

Active monitoring (watch and wait)

Sometimes, lymphoma doesn't need treatment straightaway. Instead, you might have active monitoring: regular appointments to check on your lymphoma until it needs treatment. Active monitoring is also called 'watch and wait' or sometimes '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?

Sometimes, lymphoma doesn't 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' or 'active surveillance'. You might also hear it called 'watch and wait':

- 'watch' because you have regular check-ups (monitoring)
- 'wait' because you don't start treatment unless your lymphoma starts to cause problems or your symptoms become difficult to cope with.

Active monitoring is a common approach for **low-grade (slow-growing)** types of lymphoma. These can be difficult to cure completely but they can often be controlled for many years, only needing treatment from time-to-time.

If you have low-grade lymphoma that isn't causing bothersome symptoms, you might have active monitoring when you are first diagnosed with lymphoma, or after you've had a course of treatment that hasn't completely got rid of the lymphoma.

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.



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 have active monitoring?

If you have slow-growing lymphoma that isn't causing bothersome symptoms, there are several advantages to having active monitoring instead of immediate treatment:

- you avoid **side effects** or **late effects** from treatment for as long as possible
- you only need to go to hospital appointments for outpatient check-ups
- most people enjoy a good quality of life.

Active monitoring helps you avoid unnecessary treatment. It is unlikely to affect the outcome of low-grade lymphoma.

- Treating you before the lymphoma is causing problems does not make you live longer.
- Being on active monitoring does not increase the risk that your lymphoma will change (**transform**) to a faster-growing type.
- Treatment is just as effective if you save it until it is needed.



I have no desire to have treatment for something when, overall, I am pretty well. I would rather save it for when I really need it. Then, if the problem returns, I should still be able to have treatment.

Martine, on active monitoring for follicular lymphoma

Who might have active monitoring?

Your medical team might suggest active monitoring if you have one of the following types of **low-grade lymphoma**:

- **follicular lymphoma** (except **grade 3B**)
- marginal zone lymphomas (**MALT lymphoma**, **splenic marginal zone lymphoma** or **nodal marginal zone lymphoma**)
- **Waldenström's macroglobulinaemia** (lymphoplasmacytic lymphoma)
- **chronic lymphocytic leukaemia (CLL) / small lymphocytic lymphoma (SLL)**.

Mantle cell lymphoma is usually fast-growing, but some people have a slow-growing ('indolent') form. If you have slow-growing mantle cell lymphoma that isn't causing bothersome symptoms, your medical team might suggest a period of active monitoring. Most people need treatment at some point, but this might not be for months or, rarely, years.

Some people with **nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)** also have active monitoring. This might be before treatment, or after surgery or **radiotherapy** to affected lymph nodes. NLPHL is an uncommon and usually slow-growing type of **Hodgkin lymphoma**.

Your medical team will only recommend active monitoring if:

- you have a slow-growing type of lymphoma
- you are generally well
- your lymphoma isn't causing **symptoms** that you find difficult to cope with
- your **lymph nodes** aren't too swollen and are not growing very quickly
- your **blood tests** don't find any significant problems
- none of your major organs (for example, heart, lungs, kidneys) are being affected by the lymphoma.

Because your lymphatic system runs throughout your body, it is common for lymphoma to be at an **advanced stage** when it is diagnosed. Active monitoring can be suitable for people with advanced stage lymphoma.

You can watch personal experience videos of people on active monitoring for different types of lymphoma on our **active monitoring playlist**.

Are there any other options?

Active monitoring might not be the only option suitable for you. Your medical team should discuss all your treatment options and help you decide which is best for you.

If you have **stage 3 or 4 follicular lymphoma** that isn't causing bothersome symptoms, your medical team might suggest that you have a short course of **rituximab** before you go on to active monitoring. This could help delay the need for **chemotherapy** or radiotherapy.

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.

They talk to you about how you're feeling and whether you've noticed a change 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 may need treatment
- measure your temperature, pulse, blood pressure and weight
- listen to your heart and lungs.

You are likely to 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 to reduce your 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.

Your follow-up appointments are usually every couple of months for the first year, then every 3 to 6 months if your lymphoma hasn't got worse.

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.

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:

- your **symptoms** become difficult to cope with
- you develop '**B symptoms**' (night sweats, weight loss and fevers)
- your **lymph nodes** or **spleen** start to grow quickly or you develop swollen lymph nodes in new places
- your **blood tests** or other test results show that lymphoma is affecting your major organs or is growing in your **bone marrow**.

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



My medical team have always been there for me – doctors and perhaps more importantly, the specialist nurses. I like the way they have always involved me in decision making. All that sort of input has helped me to be relaxed about non treatment and ‘watch and wait’.

Maureen, diagnosed with follicular lymphoma at 69

Living with 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, only to then be recommended active monitoring.



I found it useful to join support groups, webinars and Facebook groups. In time, I learnt to become a ‘new me’.

Ashley, diagnosed with chronic lymphocytic lymphoma (CLL)

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?

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.

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 (though does not treat your lymphoma).

- 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 support team. You could seek support from a **counsellor** or psychologist.
- Connect with others who can relate to your situation – for example, through a **Support group**, our **Buddy service**, or through an online community.
- 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.

I decided that I didn't want to let watch and wait control my life. I wanted instead to relax, and I realised that the medics are watching and waiting and that they will step in when they need to.

Andrew, on active monitoring for follicular lymphoma

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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