



Website Summary: Care Recipients & Close Support

Section 1: Introduction to advance care planning

Advance care planning is a process where people talk about their wishes and what they would like for their future care. This is important if there is a chance the person's health might get worse and they may not be well enough to share their wishes in future.

advance care planning

Voluntary: a person can choose if they want to take part.

Age: for anyone over 18.

More important for: older adults, frail individuals and adults who have a long-term health condition that might get worse.

Person-centred: considers the person's future wishes.

Honest: wishes are not always possible, so planning gives you a chance to talk about other options.

Open to all: anyone can start a conversation including a person making a plan, those important to them and health professionals.

Changeable: Plans can and should be updated if wishes change.

Not just about care: Plans cover legal, spiritual, financial and other personal matters.

Who takes part:



The person making the plan

This person is at the heart of the conversation



People important to that person

This might include a partner, family, friends, caregivers. etc



Healthcare professionals

This may include a community nurse, a general Practitioner (GP) or specialist involved in care



Legal professionals

A solicitor may be involved if the person would like to arrange for someone important to them to make decisions on their behalf

Section 2: benefits of advance care planning

- You are in control: Recording your wishes will help you to feel in control over your future.
- Peace of mind: Helps those important to you as they will know your wishes in case they have to make decisions for you in future.
- Healthcare staff will know your wishes about what treatments and care you want.
- Early conversations help you to know what is available in the future and think about other options if your wishes are not possible.
- Rights are protected: this is important if you are not able to voice your wishes in the future.
- Comfort: those important to you will know they are following your wishes.
- Reduces conflict between those important to you as your decisions will be clear.

Section 3: addressing the challenges of advance care planning

You might not feel ready: It's your choice to make a plan. It will be at your speed and you can stop and come back to it at any time.

Your wishes might not be possible: Talking about your wishes early will give health care staff a chance to talk to you about whether your wishes can be met and they can suggest other options.

You might not know who to talk to about ACP: Have the conversation with healthcare staff that you know and trust.

There might be a disagreement about what is best: These conversations can be difficult. Everyone needs space to voice their opinions, but the focus should be on the person making the plan.

Section 4: advance care planning discussions

The right time for advance care planning is **when you feel ready**. This will be different for everyone.

This might be:

- if you are in poor health
- have a new diagnosis

- an admission to hospital
- a long-term health condition getting worse

Whose job is it to start the conversation?

Anyone can start an advance care planning conversation. If you are thinking about it, you can talk to someone important to you or a healthcare professional that you trust.

Before the conversation

Plan: Think about what you would like to discuss before you meet. Write this down or share it with someone important to you.

Make sure you are in the right frame of mind: this may depend on how you are feeling on the day. You might change your mind and that is okay.

Decide who you would like to talk to: this might be a doctor or nurse that you know and trust. Maybe a nurse who visits you at home.

Bring someone important to you to join the conversation. They can help you talk through your wishes, and it will be useful for them to know what you want.

Having the conversation

Advance care planning can happen over many conversations. They can happen casually at any time with someone important to you or conversations can be formal. Formal conversations are usually organised with the health care staff who provide care (for example, a community nurse) and/or legal professionals (who might be needed to provide information on making a will or a power of attorney).

If you are unsure about something or would like more information don't be afraid to ask. There is no such thing as a silly question when having these conversations.

Remember: You can stop the conversation at **any time** if you feel anxious or uncomfortable.

Advance care planning for someone with a cognitive impairment

Cognitive impairment is a condition which affects a person's mental abilities such as their memory and thinking. This includes Dementia, a stroke or brain injury. If you are planning an advance care planning

conversation with someone important to you who has a cognitive impairment, then you should do the following:

1. Include the person in the conversation as much as possible.
2. Speak slowly.
3. Ask short questions and give them time to answer.
4. Talk about what is important to the person and their health.
5. Repeat back what you think they have said.
6. Look to see if they are upset or worried about any part of the conversation.
7. Be clear and use words that the person will understand.

With thanks to Dr Karen Harrison Denning, Dementia UK.

Respecting everyone in the advance care planning process

No one should assume they know what a person's wishes are based on their gender, ethnicity, sexual orientation, cultural or religious background.

Section 5: what is talked about in an advance care plan?

The information below includes some phrases you will hear (along with their meaning) to help you to feel better prepared for when you take part in these conversations. You might talk about one or more of these topics when discussing an advance care plan.

> Statement of wishes and preferences

This records your wishes about what matters to you in terms of your future decisions and choices.

> Realistic Treatment Options

This discusses the benefits of different treatment options and if a treatment option may not be suitable in the future.

> Emergency care planning

Contains details of the care and treatment you would prefer, and wish to refuse, in an emergency.

> Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

This involves a discussion about cardiopulmonary resuscitation (CPR) and your views on attempting CPR if your heart and breathing stops. If you do not want cardiopulmonary resuscitation to be attempted if your heart and breathing stops a DNACPR form recommending this can be included in your advance care plan.

> Advance decision to refuse treatment

This provides information on any treatment you may not want and in what situation.

> Mental Capacity

This is a legal term. If a person has mental capacity, it means that they can understand the decision that they are making. If it is decided that someone does not have mental capacity, then other people (usually a health care professional along with the people close to the person) make decisions for them in their 'best interests'.

> Best interests decision making

This happens when a choice is made for someone who is not able to make decisions for themselves because they do not have mental capacity. Any decision should be taken with the person's best interests in mind.

> Power of Attorney

This is a legal document where a person names someone to make decisions for them if they become too unwell.

Section 6: self-care

Thinking about and planning for the future can be difficult. It may bring up many emotions and you might feel worried or sad. It is important that you look after yourself and your wellbeing. If you are feeling very worried or overwhelmed, it is important that you share this with someone you trust or speak to your general practitioner (GP) for professional support.

There are things you can do to support your mental and physical health. Below are some ideas that you might want to try:



Walking or running

Exercise can improve your physical and mental health. Try a 30 minute brisk walk or run every day. The 'Couch to 5k' program has encouraged lots of people to get active for the first time.



Sleep

A good night's sleep can help you to wake feeling refreshed and ready for the day ahead. Have a think about your bedtime routine and if this can be changed to help you get a better night sleep.



Yoga

Yoga has been shown to reduce stress and boost physical and mental wellbeing.



Mindfulness

Can help to improve mental health as it helps you to tune in to what you are thinking and feeling in the present moment.



Rest

Sleeping should not be your only form of rest. Take some time for yourself when you can. Put your feet up and watch your favourite TV programme, read a book, or have a cup of tea.

Building resilience

Resilience is a person's ability to handle difficult situations. We build resilience when faced with hard times.

People with greater resilience may find it easier to deal with stressful situations and may recover from these quicker.

Source: adapted from the [QUB resilience resource](#).

Tips for building resilience:



Keep things in perspective – it can be easy to overthink and jump to worst case thinking when dealing with lots of stress. Writing out your thoughts may help you to make sense of a difficult situation.



Use your support networks (for example: family, friends and people caring for you) when you need them.



Make time for yourself: eat well, get enough sleep, rest, and do something you enjoy.



Be kind to yourself.

More information can be found within the resources section of the website:

<https://www.acpcommunity.co.uk/test/close-support/resources/>