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How to talk about your end of life care wishes

You might not like to think about it but there may come a time when you're too unwell to tell those caring for you what you do and don't want.

It's important to make sure those around you - your family, friends and doctor - know your wishes whilst you are able.

As the Specialist Information and Support Nurse at Compassion in Dying, here's how to make it easier to talk about your end of life care and treatment wishes for the future.

Start planning

It's a good idea to start thinking about your wishes for the future as early as possible. Every adult has the right to plan and you don't need to be elderly or have a life-limiting health condition to do so, so why not start now?

You don't need to do it all at once - you can pause and revisit it if you need to.

Think about your wishes. You can start by thinking about what would be important for someone to know if they were caring for you. This might include:

- Food you like to eat.
- Any values or beliefs that affect the way you want to be cared for.
- Where you would want to be cared for at the end of your life.
- Who you would want around you.
- Your wishes for medical treatment.

Write it down

It helps to write down your wishes before you start talking to others. You can refer to your notes and use these to guide your conversation.

Talking about your wishes is very important, but even more crucial is writing them down and sharing copies with the important people in your life.

If you decide that you would want to refuse treatment, make sure you record this in an Advance Decision, and write down anything else that is important to you regarding your healthcare in an Advance Statement.

An Advance Decision, sometimes known as a Living Will or Advance Directive, allows you to record any medical treatments that you don't want to have in the future. It is legally binding, so doctors have to follow it.

An Advance Statement allows you to record important information about your future care. This can include where you'd like to be cared for at the end of your life and things that are important to your well-being such as information about your diet and activities that make you feel good. Though not legally binding, it should be taken into account when decisions are being made about your care and treatment.

Compassion in Dying can provide free Advance Decision and Advance Statement forms which can be ordered via their website or information line. You can also complete an Advance Decision online at your own pace at mydecisions.org.uk.

Remember you can change your mind and update your Advance Decision and Advance Statement at any time.

Preparing to talk

Finding the right moment, when you are relaxed and have plenty of time to talk, is important. Talking in a neutral place, like on a car journey or dog walk, can help you feel at ease.

Don't worry if you don't know the perfect time or place to have the whole conversation - sometimes there isn't one. You can always pause and come back to it later or somewhere else.

Some people might have different views to you or be unsure why you want to have the conversation so it's good to be prepared for this. Allow them to ask questions but remember that this is about you and what you want. Don't be put off making your plans just because someone disagrees with you.

Speak to your doctor

We recommend that everyone discusses their wishes with their GP. You can talk things through and ask questions. You should be prepared to explain your wishes. Just as with your family members, some doctors may not understand right away. If you get a negative reaction, you can call Compassion in Dying's information line for support.

Once you've written down your wishes, you can ask for them to be added to your patient record. You can also contact your local Ambulance Trust to ask that they record a copy, which is particularly advisable if you have a lifelimiting condition or are likely to receive emergency medical attention.

Discussing your wishes with the important people in your life can help you to make decisions about your healthcare and treatment and give you peace of mind to know that others understand what matters most to you.

Compassion in Dying offers more information and support on talking about your care wishes on their website and via their free information line, 0800 999 2434.

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