Active monitoring



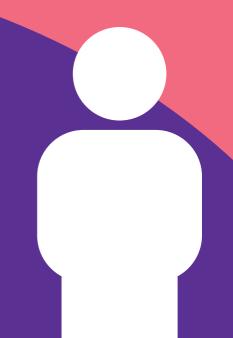
# Active monitoring (watch and wait) for lymphoma

What it is

What it involves

Living your life

**Further support** 





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 and so every penny received is truly valued.



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



# Your lymphoma type

Key contact
Name:
Role:
Contact details:

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist or key worker	

# About this book

Many people with low-grade (slow-growing) 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 lymphoma but that you're not having treatment for it. This book explains what active monitoring is and why it might be recommended to you. It also offers tips on coping well and has space for you to make notes.

Important and summary points are written in the chapter colour.



Lists practical tips.



Gives space for questions and notes.



Lists other resources you might find useful, some of which are online. If you do not have internet access, please contact our Helpline (see page 47).

If you would like the information in this book in large print, please contact us.

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approach for me because of the size of the lymph nodes, the fact that it is just in the stomach and because the lymphoma isn't affecting my lifestyle. I am physically fit and well, and I still run and exercise. They explained that while things are stable and I feel well, it's best to leave well alone.

Zoe, on active monitoring for follicular lymphoma

# What is active monitoring?

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### What is active monitoring?

Not everyone with lymphoma needs treatment straightaway. Instead, you might have regular check-ups to monitor your health and to see how the lymphoma is affecting you. 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.

It doesn't mean your lymphoma can't be treated. It means there is no benefit in starting treatment **yet**. Treatment is still available if your lymphoma starts to cause problems or if you develop symptoms that are hard to cope with.

Treating you before the lymphoma is causing problems does not make you live longer.

Active monitoring means you save treatment for when you need it.

# Why might I be offered active monitoring?

Your doctor might suggest 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, marginal zone lymphomas, Waldenström's macroglobulinaemia, chronic lymphocytic leukaemia (CLL), small lymphocytic lymphoma (SLL), mantle cell lymphoma or nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

If you have one of these types of lymphoma, you might not need treatment straightaway. This might not be what you'd expect, but research has shown that there is no benefit to starting treatment before you need it. Being actively monitored instead can help you to avoid unnecessary treatment.

I had geared myself up for treatment and it going away, but that is not the case. It is about finding a new way to live my life and learning not to be fearful of the lymphoma.

Abi, on active monitoring for follicular lymphoma



Your medical team should explain why they are recommending active monitoring for you. Ask them any questions you have.

You might also have active monitoring if you've had a course of treatment that has shrunk your lymphoma but hasn't 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, regular appointments with your medical team.
- You can have a good quality of life.
- You can benefit from newer therapies as they become available.



View our Active monitoring playlist at YouTube.com/LymphomaAction to find out more about the approach and to hear people share their experiences of active monitoring. You might worry that your lymphoma could get worse suddenly or that it could change (transform) into a faster-growing type of lymphoma while you are on active monitoring. This does not happen any more often in people on active monitoring than in people who receive treatment soon after they are diagnosed.

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.

Active surveillance really does mean surveillance 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 in Haematology

Being on active monitoring doesn't make treatment for lymphoma any less effective.

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

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### Are there any other options?

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

For example, if you have stage 3 or 4 follicular lymphoma that isn't causing bothersome symptoms, your medical team might discuss the option of a short course of rituximab before you go on to active monitoring.



- Our Low-grade non-Hodgkin lymphoma book has more information on possible treatments. Order or download a copy at lymphoma-action.org.uk/Books
- Read more about lymphoma treatment online at lymphoma-action.org.uk/Treatment



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.

Pat, on active monitoring for 3 years before starting treatment for follicular lymphoma

### When might 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 different course of treatment, but others don't need treatment for many years. Some people never need treatment.

Your medical team are likely to suggest treatment if:

- you develop any 'B symptoms' (night sweats, weight loss or fevers)
- your lymph nodes or spleen (an organ in your immune system) start to grow quickly
- 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 (the middle of your bones where blood cells are made).

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

- 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?
- What reassurance can you give me that my lymphoma won't get worse if I don't have treatment straightaway?
- When might I need to start treatment?
- How will I know what symptoms to look out for?



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

# Notes



Dr Naomi Cornish, a doctor specialising in haematology

# What happens on active monitoring?

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#### How often am I monitored?

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. You usually have these appointments at a hospital outpatient clinic. You might also be given the option of a video or telephone consultation. You might have any blood tests you need at the hospital or at your local GP surgery.

Your check-ups are usually every 2 to 3 months for the first year, then every 3 to 6 months if you still don't need treatment. 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.

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Initially, I had appointments at the hospital every 3 months, and then every 6 months, when I have blood tests. I have three support nurses who I can contact between appointments if I have any concerns.

Sylvia, on active monitoring for CLI /SLI

If you notice any change in your symptoms or any new symptoms, contact your medical team. Don't wait for your next appointment if you are worried.

### Questions to ask your medical team

- How often do I need a check-up?
- Where do I have to go?
- What tests or scans do I need, and how often?
- Who should I contact if I notice new symptoms? How do I contact them?
- How will my doctor know when I need to start treatment?



### What happens at appointments?

At your check-ups, a member of your medical team (usually your doctor or nurse) talks 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
- 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. 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.

Your medical team will also check for any signs your lymphoma might have progressed.

You also have blood tests. You might have:

- A full blood count to measure the number of blood cells in your bloodstream. This tells your doctor or nurse 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. This can happen if you have an infection, but it can sometimes be a sign that your lymphoma is growing.

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.



# Tips to get the most out of your appointments

- 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.
   You might be able to have a print-out of any test results.
- Ask your doctor or nurse if you can record what they say so you can listen back to it later.
- 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 do in the waiting room such as a book, phone or tablet, or some mindfulness colouring.
- 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 the tables on the following pages to write this down.



### Medicines and supplements I am taking

Name and dose of medicine or supplement	Date started and stopped



# Changes to my health (vaccinations, infections, or other illnesses)

Details	Dates

# What symptoms should I look out for?

Monitor any symptoms you have. Look out for any changes to them, or any new ones that develop.

Tell your medical team if:



Your lymph nodes are growing



You notice any new lumps



You feel more tired than usual



You get night sweats



You are losing weight without trying to



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



Your skin is itchy

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 pages 30 to 31 to write down any changes in your symptoms.

If your symptoms change, your medical team might 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.

When I was first diagnosed, I was quite obsessed with blood tests and felt nervous before a check-up. But after about a year, and having learnt more about active monitoring, I felt much calmer and life settled back to normal.

Peter, on active monitoring for splenic marginal zone lymphoma

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.

The consultant gave me a booklet about CLL, but most importantly, a sheet with contact details of my lymphoma clinical nurse specialist (CNS). I have contacted the CNS several times when I just don't know what's going on. It's great to have someone that can support and advise you.

Ashley, on active monitoring for CLL

Symptom	Date and notes
Example:	13 March: need a nap once a week
Fatigue	14 May: need a nap most afternoons

Symptom	Date and notes



I have been told by my GP that I will never climb mountains, but I am more than happy and take every day as it comes.

I am now on active monitoring, or watch and wait, like thousands of other people with lymphoma and love it when I see stories of people still on it 10 or 20 years later.

Kevin, on active monitoring after treatment for B-cell non-Hodgkin lymphoma

# 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 with your medical team, and frustrated that they don't seem to be doing anything about it. 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.



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.

Mark, on active monitoring for follicular lymphoma



- Find support from other people who are affected by lymphoma at lymphoma-action.org.uk/SupportGroups
- Maggie's Cancer Centres offer support and information for people affected by cancer, their family and friends.
   Find out more at maggies.org

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 had been told that I may be on active monitoring for a couple of years, so decided the best way for me to cope was to keep things as normal as possible.

Although I told management at work, I asked them to keep it private as I didn't want it to be general knowledge. I just told the people who needed to know and my close family and friends.

Carl, on active monitoring for 4 years before starting treatment for CI l

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 (see page 47).

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. 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.

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I find watch and wait really difficult. I feel out of control. When I was having treatment and doing something about it, I found it easier. The thought of having the lymphoma in my body and it coming back is really hard. People have told me it gets easier. With time I have learned to manage it, but I still do not find it easy.

Nichola, on active monitoring for follicular lymphoma

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 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).

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What I've really learned is that I need to speak to myself like I would speak to a friend if they had this kind of thing going on. I think I expect too much of myself, in a way I'd never expect it of somebody else. I'd say of course you feel like that and of course, that's just normal. So I've learnt to be a bit kinder to myself.

Louize, on active monitoring for follicular lymphoma



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

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.

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

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GPs can help with a range of things. We're focused on the whole person. You can come to us if you're struggling with low mood or anxiety, which is quite common in people who have cancer. We can also refer to other professionals like dietitians and occupational therapists and we can signpost you to help you find information and support with work and finances.

Dr Elaine Hampton, GP

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.



# Tips to help you connect with other people affected by lymphoma

- Find a support group. Search 'support group' on our website or ask your clinical nurse specialist for information about suitable support groups.
- 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.

I'm 3 years post treatment. I attended a 'Live your Life' workshop and it changed the way I see my diagnosis. I now deliver these workshops for Lymphoma Action. Over the last year, to help me manage the active monitoring, my consultant referred me to the oncology psychology services for acceptance and commitment therapy. This helps me to keep my focus on living my best life. I am better prepared for future treatment and I know that the support available through Lymphoma Action will help tremendously.

Louise, on active monitoring for follicular lymphoma

"



## Tips to help manage anxiety

- Consider techniques such as breathing exercises or a type of meditation such as mindfulness or yoga.
- 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 they could help.
   This could include showing you some patience and understanding if you are quiet, tired or irritable.



- Our Living with and beyond lymphoma book gives you tips on coping practically, physically and emotionally with lymphoma. Download or order a copy at lymphoma-action.org.uk/Books
- Search for our video How to cope with difficult feelings at YouTube.com/LymphomaAction

## 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.

You can let active monitoring 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.

Andrew, on active monitoring for follicular lymphoma

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
- The Government also produces an Eatwell Guide, which gives information about getting a balanced diet. Search 'Eatwell' at gov.uk



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

Gerry, on active monitoring for follicular lymphoma

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.



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.



We have 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
- 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.



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



Since diagnosis I've done so much more on watch and wait. I've used this time to go to New York, instead of waiting until retirement. I have a list of things to do in my 50s. I've been to the ballet and had afternoon tea at the Ritz with my mum. We've been all over England and raised £600 by doing the Lymphoma Action Bridges of Britain walk.

Becky, on active monitoring for mantle cell lymphoma



Visit lymphoma-action.org.uk/LWL for more information on physical health, emotional wellbeing and day-to-day practicalities.

# Information and support

If you'd like to talk to someone about anything to do with lymphoma, get in touch.



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



Join one of our **Support Groups**. Find one at lymphoma-action.org.uk/SupportGroups



Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details



Visit lymphoma-action.org.uk/**TrialsLink** to search for clinical trials that might be suitable for you



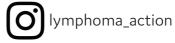
Check out our **YouTube channel** to watch personal stories and medical films

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





@LymphomaAction





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. In particular, you might find the following books helpful:

- Watch and wait for lymphoma (Easy Read version)
- Low-grade non-Hodgkin lymphoma
- Living with and beyond lymphoma
- When someone close to you has lymphoma

Find our full range of books and information, including accessible information and Easy Reads, at lymphoma-action.org.uk/Books or call 0808 808 5555.

Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful. If you don't find what you're looking for, please get in touch with our Information and Support team.

Our information is evidence-based, approved by experts and reviewed by users. 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

Volunteering is at the heart of what we do. 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 visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support team on 0808 808 5555.

#### References

The full list of references 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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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure no one faces lymphoma alone.

- Helpline (freephone) **0808 808 5555** (Mon to Fri, 10am to 3pm)
- Email information@lymphoma-action.org.uk
- Visit www.lymphoma-action.org.uk
- Live Chat via our website (Mon to Fri, 10am to 3pm)

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- ✓ Evidence-based
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