Active monitoring ('watch and wait')

Sometimes, lymphoma doesn’t need treatment straightaway. This information page is about active monitoring – where your lymphoma is monitored until you need treatment. Active monitoring is also called ‘watch and wait’ or sometimes ‘active surveillance’.

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What is active monitoring?

Some types of lymphoma grow slowly and may not cause any problems, at least for a while. If this is the case for you, your doctor might suggest active monitoring of the lymphoma.

Active monitoring (sometimes called ‘active surveillance’) is where you have regular check-ups with your medical team to monitor your health and to see how the lymphoma is affecting you. You do not have any treatment for the lymphoma until it is causing significant health problems.
You might hear this approach called ‘watch and wait’:

- ‘watch’ because you have regular check-ups (monitoring)
- ‘wait’ because you wait until the lymphoma is causing troublesome problems before you have treatment.

You might have active monitoring when you are diagnosed or after a course of treatment that has left some lymphoma behind.

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**Why is active monitoring done?**

It can be difficult to understand why your doctor is suggesting you do not have any treatment for your cancer.

*Low-grade (slow-growing)* types of lymphoma often respond well to treatment, but are usually difficult to cure (get rid of permanently). People with low-grade lymphoma often live for many years and have courses of treatment from time-to-time.

On average, people who are not having troublesome problems from their lymphoma live just as long if they save treatment until it is needed rather than having treatment straightaway. If you have mild symptoms that you can cope with, it might still be better to reserve treatment until the lymphoma is causing problems that are harder to manage.

Some people never need treatment for low-grade lymphoma or do not need treatment for many years. Active monitoring saves them unnecessary treatment.
There can be advantages to having active monitoring instead of immediate treatment:

- there is no risk of **side effects** or **late effects** from treatment
- the lymphoma cells won’t become resistant (do not respond) to treatment

It's good news to be prescribed active monitoring. It means my cancer is at a state where it does not affect other aspects of my life so I don’t need to have any treatment for the time being. Though I get anxious whenever I detect a change in my body, I know my medical team will be able to respond quickly should I need treatment.

— Scott, on watch and wait for CLL
• fewer hospital visits - you only need to go to appointments for outpatient check-ups

• most people enjoy a good quality of life and respond just as well to treatment when it is really needed.

Active monitoring 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.

As it is difficult to get rid of low-grade lymphoma completely, there is often some lymphoma left after treatment. If the leftover lymphoma is not causing problems, you are likely to have active monitoring again after treatment.

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**Who might have active monitoring?**

Types of **low-grade non-Hodgkin lymphoma** that might be monitored after diagnosis or between treatment courses include:

• **follicular lymphoma**

• 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 an ‘indolent’ form of mantle cell lymphoma that grows much more slowly than usual. If you have indolent mantle cell lymphoma, you might not need treatment straightaway. Most people do need treatment at some time.

Some people with **nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL)** also have active monitoring after the affected lymph nodes have been removed. NLPHL is an uncommon and usually slow-growing type of **Hodgkin lymphoma**.
Active monitoring is only suggested if you have a slow-growing type of lymphoma and:

- you are well
- you have no troublesome symptoms from your lymphoma
- you have small lymph nodes that are not causing problems and are not growing rapidly
- your blood tests don’t detect any significant problems
- none of your major organs (for example, heart, lungs, kidneys) are being affected by the lymphoma.

**Are there any other options?**

Your medical team should discuss all the treatment options with you.

Some people with follicular lymphoma and no troublesome symptoms have a short course of an antibody treatment, for example, rituximab, before going on to active monitoring. Rituximab is given once a week for 4 weeks. Recent evidence suggests this approach does not extend the time you might live but could delay the time until you need stronger treatment. This delay could mean that more people never need stronger treatment.

**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.

They talk to you about how you’re feeling and whether you’ve noticed any change in your symptoms or any new symptoms. They will also examine you. This might include:

- taking your temperature, pulse, blood pressure and weight
- listening to your heart and lungs
• feeling your abdomen (tummy), armpits, groin and neck to check for enlarged lymph nodes or other signs that your lymphoma may need treatment.

You 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.

Depending on the type of lymphoma you have, where it is in your body and the results of your examination and blood tests, you might also need further tests such as a CT scan or PET scan.

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

If you notice any change in your symptoms or any new symptoms, don’t wait for your next appointment – contact your medical team straight away. They can reassure you or see you sooner if necessary. 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.

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**When does treatment start?**

The time until treatment is needed varies considerably depending on what type of lymphoma you have and your individual circumstances. You might need treatment soon after diagnosis, or after a treatment course, but you might not need treatment for many years. Some people never need treatment for their lymphoma.

Your medical team are likely to suggest treatment if:

• your symptoms become too troublesome or you develop symptoms known as ‘B symptoms’ (night sweats, weight loss and fevers)

• your lymph nodes start to grow more 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 bone marrow.
Note: You can develop swollen lymph nodes for other reasons, for example infections. You might also have other health conditions that could be causing problems. If you develop new symptoms, your medical team might want to keep a close eye on you for a while or run other tests to decide whether the lymphoma is causing problems. It is important to remember that low-grade lymphomas grow slowly and there is rarely an urgent need to start treatment.

The risk that a lymphoma will transform (change) into a faster-growing (high-grade) lymphoma may concern some people with low-grade lymphoma or nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). Your medical team check for signs of transformation at your appointments, but it is important that you are aware of these signs and find out when and how to seek advice.

Do not wait until your next appointment if you develop new or worsening symptoms or have concerns that your lymphoma might be getting worse. Contact your medical team to discuss your concerns. They can reassure you or might want to arrange an earlier appointment or tests for you.

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

Some people feel relieved that they don’t need treatment yet. Others find it hard at first to know that they have lymphoma but are not having treatment to get rid of it. It can be difficult to believe you don’t need treatment and it’s not unusual to feel ‘fobbed off’. You may feel angry or frustrated and you probably have a lot of questions. These reactions are normal. Your medical team understand what you’re going through and should be able to answer any questions you have.

Family and friends might also find it difficult to accept that you don’t need treatment. It can be frustrating for you to have to explain it to them – especially if you are struggling to cope with it yourself.

The uncertainty of active monitoring can be very stressful and you may experience ups and downs in your mood. Many people feel anxious in the days or weeks before their check-ups and then feel relieved afterwards. Some people say it’s hard to plan for the future because they don’t know if or when they’ll need treatment.

It’s quite common for people on active monitoring to suffer from fatigue. This can be difficult to cope with but there are lots of things you can do to make it easier.

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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
Over time, many people find they get used to being on active monitoring and find a ‘new normal’ life where they can manage their symptoms. It helps some people to think of their lymphoma as a chronic illness like diabetes or high blood pressure, rather than as a type of cancer.

Talking to your doctor, specialist nurse, a psychologist or one of our Buddies may help. But if you are finding it very hard to cope with being on active monitoring, do make sure you let your medical team know and ask what can be done to help you.

What can I do to help myself?

If you are on active monitoring, it is important that you stay in touch with your medical team and attend your clinic appointments.

There is no evidence to suggest that you can do anything yourself to keep your lymphoma at bay. However, as you might need treatment in future, you might want to prepare for this by getting yourself as healthy as possible. This might mean making changes to your lifestyle, such as:

- eating a healthy diet and trying to maintain a healthy weight
- not smoking
- limiting your alcohol intake
- taking regular exercise.

You might also want to think about your job and responsibilities, particularly if you’re struggling with fatigue. By law, your employer must make any ‘reasonable adjustments’ that allow you to continue working.

Some people on active monitoring like to focus on the things they enjoy doing, such as hobbies, travelling or seeing family and friends. Talk to your medical team about any vaccinations you might need or precautions you should take. Some people struggle to get travel insurance – our forums can offer advice from other people in a similar situation. You might also want to learn more about your lymphoma so that you can make an informed choice when you do need treatment. This helps some people but might make others more anxious, so it’s fine if you don’t want to do this.
Many people find support groups helpful as they can talk to other people in a similar situation. You can also connect with others on our forums.

Catherine Griffiths, a Clinical Nurse Specialist, spoke about active monitoring at our 2016 annual conference. You can watch her talk, and other videos you might find helpful, on our YouTube channel.

References


Further reading

- What is lymphoma?
- Symptoms
- Living with lymphoma
- Types of lymphoma
- Rituximab
- Glossary
Acknowledgements

- We would like to thank the Expert Reviewers and members of our Reader Panel who gave their time to review this information.

Content last reviewed: March 2018
Updated: April 2018
Next planned review: March 2021

Tell us what you think and help us to improve our resources for people affected by lymphoma. If you have any feedback, please visit www.lymphoma-action.org.uk/feedback or email publications@lymphoma-action.org.uk.

All our information is available without charge. If you have found it useful and would like to make a donation to support our work you can do so on our website www.lymphoma-action.org.uk/donate. Our information could not be produced without support from people like you. Thank you.

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