Active monitoring

If you have a slow-growing or stable blood cancer, you might not need treatment straight away. Instead, your haematology team or GP will monitor you. You'll have regular check-ups and blood tests, and you'll also check your symptoms at home. This is called active monitoring or 'watch and wait'.

Summary

- Slow-growing, chronic blood cancers may not need treatment immediately after diagnosis. Instead, you may go on to active monitoring, sometimes called watch and wait.
- You may also be on active monitoring after a successful course of treatment.
- If you're on active monitoring, you'll have regular check-ups and blood tests.
- You'll also monitor your symptoms at home. This means you keep a record of new symptoms or of symptoms that are getting worse.
- If you have few or no troublesome symptoms, there is no benefit in treating your condition immediately. You can be safely monitored until your signs and symptoms change.
- This means you can avoid or delay unnecessary treatment and side effects from medicines. Treatment is still available if or when you need it.
- Some people find it hard to come to terms with having blood cancer and not having treatment straight away. It can be confusing, worrying, and hard to explain. Support is available if you need it.
- There's no fixed time when you come off active monitoring and start treatment. It depends on your diagnosis and how your condition progresses.
- Many people have a good quality of life on active monitoring. It can be an opportunity to reflect on your priorities – to live well, improve your general health and enjoy life.

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What is active monitoring?

When you're first diagnosed with chronic blood cancer, you may have no symptoms or few symptoms. If your condition is not causing you problems, you may not need treatment. Instead, you and your haematology team or GP work together to monitor your condition. This is called active monitoring. You may also hear people call it 'active surveillance' or 'watch and wait'.

Active monitoring is used when your condition isn't causing you major problems, and treatment might do you more harm than good. You might be on it when you're first diagnosed with chronic blood cancer. You might also go on to active monitoring after a successful course of treatment.

Active monitoring is a safe approach if you have a chronic blood cancer that is under control. Treatment is still available if or when you need it.

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Who might have active monitoring?

Your haematology team might recommend active monitoring if:

- You're newly diagnosed with chronic blood cancer, and you have few or no symptoms
- You've had successful treatment, and your condition is stable

Your haematology team will discuss whether active monitoring is right for you. They'll base this on your diagnosis and your medical history.

Conditions that may be managed with active monitoring

You may be on active monitoring if you have one of the following conditions:

- Chronic lymphocytic leukaemia (CLL)
- Chronic myelomonocytic leukaemia (CMML)
- Essential thrombocythaemia (ET)
- Hairy cell leukaemia (HCL)
- Large granular lymphocytic leukaemia (LGLL)
- Myelodysplastic syndromes (MDS)
- Myelodysplastic-myeloproliferative neoplasm (MDS/MPN)

- Myelofibrosis (MF) and pre-fibrotic MF
- Myeloproliferative neoplasm not otherwise specified (MPN NOS)
- Polycythaemia vera (PV)
- Prolymphocytic leukaemia (PLL)

It's a common approach for people with slow-growing or stable blood cancer. About 22 in every 100 people with chronic blood cancer are on active monitoring.

You're not alone. Around 27,000 people with blood cancer are on active monitoring in the UK.

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Benefits of active monitoring

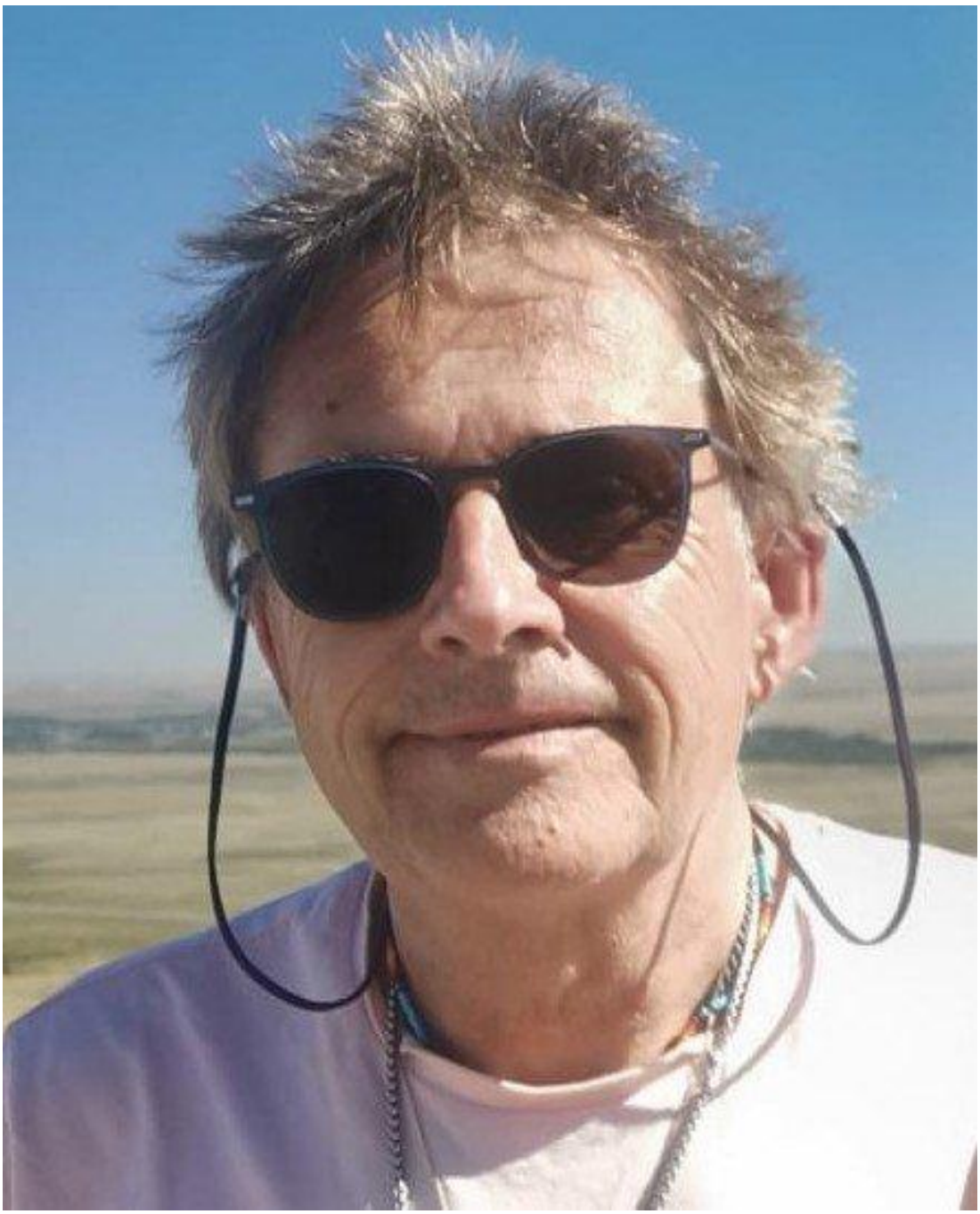
Active monitoring has good evidence to support it. It's a safe way to look after people with slow-growing or stable blood cancers that are not causing problems.

Treatments for chronic blood cancers aim to keep your condition under control. They don't cure them. Early treatment does not improve your outcomes and may make it harder to control your condition later.

Other benefits of active monitoring include:

- You avoid unnecessary treatment.
- You avoid side effects of treatment for as long as possible.
- You save treatment for when you need it, and it will have the most impact.
- You can get on with your life without as many hospital appointments or trips to the pharmacy.
- You have the chance to improve your general health. This may make you feel better and can help you prepare for treatment.
- If or when you need treatment, new medicines may be available that might be more suitable for you.

Many people have a good quality of life while on active monitoring. Some people find it motivates them to do things or visit places sooner than they would have done.



"Use it as a wake-up call to do all the things you said you would do. Spring clean your life. Little things don't matter anymore. Concentrate on what you like and who you love. It's not the end. It's the beginning."

— Steve, living with CLL since 2011

Downsides of active monitoring

Some aspects of active monitoring may be challenging, especially at first.

Coming to terms with having cancer but not having treatment immediately

When you're first diagnosed, active monitoring may come as a surprise. It can be difficult to hear that you have blood cancer, but you're not starting treatment. You might find it confusing or hard to explain to your friends or family. Especially when we're used to being told cancer needs treatment as soon as possible. But for people with chronic blood cancer, there's no benefit to starting treatment before you need it.

> "Early treatment doesn't improve your outcomes, including survival rates. It can be harmful. So, using medicines early is not in your best interests. Treatment works well when your condition is actively progressing. Then it improves your quality of life and survival."
>
> *— Dr Scott Marshall, Haematology Consultant*

Coping with anxiety and uncertainty

Some people find the uncertainty of their condition hard to cope with. You might get anxious before your check-ups or while waiting for your test results. You might worry that your condition has progressed and needs treatment. But if this were the case, you'd usually have started to feel less well. So, you often have some warning.

You may also feel a conflict between living your life while monitoring your symptoms. It can be hard to forget about it. It's best to note down when there's been a change in your symptoms, rather than checking them every day.

Understanding the approach

If you don't understand why you're on active monitoring, you may find it even more difficult. You might find the emotional side of active monitoring the biggest challenge. If this is how you feel, talk to your haematology team or your GP.

If you're finding it hard to cope while you are on active monitoring, our support services can also help.

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What happens on active monitoring?

When you're on active monitoring:

- You'll have regular check-ups, either in person, by phone or by video. Your haematology team or GP will ask about your symptoms and how you're doing.
- You'll have regular blood tests. You may also have other tests depending on your condition.
- You'll monitor your symptoms at home. This means you keep a record of new symptoms or any symptoms that are getting worse.

The timing of your check-ups may vary depending on what's happening with your condition:

- You might have frequent check-ups in the first year after your diagnosis. Some people have them every few months or so.
- If your condition is stable, you may only need to see your haematology team or your GP once or twice a year.
- If your condition is progressing and might need treatment, you'll have more frequent appointments.

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Symptoms to monitor

You have an important role to play in active monitoring. You are an expert on your body and how you usually feel. This makes you the best person to check your symptoms over time.

The key symptoms to monitor depend on your diagnosis. They often include:



Extreme tiredness



Unusual bleeding or bruising



Frequent or long-lasting infections


Unexplained fever


Losing weight without trying to


Swollen glands


Breathlessness


Feeling generally unwell


Night sweats


Losing your appetite


Feeling full quickly when you eat


Pressure or bloating in your tummy


Itchy skin


Joint or bone pain

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What to do if your symptoms change

It's best to make a note when you notice a change in your symptoms. You could use a notepad, diary, or an app on your phone or tablet to record your symptoms.

You should record:

- Symptoms that are new or changing, particularly if they're getting worse
- How your symptoms are affecting your daily life

Your haematology team or GP will tell you which symptoms or changes:

- Should prompt you to seek urgent medical help
- Can wait until your next appointment

If you're unsure how to check your symptoms or which ones are most important, contact them for advice.

If you become worried about your health at any time, contact your haematology team or GP. You don't have to wait until your next appointment.



"I take pride in knowing my own body. I might look okay on paper, but how I actually feel might be a completely different story."

— Andrea, living with PV since 2011

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Helpline: 08088 010 444

When might treatment start?

There's no fixed time until you might need to start treatment. It depends on your case and your symptoms:

- Some people need treatment soon after diagnosis
- Some people need treatment at some point in the future
- Some people never need treatment

You and your doctor will check for signs and symptoms to decide when it's time. You might start treatment if:

- Your symptoms are starting to get troublesome
- Symptoms like fatigue are affecting your daily life
- Your blood counts have got worse
- Your condition is progressing or becoming more aggressive
- Your condition is affecting other parts of your body or causing complications

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What might treatment be?

If you need to start treatment, your haematology team will explain your options. Different conditions have different treatments. Your team will explain what's involved in treating your condition and how it might affect you. You can decide together what's best for you. You may also want your family or carers to help you decide.

You might have several courses of treatment with periods of feeling well in between. You may have different treatment options next time you need it.



"Treatments have changed drastically and improved so much over the years. I'm certainly proof that you can survive HCL and live life to the full."

— David, living with HCL since 2003

If you'd like to talk to someone who understands what you're going through, contact our support services.

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Getting ready for treatment

If you have enough time before treatment starts, you might find it helpful to:

- Improve your general health and fitness, both physical and mental. This is called prehabilitation or 'prehab'. Getting fit and healthy might improve your treatment outcomes.
- Plan for time off work or study, or reduce your workload, if needed.
- Tell friends and family if you want to.
- Get a support network in place, such as friends and family. Ask people you trust to give you emotional or practical support.
- Explore other avenues of support. Your haematology team or GP may be able to refer you for counselling.

The NHS has information and guidance on living well. This includes exercise, eating well, and many other ways to take care of yourself.

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Living well on active monitoring

Everyone is different. What helps one person may not help another, but general tips for keeping well include:

- Looking after your mental health, especially if you're struggling. It can be hard to cope with the uncertainty of being on active monitoring.
- Managing fatigue by pacing yourself. Try to balance rest with activity and keep to a consistent sleep routine.
- Following a healthy and happy lifestyle. This includes eating a balanced and varied diet and exercising. But also includes doing things you enjoy.
- Keeping your body at a healthy weight. Ask your haematology team for advice if you're struggling to eat well or have problems with weight loss or gain.
- Taking care to avoid infections, such as coughs, colds and food-borne illnesses.
- Talking to your employer or education provider if you need to. You can ask for reasonable adjustments for time off if you need it.
- Attending all your medical appointments. It's important to keep up to date with recommended screening tests and vaccinations.

- Avoiding skin damage from the sun. Wear suitable clothing, seek the shade when the sun is hot, and use a sunscreen of at least SPF 30 with UVA protection.

The NHS has information and guidance on living well and tips for coping with anxiety. You may also find it helpful to access our support services.



> "When my symptoms let me, I love gardening, reading, and watching films. I also enjoy writing, drawing, catching up with my friends, cooking, and (slowly) walking the dog. My job now is to remain as well as I can. I am more than just surviving with this cancer. I am living with it in the best way that I can, and I'm so grateful for what I have."
>
> *— Lucy, living with MF since 2020*

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

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