

Active monitoring (watch and wait) for lymphoma



This book has been researched and written by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer our essential support services free of charge. As an organisation we do not receive any government or NHS funding, so every penny received is truly valued.

To make a donation towards our work, please visit lymphoma-action.org.uk/Donate



My lymphoma type, stage and date of diagnosis

My treatment plan

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist (CNS) or key worker	
Emergency hospital number	

About this book

Many people with low-grade (slow-growing) lymphoma have periods of active monitoring where they do not have treatment for their lymphoma. Active monitoring is also known as ‘watch and wait’ or ‘active surveillance’.

It can be difficult knowing you have lymphoma but that you’re not having treatment for it. This book explains what active monitoring is and why it might be recommended for you. It also offers tips on coping well and has space for you to make notes.

You might also be interested in our book: *Living with and beyond lymphoma*, which gives tips on coping practically, physically and emotionally. See page 46 for other resources you might find helpful.

We continually work to improve our information and would really value your feedback on this book. Find the details on how to share your views on page 47.

If you would like a copy of this book in large print, please contact us (page 45).

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“

After the initial confirmed diagnosis, the good news was that there was no need for any treatment at that time: the condition would be managed by active monitoring or ‘watch and wait’ where I would receive regular monitoring of my general health and any symptoms.

Pat, diagnosed with marginal zone lymphoma

What is active monitoring?

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What is active monitoring?

Not everyone with lymphoma needs treatment straightaway. For some types of lymphoma, there is no benefit in having treatment if the lymphoma is not causing problems. Instead, you have regular check-ups to monitor how the lymphoma is affecting you. This is called active monitoring (also known as 'active surveillance' or 'watch and wait').

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

Active monitoring does not mean there is no suitable treatment for you. It means there is no benefit in starting treatment yet.

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.

“

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 treatment 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 slow-growing (low-grade) 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 (FL), marginal zone lymphomas (MZL), Waldenström's macroglobulinaemia (WM), chronic lymphocytic leukaemia (CLL), small lymphocytic lymphoma (SLL), mantle cell lymphoma (MCL) or 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).

“ *I was on active monitoring for four years before it was agreed that it was time to consider treatment.*

Carl, diagnosed with chronic lymphocytic leukaemia



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.

“ *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

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.

Active monitoring involves both you and your medical team looking out for new symptoms or any changes in your existing symptoms. Any changes usually happen gradually.

Remember that you are on active monitoring because your lymphoma is slow-growing. There is rarely a need for treatment to start urgently.

When might I start treatment?

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

Your medical team might 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 will explain why and discuss the treatment options with you.

Questions to ask your medical team

Active monitoring may not have been the treatment approach you were expecting. Your medical team are there to support you and answer any questions you may have.

Here are some questions you might like to ask:

- Why are you suggesting active monitoring for me?
- Are there any other treatment options to consider?
- What are the advantages of active monitoring for me?
- What are the disadvantages of active monitoring for me?
- Could my lymphoma get worse if I don't start treatment straightaway?
- How often do I need check-ups?
- Where do I have to go for check-ups?
- Who should I contact if I have any questions between appointments and how do I contact them?
- When might I need to start treatment?

Notes





“ *I was diagnosed with follicular lymphoma fourteen years ago and have never needed treatment. I'm on active monitoring, which means I see my consultant every six months for a blood test and brief check-up.*
Mark, diagnosed with follicular lymphoma

What happens on active monitoring?

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How am I monitored?

When you are on active monitoring, you have regular check-ups. Your appointments will be specific to you, based on your individual circumstances.

Your check-ups will be with your doctor, clinical nurse specialist or another member of your clinical team. 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.

If you notice any change in your symptoms, feel unwell or have concerns about your health, contact your medical team. Don't wait for your next appointment if you are worried.

What happens at appointments?

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. In particular, they are likely to ask:

- whether you think any of your lymph nodes have got bigger
- if you've noticed any new lumps
- whether you've had any night sweats
- if you've had a high temperature
- if you've lost weight when you weren't trying to
- if you've experienced any shortness of breath
- if you've had recurrent infections
- how much energy you have or how tired you feel
- if there are any other symptoms that are troubling you.

Remember that minor illnesses such as infections can cause symptoms too. New symptoms don't necessarily mean your lymphoma has got worse.

“ *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

Your check-ups are also a chance for you to talk to your doctor or nurse about any worries or concerns you might have. Let them know how you're feeling emotionally as well as physically. Your doctor or nurse should be able to give you advice and tell you how to get further help if you'd like it. They should also be able to give you information about practical things like financial support, work and everyday life.

At your appointment, your doctor or nurse usually examines you. They might:

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

You might also have blood tests such as:

- a full blood count to measure the number of blood cells in your bloodstream to check how well your bone marrow is working
- tests to make sure your liver and kidneys are working as they should be
- tests to check for signs of inflammation in your body.

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 need further tests such as a CT scan or PET/CT scan. However, these are not usually necessary unless your doctor suspects your lymphoma is growing.

If your medical team think your lymphoma might have changed (transformed) into a faster-growing type, they are likely to arrange a biopsy (a small operation to remove a sample of tissue) to check.

If your symptoms haven't changed, your lymphoma is very unlikely to have transformed.

Making the most of your appointments

Some people feel anxious in the lead-up to an appointment. Think about what you'd like to get out of the appointment, for example, answers to any questions you have, guidance about physical activity and exercise, or where you can get emotional support. This can help to give you a sense of control and help you to feel more mentally prepared for the appointment.

To help you get the most out of your appointment, you could:

- write down any questions you think of and take them with you, so that you remember to ask them
- take notes or ask your doctor or nurse to write information down for you – there can be a lot to take in
- ask your doctor or nurse if you can record what they say so you can listen back to it later
- ask a family member or friend to go with you if the hospital allows this – as well as offering emotional support, they could help with remembering all that you'd like to ask and the information you're given.

Take something to do in the waiting room, such as a book, puzzles, phone or tablet.

It might be helpful to have a list of medicines or supplements you are taking and any changes in your health ready for your appointments. You can use these tables to write this down.

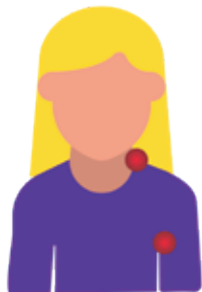
Name and dose of medicine or supplement	Date started and stopped

Changes to my health (for example vaccinations, infections)	Dates

What symptoms should I look out for?

Look out for any changes to the symptoms you have, or **any** new symptoms that develop.

Tell your medical team if:



Your lymph nodes are growing or you notice any new lumps.



You feel more tired than usual.



You experience persistent drenching sweats, particularly at night.



You are losing weight without trying to.



You have a high temperature (above 38°C) that might come and go.



Your skin is itchy.



You get more infections than normal or have difficulty getting rid of them.

“ *The best piece of advice I was given about what would alert me to anything suspicious was to ‘listen to your body’.*

Pat, diagnosed with follicular lymphoma



Your symptoms might change gradually over time. It can be helpful to regularly note how you feel so you have a record to take to your appointments.

You can use the table on page 28 to write down any changes to your symptoms.

If your symptoms change, your medical team are likely to monitor your health more closely for a while. They might see you more often or run tests to check if your symptoms are caused by the lymphoma or something else. They might arrange another scan.

Even if your symptoms are caused by the lymphoma, you might not need to start treatment yet. If your symptoms are mild, your medical team might be able to suggest effective ways to manage them. This could help you avoid treatment for longer.

If you are worried that your lymphoma might be getting worse, contact your medical team. Don't wait for your next appointment.

Symptom	Date and notes
Example: Fatigue	March: need a nap once a week May: need a nap most afternoons

Symptom	Date and notes



“ *I have been stable for two years and have regular check-ups, but I am struggling with being on active monitoring. I almost want to be receiving treatment.*

Komal, diagnosed with
Waldenström's macroglobulinaemia

Living on active monitoring

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How will I feel on active monitoring?

You are likely to have a mixture of emotions. Some people feel relieved that they don't need treatment yet. Others find it hard to be told they have lymphoma but that it's not being treated straightaway. You might even feel angry or frustrated that your medical team don't seem to be doing anything about your lymphoma.

Remember that you are being actively monitored and your medical team will offer you treatment when you need it. You aren't being treated as any less important than someone who is having treatment. You also don't need to wait until your next appointment to ask any questions you might have.

“ *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, diagnosed with follicular lymphoma

Family and friends might also find the approach difficult to understand. It can be challenging to deal with other people's emotions as well as your own. Remember that who you choose to share information with is up to you. Although people might ask lots of questions, that doesn't mean you have to answer if you are not comfortable with doing so.

“ *I decided the best way for me to cope was to keep things as normal as possible. I just told people who needed to know and my close family and friends.*

Carl, diagnosed with chronic lymphocytic leukaemia



Instead of explaining the approach yourself, you could share this book with the people you'd like to tell. We also have information on our website about active monitoring that you could signpost them to. Remember that our Helpline team are here to support both you, and those close to you (page 45).

We have lots more information on our website, including videos, webinars and podcasts. Search 'active monitoring' at lymphoma-action.org.uk



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.

“ *Feelings of anxiety arose as I felt for lumps and bumps before each appointment, but much of the time I was able to forget about the diagnosis altogether.*

Pat, diagnosed with marginal zone lymphoma



Some people find it hard to plan for the future because they don't know if or when they'll need treatment. It's important to have things to look forward to and your lymphoma shouldn't stop you from making plans and doing enjoyable things. If you have doubts about activities that might not be suitable for you, ask your medical team for advice.

We often hear from people who worry about symptoms that probably wouldn't have bothered them before they were on active monitoring. It's understandable that you might be concerned that any symptom is a sign that your lymphoma is becoming more active. Remember that some symptoms could be completely unrelated to your lymphoma and could just be a sign of a cold or other minor illness.

If in doubt, get in touch with your GP or clinical nurse specialist.

If you find being on active monitoring challenging, let your clinical nurse specialist know and find out how they can support you. They can help to identify and address your physical, practical, emotional and social needs. You might hear this 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. Search 'holistic needs assessment' at be.macmillan.org.uk

Tips to help manage anxiety

- Consider techniques such as breathing exercises or a type of meditation such as mindfulness or yoga.
- Build physical activity into your day-to-day life.
- Try a complementary therapy, for example acupuncture or massage. Your medical team can give advice on what's safe for you.
- Use self-help resources such as those available on the NHS website or through mental health charities such as MIND and No Panic.
- Let your friends and family know that you have an appointment coming up and how you feel. This will help them understand if you are quiet, tired or irritable.

Although it can take time, many people find that they are able to adapt well to being on active monitoring. Some people find it helpful 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.



Our *Living with and beyond lymphoma* book gives you tips on coping practically, physically and emotionally with lymphoma. Download or order a free copy at lymphoma-action.org.uk/Books

Remember that your GP can also offer support with any physical, practical or emotional challenges you might face.

You might want to connect with others who are affected by lymphoma. Some people find it helpful to share experiences and tips with those who can relate to their situation.

“ *One of the things I found invaluable was being able to speak with someone else who was also on watch and wait for follicular lymphoma.*



Pat, diagnosed with follicular lymphoma

Tips to help you connect with other people affected by lymphoma

- Attend a support meeting. Search 'online support meeting' on our website or ask your clinical nurse specialist for information about suitable support groups.
- Join a Life your Life workshop run by Lymphoma Action. The interactive workshops are led by someone with a lived experience of lymphoma alongside a Clinical Nurse Specialist. They aim to provide support in managing the emotional aspects of lymphoma and cover practical tips for the general wellbeing of those living with and beyond lymphoma. It is also a chance to talk to others and share experiences.
- Request a Lymphoma Action buddy. Contact our Information and Support team to see whether they can put you in touch with someone with a similar experience to you.
- Join an online community. Our closed Facebook group connects people affected by lymphoma from all over the UK.

“ *Being on active monitoring brings its own set of challenges, so it is nice to share that space with people in the same situation.*

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



What should I do while I'm on active monitoring?

During active monitoring, it's important to attend all medical appointments you're invited to, including routine screening programmes.

Make sure your GP knows you're on active monitoring.

You should also keep up-to-date with your vaccinations. Your medical team can tell you what vaccinations you should have and advise you on any that might not be suitable for you.

Remember that your medical team is there to support you. Contact them if your symptoms change or you develop new ones. Don't wait until your next appointment.

Taking care of your general health and wellbeing can have many benefits. A healthy lifestyle includes eating a healthy diet, keeping active, not smoking and limiting your alcohol intake. Take time to relax and do the things you enjoy too. As well as improving how you feel overall, these lifestyle factors can help to prepare you for any treatment you might need in the future.

The NHS website has advice, information and tools to help you make healthy lifestyle choices at [nhs.uk/live-well](https://www.nhs.uk/live-well)

Some people choose to learn more about their lymphoma so that they feel more informed and mentally prepared to make choices if and when they do need treatment. While this helps some people, others find it stressful and overwhelming. There's no right or wrong approach – do what feels right for you.

Our website contains information on all aspects of lymphoma, including potential treatment options, as well as full details of our services at lymphoma-action.org.uk



If you think you might want children in the future, speak to your clinical nurse specialist. If there's a chance that any treatment you might need later could affect your fertility, they can refer you to a fertility specialist to consider collecting eggs or sperm before you need treatment.



Read more about fertility preservation at lymphoma-action.org.uk/Fertility and see what services are available in your area at hfea.gov.uk

Day-to-day life

Many people find ways to help them manage their symptoms and adjust to a 'new normal' way of life. It's quite common for people on active monitoring to experience extreme tiredness (fatigue). This can be difficult to cope with, but there are lots of things you can do that might help.

Tips to cope with fatigue

- Take regular light physical activity, such as walking, and allow time to rest afterwards.
- Eat a healthy diet that gives you the energy you need.
- Plan your activities around your energy levels. You might want to keep a diary for a couple of weeks to help spot any patterns in your energy levels.
- Ask family and friends for help – save your energy for the tasks that only you can do or for the ones you most enjoy.
- Get enough rest and have a regular sleep pattern. You might also find relaxation techniques such as yoga or mindfulness meditation helpful.
- Find more tips at lymphoma-action.org.uk/Fatigue

If you are struggling with energy levels and you are employed, think about what might help you. You could consider taking time out of work or making changes to your job and responsibilities.

By law, your employer must make any reasonable adjustments that allow you to continue working. For example, you could consider reducing your hours or working from home. To support you in your request, your GP or hospital can write a letter to your employer to explain a bit about your lymphoma and how it affects you.

For more information about working while you are living with lymphoma:

- Search 'equality act' at gov.uk
- Watch our playlist of videos about working after cancer at [YouTube.com/LymphomaAction](https://www.youtube.com/LymphomaAction)
- Search 'reasonable adjustments' at macmillan.org.uk for information about your rights at work, including a printable guide.

Some people on active monitoring like to focus on the things they enjoy doing, such as hobbies, travelling or seeing family and friends. If you are planning to travel, talk to your medical team about any vaccinations you might need and precautions you should take. You might also need specialist travel insurance.

“ *I worry that my diagnosis has an impact, not just on me, but on my family. I have family and friends in Pakistan, Denmark and England and know that travel outside the UK may be more complicated now, especially with travel insurance.*



Komal, diagnosed with Waldenström's macroglobulinaemia



We have more information about vaccinations and insurance when travelling outside of the UK. Search 'travel' at lymphoma-action.org.uk

“ *We would do things as soon as we thought about them – 'Let's go for a run', 'Let's have a picnic', 'Let's go on holiday!' We didn't put anything off. Maybe it was being busy that helped me come to terms with the lymphoma, but all I could do was deal with it in the best way for me.*

Pat, diagnosed with follicular lymphoma



Notes

Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you are looking for, please contact our Helpline (page 45).

British Association for Counselling and Psychotherapy provides a list of accredited counsellors in your area.

Cancer Research UK has information on all types of cancer and a nurse-led helpline: 0800 800 4040.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's provides practical, emotional and social support to people with cancer and their family and friends.

Mind offer support and advice to anyone experiencing a mental health problem.



Visit [lymphoma-action.org.uk/UsefulOrgs](https://www.lymphoma-action.org.uk/UsefulOrgs) for a list of other organisations you might find helpful.

Information and support

If you or someone you love is affected by lymphoma, we're here to support you.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website.



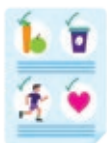
Find an **Online Support Meeting** at lymphoma-action.org.uk/OSM



Join our **Closed Facebook Group** at facebook.com/groups/LymphomaActionSupportUK



Our **Buddy Service** can connect you with someone in a similar situation to you. Call our Helpline for details.



Attend a **Live your Life** workshop, our peer-led self-management course at lymphoma-action.org.uk/live-your-life

See our website for full details of our services. For our latest news and updates, follow us on social media:



@lymphomaaction



lymphoma_action

If you're interested in finding out more about any of the topics covered in this book, we have lots more information on our website.

We also produce a number of books, which are available free of charge, including:

- *Introduction to lymphoma*
- *Low-grade non-Hodgkin lymphoma*
- *Hodgkin lymphoma*
- *Young person's guide to lymphoma*
- *When someone close to you has lymphoma*
- *Living with and beyond lymphoma*

Find our full range of books and information at lymphoma-action.org.uk/Books or call us on 0808 808 5555.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice.

Learn more at lymphoma-action.org.uk/HealthInfo



How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please scan the QR code to complete our short survey. Alternatively, visit our website at lymphoma-action.org.uk/BookFeedback, email us at publications@lymphoma-action.org.uk or call our Information and Support Team on 0808 808 5555.



References

The full list of references for this book is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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Notes

Notes



This book is about active monitoring (watch and wait) for lymphoma. It explains what active monitoring is, why it might be recommended for you, and gives practical tips on day-to-day living.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**
(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



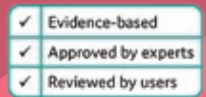
www.lymphoma-action.org.uk



Live Chat via our website
(Mon to Fri, 10am to 3pm)

Inform | Support | Connect

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