that families start to realise that things are going wrong, it's often too late for them to participate ... the person finds it very hard to grasp the concepts that you are trying to get them to think about.

(Gerontologist)

Informants from all settings indicated that a focus on end-of-life means that staff, family and the person with dementia often find the subject of ACP too confronting to raise. This is compounded because of the range of 'bad news' that often accompanies dementia and the stigma surrounding it: 'Doctors do not feel comfortable talking about [ACP] ... the doctors just don't bring up the subject' (aged care). Some informants from consumer groups in particular indicated that there are other issues that may be of greater concern to people than end-of-life issues. These can include ensuring important aspects to the person such as faith and culture are respected, and having some say in what might happen in the future around care and accommodation as the condition progresses.

It's not just about medical treatment, it might be [about planning] where someone's going to be cared for, or who they're going to be cared for by, or what kinds of things or activities do people still want to participate in.

(Carer/consumer group)

#### *Problems identified with a focus on completion of paperwork*

Across all settings participants, but particularly specialist ACP services, indicated that people are often very reluctant to commit their views in writing. There was a preference for discussions and informal plans over formally documenting wishes. People are also concerned about the ability to change ACDs if their perspectives change in the future. Formal ACDs can be changed in all jurisdictions, but the fear remains, and a diagnosis of dementia may contribute to this if there is concern about future capacity.

Many participants indicated that documents completed without expert assistance may be confusing, particularly where they deal with medical terminology.

The patient finds them [ACDs] very distressing to fill in, and so do the families, because there's a lot of specifics in there ... they get really confused about what situations to put 'yes' and what to put 'no' to.

(Primary care)

The other thing that has been a bit of barrier ... is that people are required to list treatments that they do or do not want in advance and that's really difficult for lay people to do. Most people would know what quality of life means to them, but how do you document the CPR decision ... [and] other kinds of health decisions that come along when you've got dementia or other kinds of co-morbidity.

(Carer/consumer group)



Many respondents from across a range of settings also indicated that written ACDs were often ignored or could not be found when needed. They may be ignored by family members who are not in agreement with them, or by medical staff who are not aware of their legal standing. Informants advised that on completion, they may often be put in a drawer, lost in the depths of a patient's file or kept in a doctor's or lawyer's office which means they are not available out of hours.

My personal opinion is that pieces of paper are helpful but they're not the 'be all and end all', they're not what you live and die by because, at the end of the day, a piece of paper can be ripped up, it can be disregarded, it can be questioned, ... it can also hold people back from having treatment which actually could be very effective for them ... The piece of paper is a reminder that you've had that conversation and it can be a memory prompt.

(Acute care)

There's very good evidence that doctors will be influenced by such documents [ACDs] if they can be found. Although as you are probably aware, it's rare for them to be available at the time when decisions need to be made.

(Acute care)

*Documents completed ahead of time may not provide the certainty and authority medical staff require*

Participants in acute care settings and from the government expressed concern about the clarity, reliability and currency of ACP documents, and a lack of certainty about applicability to the current situation: 'The most common comment is "these things aren't worth the paper they're written on". I must have had that said to me a hundred times this year so far' (acute care).

Some participants indicated that medical personnel would prefer to have documents completed only at the time of an admission or by the person's doctor.

The MOLST [Medical Orders for Life Sustaining Treatment] becomes a legal document because it's a medical order ... So it's not an advance care directive. It's a medical order for life sustaining treatment and because it's signed off by everyone and the doctor at the hospital can see that the GP has been involved and the health professional has been involved and the family are on board, they're much more likely to follow it.

(Aged care)

On the other hand, this approach of making decisions at the time of an acute event or hospital admission means that a person with dementia is less able to initiate these requirements, and there is reliance on the family or person's doctor to know their wishes and have these incorporated into the decision-making.

***Focusing on discussions and understanding values and wishes for the rest-of-life, within the context of relationships, is more likely to be successful***

Participants who regularly facilitate ACP described the benefits of a broader psychosocial approach, focusing more on the identification of values, the importance of conversations about a wide variety of topics and strengthening relationships. The focus should be on understanding what is valued and important to the person so that future decisions can be informed by these. These types of conversations were considered by many informants to be more positive, making it easier for the person with dementia, their family and for staff.

*Focusing on a person's values can inform decision-making*

Participants indicated that if the person's values and ideals are understood then decisions can be informed by these values in any given situation because values are less subject to change and rely less on the person's medical knowledge. There is a need to move from a focus on formal documentation to one focused on values, engagement and conversation between all parties (Siddiqui 2016).

Ideally advance care planning ... should be targeted towards a person's goals and we shouldn't make it their responsibility to say, 'yes I want this, no I don't want that' in a shopping list sort of way ... [We should be] understanding the person's goals and then fitting healthcare options to those goals rather than making people choose between the big shopping list by themselves.

(Palliative care)

*The importance of engagement with family as part of the process*

Having people make decisions in advance, without considering family and others around them, was raised by informants as an important barrier to ACP. An approach to autonomy which better recognises that people make decisions in the context of relationships, family and culture may create greater engagement with ACP and reduce later conflict when decisions need to be made. It also better recognises the approach taken to decision-making in many culturally diverse communities.

People aren't these rugged individuals that go around writing documents about their care. They are social people who are concerned about the implications of their decisions for their family and they tend to want to make them together with their family. How that's documented is probably less important than the process that they go through.

(Acute care)

*Focusing on how a person wants to live not how they want to die*

Participants from community and aged care settings noted that discussions about what the person considers important are easier for family or staff members to raise, and easier for a person with some cognitive loss to engage with. It was also felt that conversations were more positive and affirming if they focus on living rather than dying.

*Importance of discussion of a wide variety of topics*

Some participants, particularly in community and aged care settings, observed that people live with dementia for an extended period of time, and face many lifestyle decisions as well as care and health decisions as the condition progresses. This includes decisions about pets and visitors, retirement from driving, location of care and living arrangements as well as decisions about medications or medical interventions. For people in rural or regional areas, informants indicated there is often a desire to remain close to family or community, even if this limits what care is available. Examples were also given for those with younger onset dementia where there are also considerations about work and children.

There's a whole lot of decisions ... do you downsize, do you move, do you want to live with your family or not, what are the things you might need to take into account, what do you like doing, what do you want to keep doing as much as possible. Having the discussion around what's important to you, and therefore end of life issues and preferences are just part of conversation.  
(Aged care)

If I went to a doctor, the doctor would just be focused on the medical treatment side and they wouldn't be thinking about my dress standards or grooming or the kind of things that give my life meaning.  
(Carer/consumer organisation)

*Encouraging conversations*

The conversations that occur in the context of personal relationships were considered the most important aspect of ACP for many respondents. The conversations mean that a range of issues can be explored in a natural way and family and SDMs understand how the person approaches decision-making and their underlying values and what they consider most important.

So it's really that people relationship, it comes back to that. I think that's at the heart of advance care planning anyway. It's about conversations, about people, it's about relationships – that's what it's fundamentally all about, and that's what works best for us as well.

(ACP service)

The social environment in which people operate, how they take into consideration the implications for others, and whether they prefer to make decisions together or after discussion, are all important relational issues identified by participants.

The conversation is such a major part of the whole journey of advance care planning. It's something that is vital. ... We need to have people having these discussions regardless even of any documents being completed.

(ACP service)

We've got no way of knowing how many people actually go through and complete the process, but in some ways, I'm not sure that that matters. That's the icing on the cake if you like, and that's what I say to community groups when I talk to them and to service providers. I say, the cake is the conversation, the icing on the cake is completing the documentation, but the cake is actually the conversation.

(Palliative care)

### *Appointment of a SDM is crucial*

Across all settings and models of ACP one area of agreed importance was the value of appointing a trusted SDM. Two areas were highlighted as important: appointing an appropriate person who understands one's wishes and the support and knowledge a SDM needs to undertake the role effectively.

### *Importance of appointing a trusted person*

A well-chosen SDM – through a legal enduring guardian approach or through ACP – was widely regarded across community and aged care settings as critical to good outcomes. This was because it was felt that the SDM must have the capacity to be an active advocate for the person to receive care consistent with their wishes. It was felt that for people from culturally and linguistically diverse backgrounds, it is important for the SDM to have an understanding of the person's culture.

Probably the most critical element is the medical enduring power of attorney and making sure that that power of attorney knows what that person would want.

(Aged care)

Who you choose [as a SDM] is really important. I do talk to people about what kind of characteristics I think people need like clear headedness, a level of assertiveness, and an ability to be calm, ... but most importantly I say they are your voice. If they can't speak for you without their own values and preferences and wishes and ideas about what they think is best for you getting in the way, then they're not the person you should be nominating.

(Palliative care)

*Knowledge, understanding and discussion is important*

Participants across all settings identified the importance of good conversations with SDMs and family, rather than a reliance on completion of documents. Conversations were considered fundamental to planning in advance and the SDM being able to make the decision the person would have made.

It's about person-centred care at the end of the day isn't it? So if you have expressed wishes, if you have discussed it with your substitute decision maker and they know what your values are and what's important to you then you're more likely to get person-centred care or likely to get care that accords with your wishes and values as an individual.

(Aged care)

*Support is needed so that SDMs undertake their role effectively*

The difficulty for families in making decisions on behalf of a person with dementia was highlighted in personal stories provided by participants who express the anxiety and ongoing discomfort with decisions made many years previously. A number of informants from aged care and acute care indicated that families and SDMs do not always understand their role – that they should be seeking to consider what the person would want rather than what they want for themselves. This can be compounded when there is family conflict. The informants indicated greater support was needed so that SDMs understood they were making a decision on behalf of the person. Informants from aged care highlighted the benefit of talking with SDMs ahead of time so that decisions could be well informed and considered, rather than just a reaction in an emergency.

I think it is a huge barrier for health professionals to be having an advance directive but then to have a family member sitting there going, 'you've got to treat, you've got to treat' and just ignore everything they have said. It's a huge barrier.

(Consumer)

We are seeing an increase, a slow but steady increase in conflict in this setting and we really have to do far more to try and shore up our understanding of what the patient themselves actually want because in the end that's always the circuit breaker.

(Specialist, acute care)

## **Discussion**

The findings from this study of the views and experience of a wide range of informants have important implications for how ACP is best approached in order to encourage greater adoption for people with dementia and their carers.

The study findings highlight the need to address the difficulties of medically focused ACP and to frame ACP within the context of encouraging relational autonomy, particularly for those with dementia.

***Relational autonomy is considered to be very important***

The progressive impact of dementia on cognitive ability means that over time the person will find it more difficult to make their own decisions and to care for themselves. It has been argued that a sense of connectedness and being in an affirming relationship with others is a vital contributor to quality of life for people with dementia (Kitwood 1997; Nolan *et al.* 2004; Morhardt and Spira 2013; Sabat 2014; O'Rourke *et al.* 2015). Concern for family is a key motivator for older people (Levi *et al.* 2010) and people with dementia (Denning *et al.* 2013). An ACP which incorporates such values could help to alleviate this distress for both people living with dementia and their family members.

Participants in the research study widely supported a values-based discussion to strengthen the knowledge transfer to future decision-makers. This entails a move from the individualist conception of autonomy inherent in a medical approach, to one which better recognises the importance of relationships and the role of family carers (Whitlatch and Menne 2009; Pollard 2015). This approach is also likely to be more acceptable to those from culturally and linguistically diverse communities (Searight and Gafford 2005; Bullock 2011; Ekore and Lanre-Abass 2016; Siddiqui 2016).

Moving towards a values-based approach is also supported by the literature (Prommer 2010; Sinclair *et al.* 2016). A focus on identifying values and what is important to the person which can occur in informal discussions can mean that some of the barriers to ACP for those with dementia are overcome, including the reluctance or avoidance of people engaging in ACP discussions, and not finding the 'right' time to initiate ACP discussions, with subsequent loss of capacity (Brooke and Kirk 2014).

Strengthening the understanding of a person's values and preferences through a relational approach to ACP can be very helpful to SDMs in making the multitude of decisions that need to be made on behalf of the person with dementia. Where the focus includes an understanding of how decisions were approached and priorities, it can aid SDMs in making decisions about care (such as respite and residential care) as well as end-of-life care (Reamy *et al.* 2011).

***Addressing the difficulties of medically focused ACP***

Informants from all settings identified a range of barriers to medically focused ACP. The focus on determining an individual's wishes in relation to end-of-life medical interventions and reliance on completion of documents limits engagement with ACP. While this model of ACP has meant there have been resources available to develop and encourage consideration of end-of-life medical issues, this narrow approach has many significant shortcomings and is even less

effective and appropriate for people with dementia (McMahan *et al.* 2013). It is difficult for a person to predict preferences for specific interventions without the lived experience. The value of someone in a trusted relationship raising and encouraging ACP has been recognised in other studies (Briggs 2004; Rhee *et al.* 2013; Van der Steen *et al.* 2014). The potential role that a reframed approach to ACP could play in improving both engagement and decision-making for the benefit of people with dementia, their families and SDMs comes from the literature on dementia care where the benefits of a person-centred or psychosocial approach are highlighted, often in contrast with a medical model where the focus is on individuals and loss of functioning (Fazio 2013; Williams *et al.* 2014).

The suggestion from informants, that ACP needs to cover a much broader range of issues in recognition of the extended period of time in which people with dementia may not have the capacity to make their own decisions, has only limited coverage in the literature. Participation in research (Dowson *et al.* 2013; Nuffield Council on Bioethics 2009) and retirement from driving (Carmody *et al.* 2013) are other non-medical issues that have been identified as benefiting from inclusion in ACP.

Proxy decision-making can often be distressing for families (Lord *et al.* 2015). ACP relieves the stress on family members and SDMs (Detering *et al.* 2010; Chiarchiaro *et al.* 2015) and this is used to encourage take-up. Family and SDMs of those with dementia face a large number of decisions over the course of the disease and decisions other than end-of-life ones may cause greater stress, in particular placement in residential care (Elliott *et al.* 2009; Livingston *et al.* 2010; Koplow *et al.* 2015; Lord *et al.* 2015; Webb and Denning 2016). The greatest distress for family and SDMs is when decisions are made that seem to be in conflict with what the person themselves might have wanted, and where they do not have support from healthcare professionals (Lord *et al.* 2015). Family members, particularly spouses, often agonise over residential care placement, and yet people with dementia are often concerned about their family carer's wellbeing and may be more open to a move than others have realised (Whitlatch and Menne 2009).

Where family understand the person with dementia's values and preferences, this leads to greater involvement of the person with dementia in decision-making (Miller *et al.* 2016). It also can reduce decisional conflict for proxy decision-makers by having values inform treatment rather than providing firm indications about specific treatments (Kwak *et al.* 2015). In the development of a two-question ACD (Mahon 2011) that is non-threatening, encouraged discussion and recognised the uncertainties of future care, Mahon argued that 'at their best, advance directives comprise two components: designation of a surrogate decision maker and identification of factors and preferences to guide decision making' (2011: 803).



**Future directions for practice, research and policy**

This research demonstrates that a more positive and personal approach to ACP is likely to achieve greater success in engaging people with dementia and their families. Such an approach removes the barriers to ACP inherent in a medical approach focused on end-of-life, instead focusing on the matters that people with dementia and their families consider the most important. A focus on values and what has guided and informed decisions in the past also overcomes the difficulty many people with dementia have in envisaging a future self (De Boer *et al.* 2012). The priority for health and aged care professionals will be to encourage a person with dementia to appoint a trusted person to make decisions on their behalf in the future and to have discussions with them so that they know what is most valued. An ACD might also be promoted, particularly in situations where someone wishes to formalise their choices for medical care in the future, or where there is no close family member.

The findings also highlight other areas that need to be considered in relation to how decision-making is put into place and the supports that people with dementia, their families and SDMs may need. A person with dementia should be included in decision-making as far as possible, and for as long as possible. SDMs may also need support to understand their role in making the decision that the person with dementia is likely to have made if they had been able to, rather than the decision they would wish for. Encouraging a broader scope for advance planning may mean that the person with dementia raises issues which are outside the scope of practice of health professionals. This will mean that health professionals will need to develop good relationships and links with stakeholders who can support other planning/decisions if outside their knowledge, and provide guidance to the person with dementia and their family about how to find support in this area. A broader approach to ACP also provides opportunities for those in the community aged care sector to work more closely with people with dementia and their carers in identifying ‘care values’ (Whitlatch 2013, 2014) to strengthen relationships and inform consumer-directed care packages.

The amount of research in relation to ACP has grown significantly in recent years and the specific issues in relation to those with dementia have also emerged only relatively recently. However, this work has been primarily based on the issues related to end-of-life medical care rather than considering how best to encourage planning for a broader range of issues likely to be of concern for people with dementia, their SDMs and families. Research into how to support the consideration of decisions other than end-of-life care are still in the early stages and to date show mixed results (Sampson *et al.* 2011; Lord *et al.* 2015, 2016). Further research is needed to identify the areas of most concern to people living with dementia and families in considering the future and how best to incorporate this into future planning that already occurs or could be supported in a range of settings.

In order to make the ACP process more relevant for people with dementia and their families and SDMs there is a need to reframe it as one which allows

consideration of the broad range of issues of importance to people with dementia and for which decisions will need to be made over the remaining period of life. This will require greater consideration of whether the range of structures established to support ACP are appropriate for the increasing proportion of older people with dementia in the community. This will include looking at prescribed or suggested forms, the settings in which assistance is provided and the messages conveyed by medical practitioners at diagnosis, support workers, online or in promotional campaigns. It is encouraging to see that South Australia, the Australian jurisdiction who has most recently reviewed their approach to ACP, has put in place an ACD form which explicitly covers a broad range of issues and supports a person being able to indicate what is of importance to them and what should be considered in making decisions for them (Department of Health and Ageing and GOSA 2016).

The other important area to better address through policy is in relation to decision-making for those with impaired cognitive abilities. There are three aspects that are likely to benefit greatly from improved support: (a) providing guidance on the wise choice of SDMs as part of ACP; (b) supporting a person to be involved in decision-making for as long as possible, including through supported decision-making; and (c) providing assistance to SDMs to better understand their role. Given the key role SDMs play in the lives of people with dementia, and their unpreparedness for this role, there may be value in seeking to increase engagement with ACP and discussions of values to inform advance planning through specifically targeting family members who may be SDMs in the future.

Our research clearly indicates that the medical model of ACP with its focus on health interventions is not working, particularly for those with dementia. The solutions identified fit within a person-centred and social model with a focus on relationships. This points to the need for informed discussions to identify what is important to the person or most valued, the appointment of trusted substitute decision-makers who know the person well, supporting a person to be involved with decision-making as much as possible and planning how best to live the rest-of-life by considering a broad range of issues.

Future action should focus on planning ahead on a wide range of issues, including what actions can be taken to reduce the impact of disability; the importance of appointing a SDM, including how to choose; and encouraging conversations with SDMs and family on what is most valued. Achieving greater engagement with ACP for those living with dementia will mean they are more likely to receive care and support in line with their wishes, increasing their quality of life. SDMs, carers and family will benefit too, knowing that the decisions that need to be made reflect the values and wishes of the person they love and care for.

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