MACMILLAN
CANCER SUPPORT

MAKING TREATMENT DECISIONS

About this booklet

This booklet is about making treatment decisions. It is for anyone who has been diagnosed with cancer. It might also be helpful for carers, family members and friends.

The booklet explains how you can find out information about your treatment options. It discusses some things that may help when making treatment decisions.

We hope it helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

In this booklet, we have included quotes from people who have made decisions about their treatment. Some are from our Online Community (**macmillan.org.uk/community**). Others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, call **0808 808 00 00** or visit **macmillan.org.uk/otherformats**

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

Contents

FINDING OUT ABOUT YOUR TREATMENT OPTIONS

What information do you need?

There are a number of ways of finding out more about the cancer and its treatment, and how these are likely to affect you (see page 10).

How much information you need is up to you. Some people want to find out as much as they can about each treatment option. Others prefer to only know a little.

> ‘For the first few days, I was unable to make any decisions about my treatment. But after taking the news in, I started to read about the type of cancer I had.’
>
> **Sophia**

Information about the cancer

To help you make a decision about cancer treatment, it is useful to know a bit about the cancer and how it is affecting you. This will help you understand your treatment options.

Your healthcare team will usually be able to tell you:

- **where** in the body the cancer started, such as the breast, bowel or prostate
- what **type** of cancer it is
- the size of the cancer and whether it has spread to other parts of the body – this is its **stage**
- how quickly the cancer may grow – this is its **grade**.

Information about the treatment

It can help to know what each treatment involves and what the differences are between the options you have been given. It is useful to know:

- the aims of the treatment
- how the treatment will be given and how this may affect your day-to-day life
- the possible side effects of the treatment
- what will happen if you do not have treatment
- if there are other treatments available.

You should be able to get all this information from your healthcare team. They should be able to answer your questions and give you some written information to take home. You may find that this is all you need and that you are ready to get on with the treatment. But you may want more information before making any decisions.

We have information about different cancer types and treatments that you might find useful. We also have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To find out how to order these, see page 50.

What further information do you need?

Before looking for more information, think about what you really want to know. What do you need to help you decide about the treatment you have been offered? Is it more medical information, or do you want to know more about the side effects and practical aspects of the treatment?

> ‘For each treatment, I read through what was there and summarised it myself, and then underneath I wrote down what was most important for me.’
>
> **Richard**

You can use the table on the next page to help you with these decisions. It includes sections where you can write about what is important to you and the people who may be able to help you.

What are my treatment options?	What is important to me?	What do I need to know?	Who can help?

Reliable sources of information

There are many ways to find out about the treatments you have been offered. Getting information from reliable sources means you can be sure it is accurate and up to date. You can get reliable information from:

- your healthcare team
- cancer information organisations
- reliable websites
- other people who have been in a similar situation.

Your healthcare team

Your doctors and nurses can talk with you in more detail about your treatment options. They can tell you about the aims of the treatment and how it may affect you. It is a good idea to think about questions you may want to ask them (see pages 22 to 23).

Your healthcare team can also help you understand other information you may have found, such as results from research trials, and how this may relate to your situation. Any member of the team can give you information. Remember that if your situation changes, information that was relevant to you before might not be now. Your healthcare team can tell you if other information would be useful in this case.

Although a team of doctors, nurses and other specialists work together to plan your treatment, you will usually have one main cancer doctor. This is often a consultant cancer specialist (oncologist) at the hospital, but may be another type of specialist. If you are not sure who your main doctor is, ask someone in your healthcare team.

You may also have a key worker. This person is your main point of contact at the hospital for support and information. Your key worker is often a clinical nurse specialist, but may be another health professional.

It can be helpful to take someone with you to your hospital appointments, such as a family member or friend. They could take notes of what you and the healthcare professional talk about, to help you remember it later. There is space on pages 59 to 60 to write any notes. They could also ask any questions you find difficult.

After a hospital appointment, the doctor you saw will write to your GP. You are entitled to get a copy of this letter sent to you. Ask your hospital doctor if you would like a copy of the letter. Some doctors routinely send people copies of letters to the GP. If you would prefer not to have a copy, let the hospital doctor know.

Cancer information organisations

There are many organisations and charities that can give you information about cancer. Many employ specialist nurses and some use volunteers who have experience of cancer. They can often answer your questions and give you detailed information.

Charities may have written information they can send you and most will have a website (see page 55).

Reliable websites

The internet can be a good source of information. Many people use it to look for health information. However, it is important to make sure that any website you look at is reliable and can be trusted to provide accurate information.

Health & care information you can trust

The Information Standard

Certified Member

Some websites have logos to show that they have been certified as providers of up-to-date, high-quality information. For example, the Information Standard quality mark (above) seen on Macmillan's information.

To check whether a website is reliable, you should think about the following:

- **Is the information regularly updated?** Check when the information was last updated, edited or reviewed to make sure it is still accurate. You should be able to find the date on each page of information.
- **Is it clear who has written the information?** A good website should tell you about the organisation that has made the pages or written the information.
- **Are there references?** The website should list its sources of information. Check that the publication dates for the references are also up to date.
- **Is it a UK website?** Information and advice may be different in other countries.
- **Is the website sponsored by a company?** This may mean the information is biased towards that company's products or services.
- **Is the website trying to sell you something?** A good information website will not do this.

If you do not feel confident using the internet, ask someone to help you. Family members, friends or staff in your local library should be able to help. Some hospitals have cancer information and support centres where you can use the internet. There should be someone available to help you.

If you use a search engine (such as Google®), try to narrow your search to exactly what you are looking for. For example, if you are looking for information about the side effects of chemotherapy, include the name of the drug you have been offered. This will give you better results than searching for chemotherapy in general.

If you find a helpful website or some good information, you can save it as a 'favourite' or 'bookmark' it, so that you can find it easily another time. Ask someone to show you how to do this if you are not sure. It may not be possible to save these pages if you are using a computer in a library or cancer support centre, so you could print the information or take notes instead. Remember to note down the web address (URL) of the page you are looking at. For example, **macmillan.org.uk/information-and-support/treating/chemotherapy**

If you are worried about anything you read online, talk to your healthcare team. They may be able to reassure you and answer any questions you have.

Other people who have been in a similar situation

Sometimes it can help to find out about other people's experiences. You could do this through an online community or forum, or at a local support group.

Remember that everyone's situation is different. Other people will not be able to tell you which treatment will be more effective for you or exactly what side effects you will get. But they can tell you what it was like when they had the treatment, how they felt and what helped them cope with any side effects.

Our Online Community (**macmillan.org.uk/community**) is a place where you can chat to people in online forums, blog about your experiences and make friends. You can also find out about local support groups at **macmillan.org.uk/selfhelpandsupport**

Always check with your healthcare team if you have any doubts about information someone has given you.

> 'I was thankful for the people who gave me their honest opinion. I did not necessarily take their advice, but looked at all the information and then decided myself what was best for me.'
>
> **Amira**

Getting help finding more information

Your family and friends may want to help you find out more about the cancer and its treatment. It is a good idea to make sure they know exactly what information you want, so they know what to look for. You could ask them to make notes on what they find so you do not end up with lots of pages to read through yourself.

Advice on other treatment options

While looking for information, you may read about a treatment that you have not been offered. This may be because:

- it is a very new treatment that is still being evaluated in a research trial
- your hospital may not offer that particular treatment
- the treatment might not be available on the NHS
- the treatment might not be available in the UK.

If you have questions about a treatment you have not been offered, talk to your healthcare team. They can tell you if it is an option for you. You may need to be referred for a second opinion or to a private hospital. This may cause a delay in starting your treatment.

We have more information about getting a second opinion on our website **macmillan.org.uk**

Getting support

Sometimes it can be difficult to focus on the treatment options you have been given. You may think that there is too much information and feel confused or overwhelmed.

Depending on your situation and what information you are looking for, you may find that some things you hear or read are upsetting. This can be difficult to cope with when you may already be feeling emotional and vulnerable. It may help to talk about your feelings with your healthcare team, a family member or friend, or a counsellor.

Our cancer support specialists are here to answer any questions you have, offer support or simply listen if you need a chat. Call us free on **0808 808 00 00**.

Aims of treatment

The aim of treatment will depend on your situation, including:

- the type of cancer you have
- the stage and grade of the cancer
- your general health
- the treatment options available.

Treatment can aim to:

- remove a cancer
- slow down or help control the growth of a cancer
- relieve symptoms
- make another treatment possible or more effective
- reduce the risk of the cancer coming back.

Your doctors will be able to tell you about the aim of treatment for you.

Sometimes, your doctor will offer you a choice of treatments that are equally effective. If this happens, your decision about which treatment to have may be based on how the different treatments will affect you.

It is important to remember that everyone responds differently to treatment. No one can say exactly how you might feel during a treatment, or guarantee that a treatment will work for you.

Side effects of cancer treatment

Most cancer treatments have side effects. It is important to discuss your treatment fully with your healthcare team so you know what to expect. It can also be helpful to have some written information about how treatment might affect you.

Side effects usually improve after treatment finishes. But sometimes they can be long-term or permanent. Sometimes there are side effects that may occur some time after treatment has ended (late effects). Your doctor can tell you if this may be the case.

You may want to think about the possible side effects of treatment, and the impact they might have on you and other people, when deciding about treatment. There is more information about this in our booklet **Side effects of cancer treatment** (see page 50).

Your day-to-day life

Some side effects will have very little impact on your everyday life, while others may have more.

For example, you may have to go into hospital for an operation and need time to recover. Or you may have to travel to hospital regularly for radiotherapy or chemotherapy treatment. This may mean you are unable to work or continue your usual social life for a while. You may have to cancel any special events you have planned, such as weddings or holidays.

You may be happy to delay your social life for a while, so you can have your treatment and then recover from it. But you may have some events planned that make it more difficult for you to do this. You can ask your healthcare team whether the treatment can be planned to fit around your schedule. This will not always be possible, but it is worth asking.

Your healthcare team should be able to give you an idea of how long your treatment will last and how often you will need to visit the hospital. This may help you choose a treatment that best suits you.

If you cannot work because of treatment, you may find that you struggle to cope financially. Your doctor or nurse can refer you to a social worker or benefits adviser who can tell you about benefits and other sources of support. Your employer may also be able to help, so it is worth talking to your manager or human resources department.

We have more information on benefits and financial support:

- Visit **macmillan.org.uk/benefits** to read the information online.
- Visit **be.macmillan.org.uk/finances** to order free information.

If you are struggling to cope financially, you can call our support line for free on **0808 808 00 00**.

> ‘I didn’t want treatment on the weekdays that they specified. We eventually came to a compromise, which was great because it felt like I was having a bit of input.’
>
> **Rashida**

Taking part in a research trial

You may be asked to take part in a research trial. Trials help improve knowledge about cancer and cancer treatments. Many treatments commonly used today are from trials that took place years ago.

Information about the trial

If you have been asked to take part in a trial, it can help to know why it is being done and what taking part in it may mean for you.

Often, a trial will compare the standard treatment for your situation with a new treatment that the researchers think may be better. Talk to your healthcare team about the possible treatments in the trial and how they may affect you. Knowing about the different treatments will help you decide if you want to take part or to have the standard treatment instead.

Usually, several hospitals take part in these trials. It is important to know that some treatments look promising at first, but may later be found to be less effective than existing treatments. Or they may have side effects that outweigh the benefits.

The benefits and disadvantages of taking part in a trial

Taking part in a trial means that you may benefit from a new treatment. You will also be helping doctors find out which treatments may benefit future patients.

You will be carefully monitored during and after the trial. You may need to go to the hospital or GP more often. Sometimes you may have to travel to a different hospital. Ask how many extra visits will be needed and think about whether you are willing to do this. Remember that hospital appointments can be tiring and may cost you more money for travel and parking. You can ask if the research organisation will pay for your travel costs and how to claim for any extra expenses.

If you decide not to take part in a trial, your decision will be respected and you do not have to give a reason. The hospital staff will not treat you any differently and you will be offered the standard treatment for your situation. If you do decide to take part, you can leave the trial at any time without giving a reason.

We have more information about research trials that you may find helpful in our booklet **Understanding cancer research trials (clinical trials)** – see page 50 for ways to order this.

Asking your healthcare team questions

You will probably have lots of questions about treatment. Knowing what is happening and why can make you feel more involved in your care. It can also make it easier to make decisions.

It may help to write down your questions before your appointment. Keep a notebook with you and write things as you think of them. You can also make notes during appointments. This may help you to remember what is said. There is space for you to make notes on pages 59 to 60.

Example questions

Here are some questions you might like to ask.

- What is the aim of my treatment?
- Are there any other treatments that might work just as well?
- Is there a clinical trial I can take part in?
- What are the benefits and risks of each treatment option?
- What might the side effects of each option be?
- What can be done to reduce side effects and how can they be controlled?
- How can I choose between the treatments you have offered me?
- How often will I have my treatment?
- Do I need to change my lifestyle while having this treatment?
- Can I change my mind after I have started my treatment?
- How long will the treatment last?
- How long might it take until I feel back to normal?
- Can I choose not to have treatment?

We have more information about questions you can ask in our booklet **Ask about your cancer treatment** – see page 50 for ways to order this.

HELPING YOU DECIDE

Who can help you decide?

Talking to someone can help you sort out your thoughts and feelings before making a decision. You may have a specialist nurse or research nurse at the hospital you can talk to. You could also talk to your GP or one of our cancer support specialists on **0808 808 00 00**.

It does not need to be a health professional who helps you. Some people have a close circle of family and friends who they can talk things through with. Sometimes an online forum or support group, such as our Online Community (**community.macmillan.org.uk**), may be helpful.

Remember that everyone's situation is different. What may be the right choice for someone else may not be the best thing for you. Always check with your healthcare team if you have any doubts about the information you have been given.

> 'We turned to Macmillan and called them up for some help with our decision. They gave us a lot of information and were really helpful.'
>
> **Louise**

Dealing with uncertainty

There is often some uncertainty when making treatment decisions. Sometimes there is no clear right or wrong answer. The doctors may not be able to say for sure if the treatment will work and how it may affect you.

Uncertainty can be one of the hardest things to deal with. It can make you feel angry, irritable and frightened, which can sometimes cause tension with people around you.

Many people find that dealing with uncertainty gets easier as time goes by. Talking to family, friends and healthcare professionals about how you feel can help. Some people find it useful to talk about things with a counsellor. Your local cancer information centre or cancer support group may have a counsellor you can talk to. Or your doctors and nurses can help you contact one.

Statistics

Your doctor may use statistics to tell you what they know about a treatment. Statistics are a way of presenting information using numbers. They are used in many areas of daily life, not just in healthcare. You may find some statistics helpful when making decisions about treatment.

For example, information about a drug may include statistics on:

- how effective it is
- possible side effects
- how severe the side effects are
- how many people are affected by the side effects.

It is important to remember that statistics are based on large numbers of people. They cannot tell you what is going to happen to you, but they can give you an idea of how likely it is.

For example, some drugs can cause nausea (feeling sick) in some people. If a drug you are offered causes nausea in 80 out of 100 people (80%), you cannot know whether you will definitely feel sick or not, but it is quite likely. If you are offered a different drug that causes nausea in just 30 out of 100 people (30%), it is a lot less likely that you will feel sick.

Your doctors will prescribe a treatment because they believe that its benefits will outweigh any side effects. But the doctors only know what might happen. They can never know exactly how you will respond or feel.

Understanding statistics

Statistics can be complicated and difficult to understand. The following information aims to explain the different ways that statistics can be helpful.

If your doctor uses statistics that confuse you, ask them to make the information simpler. It may help if they write the statistics down. You can ask them to use the space on pages 59 to 60. Then you can look at them later, or ask a family member or friend to go through them with you.

There are different ways of showing statistics. These include:

- percentages (number out of a hundred)
- bar and pie charts
- other diagrams.

Ways of presenting information

The following example shows how information can be presented in different ways. This is just an example and does not refer to any real medicine or research. It shows that you should consider both how effective a treatment is and its possible side effects when making your decision.

A doctor talks to someone, who is going to start chemotherapy, about a new drug which may help prevent hair loss.

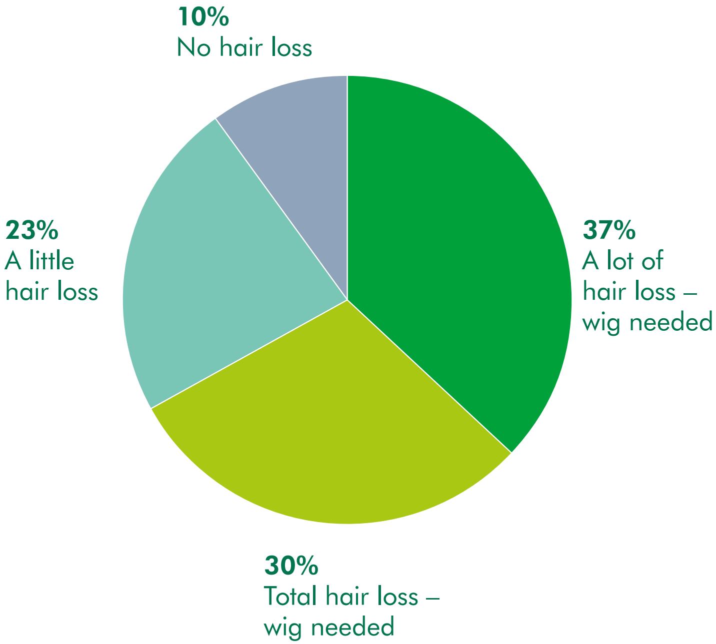
Before taking the drug, the person wants to know how well the drug works to stop hair loss.

The doctor explains the results of a study. Of the 100 people who took the new drug:

- 10 people had no hair loss
- 23 people had a little hair loss
- 37 people had a lot of hair loss and had to get a wig
- 30 people had total hair loss and had to get a wig.

In total, the new drug slowed down or stopped complete hair loss for 70 people (10+23+37), but 67 of the 100 people who took the drug had to get a wig. The numbers in each group can be shown in a diagram to make this clearer.

Pie chart showing how many people had hair loss



The person also wants to know about the possible side effects of the drug and how many people are affected.

The doctor tells them that side effects included:

- headaches
- feeling tired
- a sore throat.

Of the 100 people in the study:

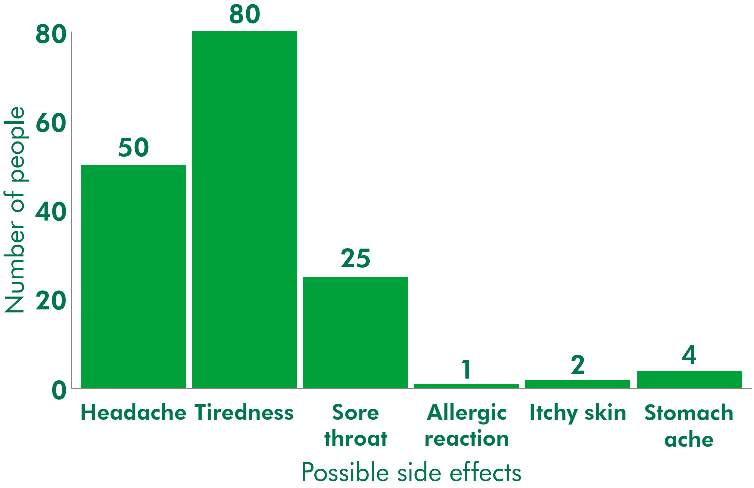
- 50 people had headaches = 50%
- 80 people felt tired = 80%
- 25 people had a sore throat = 25%.

Some people had rarer side effects:

- 1 person had an allergic reaction = 1%
- 2 people had very itchy skin = 2%
- 4 people had pain in their stomach = 4%.

Some people had no side effects at all, while others had a few different side effects.

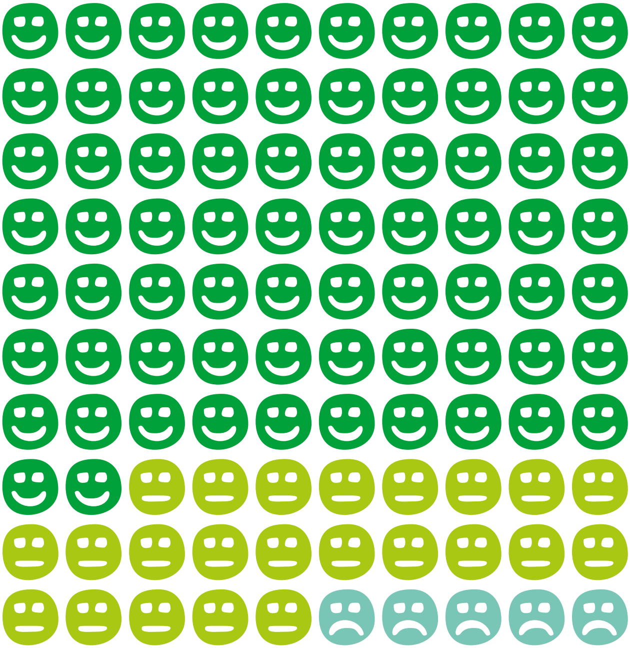
Bar chart showing how many people had side effects from the drug



The person also wants to know more about how people's lives were affected by the side effects. The doctor tells them the following:

- Of the 100 people who took the new drug, most (72 people) had mild or no side effects.
- 23 people had side effects that affected their day-to-day lives.
- Only 5 people had side effects so severe that they had to stop taking the medicine. The person who had the allergic reaction and the people who had a stomach ache did not have the drug again.

This information can be shown in a 'smiley face' diagram.



☺ People who had mild or no side effects (**72%**)

😐 People who had side effects that had an impact on their life (**23%**)

☹ People who stopped treatment due to severe side effects (**5%**)

There are many different ways of showing information. Remember that it is fine to ask for explanations to be repeated, or explained in a different way, if there is something you do not understand.

Benefit and risk

Healthcare professionals sometimes explain things using the terms benefit and risk.

Benefit

A benefit is something good or helpful that happens as a result of doing (or not doing) something. For example, a benefit of a healthy diet is that you are less likely to be overweight and less likely to develop diseases such as heart disease, diabetes and some cancers.

A benefit of cancer treatment may be that the cancer is cured or controlled for some time. A benefit can also be that the situation does not get worse. For example, the cancer may stay the same size or grow at a slower rate.

Risk

Risk is the chance that something harmful or unwanted may happen as the result of a procedure, test or treatment. Or it may be the result of not doing anything.

Life experiences may affect our view of risk, the decisions we make and the action we take. Our views of risk are likely to change at different times in our lives depending on our circumstances.

For example, if you know someone who has had lots of side effects from having chemotherapy, your view about the risks of chemotherapy is likely to be different from someone who does not know anyone who has had it. These experiences can influence your behaviour and may make you less likely to have chemotherapy.

In this example, it is important to remember that there are lots of different chemotherapy drugs and that not all of them cause lots of side effects. There are also some very good drugs to help prevent or reduce side effects.

Describing risk

Risk can be described in different ways. Healthcare professionals often describe situations as low risk or high risk. These words can mean different things to different people. Using numbers can sometimes be clearer.

Numbers can be shown in different ways. A doctor may describe risk using percentages (%), fractions or likelihood.

For example, 25 out of 100 can be described as:

- 25%
- 25 in 100
- 0.25
- ¼.

Types of risk

When describing risk, research papers and doctors sometimes talk about absolute risk and relative risk.

Absolute risk is the likelihood of something happening to a person. For example, the risk of developing a certain illness at some point in your life may be 1 in 10. This can also be described as a 10% risk.

Relative risk compares risk in 2 different groups of people. An example would be the risk of developing lung cancer in smokers and non-smokers.

The following example may help explain absolute risk and relative risk. This is just an example and does not refer to any real medicine or research.

The doctor tells you the following:

- You have a 6 in 100 (6%) risk of developing disease A at some point in your life.
- Research shows that if you take drug X, your risk changes from 6 in 100 (6%) to 3 in 100 (3%).

The reduction in risk can be described as the following:

- The absolute risk of developing the disease without drug X is 6%, but with drug X it is 3%. So the absolute risk reduction is 3%.
- In this example, the risk has been reduced by half (from 6 to 3). A half can also be described as 50%, so the risk has been reduced by 50%. This is the relative risk reduction.

Relative risk reduction often sounds more dramatic than the absolute risk reduction. It is used more often to describe how effective a treatment is.

Risk and how it relates to you can sometimes be difficult to understand. Ask your healthcare team to explain things in more detail if you are not sure.

MAKING YOUR DECISION

Making your decision about treatment

It can be difficult to make a decision about something very important. You may feel overwhelmed by all the information you have been given. Or you may feel under pressure to do what you think your relatives and friends want.

It may help to think about how you approached big decisions in the past. Are you guided by your first impressions and instincts? Or do you usually need to think things through for a long time? Do you make a decision alone or after discussing it with other people?

When you have put together all the information you have, you may find it helpful to put it aside and try not to think about it for a few days. If you can, do something different to distract you from making the decision. Taking a short break may help you look at all the information with a fresh approach. You may find it helps to talk through your options with your family or friends. If you need to decide fairly quickly, it may help to get a good night's sleep and then make the decision the next day.

> 'Do not agree to anything until you are ready, and make yourself ready by whatever means you need. It might be counselling, research or talking to friends.'
>
> **Louise**

It is your decision

It is important to do what is right for you and not what you think other people want you to do. It is easy to be influenced by the opinions of others, especially when they are very close to you. But you are the one who will be having the treatment, and you need to be sure that you have made the right decision for you at the time.

If your relatives or friends think you are making the wrong decision, explain your reasons to them. They may be happy to accept your decision once they know your reasons, but they may also have important points that you have not considered.

> ‘Find out all the information you can, ask as many questions as you can, and do make the decision that is right for you.’
>
> **Wendy**

Help with making a decision

You could write a list of the benefits and disadvantages of the treatment you have been offered. You can use the next page to do this.

Try to think about:

- the aim of the treatment
- how successful the treatment is likely to be
- the possible side effects
- how often you will need to go to the hospital and for how long
- the effects of the treatment on your family and social life
- the effects on your work and finances.

These are just examples. It is important to take enough time to make your decision. This will be hard if doctors want to start treatment soon. But it is important that you have time to think about the information you have and ask more questions if you need to.

If you cannot decide

Some people find it very difficult to make a decision. Some feel that they want their specialist to make the decision for them.

If you are having trouble deciding, talk to your family and friends. They may be able to simplify things for you. You can also make an appointment to see your doctor or specialist nurse to talk to them again. Your healthcare team may suggest a decision aid to guide you through your choices. Your doctor or nurse can talk to you about this.

If you really cannot make a decision, ask your doctor to decide for you after you have talked to them about what you want or do not want.

How will you know if you have made the right choice?

There is no right or wrong decision. People have different priorities, concerns and circumstances that will mean they make different choices.

The most important thing to remember is that the decision you make is the right one for you at the time. No one can say exactly what will happen in the future. It is likely that there will always be some uncertainty.

You may find you change your mind over time. How you feel now may be different from how you felt a few weeks or months ago. You may also feel different in the future.

As your situation changes, your choices may change too. Your healthcare team will support you and will respect the choices you make.

If the cancer comes back after having the treatment you chose, you should not blame yourself. It is possible that the cancer would also have come back if you had chosen another treatment option. Your doctors would not have offered you a choice of a treatment that might not work so well. It is important to remember that you made the right decision at the time for all the right reasons, using the information available to you.

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you will also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats** If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

We know that the people who use our information are the real experts. That is why we always involve them in our work. If you have been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you would like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we do not ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centreat **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand.
Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be foranything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search ‘My Organiser’ on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

General cancer support organisations

Cancer Black Care
Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland
Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Research UK
Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland
Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in various locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk
Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Teenage Cancer Trust

Tel 0207 612 0370
(Mon to Fri, 9am to 5.30pm)
Email
hello@teenagecancertrust.org
www.teenagecancertrust.org
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their families and friends.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

Emotional and mental health support

Mind

Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline 116 123
Email jo@samaritans.org
www.samaritans.org
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

General health information

Healthtalk

Email info@healthtalk.org
www.healthtalk.org
www.healthtalk.org/young-peoples-experiences (site for young people)
Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

Health and Social Care in Northern Ireland

www.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS Choices

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Scottish Cancer Registry

Tel 013 1275 7050
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

YOUR NOTES AND QUESTIONS

Disclaimer

We make every effort to ensure that the information we provide is accurate and up-to-date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Prof Tim Iveson, Consultant Oncologist.

With thanks to: Dr Russell Burcombe, Consultant Clinical Oncologist; Adele Cooper, Clinical Nurse Specialist; Lisa Flesher, Clinical Nurse Specialist; Rachel Keene, GP; Dr Elise Lang, GP; Dr Louise Lim, Consultant Medical Oncologist; Dr Pauline Love, GP; Pauline McCulloch, Colorectal Lead Nurse; Dr Gerry Miller, GP; Julie Orford, Clinical Nurse Specialist; Dr Lorna Porteous, GP; Dr Amen Sibtain, Consultant Clinical Oncologist; and Dr Santhanam Sundar, Consultant Clinical Oncologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

General Medical Council (GMC). Consent: patients and doctors making decisions together. www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/consent (accessed Nov 2017).
National Institute for Health and Care excellence (NICE). Patient experience in adult NHS services: improving the experience of care for people using adult NHS services. 2012 (last reviewed Aug 2016). www.nice.org.uk/guidance/cg138 (accessed Dec 2017).
NHS. The Information Standard. www.england.nhs.uk/tis/about/description (accessed Nov 2017).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Registered with FUNDRAISING REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about making treatment decisions. It is for anyone who has been diagnosed with cancer. It might also be helpful for carers, family members and friends.

This booklet describes how you can find out the different treatments available to you. It also looks at how you can decide which treatment option would be best for you.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT

MAC12163_04_N. Next planned review 2020.
Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland. Printed on sustainable material. Please recycle.