



Start2Talk

PLANNING AHEAD: COMMUNITY EDUCATION RESOURCE KIT

Scenarios: Planning ahead including advance care planning (ACP) and substitute decision making (SDM)

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Scenario 1: Home care providers supporting a person with early dementia in advance care planning (ACP)

Learning outcome

1. Understand how to a support a person with early stage dementia and their carer in decision making and ACP

Peter has just become a recipient of a low level Home Care Package. At the initial interview Peter informed the home care coordinator Alice that he had recently been diagnosed with dementia. Peter's GP had suggested that Peter undertake ACP.

Alice confirmed with Peter and his wife Jane that they had already appointed a substitute decision maker (SDM) for health, personal care and financial matters. Alice discussed the ACP process and how important it was for Jane and Peter to discuss with their SDM what was important for them in their lives and what gave their life meaning. Once Peter reached the stage where he couldn't indicate what he wanted then decisions would be made by his SDM based on these conversations and any ACP documentation. Alice provided some brochures on ACP which would be discussed at their 6 week review appointment.

At the review meeting Alice sat next to Peter and gave him her full attention. The room was comfortable and well-lit and the atmosphere relaxed. Alice prompted Peter with gentle, unhurried open questioning about what they had discussed with their SDM. Peter expressed that he and Jane had a wonderful life together that he wished to remain at home as long as possible and to continue with his hobby of painting. He was satisfied with his health care at present but that quality of life was more important to him than quantity.

Alice recorded these points in the Advance Care Plan Discussion Record for Peter's file and gave Peter and Jane their state specific Advance care plan documents to complete. Peter and Jane decided they would make an appointment to complete the ACP documents with Peter's GP, as there were a number of questions to ask the doctor about Peter's dementia and its likely progression.

Alice advised that once the documents were completed she would take copies to place on Peter's file. Alice also suggested giving a copy to their GP and the local hospital.

Alice also advised that it was important to continue to have the ACP conversation especially if Peter's care needs increased or health or lifestyle changes occurred. The ACP documents should also be reviewed at this time and redone to reflect any changes made.

- 1. What does the scenario tell you about the ACP process including
 - Timino
 - Why the appointment of a SDM is so important
- 2. What does the scenario tell you about the role of the home care provider?
- 3. What does the scenario tell you about supported decision making

Scenario 2: Home care providers concerns about the appointment of a substitute decision makers (SDMs)

Learning outcome

1. Understand the importance of how to choose a SDM for health, personal care and financial matters

Mrs Jones is a new client with a low level Home Care Package. She lives on her own in a unit with some assistance from a nephew. Mrs Jones has been recently diagnosed with dementia

As a care coordinator you routinely provided Mrs Jones with information on advance care planning at her initial care planning meeting, including appointing a SDM for health, personal care and financial matters. A routine six week follow up appointment has been confirmed.

At the subsequent appointment Mrs Jones tells you that she is very happy she will be appointing her nephew Nick to be her SDM for health, personal care and financial matters. He's a 'good boy', she tells you, 'he picks up my dirty washing and returns it nicely washed and folded and helps pay my bills.'

As the case manager you are somewhat concerned as a support worker has previously told you, that Nick has often been in the unit drunk, does not communicate much and Mrs Jones has confided to her that sometimes money goes missing from her purse and she suspects that it is Nick. The care assessment report indicates that Mrs Jones attends her local church regularly, enjoys social interactions and is a non - drinker.

You ask Mrs Jones if she has read the information you left her on appointing a SDM. She tells you 'No, it's all too much, there's too much information and I don't understand it'.

- 1. How would you approach assisting Mrs Jones in appointing a suitable SDM?
- 2. If leaving written information with Mrs Jones proved unsatisfactory is there anyone else that may be able to assist in providing information and assisting in the process of appointing a SDM?

Scenario 3: Home Care providers supporting a person appointing a substitute decision maker (SDM)

Learning outcomes

- 1. Understand the importance of nominating and appointing a SDM when a person still has legal capacity to do so
- 2. Identify a process for assisting a client and their carer with assessment of legal capacity and options for further information and assistance

Rena has just taken up a level 3 Home Care package with your Home Care service. She has dementia and she and her husband Amal live at home.

During a care planning meeting Amal tell you, that neither Rena nor himself have appointed a SDM. Amal would very much like to put this in place for Rena as decisions have to be made and people are asking him if he is the legally appointed SDM for Rena. Amal asks if you can assist him to appoint himself as Rena's SDM.

As a care coordinator you have doubts as to Rena's legal decision making capacity and her ability to legally appoint and complete the legal documents.

You explain that under law capacity is assumed unless there are doubts. You advise, that given that Rena's dementia is now in a more advanced stage, that an assessment should be undertaken by Rena's GP to determine whether Rena has capacity to undertake the legal appointment of a SDM.

You reassure Amal that if an assessment indicates that Rena no longer has legal capacity to legally appoint a SDM that he may be able to apply for legal guardianship. You advice Amal that you can provide contact details and information for the government service (public advocate) that can assist him with this process.

- 1. Why is it important to nominate and appoint a SDM when a person still has legal decision making capacity?
- 2. How can the Home Care Coordinator assist in the process of nominating and appointing a SDM?

Scenario 4: The importance of ongoing advance care planning (ACP) conversations and reviewing ACP documents

Learning outcomes

- 1. Understand the importance of ongoing ACP conversations
- 2. Understand why ACP documents including substitute decision maker (SDM) forms need to be regularly reviewed and updated as health, including cognitive function change.

Jeremy was working in the communication industry, when at 58, he was diagnosed with early onset dementia. Jeremy and his partner Patricia had heard about ACP whilst listening to a program on a local radio station. They found information on the national ACP website and had a conversation about their values and preferences for future care. At this time Jeremy identified that being able to communicate with his family and friends and being able to undertake some enjoyable activities including dining out, walks, reading and writing was important for his quality of life. Jeremy indicated that he felt, that due to his illness, his life was "shrinking" compared to what he had enjoyed previously. Jeremy's documented his values in an advance care plan and included his desire for cardiopulmonary resuscitation (CPR) if his heart stopped and to receive life prolonging treatment if he would still be able to communicate and undertake the activities her enjoyed.

Six months later Jeremy's function had deteriorated, so Jeremy and his wife made an appointment with the local ACP program and to review Jeremy's advance care plan. In his new advance care plan Jeremy added statements about the importance of being able to live independently for as long as possible and to be able to attend to his own personal care including showering and toileting. He also identified the importance of being treated with human dignity, which were things that he had previously taken for granted. Jeremy had also now changed his mind on health treatments, he no longer wanted CPR if his heart stopped and he didn't want life prolonging treatments if his condition deteriorated. Jeremy and Patricia also decided to review their SDM form as circumstances had changed. They wanted to add an additional person as a SDM as they recognised they were both getting frailer.

Four months later Jeremy's condition had deteriorated further so they decided to return to Jeremy's GP to discuss his health and care in some detail. Jeremy was clear that he didn't want to experience prolonged suffering, and if his symptoms became distressing to him and his family, he didn't want aggressive treatments. He updated his ACP indicating he no longer wanted to receive active treatment and would prefer to be kept comfortable and to be allowed to die naturally with dignity.

- 1. What does the scenario tell you about the ACP process?
- 2. How useful is the advance care plan for Jeremy, his SDM and for health professionals?
- 3. What does the scenario illustrate about reviewing ACPs and having ongoing conversations with SDM and health professionals?
- 4. What does the scenario illustrate about the nature of a chronic condition like dementia and an advance care plan?

Scenario 5: The importance of early planning including appointment of a substitute decision maker (SDM)

Learning outcome

1. Understand the importance of choosing and appointing a SDM as part of early planning

Peter is a 59 year old single male who has just been diagnosed with early onset dementia. Unfortunately Peter had not previously appointed a SDM and has now been assessed by his GP that he no longer has capacity to legally appoint a SDM for financial or for health and personal care.

Peter has lead a secluded life and has few friends. He does however have three siblings, two brothers and one sister. Peter's brother Tom and his sister Marie feel that Peter should be placed in a care facility as soon as possible. They have busy lives with, work, and children and don't feel that they can look after him. Tom and Marie occasional visit Peter with their families. Peter's other brother Michael lives interstate. He phones Peter once a fortnight and knows that Peter wants to live at home for as long as possible and continue to be involved in the local men's shed.

The siblings are in conflict as Michael knows that both Tom and Marie would potentially be identified by health staff as Peter's SDM for health and personal care, as they live close by. Michael knows that he would be less likely to be identified as a decision maker because he lives interstate. He would therefore potentially have little say in the decision about where and how Peter lives. Based on the conversations he has had with Peter, Michael doesn't think Peter should be pressured into going into a facility. He knows that Peter would want to live at home and that this could happen with additional support services that could be funded from his savings if necessary.

- 1. What could Peter have done differently so that conflict between the siblings could have been avoided?
 - o SDM
 - o ACP conversations
- 2. What does this scenario tell you about 'identified' decision makers versus a person legally appointing a SDM for a person?
- 3. What are the possible short to medium consequences for Peter for not appointing a SDM?
- 4. How can Michael assist Peter now to make decisions about how and where he wants to live?

Scenario 6: Cultural considerations and decision making

Learning outcome

1. Understand how cultural considerations affect decision making and advance care planning.

Mavis is 75 years old and identifies as an Aboriginal. Mavis moved away from the land of her birth and where she grew up and has spent her married life in the city raising her family.

Mavis has a number of chronic conditions including early dementia. Her extended family are concerned and have gathered together to be with her to make decisions about where she will live and what her wishes are regarding her health and care needs.

Mavis says that what matters most to her now is returning to country. Mavis is aware that she is approaching the 'dying time'. Talking with her family a family decision is made for Mavis to return to country. A plan is developed with an aboriginal health worker on how this plan can be managed with family support and care from the local health facility.

- 1. What does this scenario tell you about cultural differences in values and decision making?
- 2. Does this differ from your own values and approach to decision making?
 - o In what way?
 - How would you incorporate an understanding of cultural differences into your practice with clients?
- 3. How important is early planning and decision making for a person with a chronic condition like dementia?
 - o How does the person with the condition benefit?
 - o What are the potential benefits for the family?

Scenario 7: The importance of planning ahead for a person newly diagnosed with dementia

Learning outcome:

1. Understand the importance of planning ahead for a person with dementia

Doug has made an appointment with the community social worker Megan as he has been diagnosed with dementia and fears losing control of his life.

Doug expresses to Megan that what he fears most is that now that he has been diagnosed with dementia that he will not be able to make decisions for himself and will lose control of his life.

Megan discusses with Doug that planning ahead now will help him to have some control over future decisions and to maintain and extend his independence for as long as possible.

Megan discusses that planning ahead includes financial matters, personal and health care and that the important first step is to appoint a substitute decision maker (SDM) to cover all three of these matters. Once Doug has nominated and legally appointed a SDM then it is important for Doug to discus with his SDM his wishes and choices about his assets and finances, where he wishes to live and be cared for and as well as his health care.

Megan explains that Doug can still make all his own decisions but as the illness progresses he will need support from his SDM to help him make decisions and eventually his SDM may need to make decisions for him.

Megan asks if Doug has any other immediate concerns. Doug expresses that he still feels he is able to drive and is loath to give up his driver's license at this stage. Megan advises Doug that he may still be able to drive at this early stage of his dementia, however he needs to seek advice from the state driving license authority.

Megan provides Doug with contact information for Alzheimer's Australia for further information and resources, the www.start2alk.org.au planning ahead website for planning resources and links to state government information on appointing a SDM.

Doug is satisfied with the discussion and information provided and makes a subsequent appointment with Megan to discuss his health planning.

- 1. What does this scenario tell you about what planning ahead entails
- 2. What does this scenario tell you about how planning ahead is prioritised by a person with dementia

Scenario Response sheets

Scenario 1: Home care providers supporting a person with early dementia in advance care planning (ACP)

- 1. What does the scenario tell you about the advance care planning process including
 - o Timing and review of advance care plans?
 - Why the appointment of a substitute decision maker (SDM) is so important?
- Dementia poses unique challenges for planning ahead, as it is more certain that
 incapacity to make decisions will occur. The types of decision that will need to be
 made mean that planning needs to cover a range of lifestyle decision including
 decisions about accommodation and driving as well as financial and health care
 decisions. The period of incapacity is also often longer with a gradual change from
 supported decision making to substitute decision making.
- Ideally ACP should be done before diagnosis of a chronic and life limiting illness like
 dementia whilst a person is in good health. However when this does not happen then
 ACP should commence as soon as possible after the diagnosis. This will help the
 person and the family plan for the future while the person still has the capacity to
 participate fully in the process before any significant decline in their decision making
 capacity and ability to communicate.
- If ACP has been undertaken early then it is a good idea to review it when a new health condition emerges, a change in health condition occurs or in the event of other significant changes e.g. accommodation, care supports etc.
- It is vital for a person, with dementia, to nominate and appoint a substitute decision maker (SDM) before they lose legal decision making capacity.
- The SDM can support a person with dementia in making decisions.
- Conversations between the person with dementia and their SDM(s) needs to happen whilst the person with dementia still has the ability to engage and participate in discussions about their wishes and choices. This will allow the SDM to be able to advocate and to make decisions later that reflect the person with dementia's wishes and choices. These conversations may also be translated into a community and home care ACP Conversation Record and/or the relevant state or territory specific ACP documentation.
- 2. What does the scenario tell you about the role of the home care coordinator?
- The Home Care coordinator can discuss ACP, including appointing a SDM, with their clients at the initial care planning meeting. Relevant printed information can also be provided at this time.

- Review of ACP discussion records and any ACP documentation can also be made at subsequent regular care planning review meetings or after a change in health condition or when there is need for an escalation of care needs.
- The care coordinator can also ensure that any ACP discussion records and/or ACP documentation is placed on the client's care file. Prompting the client to provide a copy of the documents to their GP and local hospital should also be made. Where the client is unable to do this the care coordinator may assist the client by sending these documents to these health services with the client's consent.
- Particular care needs to be made when the person with dementia moves between care settings e.g. home to hospital or to a respite or other care facility. It is important that care coordinators or other staff with this responsibility to be sure to make available and to transfer any relevant ACP documentation between care settings.

3. What does the scenario tell you about supported decision making?

- Decision making is an important part of a person's identity and 'decision making capacity' is assumed under law unless there is clear evidence that this is not the case or compelling reasons for them not to be consulted.
- Supportive decision making will allow the person with dementia to continue to make
 decisions for themselves for as long as possible. Peisah et al (2013) ASK ME model
 of supported decision making¹ emphasizes collaboration and relationships as a way
 of maintaining a person's autonomy.
- The person with dementia can best be supported to have these conversations and make decisions when the person feels supported including: explanations are provided, simple language and one question at a time are used i.e. no double barrelled and complex questions. It is also important that there is minimal noise and distractions and a limited range of options are provided.

Scenario 2: Home care providers concerns about the appointment of a substitute decision maker

- 1. How would you approach assisting Mrs Jones in appointing a suitable SDM?
- Discuss the criteria or guidelines for choosing a SDM. Information can be found in the relevant state or territory government agency's website for SDM. Common criteria includes:

The SDM

- o Meets the legal criteria in the state or territory in which the person resides
- o Is willing to speak on the person's behalf
- Will act on the person's wishes and choices not their own
- o Is capable of being a strong advocate
- Knows the person well and what is important to them
- o Is someone the person trusts
- Is someone that can handle conflicting opinions between family members, friends and medical personnel
- Is someone in good health and can assume this responsibility well into the future
- Discuss the advantages of considering appointing more than one substitute decision maker as multiple SDMs can support each other in decision making. This is particularly important if the decisions that need to be made are difficult or challenging. However if multiple SDMs are appointed to act 'jointly' i.e. together then they each need to be able to successfully communicate with each other in order to make mutual decisions about the person.
- It is also important for the person appointing their SDMs to have discussion about beliefs and values as this will inform decision making later when the person loses the capacity to fully participate in decision making and express their wishes and choices.
- Legislation for SDM varies across Australia. It is therefore vital that care providers and staff check with the state and territory government website for information and legal documents for appointing a SDM.
- 2. If leaving written information with Mrs Jones proved unsatisfactory is there anyone else that may be able to assist in providing information and assisting in the process of appointing a SDM?
- Provide contact information including phone support or information line of the local government agency that can provide information and answer the client's questions verbally on SDM.

Scenario 3: Home Care providers supporting a person appointing a substitute decision maker (SDM)

- 1. Why is it important to nominate and appoint a SDM when a person still has legal capacity?
- It is important that a person nominate and legally appoint a SDM, whilst they still
 have decision making capacity. Once they lose this capacity it is not possible for
 them to complete the legal documents whereby they can appoint a SDM.
- If there is evidence that the person does not have the ability to make decisions themselves then referral to a medical practitioners for a capacity assessment may be needed. This is important when there are legal matters involved including legally appointing a SDM.
- 2. How can the Home Care Coordinator assist the client in the process of nominating and appointing a SDM?
- It is important that if you do not have the expertise or, knowledge to assist that you
 know where to send your clients for expert advice, information or assistance. The
 relevant state or territory government agency e.g. public advocate or equivalent can
 be found on the internet. Or check the state or territory links on the Start2Talk
 website at www.start2talk.org.au

Scenario 4: The important of reviewing advance care planning (ACP) conversation and documents

1. What does the scenario tell you about the ACP process?

- To provide better outcomes for people with dementia it is important that ACP begins as early as possible and cover a wider number of issues incorporating health, personal and financial matters. ACP can be described as a staged and iterative process. As a person's health or life circumstances change conversations and documents should be revisited to reflect changes in preferences that may occur.
- Value based conversations are important as they enable substitute decision makers (SDM) to make decisions based on an understanding of what is important in life for the person with dementia. Decision making can be based on these conversations.

2. How useful is the advance care plan for Jeremy, his SDM and for health professionals?

- The ACP documentation captures Jeremy's values, how he wants to live and his choices and wishes about health care. The ACP documentation is importantly developed with his SDM and his wife. As co-developers of the documentation they are fully aware of Jeremy's wishes and choices. When the time comes to activate the documents i.e. when Jeremy no longer has the capacity to express these wishes and make decision for himself then there will be no surprises for his SDM and wife.
- ACP documentation provides the foundation for decision making for Jeremy, his wife, SDM and home care and health professionals when Jeremy can no longer make decisions for himself.

3. What does the scenario illustrate about reviewing ACP documentation and having ongoing conversations with SDM and health professionals?

- ACP is a process not a one off event and ideally should commence early, before diagnosis of a chronic condition or soon after diagnosis.
- ACP conversations and documents should be reviewed as a person's life and health changes. As situations and circumstances change so may a person's wishes and choices and the decisions they make. The ACP documentation should be redone to reflect the changes in the person's health status and their changing choices and wishes. The document therefore keeps its relevance for the person, their SDM, family as well as the home care and health professionals that are providing care.

4. What does the scenario illustrate about the nature of a chronic condition like dementia and an advance care plan?

ACP documentation should be reviewed when health or life circumstances change.
As a person with dementia is likely to lose capacity to be involved in these
conversations and decision making, it is important to encourage discussions and to
plan as early as possible to include likely scenarios and any decisions that will need
to be made in the future.

Scenario 5: The importance of early planning including the appointment of a substitute decision maker (SDM)

- 1. What could Peter have done differently so that conflict between the siblings could have been avoided?
 - o SDM
 - o ACP conversations
- It is important to nominate and legally appoint a SDM for health and personal care and financial matters while the person had legal decision making capacity. This can prevent family conflict as there is a legal document that appoints the person(s) to take on the responsibilities of being a SDM.
- It is important that every person 18 years and over choose and appoint their own SDM(s).
- Family conflict can also be avoided or minimalised if the person has had
 conversations with the SDM about their values, wishes and choices prior to them
 becoming incapacitated. It is the responsibility of their SDM to advocate for them and
 to make decisions that they would have made, based on these conversations.
- 2. What does this scenario tell you about 'identified' decision makers versus a person who has been legally appointing as a SDM?
- If a person has not chosen and legally appointed a SDM for health and/or personal care for themselves and they lose legal capacity due to illness like dementia, or accident or injury then a decision maker may be identified by a medical practitioner. This person will be required to give consent for health treatments or other personal care decisions.
- Some states and territories in Australia have a hierarchy of people that may be
 identified as a 'substitute decision maker' if the person loses capacity. For example
 spouse, family member and close friend. It is important to check the appropriate
 government agency (e.g. public advocate) website in your state or territory for
 information about SDM.
- This person may not be the person that an individual would have chosen for themselves as their SDM.
- 3. What are the possible short and medium consequences for Peter in not appointing a SDM for himself?
- In Peter's case the identified person may well not be the person that Peter would have chosen for himself. This person may not make the decisions that the person themselves would have made but be making decisions based on their own needs and desires, as is the case with Peter's siblings Tom and Marie. This person may not be prepared for decision making responsibility. This identified person may not know what the decision the person would have wanted because there may not have been any conversations about their wishes and choices beforehand.

 Peter risks being placed in a facility long before he wants to move from his own home and losing his ability to stay connected to his community.

4. How can Michael assist Peter now to make decisions about how and where he wants to live

- Capacity is assumed under law unless there is evidence that the person has lost legal capacity.
- If there are doubts of legal capacity an assessment may be undertaken by a medical practitioner. This is important for the legal appointment of a SDM and completing or signing of legal documents.
- Other decisions regarding personal and health care can continue to me made by the
 person with dementia for as long as possible with appropriate support. See SDM
 brochure 'Can they decide for themselves? And 'Supporting a person to make their
 own decisions' on the www.start2talkorg.au website. The Capacity Australia website
 is also a useful resource.

Scenario 6: Cultural considerations and decision making

- 1. What does this scenario tell you about cultural differences in values and decision making?
- Decision making in some cultures e.g. In Aboriginal culture is less about an individual's autonomy and individual independent decision making and may involve extended family in collective decision making.
- Other variations in value systems that may be relevant to decision making include egalitarian versus hierarchical, competitive versus cooperation, self-reliance versus inter-connectedness.²
- 2. Does this differ from your own values and approach to decision making?
 - o In what way?
 - How would you incorporate an understanding of cultural differences into your practice with clients?
- CareSearch website at http://www.caresearch.com.au outlines 'culturally safe care' as:
 - Being aware of the influence of your own cultural beliefs on your care practices.
 - o Being sensitive to the cultural practices and beliefs of others
 - o Staff being trained and have skills in culturally safe practices
 - Using professional interpreting services especially in regard to significant information e.g. health and legal maters
- 3. How important is early planning and decision making for a person with a chronic condition like dementia?
 - o How does the person with the condition benefit?
 - o What are the potential benefits for the family?
- The person with dementia can fully participate in the conversations, make decisions for themselves and nominate and appoint a SDM if this is done while the person has legal decision making capacity.
- The person can have conversations with their appointed SDM about their values, wishes and choices
- These conversations and any planning documentation can reflect these conversations
- The family are clear who has been appointed as the substitute decision maker when the person has lost capacity.

Scenario 7: The importance of planning ahead for a person newly diagnosed with dementia

1. What does this scenario tell you about what planning ahead entails?

- Dementia poses unique challenges for people with dementia because their incapacity to make decisions is more certain than in other diseases and incapacity is progressive over a longer period of time.
- Planning ahead for financial, accommodation, personal and health care decisions will allow the person with dementia to have some control over decisions made in the future, including when they can no longer make decisions for themselves.
- Financial planning includes: mortgages, bank accounts, wills, insurances and assets.
 It may include specifying how you want your money spent on caring for yourself in
 older age. Assistance and information can be provided by accredited financial
 advisors, financial councillors in the community, bank managers, state or territory
 officers such as the Public Advocate, Public Trustee or Public Guardian.
- Personal care or lifestyle planning may include: accommodation/living arrangements, attendance at church or clubs, care of pets, work and driving licence requirements and travel when it is no longer safe to drive.
- Health care planning in advance (Advance Care Planning) includes thinking about, talking about and sharing wishes and choices about health care when a person can no longer express their own wishes and choices themselves.
- Further information, resources and state or territory specific documentation for planning ahead including financial, personal care and lifestyle decisions as well as substitute decision maker and advance care planning can be found at www.start2talk.org.au or https://advancecareplanning.org.au.

2. What does this scenario tell you about how planning ahead is prioritised by a person with dementia

- People are individual and will prioritise 'planning ahead' if they see benefits for themselves.
- People will prioritise specific aspects of planning ahead based on their values system and the things that they consider gives them a good quality of life.
- People assisting people with dementia, whether staff, volunteers or their family and substitute decision maker should listen to and consider the person with dementia's wishes, choices and values. This will allow them to assist the person with dementia to make decisions for themselves and when they can no longer make decisions to make decision for them based on these previously discussed wishes and choices.

Information sources

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Other information and resources

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- Website: www.advancecareplanning.org.au
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- Website: http://www.caresearch.com.au