



Living well, dying well

Talking to people who are important
to you about what matters most,
both now and in the future.



Contents

Starting the conversation

What is advance care planning?

So, what does planning
to live and die well mean?

What if I want my family or health
care team to make any decisions
for me?

Who is important to me?

What should I include in my living
well, dying well plan?

Starting my living well,
dying well plan

What next?

Starting the conversation

What matters most to you when you think about living well?

This leaflet has been co-produced with older people and people that care for them, such as their family members. It is designed to help you to think about the important things you would like those close to you, and those caring for you, to know about what makes life good for you right now, as well as what you would want to happen if you lost consciousness or the capacity to make your own decisions in the future.



What is advance care planning?

This idea of thinking ahead is sometimes known as advance care planning, but it can be confusing.

For many people it means thinking ahead and choosing what kind of care or medical treatments they would, or wouldn't, want, if they were to lose the ability to make their own health care decisions in the future. For other people it's about arranging their will or choosing their funeral service. All these things can be important for different people, but many older people living with increasing needs are far more interested in thinking about living well now than what might potentially happen in the future. That's why we focus on planning both to **live and die** well.



So, what does planning to live and die well mean?

Firstly, it is not just about medical decision making and funerals (unless you want it to be!).

It's about what matters most to you so that you can live your best life from now until the moment you die. That might include things such as: how and where you like to live, what you like to be called, your favourite food, people and communities who are important to you, things you enjoy doing, and things you'd prefer not to do. It also might involve thinking about practical adaptations you need at home, through to what medical treatments you would prefer to have, for example, artificial feeding or hydration, or not have, for example, cardiopulmonary resuscitation (CPR), which are chest compressions given in an emergency to try to restart the heart.*

Secondly, and importantly, planning to live and die well includes who you are going to tell about what matters most to you. Understanding your preferences and needs will help the people who are important to you, and any care providers, to prioritise your wishes and help you live the way that matters most to you, should you become too unwell or lose the capacity to make your own decisions in the future.

**Deciding to start CPR is a medical decision that will be made by the clinical team at the time.*

“You’re actually planning towards, not the very end, but sort of from now, step by step, from now to what is the end, whenever that may be.”

(Helen, wife)



What if I want my family or health care team to make any decisions for me?

Many older people say that rather than planning for their future care, they would rather those important to them, or their care team, make decisions for them if they lost the ability to make their own decisions in the future.

“They’ve all got their heads screwed on, and they know what’s best, and they’d say, you know, he’s better off this way, better off that way, and I trust them entirely...”

(James, older person)

But loved ones can find making these decisions difficult, especially if the older person has not discussed their preferences with them first. These situations can leave many people feeling worried that they may not be making the right decisions, and can lead to you receiving treatments you might not have wanted, or being cared for in a place that you might not want to be. Most people, family, loved ones and friends, say it is less of a burden to them if they know what the person wants and needs. If possible, it’s best to make your wishes known in case you are too unwell to do so in the future.

“I feel like my mother doesn’t want to burden me. But for me it’s less of a burden if I really know what’s happening with her and what she would like and what her needs are. If I’m trying to guess them and then something awful happens, I’d feel terrible because I didn’t realise.”

(Jenny, daughter)

Who is important to me?

As you start thinking about what matters most to you, think also about who you would like to share this with.

Use the space below to write down these important people. This could include your family, friends, neighbours, GP, care team etc. By having a conversation with someone you are comfortable talking to, you can begin to develop a plan.



What should I include in my living well, dying well plan?

Anything that is important for you. For some people, it is important that they remain at home, surrounded by the things and people they love. They'd rather not go to hospital at all, and may ask their care team to complete a "do not attempt cardiopulmonary resuscitation" form (DNACPR), which means if your heart or breathing stops, your care team will not try to restart it. They are happy to make some adaptations to their home or routines to help them maintain their independence, such as arranging for someone to clean the home, help them wash, or for equipment to help them get around the home.

"If I can even get up off the chair and walk around with a Zimmer frame, I'd love to make a cup of tea for my wife."

(Bill, older person)

What matters most to others might be to live as long as possible, maybe they are waiting for a particular event, such as a child to be born, or simply love living, and so are happy to undertake medical treatments or procedures, and multiple hospital stays as needed. Others want to be somewhere with lots going on, with lots of people and activities, so may want to remain in their community or move to a retirement complex or care home.

"I dread the day that might come, when I will not be able to get out of bed. That's why I'm doing these exercises quite, earnestly, but that [being confined to bed] really would be the last straw for me."

(Grace, older person)

"I want to be at home with my wife, but if she wasn't here, I don't know. I think I'd rather be with lots of other people, so maybe a care home?"

(Richard, older person)

Starting my living well, dying well plan

What matters most to you will be different to what matters most to someone else. Use the space below to write down what matters most to you when you think about living and dying well. Remember, you can always change your living well, dying well plan if what matters to you changes. You can use this to help start a conversation about your preferences with those close to you and those you trust to carry out your wishes, or example your GP.

What next?

You can use this leaflet to think about what matters most to you, and who you would like to discuss that with and as a way to start the conversation.

It can be hard to start talking about living and dying well, but starting with what matters most to you right now, can be helpful.

Once you have a better idea of your preferences, you can access lots of excellent leaflets, booklets and websites that provide useful information, depending on what matters most to you. Do also speak with your care provider, that might be your GP, specialist nurse or community team. Tell them what is important to you, and they will be able to point you to the most useful information for documenting your wishes.

Use the space below to write down any questions you have from reading this leaflet, and use this to help you and those important to you to plan for living and dying well, so that you receive the care and support you want, when you want it.



FUNDED BY

NIHR | National Institute for
Health and Care Research

This research was funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey, Sussex. The study was also supported by an NIHR Clinical Doctoral Research Fellowship (ICA-CDRF-2017-03-012). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Published September 2024.