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Future planning and advance care planning

Why it needs to be different for people with
dementia and other forms of cognitive decline



COGNITIVE
DECLINE
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Executive summary

The number of people living with cognitive decline in Australia is increasing rapidly as the population ages. Dementia is the leading cause of cognitive decline and is now the second leading cause of death and a significant cause of disability in Australia. When people with dementia are admitted to hospital they often receive suboptimal care, have longer, more costly hospital stays and have poorer health outcomes. Over time most people with dementia lose the ability to make decisions for themselves and are reliant on families and other carers to make decisions for them - something which is often difficult in times of crisis. Consequently, individuals may receive care or

treatment that does not accord with their prior wishes.

Advance Care Planning (ACP) has been shown to increase compliance with individuals' end of life wishes and to reduce stress and anxiety in individuals and carers. However the adoption of ACP is yet to become widespread in the Australia. For ACP to meet the needs of people with dementia, and other forms of cognitive decline, there are some important specific considerations.

This project reviewed current literature and resources, and interviewed more than 80 practitioners representing a variety of sectors across Australia with a view to identifying

key issues and successful approaches that might inform the development of a national model.

The project has made seven key findings to improve the uptake and quality of advance care planning for individuals with cognitive decline, each supported in the report with a number of specific recommendations and actions for government, organisations and individuals. It is recognised that there are additional actions that can improve advance care planning in the general population that will have a flow on effect for individuals with a diagnosis of dementia, but these are not specifically addressed in this report.



Finding 1: To provide better outcomes for individuals with dementia, advance care planning should cover an extended period of time and include a wider range of issues

Dementia poses unique challenges for ACP because incapacity to make decisions is more certain than in other diseases and is progressive over a long period. If ACP is left until near the end of life, it will be too late for those with dementia to fully participate. The decisions that need to be made as a person's cognitive function deteriorates encompass a range of financial, lifestyle and health-related domains, including about medical intervention near the end of life.

Finding 2: It is important to ensure that individuals receive a timely diagnosis of dementia and information about the potential prognosis

A timely and accurate diagnosis of dementia allows the individual and their family members to be better informed and prepared for the future. Understanding possible disease progression increases the engagement of individuals and family members with the ACP process and can have a significant impact on the choices expressed in an advance care plan. In addition to the support provided by GPs and organisations such as Alzheimer's Australia, a case manager or dementia key worker can play a valuable role to assist

individuals and families navigate the health, community and aged care system.

Finding 3: Advance care planning should be done as soon as possible after diagnosis of dementia, if not done previously

Ideally, ACP discussions should commence before an individual is diagnosed with dementia. However, when this has not been the case, discussion should occur as soon as practicable after diagnosis. This will maximise the opportunity for meaningful participation by the individual before further decline in their decision-making capacity and ability to communicate. Even if advance care planning has commenced it should be reviewed after a diagnosis of dementia to ensure it still reflects the individual's wishes and that relevant health and lifestyle factors have been considered. To achieve this goal, primary and community care providers, as well as legal and financial planning providers, need to be encouraged and equipped to facilitate early attention to ACP.

Finding 4: Effective Advance Care Planning for individuals with dementia requires conversations that focus on understanding a person's values and beliefs

Advance care plans that only address specific medical care scenarios fail to cope with the varied progression of dementia and the likelihood of an extended period of incapacity. They are open to interpretation, may not cover the required scenario and may not be authoritative for doctors. Conversations focused on values, however, encourage engagement by the individual, family members and other care providers because it entails a more positive approach than one focused exclusively on end-of-life issues. This is especially the case for cultural groups where

discussions about death and dying may be highly sensitive.

Values and beliefs tend to remain consistent over a person's life and are independent of the stage of illness. People with mild to moderate dementia are still able to express what makes their life meaningful and are able to make decisions using a values-based rationale. Values based discussions also assist substitute decision-makers to make decisions that reflect the wishes of the individual.

Finding 5: The appointment of one or more substitute decision-makers is critical

The appointment of a substitute decision-maker (SDM) enables the SDM to be an advocate for the individual with dementia. It enables decisions to be made in a timely, context-specific manner based on an understanding of the person's values and wishes. It avoids relying on finding and following written instructions, which may be unclear or inapplicable to current circumstances. It remains true, however, that SDMs are often faced with difficult decisions, particularly in late dementia, and benefit from support even if the individual's wishes have previously been discussed.

Participants in this project stressed the importance of three factors in appointing a SDM: selecting the most suitable person (someone who knows them well or has similar values); considering whether it might be advisable to appoint more than one SDM; and having discussions about beliefs and values, and possible future scenarios, ahead of time.

Finding 6: A person with dementia should be involved in discussions and decision-making as much as possible

Decision-making is an important part of a person's identity. As a matter of principle, individuals,

including those with dementia, should be presumed to be competent to participate in discussions and decisions that affect them unless there is clear evidence that this is not the case and/or there are compelling reasons for them not to be consulted. Adopting strategies such as providing explanations in simple language, minimising noise and distractions, and narrowing the range of options presented for decision, can facilitate their meaningful participation.

Assessment of a person's capacity should consider their ability to understand and communicate the reasons for their choices. Capacity is specific to a particular task or decision at a particular time. People with dementia may be capable of making certain decisions but not others.

Finding 7: Particular care is needed when individuals with dementia are transferred between health care settings

People with dementia are particularly vulnerable when there are changes in the care environment, due to impaired ability to communicate their needs, and disorientation associated with changes in environment. An individual's previously expressed wishes regarding their care can be overlooked when the continuity of care is broken as relevant documents may be unavailable or difficult to access and substitute decision-makers may be unknown. Systems need to be established, and ongoing education provided, to ensure that previously expressed preferences regarding care are easily accessed and acted upon. A consistent approach across different care settings, such as residential and acute care, is desirable.



“Families and carers find it difficult to make decisions in times of crisis and people receive care that they may not have wanted.”

Introduction

The number of people who are living with dementia in Australia is significantly increasing due to an ageing population. Dementia is now the second leading cause of death and the leading cause of disability burden for people aged 65 and over. When people with dementia are admitted to hospital they often receive suboptimal care, have longer, more costly hospital stays and have poorer health outcomes. As the disease progresses people with dementia lose the ability to make decisions for themselves and are reliant on families to make decisions for them. Families and carers find it difficult to make decisions in times of crisis and people receive care that they may not have wanted.

Advance Care Planning (ACP) increases compliance with individuals' end of life wishes and has been shown to reduce stress and anxiety in individuals and carers, and can play a role in preventing family disputes. When a written Advance Care Directive or Do Not Resuscitate order exists, carers may feel a greater sense of wellbeing after a person's death. However, in Australia the adoption of ACP is yet to become widespread. State and federal governments in recent years have attempted to increase uptake of ACP through changes to legislation, promotional activities and initiatives such as Decision Assist. There has been little attention, however, to the

particular challenges involved in assisting those with dementia to make their wishes about future care known despite the high likelihood that there will be a time when they may not be able to communicate their wishes themselves.

“Within the CDPC a wide range of research and knowledge translation activities are being undertaken with the aim of improving the quality of care for people with dementia and their carers, and providing better evidence and information for service providers and decision-makers.”

This project was developed by the Cognitive Decline Partnership Centre (CDPC) to examine how ACP can be improved so that the wishes of people with dementia and other cognitive decline can be known and upheld. The CDPC was established in 2013 with funding and support from the NHMRC and Funding Partners: HammondCare (NSW), Helping Hand Aged Care (SA), Brightwater Care Group (WA) and Alzheimer's Australia. Within the CDPC a wide range of research and knowledge translation activities are being undertaken with the aim of improving the quality of care for people with dementia and their carers, and providing better evidence and

information for service providers and decision-makers.

This project recognises that there has been a variety of ACP approaches in different settings with varying rates of success in their implementation. The research team gathered evidence detailing the best ACP approaches in order to make recommendations and develop a national model, which can be trialled before wider implementation. The aim is to develop sustainable ACP approaches that can be used in a wide range of community, health and aged care settings.

A wide range of material was examined: including a search

About this project

of the academic literature; a review of the grey literature including reports and policy documents by state and territory governments, and a review of resources and websites already available to consumers and health professionals to facilitate ACP. In addition, semi-structured interviews were undertaken, which focussed on (a) identifying barriers and facilitators for ACP, (b) what works well and what needs improvement, and (c) the different approach to ACP needed for cognitive decline.

These interviews were conducted with over 80 people including consumers, carers and their advocates; with health and aged

care providers with experience in ACP; and academics and government officials involved with ACP. Participants were drawn from all states and territories in recognition of the differing legislative basis and programmatic

approaches in different jurisdictions. A detailed overview of the interview methodology, participants and results are found in a companion document available online at www.sydney.edu.au/medicine/cdpc/

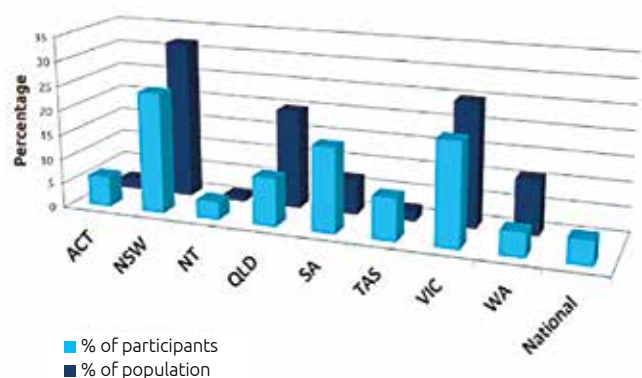


Figure 1: Interview participant's location in Australia at time of interview

Acknowledgements

“Generous support and important contributions were made by the Stakeholder advisory committee who ensured the project was well informed”

Cognitive Decline Partnership Centre. Future planning and advance care planning:

Why it needs to be different for people with dementia and other forms of cognitive decline. Sydney (Australia): Cognitive Decline Partnership Centre; 2015.

The development of this report was funded by the National Health and Medical Research Council's (NHMRC) Partnership Centre for dealing with cognitive and related functional decline in older people (CDPC). The CDPC receives funding from the NHMRC and funding partners including HammondCare, Alzheimer's Australia, Brightwater Care Group and Helping Hand Aged Care.

Generous support and contributions of time were made by the Stakeholder Advisory Committee who ensured this project was well informed by stakeholders. Members included individuals from a wide range of backgrounds and expertise – including consumer, primary care, aged care, hospital, policy and government to ensure the variety of settings and perspectives relevant to dementia specific advance care planning were taken into account. As the legislative base and health system differs across Australia members were drawn from a number of states.

The valuable personal insights and expertise contributed by interview participants is also recognised. This report brings together a wealth of information from consumers and experts in their field and their collective insight and experience provides valuable evidence to guide future service developments in advance care planning for those with dementia and other forms of cognitive decline.

Stakeholder Advisory Committee

Chair:

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Members:

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Dr Patrick Kinsella

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Terminology

This project adhered to the recommendations for consistent terminology set out in 'A National Framework for Advance Care Directives'¹⁵ endorsed by the Australian Health Ministers' Advisory Council in 2010 and which are provided below.

Advance Care Planning (ACP)

Advance Care Planning is the process of planning for future health and personal care 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, and does not 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 and may not be legally recognised.

Advance Care Directive (ACD)

An advance care directive 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 advance care directive can describe a person's wishes regarding their future care and can appoint a substitute decision-maker.

Substitute decision-maker (SDM)

Substitute decision-maker 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.

Key to symbols

Throughout the report the following symbols are used.



Actions to be completed by individuals



Actions required by community, acute care and aged care organisations



Action needed by government or policy makers

Finding 1: To provide better outcomes for individuals with dementia, ACP should cover an extended period of time and include a wider range of issues

Dementia poses unique challenges for ACP because incapacity to make decisions is more certain than in other diseases and such incapacity is progressive over a long period. If ACP is left until near end-of-life it is often too late for those with dementia to be able to fully participate.^{6,16} The types of decisions that will need to be made as a person's cognitive function deteriorates are wider than just medical decisions near end-of-life. As cognitive function decreases family members and carers are called on to make ongoing decisions, that relate to a range of financial, lifestyle and health issues.¹⁷

Due to the likely length of operation of an advance care plan for those with dementia, it can be argued that there is greater value in supporting ACP for this group. One of the main barriers to undertaking ACP is that many people do not understand the value of planning ahead.^{18,19,20} Providing the opportunity to discuss and plan for issues of high priority and relevance for the individual and their family is likely to encourage higher engagement for those with dementia. All adults should be encouraged to undertake ACP as anyone can sustain acute injuries (e.g. in a car or sporting accident) or have a sudden acute medical illness (such as acute cardiac events), but it is particularly important for older people, those with chronic illness, and people with early dementia. Regular review of ACP documents is strongly recommended. Planning can progress from discussions and nomination of a SDM, to more formal ACP depending on individual preference, health status and stage of life.²¹

The types of issues that a person with dementia may want to plan ahead for in order to exercise choice and extend control are likely to be diverse depending on their living situation and family arrangements. Current research shows that advance care plans often include restrictions on what interventions a person with dementia would want at the end of life, but do not

include information about how they want to be treated, with the exception of comfort care and pain relief.²² For some people with dementia and their carers, advance care directives are seen as problematic as they can be open to interpretation, do not cover every scenario and leave too many questions unanswered.²³

“It’s not just about medical treatment, it might be around 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. Would you rather have your money spent on a massage and a cleaner so we can keep you at home or would you rather it be spent on care in an institution” (Carer, SA)

Key areas for consideration and discussion for those with dementia are likely to be how care needs are met as capacity declines and who should be involved in assisting with decisions. Other lifestyle issues may include future living arrangements, continuation of attendance or involvement in church and/or clubs, care for pets, what is to happen when it is no longer safe to drive, provisions around visitors and/or contact (particularly where there may be conflict), and children and employment issues for those who are younger.

Recommendations

1.1 ACP should incorporate discussion and documentation of preferences related to care and lifestyle decisions as well as end of life choices²⁴

1.2 ACP should take into account what may happen if the primary carer becomes ill or dies

1.3 ACP should be conducted by disciplines and services at time points across the life span continuum, not just palliative or end of life care¹³

1.4 ACP should be conducted by disciplines and services at time points across the life span continuum, not just palliative or end of life care¹³

Actions required

1.1a Adapt advance care plans and ACDs to incorporate lifestyle decisions and future care preferences



1.1b Develop resources that support professionals and family members to guide conversations about the types of issues that may be of importance to people with dementia



1.2a Ensure that consumer education regarding ACP promotes the need to plan for a variety of potential outcomes



1.3a Develop promotional material to highlight that the goal of ACP is about living well and maintaining control



1.3b Promote the importance of ACP to the public as part of getting one's affairs in order, similar to preparing a will²⁵



1.4a Develop resources that support professionals to recognise important life span transitions and prompt completion of ACP¹²



Finding 2: It is important to ensure that individuals receive a timely diagnosis of dementia and information about the potential prognosis

It is important that a timely and accurate diagnosis of dementia is provided to all people with dementia.²⁶ This not only enables appropriate care, but importantly facilitates future planning, including ACP.²⁷ The majority of substitute decision-makers feel that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the person's cognitive decline and eventual death.^{28,29} A lack of knowledge about dementia and its likely progress leaves people with dementia and their family-members or carers unprepared for decision-making.^{18,30}

Family members and carers are often well placed to notice changes in a person's cognitive abilities and can play an important role in encouraging the individual to seek medical attention.³¹ Providing guidance for families and carers about when and how to seek medical advice would facilitate a more timely diagnosis and can enable all involved to adjust to the diagnosis and provide appropriate support.³²

An Australian study has shown that GPs who communicate a diagnosis and disclosure of a memory problem to their older patients significantly improve the quality of life of older people living in the community.²⁶ Respondents in this current study identified problems when diagnosis was delayed and the individual already lacked capacity.

“Only 50% of people ever get their diagnosis of dementia and very often 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, TAS)

Understanding, and being able to visualise, possible disease trajectories is important in helping individuals and families to engage with ACP.³³ People's knowledge of dementia and how it might progress can have a significant impact on the choices they make in an ACD.³⁴

Research has shown that seeing a video clip that shows how advanced dementia may be experienced resulted in improved knowledge of dementia, increased the likelihood of choosing comfort care and significantly improved the concordance of the preferences of elderly patients older people and their substitute decision-makers.^{35,36} This is further supported by qualitative research undertaken for this project, with a large number of participants identifying that the lack of communication with individuals, families and carers about the terminal nature of dementia impaired efforts regarding future planning.

“If people don’t really understand what dementia is about then these terrible things will keep happening” (Acute care, TAS)

While GPs and community support services, such as Alzheimer's Australia, can provide ongoing education and support to people diagnosed with dementia, there are also recognised benefits from having a dementia specific key worker or case manager. This involves a person being allocated a case manager to support them after diagnosis and assist them and their caregiver in health care navigation. This role was perceived to be very beneficial in assisting people with dementia, families and carers to determine what is important following a diagnosis of dementia and to support future planning.

“The key worker is a person who would form an ongoing relationship with a person diagnosed with dementia and their primary carer for the very specific purpose of enabling them to understand what’s out there to support them.” (Academic, QLD)

Recommendations

2.1 Investigation of impairment in cognitive function should occur in a timely manner^{26,27}

2.2 Ongoing follow up should be provided to people with dementia and, with consent, their family or carer

2.3 Increase community awareness on the benefits of early diagnosis of dementia

Actions required

2.1a Provide ongoing education to increase GPs' skills and confidence in the identification and diagnosis of cognitive impairment^{27,37}



2.1b Encourage and support GPs to refer for diagnosis of dementia³⁷



2.1c Provide information to carers and family members about signs of cognitive decline and when and how to seek medical advice.³²



2.2a GPs provide those involved with realistic information on possible prognosis early in the dementia journey to allow time for adequate planning^{18,38}



2.2b Put in place a dementia specific key worker or equivalent to provide regular support and follow up of people diagnosed with dementia



2.3a Continue and expand programs in the community to increase knowledge of dementia



Finding 3: ACP should be done as soon as possible after diagnosis of dementia, if not done previously

When ACP has not been discussed prior to diagnosis it should occur as soon as possible after diagnosis, usually within a few months. This timing is important so that ACP is commenced while there is still opportunity for the person with dementia to engage meaningfully in the process^{6,23,30} and before substitute decision-making becomes necessary.³⁰ If the person with dementia already has an advance care plan in place this should be reviewed after a diagnosis to ensure it still reflects the values of the person and to allow the consideration of other health and lifestyle factors. While some people with dementia may already have impairment in cognitive function that can reduce insight and motivation and may impair their ability to plan ahead,³⁹ it is important to gain their input before there is a further decline in their decision-making capacity and their ability to communicate.

People with dementia, family members and carers all report avoiding discussion about the future until it is too late, due to a lack of understanding of the benefits of planning ahead.^{18,19,20} However, research has shown that certain triggers can prompt planning discussions amongst family and carers of people with dementia¹⁹ and that health care providers can play an important role in moving people along the continuum of considering and then nominating a substitute decision-maker⁴⁰ and putting an advance care plan in place.

“The biggest difference is having a more limited window for catching people. So, making sure that people are being introduced [to ACP] and having the opportunity to have those discussions very early on in their illness when they can still participate” (Medicare local, VIC)

Currently ACP is often prompted by the surprise question “Would you be surprised if this person died in the next 6-12 months?”, or upon entry to a residential aged care facility. In either case the timing may be too late for those with dementia as decision-making capacity

and ability to communicate reduces as the disease progresses.⁶ A systematic review of the effectiveness of ACP for people with dementia found that all ACP studies for this group had been undertaken in nursing homes and only up to 36% of participants were judged to have capacity. While there are still benefits in ACP for these groups, commencing ACP at this stage may be too late for most people with dementia.⁴¹

To ensure that ACP is approached before or soon after a diagnosis of dementia it is important that primary and community care providers are equipped to support ACP. The community setting is often seen as the optimal setting for ACP because a person’s condition is relatively stable, they are generally in good health and are more likely to have decision making capacity. It is also recognised that people are more empowered in primary care than in other health care settings.⁴² GPs, practice nurses and other community based health professionals are also thought to be in an ideal position to facilitate ACP because they have an existing relationship and often understand the person well.⁴³ Many respondents, including GPs, identified 75+ health checks and chronic disease management plans as ideal times to encourage ACP. Other support services such as case managers and social workers also have a role to play in prompting ACP, and carers and family members can also prompt formal and informal planning.

There is also an important role for the legal and financial planning sectors in prompting and facilitating the completion of a wider variety of planning behaviours. People with dementia are more likely to undertake practical, personal, and financial future planning (such as making a will, appointing someone to be power of attorney for financial matters and putting their assets in a trust), than they are to complete advance care plans.^{23,44} The much higher proportion of people living with dementia who have financial powers of attorney in place may be due to the influence of solicitors advising of their importance.²³ By promoting ACP as part of getting one’s affairs in order and increasing skills and availability of education material to non-health care professionals such as lawyers, accountants and financial planners, uptake of ACP can be increased, as these professionals are already involved in assisting people to plan for the future.¹⁹

“I think if we do things early enough and normal enough then once a person does have diminished capacity then everything’s in place.” (Medicare local, NSW)

Recommendations

3.1 Increase awareness of the benefits of ACP and encourage early completion with regular review

3.2 Increase involvement of primary care providers in ACP^{38,46}

3.3 A prompt to undertake ACP should occur at or soon after diagnosis of dementia and be actioned as soon as practicable (within months)

3.4 Advance care planning should be promoted as an important part of general planning ahead and getting one’s affairs in order

3.5 Community organisations, and community aged care providers should support ACP⁴⁵

Actions required

3.1a Promote ACP for all adults,⁴⁵ especially people over 50 years of age



3.2a Continue funding of initiatives that support ACP in primary care ⁴⁷ such as Decision Assist¹⁴



3.3a GPs follow up person with dementia shortly after diagnosis to encourage ACP



3.3b Include alerts in electronic prescribing software that prompt GPs and specialists to raise ACP at the time of prescribing dementia medications



3.3c Government consider requiring ACP to be addressed when prescribing dementia medications under the PBS



3.4a Provide material and education for lawyers, financial planners and other community based professionals to encourage referral for, or completion of, ACP when completing other planning documents^{19,23,44,48,49}



3.5a Community aged care providers develop and implement systems to enable the identification of an individual’s wishes and their use to guide care plans



Finding 4: Effective ACP for individuals with dementia requires conversations that focus on understanding a person's values and beliefs

Due to the varied progression of dementia and the likelihood of an extended period of incapacity, advance care plans that focus only on outlining specific medical care can be seen as problematic as they are open to interpretation, may not cover the required scenario and leave too many questions unanswered.²³ People with dementia are more likely to engage, and to participate meaningfully, in a values-based conversation with family and carers.^{50,51} Focussing on values and beliefs may also make it more likely that health and aged care providers will raise the topic of ACP because of the more positive focus, thereby overcoming a major deterrent to ACP that focuses exclusively on end-of-life issues.⁶

It has been demonstrated that people with mild to moderate dementia are able to contribute to discussions about their care and express what makes their life meaningful. Values and beliefs are seen to remain consistent over a person's life and to be independent of the stage of illness. Values-based discussions may also be appropriate for those from cultural backgrounds in which it is less acceptable to discuss end-of-life issues.⁵² Furthermore, it has been demonstrated that people with dementia are able to make decisions using a values-based rationale⁵⁰ and that these values are as consistent and stable as those of people without dementia.⁵³

Without discussions of values there can often be a discrepancy between the identified values of a person with dementia and their SDMs.⁵⁴ In such circumstances, SDMs are likely to project their own treatment wishes.⁵⁵ In order to make ACP more effective, and to increase the likelihood that care is in line with what people want, some providers have begun to prepare advance care plans that incorporate information about peoples' values and priorities.^{56,57}

“People: they don’t change their mind about what’s important to them in life” (ACP service, VIC)

ACP approaches which rely solely on completion of documentation face significant barriers.⁶ They are often not written in a way that is authoritative for doctors; language is considered unclear or they do not apply to the current situation. ACDs made without prior discussion with those who will make decisions do not generally lead to better outcomes.

Many people living with dementia, and their family and carers, have a strong preference for informal discussions rather than written documents. Reasons for this include the need for more flexibility when the future is so uncertain and the impossibility of covering all eventualities in a written document. ACP discussions alone may be sufficient where there is a close and trusting relationship, and the SDM understands the preferences of the person and is confident in ensuring the person's preferences are followed. Discussions are also useful where a person does not wish to undertake formal ACP but would prefer to leave decision-making to family or health staff, so that those who are likely to make decisions understand this preference. Increased awareness of cultural factors that may influence an individual's understanding of ACP and how best to approach ACP may help increase engagement in ACP with individuals from varied cultural backgrounds.^{7,58}

A focus on identifying the values of a person with dementia, as part of the development of care plans for services likely to be needed into the future, has resulted

in improved outcomes - such as reduced caregiver stress and an increased likelihood of remaining in a preferred environment.^{59,60,61} People with dementia often place a high value on not being a burden to family caregivers and yet this is often not understood by the caregivers who then feel guilty about accepting assistance in supporting them in their caring role.⁵⁴ Discussion and identification of the values of the person with dementia could be readily integrated into the planning of consumer-directed care packages, using tools such as the Values and Preferences Scale.^{59,62,63}

“Many of the people with dementia weren’t able to write things down for themselves to actually conceptualise and to get the details of what they wanted, but many people were able to be clear in the discussion process about not wanting life extending treatment when they are in the terminal phase of a terminal illness. Most people were very clear in saying they wanted comfort and pain relief and didn’t want machines and all of that sort of stuff, “(Consumer group, SA).

In the consultations undertaken for this current research project participants across a range of settings and professions were supportive of the idea that it is the conversation that occurs amongst family and SDMs that was most effective in ensuring that care reflects the wishes of the individual.

“Having a conversation with family and friends and/or anybody who may have to make a decisions on your behalf if you lose capacity, - that’s absolutely the most important part of the process”
(Palliative care, TAS)

It was also recognised by participants that having a written ACP, or formal ACD, can provide support to the SDM at a difficult time when seeking to implement the person’s wishes, particularly when other family members or medical staff question the preferred course of action. Documentation can be valuable when there is no close family, the SDM is not available or the person with dementia moves between different care settings.

Finding 4: Effective ACP for individuals with dementia requires conversations that focus on understanding a person's values and beliefs

Recommendations

4.1 Increase the focus of ACP on the individual's values, beliefs and a discussion of lifestyle preferences²⁴

4.2 Focus ACP promotion on encouraging discussion between families and substitute decision-makers^{64,65}

4.3 Develop care plans for current and future care in line with the underlying values of the person with dementia

Actions required

4.1a Adopt advance care plans and ACDs that promote discussion of values and beliefs^{38,53}



4.1b Use values based advance care plans and directives that can be understood and be completed by those with cognitive decline⁵³



4.2a Develop resources and programs that engage families of people with dementia in ACP^{47,52,66,67}



4.2b Provide people with dementia and families and carers with access to written and audio-visual resources that increase understanding and uptake of ACP^{16,21,68,69}



4.2c Utilise group community education sessions to promote and increase uptake of ACP^{52,66,70,71}



4.3a Community aged care providers incorporate discussion and identification of the person with dementia's values in developing consumer-directed care plans.





Finding 5: The appointment of one or more substitute decision-makers is critical

The appointment of a substitute decision-maker (SDM) enables decisions about treatment and care issues to be decided in the actual context with detailed information where discussion with the treating health professionals can occur. It enables a dynamic approach, based on an understanding of the person's values and wishes, rather than relying solely on a static ACD document. It also allows the SDM to be an advocate, rather than depending on others to find and follow written instructions which may not be clear, or in situations of unforeseen circumstance.^{23,46,51}

A USA study⁵¹ utilising focus groups of people and SDMs, identified four key success factors: 1) identify values based on past experiences and quality of life, 2) choose SDMs wisely and verify that they understand their role, 3) decide whether to grant flexibility in substitute decision making, and 4) inform other family and friends of one's wishes to prevent conflict. Helping a person to understand that decisions are more likely to be in line with their own wishes if they nominate someone who knows them well, or has similar values, is likely to result in better outcomes than, for example, assuming it should be the oldest offspring.^{55,72}

Some participants in the present study identified the most important parts of nominating a SDM as being (a) to consider who is the most suitable and whether it might be advisable to have more than one, and (b) having discussions with the SDMs ahead of time about beliefs and values, and possible future scenarios.

"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, TAS)

Some participants indicated they would prioritise completion of enduring guardianship and enduring power

of attorney paperwork and indicated they would prioritise their completion above an ACD. Reasons provided for this strategy were related to a sense of urgency with regard to potential loss of capacity to legally nominate a SDM and perception it is easier and requires less time to complete SDM forms than to document a person's wishes in an advance care plan.

"Probably the most critical element is the medical enduring power of attorney [substitute decision-maker] and making sure that that power of attorney [substitute decision-maker] knows what that person would want. So whether the patient gets around to actually doing a statement of choices or an advance care directive, if they've got that power of attorney and they've had that discussion with family or their power of attorney about what their preferences would be, that seems to make the greatest impact, reducing that stress and improving their outcomes if they do end up in hospital" (Medicare local, VIC)

An ongoing difficulty, is that SDMs are often not able to accurately identify an individual's wishes, even if they have previously discussed them.^{51,73} SDMs are also often unprepared for the decisions that need to be made in late dementia. Providing support to SDMs and helping them to make decisions may be beneficial in improving their comfort and ability to make decisions.⁴⁰ SDMs who are offspring of a person with dementia may need additional support in decision-making as they may have a less complete knowledge of the person than the person's spouse.⁷⁴

Recommendations

5.1 The focus of education and promotion of ACP should highlight the importance of nominating appropriate substitute decision-maker/s, together with how to make nominations legally binding⁵¹

5.2 Increase knowledge of how to choose the best SDMs

5.3 Involve SDMs in ACP discussions^{4,76}

5.4 Support SDMs in their role⁴

Actions required

5.1a Promote the value of the legal appointment of SDMs as a critical part of ACP and planning ahead¹³



5.1b Health and aged care providers highlight the value of having an appointed SDM³⁸



5.1c Include identification of appointed SDMs in admission processes¹³



5.1d Include a requirement to identify appointed SDMs in accreditation for hospitals and aged care services⁷⁵



5.2a Develop ACP-related education and information resources to highlight how to choose the most appropriate SDMs⁵¹



5.3a Health and aged care providers include SDMs in ACP conversations through scheduling appropriate appointments



5.4a Develop programs to provide information and resources for SDMs so they understand their responsibilities to represent the wishes of the person, with support and advocacy where needed⁷⁷



Finding 6: A person with dementia should be involved in discussions and decision-making as much as possible

It is important that a person with dementia is enabled to make decisions for themselves for as long as possible and should be involved as much as possible in any ACP discussions.²⁶ They should be presumed to have capacity and be involved in discussions and decisions unless there is clear evidence they are not competent and there are compelling reasons for them not to be consulted. Strategies should be used to support the person with dementia to remain engaged in decisions that affect them and to avoid the stigma and disempowerment often associated with the diagnosis of dementia.

There is evidence that individuals with dementia are able to provide meaningful input and contribute effectively to decisions that affect them, even with more advanced dementia.^{78,79} Strategies to include individuals with dementia in decision making include providing clear explanations, minimising noise and distractions and narrowing the range of options to avoid confusion.¹⁷ Approaches which recognise and overcome the limitations of dementia such as using simple language, minimising load on short-term memory, while relying on remaining cognitive functions such as reading and long-term memory are also more successful.⁶¹ Respondents in this research project identified that, with appropriate support, people with mild to moderate dementia can and should be involved in making decisions about current and future care through ACP.⁵³

“There’s a reasonably long period of time when ... you might have cognitive decline but you still have capacity. (Primary care, VIC)

Determining capacity and whether someone has impaired decision making should not be approached primarily as a medical assessment but instead start as a conversation, with capacity presumed unless it is clearly absent.⁸⁰ If the individual shows signs they are unable to understand what they are being asked, further questioning is warranted. Assessment of capacity should consider the individual’s

ability to understand, appreciate and communicate the reasons for his or her choices in a manner that is specific to a particular task and at that particular time.^{80,81} Importantly it needs to be recognised that capacity is decision specific and that people with dementia may be capable of making certain decisions but not others.⁸⁰ Decision making capacity may also be improved by holding discussions earlier in the day when the person is rested and in an environment without distractions.⁶⁰ A number of resources are available that can assist clinicians to increase their understanding and improve their confidence in determining decision specific capacity.^{82,83}

“Anecdotally I see across the hospitals and across lawyers, across society generally, that people who are very old are often assumed not to have capacity even if they’re well and able to make their own decisions. I hear the same things in relation to people who have early dementia. They say about people who have at least some mild form of intellectual disability, ‘you have a disability, therefore you can’t decide anything’. (Academic lawyer, Qld)

The way in which people interact and respond to a person diagnosed with dementia can have a significant impact on their ability to engage with others and remain involved in society.^{17,84} Decision-making is an important part of a person’s autonomy and identity and can contribute to improved quality of life.⁸⁵ It therefore should be encouraged and assisted as much as possible for people with dementia. Supported or assisted decision-making is one mechanism that can also help the person with dementia to be involved in the decision-making process.¹⁷

“People can still participate but maybe in limited capacity so that the idea of competency is not black and white and people may be able to . . . participate earlier in the day” (Primary care, VIC)

Despite this, a diagnosis of dementia can mean that others do not take time to speak with the person, but rather direct all communication to carers and family members.⁸⁶ This may be due to the stigma associated with dementia,

where people lack knowledge and understanding about the capabilities of a person with dementia and can mean they often do not take the time and make the effort to engage with the person.

Recommendations

6.1 The person with dementia should be included in planning discussions and decision making as much as possible^{17,80}

6.2 Competence and ability to participate in discussions should be assumed, unless it is clear this is not possible

Actions required

6.1a Amend policy and practice to recognise that a person with dementia should still be involved in any discussion that concerns them unless clear evidence for their exclusion exists⁸⁰



6.1b Adopt strategies to include the person with dementia in decision making, including using simple concrete examples, avoiding medical jargon and limiting distractions¹⁷



6.1c Develop and provide easy to use guides for how to assist a person with dementia to continue to be involved in decision making as far as possible⁸⁷



5.1d Educate health professionals to increase knowledge of dementia, awareness of stigma and improve their ability to involve people with dementia in decision making⁸⁸



6.2a Use available resources that provide guidance in capacity assessment if required^{75,82}



Finding 7: Particular care is needed when individuals with dementia are transferred between health care settings

There is concern among consumer and healthcare organisations that individuals' wishes regarding their care are often not followed.⁴⁶ Part of the reason for this is the lack of continuity of care, which means that relevant documents or SDMs may not be known or available. Accessing ACDs is difficult because they are not incorporated into a standard electronic record and is further complicated when care moves across settings,⁸⁹ or occurs out of hours, or when locums may be used.⁴⁶

People with dementia are particularly vulnerable when there are changes in the care environment and are more likely to have poor outcomes,⁹⁰ due to impaired ability to communicate their needs, and disorientation associated with changes in environment.⁹¹ Given that a person with dementia is likely to make a number of transitions in health and care arrangements as the disease progresses this is of real concern. It has been shown that ACP can reduce unnecessary hospital transfer^{92,93} and can reduce the use of invasive assessment and unnecessary interventions.⁹⁴

For ACP to be effective it is important that there are systems in place within the health sector to identify the wishes of a person with dementia and to ensure these are followed. Systems need to be established, and ongoing education provided, to ensure professionals and carers understand the need to identify previously expressed preferences.

“Even though we might have actually filled out a ‘not for resuscitation’ form and that might be in the front of the notes, that might not actually be looked at or referred to and the patient may be transferred out and it’s missed completely.” (Palliative care, NSW)

A number of people interviewed for this research project described situations where people with dementia or family members had tried to present a written ACD when admitted to an acute care facility and staff did not know what to do with it. Similar concerns were expressed with ambulance officers taking possession of documents. In both situations documents were misplaced. It is essential that systems exist to respond to a person's previously expressed wishes including asking for advance care plans and about SDMs on admission and ensuring there are systems for managing and responding to documented wishes.

There are a range of steps that can be taken to improve the accessibility of ACP documents such as area-wide, user-friendly, readily downloadable ACP templates, storing ACP documents with electronic medical records and providing wallet cards or alert bracelets to flag the existence of documents for ambulance services and emergency physicians.³⁸

“The... (Hospital) has recently developed a wallet card....it’s almost like an organ donor card that sits in people’s wallet that says, “I have an advance care plan and my medical enduring power of attorney is this person, and... the phone number so they know to contact people”. (ACP Service, VIC)

An important factor in implementing ACP in residential care is to have an integrated approach involving a range of stakeholders, including residents, their families, doctors and direct care staff. The approach is best if it is consistent across care settings such as residential and acute care.⁹⁵

Recommendations

7.1 When transferring care of a person with dementia, it is critical to conduct a comprehensive handover process, including previously expressed wishes regarding care¹³

7.2 Up to date ACP documentation should be stored in an accessible way⁴⁶

7.3 Health and aged care providers should ask about any ACP and SDM as part of admission processes

7.4 Improve coordination and collaboration between health and aged care providers in a region^{12,46}

Actions required

7.1a Health and aged care providers provide copies of ACP and SDM documentation or information to new providers (including a temporary one)¹³



7.1b Discharge summaries include information on any ACP discussion that has occurred¹²



7.2a Health care organisations develop systems for the storage, regular update and easy retrieval of ACP documents^{12,75,96}



7.2b Develop the Personally Controlled Electronic Health Record to allow the inclusion of ACP documentation^{12,18,45,46}



7.3a Health and aged care providers review admission policies and procedures to ensure any ACP and SDM is recorded (with opportunity to review if appropriate) and readily available⁷⁵



7.3b Ambulance services develop procedures that enable them to identify and follow an individual's wishes regarding their care⁹⁷



7.4a Health services develop local networks and meet regularly with aged care services to improve communication and coordination of care⁹⁵



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