

Treatment decisions

If you have blood cancer or a related condition, you'll be asked to make decisions about your treatment. This can be a difficult thing to do, particularly if you have to make these decisions very quickly.

This fact sheet will help you understand the types of treatments available and what choices you'll be asked to make.

Your healthcare team

Your healthcare team are here to help and support you to make decisions about your treatment.

Your care will probably be managed by a team called a multi-disciplinary team (MDT) made up of specialists from different sections of your hospital.

Your team should include a clinical nurse specialist (CNS), who is usually your main point of contact throughout your treatment – sometimes called your 'key worker'. Your key worker should talk to you about every part of your treatment and care.

Your team should provide you with the information you need to make decisions about your treatment. Have a talk with your key worker or consultant (specialist doctor) if you'd like to know more details about your MDT or any other discussions about your treatment and care.

You should have regular meetings with members of your team. If you're feeling anxious about these meetings, it might be helpful to write down important questions before or take notes during the meeting. You can take someone with you for support, or ask them to take notes for you to read later.

Different people like to know different amounts of information. Let your team know how much

information you want at each stage of your treatment.

Everyone has the right to receive a second opinion from another consultant, so if you're unsure about anything, you should feel free to do this.

What are my treatment options?

There are many different approaches to treating blood cancer. Before your team recommends a treatment for you, they will look at:

- › the type of cancer you have,
- › your general health and the results of any tests you've had, and,
- › what treatments are available, how well they work and any risks or side effects.

They'll consider:

- › whether the benefits outweigh the risks of the treatment,
- › if there's a risk that your cancer might get worse (progress) or return after treatment, and,
- › your thoughts, feelings and wishes about your treatment.

Your doctors will always refer to trustworthy medical sources to make sure you are given the best treatment option for you as an individual. This includes published reports of clinical trials, scientific studies and medical guidelines.

Types of treatment for blood cancer

This fact sheet covers types of treatment for different types of blood cancer. Not all of the sections will be relevant to you.

Your healthcare team can tell you which of these options are open to you.

Intensive treatment

Intensive treatment means using strong drugs such as chemotherapy (cell-killing drugs), a stem cell transplant or radiotherapy.

These treatments are aimed at curing blood cancer. They often have severe side effects, although side effects vary a lot between treatments and people.

If you have a fast-developing (aggressive) type of blood cancer, you'll probably need treatment straight away and will have to make decisions about your treatment quickly.

For more information about chemotherapy and stem cell transplants go to [bloodwise.org.uk](https://www.bloodwise.org.uk) or call us on **0808 2080 888** (freephone)

Not everyone will benefit from intensive treatment. Your healthcare team can talk you through your options.

Non-intensive treatment

Non-intensive treatments like low-dose chemotherapy are usually gentler and cause fewer side effects. These treatments are normally aimed at controlling your symptoms or reducing blood cancer, rather than curing it.

Your team might recommend this type of treatment if they don't feel that you'll benefit from more intensive treatment, or if you don't want the side effects of more intensive treatment.

Some people switch to non-intensive treatment after having intensive treatment if the treatment was not as successful as they and their team had hoped for.

For whatever reason, if treatment to try and cure your cancer isn't right for you, your team will discuss your options with you.

Watch and wait

One type of treatment for some people with certain types of slow-developing blood cancer is called 'watch and wait' or 'active monitoring'.

This means you won't start treatment straight away, but you'll have regular appointments where you'll be monitored closely for any changes.

You'll only be given further treatment – usually chemotherapy – if and when you need it. This means you won't have to go through any of the side effects of chemotherapy unless your condition changes.

Some people find being on watch and wait an anxious time, particularly around the time of check-up appointments. Your team will only recommend watch and wait for you if you feel well and there will be no harm or disadvantage to if you delay the start of your treatment.

Supportive care

People having intensive or non-intensive treatment will have supportive care alongside this.

Supportive care means treatments that don't directly treat blood cancer but will help you to feel better. For example, you may need blood transfusions for anaemia (a condition caused by a lack of red blood cells), or antibiotics to prevent or treat an infection.

Palliative care

Palliative care means care or treatment that you have to help with your symptoms. It aims to give you a good quality of life and look after your emotional and physical well being, and the needs of your family.

There are many types of palliative care, including low-dose chemotherapy, pain relief, and psychological and emotional support.

Palliative care isn't just available at the end of life. You might be offered palliative care earlier, while you're still having other treatments.

Your care team will be able to tell you about what services are appropriate and available to you, such as hospital-based services or respite or hospice care.

Marie Curie provides support and information about palliative and end of life care. Go to mariecurie.org.uk/help

How do I decide what treatment to have?

Any treatment decision is a careful weighing up of the possible benefits of the treatment against the possible risks.

You should think about your own priorities and goals as well as your general health. How you're feeling physically and mentally can affect your decision.

Whatever your condition, and whichever treatment you're being offered, there are some questions that you may want to ask your doctor. These include:

- › What does the treatment involve?
- › How effective is it likely to be?
- › What could the side effects be?
- › How could it affect my everyday life? (How will it affect my work, my family, my need to travel for treatment?)

These may be decisions that are difficult to make on your own. It's important for you to discuss all your options with your healthcare team so that you both agree the best choice for you.

You might also need to stay flexible as things change. Remember that you can reconsider your decisions at any time and the final decision about your treatment will always be yours.

Who can make treatment decisions?

Sometimes people prefer to leave treatment decisions to their doctor or healthcare team, and if this is something you think you'd prefer, you should let your doctor know.

Even if you let your doctor or team decide, you'll still need to know information about your condition and the treatment you've confirmed. You can also ask for a second opinion if you're unsure about any decision.

You may wish to choose a family member to be told about your condition and treatment. If this is the case for you, you should let your team know.

Although some people prefer for important decisions to be made by a family member or their family as a whole, British law means that in practically all cases permission (consent) can only be given by the person being treated.

The NHS provides information on giving and refusing permission for treatment at nhs.uk/Conditions/Consent-to-treatment

Why am I not being offered intensive treatment?

Not everyone will be fit enough to receive intensive treatment. This particularly applies to older people, but it can also include younger people with other medical problems.

As each person is different, doctors can't always say how age will affect your fitness for treatment, but, in general, as people age their bodies are less able to cope with intensive chemotherapy, and the side effects can do more harm than good. For these people, supportive or palliative chemotherapy can maintain their quality of life. The possible benefits of treatment will always be weighed against the risks.

Improvements in treatment and supportive care mean that intensive options can now be offered to more people, where this had not been possible before. This means that some people may have to choose between lifesaving but demanding treatment, supportive care or palliative care to maintain their quality of life.

Should I take part in a clinical trial?

Clinical trials are planned research studies involving people with blood cancer.

Trials are usually designed to test new treatment approaches, and it's possible that you may be offered the opportunity to take part in a clinical trial if you meet the entry conditions. If you do meet the conditions, your team will discuss clinical trials with you and give you all of the information you need.

You and your doctor will need to consider the benefits and risks, but it's your final decision whether you'd like to take part.

You can find out more information about clinical trials in our booklet **Clinical trials** or online at bloodwise.org.uk

What happens if I already have another illness?

General health is an important factor in how well your body can cope with treatment, and certain conditions can make intensive treatments like chemotherapy more risky for you. Having another illness can narrow the treatment choices available.

Your healthcare team will have all your medical information and will discuss this with you if you have any other existing medical conditions. Sometimes it's helpful to take a list of the medications that you're taking to your hospital appointments.

Can I refuse treatment?

If you've balanced the possible benefits against the risks, and discussed these with your healthcare team, you may, in the end, decide not to have treatment. Some people feel this way if they think the treatment will be of little benefit to them, or if they're unwilling to accept the possible side effects.

If this is the case for you, your doctors will want to be sure that you understand the full situation and outcome of your decision. You may be asked to sign a document that confirms your choice.

People who are very ill sometimes decide that they do not wish to be resuscitated if they have a cardiac arrest. When this is the case, this will be clearly recorded in your notes - this is known as DNACPR (this stands for: Do Not Attempt Cardiopulmonary Resuscitation) and it means that your healthcare team will not restart your heart using CPR, which involves chest compressions and high-voltage electric shocks. DNACPR does not cover other life-saving hospital treatments you might receive, like antibiotics.

This can be a difficult decision to make and your healthcare team should be available at any time to talk to you. A decision for DNACPR can be changed at any time.

Finding out more



Bloodwise offers information on many blood cancer types and topics, online and in free printed booklets. They cover everything from symptoms and diagnosis through to treatment and living with your condition. Go to bloodwise.org.uk/information-and-support



We also have an online community you may like to join bloodwise.org.uk/our-community



You can call our support line on **0808 2080 888** (Mon–Fri 10am–4pm). This is a freephone number.



See our website for more details of cancer information specialists and support groups. Go to bloodwise.org.uk/living/where-get-help-and-support

About Bloodwise

We're the UK's specialist blood cancer charity.

We've been working to beat blood cancer since 1960.

We fund world-class research; provide practical and emotional support to patients and their loved ones; and raise awareness of blood cancer.

We'd like to thank Gill Brisley and Alison Paterson for their help and support in developing the content and checking for clinical accuracy. A list of references used in this fact sheet is available on request, please email information@bloodwise.org.uk

Our fact sheets contain general information. Always listen to the advice of your specialist about your individual condition – because every person is different.

Disclaimer

We make every effort to make sure that the information in this fact sheet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health.

Bloodwise can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

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