COGNITIVE DECLINE PARTNERSHIP CENTRE

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Framework for the implementation of planning ahead, including advance care planning, for people with dementia in the community

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Contents

Executive summary

The number of people living with dementia in Australia is significantly increasing due to the ageing population. The project *Future planning and advance care planning: Why it needs to be different for people with dementia* identified seven key principles to improve advance care planning (ACP) for people with dementia. These principles are: A timely diagnosis and information about dementia; planning early; advance care planning should cover an extended period of time and include a wide range of issues, nominating a substitute decision maker; having multiple conversation over time; involving the person with dementia in decision making as much as possible; and the sharing and transferring of advance care planning documentation between care settings.

Based on these principles early planning, including advance care planning, needs to be promoted and undertaken in the community. Community groups including veterans, seniors and carers, non-government organisations (NGOs) like Alzheimer's Australia and national planning and ACP websites like www.start2talk.org.au and http://advancecareplanning.org.au have an important role to play in ACP by providing information and resources to the public to raise awareness of the benefits of early planning and ACP. The technical and further education (TAFE) and similar training facilities have a role to play in training future staff for the community, home care and health sectors. Community and home care providers, in particular, are ideally placed to provide information and to actively engage people with dementia and their carers and family in early planning including ACP. Implementing sustainable ACP into community and home care relies on strong leadership and change management including behaviour change and quality improvement methodologies.

The purpose of this Framework document, as well as the accompanying resources that have been developed is to assist in the successful implementation of ACP for people with dementia in the community. The resources include the *Planning ahead community and home care toolkit*, and the *Planning ahead community education resources kit*. These resources are housed on the Alzheimer's Australia Start2Talk website.

Aim

The purpose of the Framework and the accompanying *Planning ahead community education resources kit* and the *Planning ahead community and home care toolkit* that are housed on the Start2Talk national website, have been developed for the community sector to educate and promote the benefits of early planning especially for people with dementia. In particular, the community and home care sectors have been identified as key contact points and are ideally placed to actively engage their clients and community members, especially those with dementia, in early planning including appointing substitute decision (SDM) makers and undertaking advance care planning (ACP).

In order to be successful in implementing sustainable ACP in their organisations community and home care providers will need to undertake change management practices incorporating staff behaviour changes. This Framework will describe enablers and resources that will assist in this process.

Background

The number of people living with dementia in Australia is significantly increasing due to the ageing population. Dementia is now the second leading cause of disability burden for people 65 and over.[1] When people with dementia are admitted to hospital they often receive suboptimal care, have longer, more costly hospital stays and have poorer health outcomes.[2] As the disease progresses people with dementia lose the ability to make decisions for themselves and are reliant on others 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 want.

ACP has been shown to increase compliance with individuals' end of life wishes.[3,4] Some studies indicate that it may reduce stress and anxiety in individuals and carers[5] and can play a role in preventing family disputes.[6]

The project *Future planning and advance care planning: Why it needs to be different for people with dementia and other forms of cognitive decline* was developed by the Cognitive Decline Partnership Centre (CDPC) to examine how ACP can be improved so that the wishes and choices for people living with dementia and other cognitive decline can be known and upheld.[7]

The project's initial phase included conducting an analysis of the literature and interviews with participants around Australia. The research identified 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

The purpose of the second part of this project was to translate these recommendations into the development of sustainable approaches to advance care planning in the community and home care sectors.

A copy of the report is available at: http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php

Seven key principles to support planning ahead for people with dementia

1. **Timely diagnosis and information about dementia**

   A timely and accurate diagnosis of dementia and information about its potential progress will allow the individual and their family to be better informed and to plan ahead.

2. **Planning early, soon after diagnosis if not before**

   Planning early for the person with dementia is important in order to ensure they can fully participate before decision-making and planning capabilities and communication are seriously impacted.

3. **Planning should cover an extended period of time and include a wide range of issues**

   Planning for the person with dementia needs to be about planning for the rest of their life, not only the end of life, and it should cover a wide range of issues including lifestyle and financial issues, as well as health. This will ensure that all aspects of their life are covered and will make decision making easier as decisions need to be made into the future.

4. **Nominating a substitute decision maker**

   If not already undertaken the person with dementia should appoint a SDM and that person and any other carers/family and care providers should involve that person with decision making as much as possible.

5. **Having multiple conversations over time with a focus on what is valued and important to the person**

   The person and their SDMs should have staged planning discussions to ensure the SDM understands what is important for the person to guide health, financial and lifestyle decisions and then progressing to conversations with their GP or ACP trained care manager on goals of care and, if appropriate, about specific treatment preferences.

6. **Involving the person with dementia in decision making as much as possible**

   As decision making is an important part of a person's identity, it is important that the person with dementia participate in discussions and decisions that affect them as far as they are able to. Strategies to maximise the person's ability for meaningful participation should be adopted.

7. **Sharing and transferring ACP documentation between care settings.**

   Sharing copies of ACP documentation with the person's SDM, GP, local hospital or other health facilities attended by the person is important for continuity of care. As people with dementia do very poorly with changes in care settings, care is needed at this time, including ensuring ACP documents are transferred with the person.

Terminology

Advance care planning terminology varies across the states and territories and there is currently no consistent terminology. Sometimes even experienced health and other professionals will use the terms 'advance care plans' interchangeably with 'advance care directives' or 'health directions'. This causes confusion as some documents are statutory (legal) documents and some are 'prescribed' or 'recommended' only. Inconsistencies in terminology pose challenges in the development of national resources. For the purposes of this document and the resources developed we have used the terminology set out in *A national framework for advance care directives* endorsed by the Australian Health Ministers' Advisory Council in 2010.[8]

Advance care planning (ACP) is used as a generic term for the 'process' of planning for health care in the future. This process includes values based conversations and may also include a record of these conversations.

Substitute decision maker (SDM) is the generic term for the person or persons that are legally appointed or determined by law to be able to make decisions in the event a person loses capacity.

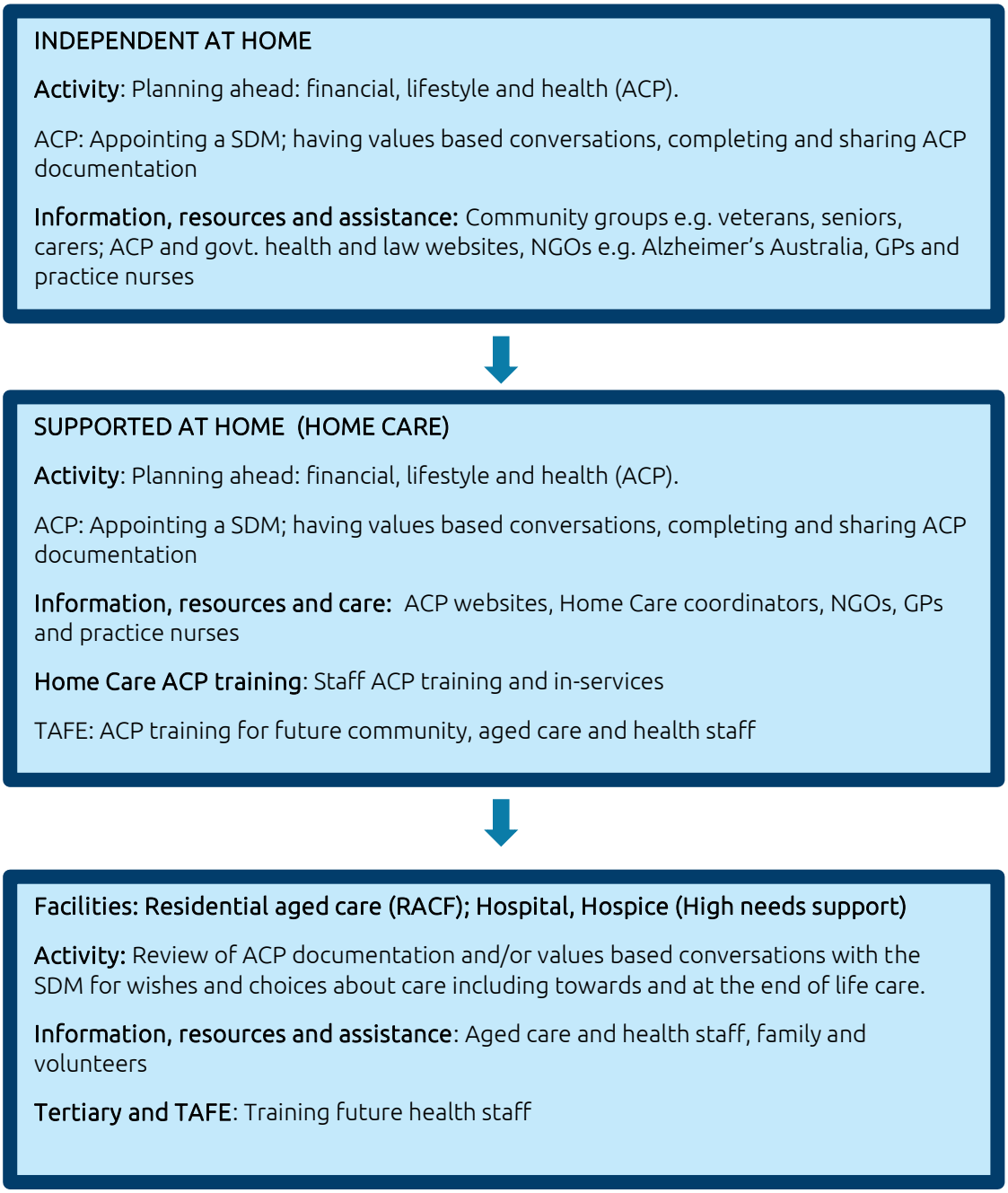
It is important that the terminology and the prescribed documents are used for the state or territory where the delivery of ACP services are being undertaken. The national http://advancecareplanning.org.au and www.start2talk.org.au websites include links to the relevant state and territory government websites that contain the necessary information, documents and resources to help complete ACP and legal appointment of SDM(s).

Setting the scene

Early planning, including ACP, for people with dementia should be undertaken in the community. It is within the community that people with dementia have the opportunity and time to plan ahead including nominating a SDM, having values based conversations and completing and sharing ACP documentation. Undertaking these activities in a hospital emergency ward or in a crisis situation can be distressing and result in an individual receiving care they may not have wanted.

There is an important role to play for community groups including seniors and veterans groups to raise awareness and educate the public about the benefits of early planning. Home care providers also have a vital role to play in their ability to engage people early in the disease trajectory to engage in future planning. The TAFE sector and equivalent education services have a valuable role to play in educating future staff for community, home care and health services. GPs and practice nurses also have a role to play in supporting early ACP in the community. Other Commonwealth initiatives are developing training and resources for the primary health sector.

Figure 1. Planning ahead, including ACP, for people with dementia in the community



ACP in home care provision

Why is planning ahead so important: Who benefits?

Person with dementia

It is important that people with dementia are enabled to make decisions for themselves for as long as possible and should be involved as much as possible in any advance care planning discussions. With appropriate support, people with dementia can be involved in communicating their wishes and making decisions about current care and future care through ACP. If they are unable to contribute, the care planning should be focused on what the person with dementia would have wanted based on previous conversations, including values that the person with dementia may have expressed.

"I have appointed my wife to speak on my behalf, legally. We've talked about things, she knows what I want…. I want to live at home for as long as possible. When the time comes when I need extra care I have asked her to put me a residential aged care home. I don't want her to have to worry or struggle. We have done the advance care plan together so everyone will know what I want…the doctors and home care people." (Consumer, ACT)

Care partners

Family and friends of a person with dementia or cognitive decline face a journey with significant challenges. Knowing a loved one's wishes and what gives life meaning to them can make decision making less difficult on a whole range of financial, personal and health care issues and result in less guilt and distress when making decisions on behalf of someone else

"It's not just about medical treatment. It might be around when 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, SA)

Home care providers and their staff

Planning in advance can ensure that the care provided by a home care service meets the client's expectations and choices. This will help reduce possible conflict in decision making and improve the quality of the service. Subsequently staff feel supported when caring for individuals with dementia which can improve staff satisfaction and retention.

For care staff in home care there are distinct benefits in engaging their clients in early planning, including advance care planning. ACP is comforting to staff, knowing that the care they are providing in the short, medium and long term reflects the wishes of the person even when they are unable to express these preferences themselves. It assists in maintaining dignity of the individual throughout the course of their dementia journey.

"The biggest difference is having a more limited window for catching people. So making sure that people are introduced (to ACP) and having the opportunity to have those discussions very early on in their illness when they can still participate." (Primary Health Network, Victoria).

Getting started

The implementation of sustainable ACP requires the unequivocal endorsement and support of senior management. To get started a team involving representatives from management should be developed. This leadership team can empower their staff to undertake ACP by providing leadership, developing ACP systems in the organisation, and providing systematic training and resources to staff. Ultimately, for ACP to be sustainable in the organisation, the leadership team needs to ensure that ACP is firmly embedded into standard organisational practices and its culture.[9]

To develop sustainable approaches to ACP a change management methodology is recommended. An important component of change management, and of particular importance to ACP, is the behaviour changes that are needed at all levels of the organisation's staff from the top down. Staff

need to fully embrace the benefit of ACP and to actively promote and assist clients in the ACP process. For staff to make this change their management will need to convey to staff the benefits of the change, why it is important, how the change is going to be implemented and who will be responsible. See Kotter's Eight Step model summary (Appendix D).

First steps

The ACP leadership team should consider:

- Creating an ACP Implementation Team
- Conduct an audit of current ACP systems (refer to the *Planning ahead community and home care toolkit*)
- Communicate the need and benefits for the organisation, staff and clients
- Consider any barriers to ACP and ways to overcome those barriers (Appendix B and C)
- Develop an implementation plan that considers:
    - how ACP discussions can be incorporated into current care planning meetings;
    - state or territory specific requirements for appointing substitute decision makers (SDM) and documenting ACP conversations
    - where ACP documents and records of conversations will be stored in client files and/or electronic patient records;
    - what ACP resources are needed e.g. information brochures/flyers
    - how to systematically train staff, including who will train and when.

Incorporating ACP into regular quality audits can ensure change is sustainable. Data could include what percentage of clients have SDM and/or ACP documents or information in the client's file. Quality audits might also measure the extent to which the actual care provided to the client matches the wishes in their ACP, over a specific period (e.g. in end of life care). In home care these audits may be conducted to review care over the previous calendar year or at a trigger point e.g. higher care needs assessment and whether it matched the wishes and preferences recorded in the client's ACP.

Resources to support planning ahead

The following resources have been developed to support the implementation and quality improvement of ACP in the organisation:

Planning ahead community and home care toolkit

- Guide to implementing sustainable systems for advance care planning
- Advance care planning continuum of practice model
- The advance care planning continuous quality improvement audit tool
- The advance care planning continuous quality improvement guide

Planning ahead community education resources kit

- Planning Ahead including advance care planning: A facilitator's guide
- Case studies: Planning Ahead including advance care planning and substitute decision making
- Scenarios: Planning Ahead including advance care planning and substitute decision making
- Planning ahead including advance care planning video
- Planning ahead including advance care planning podcasts
- Planning ahead including advance care planning presentation template

Planning ahead workbooks

- Start2Talk information and worksheet booklet
- Start2Talk quick guide to planning ahead

Brochures: Substitute decision making

- Supporting a person to make their own decisions
- Can they decide for themselves?
- When you need to make a decision for someone
- Who will speak for you if you can't?

Videos: Planning Ahead including Advance Care Planning

- Planning ahead including advance care planning and why it is important
- Knowing the persons wishes and choices as a substitute decision maker
- Decision making capacity and people with dementia
- How planning ahead including advance care planning can help carers of loved ones with dementia
- Knowing the person's wishes and choices as a substitute decision maker
- Who can assist a person with advance care planning?
- How to ensure advance care planning documents are available when needed
- Advance care plans can assist health professionals in their patient care

Podcasts: Planning Ahead including Advance Care Planning

- Staying in control
- Standing in a person's shoes as a substitute decisions maker

ACP in service provision

"Be the change that you wish to see in the world", Mahatma Gandhi.

Embedding ACP into service provision requires staff to not only have a working knowledge of ACP but also to have an 'insider' understanding of ACP. This requires that staff can 'walk the talk' so to speak. Staff are encouraged to complete to undertake the ACP process. Including to have a conversation with their own families and loved ones about their values, wishes and choices. This isn't just a 'nice' thing to do, it actually enables staff to better understand the challenges, barriers and benefits that may come with the ACP process. Insights gained from this process will develop empathy for their clients and build confidence in their ACP work because there is understanding and conviction behind their work. It also assists in 'normalising' the process as staff can indicate in raising or discussing the issue with clients that they have done it themselves.

Home Care Common Standards. 1.5 Effective management – Continuous quality improvement

Resources to support

- ***Planning ahead community education resource kit: Advance care planning: A facilitator's guide.***

Case study: Home care manager and area team leader: Change management and resistance to ACP for clients with dementia

Home care manager Alisa has commissioned the ACP implementation team to give a series of presentations on ACP to all area team leaders as part of the ACP implementation strategic plan.

Kaleb, one of the area team leaders, has subsequently approached her separately to voice his concerns over the difficulties of implementing ACP for clients with dementia. Kaleb feels that ACP for this group of clients is problematic given that he feels it is too late for these clients to meaningfully participate in ACP. Alisa is sensitive to the fact that Kaleb may be resistant to any change that may place a perceived extra workload on his staff.

Alisa discusses the benefits of undertaking ACP with this client group as early as possible and that ACP is a part of an open conversation about the person's values and preferences which is a part of current care planning practices. These values and preferences would help guide care and would ensure that the client and their family's expectations can be met. This in turn helps improve staff morale and lessen their stress levels. Home care services are ideally placed in the community to target people who are receiving low level packages 1 and 2. ACP at this stage includes broader planning around financial, personal and health care. Ongoing conversations build on previous conversations and make these later conversations far less 'difficult'. Staff training would be systematically given on ACP, ACP mentors identified across the organisation and client resources made available to staff.

Case study: Client services area team leader and client care coordinator: staff resistance in having an ACP conversation

Chandra is a client care coordinator in a home care service that implemented ACP into service delivery earlier in the year. She has found that staff, who have been trained in ACP, are still resistant to having conversations with their clients about ACP as they feel they are 'difficult conversations'. Chandra has gone to her area team leader, Max to discuss the issue.

Max asks Chandra if she has completed an ACP for herself, including appointing a substitute decision maker. Chandra has not done this as she has regarded ACP as something for the clients only. Max discusses the benefits that undertaking ACP for yourself and loved ones as a way of providing first hand insights into the process as well as an opportunity to reflect on the advantages and benefits of ACP. Both the process and insights gained will help her to discuss with staff their own concerns about having these conversations with their clients.

Max also suggests that a case study can be discussed at the regular staff meetings. This will enable staff to discuss any issues and ways to overcome any challenges or barriers to ACP. As a mutual learning exercise this will also improve staff confidence in having conversations about ACP, improve the quality of ACP in service delivery and help embed ACP into regular service delivery.

ACP is recognised as a person centred care intervention, where open ended conversation around values and preferences are promoted. These conversations guide the care that is delivered and assists in ensuring that the client and their carer's needs are being met.[13] Brooker in her 2007 book [12] describes person centred dementia care as: valuing the person, and those who care for them by promoting their rights and entitlements; treating people as individuals with a unique history; understanding the world from the perspective of the person with dementia and lastly, that a person with dementia requires an enriched social environment which compensates for their impairment and fosters opportunities for personal growth and a better life.

ACP is very much aligned with home care packages and consumer directed care. As such consumers are able to have more say in the services and care that they are accessing now and into the future and the development of their individual care plans which reflect their values and preferences.

Planning ahead

Future planning covering lifestyle, financial and health aspects, is particularly important for people who have been diagnosed with dementia or other forms of cognitive decline as it is more certain that they will lose capacity to make decisions for themselves. Planning ahead allows their voice to be heard and can ensure their wishes and choices are adhered to even when they lose capacity. As we do not know who will go on to develop dementia or who will lose decision making ability due to accident or injury, encouraging early planning is important for everyone.

Home Care Common Standards. 2.3 Appropriate access and service delivery - Care plan development and delivery

Service provider:

- Encourage the individual and their carer to plan ahead by highlighting the benefits
- Provide information and resources to help in this process

Home Care Common Standards. 3.1 Service user rights and responsibilities - Information provision

Resources to support

- ***Planning ahead workbooks: Start2Talk information and work sheet booklet***
- ***Planning ahead workbooks: Start2Talk quick guide to planning ahead***

Nominating a SDM

Nominating and appointing a SDM is important for all adults 18 years and over as it means that if the person loses capacity then the nominated person will be able to act and to make decisions on that person's behalf. Under law an individual is **assumed to have legal capacity** unless there is clear evidence that this is not the case. For the person who has dementia it is particularly important that, if they have not already nominated a SDM, that this is done as soon as possible after diagnosis whilst they still have legal capacity to complete a legal document e.g. appointing a substitute decision maker.

Service provider:

- Encourage the person with dementia to choose and appoint a SDM(s) by highlighting the benefits as well as the challenges that can arise if this is not done e.g. family conflict.

Resources to support

- ***Brochure: Substitute decision making: Who will speak for you if you can't?***

Case study: Conversation commenced

Bob and I accessed a low level aged care package with a home and community care provider earlier this year. Our case manager Judith had asked us if we had appointed a substitute maker (SDM). This was timely as we had long thought about it but had never done anything about it. She also talked briefly about the advantages of advance care planning (ACP).

Judith left me and Bob some pamphlets on SDM as well as ACP and set up the 6 week review meeting.

When we met with Judith again we had appointed each other, as well as our son Jake, for financial matters, and my younger sister Meredith as our SDM for health and personal care. This was such a relief that we had finally done what had been sitting on the back burner for so long.

Judith took a copy our SDM document to put on our care file. We discussed the ACP and decided that we didn't want to formally do an advance care plan at this time, but appreciated the information as something to think about.

Decision making capacity

Making decisions for oneself is a basic human right. If there is disability around decision-making then professionals have a responsibility to provide assistance and maximise capacity as far as possible.

What is capacity?

In general a person has decision making capacity if they can:

- Understand information that may be relevant to the decision, including the consequences;
- Use the information to make a decision
- Retain such information even for a short time; and
- Communicate the decision (in some way).

Capacity is time and decision specific – it depends on the particular decision being made. A person may have decision-making capacity for some decisions but possibly not others.

Legally, a person's capacity to make decisions is assumed unless there is evidence to the contrary. If in doubt a medical practitioner may undertake an 'assessment of impaired decision making capacity'.

A person's decision making ability can vary at different times of the day and be affected by infection, medication, anxiety and the environment. Environmental factors may include:

- time of the day i.e. is the person better at making decisions in the morning?
- location e.g. is the person at home and feeling secure?
- noise and disruptions e.g. low level background noise and disruptions may stop the person from dementia being able to concentrate
- who is present at the meeting – too many people, especially people not known to the person with dementia, can be a distraction
- a sense of being rushed, or overwhelmed, with too much information at one time.

Service provider:

- Support the person with dementia in making decisions
- Support the SDM when they need to make decisions for someone who has lost legal capacity
- If legal capacity is in doubt and decisions need to be made that require it then refer the client to their GP for an assessment of capacity.

Resources to support

- ***Brochure: Substitute decision making: Supporting a person to make their own decisions;***
- ***Brochure: Substitute decision making: Can they decide for themselves?***
- ***Brochure: Substitute decision making: When you need to make decisions for someone***

ACP and having the conversation

ACP can be described as a continuum that starts early with one or more values based conversation that is less threatening to the individual and their family. The initial values based conversation starts with the person thinking about, discussing with their SDM, family and friends their wishes and choices and what is important to them in life. The essence of these values based reflections and discussions can be recorded and shared with the people who provide care including the person's SDM, family, GP, care provider and local hospital. Decisions that need to be made currently and into the future will be based on and reflect these values. It is important that a person with dementia actively participates in thinking about, talking and sharing their thoughts, values, wishes and choices with their carers, SDMs and care providers as soon after diagnosis as possible.

This initial conversation is followed by other conversations when triggered by a change in life circumstance or health and/ or when there is an escalation of care needs. The conversation may then progress to general goals of care and then wishes and choices around specific treatments.

Discussing details about what specific treatments that are not wanted towards the end of life may also be valuable. If the individual is interested and able to discuss end of life preferences, while they still have capacity to do so this should be encouraged. Sometimes, if a person lacks capacity, these conversations will need to be had with substitute decision makers. It is important to ensure that the substitute decision makers is asked, if the person with dementia expressed any wishes before they lost capacity and if these have been recorded in an ACP. [13] (See Appendix E Advance care planning in community and home care services continuum.)

Home Care Common Standards. 1.5 Effective management – Continuous quality improvement

Case study: Conversation continues

Bob had just been diagnosed with dementia. At our next review meeting, Judith, our care manager talked to us about ACP. Judith encouraged us to think about and talk to each other and Meredith, our SDM for health and personal care, about what was important to us in our life, what we most enjoyed at present and our goals for the future. Judith said that knowing this would enable them to tailor the services provided to us to reflect these values, wishes and choices. Judith also asked us if there was anything that we feared in the future and what we may want to happen if Bob's care needs increased so that it would no longer be possible to stay at home.

Bob and I talked with Meredith over a cuppa. Bob said he wanted to stay at home for as long as possible, but that he didn't want to become a burden to me. He asked Meredith to make sure that when he became incapacitated and required high care that he wanted to go into a facility. He wanted to continue to see his grandchildren as much as possible and to continue to work in the garden and go for walks as long as possible.

At our next meeting with Judith she said that these conversations were a good start to ACP because knowing what Bob's wishes were and how he liked to live made decision making a lot easier.

Judith recorded the conversation in an ACP discussion record and encouraged us to complete the ACP documents at the next care plan review session.

Case study: Conversation continues

Bob had a fall the other day and had to be admitted to hospital for a short while. He is back home now but seems more housebound. He likes to potter about in the garden, but no longer wants to go out and see people or go for walks. This is quite a change from what he used to like.

At a care review meeting Judith suggested that we see Bob's GP to talk about advance care planning. Judith suggested that we ask the doctor about what Bob's goals of care were and treatment that he might want or not want. Judith said that this could then be recorded on the advance care plan. Judith said that she would then put a copy of the plan on Bob's care plan file.

Service provider:

- Discuss the benefits of ACP and having a conversation about values. Explain how this forms the basis for decision making now and into the future when the person can no longer express these things for themselves.
- Provide state and territory specific information and resources on ACP.
- Refer the client to their GP for advice and assistance, especially if it relates to their illness, goals of care and treatment preferences.

Home Care Common Standards. 3.1 Service user rights and responsibilities – Information provision

 See: http://www.advancecareplanning.org.au or www.start2talk.org.au for links to state or territory information and resources

 See: MyWishes - Guidelines for staff in initiation and conduct of ACP discussions

Record

While the ACP conversation is important, a written record of the essence of the conversations including values, preferences, wishes and choices can help to ensure that any decisions about care reflects these preferences. A written record is provides evidence of the person's voice and is a quality assured record that can be easily transferred between care settings e.g. home, home care, primary and tertiary health settings.

Service provider:

- Capture the essence of any relevant conversations in an ACP discussion record document if the person is not ready to formalise the conversation
- Provide the client and their carer or SDM the relevant state or territory specific ACP documents if the person wants to formally record their wishes in an advance care plan or similar
- Trained ACP facilitator on staff may assist the client to complete the documents.

Home Care Common Standards. 3.1. Service user rights and responsibilities – Information provision

 See: The advance care planning national website http://advancecareplanning.org.au/ or http://start2talk.org.au/ for links to state or territory specific documents

Storage and retrieval

All original ACP documents should be kept in a safe and easily accessible place by the client and their carers and/or SDM.

Service provider:

- Ensure a **copy** of any documents is placed on the client's record or uploaded to the electronic patient records in an easily accessible area
- Ensure staff are trained to review the ACP documents when planning or reviewing care
- With client consent, send a copy to the person's GP and local hospital or other health facility attended by the person
- Encourage the person to create a record on MyHealth at https://MyHealth.gov.au and upload their ACP documentation onto their health record.

Home Care Common Standards. 2.3 Appropriate access and service delivery – Care plan development and delivery

Review and transfer of ACP documents

Discussion records and relevant ACP documents should be reviewed regularly, especially after significant health incidents or deterioration or other life or lifestyle change e.g. change of residence, change in care needs. This is particularly important for the person with dementia who will experience cognitive impairment over time and decreasing functioning.

Service provider:

- Review any ACP documents with the client at regular care review sessions especially on deterioration of health or escalation of care needs and redo as necessary according to current health status
- Provide a standardised process, e.g. colour coded folder, for all relevant documents, including ACP documentation, to be transferred with the person to any new care facility or between care settings.

Conclusion

Planning ahead, including ACP, is a reliable means to ensure that people with dementia and their carers and family are able to live their lives fully and as independently as possible for as long as possible. Early planning happens in the community and not in hospital in a crisis or at the end of life. Community sector agencies and the community and home care sector are instrumental to raise awareness about the benefits of planning ahead. This can be achieved by providing information, resources and assistance in planning ahead including nominating SDMs and having values based conversations. The *Planning ahead community education resources kit* and *Planning ahead community and home care toolkit* have been developed to support these sectors in this important work. These resources are available on the Alzheimer's Australia Start2Talk website.

Appendix A: Useful information

Change management in health care

- Haines' *Roller coaster of change* and the *Blueprint for improvement* at

  https://www.aci.health.nsw.gov.au

- Change management theories including Kotter, under Palliative Care at

  https://www.aci.health.nsw.gov.au

- The Institute of Healthcare Improvement (USA) web site
  http://www.ihi.org/resources/Pages/HowtoImprove/default.aspx

Advance care directives framework

- *A national framework for advance care directives*

  This framework was developed for and endorsed by the Australian Health Minister' Advisory Council in 2011.This document is aspirational and provides a framework for advance care planning nationally. It describes policy and practice objectives as well as best practice standards and a code of ethical practice. (8) Available at:

  http://www.coaghealthcouncil.gov.au/Publications/Reports/ArtMID/514/ArticleID/63/National-Framework-for-Advance-Care-Directives

Standards

- *Home And Community Care Standards*

  The Australian Government Australian Aged Care Quality Agency have developed the Home Care Common Standards. Whilst there is not specific reference to the provision of ACP the standards most pertinent to advance care planning include: 1.5 Effective management: Continuous quality improvement; 2.3 Appropriate access and service delivery: Care plan development and delivery and 3.1 Service user rights and responsibilities: Information provision. (10) These Standards are available at:

  http://www.aacqa.gov.au/for-providers/home-care/processes-and-resources/resources-specifically-for-home-care/fact-sheets/homecarecommonstandardsv14_0.pdf

Guidelines

- *The clinical practice guidelines and principles of care for people with dementia in Australia*

  The guidelines has been developed to provide health professionals and carers in the primary, aged care and tertiary sectors with a number of recommendations to apply to both their workplace and to better respond to the needs and choices of the person living with dementia and their carers and family. (11) The guidelines are available at

  http://sydney.edu.au/medicine/cdpc/resources/dementia-guidelines.php

Appendix B: Advance care planning barriers and enablers

BARRIERS	ENABLERS
Sharing advance care planning (ACP) documentation across sectors	Use a coloured coded folder that contains relevant client information including advance care planning documentation Encourage client to create a 'My Health Record' on the https://myhealthrecrod.gov.au website. ACP documents can be uploaded to the person's health record by the individual. The individual can then give consent for health care professionals to access these documents as and when necessary.
Staff time	ACP implementation team to be clear on staff role and responsibilities. Advocate that ACP is a shared role across the organisation. E.g. administrative staff may ensure that planning ahead, including ACP information and resources are available to staff, clients and their families; care coordinators to include planning ahead, including ACP, conversations and information as part of routine care discussions at the initial care planning meetings and any subsequent care review meetings; Care coordinator and training managers to ensure that staff training in ACP and mentorship is readily available to all new staff and refresher training is scheduled in the annual training calendar.
Staff lack of awareness and education about planning ahead including ACP	ACP champions have been identified by the ACP implementation team and promoted as the 'go to people' for questions or challenges associated with ACP. The ACP champions themselves can be supported by the implementation team especially when issues need to be escalated to management to discuss system issues solutions or QI activities. Successes stories and case studies can be broadcast via the organisation's print and electronic promotion outlets.
The perception amongst staff that ACP is a 'difficult conversation'	Reframing ACP that it is a part of planning ahead more broadly. Here the emphasis is not on end of life but a focus on ACP in its broadest sense i.e. about a person 'living their life', identifying what is important to them, maintaining and extending a person's independence and maintaining their control and not giving up their control. Issues or decisions discussed may include driving, use of aids and assistance, activities – including those that carry risks (e.g. climbing ladders) pets, accommodation, personal grooming e.g. preferences for clothes and hair.
Staff experiencing that clients don't want to commit to completing ACP documentation because they feel it is too early and will 'lock them into choices' and they may change their mind.	Ensure that an 'ACP Discussion Record' is available to staff to use to capture pertinent choices and wishes expressed by clients. This Discussion Record can be referred to and used as a basis by staff and the client to complete ACP documentation when the client is ready to complete an ACP. Sometimes if this is never done the

	Discussion Record can still be a useful document and can be used by care staff to discuss care preferences with the client.
Staff perception that planning ahead and ACP is best completed by health or medical staff	Community and home care is undertaken in the community and a person's home. This is a familiar, safe and non-threatening environment. Community and home care staff see the person regularly, they have the opportunity and time to build rapport over an extended period of time. Sometimes the communication between the care coordinator and the client may be perceived by the client as just 'chatting' about life matters. This 'chat' is non-threatening. However the care coordinator is aware that pertinent and valuable information about the client's wishes and preferences about care can be gleaned from the 'chat'. The chat may cover a range of planning ahead issues across financial, lifestyle and health issues.

Appendix C: Trouble shooting: Frequently asked questions

Q. *We are implementing ACP but there is not much activity as the group who are implementing seem to be very quiet about any activity. We simply don't know what is happening and when?*

A. The implementation group needs to ensure its team and the team leaders and champions in the organisation run orientation and awareness raising sessions amongst its staff. It needs to broadcast its activities via news bulletins about what they are doing and when so staff are aware of this and are included. This will ensure that there is greater buy in from all staff so that staff can own the change that is happening in the agency. Ultimately this will ensure greater success for a sustainable change.

Q *We seem to have so many demands and competing priorities that ACP just seems to drop off as a priority so not sure how we can give it attention it deserves*?

A. ACP needs to be integral part of the care planning process and 'best practice' care for your clientele so that it is not something separate or an add-on. Incorporating questions about SDM and ACP needs to be integral part of the initial care planning meeting agenda with the client as well as standard review care sessions.

Q. ACP seems so overwhelming that the implementation seems to have stalled what can we do about this?

A. Start with a pilot site to look at workflows and care planning processes and what consumer handouts and documents are needed. Once systems are put in place and tested and issues resolved then the pilot can be rolled out across the organisation. If resourcing is an issue then start with a specific population group e.g. people newly diagnosed with dementia or suspected of having dementia or other form of cognitive decline.

Q. *We have a policy on advance care planning that was distributed to us and sporadic training has happened but nothing seems to be organised.*

A. The agency needs to identify an ACP training provider, who is to be trained e.g. care managers and to develop a systematic schedule for their staff. Refresher training may also be provided on an annual or biannual basis for previously trained staff. Case studies and discussion can be incorporated into the case manager's regular meetings. This may assist in identifying and ironing out any system issues as well as improve quality of facilitated ACP conversations.

General information about what ACP, why it is important and ACP champions contact details can also be given at new staff orientation sessions.

The agency can also identify a person or persons who can be 'champions' for ACP. These are the 'go to person or people who other staff can go to for advice, assistance or to report issues or QI initiatives.

Success stories of clients who have an ACP and who report better care and support because of ACP can be celebrated, acknowledged and broadcast via the organisation's promotion outlets.

Q. *How will after hours staff be training?*

A. Communicate with the agency's training providers to ensure that training can be provided online and after hours staff can have opportunity for access to face to face training during the day.

Q. **Staff complain they don't have the time to do ACP - How can I respond?**

Starting ACP conversations early can be seen as planting seeds that can be developed over a period of time i.e. not in one sitting. An ACP conversation can be woven into the initial regular care planning meeting. At this stage just asking questions and providing information is really useful to start the ACP process and does not take 'extra time'. For instance 'Have you nominated a SDM?'

would you like information about SDM or ACP? How much do you know about dementia? Would you like some information on planning ahead and why it is important especially if you or a loved one has been diagnosed with dementia? Starting these conversations early will allow further conversations to build upon these earlier conversations and will mean less difficulty both for the client and their family and care staff further down the track. These conversations are an important part of regular care planning for people with dementia.

Q. The previous care coordinator has had an ACP conversation with a client but unfortunately I cannot find any paperwork. What can I do?

The service provider needs to ensure that there is an ACP 'discussion record' document available at all care planning meetings. This will ensure that any conversations about the client's values and/or preferences about care are recorded. Systems should be put in place to ensure that these documents as well as any ACP or SDM documentation are systematically and routinely placed on the client's hard copy and/or electronic file and are easily accessible 24/7. These documents are an important component of quality care and once on the file can be more easily retrieved, reviewed and transferred between care settings as needed.

Q. The care coordinator has discussed an ACP with her client but the carer, who is her SDM, says that he has never heard of the preferences expressed in this document. What can I do?

It is important when discussing ACP that this is done with the person's SDM(s) as it is they who will assist the person make decisions. Once the person loses decision making capacity and the ability to express these decisions and preferences for themselves it will be the SDM(s) who will be responsible for making decisions for that person. Always ensure that, the SDM, is available and participates in these conversations.

Q. I am a care manager and one of my care coordinators has told me she does not feel confident to have an ACP conversation with her clients even though she has recently done the training– what can I do?

ACP training is best seen as not a one off class room event but continued training on the job. We learn as we do, and then reflect on what we have done and how we can improve. Staff members may be offered mentorship by more experienced ACP facilitators in their initial client care planning sessions. Refresher training may also be provided for those who have already received training. Case studies may also be included for discussion during regular staff meetings to look at issues, barriers and solutions and to improve ACP facilitation.

Q. Staff interest in ACP has waned over time what can be done to improve it?

Like any new change in an organisation all successes should be celebrated. Staff who have successfully completed ACP for their clients can be celebrated with a certificate or other recognition for a job well done for improved care for their clients.

Client stories can also be shared with staff to remind staff of the importance of their work and how that service makes a real difference to their clients, the people they so expertly and compassionately serve.

Appendix D: Change management methodology

Implementing advance care planning (ACP) into a community aged care service using change management methodology will allow for greater success for long term sustainability.

The following are based on John Kotter's eight change management steps:

1. Create a sense of urgency i.e. the reason for the action
2. Create a group of people who are united in purpose and committed to action
3. Develop a vision of what the organisation wants to achieve and that staff can relate to
4. Communicating the vision in a variety of formats for example small group and larger group presentations; emails; advertising/marketing via organisation: electronic newsletters/DVDs
5. Empower staff who will take action by removing obstacles and providing them leadership and the required resources
6. Create opportunities for small gains and then celebrate them! This provides the incentive for more change and bigger gains in the long term
7. Build on each new gain so that the change process continues
8. Embed the new approaches in the organisation culture so that it becomes 'this is how we do things around here'. *

*Reference: Beth Israel Deaconess Medical Center (2014) *Conversation ready: Champion toolkit*. Boston, Mass.: The Medical Center in association with the Institute of Healthcare Improvement

Appendix E: Advance care planning in community and home care service continuum

	Healthy adult	After a diagnosis of dementia	Advanced disease
Appointment of a substitute decision maker (SDM)	Appointment of a SDM recommended.	Appointment of a SDM is strongly encouraged whilst the person still has legal capacity. If in doubt a referral to the GP may be necessary for medical assessment and certificate.	N/A due to incapacity of the person to make legal decisions.
Role of home care services	Discuss benefits of appointing a SDM to the person and their carer/family and provide information about websites and/or provide SDM brochure. If a SDM exists place document on the client's file.	Discuss benefits of a conversation with the SDM around their values, wishes and choices on lifestyle and health issues as an understanding of this will help with supporting a person making a decision as the disease progresses, as well as assisting their SDM when they need to makes decisions later when capacity is los.t	If the person has previously appointed a SDM discuss basing decisions on previous discussions of values, wishes and choices and any ACP if completed – what would the person have decided if they still could?
Advance care planning (ACP)	The person can access the national ACP websites for links to state or territory information and resources to complete their ACP independently.	A conversation should begin between the person, SDM and carer about values i.e. what is important to the person in life and what gives life meaning to them. What are their treatment preferences and preferred outcomes? Refer to GP if preferred for discussion and completion of ACP documents.	Identification of treatments and interventions that the person/SDM want or don't want.
Role of home care services	Discuss the benefits of early planning. Provide material on state/territory specific ACP pamphlets/flyers and recommended web sites.	Discuss the advantages of planning including ACP giving examples of how it can help. Encourage ongoing conversations (as above) and how this forms the basis for decision making. Provide state or territory specific information, documents. Assist the person and SDM complete ACP documents or refer to GP for same. Place documents on the client's care file. Encourage copies to be given to GP and local hospital medical records Ensure documents are transferred between care settings.	Ensure that all SDM and ACP documents have been transferred and are being reviewed for the provision of care in line with the person's values wishes and choices at the end of life.

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