

What to expect from your appointments

This fact sheet explains what to expect from your hospital appointments if your doctor thinks you might have blood cancer, or if you've just been diagnosed with blood cancer or a related condition.

What will happen at my first hospital appointment?

If you're going to hospital for the first time, your appointment may take some time, as the doctor will want to know about your medical history and your health in general. The doctor will also want to examine you, for example, check your temperature and your blood pressure. You'll be asked about any symptoms you're experiencing as this will help the doctor to decide what tests you'll need to get a diagnosis.

You should bring an up-to-date list of any regular medication you're taking so that this can be recorded in your medical notes.

After your first appointment you may need to have some tests, such as a blood test, bone marrow biopsy or scan. The doctor will explain why you're having these tests – you can ask at any time if you don't understand why you're having a certain test. Your next appointment should also be made for you.

Our website and patient information booklets have more information about blood and bone marrow tests and scans. Go to [bloodwise.org.uk/information-and-support](https://www.bloodwise.org.uk/information-and-support)

If at all possible, it's a good idea to bring someone with you (like a partner, family member, friend or carer). Appointments can sometimes be stressful and overwhelming and often the support of someone you know

can help. Don't worry if there isn't anyone who can come with you, as there's often a nurse who can sit with you and offer you support while you see the doctor.

Receiving your results or diagnosis

When you go to your second appointment, this may be the time that your doctor discusses your test results with you. Depending on your results, your doctor may be able to tell you if they have found out what condition is causing your signs and symptoms (give you your diagnosis), or you may need to have further tests, such as a bone marrow biopsy, CT scan or MRI scan. Your doctor should make this very clear and should make sure that you have the opportunity to ask any questions you may have at this point.

Don't be afraid to ask your doctor to explain anything that you don't understand.

You might find it helpful to write things down, or ask the person you're with to take notes for you. You may also find this useful if you wish to explain your condition later to family and friends.

Some people find it useful to write down the questions they want to ask at an appointment before they get there, as it's easy to forget the questions you wanted to ask when you're trying to take in lots of new information.

However, don't worry if this doesn't happen, as you should be given the contact details for your key worker, who should be able to answer any questions you may have at a later date. If you don't receive this information, consider asking your doctor who your key contact will be.

What happens after my diagnosis?

After your diagnosis, you'll be given another appointment to see the doctor, if this is necessary. Often once you've been given your diagnosis you'll begin on a treatment plan. Your doctor and healthcare team should discuss this with you once the doctor has all of your test results.

There are many different types of treatment plan, including:

- › 'watch and wait' (which means you don't need any treatment at the moment),
- › outpatient based treatment (meaning you'll stay at home most of the time and only visit hospital for treatment or check-ups),
- › inpatient based treatment (meaning you'll stay in hospital for a period of time while you're having treatment).

You should be given the contact details of someone at the hospital who you can contact any time to explain any part of your diagnosis or treatment plan.

Your healthcare team

Your condition may be discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who will be looking after you. These meetings are often held regularly. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

The healthcare professionals that usually make up the MDT are:

- › haematologists/oncologists (your consultant, and other blood cancer specialists),
- › your key worker (usually a clinical nurse specialist) who is your point of contact with the rest of your healthcare team, and should be on hand to offer advice and support whenever you need it,
- › radiologists (specialists in scans), and,
- › pathologists (specialists in examining any biopsies (tests) that you may have had).

There are a number of other professionals who you should have access to throughout your treatment if their help is needed. These include a:

- › dietitian,
- › social worker/benefits advisor, and,
- › physiotherapist.

Speak to your key worker or consultant if you want more details about your MDT and their discussions about your care.

Travelling to your appointments

Using your own transport

If you're travelling to your appointments using your own transport, it's best to leave enough time before your appointment to allow you to park and find the department you're going to. Some hospitals will have free parking but there may be a fee for others. It's worth checking with the hospital as you may be able to get a discount on your parking fee.

Public transport

It's a good idea to check with your consultant or key worker whether it's acceptable for you to travel on public transport, as some test procedures and treatments may mean that this type of travel isn't recommended – for example, if you're at an increased risk of infection. If you're travelling by public transport, you should check locally so that you know which bus or train you need to catch.

Hospital transport

Transport can usually be provided for you if you need it. Your healthcare team should assess your individual needs and arrange suitable transport for you. Speak to either your key worker or the nursing staff, who should be able to give you further information and advice about this.

Arriving at the hospital

Outpatient (check-up) appointments

If you're arriving for an outpatient appointment (meaning you don't need to stay in hospital overnight), make sure you arrive in plenty of time. When you arrive, you may have to have a blood test before you see the doctor – your healthcare team should let you know if this is the case.

The department for blood tests (phlebotomy) may be in a different area of the hospital from the outpatient department.

When you've had your blood test, make sure that you check in with the outpatient staff so that they know you've arrived. At this point you may be asked if you want to be weighed (this helps the doctor to monitor your weight closely). After this you'll be asked to take a seat to wait for your blood results (if these are needed) and to see the doctor.

Treatment on the day unit

Your treatment may be given to you as a day case. This means that you'll go to use the day unit, which is based in the hospital. Your healthcare team should make this clear to you when your treatment options are being discussed.

You may have to go to the day unit for one day every few weeks, or you may have to go for more than one day each week.

You can ask your consultant or key worker (usually your clinical nurse specialist) what you need to bring with you to make your time at the day unit as comfortable as possible. Some people find it useful to bring a small overnight bag and toiletries,

just in case they're unexpectedly asked to stay overnight, for example because of an infection or a high temperature.

Inpatient stay

Your treatment might mean you have to stay in hospital overnight or for a number of days. Your healthcare team should discuss this with you and let you know which ward you'll be staying on (admitted to), what time to arrive and what you need to bring to make sure that your stay is as comfortable as possible.

Follow-up appointments

It's likely that you'll have regular follow-up appointments after your treatment is finished. The aim of a follow-up appointment is to look out for signs of the disease coming back (relapse), treatment complications or to monitor your condition (which is sometimes called watch and wait if you're not receiving treatment).

How often you'll have follow-up appointments depends on the condition you're being treated for. For the first year after your treatment, you're likely to have a check up every one to two months.

Your check-ups should gradually happen less and less often, and in some cases you may only need to see your GP, rather than go into hospital for your appointments (you might hear this called being 'discharged back to the care of your GP'). If you're on a watch and wait treatment plan your follow-up may be lifelong.

Your follow-up should include regular blood tests and may also include testing of your bone marrow using a bone marrow aspirate, like you had when you were diagnosed. Your doctor should also ask questions about your general health since your last visit.

Finding out more

We offer patient 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.



For our patient information, go to **bloodwise.org.uk/information-and-support**



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



Or 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 Madeline Ward and Dr Chris Hatton 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.

The information in this fact sheet is correct at the time it was printed (January 2017).
Date of next review January 2019.

Bloodwise, 39–40 Eagle Street, London WC1R 4TH
020 7504 2200 | info@bloodwise.org.uk | bloodwise.org.uk

© All rights reserved. No part of this publication can be reproduced or transmitted without permission in writing from Bloodwise.

Registered charity 216032 (England and Wales) SC037529 (Scotland).