



My Wishes

Sydney South West My Wishes Advance Care Planning Program Guidelines for staff in initiation and conduct of ACP discussions

This document provides guidelines for any staff who want to initiate and conduct ACP discussions with their patients/clients/residents. It takes a step-by-step approach, identifies key issues at each step, and provides prompt comments and questions. It can be used by individual workers or as a guideline within staff training programs on ACP.

Getting ready for ACP discussions

Stages of process	Key issues
Recognising when ACP may be appropriate	<ul style="list-style-type: none"> • A person (whether in hospital, aged care facility or the community) or a family member may initiate ACP discussion with a healthworker. • If that is not the case, some of the triggers that may prompt a healthworker to raise ACP with a person include: <ul style="list-style-type: none"> ** Admission to a residential aged care facility ** Commencement of a Community Aged Care, Transitional Age Care or Extended Aged Care in the Home Package ** Obvious shift to a higher level of care for a residential or community care client ** Diagnosis of the late stage of a chronic disease e.g. renal, cardiac, respiratory ** Diagnosis of life-limiting illness e.g. cancer ** Diagnosis of early cognitive impairment ** Significant deterioration in an ongoing medical condition • A safe bottom line is that ACP should be offered to any persons that a healthworker suspects might die within 12 months.
Deciding how to introduce ACP	<ul style="list-style-type: none"> • How you introduce ACP will depend on the clinical situation and on the policy and practice framework for each organisation.



	<ul style="list-style-type: none"> • Aged care facilities may routinely give new residents and their family information on admission and then have ACP as a set agenda item on the initial and annual case conferences. • Clinical services may routinely provide information to patients fitting the above criteria and ask them if they wish to discuss the issues further on subsequent visits. • Healthworkers need to use their judgement in how strongly to introduce ACP. Many persons will not want to discuss these issues and their choice needs to be respected. However, it may be that the person is a bit tentative and wants the healthworker to persist. It may also be important if the healthworker believes it is clearly in the interest of the person e.g. if the person is approaching a palliative stage and it seems there will be confusion or conflict around decision-making. • It is important to be clear about the reason for introducing ACP and to explain this clearly to the person or persons involved. It may be a routine part of care, a chance to explore specific interventions that are likely to occur for that person in the future or it may be to help plan current care by bringing issues out into the open if the person is approaching a palliative stage. • It is not recommended to introduce ACP while a person is in an acute stage of an illness. • While it is reasonable to provide verbal and written information when a person is admitted to a residential care facility, it is not recommended to have a full discussion on admission. However it is important to include ACP discussion at first family case conference and subsequent case conferences and care planning meetings.
<p>Who should initiate ACP discussions?</p>	<ul style="list-style-type: none"> • Initiating and conducting ACP discussions is not the province of one group of healthworkers. • GPs and Specialist doctors who have an ongoing relationship with the person are well placed to do this because they can explain prognosis and possible treatment choices to be made in the future. • However, not all doctors are comfortable discussing ACP and may find it difficult to devote the time needed. • Other staff who may be appropriate include social workers, nurses, psychologists and experienced care workers. • What is important is that the staff member is comfortable in the role, has a good knowledge of the issues to be able to answer questions and can develop a trusting relationship with the person. • It is preferable if the staff member initiating ACP has an ongoing relationship with the person rather than a one-off encounter as ACP is a process that unfolds over time. • Whichever person takes on this role, it is vital that the information is shared as part of a team approach to care. For example, a senior nurse in an aged care facility may undertake ACP discussions but these would need to be acknowledged and respected by the person's GP and other staff within the facility.



<p>Who should be involved in ACP discussions?</p>	<ul style="list-style-type: none"> • One core aspect of ACP is promoting a person’s right to determine their future care, even though they cannot speak for themselves at that time. To that extent, the person should determine who they want to be involved and not involved in these discussions. • ACP is also seen to have an important role in helping people prepare for death, strengthening relationships and anticipating decisions that family and loved ones may have to make, thereby making he decisions clearer and easier when they have to be made. To that extent, ACP discussions should ideally include those close to the person who may be called on to make decisions for them in the future. • For many people, understanding who will be involved in substitute decision-making for them is a key component of the advance care planning process. It is important to explain the concept of ‘person responsible’ to patients and families. • It may also be the case, especially in residential care facilities, that the person has already lost decisional capacity and therefore cannot be responsible for ACP discussions. In this case, the ‘person responsible’ (as defined under the NSW Guardianship Act 1987) and other key family members should be involved in working with the GP and facility staff to undertake ACP on behalf of the person. Individuals who have lost capacity can still be involved to a greater or lesser extent in ACP discussions as appropriate to each individual situation. • If a person has already lost capacity, it will be necessary for staff to identify who are appropriate substitute decision-makers for the person. In most situations, this will be fairly clear as one or two primary carers will normally accompany the person and organise medical appointments, admission to residential facility etc. There may be some situations where there is nobody in this role or else several people with different views about the person’s care. There may be a need for significant communication skills to gain consensus from people. Staff should also become familiar with the concept of “person responsible” – the person defined under the Guardianship Act as the person to provide substitute consent for medical and dental treatment for people without capacity.
<p>Setting up the discussion</p>	<ul style="list-style-type: none"> • There is no set format for ACP discussions. They may occur at a doctor’s surgery, in a person’s home around the kitchen table, by the bedside in hospital or in a nursing home. • What is important is to allow enough time for proper discussion. It is ideal if discussion can be in a quiet, private place without interruptions. • Not all ACP discussions will be formal or occur in a structured environment. It is important to recognise that unplanned and informal discussions can contain very relevant ACP information. These should be documented as per facility/service protocols. • The ACP process typically requires ongoing discussions, rather than being a one-off event,



My Wishes

Guiding the person or persons through the discussion

The possible questions or prompts outlined below are provided for assistance only. It is most important to really listen to what the person is telling you and respond to that, rather than following pre-set questions.

Stages of discussion	Key issues	Possible questions or prompts
Introducing the discussion	<ul style="list-style-type: none"> • Introduce all participants and explain their roles in the discussion • Explain the purpose of the discussion and ensure others are clear about this. • The purpose will vary depending on the circumstances e.g. it might be routine after admission to a residential care facility, because of worsening chronic diseases. • Explain the purpose in a positive light, such as wanting to respect the person’s wishes and ensuring they get the best quality of care. • Explain that ACP is about exploring the best ways to help the person live well in the late stages of their life, rather than just focusing on refusal of treatments. 	<p>“We want to have this discussion because we want to provide care to you (or X) that matches what you really want for yourself. This may become relevant in the future if you get to a point where you are not able to speak for yourself.”</p> <p>“Talking about your (or X’s) values and how you see quality of life will help the people who may have to make decisions for you in the future. It will make them more confident they are deciding what you would have decided yourself.”</p> <p>“This discussion will include how you (or X) can get the most out of your (their) life and how you can achieve the sort of things that are important to you”</p>
Being sensitive to and acknowledging the emotional context	<ul style="list-style-type: none"> • Raising issues around ACP may be very confronting for the persons involved in the discussions. • There may be a range of emotions such as fear, anxiety, guilt, anger, or relief • It is important to be aware that people will not always react emotionally in the way you expect. • It may not be possible to have effective and meaningful discussions if people have not felt heard and acknowledged 	<p>“I am aware this can be a difficult time for many people. Can you let me know how the situation is affecting you at the moment?”</p> <p>“It’s important to me that I understand how you are feeling about the current situation. Please feel free to talk to me about how things are going for your personally”</p>
Finding out what people understand about the issues	<ul style="list-style-type: none"> • Finding out what people already know and feel gives a good starting point for discussion. • They may have already thought about and discussed the issues thoroughly. In this case you 	<p>“Tell me what your understanding of your own (or X’s) current condition is and how that is likely to develop over the next 6-12 months (vary time as appropriate)?”</p>



	<p>can move straight into the discussion.</p> <ul style="list-style-type: none"> • On the other hand, they may have no idea the person is so sick or may have unrealistic expectations of their prognosis and future treatment options. In this case, the staff will need to spend more time sensitively explaining about the person's condition and likely future scenarios. • Use language and phrasing that is appropriate to the person you are having the discussion with. Check back with the person that they really understand what is being discussed and are not just parroting responses they have heard spoken by the healthcare team. 	<p>"How do you think your (or X's) condition has changed over recent times?" "Why do you think that you (or X) needed to come into hospital / facility / service?" "What worries do you have about how your (or X's) condition will progress over time?"</p>
<p>Clarifying issues around the person's condition and prognosis</p>	<ul style="list-style-type: none"> • After listening to the person and others' understanding of their situation it is helpful to either confirm what they have said or else provide information about the person's condition and prognosis. • The healthworker conducting the ACP discussion needs to be sensitive to how these issues are discussed. The person's doctor may feel they should be the only one to discuss these issues. The best situation is to have a teamwork approach where the doctor can be consulted even if they are not directly involved in the fuller ACP discussion. These arrangements should be negotiated within each facility as appropriate. • There should be some discussion about likely scenarios that may happen in the future e.g. decline of late-stage dementia, increasing shortness of breath in lung disease. This may lead to discussion of treatment options that may have to be considered and what the benefits and burdens of these options are. This could include discussion about where the patient wants to be cared for and the pros and cons about being transferred to 	<p>"X is in a moderate stage of dementia. While we cannot predict exactly what will happen and when, this condition normally gets worse over time. Over time, the person will typically not recognise people, have difficulty walking and talking and eventually have trouble swallowing." "You have quite severe kidney disease already and before long you will have to decide what further types of treatment you want. There are pros and cons for these treatments and maybe now is a good time to discuss these more fully with your doctor. How about I organise a meeting with her?"</p>



	<p>hospital if they become unwell.</p> <ul style="list-style-type: none"> • A simple explanation of chronic disease as a non-curable illness may be relevant at this time. 	
<p>Discussing values</p>	<ul style="list-style-type: none"> • Understanding some of the core values of the person will help others who may have to make decisions on their behalf. • Each person has their own view of what constitutes quality of life for them and this needs to be understood and respected. 	<p>“What makes life worth living for you?” “What is most important to you as you get closer to the end of your life?” “Have you seen end-of-life experiences of other people that you want to experience for yourself or avoid?” In what circumstances would you not want your life to be prolonged by artificial means such as being fed by a tube into the stomach?” “What role does religion or spirituality play in your life, especially in terms of the end-of-life?” “Does your family or cultural background have an impact on your way of approaching the end-of-life?” “What are some of the things you would like to do with the rest of your life?” “What are your hopes and fears about the end-of-life?” “How can your family and loved ones best support you towards the end-of-life?”</p>
<p>Explaining goals of care</p>	<ul style="list-style-type: none"> • Many people do not understand the levels of care that are available in the health system and how each of these may be relevant to their individual situation. • While there are various ways of explaining this, one suggestion is that of Molloy (2004) which describes four general levels of care: palliative, limited, active/surgical and intensive. It may be helpful to provide a leaflet on this and explain the model as part of the discussion. • The discussion could then focus on the appropriate level of care for the person at this time. • It should be emphasised that the level of care 	<p>“Now that we have a better idea of your underlying condition and some of your core values, it is helpful to look at some broad goals of care. One way of describing approaches to care talks about four levels: palliative, limited, active/surgical and intensive. It’s not that one is better than the others – it’s more a matter of matching the goal to each person’s situation.” “Maybe I could go through this leaflet that explains the four goals of care a bit more fully?” “If you reached a point in the future where: your quality of life was very low, your underlying medical condition was irreversible and you had a severe life-</p>



	<p>needed by the person may change over time.</p> <ul style="list-style-type: none"> • It should also be emphasised that less intensive care does not mean less care, and that the person will always receive quality personal and physical care appropriate to their needs. • If the person is getting close to the end-of-life, it may be appropriate to discuss or provide some written information on what will happen as death gets closer. 	<p>threatening illness, which of the four levels of care would you want?"</p> <p>"How does your choice of goals of care match up with your own personal values and goals?"</p>
<p>Discussing CPR</p>	<ul style="list-style-type: none"> • It may not always be appropriate to discuss CPR. However this is the issue that needs to be acted on most urgently when it occurs and the decision whether to initiate it is most likely to cause stress to staff and family if it has not been discussed. • Many people have unrealistic expectations that CPR is appropriate in any cardiac arrest and will mostly be effective. • It may be useful to explore the person's understanding of CPR and then explain the reality of CPR in end-stage disease or in frail nursing home level patients. This could be through discussion as well as providing some written information. • It should be explained that if a No-CPR Order is in place, the person will still receive full comfort care for their underlying condition. • You may need to discuss other specific life-prolonging treatment choices related to the patient's specific illness 	<p>"Discussing resuscitation after a sudden heart attack is difficult for most of us. However it is important to put these cards on the table. Most people have an unrealistic idea about CPR that they get from television. The reality is for someone in your (or X's) condition, CPR would almost definitely be ineffective and would not return you to your current level of functioning. It is also more likely to lead to you being sent to hospital and having a number of invasive and uncomfortable procedures."</p> <p>"Deciding not to have CPR does not limit other treatments that you (or X) would receive. It just means they would get good quality comfort care."</p> <p>"A more positive way of looking at a No-CPR Order is to see it as Allowing Natural Death – which provides more dignity and comfort at the person's end-of-life"</p>
<p>Clarifying if there are any questions or other issues</p>	<ul style="list-style-type: none"> • Staff undertaking ACP need to use their professional judgement about how much is being taken in by the other participants. • ACP is a process over time rather than a single interview. • It is vital that any discussions reflect the persons' understandings and needs at that time. 	<p>"My understanding of what we have agreed today is.....Is that your understanding as well?"</p> <p>"If not, what else would you add or change?"</p> <p>"I understand these issues can be very difficult to deal with and we are here to offer you ongoing support as you need it."</p> <p>"Are there any issues you want to clarify or discuss further?"</p>

My Wishes



	<ul style="list-style-type: none"> • Staff need to summarise what has been discussed and feed it back to the others in the discussion. • Staff need to recognise and respond to the emotional impact this discussion may have on participants. • People should always be given a chance to clarify any issues that have been discussed, get further information and make arrangements for further discussion as appropriate. 	
<p>Confirming ongoing arrangements</p>	<ul style="list-style-type: none"> • There should be agreement about actions arising from the discussion and what type of follow-up discussions are appropriate. • It should be emphasised that ACP is an ongoing process and outcomes from today will be reviewed and updated as circumstances change • This may be a time to check whether any other persons need to be included in future discussions and how other family members should be informed about the outcome of these discussions. 	<p>“What we will do from here on is.....” “What sort of follow-up discussions would you like to have?” “It is important to realise that any decisions we make can be reviewed and changed at any time.” “Is there anyone else we should involve in these type of discussions in the future?” “Who are the people that should know about the outcome of these discussions and how should they be informed?”</p>

“We have learned that advance planning involves planting seeds and then watering and nurturing those seeds.” (Gillick, 2004, pg.360)



References

Briggs, L. (2004). Shifting the focus of advance care planning: using an in-depth interview to build and strengthen relationships. *Journal of Palliative Medicine*, 7(2): 341-349.

Emanuel, L.L., Danis, M., Pearlman, R.A. & Singer, P.A. (1995). Advance care planning as a process: structuring the discussions in practice. *Journal of the American Geriatrics Society*, 43(4): 440-446.

Fischer, G.S., Arnold, R.M. & Tulsky, J.A. (2000). Talking to the older adult about advance directives. *Clinics in Geriatric Medicine*, 16(2): 239-254.

Gillick, M.R. (2004). Adapting advance medical planning for the nursing home. *Journal of Palliative Medicine*, 7(2): 357-361.

Quill, T.E. (2000). Initiating end-of-life discussions with seriously ill patients: addressing the "elephant in the room". *Journal of the American Medical Association*, 284(19): 2502-2507.

Dr Peter Saul. ACP: A guide for doctors in NSW (Unpublished, undated leaflet)

Volicer, L., Cantor, M.D., Derse, A.R et al. (2002). Advance care planning by proxy for residents of long-term care facilities who lack decision-making capacity. *Journal of the American Geriatrics Society*, 50: 761-767.

Other resources

The Sydney South West My Wishes Advance Care Planning Program

Further information about this program and copies of the ACP forms and other resources can be obtained from www.mywishes.org.au or by calling (02) 9612 0646.

Using Advance Care Directives NSW

A 13 page booklet published by NSW Health to provide advice to health professionals on the best practice use of advance care directives within an advance care planning process. Available from the web at: www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_056.pdf

Guidelines for end-of-life care and decision making

A 17 page booklet published by NSW Health that focuses on a process for making end-of-life decisions about care. Available from the web at:

http://www.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_057.pdf

My Health, My Future, my Choice

A 31 page booklet written specifically for NSW that also contains a directive form that can be filled out. Published by the Advance Care Directive Association, an order form can be obtained by ringing 0423 157 003 or through the web at: <http://www.advancecaredirectives.org.au>

For further information go to:
www.mywishes.org.au