

# Advance Care Planning Policy Development – Guidance for Disability Service Providers

Advance Care (AC) planning is starting to be used more by people with learning disabilities, and is an area of work that some disability service providers want to prepare for. This document has been developed to help guide disability service providers who wish to develop relevant policy.

The information below is separated into content areas related to the use of AC planning within disability services:

- Overarching policy statement
- Starting the AC planning process
- Roles and responsibilities
- Exclusions
- Documentation
- Review process

Each content area describes the type of policy decisions which need to be made, factors to consider when making decisions, and possible policy wording, which takes best-practice into account.

For more information on AC planning, please refer to <https://www.myacp.org.nz/>

## Overarching Policy Statement

### **Policy decisions:**

- Decide what your organisation believes and values about the planning process
- Decide what level of support/involvement your organisation is able to provide to people who want to develop an AC plan

### **Factors to consider:**

- AC planning is highly beneficial when people come to the end of their lives. Decision-making is made easier, people are more likely to be supported in the way that they wish to be, end of life experiences are more positive, and the situation is less stressful for carers and family. It is a process that can be successfully navigated by many people with learning disability, if they are given the right support.
- Although primary care providers (medical centres) usually help to facilitate the AC planning process (and receive funding to do so in some regions), people with learning disability often require additional time and specialised support to learn, to think, to talk about their options, and to record their choices. Collaboration between the primary care provider, the person, the disability service provider, and the person's family and whānau (when the person gives consent) will likely be required to achieve a successful outcome. Your contribution to this process may depend on the skills of the relevant primary care provider, a family's involvement, and the availability of your own staff to contribute.
- Not all primary health care services will have considered AC planning as an option for people with learning disability, and may want guidance on how to approach this.

**Possible policy content:**

We value of the process of having AC planning conversations to develop a shared understanding of people's end of life wishes. We will follow each person's wishes, as outlined in their AC plan.

We will encourage and support all people with learning disabilities, alongside their family and whānau and health professionals, to develop an AC plan. We will encourage this process to start as early as possible if people are diagnosed with serious or life-limiting health conditions, and as people age. When people's decision-making is interdependent, we will support the development of plans via a Supported Decision-Making (SDM) process.

**Starting the AC Planning Process****Policy decisions:**

- Decide who with, when, and how you will start the AC planning process
- Decide who, within your organisation, will initiate AC planning conversations, and what training or background are required of them
- Decide whether your organisation will provide support with both pro-active and re-active planning, or only reactive planning (when people are already unwell)

**Factors to consider:**

- Parts of an AC plan have legal standing (Advance Directives, nomination of an Enduring Power of Attorney, Wills). These legal decisions must be wholly the person's own and CANNOT be made by substitute decision-makers.
- Other parts of the AC planning process focus on people's values, beliefs, and what is important to them. Everyone can be supported to make decisions about these aspects of an AC plan, if an appropriate SDM supports are in place.
- People's decision-making capacity is not static, and can be developed/built upon. While someone may not understand enough to decide whether they want to be intubated, for example, they may understand enough to decide that they want to die at home if possible, or who they trust to make decisions for them, or who they wish to give a prized possession to after their death. Capacity/capability should be considered on a decision-by-decision basis, rather than an all-or-none basis, and only after a person has had the opportunity to learn.
- As a minimum, the decisions in an AC plan should include a) a person's values and what is important to them, b) who they would like to help make decisions for them if they are unable to do so themselves, and c) a person's treatment preferences if they were to become seriously unwell and unable to communicate their wishes (ie to have all available life-sustaining treatments, to have only treatments that maintain quality of life, to have comfort care only).
- People with learning disability are often wrongly assumed to not be able to make these choices, and are denied access to AC planning as a result. This contravenes their rights under the United Nations Convention on the Rights of Disabled Persons and the New Zealand Code of Health and Disability Consumers' Rights.
- Many people with learning disabilities will be able to understand and make decisions about the key components of AC planning if they are provided with support to meet their needs. There are many good resources that can help people to understand their options and to make their own choices. When existing resources don't work for a particular individual it is always possible to adapt information, to draw pictures, or to explain in simple language. These steps should

always be taken before deciding that someone cannot understand enough to make their own choices.

- Planning pro-actively (while people are younger and well) is less stressful and easier to navigate than when people are unwell. It also has the added benefit of building comfort with the topic, so that if/when people do become unwell it is easier to revisit the plan and update it.
- Middle-age is recommended as a good time to start thinking about pro-active AC planning.
- It is likely to take several conversations over a period of time before people choose to participate in AC planning.
- Not everyone will want to take part in AC planning.

### **Possible policy content:**

We will encourage and/or initiate AC planning conversations with people and their families and whānau:

- As early as possible after a person is diagnosed with a serious, deteriorating or life-limiting condition. In these situations, we will work with health professionals to ensure that the person is told their diagnosis and prognosis, is supported to understand what this means
- When a person is nearing the end of their life
- When a person reaches 45 years of age, and every 5 years following

All AC planning conversations will be initiated by people who have been trained and are able to do so with honesty, sensitivity, and respect.

## **Roles and Responsibilities**

### **Policy decisions:**

- Decide how your organisation will support the development of people's AC plans
- Decide the level/role of staff who are able to facilitate the AC planning process. For example, senior support workers, service managers, health advisors
- Decide the role of other staff

### **Factors to Consider:**

- AC planning is not a one-off conversation and can take some weeks or months to complete. It is important for people to have time to learn, think, talk to people they trust, and make choices that are right for them
- Within the general population health professionals usually introduce the AC planning process and follow up once decisions have been made. However, people with learning disability will often need additional time and targeted support to develop a valid plan (to learn, to fully understand their options, to weigh up the pros and cons of choices, and to record their final decisions). This is likely to require input from an additional person to help guide them or to co-ordinate the process – a trusted and informed staff person, a friend, or family or whānau member.
- Evidence is clear about who is best placed to co-ordinate/guide the AC planning process. These are people who:

- Have knowledge of AC planning (are trained and have completed the HQSC level one e-learning as well as a specific module related to ACP and disability)
- Have capacity to work alongside people with learning disability from time to time to help them learn about their options and work through decisions, or to share this responsibility with support workers or family and whānau (more likely to be a person from the disability service)
- Know the person
- Are trusted by the person
- Are objective and will not influence the person's decisions
- Your organisation may wish to include in policy the key components of an AC plan. These include:
  - Values - what is important to the person, and their cultural, spiritual, and personal beliefs, and the support they need to align with these
  - Concerns – any concerns or fears the person has about the future, related to health or other aspects
  - Goals – the person's priorities or goals for the future, including anything that is important for them to do before they die
  - Decision-making - how the person makes decisions, how much they wish to be involved in decision-making, who else they wish to take part in making decisions (including guardians or EPOA)
  - Care when dying – how the person wants to be cared for or treated in general, any specific wishes they have, advance directives (where appropriate)
  - Place of care – where the person wants to be cared for while unwell and when dying
  - After death – what the person would like regarding organ donation, care of their body, funeral wishes, how they wish to be remembered, plans for their property and belongings, and other important practical elements.

**Possible policy content:**

- We will identify staff to co-ordinate/guide the AC planning process with people who use our services
- Identified staff will complete training prior to their involvement in AC planning
- Identified staff will collaborate with the person's GP or medical specialist to support the development of an AC plan. They will:
  - Link with the appropriate health professionals (GP or specialist) and ensure open communication
  - Liaise with the person's family or whānau (when the person gives consent), to encourage and support their participation. In some instances, the person's family or whānau may prefer to take on the co-ordination/guiding aspect of the process. We will support them to do this
  - Ensure that the person is supported to learn about each component of the plan (using resources and materials that they can understand), think, and talk to people they trust, prior to making and recording decisions
  - Ensure that the person speaks directly with their GP or specialist about health/medical decisions
  - Support the person to have their decisions presented in a way that they can understand
  - Support the person to complete a full AC plan that covers the usual content that is expected and familiar to health professionals
  - Ensure that the person returns to their GP or specialist to have the plan checked, verified, signed, and recorded officially

## Exclusions

### **Policy decisions:**

- Decide under which circumstances a person would be excluded from AC planning, for example, children
- Decide whether there is a specific alternative process for anyone who is excluded from this policy
- Decide how your organisation will make decisions about who can/cannot take part in AC planning.

### **Factors to consider:**

- Alternative processes for people who are excluded from the policy
- When people are not able to make decisions independently, SDM processes may be effectively used to identify the person's preferences in many areas.

### **Possible policy content:**

The approach to AC planning that is described in this document is not intended for use with children and young people. Specialist advice should be sought when planning needs to occur for children or young people who are dying.

## Sharing and Storing the Plan

### **Policy decisions:**

- Decide where/how specific plan decisions (or the whole plan) will be stored/recorded, so that important information (especially advance directives or treatment preferences) is known about and can be accessed.
- Decide who is responsible for sharing the plan with health professionals and any others.

### **Factors to Consider:**

- A plan can only be implemented if it is known about and can be accessed by health professionals at the time that a person becomes unwell. It is therefore important that it is shared with them, and with all others that may need to advocate on their behalf (with consent from the person).
- In the South Island, health professionals will enter the AC plan into the person's electronic health record. It is therefore accessible to all health professionals, including ambulance staff. This is not possible in all parts of New Zealand. If a person travels outside of the South Island their plan will not be electronically accessible to other health professionals, and a paper copy will need to be carried.
- Some people may wish to keep aspects of their AC plan private, and it may not be appropriate for the whole plan to be accessible to all staff.

### **Possible policy content:**

- We will encourage the person to share their plan with the relevant health professionals, and for this to be recorded in the electronic health record

- We will encourage the person to share their plan, or relevant aspects of their plan, with other relevant individuals or services
- We will record in the person's individual file:
  - Where the plan is stored (for ease of access in case of medical emergency)
  - Any aspects of the plan that are relevant to our service provisions, or on which we may need to act
- In the event of a medical emergency we will inform first responders and/or health professionals of the AC plan, and provide a copy (when necessary)

## **Reviewing the Plan**

### **Policy decisions:**

- Decide how often you will encourage/recommend/require a review of the person's plan

### **Factors to consider:**

- There are currently no specific recommendations on how often a person's plan should be reviewed, except in circumstances where a person's health situation has changed.
- You may wish to link the review to other planning cycles within your organisation

### **Possible policy content:**

We will encourage and support a review of people's AC Plan:

- At least every 5 years
- If there are changes in the person's health
- If the person wishes to change a decision that is recorded in their AC plan.

When a person wishes to make changes to their plan, we will ensure that this is communicated to their health team, and all relevant others (with consent from the person). We will ensure that the plan and any file notes are updated.