



## Active monitoring (watch and wait) for lymphoma

### About this book

Many people with low-grade (slow-growing) non-Hodgkin lymphoma have periods of active monitoring (also referred to as watch and wait or active surveillance) where they do not have treatment for their lymphoma.

It can be difficult knowing you have an illness, but are not having treatment. This booklet explains what active monitoring is and why it might be offered to you. It also provides tips on coping well and there is space for notes.

Important and summary points are in the chapter colour.

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You can fill in the following information.

Your lymphoma type

Key contact

Name:

Role:

Contact details:

Other people involved in your care

Job title/ role: GP

Name and contact details:

Job title/ role: consultant haematologist/oncologist

Name and contact details:

Job title/ role: clinical nurse specialist

Name and contact details:

## Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel, Lymphoma Nurse Forum and other expert advisers as well as our Reader Panel. In particular, we would like to thank the following experts for their assistance with this booklet:

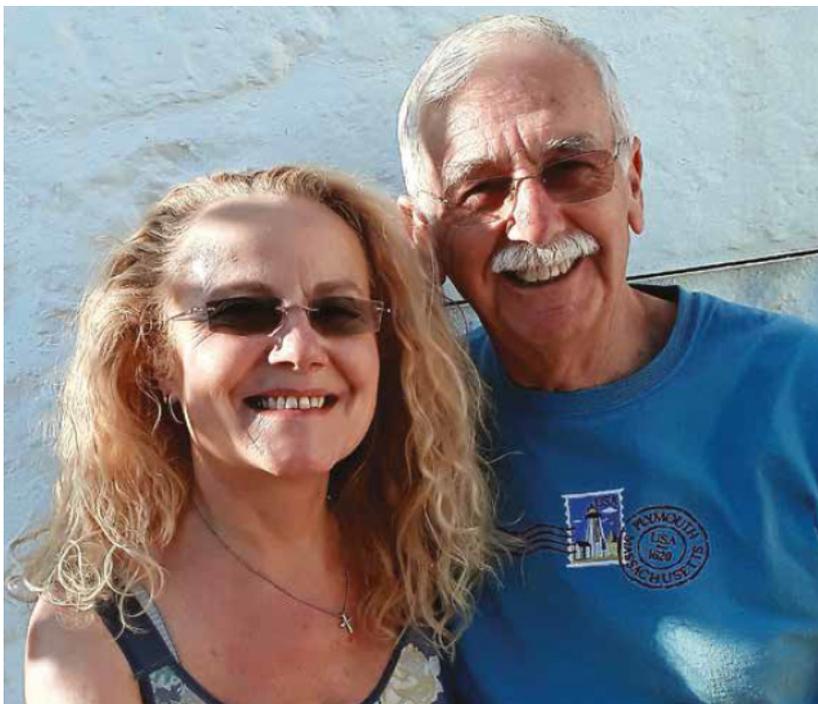
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'I have no desire to have treatment for something when, overall, I am pretty well. I would rather save it for when I really need it. Then, if the problem returns, I should still be able to receive treatment.'

Quote from Martine

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## What is active monitoring (watch and wait)?

Some people with lymphoma have regular check-ups after diagnosis, but do not have treatment for lymphoma straightaway. This approach is called 'active monitoring', 'active surveillance' or 'watch and wait':

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

Active monitoring might be suggested if your lymphoma is growing slowly and is not causing you troublesome problems. It doesn't mean your lymphoma can't be treated, but that there is no benefit to treating it until it is causing problems that can't be managed well. On average, people without troublesome symptoms who save treatment until it's really needed live just as long as people who have treatment straightaway.

Active monitoring means you can have treatment at the time you need it.

You might also have active monitoring if you have already had treatment for low-grade lymphoma but it hasn't been completely cleared. If the lymphoma that is left isn't causing significant problems, active monitoring might be right for you until more treatment is needed.

You have regular check-ups so your medical team can monitor your health and can see how the lymphoma is affecting you.

## Why is active monitoring being suggested for me?

If your doctor suggests active monitoring, this is usually because you have a low-grade (slow-growing) type of lymphoma that is not causing problems that interfere too much with your day-to-day life. Some people with low-grade lymphomas never need treatment for their lymphoma or might not need treatment for 10 years or more. Active monitoring helps these people avoid unnecessary treatment.

See our Watch and wait video for an overview of this approach at [YouTube.com/LymphomaAction](https://www.youtube.com/LymphomaAction)

‘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.’

Quote from Jackie

Avoiding treatment for as long as possible has advantages:

- The full range of treatments are still available to you when you really need them.
- You avoid treatment side effects and late effects (side effects that only develop a long time after treatment) for as long as possible.
- You can have a good quality of life with only occasional outpatient check-ups.

Treating low-grade lymphoma early is unlikely to improve your outcome.

Ask your medical team any questions you have. They should be able to explain why they are recommending active monitoring.

You might worry that your lymphoma will suddenly get worse or that it will transform (change) into a faster growing type of lymphoma while you are on active monitoring. Any changes usually happen gradually. Active monitoring involves both you and your medical team looking out for changes in your symptoms or new symptoms. Being on active monitoring doesn’t make treatment for transformed lymphoma any less effective.

Remember that your lymphoma is growing slowly and there is rarely an urgent need for treatment even if you start to develop symptoms.

## Are there any other options?

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

Some people with follicular lymphoma who don't have troublesome symptoms have a short course of an antibody treatment (for example, rituximab) before going on to active monitoring. Recent evidence suggests this approach does not extend the time you might live, but could delay the time until you need stronger treatment.

Our Low-grade non-Hodgkin lymphoma booklet has more information on possible treatments. Order a copy of the booklet at [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk) or read more about lymphoma treatment online at [www.lymphoma-action.org.uk/Treatment](http://www.lymphoma-action.org.uk/Treatment)

## When am I likely to begin treatment?

Most people have active monitoring for several years before they need to begin treatment. However, 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 you might not need treatment for many years. Some people never need treatment for their lymphoma.

'My lymph nodes weren't causing problems, I had no other symptoms and my tests didn't show lymphoma in my internal organs; I was put on watch and wait. The lymphoma didn't start to affect me until nearly 3 years later.'

Quote from Pat

## Questions to ask your medical team

- Why are you suggesting active monitoring for me?
- Are there any other treatment options I should 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 have treatment straightaway?

## Notes

You can write notes here



'It helps if someone can come to your appointments with you. They can listen and make notes so you have a record of what was said, and also be available to discuss things afterwards in case you missed anything. These records make it easier for you to spot real changes and eliminate imaginary ones.'

Quote from Maureen

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## How often am I monitored?

If you are on active monitoring, you have regular checkups with your doctor, clinical nurse specialist or another member of your medical team to make sure your lymphoma doesn't need treatment. These usually take place in a hospital outpatient clinic. Occasionally, they may take place at your GP surgery.

Your check-ups are usually every couple of months at first, then every 3–6 months if your lymphoma doesn't get worse. The exact follow-up schedule varies depending on your hospital's usual practice and your individual circumstances, including the type of lymphoma you have and where it is in your body.

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

## Questions to ask your medical team

- How often do I need a check-up?
- Where do I have to go?
- What scans or tests do I need, and how often?
- If I notice any new symptoms, who should I contact?
- Will it be clear to me when I need to start treatment?

## Notes

You can write notes here

## What happens at appointments?

At your check-ups, your doctor or nurse talks to you about how you're feeling. They want to know whether you've noticed any change 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 or you've noticed any new swellings
- whether you've had any night sweats, lost weight when you weren't trying to, or had fevers
- how much energy you have or how tired you feel
- if there are any other symptoms that are troubling you.

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

Your check-up is also a chance for you to talk to your doctor or nurse about any worries or concerns you have. Don't be afraid to talk about how you're feeling emotionally as well as physically. Your doctor or nurse should be able to give you advice and point you in the right direction for further help if you need it. They should also have information about practical things like benefits, work and everyday life.

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

- take your temperature, pulse, blood pressure and weight
- listen to your heart and lungs
- feel your abdomen (tummy), armpits, groin and neck to check for enlarged lymph nodes or other signs that your lymphoma may need treatment, such as an enlarged liver or spleen (an organ of your immune system).

You also have blood tests. These may include:

- a full blood count, which measures the number of red blood cells and white blood cells (sometimes called immune cells) in your bloodstream; this can help monitor how well your bone marrow (the spongy part of your bones that makes blood cells) and your immune system are working
- liver function tests (LFTs), to make sure your lymphoma isn't affecting your liver
- urea and electrolytes (U&Es), chemicals that measure how well your kidneys are working
- tests of inflammatory markers, which are chemicals that go up if you have inflammation in your body; this can be down to something simple like a minor infection but it can be a sign that your lymphoma is becoming more active.

You might have a few blood samples taken in different coloured tubes for your blood tests.

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 scan. However, this is not usually necessary unless your doctor suspects your lymphoma is growing.

You are more likely to need a scan if your lymphoma is in a place in your body that isn't easy to feel (inside your chest, for example). If this is the case, you won't have a scan more than once or twice a year to make sure you're not exposed to unnecessary radiation.

If your doctor thinks your lymphoma might have changed (transformed) to a different type, you might need a biopsy before starting treatment.

## Tips to get the most out of your appointments

- Write down any questions you think of beforehand so you don't forget them.
- Take notes or ask your doctor or nurse to write information down for you – there can be a lot to take in.
- Think about whether you'd like to take a friend or family member with you for support and to talk through your appointment afterwards.
- Take something to pass the time in the waiting room such as a novel, puzzle book, or some mindfulness colouring.

It might be helpful for you to note down any infections you have, any medicines or supplements you are taking and any other changes in your medical history so that you have these to hand for your appointments.

Use the tables on the following pages to note down this information.

## Medicines and supplements I am taking

Name and dose of medicine/  
supplement

Date started and stopped

Changes to my medical history (vaccinations, infections, new  
conditions)

Details

Dates

## What should I look out for?

Keep an eye on any symptoms you have and look out for new symptoms appearing. Your symptoms might change gradually, over time. A change in your symptoms does not necessarily mean you need to start treatment. If mild symptoms can be managed, it might still be better to reserve treatment until the lymphoma is causing problems that are harder to cope with.

It is important that your medical team is aware of any changes in your symptoms. It can be helpful to regularly note down any differences in how you feel so you have a record to take to your appointments. Tell your medical team straightaway if your lymph nodes are growing.

You can use the table on following pages to keep a record of changes in your symptoms.

Many people on active monitoring worry about minor symptoms, aches and pains. Very often, symptoms are related to infections, such as colds or flu, and might settle down in a few days.

Contact your medical team if your lymph nodes grow. Watch out for rapid changes in your other symptoms or the development of 'B symptoms', which are:



Night sweats



Weight loss



Fevers

You do not have to wait for your next appointment if you are having problems. If your symptoms persist or you are worried that your lymphoma might be getting worse, contact your medical team. They can reassure you or might want to keep an eye on you for a time to see if your symptoms settle down. If they have any concerns, they might send you for tests or arrange an earlier appointment for you.

## Notes

You can write notes here

Symptom

Date and notes

Example: Fatigue

13 March: need a nap once a week  
14 May: need a nap more often - most  
afternoons



'You can let watch and wait control your life, or you can relax and realise that the medics are watching and waiting and they will step in when they need to.'  
Quote from Andrew

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## How will I feel on active monitoring?

Some people feel relieved that they don't need treatment yet, but others find it hard at first to accept that they have lymphoma, but are not having treatment to get rid of it. You are likely to have a mixture of emotions. It can be difficult to believe you don't need treatment; it's not unusual to feel you're being '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.

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

Quote from Mark

Family, friends and colleagues 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. You could share this booklet with them or direct them to information on our website so they can learn about it for themselves.

The uncertainty of active monitoring can be very stressful and you are likely to 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.

Your lymphoma shouldn't stop you making plans. Any symptoms are likely to develop slowly.

### Tips to manage anxiety about follow-up appointments

- Let your friends and family know that you have an appointment coming up and how they could help. This could include showing you some patience and understanding if you are quiet or irritable.
- Consider anxiety or stress-relieving techniques such as breathing exercises, meditation or yoga

Our Living with lymphoma booklet gives you tips on how to manage some of the feelings you may have, how to cope with symptoms and how to deal with the practicalities of living with lymphoma. You can download or order a copy at [www.lymphoma-action.org.uk/information-and-publications](http://www.lymphoma-action.org.uk/information-and-publications)

Search for our video How to cope with difficult feelings at [YouTube.com/LymphomaAction](https://www.youtube.com/LymphomaAction)

It's very common for people on active monitoring to worry about symptoms that would usually not have bothered them. It's understandable to worry that any illness is a sign that your lymphoma is becoming more active. Remember that symptoms may be completely unrelated to lymphoma – you're as likely as anybody else to get coughs, colds and other minor illnesses.

If in doubt, get in touch with your doctor or nurse.

'The problem with watch and wait is that every little ache or pain, cough or cold makes you worry that things are about to go wrong.'

Quote from Martine

## Tips to help you cope with active monitoring

- Go to a support group. Find your nearest one at [www.lymphoma-action.org.uk/support-groups](http://www.lymphoma-action.org.uk/support-groups). Your nurse specialist may also be able to direct you to any cancer support groups in your area.
- Use online forums to be in touch with other people affected by lymphoma at [www.lymphoma-action.org.uk/forum](http://www.lymphoma-action.org.uk/forum). Macmillan, Shine Cancer Support and Carers UK also host online forums for people with cancer or their relatives and friends.
- Request a lymphoma buddy – our Information and Support team may be able to put you in touch with someone with a similar experience to yours. Visit [www.lymphoma-action.org.uk/support-you](http://www.lymphoma-action.org.uk/support-you)

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

If you're struggling with life on active monitoring, 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, let your medical team know and ask what can be done to help you.

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

During active monitoring, it is important to stay in touch with your medical team and attend your clinic appointments.

'I think watch and wait is probably the most difficult part of this form of lymphoma because nobody's doing anything – or that's what you think.'

Quote from Andrew

It can feel as if nothing is being done while you're on active monitoring. This is not the case: you are being actively monitored and your medical team will step in if you need treatment or support.

Although there is no evidence to suggest that you can do anything yourself to keep your lymphoma at bay, there are things you can do to help your overall health. As you might need treatment in future, you might want to prepare by getting yourself as healthy as possible.

'I weigh myself and make sure to notice that there are no other likely signs of the cancer spreading that would require me to contact my hospital. But I do not do this every day.'

Quote from Gerry

## Tips to keep yourself healthy

- Take regular exercise.
- Eat a healthy diet and try to maintain a healthy weight.
- Do not smoke.
- Limit your alcohol intake.

Make sure your GP knows you're on active monitoring. Talk to your medical team about vaccinations they recommend or any that you should avoid.

If you're of childbearing age and you think you might want to have children in the future, let your doctor or nurse know. If there's a chance that any treatment you might need later on could affect your fertility, they can refer you to a fertility specialist to discuss collecting eggs or sperm before you need treatment.

Read more about fertility preservation at [www.lymphoma-action.org.uk/reduced-fertility](http://www.lymphoma-action.org.uk/reduced-fertility) and see what services are available in your area at [www.hfea.gov.uk](http://www.hfea.gov.uk)

## Day-to-day life

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. Many people find ways to help them manage their symptoms and adjust to a 'new normal' way of life.

### Tips to cope with fatigue

- Pace yourself.
- Plan your day so you do active things when your energy levels are at their highest.
- Have a regular sleep pattern.
- Try using relaxation techniques.

You might 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. For example, you could consider reducing your hours or working from home.

Watch our playlist of videos about working after cancer at [YouTube.com/LymphomaAction](https://www.youtube.com/LymphomaAction)

Macmillan Cancer Support has more information about your rights at work, including a printable guide to 'reasonable adjustments'. Search for this at [www.macmillan.org.uk](http://www.macmillan.org.uk)

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 or precautions you should take. You might need specialist travel insurance – our forums can offer advice from other people in a similar situation.

Visit our forums to see what other people affected by lymphoma have to say at [www.lymphoma-action.org.uk/forums](http://www.lymphoma-action.org.uk/forums)

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 it's a source of anxiety for others; it's fine if you don't want to research your lymphoma.

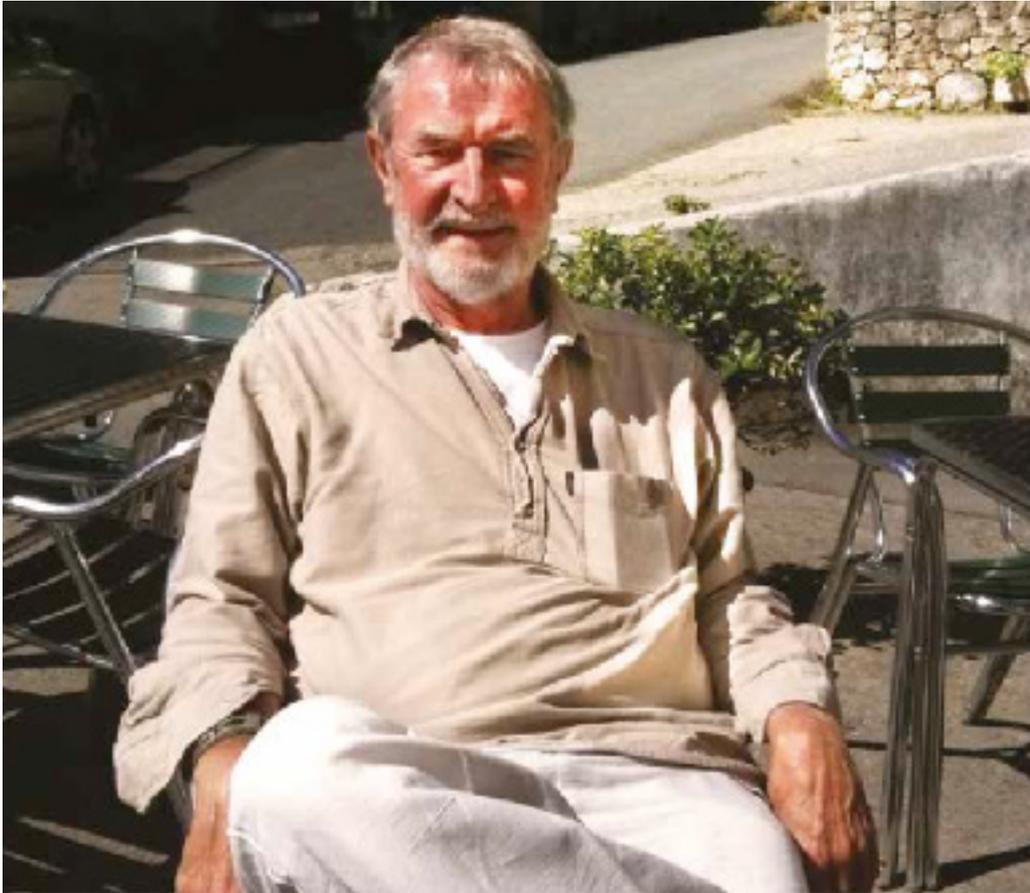
## Tips for living with active monitoring

- Be kind to yourself – don't take on things that you don't feel up to either physically or emotionally.
- Look after yourself – try to keep active, attend any routine appointments or screening tests you're called for, and find ways of dealing with your emotions that suit you.
- Have things to look forward to – even just planning what to plant in the garden this summer, for example, can give you a sense of normality.
- Contact your medical team if you have any concerns at all.

“Most of the time I do my best not to think about having follicular lymphoma at all. And most of the time I succeed in this.”

Quote from Gerry

- Find more information on physical health, emotional wellbeing and day-to-day practicalities in the living with lymphoma section of our website at [www.lymphoma-action.org.uk/living-with-lymphoma](http://www.lymphoma-action.org.uk/living-with-lymphoma)
- The Government's Eatwell Guide has information on how to get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group. Search 'Eatwell Guide' at [www.gov.uk](http://www.gov.uk)



'I am able to not think about lymphoma on a daily basis, while at the same time being fully aware of the possible symptoms of it spreading. A useful analogy is driving a car: there is no point in thinking that you might have an accident whenever you start to drive, but safety measures need to be consciously employed. These can be done automatically without continually thinking, 'If I don't do these things I'll have an accident.' That is the approach I also take to watch and wait.'

Quote from Gerry

## Notes

You can write notes here

## Information and support

If you'd like to talk to someone about anything to do with lymphoma (including how you feel) get in touch.

Call our Information and Support team Monday to Friday on 0808 808 5555. You can also use Live Chat on our website

Come to one of our support groups. Find one near you at [www.lymphoma-action.org.uk/support-groups](http://www.lymphoma-action.org.uk/support-groups)

Join our online forum to chat with others who are affected by lymphoma

Get in touch with a buddy, someone affected by lymphoma

Like us on Facebook

Follow us on Twitter

Check out our YouTube channel

Follow us on Instagram

On our website at [www.lymphoma-action.org.uk/UsefulOrganisations](http://www.lymphoma-action.org.uk/UsefulOrganisations), you'll find a list of other organisations you may find helpful.

## How you can help us

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this booklet. Please visit our website at [www.lymphoma-action.org.uk/book-feedback](http://www.lymphoma-action.org.uk/book-feedback) or email us at [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) with any comments. You can also call our Information and Support Team on 0808 808 5555.

We produce other publications that give information about lymphoma and what to expect from treatment. Visit our website at [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk) or call 0808 808 5555 for more information.

## References

The full list of references is available on request. Please call 01296 619409 or email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) if you would like a copy.



'I don't think the term watch and wait helps. In reality I feel that I'm not so much 'waiting' as 'living my life'.'

Quote from Mark

Lymphoma Action is the UK's only charity dedicated to lymphoma, and has been providing in-depth, expert information and support for over 30 years.

To make a gift towards our work, please visit  
[www.lymphoma-action.org.uk/Donate](http://www.lymphoma-action.org.uk/Donate)

Thank you

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This booklet will help you understand more about active monitoring (watch and wait) for lymphoma. It covers what you should look out for and gives advice for day-to-day living.

Lymphoma Action has been providing information and support to people affected by lymphoma for over 30 years. We're here for you.

Freephone helpline 0808 808 5555

[information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)

[www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)

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