Advance Care Planning

1. What is Advance Care Planning?

Advance Care Planning is a voluntary process of discussion and shared planning for future health care. It involves the person who is preparing the plan, and usually involves family / whānau and health care professionals with the person's consent. The process assists the individual to identify their personal beliefs and values and incorporates them into plans for future health care. It may also involve discussion about medical care and a wide range of other matters.

Advance Care Plans (ACP) and **Advance Directives (AD)** are outcomes of Advance Care Planning. It is formulated by the person and sets out their views about care towards the end of their life. It may also include views about medical care and a wide range of other matters in an **Advance Directive**. It may also indicate who the nominated **Enduring Power of Attorney** is.

2. Entry points

Entry points include: person and family, non-governmental organisations e.g. Age Concern, Stroke Foundation, Cancer Society, Grey Power, Positive Ageing, marae, churches, lawyers, GP Practices, hospice, hospital, service groups, Aged Residential Care

Advance care planning is better to occur in advance of serious illness progression and within the community setting rather than when a person is in their last year of life or admitted to hospital / aged residential care.

3. ACP and Competency Considerations

A Guide for the NZ Health Care Workforce states that:

"in the context of ACP, competency relates to an individual's ability to make a decision regarding their own health care (that is, competence at decision-making or decision-capacity). At a minimum, decision making capacity requires the ability to understand and communicate, to reason and deliberate, and the possession of a set of values".

ACP relies on the person being competent to share in the planning process and so should be considered early in the care of the person for whom the diagnosis of dementia is suspected. A person with dementia does not necessarily lack capacity, however, it should be anticipated that their capacity will fluctuate and decline over time.

See further information on Dementia Support.

The following people may require special considerations. People with:

- Mild cognitive impairment
- Intellectual impairments
- A visual and/or hearing impairment
- Physical impairments
- Speech impairments
- People requiring an interpreter

4. ACP and Protection of Personal & Property Rights (PPPR) Act

The PPPR Act allows people to decide in advance who they would like to make decisions for them if they become incapable of making decisions for themselves. They do this by giving another person an enduring power of attorney.

Protection of Personal and Property Rights Act 1988

The Court and Enduring Power Of Attorney

New Zealand Code of Rights

Ethical Challenges in Advance Care Planning

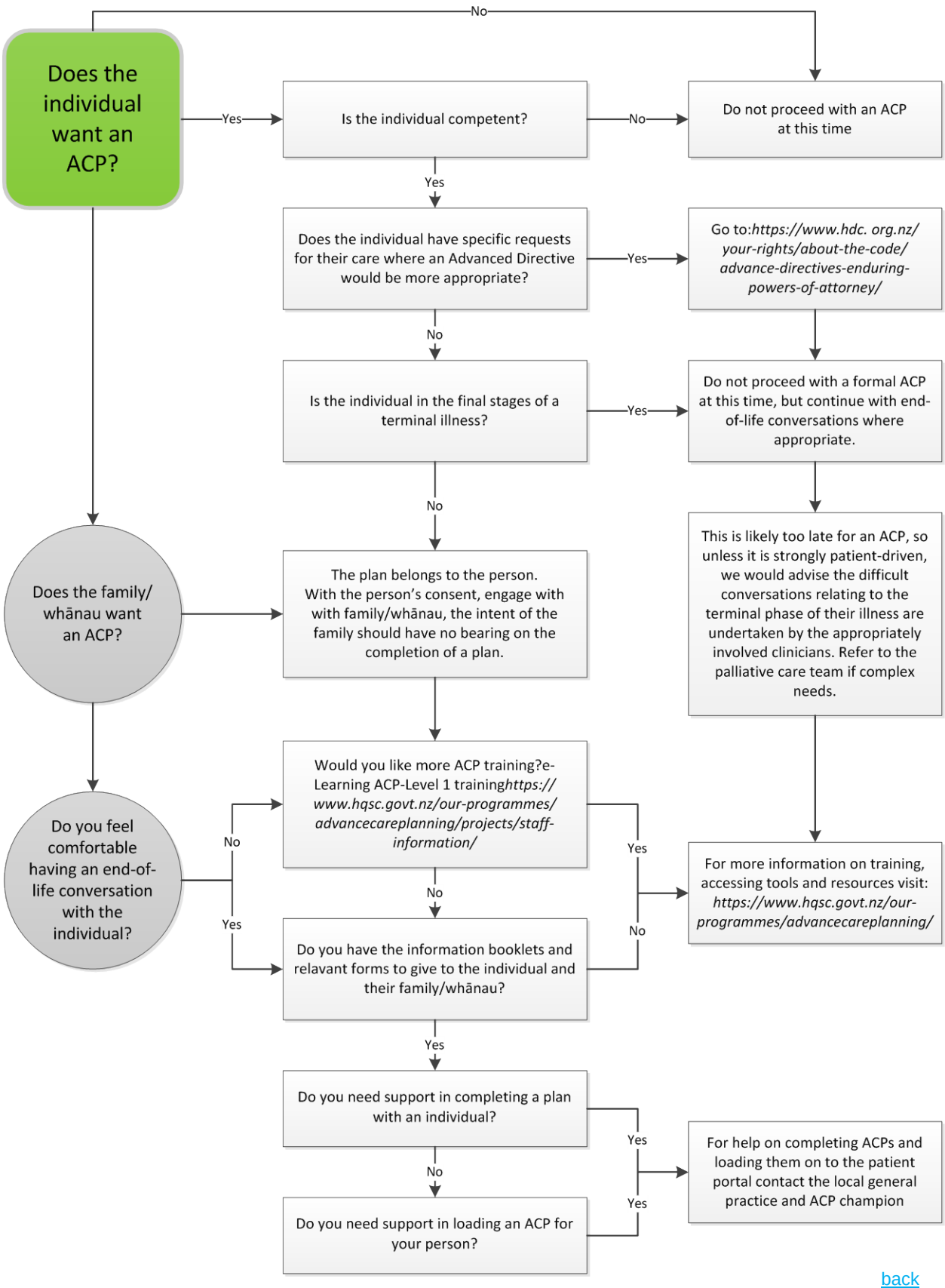
Super Seniors

Waikato DHB General Medicine Capacity Assessment guideline

Waikato DHB Informed Consent policy

For advice, contact Waikato DHB Legal Services

5. Deciding when to have an ACP Conversation



back

Follow the 5-Step ACP Process for Healthcare Workers

6. Step 1 – Preparing

An ACP conversation is better to occur early in a disease process and within the community setting rather than when a person is in their last year of life or admitted to hospital or an aged residential care facility. The health professional may consider raising the topic of ACP if they wouldn't be surprised if the person died in the next 12 months.

Any person over 18 years can make an ACP unless they are already unable to make their own decisions due to disability, illness or injury. Other occasions when it might be appropriate to discuss include:

- The person or their family / whānau / carer, with permission of the individual, enquires about palliative care
- The person has been hospitalised recently for a severe progressive illness or condition or has required repeated admissions for a serious condition
- The person says they want to forego life-sustaining treatment

ACP discussions can occur at any time, not necessarily only when a person has been diagnosed with a life-limiting illness. If a person is well, discussions are likely to focus on what they would want should they have an unanticipated sudden illness or accident.

Such discussions would generally be prompted by a specific patient request but could also be recommended by health care professionals or family / whānau members, with permission of the person, who recognise that the person has care preferences that differ from the mainstream.

Some patients will prompt the ACP discussions themselves, but many will expect health care professionals to initiate these discussions, and many patients welcome the opportunity to discuss end-of-life care in advance. However, not everyone will choose to participate in ACP.

ACP is most easily accomplished when a patient is in a stable state of health or when they have had time to adjust to a new illness. Sometimes, however, discussions may take place when the clinical situation is unstable.

Conversation Guide for Clinicians

Before advance care planning (ACP) is introduced, it is important that the person understands its relevance so that the conversation can be placed in context. Reaching this level of understanding may involve exploring the person's understanding of their prognosis and general health issue/s. Ideally ACP discussions would first occur when the person is receptive and calm and in a supportive environment.

Think in advance:

- Is the timing appropriate for this person?
- Does this person need a multidisciplinary approach?
- Will ACP benefit the person?
- Will there be any decisions today?
- Provide the person with a family communication guide / leaflet

Resources:

- ACP Level 1 e-learning
- Serious Illness Conversation clinician guide
- A Guide for the New Zealand healthcare workforce - ACP Cooperative

7. Step 2 - Talking

The Advance Care Planning (ACP) process can empower an individual to make informed decisions about their future care. The content of any discussion must be determined by the individual concerned, and, if they do not wish to engage in ACP or conversations about their future care, this preference must be respected.

Use open questions to encourage dialogue, explain the process, and get the discussion started. Avoid a rigid, prescriptive method of interviewing.

1. **Explain:** explain the process and why ACP is important
2. **Understanding:** What is your understanding now of where you are with your illness? Ask what they understand about their current health / illness and what they think might happen in the future.
3. **Information preferences:** how much information about what is likely to be ahead with your illness would you like from me (e.g. time, what to expect or both of these)?
4. **Prognosis:** share prognosis, tailored to information preferences. Encourage individuals to focus on what is important to them and to understand that they are in control of their future care. Types of care and/ or treatments that that may be beneficial in the future and their potential availability. Where is the person's preferred place of care (and how this may affect the treatment options available)
5. **Goals:** if your health situation worsens, what are your most important goals? Ensure the individual is aware that they are able to change their preferences for future care and / or treatments at any time.
6. **Fears/worries:** what are your biggest concerns, fears, wishes and worries about the future with your health? Elicit and clarify concerns, expectations, and fears about the future in relation to their healthcare, including death and dying. What needs do they have in regards to for religious, spiritual or other personal support?
7. **Function:** what abilities are so critical to your life that you can't imagine living without them? Ask about past experiences with their own or other people's illnesses.
8. **Trade-offs:** if your condition worsens, how much are you willing to go through for the possibility of gaining more time? What are the person's views and understanding about interventions that may be considered or undertaken in an emergency (such as cardiopulmonary resuscitation)?
9. **Family:** how much does your family / whānau know about your priorities and wishes? Are there family / whānau members or others that they would like to be involved in decisions about their care (this may include the appointing of an Enduring Power of Attorney)

Offer the option for family / whānau to be present at the next visit to discuss together. Jointly decide whether, and when, to proceed with a written ACP and if the individual wishes to share.

Resources:
Serious Illness Conversation clinician guide

Organ and Tissue Donation
Ensure individuals are aware that age and certain medical conditions may preclude them from **donating organs and tissue**. For advice, phone Organ Donation New Zealand on **(09) 630-0935** (24 hours a day) www.donor.co.nz

8. Enduring Power of Attorney

An Enduring Power of Attorney (EPA) is a power given by an individual to a person appointed to make decisions on behalf of that individual if, and when they cannot make, or communicate, those decisions for themselves.

There are two types of EPA:

- Personal care and welfare EPA appoints an attorney to make decisions about an individual's personal care and welfare on their behalf
- Property EPA appoints an attorney to manage and make decisions about a person's property

Enduring Power of Attorney information:

- Ministry of Justice – The Court and Enduring Power Of Attorney
- Age Concern – Planning Your Future
- Super Seniors – Enduring Power of Attorney Frequently Asked Questions

9. Advance Directives

On occasion, the process of discussion and planning may clarify that the person has very specific preferences for their future treatment. These can be communicated in an Advance Directive (AD). An AD is a written or oral directive / instruction of consent or refusal to specific treatment(s) which may or may not be offered in the future when the person no longer has capacity.

An AD cannot be created on behalf of another person and means people cannot demand treatments. It enables a person to make choices about possible future health care treatment(s) and becomes effective only when the person loses the capacity to make those choices themselves.

The legal authority of an AD rests with its validity, which must be established before it is honoured or given effect.

There are four legal criteria that an AD must meet, as follows:

1. The person was competent to make the particular decision, when the decision was made
2. The decision was made free from undue influence
3. The person was sufficiently informed at the time of making the AD and intended the directive or choice to apply to their current circumstances.
4. The existence and validity of the AD must be clearly established.

For further information pertaining to ADs and templates see:

New Zealand Medical Association Advance Directive

Waikato DHB General Medicine Capacity Assessment guideline

Waikato DHB Informed Consent policy

Protection of Personal and Property Rights Act 1988

MCNZ informed consent

10. Step 3 – Documenting

There is great value in having ACP conversations but unless they are documented they may get lost.

Individuals should be made aware that a key factor in the success of ACPs is recording and sharing the plan appropriately with others. ACP information, like all health information, cannot ordinarily be shared without the agreement of the individual concerned.

ACP discussions should be documented in the individual's health record as having taken place. The record must include the content of the discussions and the plan developed. This level of documentation is in keeping with the obligation on health care professionals to keep full and accurate records of all discussions with patients / individuals. The actual plan can be documented on the National ACP Plan or the ACP Summary form or written within the individual's health record or correspondence.

The individual must be provided with the opportunity to confirm the accuracy of the record and any disagreements noted. With the individual's understanding and permission, all relevant health care professionals should be made aware that ACP discussions have taken place and should have access, if required, to any plan produced.

Complete any of the following:

- Advance Care Planning Guide
- Local ACP form or documentation ACP Summary form
- Complete electronic version at GP Practice.

Completed copy of ACP:

- The person can keep the original in a safe place known to family, carer etc (e.g. note the location in a life tube - available from Age Concern)
- The person can keep a card in their wallet alerting that an ACP exists and its location
- The person can place an ACP magnet on the fridge at home (to alert St John)

A copy of the completed ACP should ideally be:

- Kept at the GP practice saved in the Shared Electronic Health Records in the Practice Management System (PMS)
- The person's ACP can then be viewed by St John and secondary care via Clinical Workstation (CWS)
- It is the person's own decision if they want to give a copy to their family / whānau or to their lawyer.

Local processes

At a follow up appointment, follow the documentation process if the individual wishes to:

- Create an electronic version for sharing (see below)

- Use the ACP summary form
- Only have a paper version
- Give the individual a copy of the Advance Care Plan Guide.
- Alternatively, individuals can download a copy of the form at home or complete it electronically via their GP Practice

Electronic advance care plan

- An electronic version is available for patients via their GP Practice or via the Patient Portal in ManageMyHealth or MyIndici
- Individuals can enter the keyword "ACP" in the website search to find the plan.
- Individuals can fill in Part A on their own, then make a follow-up appointment to complete Part B with their healthcare worker.

Remind individuals that they can make changes to their advance care plan at any time, offering guidance on how to do this and who to contact.

11. ACP Alert in SECONDARY CARE - Waikato DHB

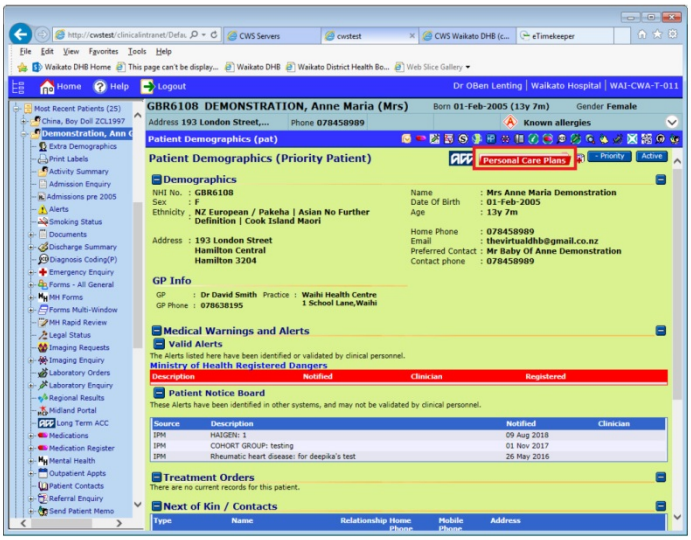
Advance Care Plans in Clinical Workstation

Advance Care Plans and Advance Directives

When a patient has Advance Care Plans and/or Advance Directives an indicator will appear on the Patient Demographics screen. This indicator is highlighted below with a red rectangular and carries the words Personal Care Plans.

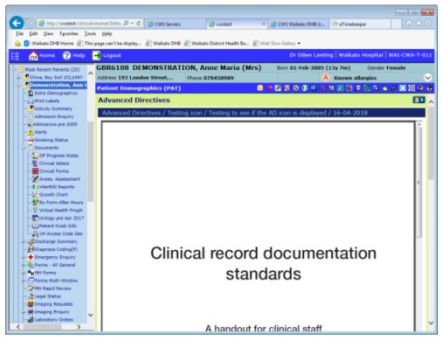
The system shows this indicator when at least one document is in one of the following document storage places:

1. MedTech ManageMyHealth Primary Care Electronic Health Record, which is loaded from the MedTech GP Practice Management System
2. Indici's Single Electronic Health Record (SEHR), which is loaded from the Indici GP Practice Management System
3. CWS Clinical Document store in the Advance Directives Document Class



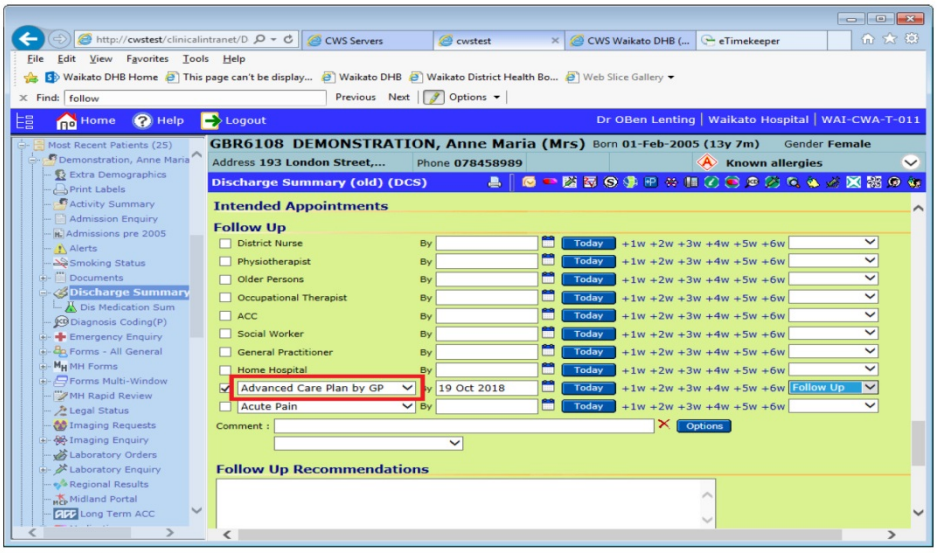
When the user clicks on it the documents will be shown in a continuous scroll with headers on a dark blue background where they come from in a reversed chronological order (latest document first).

The document in the image comes from within CWS's Clinical Document Store.



Discharge Summary (below)

A new option is created for the Follow Up section in the Discharge Summary to ask the GP to start or continue an Advance Care Planning procedure with the Patient.



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12. ACP Alert – PRIMARY CARE - READ codes

The following READ codes are utilised in primary care when documenting ACP discussions and plans in PMS:

Plan	READ Code
Advance Care Planning discussions	9X3.00
Advance Care Plan complete	9X4.00
Advance Directive / Living Will completed	9x.00
Enduring Power of Attorney completed	9W.00
Advance Care Planning declined	9X5.00

13. Step 4 – Using complete/ submit/ view / edit / remove / print

Recording information and sharing it with primary and secondary care providers and members of multidisciplinary teams is important to maximise the benefits of an ACP. Use any of the following:

- Via Individual Patient Portal
- Via General Practice
- Via paper copy
- On discharge from Waikato DHB, send a copy to the GP Practice with discharge summary form.

Print a copy of the plan, return the original to the individual and encourage them to share it with family / whānau.

Resource: Using advance care planning to guide care

14. Step 5 – Reviewing

Any ACP record should be subject to review and, if necessary, revision. This possibility and reasons why it may be needed can be made clear during the ACP discussions. Processes that ensure review and revision may also need to be developed. A record of who has copies of ACP documentation will facilitate future updating and review. The ACP can be reviewed at any time according to the individual's wishes and as necessary.

Consider reviewing or having further discussions about Advance Care Planning:

- If clinical circumstances change
- In the event of a significant life event
- At annual clinical and health assessment
- At comprehensive clinical assessment (e.g. InterRAI assessment)
- After hospitalisation
- If there are significant changes to the person's care needs

View the history of an ACP. Each time the plan is saved or approved at the GP Practice, the system records the version changes, the date they were made, and the person who made them.

- The person may need time for reflection and discussion after they receive this information
- If the person's circumstances change, the plan can be updated accordingly by the individual or with support from a healthcare worker.
- Healthcare workers must be sensitive to different cultural perspectives on illness, death and dying and on how end-of-life decisions are to be made, and by whom.

Resources:

- Advance Care Planning website
- How to - 5 steps
- Serious Illness Conversation Guide for Clinicians