

Active monitoring (watch and wait)

Lymphoma doesn't always need treatment straightaway. Instead, you might have active monitoring. This means that you have regular appointments to check on your lymphoma until it needs treatment.

Active monitoring is sometimes also called 'watch and wait' or 'active surveillance'.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

What is active monitoring?

Lymphoma doesn't always need **treatment** straightaway. Instead, you have regular check-ups with your **medical team** to monitor your health and to see how the lymphoma is affecting you. You don't start treatment unless the lymphoma begins to cause significant health problems. This approach is called active monitoring. You might also hear it called 'watch and wait' or 'active surveillance'.

This may not be what you were expecting as it is different to treating other types of cancer. This can take some time to understand and adjust to.

Active monitoring means that, for your type of lymphoma, there is no benefit in starting treatment before it is needed.

It does **not** mean that:

- there is no treatment available for your lymphoma
- you are too old to be treated, or that
- your doctors are trying to save money on your treatment.

This approach means that, while you are well, you can avoid the possible side effects of treatment for as long as possible. Treatment is still available for you when you need it, but this might not be for months or years. You might never need treatment.

Treatment is just as effective if it is saved until it is needed.

You can watch Professor Simon Rule explain what active monitoring is and why it is often recommended for low-grade non-Hodgkin lymphoma at:

<https://youtu.be/wW34Ca8wE1A>



For most people, once the shock of a cancer diagnosis has sunk in, you expect the next stage to be treatment, probably chemotherapy. When it's suggested we will watch and wait, lots of thoughts flood your imagination, like is my cancer too advanced for treatment? But I've now avoided chemotherapy for more than 10 years.

Jackie, on active monitoring for splenic marginal zone lymphoma

Why might I be offered active monitoring?

You might be offered active monitoring if you have a **low-grade (slow-growing)** type of lymphoma that is not causing problems that affect your day-to-day life.

Types of lymphoma that might be actively monitored include:

- **follicular lymphoma** (except grade 3B)
- marginal zone lymphomas (**MALT lymphoma**, **splenic marginal zone lymphoma** or **nodal marginal zone lymphoma**)
- **Waldenström's macroglobulinaemia**
- **chronic lymphocytic leukaemia**
- **small lymphocytic lymphoma**
- **mantle cell lymphoma**
- **nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)**.

Your medical team might suggest active monitoring if:

- your lymphoma is not causing troublesome **symptoms**
- your lymphoma is not growing quickly
- your **blood tests** don't show any significant problems
- your lymphoma is not affecting any of your major organs (such as your heart, lungs or kidneys).

You might have active monitoring when you are first diagnosed with lymphoma, or after a course of treatment that has shrunk your lymphoma but has not got rid of it completely. If the lymphoma that is left isn't causing problems, active monitoring might be right for you until you need more treatment.

Avoiding treatment for as long as possible has a number of advantages:

- you avoid treatment **side effects** and **late effects** (side effects that only develop a long time after treatment) for as long as possible
- the full range of treatment is still available to you if you need it
- you only have occasional, routine appointments with your medical team
- you can have a good quality of life
- you can benefit from newer therapies as they become available.

I finished my treatment in January 2023, and was told that there was no further evidence of disease. However, I am currently on long term active monitoring because of the follicular lymphoma aspect of my diagnosis. For me, finishing treatment is where I felt my journey actually began.

Jacqueline, diagnosed with a mixture of both follicular lymphoma and diffuse large B-cell lymphoma

What happens on active monitoring?

If you are on active monitoring, you have regular check-ups with your doctor, clinical nurse specialist or another member of your **medical team** to make sure your lymphoma doesn't need treatment yet.

You usually have these appointments at a hospital outpatient clinic. You might be given the option of a video or telephone consultation.

You will usually have between 1 and 4 check-ups a year. The exact follow-up schedule depends on your hospital's usual practice and your individual circumstances, including how active your lymphoma is and where it is in your body.

Your appointments will be specific to you, based on your individual circumstances. At your check-ups, a member of your medical team will talk to you about how you're feeling. They want to know whether you've noticed any changes in your **symptoms** or any new symptoms. They might also:

- feel your tummy (abdomen), armpits, groin and neck to check for **enlarged lymph nodes** or other signs that your lymphoma might need treatment
- measure your temperature, heart rate, blood pressure and weight
- listen to your heart and lungs.

You might also have blood tests to check your **blood count**, look for signs of inflammation or infection, and make sure your **bone marrow**, liver and kidneys are working as they should be. You won't usually have a scan unless your medical team suspects your lymphoma is growing, this is to reduce exposure to unnecessary radiation.

Your medical team also check for any signs your lymphoma might have changed (**transformed**) into a faster-growing type. If they think it might have done, you are likely to have a **biopsy** to check. Your lymphoma is very unlikely to have transformed if your symptoms haven't changed.

If you have been on active monitoring without requiring any treatment, you may be offered a form of **patient-triggered follow-up**. Instead of a schedule of regular pre-booked appointments, you are able to book your own follow-up appointments when you need to. Watch our [video](#) with Dr Wendy Osborne who discusses this approach and its benefits on our website.

If your symptoms have changed or you're worried about your lymphoma, contact your medical team. Don't wait for your next appointment.

When should I contact my medical team?

Contact your medical team straightaway if you notice a change in your symptoms or any new symptoms. They can reassure you or see you sooner if necessary.

A change in symptoms doesn't necessarily mean your lymphoma has got worse. Lymph nodes can swell for lots of reasons, or you might have another health condition that is causing problems. If you develop new symptoms, your medical team might monitor your health closely for a while. They might run tests to decide whether or not your symptoms are due to the lymphoma.

Remember that you are on active monitoring because you have a slow-growing type of lymphoma, so urgent treatment is rarely needed even if you start to develop symptoms.

Active monitoring really does mean monitoring is active. It means symptoms and blood tests are being regularly reviewed and that any changes will be acted upon. If you are on active monitoring it means you have fast and easy access to specialist advice when you have any concerns.

Charlotte Bloodworth, Advanced Nurse Practitioner

When will I start treatment?

It can be hard to predict how long it might be until you need treatment. It varies a lot depending on the **type of lymphoma** you have and your individual circumstances. Some people need treatment soon after diagnosis or a treatment course, but others don't need treatment for many years. Some people never need treatment.

Your **medical team** are likely to suggest treatment if:

- test results show that lymphoma is growing in your bone marrow (the middle of your bones where blood cells are made) and affecting your blood counts

- your lymphoma is affecting the functioning of your major organs
- your **lymph nodes** or **spleen** (an organ in your immune system) start to grow quickly
- you develop any '**B symptoms**' (night sweats, weight loss or fevers)
- your **symptoms** become difficult to cope with.

If your medical team think you need to start treatment, they can explain why and discuss the treatment options with you.

Living on active monitoring

Living with cancer can be challenging, and active monitoring can bring a range of **feelings and emotions**. Some people feel relieved that they don't need to start treatment straightaway. Others find it hard to first be told they have lymphoma but that it's not being treated straightaway.

Family and friends might also find the approach difficult to understand. It can be an additional challenge to have to deal with other people's emotions as well as your own. You could signpost them to our information about active monitoring, instead of having to explain it yourself. Remember also that our **helpline team** are **here to support** both you, and those close to you.

Speak to your medical team for advice about how they can support you. They can help to identify and address your physical, practical, emotional and social needs. This is sometimes called a holistic needs assessment (HNA). Macmillan Cancer Support produce a booklet called **Holistic Needs Assessment: Planning your care and support**, which is free to download or order.

Many people find that they are able to adapt well to being on active monitoring. Some people find it helps to think of their lymphoma as being a long-term (chronic) illness to manage and live with, a bit like diabetes or high blood pressure.



Active monitoring is counter-intuitive: 'I have cancer, but it's not being treated.' There is no physical battle, but there is a psychological challenge.

Mark, on active monitoring for follicular lymphoma

What can I do to help myself?

Whilst on active monitoring you can look after your general health and wellbeing. This includes eating a **healthy diet**, **keeping active**, **not smoking** and limiting your **alcohol intake**. As well as improving how you feel physically and emotionally, these lifestyle factors can help to prepare you for any treatment you might need in the future.

It's also important to go to any medical appointments or screening tests you're invited to, as well as to have any **vaccinations** your medical team advise. Speak to a member of your medical team if you have questions or concerns – don't wait until your next planned appointment.

Uncertainty is a common challenge for people who are on active monitoring. Many people feel anxious in the days or weeks before their check-ups and then feel relieved afterwards. Think about what helps lower your **stress** and anxiety levels. This might include, for example:

- **Meditation techniques**, such as **yoga** and **mindfulness**, which aim to calm the body and mind.
- A **complementary therapy**, such as **acupuncture** and **massage** to improve your mental wellbeing.

- Setting aside ‘worry time’ to think about any fears or concerns you have and what you can or cannot do about them. Although it can take practice, some people find that it helps stop worrying thoughts from being on their mind all the time.
- Using self-help resources. The NHS website has information and [tips on managing anxiety, fear and panic](#). Mental health charities also offer a range of resources such as guides and podcasts. For example, Mind has [information about anxiety](#), including [self-care tips](#), and No Panic has a number of [mental wellbeing resources](#).

Show yourself patience and kindness. There might be days when you struggle emotionally. Remember that ups and downs are natural. However, if you experience low mood or difficulties sleeping that continue for a while, speak to your GP or clinical nurse specialist for support.

Although different things help different people, we offer some tips below that you might like to consider:

- Let someone know how you’re feeling, whether it’s a friend or a member of our [helpline service](#). You could seek support from a [counsellor](#) or psychologist.
- Connect with others who can relate to your situation – for example, through an [online support meeting](#), our [Buddy service](#), or through an online community, such as our [closed Facebook group](#).
- Plan things to look forward to, whether it’s time to sit down and read a book, a catch up with friends or a day out. You might want to plan a [holiday](#) – just be sure to check with your medical team about any [safety precautions](#) you should take if you are travelling outside the UK. It’s also important to get suitable [travel insurance](#).
- If you struggle with [fatigue](#), consider what you can do to help yourself. This might include [planning your activities around your energy levels](#).
- Consider speaking to your employer about any temporary changes you might need to your [working hours](#) and responsibilities.

Watch our videos on active monitoring

In May 2023 we held a webinar on active monitoring. Our guest panel included a consultant and nurse who support people on active monitoring, and two individuals with lived experience of active monitoring.

https://www.youtube.com/watch?v=h6-Q_rDt3D0&t=247s

In 2021, lymphoma clinical nurse specialist, Sarah Wells, gave an overview of active monitoring, as part of our virtual national conference.

<https://www.youtube.com/watch?v=0NL4HoQ0piA>

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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