Active monitoring for CLL

If you don't have any symptoms of chronic lymphocytic leukaemia (CLL) or your symptoms are not causing you problems, you might not need treatment straight away. Instead, you might be monitored through regular check-ups and blood tests. This is called active monitoring or 'watch and wait'. Treatment is still available when you need it. Find out more about active monitoring, what it is and why it is used.

Summary

- Chronic lymphocytic leukaemia (CLL) often doesn't need treatment straight away because it is slow-growing. Instead, you may be offered active monitoring, sometimes called 'watch and wait.
- You may also be on active monitoring after a successful course of treatment.
- If you have few or no troublesome symptoms, there is no benefit in treating CLL. You can be safely monitored until there are signs and symptoms that your CLL is progressing.
- If you are on active monitoring, you'll have regular check-ups and blood tests with your haematology team or GP.
- You'll also be asked to monitor your symptoms at home. This means you keep a record of new symptoms or of symptoms that are getting worse.
- You might have long periods of active monitoring after a diagnosis of CLL or after successful treatment for CLL. Some people with CLL don't need treatment for a long time. Some never need treatment.
- You might find it hard to come to terms with having blood cancer and not having treatment. It can be confusing, worrying, and hard to explain.
- However, the benefit of this approach is that it saves treatment for when you need it most. It also helps you to avoid side effects from medicines that may affect your quality of life.
- There is no fixed time when you come off active monitoring and start treatment. It depends on your case and how your CLL progresses.
- Although it can be challenging to be on active monitoring, many people have a good quality of life for many years. You can take steps to live well while on active monitoring.

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What is active monitoring for CLL?

You may not have troublesome symptoms when you are first diagnosed with chronic lymphocytic leukaemia (CLL). 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', 'watch and wait' or 'watchful waiting'.

Treatment is still available if or when you need it. CLL is usually a slow-growing blood cancer so some people do not need treatment for many years. Some people never need treatment.

You may also be on active monitoring after a successful course of treatment. Most people have long periods of feeling well between courses of treatment. Treatments for CLL have changed over the years so you may have a different treatment next time you need it. New treatments work well, sometimes better than previous treatments, and often have fewer side effects.

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What does active monitoring involve?

When you are on active monitoring, you and your haematology team work together to monitor your condition:



You will have regular check-ups, either in person or by phone or video. Your haematology team will ask about your symptoms and how you are doing



You will have regular blood tests. Sometimes your team may offer you other tests depending on your condition.



You will also monitor your symptoms at home. This means you keep a record of new symptoms or any symptoms that are getting worse.

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You might have more frequent check-ups with your haematology team in the first year after your diagnosis, perhaps every few months. If your condition is stable, you may only need to see your haematology team or your GP once or twice a year. If your CLL is progressing and you might need to start treatment soon, you will have more frequent appointments.

Symptoms to monitor

Symptoms to monitor at home include:

- Swollen glands
- Tummy pain, bloating or a feeling of fullness
- Unexplained weight loss
- Unexplained fever
- Night sweats
- Fatigue
- Frequent or long-lasting infections
- Feeling breathless or dizzy
- Bleeding or bruising

You could use a notepad, diary, or an app on your phone or tablet to record your symptoms.

> **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**

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Who might have active monitoring?

Your haematology team might recommend active monitoring if:

- You've just been diagnosed with CLL and you have few or no symptoms
- You've had successful treatment for CLL and your condition is stable

Your haematology team will discuss whether active monitoring is right for you based on the stage of your CLL and your medical history.

Active monitoring is also used for other chronic blood cancers. You may take comfort in knowing that there are around 27,000 people with blood cancer on active monitoring in the UK. You are not alone.

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Benefits of active monitoring

Active monitoring has good evidence to support it. It is a safe approach and the best way to look after people with CLL who don't need early or continuous treatment.

After diagnosis, if you have few or no troublesome symptoms, having early treatment doesn't improve your outcomes. Treatment aims to keep your CLL under control rather than cure it. If you have treatment in the early stage of CLL, it may make it harder to treat at a later stage when it is more important to get on top of it.

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.

Other benefits of active monitoring include:

- You avoid side effects of treatment for as long as possible.
- You can save treatment for when you need it.
- Although effective treatments are available now, new medicines may be available by the time you need them that might work better for you.
- You can get on with your life without so many hospital appointments or trips to the pharmacy.

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Downsides of active monitoring

When you are newly diagnosed with CLL, it can be difficult to hear that you have cancer but are 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. However, for people with CLL, research shows no benefit to your outcomes from starting treatment before you need it.

- Some people get anxious in the lead-up to their check-ups and while waiting for their test results.
- You may feel a conflict between getting on with your life while monitoring your symptoms.
- It can be hard to forget about it.

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

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When might treatment start?

There is no fixed time until you'll be offered treatment. It depends on your case and your symptoms. As a guide:

- Around 1 in 3 people need treatment soon after diagnosis
- Around 1 in 3 people need treatment at some point in the future
- Around 1 in 3 people never need treatment

You and your medical team will look for signs and symptoms to decide when it is time. You might start treatment as a result of symptoms you've noticed or the results of blood tests, including:

- You are losing weight without trying
- You are extremely tired or fatigued
- You have unexplained fever
- You have night sweats
- Your blood counts are too low
- Your lymph nodes or spleen are swollen enough to cause problems
- Your lymphocyte count is increasing quickly

- You have complications of CLL caused by your immune system mistakenly attacking your blood cells
- CLL is affecting other parts of your body

You and your medical team can decide together based on your case and how you feel about starting treatment. You may also want your family or carers to be involved in the decision.

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Living well on active monitoring

Everyone is different and what helps one person may not help another. However, general tips for keeping well include:

- Managing fatigue by pacing yourself, balancing rest with activity and keeping to a consistent sleep routine.
- Following a healthy and happy lifestyle including eating a balanced and varied diet, exercising and doing things you enjoy.
- Keeping your body at a healthy weight. Ask your haematology team for advice if you are struggling to eat well or have problems with weight loss or gain.
- Taking care to avoid infections where possible, such as coughs and 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.
- Keeping up to date with vaccinations, such as flu, covid and shingles.
- 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.

You may also find it helpful to access our support services.

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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 →

Help us improve our information

We aim to provide information that's reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

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About our information

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional. Find out more about our information.

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