

# Making treatment decisions



# About this booklet

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

The booklet explains how you can find out information about your treatment options. It discusses how your healthcare team and others can support you to make decisions about your treatment.

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

This 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](#) to help you.

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

At the [end of the booklet](#), there are details of other organisations that can help.

There is also [space to write down questions and notes](#) for your doctor or nurse.

## Quotes

In this booklet, we have included quotes from people who have had cancer, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit

[macmillan.org.uk/shareyourstory](https://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](tel:08088080000), 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://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](tel:1800108088080000), 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, visit [macmillan.org.uk/otherformats](https://macmillan.org.uk/otherformats) or call [0808 808 00 00](tel:08088080000).

### 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.

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# Finding out about your treatment options

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# Understanding your treatment options

People often want to be more involved in decisions about their health and care. You might make decisions on your own. Or you might reach a decision with support from doctors, nurses and other healthcare professionals.

Some people prefer to leave decisions about treatment to their cancer doctor. Even if you decide this, your cancer doctor must still give you clear explanations about your treatment and any risks. They also need to ask for your consent.

Some people may find it difficult to understand the information they need to make decisions. This might be because English is not their first language, or for other reasons.

We have more information about [ways your healthcare team can support you to fully understand your options](#).

## The multidisciplinary team

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

To help the MDT decide, they look at things including:

- the stage and type of cancer you have
- your general health
- any treatment guidelines.

After the MDT meeting, you will usually see your cancer doctor and specialist nurse. They will talk to you about your treatment plan. This is when you start making treatment decisions. You may need more information about the cancer, the different options for your treatment, and how it is likely to affect you.

We have more information about the MDT at [macmillan.org.uk/mdt](https://macmillan.org.uk/mdt)

## Shared decision-making

Shared decision-making means you, your cancer doctor, specialist nurse and other healthcare professionals from your cancer team working together. The aim is to reach a decision about your treatment or care that is right for you.

Your healthcare team gives you [information and support](#) to help you make a decision. You can tell them about your wishes and what is important to you. You may need more than 1 meeting with your healthcare team before you decide. You can usually take some time to decide. But this may not be possible if you have a cancer that needs to be treated urgently.



## Treatment options and your preferences

There is often more than 1 approach to treatment or care. Your cancer team will help you to understand the benefits and risks of different options. This helps you to think about your choices and make the best decision for you.

Sometimes it can help to tell your doctor what is important to you. This might be linked to:

- your personal values
- your cultural, spiritual or religious beliefs
- something unique to you.

You do not have to talk to your doctor about these things. But it might help your healthcare team to understand the treatment you would prefer, and what matters to you.

If you have had negative experiences of healthcare in the past, you might feel uncertain about the advice you get. You might want more time to think, or want a [second opinion](#). Try to talk to your doctor or nurse to understand the reasons for their advice.

## Aims of your treatment

Understanding the aims of your treatment can often be helpful. Your cancer doctor and specialist nurse will explain this to you.

Treatment can aim to:

- completely remove the cancer or destroy all the cancer cells
- slow down, or help to control, the growth of a cancer
- relieve symptoms
- give you the best quality of life.

The aim of your treatment often affects the decisions you make. For example, you may find it easier to accept intensive treatment if it offers a possible cure. Different things, such as your general health, can also affect the treatment you have.

Age, depending on your general health, does not stop you from having the same treatment as anyone else. But it may change how you think about having intensive treatment. We have more information about age and cancer at [macmillan.org.uk](https://www.macmillan.org.uk)

**“ Good cancer care and support is making everything patient-focused, working to the patient's agenda, not the professional's. ”**

Lynn, Clinical Nurse Specialist

# Getting the information you need

It is up to you how much information you need to make decisions about your treatment. Some people want to find out as much as possible about the cancer and each treatment option. Others prefer to know less.

## Information about the cancer

You might want more information from your healthcare team about:

- where the cancer first started – the primary site
- the type of cancer it is – some cancers have different sub-types
- its stage – the size of the cancer and if it has spread
- its grade – how quickly the cancer may grow, based on how the cells look
- any genetic changes in the cancer cells that tell doctors which drugs are most likely to help.

## Information about treatment

You need information to help you think about the benefits and risks of each treatment option. For example:

- if the treatment can cure the cancer, or help you live longer
- whether there are other treatment options available
- possible [side effects of treatment](#), either short-term or long-term
- [how treatments affect your everyday life](#)
- what will happen if you do not have treatment.

This can be a lot to think about. Your healthcare team can usually give you written information to read in your own time. They can also answer any questions you have about each treatment option.

**“ I asked for a print-out of my clinical report so I could educate myself. I did a lot of my own research to help me understand, and to feel more in control of my treatments. ”**

Martha, diagnosed with cervical cancer

## Side effects of treatment

Different treatments have different side effects. This might affect your decision about which treatment to have. It is important to understand the possible short-term and long-term side effects. Your cancer team can explain these to you.

Side effects usually improve after treatment finishes. But some side effects might be permanent. These are called long-term side effects. Or they might develop months or years after treatment. These are called late effects.

For example, you might want to know if a treatment:

- causes permanent infertility
- affects sex and intimacy
- is likely to cause changes to how your bladder or bowel work.

It is important to have these conversations with your cancer team before treatment starts. If you have treatment to preserve your fertility, this needs to start before you begin cancer treatment.

Talk to your team about balancing the possible benefits and side effects of the treatment.

We have more information about side effects on our website. Visit [macmillan.org.uk/sideeffects](https://www.macmillan.org.uk/sideeffects)





## Effects of treatment on everyday life

The effects of treatment on everyday life are different for everyone. For example, some people might be able to continue working, while for others this will not be possible.

If you have an operation, you may need to stay in hospital for weeks, or longer, to recover. Or you may have to travel to hospital regularly for radiotherapy or chemotherapy. This can take time and make you more tired.

You might want to know how different treatments could affect your everyday life. For example, which treatment:

- has side effects that are least likely to affect you
- involves the least time in hospital
- has the smallest effect on your home and social life
- allows you to carry on working for financial reasons.

We have more information about money and insurance at [macmillan.org.uk/money-finance-insurance](http://macmillan.org.uk/money-finance-insurance)

## Prognosis

A prognosis gives an idea about whether the cancer can be cured and what might happen in the future. Your cancer doctor is the best person to answer questions about your prognosis.

Not everyone wants detailed information on prognosis, but some people find it helpful in making treatment decisions. Asking about your prognosis may be difficult, and sometimes the answer might be upsetting. It is important to think about how much you want to know first, before asking for a prognosis. We have more information at [macmillan.org.uk/prognosis](http://macmillan.org.uk/prognosis)

## Statistics

Doctors sometimes mention statistics when describing treatment options. They can explain how statistics relate to your treatment options. This may be a useful way to compare certain treatments. But it is important to remember that [statistics](#) cannot predict how well a treatment will work for you. They can sometimes be difficult to understand.

## Why other treatments might not be possible

Sometimes you might read about a treatment that you have not been offered. This might be for different reasons. For example, the treatment may not be:

- suitable for the type or stage of cancer you have
- suitable because of your general health
- approved, if it is still being tested in a clinical trial
- offered at your hospital
- available on the NHS
- available in the UK.

Even if you have the same cancer as someone else, your treatment may be different. For example, their cancer may be at a different stage, or they may have other medical conditions to consider.

If you have questions, talk to your cancer doctor or specialist nurse. They can explain whether a treatment may be an option for you.



## If a drug or treatment is not available

If a treatment or drug is not available, there are ways you might be able to get it. If you and your cancer doctor agree that you would benefit from a treatment, you can apply to the NHS for funding. There are different ways of doing this depending on which country in the UK you live in. We have more information about applying for funding at [macmillan.org.uk/money-finance-insurance](https://www.macmillan.org.uk/money-finance-insurance)

## Second opinion

If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns and ask them to explain anything you do not understand. This might help reassure you.

Getting a second opinion may delay the start of your treatment. But for some people it offers different treatment options.

We have more information on our website.  
Visit [macmillan.org.uk/second-opinion](https://www.macmillan.org.uk/second-opinion)



# 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 specialist doctor, nurse or other members of your healthcare team
- cancer information organisations
- recommended websites
- other people who have been in a similar situation.

Family and friends may want to help you find out more about the cancer and its treatment. This can be helpful if you are feeling tired or already have enough to think about. Tell them exactly what information you want. You could ask them to make notes or to print off the most useful information for you.

## Your cancer team

Different healthcare professionals make up your cancer team. A team of doctors, nurses and other healthcare professionals work together to plan your treatment. But you will usually have 1 main cancer doctor. This may be a specialist surgeon or a consultant cancer specialist (oncologist). Or it could be a doctor who specialises in cancers of the blood (haematologist).

You may meet more than 1 specialist, depending on the type of cancer you have. If you are not sure who your main doctor is, ask someone in your healthcare team.

You may also have a specialist nurse who gives you information and support. This might be your key worker, who is your main point of contact at the hospital for support and information. Other healthcare professionals from the cancer team, such as radiographers, may give you information and support through your treatment.

Your doctors and nurses can help you to understand other information you may have found. For example, they can explain the results of clinical trials and how they might relate to your situation.

After a hospital appointment, your cancer doctor will write to your GP. If you would like a copy of this letter as well, ask your cancer doctor. Some doctors routinely send copies of letters to the GP. If you would prefer not to have a copy, let them know.

**“ The first meeting was confusing and overwhelming. My mind just went blank. A clinical nurse specialist took my husband and me into a room and gave us some time to ask more questions. ”**

Martha, diagnosed with cervical cancer

## Cancer information organisations

There are many [organisations and charities](#) that can give you information about cancer. They may have specialist nurses who can give you information. Or they may have volunteers with experience of cancer who you can talk to. Organisations often have a website and can send you written information.

## Reliable websites

The internet can be a good source of health information. But it is important to make sure any website you use is reliable and provides accurate information. You could ask your team which websites they recommend.

Some websites have logos to show they have been certified as providers of up-to-date, high-quality information. Look for the Patient Information Forum (PIF) TICK on leaflets, websites, videos or apps.

It shows that the health information has been through a professional and robust production process. You can find the PIF quality mark on Macmillan's information.



To check if a website is reliable, think about the following:

- What does the website address end in? This can give you an idea of who is providing the information. For example:
  - charity and non-profit websites often end in **.org.uk** or **.org**
  - UK government websites end in **gov.uk**
  - academic institutions end in **ac.uk**
- Has it got a PIF TICK or a similar quality mark?
- Is it a UK website? Information and advice may be different in other countries.
- Is the information regularly updated? Medical information changes over time. Check when it was last reviewed to make sure it is still accurate. You should be able to find this date on each page, and the date the information will be reviewed next. PIF TICK guidelines recommend information should be reviewed at least every 3 years.
- Is it clear who has written the information? A good website should tell you about who has produced the information. For example, is it written or approved by healthcare professionals?
- Are there evidence sources that the information is based on (references)? References should be listed, and up to date.
- Is the website sponsored by a company or trying to sell you something? This might mean the information is biased towards that company's products or services.

## Using the internet

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 and talk to someone who can help you. Macmillan has different [support centres in hospitals and libraries across the UK](#).

Save helpful websites as a favourite, or bookmark it so you can find it easily. If you are using a computer in a library or cancer support centre, it may not be possible to save these pages. 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](http://macmillan.org.uk/information-and-support/treating/chemotherapy)

If you are worried about anything you read online, talk to your cancer doctor or specialist nurse. They can answer questions and talk to you about your situation.

**“ I had to make a decision about which treatment I felt would be best for me. I spoke to a Macmillan specialist nurse – she didn’t tell me directly what would be best, but our conversation definitely got me thinking more clearly. ”**

Clive, diagnosed with prostate cancer

## Other people in a similar situation

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

Other people will not be able to tell you which treatment is best for you, or which side effects you will get. But they can tell you how they felt and what helped them to cope during treatment.

Our Online Community is a place where you can chat to people in online forums, blog about your experiences and make friends. Visit [macmillan.org.uk/community](https://macmillan.org.uk/community)

You can also find out about local support groups at [macmillan.org.uk/selfhelpandsupport](https://macmillan.org.uk/selfhelpandsupport)

If you have any doubts about information someone has given you, always check with your healthcare team.

## 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.

You may hear or read things that are upsetting. This can be difficult to cope with when you are already emotional. 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](tel:08088080000).

# Taking part in a clinical trial

You may be asked to take part in a clinical trial. Clinical trials may also be called cancer trials or research trials. Trials help improve knowledge about cancer and its treatments. Many treatments today are available because of trials that took place years ago.

If you have been asked to take part in a trial, your team will give you information about why it is being done. Often, a trial will compare the standard treatment with a new treatment the team thinks may be better. Sometimes a new treatment is added to the standard treatment to compare with the standard treatment on its own.

Taking part means you might benefit from a new treatment. You will also be carefully monitored during and after the trial. But it may mean attending hospital more often than for the standard treatment. It may involve travel to a different hospital.

Talk to your healthcare team about the possible treatments and how they may affect you. This will help you to decide if you want to take part. If you decide not to take part, you will be offered the standard treatment for your situation.

We have more information about clinical trials on our website. Visit [macmillan.org.uk/clinicaltrials](https://www.macmillan.org.uk/clinicaltrials)







# Helping you decide

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# Who can help you decide?

Before you make a decision, talking to someone can help you with your thoughts and feelings. You will usually have a specialist nurse at the hospital you can talk to. You can also talk things over with your GP. If you have any doubts about the information you have been given, always check with your healthcare team.

A psychologist or counsellor may support you to make decisions about:

- intensive treatments
- treatments that change your appearance or how your body works.

Your cancer doctor or specialist nurse can usually arrange this.

Healthcare professionals are not the only people who can help you.

You might have family or friends to talk things through with.

Sometimes a [support group or organisation](#), or an online forum, such as our [Online Community](#), can be helpful.

Everyone is different. The right choice for someone else may not be best for you.



**“ I saw 3 different consultants, who each presented a different option for treatment. ”**

Ken, diagnosed with prostate cancer

## Dealing with uncertainty

When making treatment decisions, there is not always a clear right or wrong answer. Your cancer doctor may not be able to say for sure whether a treatment will work, or how it may affect you.

Uncertainty can be hard to deal with. It can make you feel:

- anxious
- angry
- irritable
- frightened.

This might cause tension with people around you. Dealing with uncertainty sometimes gets easier as time passes. Talking to family, friends and healthcare professionals about how you feel can usually help.

Some people find it useful to talk to a counsellor or psychologist. [Your local cancer information centre or support group](#) may have a counsellor you can talk to. Or your healthcare team might be able to refer you to a psychologist or counsellor.

# 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 healthy diet benefits your health because you are less likely to be overweight. As a result, you reduce your risk of heart disease, diabetes and certain cancers.

A benefit of cancer treatment may be that the cancer is cured or controlled, sometimes for many years. The cancer staying the same size, or growing at a slower rate for a time, can also be a benefit.

## Risk

Risk is the chance something harmful or unwanted might happen because of a test or treatment. Risk can also be the result of not doing anything.

How you feel about risk might be affected by your experiences. For example, if you know someone who has had lots of side effects from a cancer drug, this might affect your view of all cancer drugs. You may worry more about your risk of side effects than someone else who has not had this experience. But it is important to remember that:

- different cancer drugs have different types of side effects
- even with the same drug, not everyone has the same side effects
- there are also effective ways to help to prevent or reduce side effects.

## Drug side effects and risk

You can read more about cancer drugs and their risk of side effects. Visit [macmillan.org.uk/treatments-and-drugs](https://www.macmillan.org.uk/treatments-and-drugs)

We do not list every side effect. If you want more information, your cancer doctor, specialist nurse or pharmacist can explain this.

You can also visit the electronic Medicines Compendium (eMC) for detailed information. Visit [medicines.org.uk/emc](https://www.medicines.org.uk/emc)

It uses the following terms to describe how likely a side effect is to happen:

- very rare – may affect up to 1 in 10,000 people
- rare – may affect up to 10 in 10,000 people
- uncommon – may affect up to 100 in 10,000 people
- common – may affect up to 1,000 in 10,000 people
- very common – may affect more than 1,000 in 10,000 people.

This kind of information can help you to view risk in a realistic way. The information is based on evidence and studies of each side effect. Even common side effects may be less likely than you thought, before looking at these numbers.

It is important to get good evidence to help you make informed decisions. You can then talk to your cancer doctor or specialist nurse, who can help you to understand what it means for your situation.



## 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.

You can show numbers in different ways. A doctor might describe risk using percentages (%), fractions or likelihood.

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

- 25%
- 25 out of 100
- 0.25
- $\frac{1}{4}$ .

It can help to think about risk in both ways. For example:

- 25 out of 100 people had this side effect
- 75 out of 100 people did not have this side effect.

## Types of risk

It can be difficult to understand how risk relates to you.

When describing risk, doctors sometimes talk about absolute risk and relative risk. Or you might read these terms in a research paper.

Ask your GP or cancer doctor if the numbers they give you are absolute or relative risk. If you are not sure about what a level of risk means, ask your GP, cancer doctor or specialist nurse to explain things in more detail.

Absolute risk is the likelihood of something happening to a person over a time. For example, a person might have a 1 in 10 risk of developing a certain disease in their life. This can also be described as a 10% risk.

Relative risk compares risk in 2 different groups of people. For example, the risk of developing lung cancer in a group of smokers and a group of non-smokers.

### Understanding absolute risk and relative risk

The following examples explain the difference absolute risk and relative risk.

This is just an example and does not refer to any real medicine or research. The doctor tells someone the following:

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

The reduction in risk can be described in 2 different ways.

### **Absolute risk**

The absolute risk of developing the disease without drug X is 6%. But with drug X it is 3%. The absolute risk reduction is 3% (6 minus 3).

When deciding on a treatment, you and your cancer doctor could talk about whether the reduction in absolute risk outweighs the overall risks and side-effects.

### **Relative risk**

The risk has dropped from 6% to 3%. It is now half as large as it was. Because a half can also be described as 50%, the risk has been reduced by 50%. This is the relative risk reduction. If you hear that a drug or treatment reduces your risk by 50%, you would probably be very interested. You may feel differently to hear that it reduces your absolute risk by 3%.

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

It is important to talk to your team about both types of risk and what this means for your situation.

It can be difficult to think about how statistics relate to you as an individual and which percentage group you are likely to be in. You can talk to your cancer doctor or specialist nurse and ask for their advice on your situation.



# Statistics

Your cancer doctor will prescribe a treatment because they believe that its benefits will outweigh any side effects. But they cannot know exactly how the cancer will respond to the treatment or how you will feel.

Your cancer doctor may use statistics to tell you what they know about a treatment. Statistics are a way of presenting information using numbers. You might find some statistics helpful when making treatment decisions.

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

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

Statistics are based on large numbers of people. They cannot tell you exactly what is going to happen to you. But they can give you an idea of how likely each outcome is.

For example, a drug you are offered may cause sickness (nausea) in 80 out of 100 people (80%). You cannot know whether you will feel sick. But as it is quite common, you might expect to.

If you are offered a different drug that causes sickness in just 30 out of 100 people (30%), it is a lot less likely you will feel sick.

## Understanding statistics

Statistics can be complicated and difficult to understand.

If your doctor uses statistics that you do not understand, ask them to make the information simpler. It might help if they write the statistics down. 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 100)
- bar and pie charts
- other diagrams.

It can be difficult to think about how statistics relate to you as an individual and which group you are likely to be in. You can talk to your cancer doctor, specialist nurse or other healthcare professionals from your cancer team for advice on your situation.

## Ways of presenting information

The following example shows how information can be presented in different ways. This is an imaginary example. It does not refer to any real drug or research. It shows that when making treatment decisions it is important to think about both:

- how effective a treatment is
- its possible side effects.

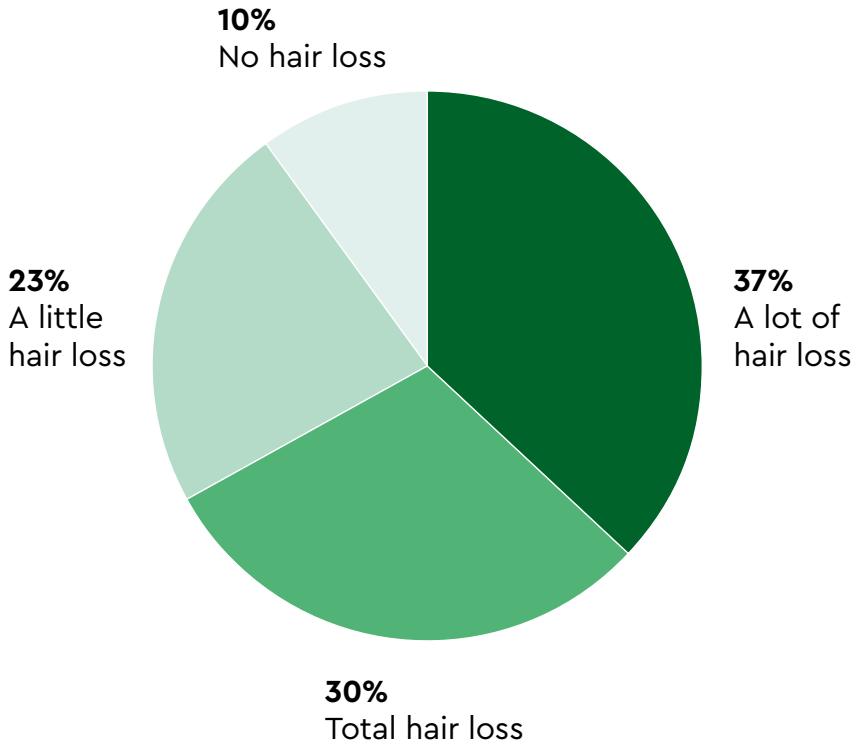
Example: A cancer doctor talks to someone who is going to start chemotherapy about a new drug which may help to prevent hair loss. Before taking the drug, the person wants to know how well the drug works. Of 100 people who took the new drug:

- 10 people had no hair loss (10%)
- 23 people had a little hair loss (23%)
- 37 people had a lot of hair loss (37%)
- 30 people had total hair loss (30%).

The new drug slowed down or stopped total hair loss for 70 people (10+23+37). But 67 of the 100 people who took the drug had a lot of or total hair loss (37+30).

The numbers in each group can also be shown in a diagram to make this clearer.

## Pie chart showing how many people had hair loss





The person now has an idea of how effective this drug is. But they also need to know its possible side effects 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:

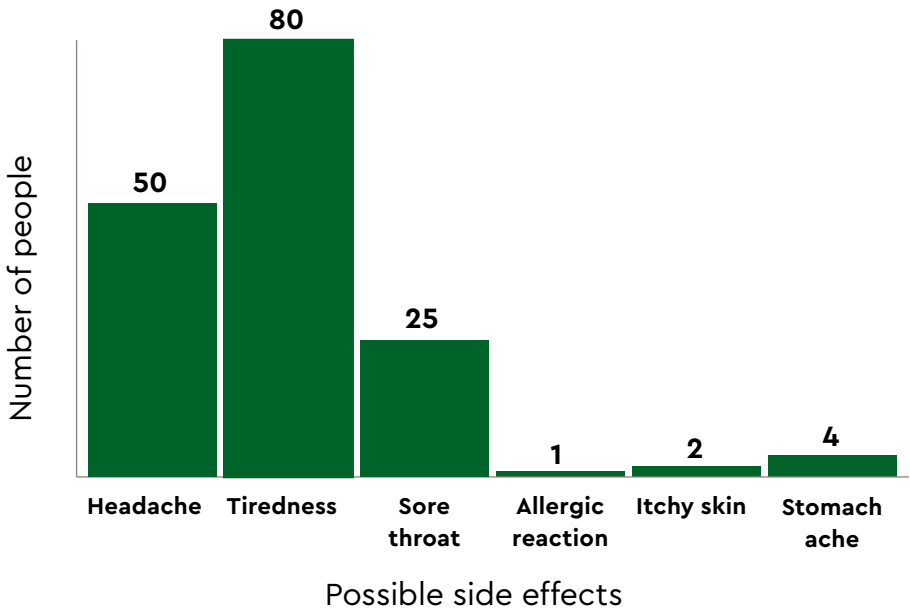
- 50 people had headaches (50%)
- 80 people felt tired (80%)
- 25 people had a sore throat (25%).

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 more than 1 side effect.

## Bar chart showing the possible side effects of the drug

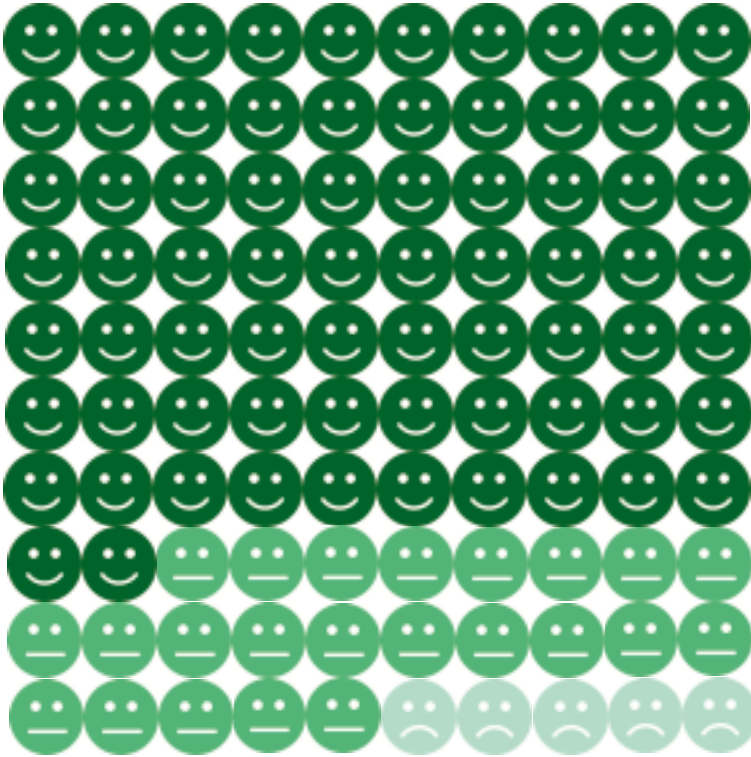


The person also wants to know how people's lives were affected by the side effects. The doctor tells them that of the 100 people who took the new drug:

- 72 people had mild side effects or no side effects (72%)
- 23 people had side effects that affected their daily lives (23%)
- only 5 people had side effects so severe they had to stop taking the drug (5%).

This information can be shown in an emoji (smiley face) diagram.

## Emoji diagram of side effects



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%**)



# Making your decision

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# Help with making a decision

When you have decisions to make, it is often useful to write things down. This can help you to think about all the different parts of your situation. One useful technique is to write a list of the benefits and disadvantages of the treatment or treatments you have been offered.

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.
- what happens if you do not have a particular treatment.

Other useful things to ask yourself:

- Who you have around you to help practically and help you cope emotionally?
- How have you made sometimes difficult decisions in the past?
- What are the things you value in life and how might you stay connected with these even during treatment? For example, if work is important to you, how can you keep in touch with colleagues?

You can make an appointment with your cancer doctor or specialist nurse to discuss this with them. They may be able to suggest a decision aid to guide you through your choices. Talking to family and friends may help.

You do not have to make a decision on your own. You and your cancer doctor can decide together. This is called shared decision-making.

If you prefer, you can ask your doctor to decide for you. But talk to them first about why this is and what you want or do not want.



# Tools to help you make decisions

There are different tools to support people making treatment decisions. They can help you to get the information you need and think about what is important to you. Some tools include questions to ask your doctor or nurse to help you make better decisions together.

## Ask 3 questions

- What are my options?
- What are the benefits and disadvantages of each option for me?
- How do I get support to help me make a decision that is right for me?

## BRAN

This asks the following 4 questions:

- B – What are the benefits?
- R – What are the risks?
- A – What are the alternatives?
- N – What if I do nothing?

## PREDICT tools

Certain cancers have specific patient decision-making tools. They help you to understand how well different treatments have worked for people with the same type and stage of cancer.

Your healthcare team can tell you more about these. These tools are regularly updated and based on the best current evidence.

Some examples of patient decision-making tools are:

- PREDICT Breast – if you have had surgery for early invasive breast cancer and are deciding which other treatments to have.  
Visit [breast.predict.nhs.uk/tool](https://breast.predict.nhs.uk/tool)
- PREDICT Prostate – if the cancer is contained in the prostate and you are deciding on what type of treatment to have.  
Visit [prostate.predict.nhs.uk](https://prostate.predict.nhs.uk)

## My information table

You can use this table to help you decide what information you need, what is important to you and the people who may be able to help you.

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

**“ Different people  
may have the same  
cancer diagnosis,  
but what's important  
to 1 person may be  
completely different  
to what's important  
to someone else. ”**

Shona, Clinical Nurse Specialist

# Making treatment decisions

You may feel overwhelmed by all the information you have been given. Or you may feel under pressure to do what you think your family and friends want. It may help to think about how you have approached big decisions in the past:

- Are you guided by your first impressions and instincts?
- Do you usually need to think things through for a long time?
- Do you make decisions alone, or after talking through your options with family or friends?

If you can, taking a short break may help. You can then look at all the information together. If you need to decide quickly, it may help to get a good night's sleep and make your decision the next day.

## How do you know it is the right choice?

There is no right or wrong decision. People make different choices for different reasons. Your decision is the right one for you at the time you make it.

Doctors only usually offer a choice of treatments if they work equally well.

You may be able to change your mind about a treatment. If your situation changes, your choices may be different. Your healthcare team will always support you and respect the choices you make.





# Getting more support

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# 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 handy and write things as you think of them, or you can order a free [Macmillan organiser](#).

You can also make notes during appointments. You may find it helpful to bring someone with you to appointments, such as a family member, friend or carer. They may also be able to make notes and help you to remember what is said.

We have more information about questions you can ask in our booklet [Ask about your cancer treatment](#).

You can order our booklets and leaflets for free.

Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on [0808 808 00 00](tel:08088080000).



## Questions about treatment

Before you start treatment, 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?
- How can I choose between the treatments you have offered me?
- What are the benefits and risks of each treatment option?
- Will side effects eventually go away, or might some be permanent?
- Is there a clinical trial I can take part in?
- Can I change my mind after I have started my treatment?
- How often will I have my treatment?
- Do I need to change my lifestyle while having this treatment?
- Will the treatment affect my fertility or sex life?
- How long is my recovery likely to take?

# If you do not speak or understand English well

The NHS must make sure that anyone who uses their services can get all the information they need. If language is an issue, they should offer:

- a professional interpreter in the language you choose
- translation in the written language you choose.

These services are free. For more information look at the [NHS website in your area](#).

## Interpreters

The NHS should always use professional interpreters, rather than your family or friends. This means your family or friends can focus on being there to support you to make a decision. It also means there is less risk of getting important information wrong.

Interpreters translate everything your cancer doctor says to you, and everything you want to say back. If you would like an interpreter, tell the hospital as soon as possible.

You can also speak to the Macmillan Support Line team in your language using our interpreter service. Call us free on [0808 808 00 00](tel:0808 808 00 00) to tell us, in English, the language you or someone that you are calling in support of needs.

## Translated health information

Your healthcare team should provide you with written information about health and care services. This is often a series of leaflets, and should be in a language and format that you understand. Some hospitals may provide cancer information in different languages.

If translated information is not available in your preferred language, the NHS should provide it free. These websites provide a selection of health information in different languages:

- [nhsinform.scot/translations](https://nhsinform.scot/translations)
- [nhs.uk/about-us/health-information-in-other-languages](https://nhs.uk/about-us/health-information-in-other-languages)
- [www.healthinfotranslations.org](http://www.healthinfotranslations.org)

Macmillan has a range of information in languages other than English at [macmillan.org.uk/translations](https://macmillan.org.uk/translations)

This includes information about:

- different cancer types
- being diagnosed
- cancer treatment
- side effects.

# Language or culture

You might have difficulties in understanding information or getting your GP or cancer doctor to understand your concerns for different reasons.

This could be because English is not your first language. Or there may be things to do with your culture that affect how you feel about your treatment or care.

To give you the best care and treatment, your healthcare team should:

- try to understand anything that might affect your decisions about your treatment and care
- make sure you are not disadvantaged, whatever your ethnicity or culture
- make sure that your culture or language do not prevent good communication and understanding between you and your healthcare team.

Translators and interpreters can help you get the information you need to understand your treatment.

# If you have a physical or learning disability

If you have a physical disability, learning disability or neurodivergence, you might find it harder to have the conversations you need with your healthcare team.

They should communicate with you in the most effective way to give you the information you need.

The NHS has to make sure that disabled people can use health services as easily as people without disabilities. This is called making reasonable adjustments.

It could include:

- making sure there are no physical barriers for people using wheelchairs or with mobility issues
- longer appointments to give you more time with a cancer doctor or specialist nurse
- offering an appointment at the beginning or end of the day, or a quiet place to wait, if activity and noise makes you more anxious
- providing easy read information or simple pictures to help you to understand treatments and side effects.

You can ask for information about your reasonable adjustments to be recorded in your medical notes or another document.

## If you find printed text difficult

If you have a learning difficulty like dyslexia, or find printed text difficult to read, Macmillan provides the following:

- Audiobooks – visit [macmillan.org.uk/audiobooks](http://macmillan.org.uk/audiobooks)
- Easy read information – this uses simple words and pictures to explain cancer symptoms, diagnosis, treatment, and end of life. Find the full range at [be.macmillan.org.uk](http://be.macmillan.org.uk)

## If you are deaf or blind

If you are deaf or blind, your healthcare team should make reasonable adjustments to help you get the same care as anyone else. This can also include some people who have low vision or are hard of hearing. Your healthcare team should make sure you:

- get information in formats you can read and understand – for example, audio, Braille, easy read or large print
- have a communication professional at your appointments – for example, a British Sign Language (BSL) interpreter
- can contact them using email or text message if you find this easier.

If you use BSL, you can email us or chat online to arrange a free call to the Macmillan support line [0808 808 00 00](tel:0808808000) with a BSL interpreter. Or a hearing family member or friend can call the support line to organise this.

Find out more about using the Macmillan Support line with BSL at [macmillan.org.uk/bsl](http://macmillan.org.uk/bsl)

We also have a small range of videos about cancer using BSL. You can watch them at [youtube.com/macmillancancer](https://youtube.com/macmillancancer)

Our easy read booklets can also be useful for people who use BSL. You can download a PDF or order a printed booklet. Find the full range at [be.macmillan.org.uk](https://be.macmillan.org.uk)

We also have a new service in partnership with Self Help UK to improve access to cancer information and support for deaf people.

For people who are blind or have low vision, we produce information:

- in Braille
- in large print
- as audiobooks.

## If you have speech problems

If you have problems with your speech, you may use different types of communication aids or BSL. Let the hospital know what your needs are, so they can support you with the type of communication aid you are most comfortable using.

Organisations that can support you include:

- British Deaf Association – [bda.org.uk](https://bda.org.uk)
- National Autistic Society – [autism.org.uk](https://autism.org.uk)
- Royal National Institute of Blind People – [rnib.org.uk](https://rnib.org.uk)
- Sense – [sense.org.uk](https://sense.org.uk)
- SignHealth – [signhealth.org.uk](https://signhealth.org.uk)





# If you need help to get your views understood

If you find it hard to get your healthcare team to understand your views on treatment, someone might be able to speak on your behalf. These people are called advocates. They are not employed by the NHS.

They can help you to:

- talk about how you feel about your treatment and to make decisions
- get your views and wishes about treatment understood by your team.

An advocate can also be a friend or family member you take with you to important meetings. You might want them there for moral support and to get your views understood.

Depending on where you live in the UK, different organisations can give help and advice.

- Search [nhs.uk](https://www.nhs.uk) for 'advocate'
- Care Information Scotland – [careinfoscotland.scot](https://www.careinfoscotland.scot)
- Search [mygov.scot](https://www.mygov.scot) for 'advocacy'
- Scottish Independent Advocacy Alliance – [siaa.org.uk](https://www.siaa.org.uk)
- Advocacy Support Cymru – [ascymru.org.uk](https://www.ascymru.org.uk)
- Llais – Your voice in health and social care in Wales – [llaiswales.org](https://www.llaiswales.org)



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# 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 booklets or leaflets like this one.

Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on [0808 808 00 00](tel:0808 808 00 00).

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

## Online information

All our information is also available online at [macmillan.org.uk/information-and-support](http://macmillan.org.uk/information-and-support) You can also find videos featuring 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
- interactive PDFs
- large print
- translations.

Find out more at [macmillan.org.uk/otherformats](http://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](mailto:cancerinformationteam@macmillan.org.uk) or call us on [0808 808 00 00](tel:0808 808 00 00).

## The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

You can read more about how we produce our information at [macmillan.org.uk/ourinfo](https://www.macmillan.org.uk/ourinfo)

# 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. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on [0808 808 00 00](tel:08088080000). We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to [macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call [0808 808 00 00](tel:08088080000) and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at [macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres) or call us on [0808 808 00 00](tel:08088080000).

## 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. Please note the opening times may vary by service.

## Financial guidance

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

## Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.



### Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on [0808 808 00 00](tel:0808 808 00 00) to find out more about Macmillan Grants.

### 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](https://macmillan.org.uk/work)

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on [0808 808 00 00](tel:0808 808 00 00) to speak to a work support adviser.

## **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 bring people together in their communities and online.

### **Support groups**

Whether you are someone living with cancer or a carer, family member or friend, 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](https://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](https://macmillan.org.uk/community)

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

## **Macmillan healthcare professionals**

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.

# Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

## General cancer support organisations

### Black Women Rising

[www.blackwomenrisinguk.org](http://www.blackwomenrisinguk.org)

Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

### Cancer Black Care

Tel **0208 961 4151**

[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)

Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

### Cancer Focus Northern Ireland

Helpline **0800 783 3339**

[www.cancerfocusni.org](http://www.cancerfocusni.org)

Offers a variety of services to people affected by cancer in Northern Ireland.

## **Cancer Research UK**

Helpline **0808 800 4040**

[www.cancerresearchuk.org](http://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**

[www.cancersupportscotland.org](http://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](http://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**

Tel **0300 123 1801**

[www.maggies.org](http://www.maggies.org)

Has a network of centres in many 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**

[www.pennybrohn.org.uk](http://www.pennybrohn.org.uk)

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

### **Riprap**

[www.riprap.org.uk](http://www.riprap.org.uk)

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

### **Tenovus**

Helpline **0808 808 1010**

[www.tenovuscancercare.org.uk](http://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.

## **General health information**

### **Health and Social Care in Northern Ireland**

[www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)

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

## **NHS.UK**

[www.nhs.uk](http://www.nhs.uk)

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

## **NHS 111 Wales**

[111.wales.nhs.uk](http://111.wales.nhs.uk)

NHS health information site for Wales.

## **NHS Inform**

Helpline **0800 22 44 88**

[www.nhsinform.scot](http://www.nhsinform.scot)

NHS health information site for Scotland.

## **Patient UK**

[www.patient.info](http://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.

## Counselling

### British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**

[www.bacp.co.uk](http://www.bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'How to find a therapist' page.

### UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**

[www.psychotherapy.org.uk](http://www.psychotherapy.org.uk)

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## Emotional and mental health support

### Mind

Helpline **0300 123 3393**

[www.mind.org.uk](http://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](http://www.samaritans.org)

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**

Textphone **028 9031 1092**

[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Carer's Allowance Unit

Tel **0800 731 0297**

Textphone **0800 731 0317**

[www.gov.uk/carers-allowance](http://www.gov.uk/carers-allowance)

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

### Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

### England

Helpline **0800 144 8848**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)



## Scotland

Helpline **0800 028 1456**

[www.cas.org.uk](http://www.cas.org.uk)

## Wales

Helpline **0800 702 2020**

[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)

## Civil Legal Advice

Helpline **0345 345 4345**

Textphone **0345 609 6677**

[www.gov.uk/civil-legal-advice](http://www.gov.uk/civil-legal-advice)

Has a list of legal advice centres in England and Wales and solicitors that take legal aid cases. Offers a free translation service if English is not your first language.

## Disability and Carers Service

Tel **0800 587 0912**

Textphone **0800 012 1574**

[nidirect.gov.uk/contacts/disability-and-carers-service](http://nidirect.gov.uk/contacts/disability-and-carers-service)

Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

## GOV.UK

[www.gov.uk](http://www.gov.uk)

Has information about social security benefits and public services in England, Scotland and Wales.

## **Jobs and Benefits Office Enquiry Line Northern Ireland**

Helpline **0800 022 4250**

Textphone **0800 587 1297**

[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

## **Law Centres Network**

[www.lawcentres.org.uk](http://www.lawcentres.org.uk)

Local law centres provides advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

## **Local councils (England, Scotland and Wales)**

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

### **England**

[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)

### **Scotland**

[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)

### **Wales**

[gov.wales/find-your-local-authority](http://gov.wales/find-your-local-authority)

### **Macmillan Benefits Advice Service (Northern Ireland)**

Tel **0300 1233 233**

### **Money Advice Scotland**

[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)

Use the website to find qualified financial advisers in Scotland.

### **mygov.scot**

[www.mygov.scot](http://www.mygov.scot)

Provides access to public services in Scotland, including health and social care, benefits and grants.

### **NI Direct**

[www.nidirect.gov.uk](http://www.nidirect.gov.uk)

Has information about benefits and public services in Northern Ireland.

### **Northern Ireland Housing Executive**

Tel **0344 892 0902**

[www.nihe.gov.uk](http://www.nihe.gov.uk)

Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

### **StepChange Debt Charity**

Tel **0800 138 1111**

[www.stepchange.org](http://www.stepchange.org)

Provides free debt advice through phone, email, the website and online through live chats with advisers.

## **Unbiased.co.uk**

Helpline **0800 023 6868**

[www.unbiased.co.uk](http://www.unbiased.co.uk)

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

## **Patient advocacy organisations**

### **Advocacy Support Cymru**

Tel **0292 054 0444**

[www.ascymru.org.uk](http://www.ascymru.org.uk)

Provides professional, confidential and independent advocacy in Wales, so people can understand their rights and have their voices heard.

### **Care Information Scotland**

Tel **0800 011 3200**

[www.careinfoscotland.scot](http://www.careinfoscotland.scot)

Provides information and advice for carers and people planning their own care in Scotland.

### **Llais**

Tel **0292 023 5558**

[www.llaiswales.org](http://www.llaiswales.org)

Collects experiences of people using health and social care in Wales. Supports services users to make complaints when things go wrong.

## **Scottish Independent Advocacy Alliance**

Tel **0131 510 9410**

[www.siaa.org.uk](http://www.siaa.org.uk)

Supports and promotes independent advocacy across Scotland. Use the 'Find an advocate' webpage to find local support.

## **Support organisations**

### **Age UK**

Helpline **0800 678 1602**

[www.ageuk.org.uk](http://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.

### **British Deaf Association**

[www.bda.org.uk](http://www.bda.org.uk)

Works directly with Deaf people who use British Sign Language (BSL). Campaigns for equal rights and empowers Deaf people to access their local public services.

### **National Autistic Society**

Tel **0207 833 2299**

[www.autism.org.uk](http://www.autism.org.uk)

Provides advice and support for autistic people and their families. Has a directory of autism services.

## **RNIB**

Helpline **0303 123 9999**

[www.rnib.org.uk](http://www.rnib.org.uk)

Offers support and advice to blind and partially sighted people in the UK.

## **Sense**

Tel **0300 330 9256**

[www.sense.org.uk](http://www.sense.org.uk)

Supports people who are deafblind or who have complex disabilities to express themselves, to develop their skills and confidence, to make choices and to live a full life.

## **SignHealth**

Text **0786 003 3214**

Tel **020 3947 2600**

[www.signhealth.org.uk](http://www.signhealth.org.uk)

Works with the NHS and health and social care providers to remove barriers to good health and wellbeing for Deaf people.

## **LGBT-specific support**

### **LGBT Foundation**

Tel **0345 330 3030**

[www.lgbt.foundation](http://www.lgbt.foundation)

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### **Live Through This**

[www.livethroughthis.co.uk](http://www.livethroughthis.co.uk)

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

## **Support for carers**

### **Carers Trust**

Tel **0300 772 9600**

[www.carers.org](http://www.carers.org)

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

### **Carers UK**

Helpline **0808 808 7777**

[www.carersuk.org](http://www.carersuk.org)

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

## **Cancer registries**

The cancer registry is 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. They are run by the following organisations:

### **England – National Disease Registration Service (NDRS)**

[digital.nhs.uk/ndrs/patients](https://digital.nhs.uk/ndrs/patients)

### **Scotland – Public Health Scotland (PHS)**

[publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview](https://publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview)

### **Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)**

Tel **0292 010 4278**

[phw.nhs.wales/wcisu](https://phw.nhs.wales/wcisu)

### **Northern Ireland – Northern Ireland Cancer Registry (NICR)**

Tel **0289 097 6028**

[www.qub.ac.uk/research-centres/nicr](https://www.qub.ac.uk/research-centres/nicr)





## 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 members of Macmillan's Centre of Clinical Expertise.

With thanks to: Tanya Andrewes, Senior Lecturer in Adult Nursing; Dr Russell Burcombe, Consultant Clinical Oncologist; Dr Jayne McAuley, Consultant in Palliative Medicine; Pauline McCulloch, Colorectal Lead Nurse; Kathleen McHugh, Consultant Clinical Psychologist; Dr Adeola Olaitan, Consultant Gynaecological Oncologist; and Jacque Warwick, Macmillan Clinical Nurse Specialist.

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](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

Below is a sample of the sources used in our information about making treatment decisions. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Hayter C, Andrewes T. Factors affecting patients' decision-making about treatment for cancer: a literature review. *Cancer Nursing Practice*. doi: 10.7748/cnp.2021.e1769 [accessed January 2023].

National Institute for Health and Care Excellence. Shared decision making. NICE; 2021. Available from: [www.nice.org.uk/guidance/ng197](http://www.nice.org.uk/guidance/ng197) [accessed January 2023].

## Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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

#### 1. Share your cancer experience

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

#### 2. 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.

#### 3. 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?

#### 4. Raise money

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

#### 5. Give money

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

## 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 / /

## Do not 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.

If you would rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)



**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 and friends.**

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This booklet describes how you can find out the different treatments available to you. It also looks at how you can decide on the treatment option that is best for you.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call [0808 808 00 00](tel:0808808000) or visit [macmillan.org.uk](https://www.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](tel:1800108088080000), 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](https://www.macmillan.org.uk/otherformats) or call our support line.

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The logo consists of a blue rounded rectangle containing the text 'Trusted Information Creator' in black. To the right of the text is a large green checkmark.

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*Patient Information Forum*