

Watch and wait

Some people with blood cancer don't need treatment straight away – and some never need it. 'Watch and wait' is a way of monitoring these people with regular check-ups and blood tests. You may also hear it called 'active surveillance' or 'watchful waiting'.

Why am I not being treated?

Researchers are constantly looking for ways to improve treatments for blood cancer and have made lots of progress so far, but many of the treatments offered today still cause unwanted side effects that can make you feel unwell. By delaying the start of treatment, it's possible to avoid these side effects.

You'll start treatment if and when you need it and you'll continue to be monitored once your treatment is complete. Research shows that people on watch and wait aren't any more at risk of their condition getting worse than people receiving active treatment, like chemotherapy.

Knowing that you have cancer but aren't being treated straight away can be frightening and confusing, but it's important to remember that your doctor will only ever recommend watch and wait if they think it's best for you. You're not alone and there's lots of support available to you and those close to you.

For a brief introduction to watch and wait, go to bloodwise.org.uk/watchandwait to watch our animation.

Who can be on watch and wait?

Watch and wait is usually only an option for people with few or no worrying symptoms, whose quality of life and prognosis won't be affected by delaying treatment. It's also only recommended for people with blood cancers or related conditions that are stable and slow-growing (chronic or indolent).

These include, but are not limited to:

- chronic lymphocytic leukaemia (CLL),
- hairy cell leukaemia (HCL),
- large granular lymphocytic leukaemia (LGLL),
- low-grade forms of non-Hodgkin lymphoma (low-grade NHL),
- asymptomatic (or 'smouldering') myeloma,
- myelodysplastic syndromes (MDS),
- myeloproliferative neoplasms (MPN), and
- monoclonal gammopathy of undetermined significance (MGUS).

The decision about whether to watch and wait before starting treatment will be based on how you're doing and not on the cost to the NHS, or any other reason.

About 27,000 people in the UK are currently on watch and wait; around 13% of everyone living with blood cancer. Each year, around 5,000 people are put on watch and wait.

Visit bloodwise.org.uk/watchandwait to read about Erica's, Kate's, Trevor's and Elizabeth's experiences of watch and wait.

How long before I need treatment?

The length of time people spend on watch and wait varies, as conditions will progress at different speeds for different people. Your healthcare team will be able to give you a clearer idea of when you might need to start treatment.

It's important to know that lots of people have a good quality of life on watch and wait for years before needing treatment – and some never need it.

What are the advantages and disadvantages?

Before going on watch and wait, you'll discuss your treatment options with your doctor, and this can be a good time to discuss any concerns or questions you have. It may also help to know what being on watch and wait might mean for you.

The main advantage to being on watch and wait is that you won't be exposed to the side effects of treatment unless it's absolutely necessary. It also means that you're less likely to become resistant to treatments, which could affect your treatment options at a later date.

However, it's also important to understand that watch and wait can affect some people emotionally. Some patients describe this period of monitoring as 'watch and worry' because it can understandably be a very stressful time.

It's completely normal to feel anxious between appointments – particularly the week beforehand. If you find that you feel increasingly anxious or upset, speak to your healthcare team about coping strategies or call our Support Line. Maggie's – a national network of drop-in centres providing practical, emotional and social support for anyone affected by cancer or a related condition – is another great place to go for support, while joining a support group can be a good way to get in touch with other people going through the same thing.

To find out how other people have coped with the emotional impact of watch and wait, go to bloodwise.org.uk/watchandwait

What are blood counts?

Blood cancers and related conditions can affect the cells in your bone marrow that produce blood. This can lead to you not having enough healthy cells in your blood, which can make you feel unwell.

A full blood count (FBC) is a blood test that measures the number of cells in your blood. Blood counts are a useful way of monitoring your condition if you're put on watch and wait, and you may find that your doctor recommends you have an FBC each time you go for a check-up.

If your condition gets worse or you're receiving treatment, your blood counts may increase or decrease, but if you're on watch and wait and your condition is stable, you shouldn't notice much change. Your healthcare team can explain what your FBC results mean for you.

To find out what a 'normal' blood count looks like, go to bloodwise.org.uk/info-support/blood-cancer/what

Keeping a record of your blood counts

You may want to keep a record of your FBC results so, if you develop symptoms, you know more about what's causing them and how to cope with them. Below are some examples of occasions where it might help to know more about your blood counts.

- A low red blood cell count and low levels of haemoglobin (anaemia) can make you feel tired most of the time. Anaemia affects different people in different ways, so you should speak with your doctor to find out whether your symptoms could be a result of it. If they are, you may want to avoid activities that drain your energy, or consider talking to your line manager or HR department about working part-time.
- If your platelet counts are very low (less than $50 \times 10^9/l$), you can bruise or bleed more easily than someone with higher levels. You may want to avoid activities that involve forceful physical contact or risk you getting hurt. You may also wish to speak to your doctor to make sure you're not taking any unnecessary tablets that could make you more prone to bleeding (for example, some painkillers).
- If your white blood cell count is low (especially if your neutrophil count – the white blood cells your body uses on a daily basis to fight bacteria and fungi – is less than $1.0 \times 10^9/l$), your immune system will struggle to fight infections. This is called neutropenia. If you develop a fever or any other signs of infection and have a low white blood cell count, you should contact your healthcare team or hospital straight away.

If you would like to refer to your blood counts between your appointments, you can ask your doctor for a copy of your test results.

If you become neutropenic, you may find our Eating well with neutropenia booklet helpful. Go to bloodwise.org.uk/information to download or order it.

What to expect from your appointments

It's normal to feel anxious in the months, weeks or days leading up to your next appointment, but knowing what to expect from these check-ups can help. If you do feel upset or worried, there's plenty of support available to you and those close to you.

Where will I go for my appointments?

Some people will go to a clinic or hospital to see a doctor specialising in blood cancer (a haematologist / haematology consultant) for their appointments, while others will visit their local GP surgery. It's not unusual for people with chronic lymphocytic leukaemia (CLL) to visit their GP for their appointments, for example. The specialist you see when you're diagnosed will explain whether you'll continue to see them or your GP.

How often will I see my doctor?

The length of time between your check-ups will depend on the type of blood cancer or related condition you have and how it is affecting you. If you develop new symptoms or your blood counts change, your doctor may decide to shorten the length of time between your appointments, or recommend that you start treatment.

You can use the table below as a rough guide, but you should speak to your doctor to find out exactly how often your check-ups will be.

Type of blood cancer or related condition	Typical length of time between appointments
Chronic lymphocytic leukaemia (CLL)	You'll be seen at least twice within the first year, although some people will be seen every three months. After this, if your condition remains stable, your consultant may decide to reduce your visits to once a year.
Hairy cell leukaemia (HCL)	People on watch and wait for HCL are usually seen every three to 12 months.
Large granular lymphocytic leukaemia (LGLL)	Usually the same as for CLL.
Low-grade non-Hodgkin lymphoma (low-grade NHL)	People on watch and wait for low-grade NHL are typically seen every three to four months.
Asymptomatic (or 'smouldering') myeloma	People on watch and wait for asymptomatic myeloma are usually seen every three months.
Myelodysplastic syndromes (MDS)	Some people with MDS only need monitoring once a year, while others visit their doctor every few weeks. Your doctor will base their recommendation on your symptoms and blood counts.
Myeloproliferative neoplasms (MPN)	People on watch and wait for MPN are typically seen every three to six months.
Monoclonal gammopathy of undetermined significance (MGUS)	You'll be seen every six to 12 months if you're on watch and wait for MGUS and your paraprotein levels are low. Your appointments will be more often if these levels are higher.

What will happen at my appointments?

At each appointment your consultant or GP will check to see if you've developed any new symptoms and run some tests. Below is a more detailed description of what you can expect, depending on the type of blood cancer or related condition that's being monitored.

Chronic lymphocytic leukaemia (CLL)

If you're put on watch and wait for CLL, at each appointment your doctor will check for new symptoms, such as swellings on your lymph nodes, liver or spleen. They'll also run a full blood count to check the number of cells in your blood, test your kidney and liver function and may carry out other routine blood tests.

Hairy cell leukaemia (HCL)

If you're diagnosed with HCL but haven't experienced any troublesome symptoms and your blood counts aren't too low, your doctor may recommend a watch and wait approach. Your check-ups will be very similar to those for CLL (see above).

Large granular lymphocytic leukaemia (LGLL)

About half of all patients diagnosed with LGLL won't need treatment straight away, and are instead monitored with regular appointments. These will involve the same checks as for CLL (see above).

Low-grade non-Hodgkin lymphoma (low-grade NHL)

There are lots of types of low-grade NHL, but the most common is follicular lymphoma. If you're put on watch and wait for this, your check-ups will be very similar to those for CLL (see above).

Your doctor may also want to perform or repeat a CT scan of your chest, stomach and pelvis within the first two to three years that you're on watch and wait, especially if you have new symptoms. After that, if your condition remains stable, you'll have these scans less often.

If you're put on watch and wait for another form of low-grade NHL, your doctor will be able to tell you more about what to expect at each appointment.

Myelodysplastic syndromes (MDS)

Like low-grade NHL, there are different types of MDS. If you're put on watch and wait for one of these syndromes, at your appointments your doctor will run a full blood count and check for new symptoms, such as shortness of breath (a symptom of a low red blood cell count) or persistent infections (often the result of a low neutrophil count).

Myeloproliferative neoplasms (MPN)

Like MDS, there are several different types of MPN. These include polycythaemia (PV), essential thrombocythaemia (ET) and myelofibrosis (MF). If you're put on watch and wait for one of these conditions, your doctor will check your full blood count and check for new symptoms, such as a swollen spleen, at regular appointments.

Monoclonal gammopathy of unknown significance (MGUS) or asymptomatic (or 'smouldering') myeloma

If you're on watch and wait for MGUS or asymptomatic myeloma, at each appointment your doctor will check for signs or symptoms that suggest your condition might be progressing or developing into myeloma. This usually involves tests to check your full blood count, measure the amount of calcium in your blood, detect whether there are any paraproteins or free light chains in your blood, and to see how well your kidneys are working.

Getting the most out of your appointments

If possible, it's a good idea to bring someone with you (like a partner, family member, friend or carer), so they can write things down while you chat to the doctor, or ask questions you might not think of. 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.

You may also find it helpful to bring a notebook with you so you can jot down notes. Between your appointments, you could use this notebook to write down any new symptoms you experience, medication you're taking or questions you have, so you have this information to hand when you see your doctor.

Our **My diary** booklet provides space for you to write these things down. Go to bloodwise.org.uk/information to download or order it.

Questions to ask your GP or consultant

You might find it helpful to print out this list of questions and take it with you to your next appointment. You can ask your doctor to write down the answers, so you have them to hand whenever you need them.

- Why is watch and wait recommended for me?
- What are my other treatment options at this stage?
- What tests will I need, and how often will I have them?
- Where will I need to come for my appointments?
- What signs and symptoms should I look out for?
- Who should I contact if I feel unwell or develop new symptoms?
- Should I take any precautions while I'm on watch and wait (e.g. Do I need the flu jab? Should I avoid the shingles vaccine or other live vaccines? Could my condition affect any unrelated routine operations or procedures I might need)?
- How will I know if I need to start treatment and what will this involve?
- What is the best outcome I can hope for?

Getting your results

Some test results may be ready the same day, while others may take a few days or sometimes weeks, but your doctor will tell you when you can expect yours. Usually, you'll need to wait at least 24 hours for the results to a full blood count (FBC), liver function or urea and electrolyte test – though if your doctor needs to check your blood count urgently, you'll get your FBC results straight after the test. You might need to wait a week for the results to a serum free light chain test (which tests for free light chains in the blood) or a urine sample to test for free light chains in your urine.

You may find that your doctor arranges for you to have some or all of your tests at your local GP surgery, hospital or clinic a few days before your check-up, so you can then meet with your consultant or GP to discuss the results once they're ready.

Your doctor will talk you through the results and can answer any questions you have. If the length of time between your appointments is going to change, they will explain the reasons for this. Equally, if they recommend that you need to start treatment, they will discuss your treatment options with you.

If your doctor recommends that you start treatment, our **Treatment decisions** fact sheet can help you understand the different types of treatments available, along with the choices you might be asked to make. Go to bloodwise.org.uk/information to download it.

Symptoms to look out for

It's important to let your doctor know if you notice any change in your symptoms while you're being monitored. People with different conditions will have different symptoms, and not everyone with the same condition will share the same experience. However, in general, you should keep an eye out for:

- painless, persistent swellings or lumps,
- unexplained fever,
- drenching night sweats,
- unexpected weight loss,
- frequent infections,
- unexplained tiredness,
- new bruising or bleeding,

- weakness, or
- new bone pain.

You can find out more about symptoms for specific conditions by visiting the relevant condition page at bloodwise.org.uk/info-support, or by ordering or downloading the relevant information booklet or fact sheet from bloodwise.org.uk/information

Who to contact if you notice new symptoms

Because blood cancer and related conditions can affect different people in different ways, the symptoms listed here, and on the relevant conditions pages, should only act as a guide. You should contact your healthcare team, GP, or the hospital or cancer centre you attend straight away if you experience **any new symptoms**, whether they're listed here or not, or if you feel increasingly poorly.

10 ways to cope with anxiety

We asked people on watch and wait how they deal with the emotional and psychological impact of delaying treatment while living with blood cancer. Here are some of the things that help them stay positive.

1. Talk to the people you love

If you have the support of family and friends, don't be afraid to embrace it and share your worries or concerns with those close to you. Sometimes, just spending time with the people you love can make all the difference, as Karen Knighton explains.

"I try to keep a positive attitude and look after myself but I do find it difficult leading up to check-up time," she reveals. "My family and friends are a great support – they treat me exactly as they did before my diagnosis, which really helps me cope. I am very lucky to have them."

2. Look for peer support

It's not just those close to you who can offer valuable support. Some people treat watch and wait as an opportunity to find others who are going through a similar situation.

Adrian Cox, who was diagnosed with chronic lymphocytic leukaemia (CLL), has found great support from people who share his diagnosis. "At 45 years old, it took quite a while for my diagnosis to sink in, but support from my family and people who have CLL have been the best things of all, as we are going through this all together. No one should have to go through this alone."

3. Make use of support organisations

There are also plenty of support networks you can access through charities and organisations across the UK and beyond. Elaine Cameron found fantastic support at her local Maggie's centre. "Watch and wait can be stressful, but I found going to Maggie's really helped me control the anxiety," she says.

Meanwhile, Jane Lancaster found a meeting of MDS patients in Manchester, "a wonderfully positive experience".

You can call our Support Line for free on **0808 2080 888** (Mon–Fri 10am–4pm). Or, for a list of other support organisations that we recommend, go to bloodwise.org.uk/info-support/living-with

4. Appreciate the good things

There's nothing to say you have to be positive all the time; everyone has their bad days. But some people find that their diagnosis actually helps them appreciate the little things in life, and this positivity can help to keep worries at bay.

Sarah Chapman recommends focusing on the bigger picture to keep a positive frame of mind – “however difficult this may seem, and whatever the setbacks”, she adds. Carol Hojenski Lowrie has a similar outlook. “Watch and wait does cast a shadow over your life, but every day I don't need treatment is a real gift, so I try to appreciate each one,” she says.

5. Take each day as it comes

For others, simply focusing on the here and now can stop them worrying too much about the future. “I can't do anything about yesterday or tomorrow, so I do what I can with this day and I will deal with any eventuality when it comes,” Kit Jones explains.

6. Look after yourself

Another way to stay relaxed and positive is to take care of yourself – both physically and mentally. The value of treating yourself should never be overlooked, as Daisy Evans, now in her 8th year of watch and wait, explains.

“At first it was very hard, with a big shadow hovering above everything I did and the anxiety cropping up whenever it felt like it,” she says. “However, I've learned to cope with it by keeping busy, surrounding myself with amazing people and experiences and just being grateful to still be here. There is still that sick feeling when waiting for the blood test results every three to four months, but having a cuppa and cake on appointment day always helps!”

7. Stay as active as you can

Everyone's fitness levels vary, but you may find that exercise helps to lower your stress levels. “I work out as much as I can to stay in good shape, if the time comes for treatment,” says David Chase, who's been on watch and wait for the last three years. “I feel very blessed to be in this situation compared to a lot of people receiving treatment.”

Andy Lambert took a similar approach while on watch and wait before undergoing chemotherapy during the second half of 2016. “I coped by doing every sports event Bloodwise could throw at me,” he reveals.

8. Don't be afraid to access counselling

Counselling can also be extremely beneficial, particularly if you're worried about sharing everything with your loved ones. Bethan Cawley has found it takes a great weight off her chest. “It's a moment in time to offload and say what you really feel and fear; a time to reflect without protecting those you love,” she explains.

9. Trust your healthcare team

It can be hard to accept that delaying treatment can be a good thing, but having faith in your healthcare team, and the years of research that show watch and wait is safe, can help to put your mind at rest.

Vivien Dagley has found this really empowering. “Every time I see my consultant he assures me that the side effects from chemo can be a lot worse than no treatment and, as I am doing well, it's best to leave treatment well alone,” she explains. “Now, I feel very lucky to be on watch and wait.”

10. Do what works for you

There's no wrong or right way to cope with anxiety, so take the time to find out what works for you. Beverley Renfrew tells us that she fulfilled her life-long dream of joining a circus – so anything goes!

We hope that you find these tips helpful. Please note that these are the personal opinions of the people who have contributed to this list, and not a substitute for medical advice. If you start to feel increasingly anxious, you should speak to your doctor.

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 a blood cancer or related condition.

- For more information about watch and wait or specific conditions, go to **bloodwise.org.uk/info-support**
- 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: **bloodwise.org.uk/info-support/living-with**

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.

This is a printer-friendly version of information available on our website at **bloodwise.org.uk/watchandwait** and is correct at the time it was created (October 2017).

For the very latest information, please go to **bloodwise.org.uk/watchandwait**

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