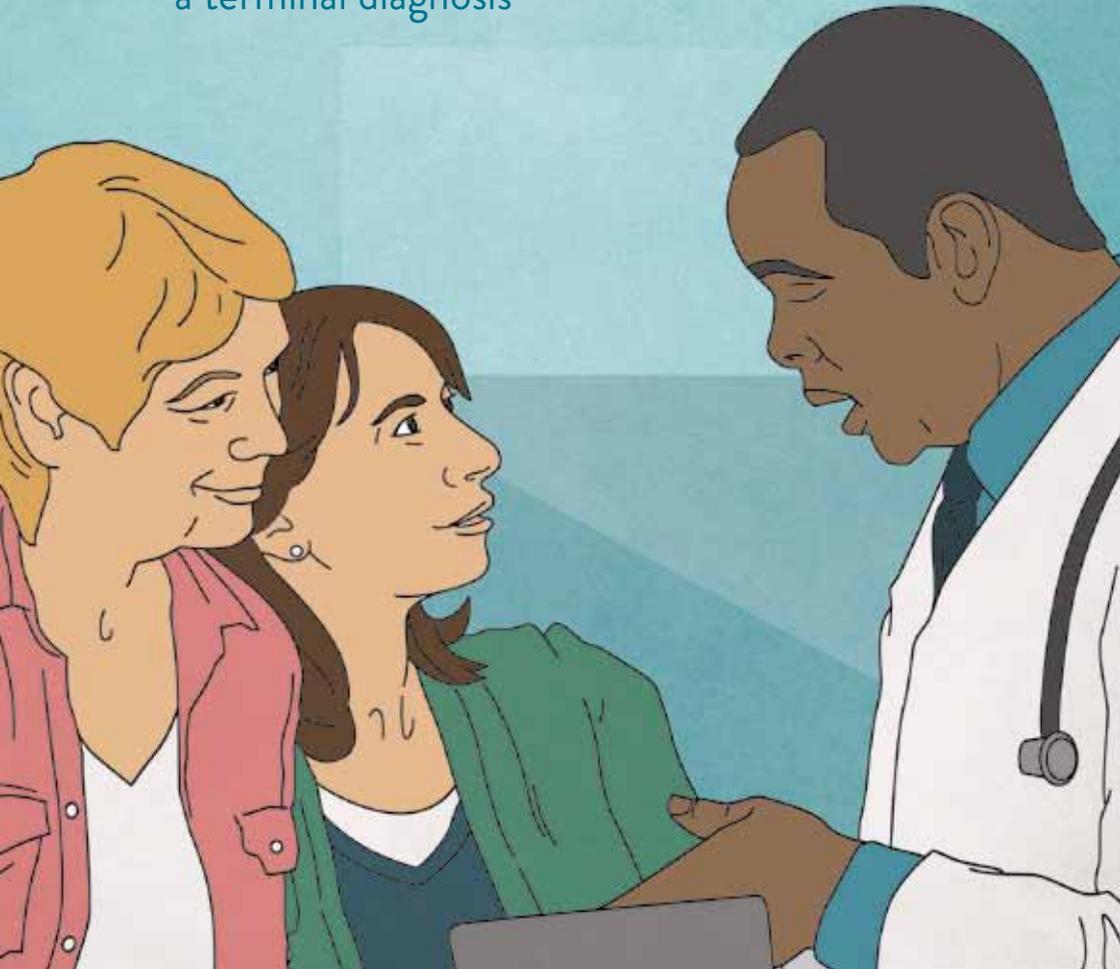


What now?

Questions to ask after
a terminal diagnosis



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Who is this booklet for?

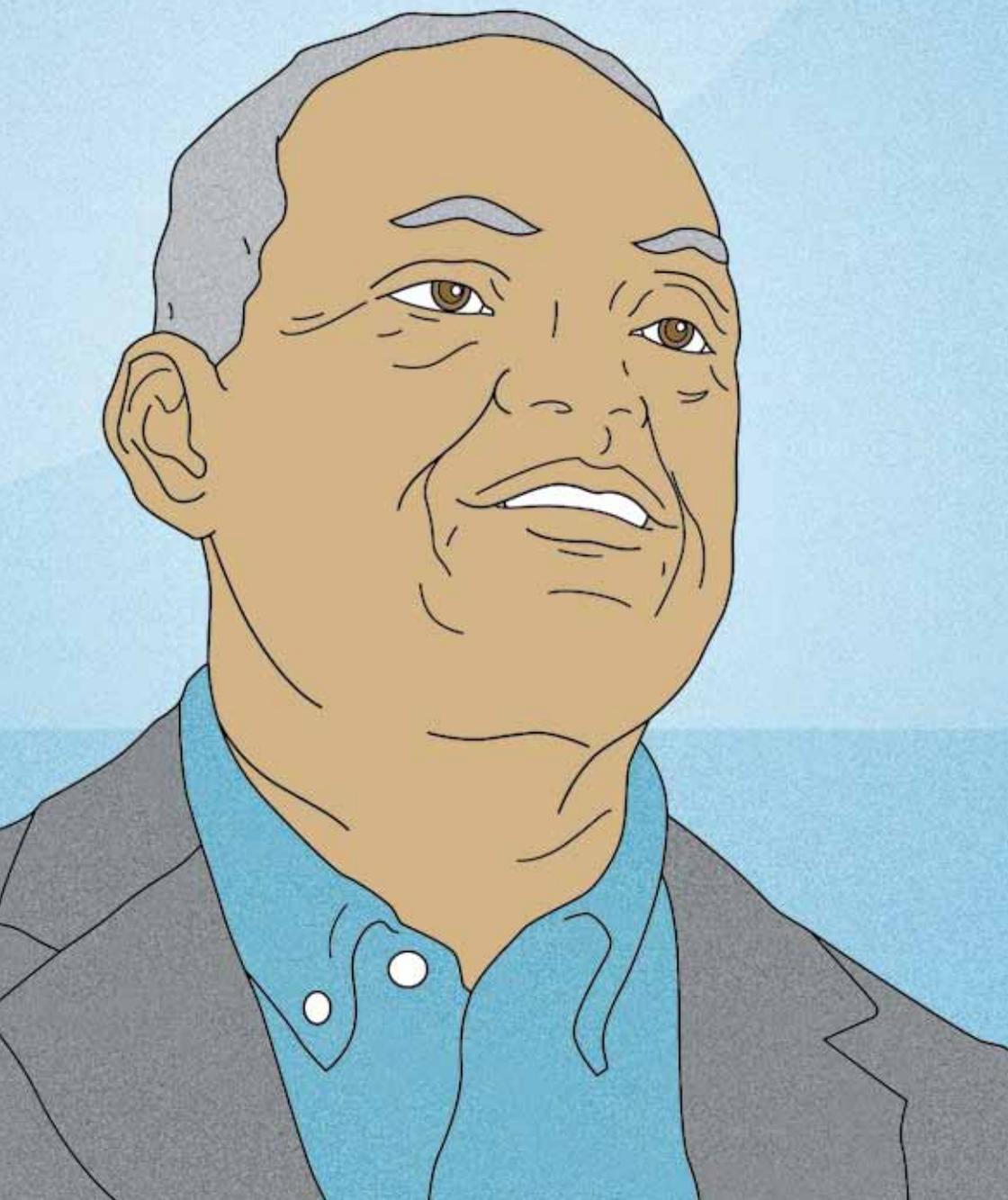
This booklet is designed for people with a terminal illness (an illness that will cause you to die), but it can be used by anyone who has to make a decision about their treatment or care, for example if you are living with a serious illness that may mean a big change to your lifestyle. Examples of terminal or serious illness are cancer, dementia, motor neurone disease, multiple sclerosis, Parkinson's disease, heart attack, stroke, supranuclear palsy, multiple system atrophy and organ (heart, lung, kidney or liver) failure.

Introduction

This booklet is here to help you find information and ask questions, so that you can make decisions about your treatment and care that are right for you. It will help you think through what you want to know, and offers ideas for questions to ask to get the information you need.

It also shares experiences and advice from other people who have lived with terminal illness.

We talked to more than 600 people living with a terminal illness or caring for someone at the end of life. The quotes used throughout this booklet are from the insights they kindly shared. Not surprisingly, the experiences people shared with us differed greatly. The quotes in this booklet have therefore been chosen to show the range of thoughts, feelings and experiences people can have. Sometimes the quotes might contradict each other, but that is because we are all different and each person's experience of terminal illness is different.



Why should I ask questions and make decisions about my illness?

The people we spoke to said that when they asked the right questions it helped them to make informed decisions. This in turn helped them get the care and treatment that was right for them, and helped them to live well in the time they had left.

Understanding what is going to happen in the future will help you to make plans, and can help you feel in control by giving a picture of what lies ahead.

We are all individuals. Your choices might be very different from someone else's.

“Our choices were supported and we were prepared to make the necessary decisions, but that was because we had thought and talked about it. We knew the questions to ask and that's important. Many on our medical team would not offer the information we needed unless we asked for it.”

“You might need to push for what you want to happen. You don't have to accept what your medical team think is best for you.”

“ We were not prepared for the exhaustion terminal illness brings. Put energy into making decisions, and arranging your care as early into the process as possible because further down the line you may not be able to.”

Other people's thoughts and experiences

How does it feel to get a terminal diagnosis?

It is natural to feel a wide range of emotions when you are diagnosed with a terminal illness. You might feel angry because you feel more could have been done to prevent it, you might feel it is unfair, or you may now be worried about what the future will bring. You might also have feelings of denial, sadness or shock.

“I was relieved to finally know my diagnosis after almost two years of rapid physical deterioration and difficulties in finding what was wrong.”

“It was initially a shock. I didn't take the news well and became very angry. Now I live with it, I just take every day as it comes.”

“The news was devastating, to be told you have a progressively debilitating incurable disease, at the time it felt truly hopeless, I thought I would lose my identity. But now I find it worse for my loved ones than me. I am very positive in my outlook.”

What is it like to live with a terminal illness?

As your illness progresses, you may need to make changes to your lifestyle and daily routine. You may also experience emotional changes, and these can affect you and your way of life.

“I feel as if I’m carrying a rucksack I can’t put down and is always there.”

“My emotional state changes, one day I’m positive, the next I feel downright angry.”

“You think you are in control but then lose it over the most trivial thing, and only then realise how stressed you are.”

“It’s hard not to feel resentful of the ‘well’, although I know there are many far worse off than me.”

“For me it is both frightening and rewarding. It can be hard. Sometimes it feels like nobody else could possibly understand my day-to-day life.”

The impact on family and friends

When nearing the end of your life, you may find that the people close to you become even more important. Living with a terminal illness can sometimes make these relationships difficult, but it can also bring people closer together.

“Having a terminal illness, oddly, has brought us closer as a family. We talk much more openly and I feel more able to talk about how I feel. Maybe it’s because if I don’t do it now I know I won’t be able to later. In a way it’s a gift.”

“I’m upset by the blasé attitude of some of my family. It’s like they don’t understand what’s happening, or don’t want to, but I want to talk about it and make plans for what time I have left.”

“I wasn’t prepared for people’s reactions. I have had time to get used to the idea as it’s been a long time coming. But the sorrow I see when people look at me and then cry makes it really hard.”

“I hate it when people say “You look so well!” I don’t feel it.”

“My daughter’s reaction was hard - she wants me to live forever but that’s not possible for me.”

“It’s hard with my disease (MS), because there is nothing to ‘see’ people don’t understand how crippling it is.”



Advice from others

Ask for help

“Find out what local services and support are available, such as GP home visits, specialist nurses, home care, and support with shopping.”

“Don't be afraid to ask for help. I always call on my siblings to help make any decisions. No way could I handle some of the choices on my own.”

Talk to people

“Talk about how you feel and what you want. If there are support groups in your area, try them out. I found it really helpful to talk to others.”

“Ask for a counsellor if you need one. Talking things through does help.”

“Take the care offered. There will come a time when you can't do some things so you'll be glad for the support.”

Money and benefits

“Find out what financial support you are due, like attendance allowance. You may have extra expenses you don't foresee like bedding, nightwear, and incontinence pads.”

Independent living

“Ask to speak to an occupational therapist who can advise about lifts, bathing aids, toilet adaptations, and alterations to clothing to make it easier to take them on and off.”

“Ask your occupational therapist for information about how to use a bottle bedpan or commode independently, so you have some dignity in that area if you need it.”

“You may be entitled to financial help for equipment like a raiser bed (very helpful), stair lift, shower seat, and lightweight plastic drawers on wheels for medical needs.”

Other practical tips

“There are lots of little things that are worth asking about, that you might not consider. For example if you are self-administering injections, where to get the sharps bin collected?”

“We found you can buy lemon and glycerine mouth swabs to use when the dying person can no longer swallow. The care agency also told me we could use plain swab sticks dipped in pineapple juice.”

“Think about if you are restricted to bed or home, what would you need to make life comfortable?”

“If you live on your own you might need a ‘pendant alarm’, so you can alert social services if you are in trouble.”

“Make sure there is enough medication especially at weekends and bank holidays, and ensure your healthcare team have considered anticipatory drugs to control any symptoms.”

Getting the treatment and care that is right for me

Finding the information I need

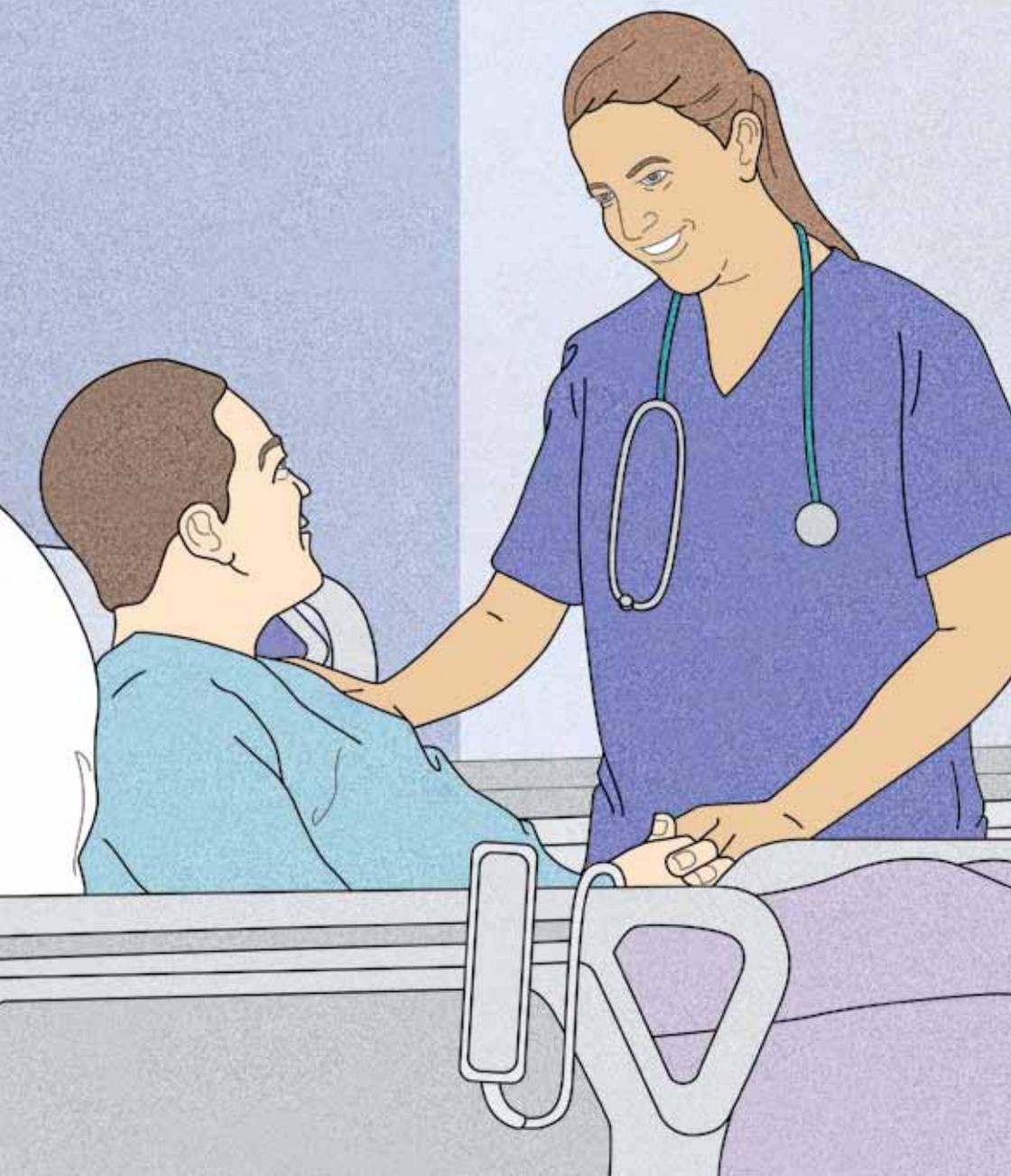
It is important that any questions you have about your illness are answered. Your healthcare team should answer your questions sensitively and honestly. See page 18 for more information about who you can talk to.

“The hospital staff were wonderful. The doctors and nurses shared information, and explained all aspects of my disease, treatment, and prognosis. They showed me what warning signs to look out for and what to do when something unexpected happened.”

“The medical professionals have been great in terms of information on current treatments but not much use for information on emotional support or lifestyle.”

“I wasn’t prepared for health professionals not giving you the information you need or not answering your questions at all.”

“The information shared between the NHS and the care home was poor. One major thing we’ve learned is that you should never assume that information is shared between professionals.”



What information should I be given about my illness?

Your doctor should be honest and explain to you, in clear language, what your diagnosis means and what your treatment options are. This includes explaining any medical terms that you do not understand.

They should give you all the information you need to make a decision about treatment, and should also explain the advantages and disadvantages of each treatment option, including any potential risks and side-effects. Your doctor can recommend a treatment to you but should not pressure you to accept it.

When discussing your illness you may not want to be given all of the information at once. It is important to let your doctor know how much information you want, and to tell them if you want to go over something again, or wait until a later appointment.

What if I do not understand?

If you do not understand something your doctor has said, let them know. They should repeat it or try to explain it in a different way.

Understanding statistics

Your doctor might explain things by using statistics. For example, they may say ‘90% of people treated with this drug get a good response’. Another example is ‘20% of people with this illness live for five years’. This might give you a better understanding of your treatment options or the likely progression of your illness.

What if I do not want to know?

Some people find talking about difficult subjects upsetting and would rather talk about their illness in stages, or avoid the topic altogether. You can tell your doctor how much you want to know.

Some people had a good experience speaking to their doctor about their illness. Others told us they found it frustrating. We asked a doctor why this might be:

“Doctors don’t want to unduly distress their patients and so are often sparing with the truth in order to be kind if they think the person in front of them may be very distressed by the harsh reality. Once something has been said it cannot be unsaid so doctors are naturally cautious, especially when giving bad news.

It’s also possible that your doctor may not have the exact answers to questions you ask. If they reply ‘it depends’ to any of your questions it may mean that the answer is not definite. You can check this by asking directly ‘is there no definite answer?’

You should also remember that not all doctors are good at communication. And even those that are might be rushed or stressed at the time of talking to you. So being prepared with a list of questions is a good start.”

Asking questions

Why ask questions?

Asking questions can help you to better understand what is happening, and the options available to you.

“I did not feel well informed on the last day of my mum’s life. She was unconscious, but I did not realise she was so close to death. Although the live-in carer was aware of this, and the surgery nurse came to the house to give her an injection to ease her breathing, they spoke to my father and myself in euphemisms rather than clearly explaining what was happening and how little time she had left. I wish I had known the right questions to ask.”

“Get all the information you can about your diagnosis, possible treatments and prognosis. Be strong – you may have to push for this. Ask about side-effects and think carefully about whether you want to undertake particular treatments or not. Your quality of life is important.”

I do not know how to start

Your job is not to come up with a list of treatment options - that is your doctor's job. Your role is to help your doctor understand what matters most to you. Then your doctor can discuss your options in the context of your situation and your wishes. You can then make the decision that is right for you.

There is a list of questions at the end of this booklet that will help you think about what you want to know, and how to ask.

Who can I ask?

You might feel unsure about when to ask your questions, or who to ask. You will probably be cared for by a multidisciplinary team. This is a group of different health and social care professionals who work together to coordinate your treatment and care. You might be seen by some or all of these people, and you can ask any of them questions:

- A specialist in your particular condition, such as an oncologist or a haematologist
- A clinical nurse specialist, who is an expert in a particular area of medicine, such as end of life or pain management
- A Macmillan or chemotherapy nurse
- A Marie Curie nurse
- A surgeon
- A radiologist, who specialises in x-rays and scans
- Palliative care professionals, who specialise in making sure you are comfortable and ensuring all your needs are attended to at the end of life
- Your GP
- A psychologist or counsellor
- A social worker
- A nutritionist or dietician
- An occupational therapist or physiotherapist

When can I ask?

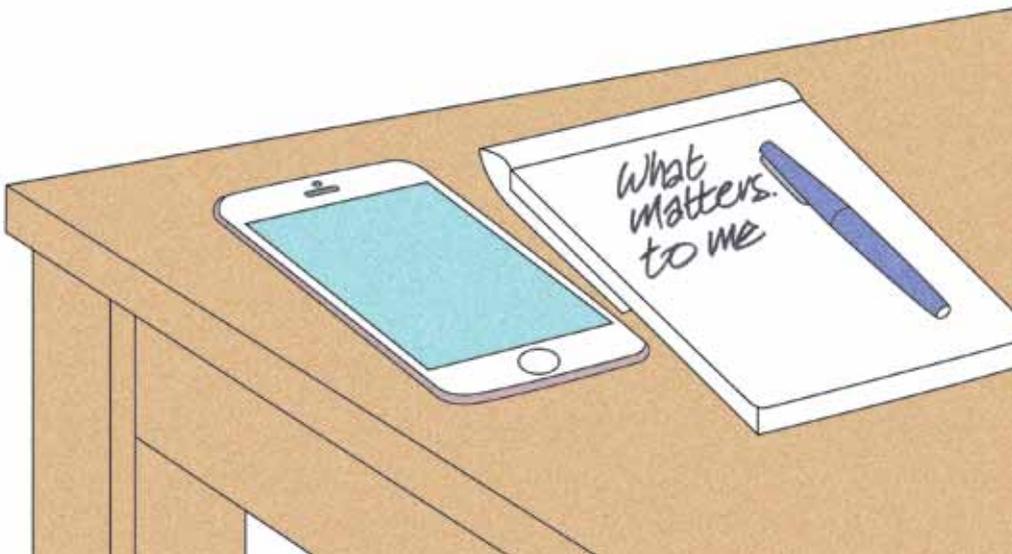
You can ask questions at any time. You may prefer to be given information in stages, or to know all the information available as soon as possible.

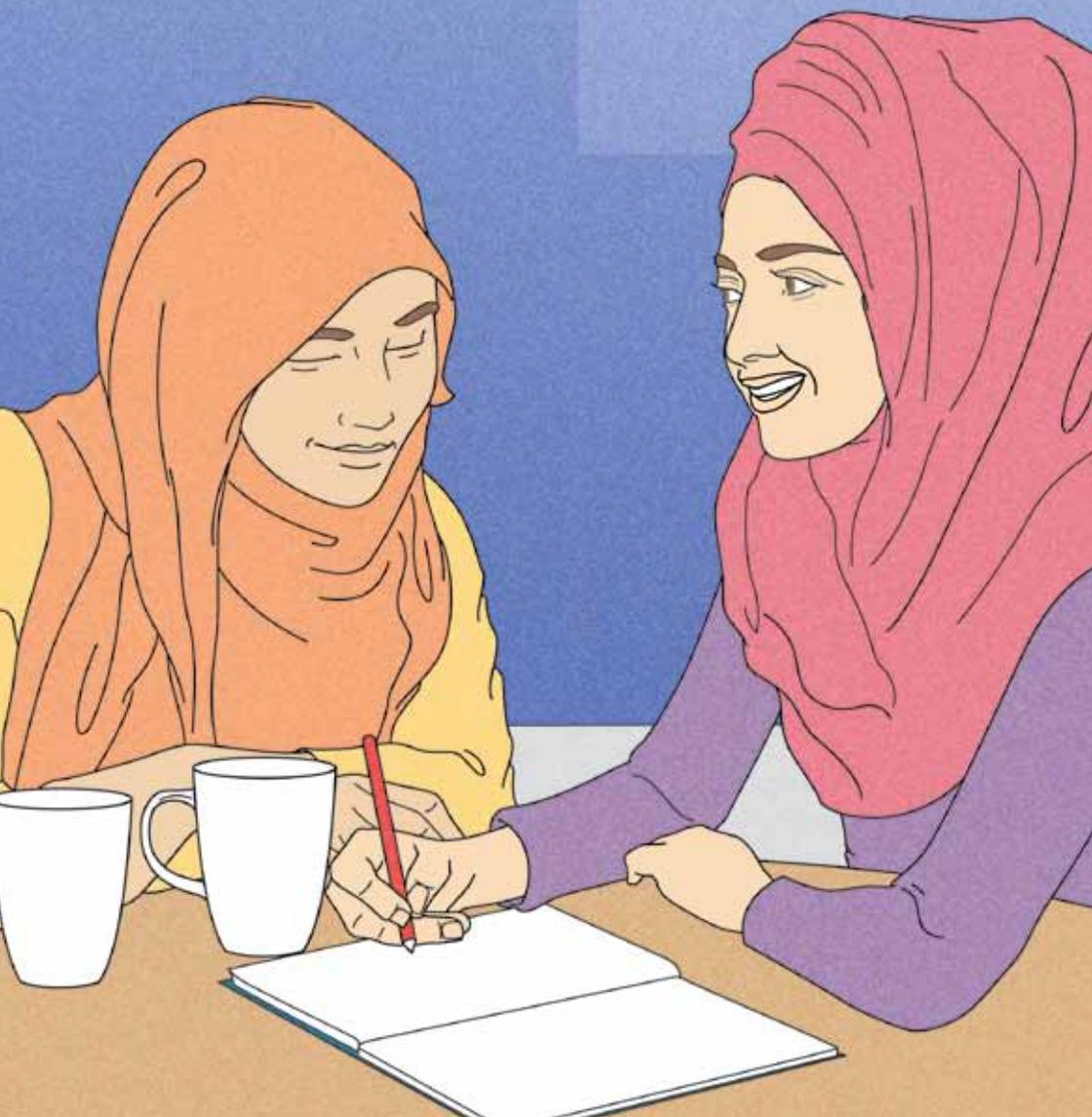
What if I do not want to ask questions?

You may not want to ask your healthcare team questions. This may be because you do not feel comfortable talking to your doctor, or you want to do research in your own time.

Many people we spoke to said the internet was a great source of help, however it is important to only use information from trusted sources online.

“The growth in support on the internet has been a total game-changer and I wish it had been available when we needed it. It was still in its infancy when we were looking for information.”





Tips for talking to your healthcare team and asking questions

“When you are first diagnosed you might go into shock and therefore might not know the questions you want to ask until your head clears. So ask for a follow-up appointment.”

“Write it down! Make a list of your questions beforehand and also take notes when you’re there (or get the person with you to take notes).”

“You don’t have to ask all your questions in one go. You might feel tired or that you’ve heard enough for one day.”

“It’s ok to say you don’t understand and ask them to explain in a different way.”

“If you feel the conversation is going too fast you should say so.”

“It can help to have somebody you trust alongside you because you might not always feel well enough to speak up for yourself or remember what is said.”

“If you feel like you aren’t getting the information you want don’t give up! Sometimes you might have to persevere but you have a right to know what you want to know.”

Making decisions

How will I know what the right decision is?

The different perspectives in this booklet show there is no ‘wrong’ decision. It is about what is right for you, and that will depend on your circumstances, priorities, and goals. As your situation changes, what you want might also change. All you can do is make a decision based on what is right for you at that time.

You should be given time, information, and support to make your decision.

What sort of decisions might I have to make?

We asked a doctor about the types of decisions you might be faced with at the end of life:

“There are lots of different decisions you might want to make about your treatment and care towards the end of life. Examples are ‘Would you like medication that relieves your pain but makes you drowsy and unable to talk to your family, or would you prefer less pain relief that will allow you to be alert?’, ‘Would you like a surgical operation that may give you two extra years of life but leave you with impaired mobility or discomfort, or would you prefer not to have the operation and live for a shorter amount of time but with a better quality of life?’, ‘Would you like to spend the last fortnight of your life in a hospice where you will be in unfamiliar surroundings but have 24 hour nursing care available or stay at home where you will be in more familiar surroundings but the level of care you can receive will be different?’”

“When the first radiotherapy and chemotherapy combination failed, we had to decide whether or not to accept the option of a second different chemotherapy treatment, with limited chance of success and the potential to shorten my wife’s life. Deciding whether to take it or not was difficult. We decided not to take the offer and prioritise her quality of life.”

“I was asked if I would want to be resuscitated if my heart stopped. This was tough as it felt out of the blue, but I’m glad they asked.”

What next? Recording 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. It also stops you having to explain the same thing to lots of different healthcare professionals when you are feeling low on energy or not very well.

“Making an Advance Decision helped to start a conversation with my family and doctor. It gave me peace of mind - my family now know exactly what I want and won’t have to make difficult decisions on my behalf.”

“Be clear about what you do or don’t want. It is hard for health professionals to make decisions for you so it is better for everyone if it is written down.”

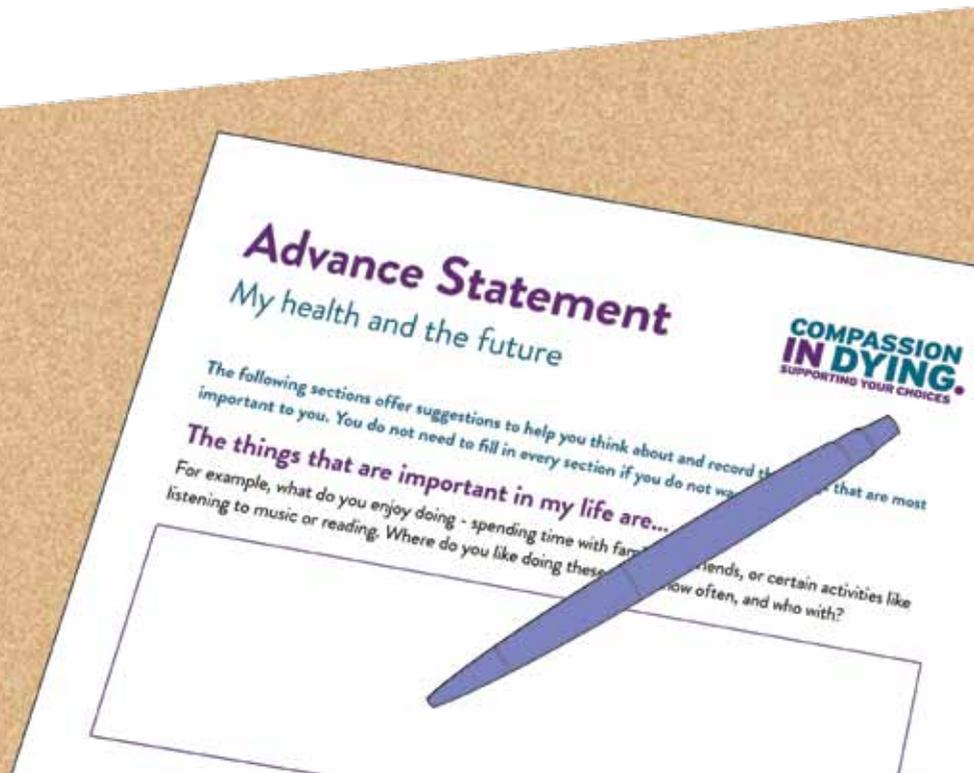
Many people think that their family members will be able to make health decisions on their behalf if they become unwell. This is not the case. Doctors have a duty to speak to those close to you about your wishes if you cannot make a decision for yourself, but this does not give those people the final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

How can I record my wishes?

To record your wishes you can:

- record your preferences and priorities in an **Advance Statement**, or **Advance Care Plan**
- refuse treatment in advance in an **Advance Decision**
- give someone else power to make decisions for you with a **Lasting Power of Attorney for Health and Welfare**

Compassion in Dying can help you do this. If you would like support to think about and record your wishes, our contact details are on the back of this booklet.



Questions for my healthcare team

What are these questions for?

Like most people who are diagnosed with a terminal illness you may have questions and concerns you want to address with your healthcare team. But often these can be forgotten in the moment, maybe because you are finding it difficult to take the information in, or because the conversation goes in a different direction. The purpose of the questions listed on the next few pages is to help you get the information you want about your care and your illness.

Who wrote these questions?

We developed these questions with the help of people who are living with a terminal illness or who have supported a loved one at the end of life. We asked people about the information they would like to have known earlier and the information that helped them to make decisions. We also spoke to healthcare professionals about the questions they often get asked.

How should I use them?

Use these questions in whatever way feels most helpful.

You can tick the questions you would like to ask, and add your own thoughts or questions at the bottom of each page.

The pages are perforated, so you can tear them out and take them with you to your appointment.

You might also find these questions helpful when talking to your loved ones about your health and the future.

You do not have to ask all the questions. Everyone is different and you might not feel they all apply to you.

If you would like to talk to someone about how to use these questions or how to talk to your family or healthcare team about your options, Compassion in Dying can help. Our contact details are on the back of this booklet.

I want to know...

What does my diagnosis mean and what can I expect?

- What is my outlook for the future, as you see it?
- How was the diagnosis made?
- Might my diagnosis change?
- How advanced is my illness?
- What are the symptoms I am likely to experience, both now and as my illness progresses?
- What kind of changes will I have to make in my work, family life, sex life, and leisure time?

My other thoughts and questions

Will I get the support I need?

- Where will I be cared for?
- Who will be part of my healthcare team? Will there be different people involved?
- Will I need any equipment in my home as my condition progresses?
- What support is available to help me and my family?
- Who should I contact if things get worse?
- Can my family members be involved in decisions?

How long have I got?

- How long am I likely to live for?
- Am I likely to die from this illness?

What will happen when I am dying?

- What will happen to me at the very end?
- How will I actually die?
- Will I be conscious at the end?
- Will I be in pain?

My other thoughts and questions

My priority is...

To live as long as possible

- What treatments will enable me to live as long as possible?
- Can you slow down the progression of my illness?

To have a good quality of life

- Would your recommendation change if I told you that my priority is having a good quality of life, so, living as normally as possible for as long as possible?
- How will this illness affect my quality of life?
- I like to
how can I ensure I get to do these things for as long as possible?
- What are the best things I can do to stay as healthy as possible?
- I do not want to swap a bad situation for something worse. Could this treatment make me feel worse than my illness already makes me feel?

Treatment decisions

What are my treatment options?

- What are my treatment options? Can you explain the benefits and things I should consider for each one?
- Are there other ways to treat my illness?
- Do I need more than one sort of treatment?
- Is my decision urgent or can I take more time to think about it? What will happen if the treatment is delayed?
- What will the treatment be like? How long will it take?
- If the treatment you are suggesting does not work, or the side effects are bad, what are the other options?
- Where will I have this treatment? Will it be in hospital? How long will I be in there?

My other thoughts and questions

What will this treatment do?

- What is the aim of this treatment? Will it cure the illness or will it just help my symptoms or slow the illness down?
- Are there any risks with this treatment?
- Is there any chance that this treatment will make me worse?
- How will I know if the treatment is working?
- How many people in my situation benefit from this treatment?

Are there side effects?

- Are there any side effects? If there are side effects what are they like, and can anything be done about them?
- If I find the side effects unacceptable can I stop the treatment?

Not having treatment

- What will happen if I choose not to have treatment?
- What is the natural course of my illness if left untreated?

After treatment

- How will I feel after the treatment?
- How long will it take after treatment to recover?
- What will my life be like during and after the treatment?
- I like to
will I be able to do these things after this treatment?

My other thoughts and questions

Having tests

- What will the results of this test tell me?
- How will the result affect your recommendation for my treatment?
- How will this test help me make a decision about treatment?

My religion and spiritual beliefs

- How can I access spiritual support?
- How can I be supported to ensure any rituals important to me are honoured?
- How can I be referred to a representative of my faith or a Chaplain?

Things to find out about

- Where can I get counselling?
- Are there any support groups for me and/or my carer?
- What benefits am I entitled to?
- What support is available at home, for example nursing, help with washing and dressing, and help with shopping?
- Will I need practical living aids and equipment, and how can I arrange this?
- Who can I call if I am worried or my health changes?
- I live on my own, so do I need a personal alarm to alert people if I fall or am in trouble?
- Am I entitled to a disabled badge?

My other thoughts and questions

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**COMPASSION
IN DYING.**
SUPPORTING YOUR CHOICES

