

STARTING THE CONVERSATION:

PLANNING AHEAD FOR **YOUR** FUTURE TREATMENT AND CARE



CONTENTS

PAGE

Introduction	2
Why is it important to have the conversation?	3
Before I start: Thinking about my wishes and getting ready to talk	5
Having the conversation with people I'm close to	7
Having the conversation with my doctor	18
What next? Recording my wishes	23

How can we help?

If you would like to talk to someone about your wishes and planning ahead you can contact Compassion in Dying's Information Line on:

T 0800 999 2434

E info@compassionindying.org.uk

INTRODUCTION

This booklet aims to support you to talk about your wishes for care and treatment with your family, friends and doctor.

You may have thoughts about where you want to be cared for, how you would like to be treated if something happens to you, or what is important to you at the end of life. In the future, you could become unable to explain what you want or make these decisions for yourself. Talking about what is important to you helps make sure that people understand what you want, and can respect your wishes.

Some people find talking about their wishes easy. Others find it more difficult. You may feel worried about upsetting people you care about, that your family will not be supportive or that they will disagree with what you want. Whatever your thoughts and feelings are, it is important to remember that there is no right or wrong way to have the conversation. Everyone is different.

Many people decide, once they have had the conversation, to put their wishes in writing. This is an important step because it will help make sure that your wishes are clear and that they can be followed by healthcare professionals. This booklet explains the different ways you can do this.

When writing this booklet we spoke to over 300 people about their experiences of discussing their wishes for health and care. The quotes used are taken from the insights they shared.

WHY IS IT IMPORTANT TO HAVE THE CONVERSATION?



Talking about your wishes for care and treatment is important for both you and the people around you.

For you, talking about your wishes can:

- **Help you to make informed decisions** in your own time by considering your options.
- **Give you control** over the care and treatment you receive, whether that is tomorrow or further in the future.
- **Give you peace of mind** that you have taken steps to make sure your wishes are known about, recorded and respected.

For those close to you, talking about your wishes can:

- **Help them to feel involved** in your decisions and to understand your wishes.
- **Make sure they are not left guessing** what you want if doctors ask them to help make a decision about your care or treatment.

I felt it was better not to talk about things in case it made them happen. But when I did, I felt relieved. It wasn't without challenges, but it's my life and I want my family to know what's important to me.

"Telling our loved ones our wishes helps them have the confidence and comfort to know they're doing what we want them to do."

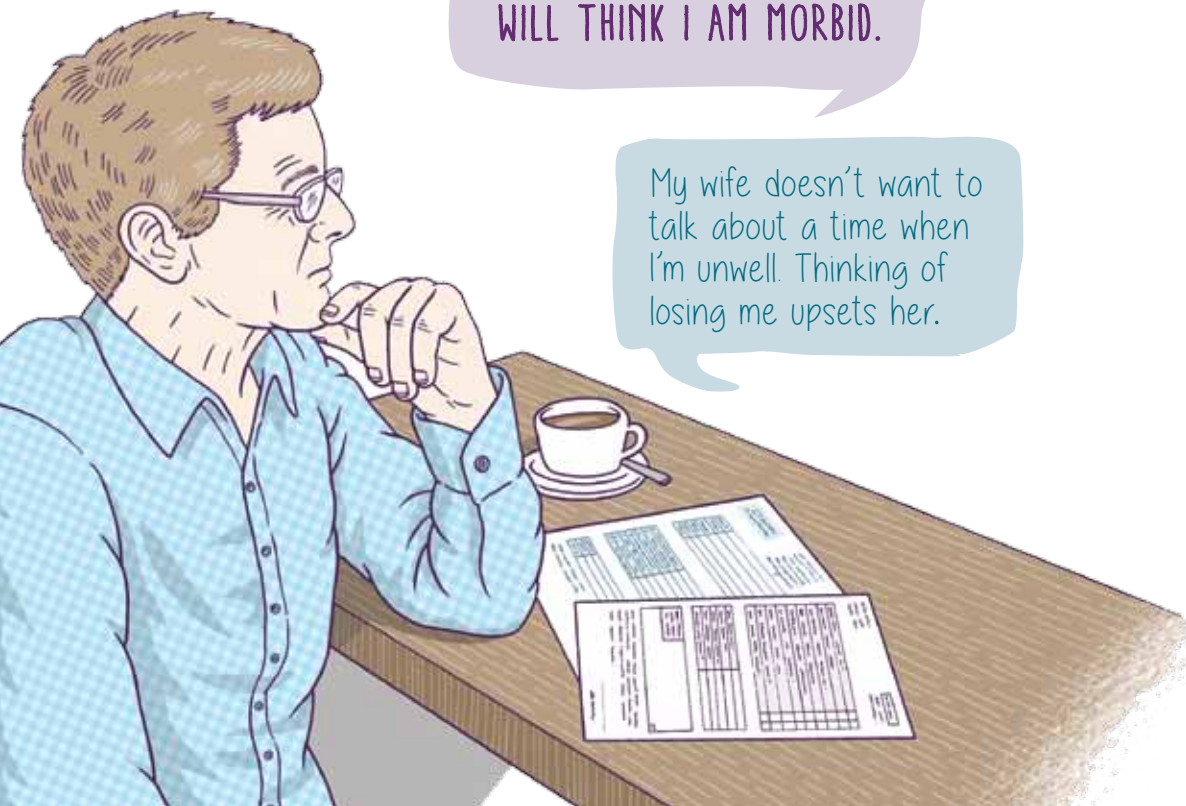
IT FELT EMPOWERING, LIKE I HAD TAKEN CONTROL. IT ALLOWED ME TO GET ON WITH ENJOYING LIVING NOW.

BEFORE I START: THINKING ABOUT MY WISHES AND GETTING READY TO TALK

Some people find it easier than others to talk about the future and what might happen if they are near the end of life. If you have concerns about starting such a conversation, you are not alone:

I'M WORRIED MY FRIENDS WILL THINK I AM MORBID.

My wife doesn't want to talk about a time when I'm unwell. Thinking of losing me upsets her.



WHAT DO I WANT?

Before you start the conversation, it may be helpful to think about what you want and what you are going to say.

You could start by thinking about what would be important for someone to know if they were caring for you, such as:

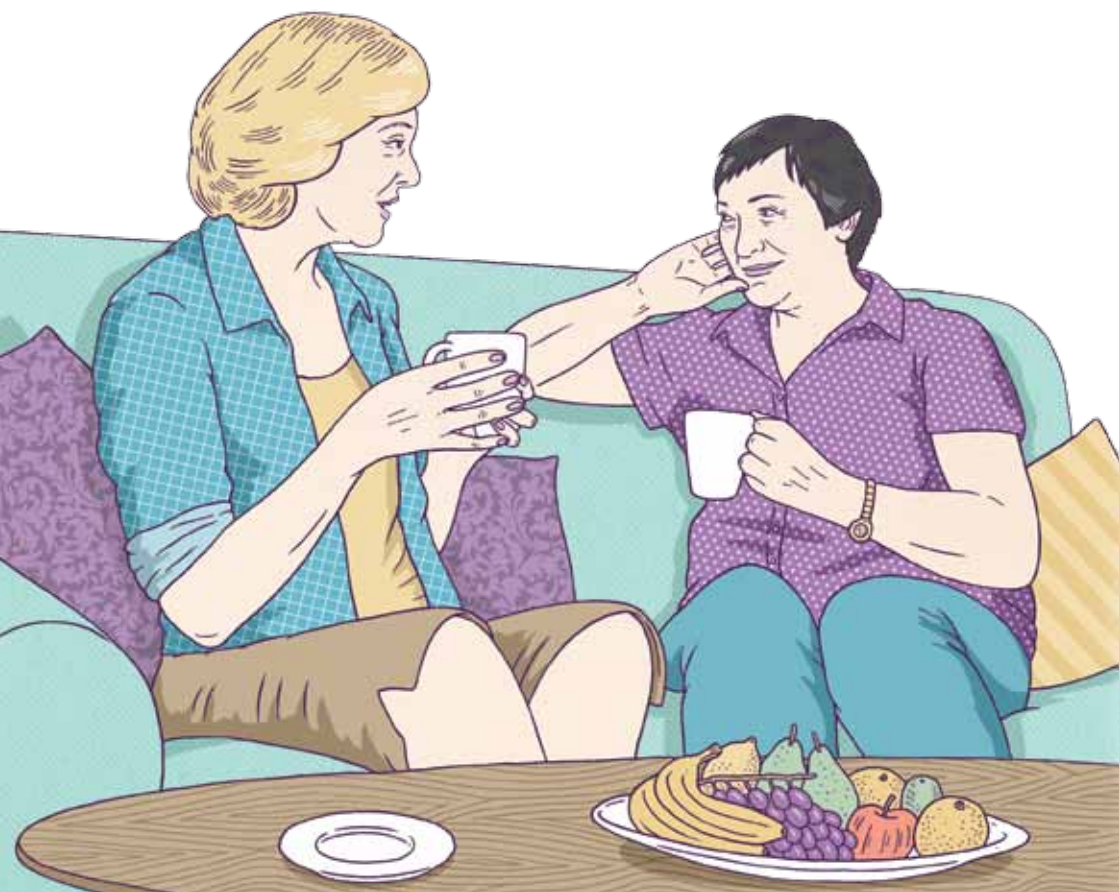
- Day-to-day things like the food you would like to eat or the clothes you would like to wear.

- Any values or beliefs that affect the way you want to be cared for.
- What is important to you in the last days and hours of life, for example where you want to be cared for or who you would like to be with you.
- Your wishes for medical treatment, for example there may be some treatments that you do not want to be given.

You may also find it helpful to write down what you want to say.

THINK ABOUT WHAT YOU WANT AND GET IT CLEAR IN YOUR MIND – SO YOU CAN PRESENT YOUR THOUGHTS CLEARLY.

first, write down what you have thought about, so you have it all straight before you speak to anyone else.



HAVING THE CONVERSATION WITH PEOPLE I'M CLOSE TO

This section offers ideas from real people that might help you to start your conversation. Some of the suggestions and opinions say opposite things but we have included them because there is no right or wrong way to do it – it is important that you do what feels right for you.

START EARLY

Losing the ability to make decisions for yourself can happen unexpectedly, and thinking about your wishes can take time, so it is best to begin as early as you can.

Start as soon as possible. Ideally, long before you have a life threatening illness. That way the subject has been broached when the end of life seems a long way off, so the whole topic is hypothetical and feels much easier to cope with.

“Do it before it is too late. We never know what’s around the corner. Not doing it could mean your wishes aren’t respected – that’s far worse than discussing a sensitive subject in your own time.”

Don’t rush, it’s a process.

GIVE PEOPLE WARNING THAT YOU WANT TO TALK

Gently letting someone know what you want to talk about a few days or weeks before you start can help them prepare for the conversation.

FINDING THE RIGHT MOMENT IS CRUCIAL. A SHORT 'WARNING' THAT YOU WOULD LIKE TO TALK ABOUT END-OF-LIFE WISHES SOME DAYS BEFORE THE DISCUSSION MIGHT HELP SO IT DOESN'T COME AS A SHOCK.

"Drop a few little hints or ideas into normal conversation beforehand so they get used to you talking about the subject before you have a full conversation."



LITTLE AND OFTEN

Having a long conversation about a sensitive or emotional issue can be tiring. It may be helpful to talk about your wishes in a series of shorter conversations.

"Take time and be patient. If they are finding it hard, just leave it and come back to it another day."



FIND A GOOD TIME AND PLACE

Finding the right moment, when you are relaxed and have plenty of time, can help you start the conversation.

Car journeys are a good time as you're together but not face-to-face.

Choose a time when people are together or if you feel it is going to be a difficult conversation, choose your moment with each individual.

I SPOKE TO MY HUSBAND WHEN WE WERE WALKING THE DOG. IT HELPED BECAUSE HE COULD THINK ABOUT WHAT I WAS SAYING WITHOUT FEELING PRESSURE TO FILL ANY SILENCE.

MAKE TALKING ABOUT YOUR WISHES PART OF YOUR EVERYDAY PLANNING

When we talk about 'putting our affairs in order', we often focus on what will happen to our money and property. Thinking about planning ahead for our wellbeing in this way can make it seem more 'everyday' and easier to talk about.

YOU ARE MORE IMPORTANT THAN YOUR MONEY OR YOUR PROPERTY, YET YOU'RE PROBABLY MORE COMFORTABLE TALKING ABOUT MAKING A WILL THAN YOU ARE TALKING ABOUT YOUR CARE WHEN YOU DIE. THE TWO ARE REALLY NO DIFFERENT.

The more naturally you speak of it, the easier it gets and, even if they don't like to hear it, the family will at least know what you want to happen.

Make it as matter of fact as possible - "I've decided ..." - rather than opening a discussion. Some people get embarrassed if they think you rely on their opinion.



RELATE THE CONVERSATION TO SOMETHING FAMILIAR

Relating a topic to something in our everyday lives can make it easier to talk about and can help others to understand the importance of it.

BEGIN BY REFERENCING A SHARED EXPERIENCE OF A CLOSE FRIEND OR RELATIVE FOR EXAMPLE "IF I WERE IN THEIR SITUATION, I WOULDN'T WANT THAT. I WANT TO MAKE SURE THAT IF I'M SERIOUSLY ILL..."

Watching a TV programme, reading an article, hearing something on the news... anything to open the discussion.

"I SAID "SINCE LOSING MY FRIEND, I'D LIKE SOMEONE CLOSE TO ME TO KNOW WHAT MY HOPES AND WISHES ARE. HAVE YOU EVER THOUGHT ABOUT THIS BEFORE?"... THEN IT NATURALLY SEEMED TO CONTINUE."

BE CLEAR ABOUT WHAT YOU WANT AND DON'T GIVE UP

Although conversations can be difficult to get started, they can also get easier as you go along. It may take a little or a lot of bravery to begin, but it is an important step in making sure that other people know what you want.

DON'T ALLOW SOMEONE ELSE'S ISSUES OR BARRIERS TO PREVENT YOU FROM EXPRESSING YOUR WISHES.

Just do it! There is probably no good time but my own theory is that the more naturally you speak of it, the easier it gets and, even if they don't like to hear it, your family will at least know what you want to happen.

BE HONEST, BE CALM, BE DETERMINED.

"GO AHEAD. BE BOLD. YOU MAY FIND THEM MORE IN TUNE WITH YOU THAN YOU THOUGHT. EVERYONE HAS AN OPINION AND HAS A RIGHT TO VOICE IT, YOU INCLUDED!"

WHAT IF I DON'T HAVE ANYONE I CAN TALK TO OR CAN'T HAVE THE CONVERSATION?

You may not have anyone you feel you can talk to about your wishes, or you may find it too difficult to have the conversation. If this is the case, you can still plan for the future by recording what is important to you in writing and sharing this with your doctor and healthcare team. The section in this booklet called 'What next? – Recording my wishes' gives you more information on how to do this.

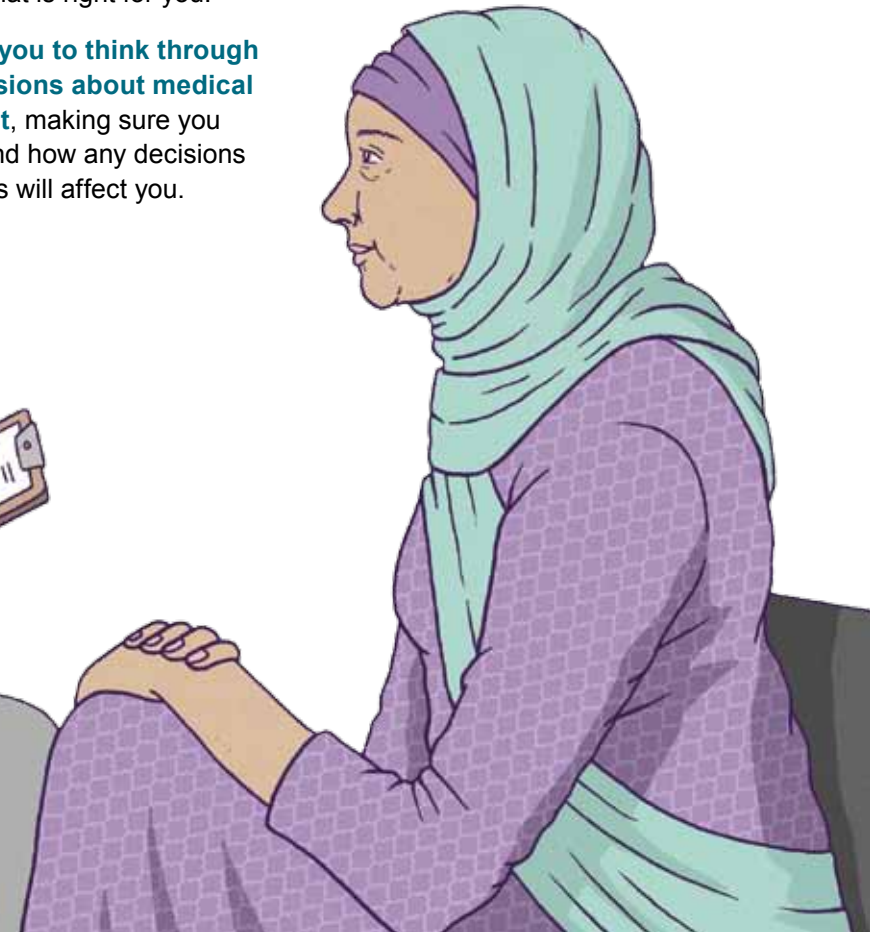


HAVING THE CONVERSATION WITH MY DOCTOR

It is important to speak to your doctor about your wishes for care and treatment. Your doctor can:

- **Help you to understand your treatment options** so you can decide what is right for you.
- **Support you to think through any decisions about medical treatment**, making sure you understand how any decisions or choices will affect you.

Any choices you make about your future medical treatment are your own. If your doctor disagrees with your choices, this does not necessarily mean you should change them.



Talking about your wishes for care and treatment with your doctor can feel challenging.

In this section, we have included some concerns raised by the people we spoke to, and suggestions from others about how to address them.

Concern
1

I haven't begun the conversation yet... I would like to but I'm worried it would be seen as wasting time when she has such a lot of patients to see.

DON'T WORRY ABOUT WASTING TIME - THIS IS AS IMPORTANT AS TAKING PERSONAL RESPONSIBILITY FOR EVERY OTHER AREA OF YOUR LIFE.

My doctor said he wished more people planned in advance. Life is simpler if doctors know what you want.



Concern

2

My doctor doesn't want to talk to me about dying. I think he feels his job should be to make me feel better.

DON'T ACCEPT UNWILLINGNESS TO DISCUSS YOUR FUTURE TREATMENT OR THE END OF LIFE. IF NECESSARY, ASK TO SEE A DIFFERENT DOCTOR.

Advise the surgery what the appointment is for beforehand, so that the GP is forewarned and it will then be easier to start the conversation.

BE PREPARED. DO RESEARCH FIRST AND DON'T BE AFRAID TO ASK DIFFICULT QUESTIONS.

Concern

3

I've recently changed GP and I'm worried she won't take me seriously if I talk about when I die as I've got nothing wrong with me.

I TOOK MY COMPASSION IN DYING FORMS INTO THE APPOINTMENT WITH ME. IT GAVE THE TOPIC LEGITIMACY – IT SAYS "LOOK, SOMEONE ELSE HAS BEEN THINKING ABOUT THIS TOO!"

Concern

4

I often struggle to get an appointment. Once I'm in there, five minutes doesn't really seem long enough to get into the conversation.

I made a double appointment, which gave us more time to talk.

WHAT NEXT? RECORDING MY WISHES

82% OF PEOPLE HAVE STRONG VIEWS ABOUT THEIR CARE AT THE END OF LIFE, YET ONLY 4% OF PEOPLE HAVE RECORDED THEIR WISHES IN A LEGALLY BINDING WAY, SUCH AS AN ADVANCE DECISION OR A HEALTH AND WELFARE LASTING POWER OF ATTORNEY.

WHY DO I NEED TO RECORD MY WISHES?

Recording your wishes helps to make sure that those around you and your healthcare team know what you want. If your wishes are written down it can give them legal weight and will make them more likely to be followed.

Many people think that their family members will be able to make health decisions on their behalf if they become unwell. This is not the case. Whilst doctors have a duty to speak to those close to you about your wishes, this does not give those people the final say about your treatment if you cannot make a decision for yourself.

HOW CAN I RECORD MY WISHES?

There are three ways you can record your wishes and plan ahead in England and Wales. You can make:

- an Advance Decision (Living Will)
- an Advance Statement
- a Lasting Power of Attorney for Health and Welfare

If you live in Scotland or Northern Ireland and would like information on how to plan ahead please get in touch.

ADVANCE DECISIONS

An Advance Decision allows you to write down any medical treatments that you do not want to be given in the future, in case you later become unable to make or communicate decisions for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is also sometimes called a Living Will or an Advance Directive.

You can use an Advance Decision to refuse any treatment, including life-sustaining treatment such as resuscitation, artificial nutrition and hydration, or breathing machines.

An Advance Decision is legally binding in England and Wales, as long as it meets certain requirements. This means that if a healthcare professional knows you have made an Advance Decision, they have to follow it.

LASTING POWERS OF ATTORNEY FOR HEALTH AND WELFARE

A Lasting Power of Attorney for Health and Welfare (LPA) allows you to give someone you trust the legal power to make decisions on your behalf, in case you later become unable to make decisions for yourself.

Your attorney can make decisions about anything to do with your health and welfare. This can include refusing medical treatment, where you are cared for and the type of care you receive, as well as day-to-day things like your diet, dress and daily routine.

ADVANCE STATEMENTS

An Advance Statement allows you to write down anything that is important to you, in case you later become unable to make or communicate decisions for yourself. For example, you can use it to explain your preferences for care or any values or beliefs that affect the way you would like to be treated.

Legally, a healthcare professional does not have to follow the exact instructions in your Advance Statement, however these wishes must be taken into account when a decision is being made on your behalf.

You can choose just one or you can do all three. These documents will only be used if you can no longer make or communicate a decision for yourself.

ABOUT US

Compassion in Dying is the only UK charity working to inform and empower people to exercise their rights and choices around care. Our vision is of a world in which individuals are placed at the centre of their end-of-life care. We believe everyone should be given the information and support needed to make decisions about their treatment and be helped to plan ahead to ensure that their wishes are known and followed.

The quotes in this booklet are from real people who responded to an online survey sent out by Compassion in Dying in October 2014 to people who used our Information Line service. The survey asked people about their experiences of talking about their future treatment and wishes for their end-of-life care with people close to them and their doctor. Over 300 people responded to the survey. The quotes in this booklet are taken from their responses and have been anonymised to protect their privacy.






For more information on Advance Decisions, Lasting Powers of Attorney for Health and Welfare, Advance Statements or planning ahead more generally you can contact Compassion in Dying's information line on:

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