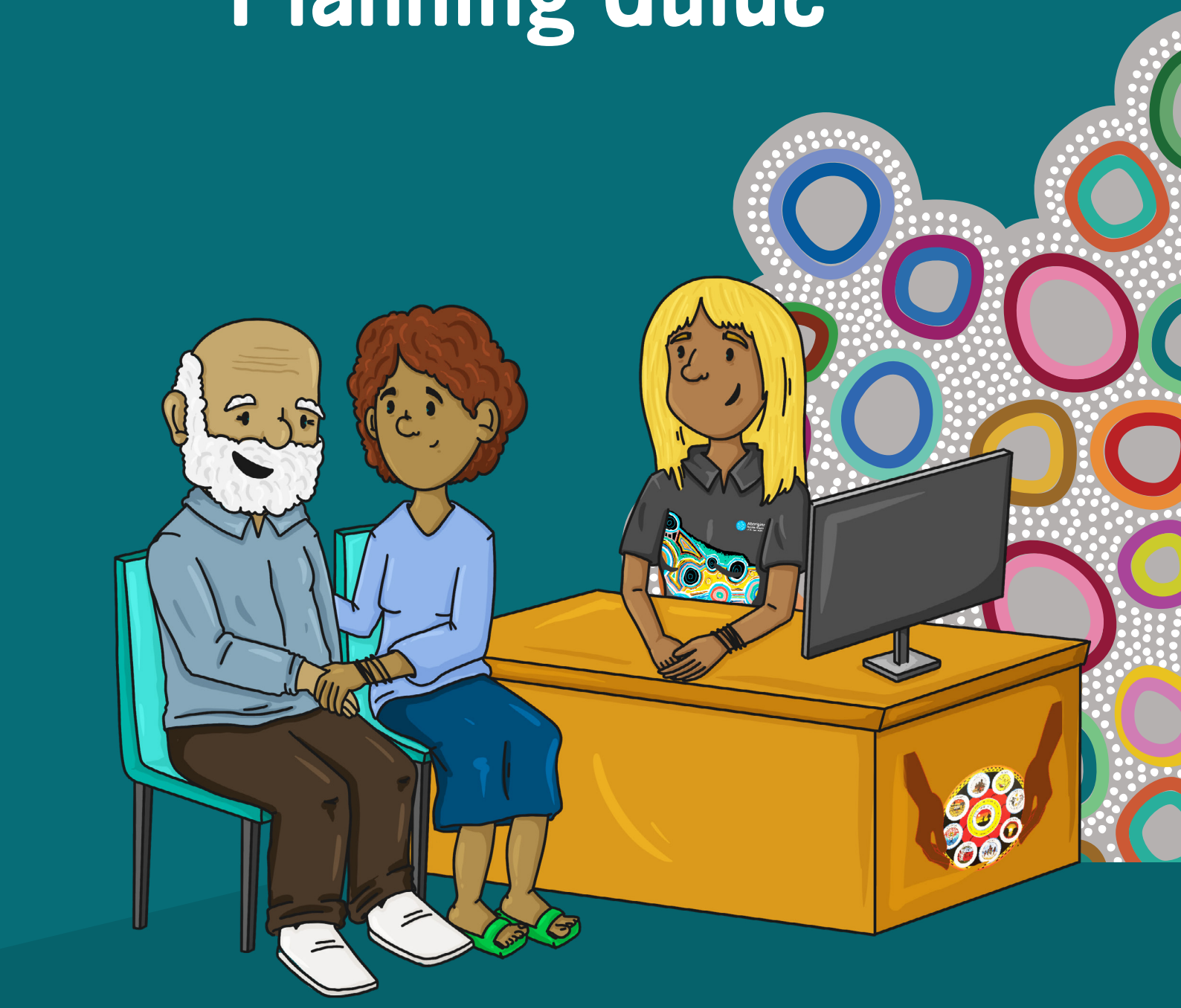
Aboriginal Health Council of Western Australia

Public Health **Continuous Quality Improvement**

Advance Care Planning Guide



Aboriginal Health Council of Western Australia acknowledges Traditional Owners across the Lands and pays our respects to Elders past and present.

This guide is for health care workers at ACCHS, to assist you in the discussion of Advance Care Planning.

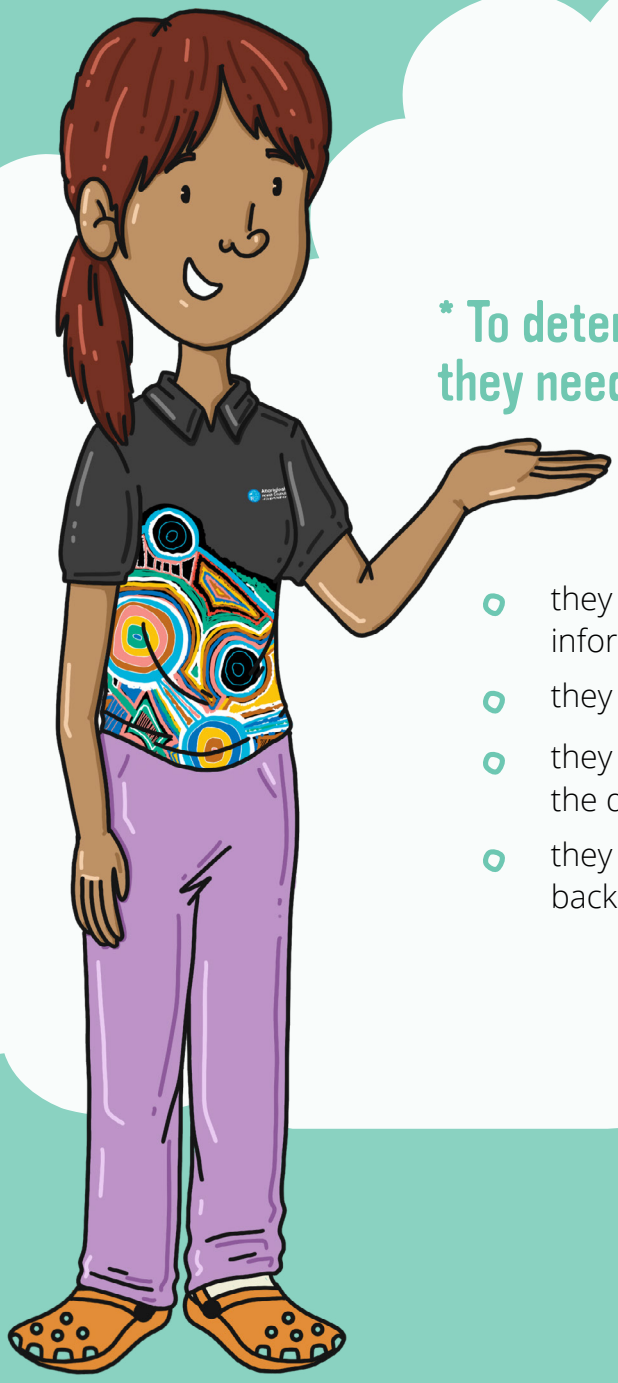
This is planning for a time when a client cannot express or make decisions for themselves, and often involves talks about what the patient wants during their passing on.

It can help the loved ones of the client, by indicating their preferences around sad times and sorry business. As a health care worker, you can make sure the care during these phases of life is what your client would have wanted, by documenting their future choices. This guide was created to assist you in having this clinical yarn with your client, and documenting it correctly.

Contents

What is Advance Care Planning?

Advance Care Planning (ACP) is the ongoing, voluntary clinical yarn between healthcare professionals, a client with capacity*, and people important to the client; about the client's preferences regarding future care if they are no longer able to express or make decisions.



* To determine if your patient has capacity, they need to fulfill the following criteria:

- they have the ability to understand the information about the decision
- they are able to retain this information
- they are able to use this information to inform the decision-making process
- they are able to communicate this decision back to you.

Note that capacity is dynamic, and depends on the decision being asked.

This section has been adapted from the WA Cancer and Palliative Care Network's resource, *Advance Care Planning: a step-to-step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life.*

When these discussions are written down, they are called ACP documents. Some ACP documents are legal documents including an Enduring Power of Guardianship, an Enduring Power of Attorney or an Advance Health Directive.

An Enduring Power of Guardianship document is a legal document that gives one or more adults (that your client has chosen) the legal authority to act for them and make decisions on their behalf. Another legal document in the ACP process is an Enduring Power of Attorney, which is similar to the Enduring Power of Guardianship but relates only to decisions around property or financial matters.

ACP discussions can lead to the creation of an Advance Health Directive, which is a legal document that includes formal instructions regarding future treatment preferences. This document is legally binding, must be signed off by specific witnesses, and only takes effect once a person loses capacity* to make or communicate decisions. If a client has an Advance Health Directive and they lose capacity this document must be followed exactly.

Advance Care Plans are expressions of preferences around future health care if capacity is lost. An Advance Care Plan can be any documented expression made when a client had capacity. For example a video, a written document, an audio recording, or the Values and Preferences Form.

For more information go to HealthyWA's website at www.healthywa.wa.gov.au/AdvanceHealthDirectives.

Who should be considered for Advance Care Planning clinical yarns?

Any person with capacity* can make ACP documents, at any time of their life. The earlier a person completes an ACP document, the better.

Have an ACP clinical yarns if the client

- has advanced chronic illness e.g. Chronic Obstructive Pulmonary Disease, diabetes, heart failure
- has a life-limiting illness e.g. dementia, advanced cancer
- is an older person (for Aboriginal and Torres Strait Islander people 55+)
- is a resident in a nursing home
- is applying for assistance e.g. Aged Care Assessment Team assessment or National Disability Insurance Scheme (NDIS)
- is at risk of losing capacity* e.g. early dementia
- has a significant new diagnosis e.g. metastatic cancer, transient ischaemic attack
- has had two or more admissions to hospital for a chronic or life-limiting illness within 12 months
- does not have a substitute decision maker
- anticipates decision-making conflict about future health care
- has a carer
- has a strong preference to remain on Country for care
- is frail clients, with multiple co-morbidities that impact their day to day living and deteriorating functional status
- if you've answer 'No' to 'would I be surprised if this person passed on in the next 12 months?'

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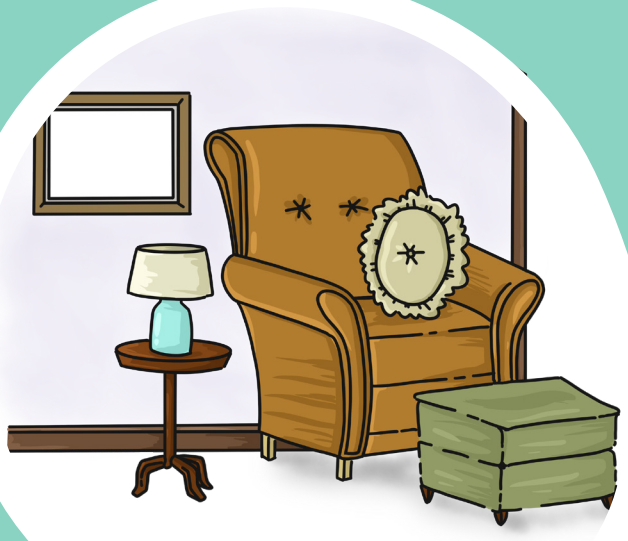
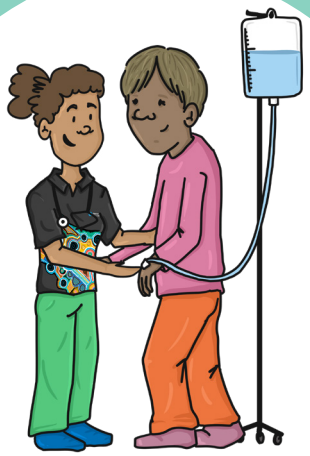
Your client may benefit from a clinical yarn if they ask any of the following questions

"How will I know when the time comes to stop this treatment/medication?"



"How will you make sure I stay comfortable?"

"What's going to happen in my future?"



"Do you think palliative care could help my mum/dad?"

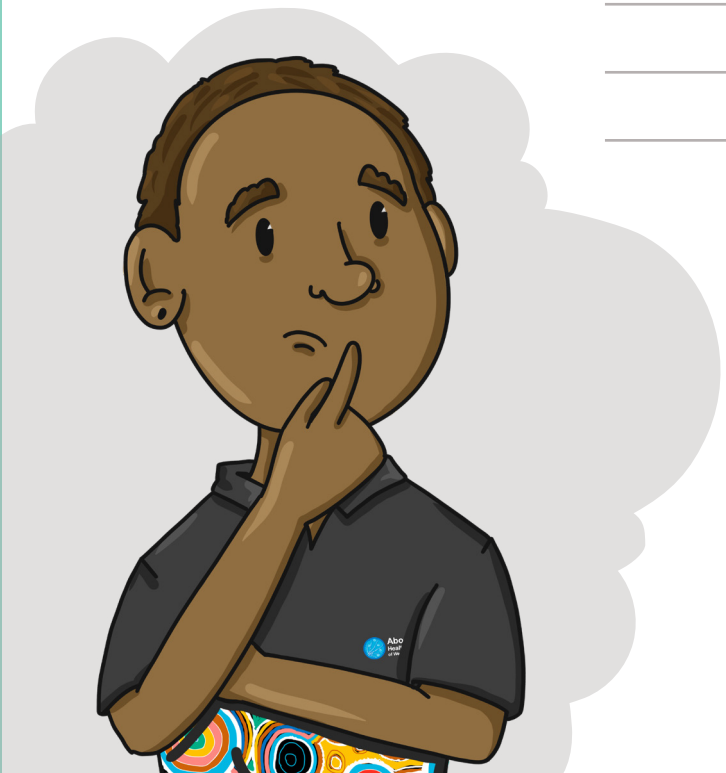
This section has been adapted from the WA Cancer and Palliative Care Network's resource, *Advance Care Planning: a step to step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life*, as well as from Advance Care Planning Australia's Factsheet for General Practice.

Roles & Advance Care Planning

Any health professional can be involved in ACP clinical yarns if they have adequate knowledge.

Discuss with your practice team members how you as a staff member can contribute to ACP clinical yarning. An Aboriginal Health Practitioner is well placed to ensure these discussions are culturally safe. Their presence can be particularly helpful during a yarning process which can be difficult for clients and which requires sensitivity from health professionals.

How could your role contribute to ACP clinical yarning at your service?



Health professionals can undertake training to gain knowledge of the ACP process. Here's how you can assist your client

- ensuring you and your treating team are adequately prepared for ACP discussions
- identifying clients who would benefit from having ACPs created, and discussing with your treating team who has the best rapport with the client to start that conversation
- assessing your client's capacity, to ensure they are able to contribute to ACP clinical yarns
- starting the conversation about your clients preferences regarding passing on/ sad news, and seeing if they are interested in pursuing this chat further
- explaining the purpose of ACP, and how it can involve both discussions about preferences and informing the creation of legal documents if they wish, including the Advanced Health Directive, Enduring Power of Guardianship and Enduring Power of Attorney
- explaining the benefits of having an ACP documented, especially if uploaded to My Health Record, to ensure that your client's preferences are known by both the local service and other services within Australia if they receive healthcare at multiple locales
- asking your client who they would want involved in this discussion – which members of the treating team, and if they would like to bring in any family/ friends/carers to be part of this conversation
- making sure your client knows that this doesn't indicate "giving up", simply that you want to make sure that the client has their wishes known if they are ever unable to communicate them
- documenting if you initiated this discussion, and anything discussed with your client
- communicating this with other members of your client's treating team
- gaining consent from your client to upload these documents to My Health Record
- encouraging your client to keep copies of these documents, and to share them with family as well as all healthcare providers involved in their care
- letting your client know that a copy will also be kept locally
- reviewing this plan annually or after big events, to ensure that the plan is current with your client's wishes for the future.

It's important to know as a healthcare professional that this discussion is not a 'once off'. This clinical yarn is ongoing and can take place over several visits.

How to start the Advance Care Plan clinical yarn

Before the clinical yarn

- do you have a private space with no interruptions?
- have you ensured that there is enough time available to have this clinical yarn properly?
- does the client (and/or carer/family/friends) have the decision-making capacity to participate in the clinical yarn?
- what are the language groups in your area?
- are there cultural traditions your service is aware of around end of life in these groups?
- What are the language groups in your area?

  _____

- Are there cultural traditions your service is aware of around end of life in these groups?

  _____

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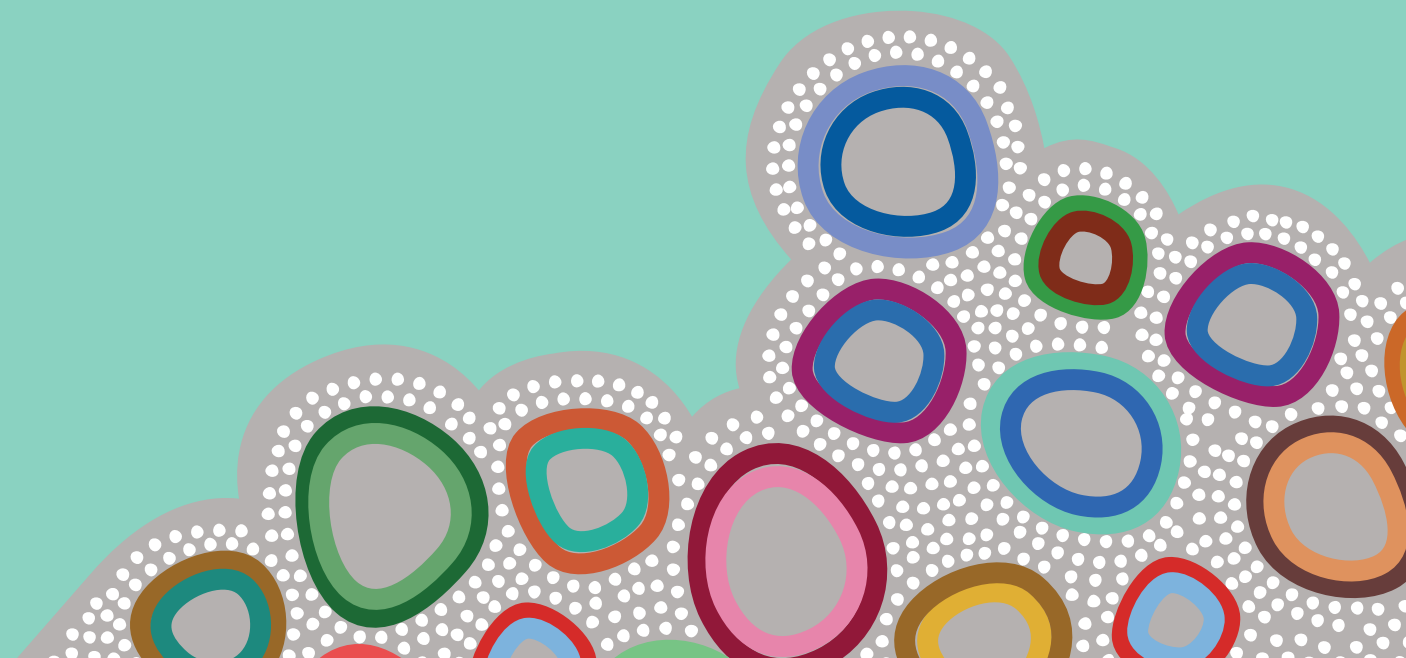
  _____

- consider cultural safety and cultural needs
- ensure all relevant clinical information is available
- consult with other health care professionals involved with the client's ongoing care e.g. other members of the treating team, specialists involved with their ongoing care
- organise a translator if required.



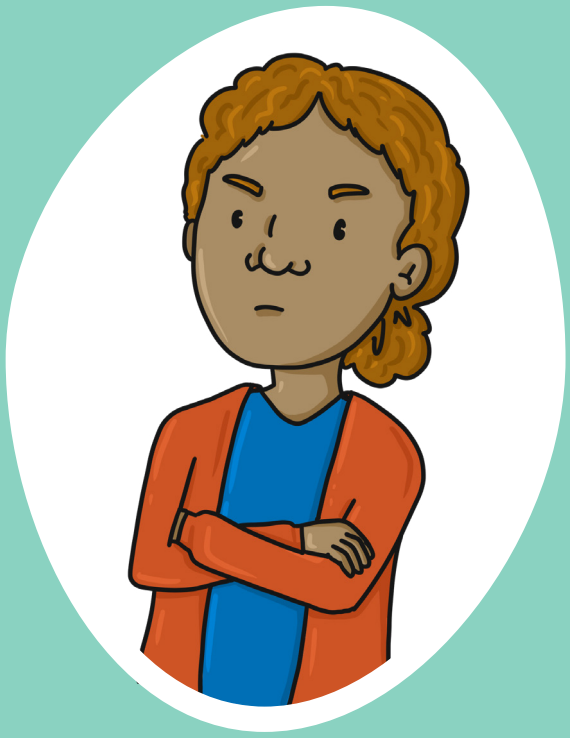
Examples of phrases to use to start the clinical yarn

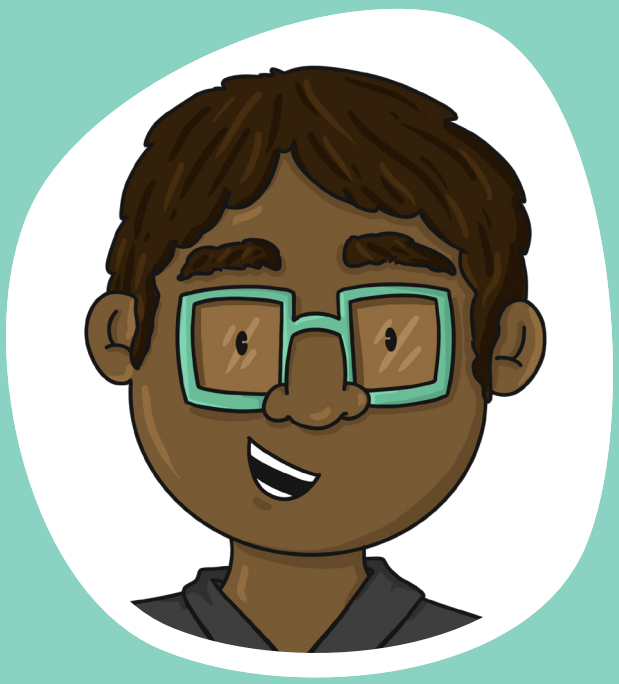
- "Have you thought about where, or the type of care you'd like to have, if you ever become too sick to look after yourself?"
- "Is there someone you would prefer to make decisions about your treatment if there was ever a time that you couldn't tell us yourself?"
- "Recently you (went to hospital/had a new diagnosis), if this was to get worse what would you want to happen?"
- "Some people have thought about what they want and document their wishes in an Advance Health Directive or Living Will.
  Do you have one? Would you like to learn more about this?"

If your client is not interested

If the client is not interested in having a clinical yarn about ACP at this time, ensure they know that they can come back to the topic at any time in the future. Consider providing them with written resources to go home with if appropriate.

There are some reasons why a client may not be interested in having this conversation. They could have been negatively affected in the past, they may have mistrust with documenting these wishes down, it could be re-traumatising to discuss, and they may not have enough knowledge on the process.





Topics to cover in the introduction

- explain what ACP is and outline some reasons why clients, their families and carers may want to have these clinical yarns
- check if the client already has a Values and Preferences form, an Advanced Health Directive, Enduring Power of Guardianship, Enduring Power of Attorney, or something similar. If they do, would they like it to be reviewed?
- discuss the role of a substitute person or Enduring Guardian for decision-making.

This section has been adapted from the WA *Cancer and Palliative Care Network's resource, Advance Care Planning: a step to step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life.*

Identify client's goals and wishes

Consider what is important to your client

- "Think about what is most important to you in your life. What makes life meaningful or good for you right now?"
- "At this point, given your health, how could we as health professionals help you live well?"
- "Are there any special events/activities that you are looking forward to? e.g. birthdays, weddings, events, holidays"
- Need more prompts for how to start conversations with clients about cultural conversations - discuss with cultural mentors?

What are your client's goals of care?

- "What is your understanding of your condition now and its prognosis?"
- "If you have to choose between living longer and quality of life, how would you approach this balance?"
- "What beliefs do you have around sickness, health care decision making, or passing on/ finishing up?"
- "Are there any particular scenarios or interventions you definitely don't want? E.g. Cardiopulmonary resuscitation, ventilation, dialysis etc?"

Tips for effective ACP clinical yarns

- non-biased, non-judgmental
- active listening
- use clarifying questions
- paraphrase and summarise information back to the client.

A resource that can be useful when having these clinical yarns are the "Dying to Talk" discussion cards, which can be found on the Palliative Care Australia website

This section has been adapted from the WA Cancer and Palliative Care Network's resource, *Advance Care Planning: a step to step guide for health care professionals assisting patients with chronic conditions to plan for care towards end of life.*

Things to keep in mind

- does the client wish to fill out an Advanced Health Directive?
- consider referral to palliative care (if appropriate) and preferred place for future care e.g. home, hospital, hospice, on country etc
- is this an appropriate time to discuss organ and tissue donation?

What are some local words that could be included in the ACP yarn?

Strong: _____

Spirit: _____

Health: _____

Good: _____

Bad: _____

Heart: _____

Lungs: _____

Chest: _____

Brain/head: _____

_____

_____

_____

_____

Closing the Advance Care Plan clinical yarn

- summarise the clinical yarn with the client and others present
- clarify any inconsistencies or misunderstandings
- offer additional resources if required
- gain consent to upload an event summary to My Health Record to ensure this information about future wishes will be known about across all health services
- encourage or assist the client to upload their ACP documents onto My Health Record
- document all details of the ACP clinical yarn
- organise for future meetings if required, and let your client know that these decisions can be updated at any time, but should be reviewed at least every two years
- encourage the client to continue this yarn outside the clinic, with their family and their community.

Ensure all documentation follows local organisational policy, and should include the following

- details of all individuals who were present, as well as anyone consulted
- record details of topics discussed, including what the client considered acceptable treatment, along with specifics of any treatment decisions
- document whether there was a Values and Preferences form, an Advanced Health Directive, Enduring Power of Guardianship or Enduring Power of Attorney created
- document any Not for Resuscitation (NFR) orders
- include a note/flag in the client's ACCHS medical file to alert others of ACP documentation e.g. under notes in Communicare
- upload an event summary to My Health Record
- encourage or assist client to upload their ACP documents onto My Health Record
- put a recall on your system to consult this client again about their ACP documents in two years.

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Resources for Advance Care Plan clinical yarning

For Clients

Dying to talk discussion starter resources. Client booklet or discussion starter cards, can assist conversations around difficult topics.

Taking Control of Your Health Journey. Benefits of Advance Care Planning for clients.

Taking Care of Dying Time. Yarn about the importance of Advance Care Planning.

For Clinicians

Advance Care Planning Australia Learning modules. Guides through whole process from start to finish, including how to have the conversations and legal implications.

Gwandalan Palliative Care eLearning modules and resources. Aboriginal specific information, numerous resources and eLearnings that can assist Advance Care Planning.

Palliative Care Helpline. Information and support with Advance Care Planning, palliative care, and grief and loss.

1800 573 299 (9am-5pm every day of the year)

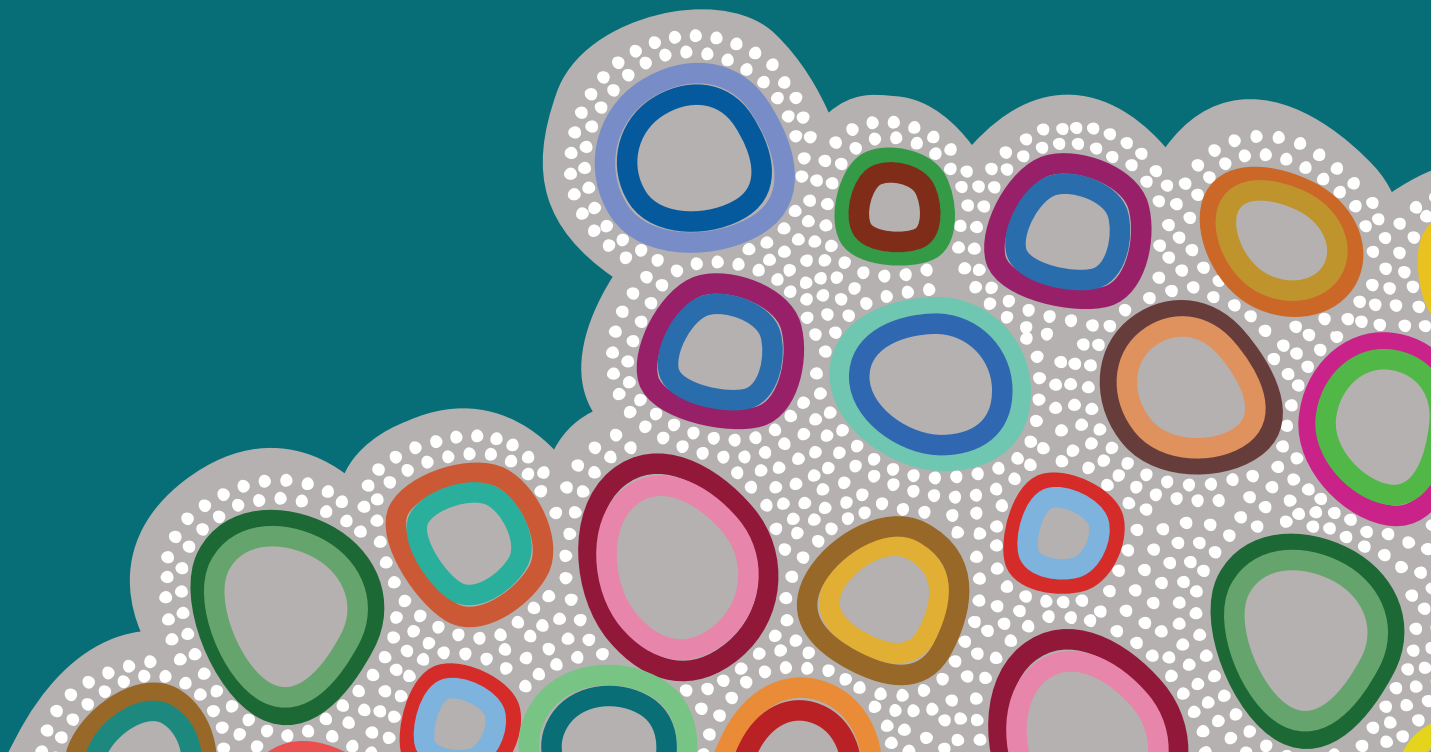
Health Professional Guide to Advance Care Planning in WA. Government of WA, Department of Health.

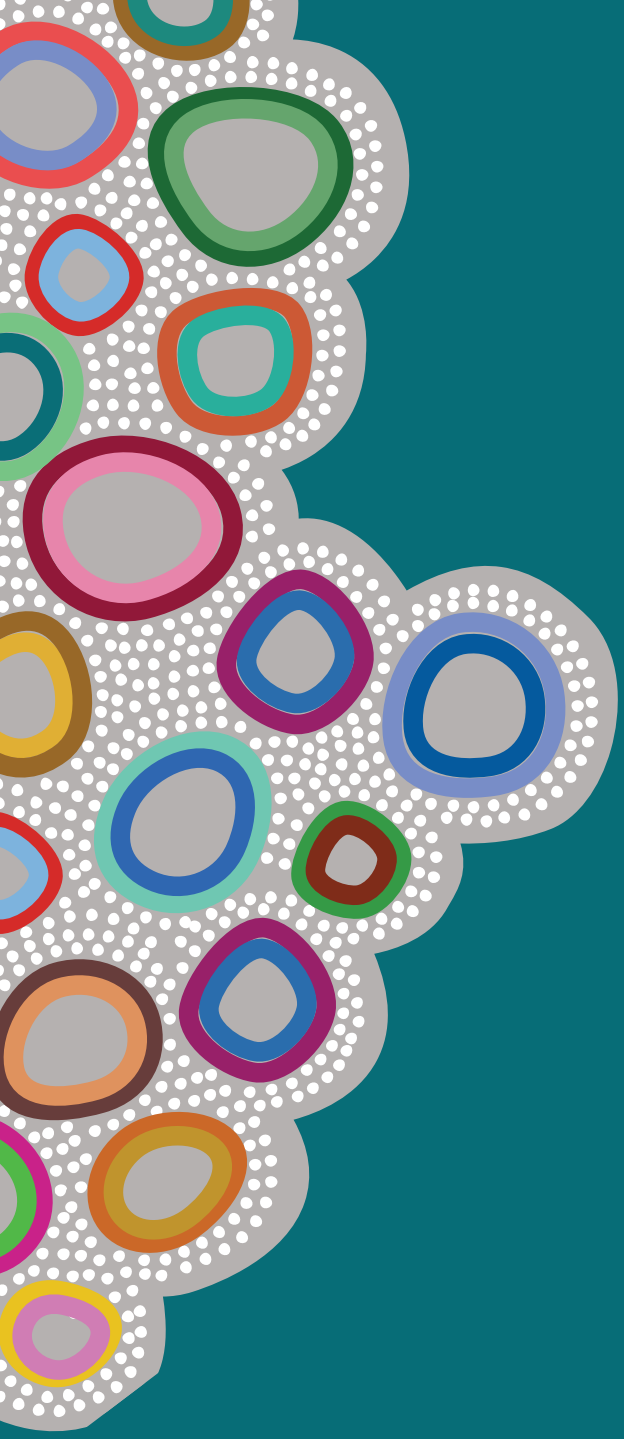
For Adaptation

If looking at resources to adapt for your own service consider the *Northern Territory's Advance Personal Plan document.*

WA ACP Workbook.

It’s never too early
to start the conversation.





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