UNIVERSITY OF SURREY

Helping others plan for living well and dying well

Helping those important to you to talk about what matters most to them so they can plan their care - both now and in the future.

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Starting the conversation

Older people living with multiple care needs are often also living with frailty. This means they are much more likely to become suddenly unwell than a person of the same age who isn't frail.

They are more likely to experience multiple infections, are less likely to fully recover from illnesses, may start to fall (or fall more), may find themselves experiencing multiple unplanned hospital admissions (which they may or may not want), and may lose the capacity to make their own decisions about their care. Advance care planning, or talking about what matters most and planning for the future, is therefore really important, but it can also be really hard.

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 support the person you care for to start thinking about what matters most to them - the important things they would like those caring for them to know about what makes life good for them right now - as well as what they would want to happen if they were to lose consciousness or otherwise lose their capacity to make their own decisions.

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 frailty 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, it's about what matters most to the older person so that they can live their best life from now until the moment they die.

That might include how and where they would like to live, what they would like to be called, their favourite food, people and communities who are important to them, things they enjoy doing, and things they'd prefer not to do. It also might involve thinking about practical adaptations they might need to make to their home, through to what medical procedures they 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.*

**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)

Why should I try to start or support conversations about living and dying well?

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 capacity to make their own decisions about their care.

"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 the older person receiving treatments they might not have wanted, or being cared for in a place that they did not want to be.

While starting these conversations can feel uncomfortable, 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, so they are not left trying to guess 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)

Top tips for supporting living well and dying well conversations:

We talked to older people living with frailty and those who cared for them, and they suggested the following top tips:

1

Start conversations early, when the person is well

This gives the older person the greatest chance to think and talk about what matters most to them, at their own pace, and to make and revise decisions over time.

2

Prepare for the first conversation

Talking about living and dying can be difficult. Older people living with frailty said they appreciated time to prepare for conversations so they could think about what matters most to them. You could give them the *Living well, dying well* leaflet and suggest they read it, or suggest you read it together. Some carers said discussing what was most important to themselves, and the things they would like others to know about their future care choices, helped them start conversations.

3

Start the first conversation with living well

Older people living with frailty are often more interested in living well day to day than planning for the future. It can be helpful to start any planning conversation with questions like “What matters most to you?”, “What makes today a good day?”, “What helps you live well now?”, or “What can others do to help and support you to live well?”. Starting with living well first means conversations can take place anywhere, such as on a car journey or as part of a wider family discussion. Conversations don’t need to be formal or focus only on planning.

4 Make planning for living well and dying well relevant

Older people living with frailty may not believe planning ahead is relevant to them. It can help to reflect with them about their recent experiences of ill health or a recent hospital stay, what they found acceptable and what they would rather avoid in the future. Some older people find hearing about other people's experiences helpful, how their friends or neighbours experienced health care, or by reading and reflecting on stories. Two examples some people found helpful are told by Florence and Fred below:

"I want to remain at home for my care until I die, being helped by my family and care team. If I get really unwell, so that I'm not able to be as independent as I am now, I'd rather move to a care home, I don't want my family to have to care for me in that way. I don't want to go to hospital again and I don't want CPR. I don't mind having antibiotics or something at home, but nothing that needs the hospital. I know it might shorten my life, but I don't want to go back."

(Florence)

"I've been in hospital quite a few times over the last few months. I'd rather not go back again, but me and Debbie, my wife, want me to have every opportunity to live for as long as possible. I want any treatments that I need. I'm ok going into intensive care, having a tube to feed me if I can't swallow, and I want CPR. I know it might not work, and I might never come out of intensive care, but I want every chance, I want quality and quantity of life, but quantity is the most important."

(Fred)

5 Hoping for the best while planning for other outcomes

As well as planning for living well, it is important to understand what the person's future care wishes are so that you can support them to be cared for in the way they would want to be both now and in the future. You might want to ask "If you become ill, or not as able as you are now, what would you like to happen? ...what would you prefer to avoid?" or, "If you weren't able to make decisions for yourself in the future, who would you like to speak for you?". This conversation might include checking if the person has, or would like their care team to complete, a "do not attempt cardiopulmonary resuscitation" form (DNACPR), which means if their heart or breathing stopped, their care team would not try to restart it. Further details regarding DNACPR can be found in the Resources section.

6 Decision-making

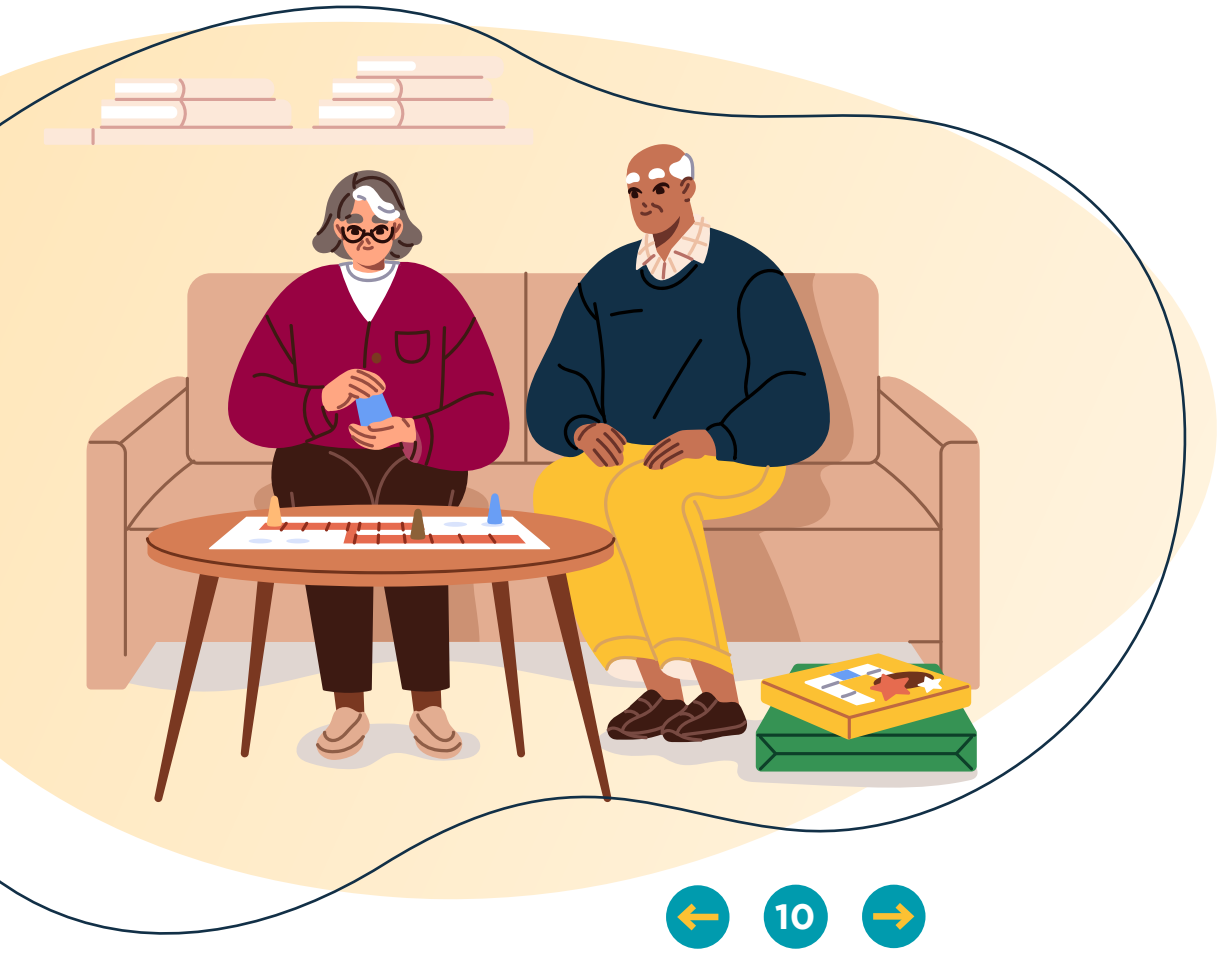
Many older people would rather those important to them, or their care team, make decisions for them if they lose capacity. If they would like you, or someone else, to have the legal authority to make health and care decisions for them in this situation, they will need to complete and submit a Lasting Power of Attorney for Health and Welfare. Details of this form can be found in the Resources section.

What next?

The '*Living well, dying well: Talking to people who are important to you about what matters most, both now and in the future*' leaflet has been co-produced with older people living with frailty and people that care for them, and is designed to help older people living with frailty to engage with conversations about living well and dying well. Share this with the person you care for as a way to start the conversations.

The Resources section below contains links to several documents. While these resources were not specifically developed for older people living with frailty, the carers we worked with found them helpful in preparing the older person and themselves for living and dying well conversations.

Do also encourage the older person to speak to their care provider, for example, their GP, specialist nurse or community team. They need to know what is important to the older person so they can support the care the older person wants, and will also be able to point them, and yourself, to the most useful information for documenting their wishes.



Resources

Resources about what planning for the future means and can cover

Thinking about end of life. Age UK (2023)

Age UK have multiple helpful online resources for older people. Our carers particularly liked this one which they thought was very clear, easy to read, and had a positive tone.

www.ageuk.org.uk/globalassets/age-uk/documents/information-guides/ageukig51_thinking_about_end_of_life_inf.pdf

Planning for the end of life. Thinking ahead now for peace of mind later. Independent Age (2022)

This booklet has lots of helpful information. Our carers thought it was easy to read and well presented but felt it may be too long for some older people with frailty and may be more relevant for their carer to refer to.

www.independentage.org/get-advice/planning-for-end-of-life

Planning ahead: My treatment and care. Compassion in dying (2023)

This booklet is more extensive than others and went into greater depth about different elements someone might want to think of when planning for the future. Our carers thought it was "particularly good", warm, engaging, and liked the "stories", but also felt this was better for the carer to use with the older person, or to refer to, as it might be too extensive for most older people living with frailty.

www.compassionindying.org.uk/how-we-can-help/planning-ahead/#why-should-i-plan-for-my-treatment-and-care

Resources to help start the conversation

My future Wishes. Conversation Starter Pack. Tools to enable people with any long term health condition to discuss and plan future wishes. West Yorkshire and Harrogate Health and Care Partnership and Alzheimer's Society

This pack has four topic cards that help people to think and talk about planning for the future. Our carers liked the questions and space for notes, and one said she "would definitely use".

www.wypartnership.co.uk/application/files/9915/8615/3369/My_Future_Wishes_Conversation_Starter_Pack_04.20.pdf

Starting the conversation. Planning ahead for your care and treatment. Compassion in dying (2023)

This is another conversation pack that has more information as to why you might want to start the conversation, through to having the conversation with a GP, and what's next. Our carers thought it had a good layout, was accessible and, although a little wordy, it had a "nice tone".

www.compassionindying.org.uk/wp-content/uploads/starting-the-conversation-guide-v1.2.pdf

Resources

Resources to document the conversation

My Future Wishes.
Advance Care Plan. What matters? Thinking ahead...
West Yorkshire and Harrogate Health and Care Partnership (2020)

This is a form to record a person's preferences and care wishes. Our carers liked the wording and found it easy to read.

www.wypartnership.co.uk/application/files/6017/2199/7374/My_future_wishes_V6_July_2024_FINALv2.pdf

Other resources

To make, register or end a lasting power of attorney:

www.gov.uk/power-of-attorney

This link covers both types of lasting power of attorney, health and welfare, and finances and property.

To learn more about Advance Decisions to Refuse Treatment (Living Wills):

www.nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/

For further information on making a will, lasting power of attorney, financial support, living wills, what happens when someone dies and coping with bereavement:

www.ageuk.org.uk/information-advice/money-legal/end-of-life-planning/

For information about getting help at home, home adaptions, moving to a care home and other practical questions:

www.independentage.org/get-advice/end-of-life/considering-where-to-live-at-end-of-your-life

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