

Questions to ask your medical team about lymphoma

On this page, we've listed some of the questions you might like to ask your medical team if you've been diagnosed with lymphoma. Discussing these questions with your family, friends or loved ones may be helpful when it comes to organising your thoughts. Some topics might not be relevant to you, or only become relevant at certain points.

Go at your own pace and ask as many or as few questions as you want to. If the answer isn't clear, don't be afraid to ask again, or ask them to write it down for you. Health professionals are used to explaining things and will want to help you.

We have provided boxes to write answers to your questions if needed.

On this page

Finding out about your lymphoma

Questions to ask your doctors about your lymphoma

Questions to ask about tests and scans

Questions to ask about staging (how advanced your lymphoma is)

Questions to ask about active monitoring (watch and wait)

Questions to ask about treatment

Questions to ask about side effects

Questions to ask about the effects of lymphoma and treatment on other areas of your life

Questions to ask about clinical trials

Questions to ask about finishing treatment

Questions to ask about follow-up

Questions to ask about relapse

We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

Finding out about your lymphoma

How much you choose to find out about your lymphoma is a very personal decision. You might want to know as much as you can, or you might prefer to have just basic information. The amount you want to know could change over time too. Go at your own pace; you don't have to ask all of your questions at once if you'd prefer to find out more detail later.

Below are some tips that you might find helpful:

- Write down any questions as they come to your mind. Take these with you to your next appointment.
- Note down the information you get during your appointments. You could ask the hospital whether it's OK to make an audio recording of the consultation.
- If you need them, ask for simpler explanations during your appointments. Sometimes health professionals might use terms that are unfamiliar to people who don't have medical training. Ask for clarity if it is needed.
- If possible take someone with you to appointments, both for emotional support and to help remember or note down key points.
- Some people find that many of their questions are answered in the Care Plan from their Holistic Needs Assessment (HNA), if they have one. It may be helpful to use this as a starting point when finding out more information about your lymphoma.


The health professionals in your **medical team** are best-placed to give you information specific to your individual situation. Remember that we are also here to **support you**, your family and friends.

If someone knows more about what is happening, it can help them to feel more in control, and empower them to consider what may be helpful for them in managing their situation.

Sharon, Lymphoma Action helpline services team

Questions to ask your doctors about your lymphoma

- What **type of lymphoma** do I have specifically?
- Where in my body is the lymphoma?
- Is the lymphoma a high-grade or fast-growing lymphoma or is it low-grade or slow-growing?
- What is my outlook?
- Does the type of lymphoma I have generally respond well to treatment?

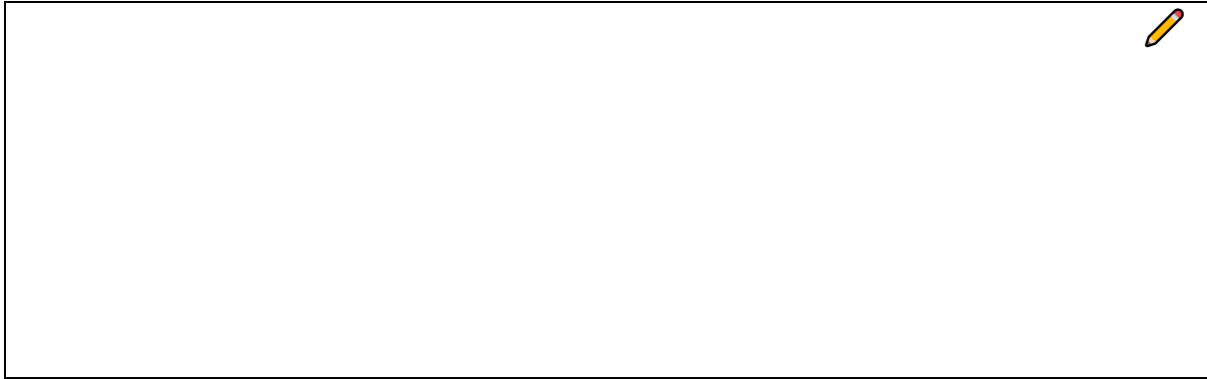


Talk to your doctors about any **symptoms** you are experiencing. Let them know how they are affecting you, physically and **emotionally**. Find out from them what you can do to help lessen them, or if there is any treatment they can offer to help ease them.

Questions to ask about tests and scans

- What **tests** do you recommend for me and why?
- What will the test tell me about my lymphoma?
- What do the tests involve?
- Could the tests cause me any harm?
- Are the tests painful? Will I be given anaesthetic or offered a sedative?
- Are there other factors to consider, such as enclosed spaces?
- Where and when will I have the tests?
- How long will the tests take?
- Is there anything I need to do to prepare for the tests or scans?
- How might I feel after the tests?
- Can I drive myself home afterwards?
- Are there any precautions I need to take after the test or scan?
- Do I need to take time out of **work** or **education** after the test?

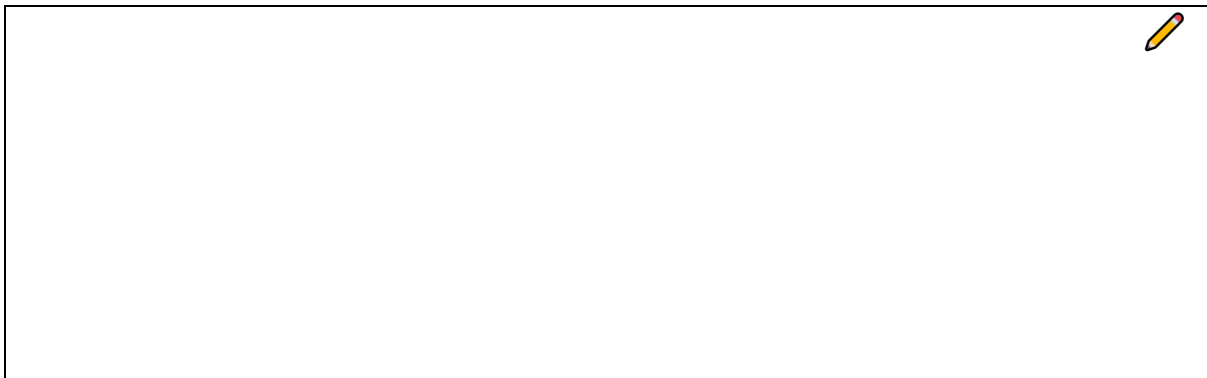
- How long will I be **waiting for test results**?
- How will I get the results?
- Who will explain my test results to me?



Questions about staging (how advanced your lymphoma is)

- What **stage is my lymphoma**? What does this mean?
- Is my lymphoma considered to be at an **early stage or an advanced stage**?
- What might this mean for me in terms of **treatment**?

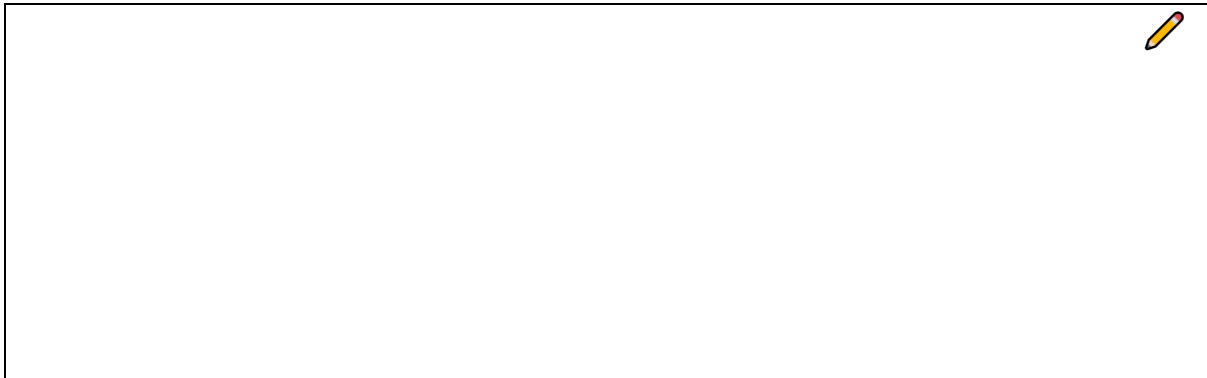
Note that the **staging system** is not used in all types of lymphoma.



Questions to ask about active monitoring (watch and wait)

- Why are you recommending **active monitoring** (watch and wait)?
- Can you explain to me why you think this is the right approach for me?
- Are there any other options that might be suitable?
- Might my lymphoma get worse if I don't have treatment straightaway?
- How often will I have **follow-up** appointments to check on my lymphoma? What happens during these appointments?

- What **symptoms** should I look out for between follow-up appointments?
What should I do if I notice these?
- What can I do to help myself stay as well as possible while I am on active monitoring?
- If I have any worries or concerns about this at any point, who can I talk to?
- How long do you expect me to be on active monitoring?
- What active treatment might I be offered afterwards?




We have more information about **active monitoring** on our website. We also produce a book: *Active monitoring (watch and wait) for lymphoma*, which you can **download or order free of charge on our website**.

Questions to ask about treatment


- What **treatment** or treatment options are you recommending for me and why?
- How does this treatment work?
- How is the treatment given? Is it painful?
- Is there a risk of adverse reactions and, if so, how is this risk managed?
- Where will I have the treatment?
- How long does each treatment session last? How often do I have the treatment?
- How long does the whole course take?
- Will I need to stay in hospital overnight?
- Can I drive myself home after my treatment?
- What is the aim of the treatment? How and when will we know if it is working?
- How successful is the treatment likely to be?
- How might I feel afterwards?

- What **emotional support** is available to me during this time?



Questions to ask about side effects of treatment

- What **side effects** might I get from this treatment? Are these likely to happen soon after having treatment?
- How long can side effects last?
- Is there anything I can do to lessen or prevent side effects?
- Are there any treatments to help with side effects?
- Will the treatment affect my **fertility**? If so, how?
- How may my treatment affect my physical appearance?
- Are there any potential **late effects** of the treatment (which happen months or years after having treatment)? If so, is there anything related to these that I should take into consideration in the future, for example the importance of screening tests?
- Who can I talk to if I'm worried about side effects?



Questions to ask about effects of lymphoma and treatment on other areas of your life

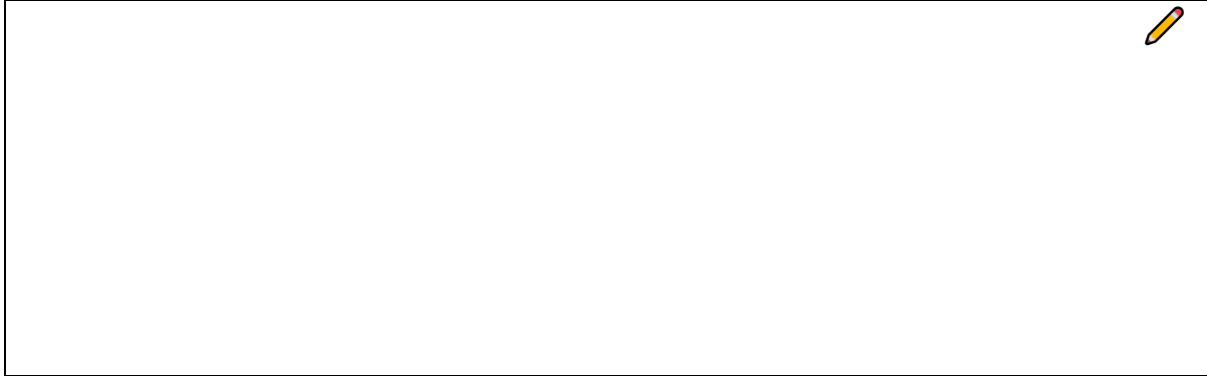
- Can I continue with my usual **day-to-day** routine during treatment?
- Am I likely to need to take time out of **work** or **education** during or after treatment?
- Can I continue to **exercise** during treatment?
- Is it safe to **travel to another country** while I'm having treatment?
- Can I go on holiday within the UK?
- Are there any **foods**, supplements or medicines I should avoid while I'm having treatment?
- Are there any foods, supplements or medicines that might be beneficial to me during treatment?
- Is it safe for me to eat out at a pub, restaurant or café while I'm having treatment?
- Is it OK for me to **diet**?
- Can I drink alcohol?
- Can I have sex during treatment? Should I use contraception?
- What **emotional support** is available to me?



Questions to ask about clinical trials

- What is a **clinical trial**?
- Are there any **clinical trials available to me**?
- What are the potential advantages and disadvantages of taking part in a clinical trial?


- What happens if I start a trial but then no longer want to continue with it?
- When will the results of the trial be available?
- Will I be told the results of the trial? If so, how and when?



We have a more [questions to ask about clinical trials](#) that you might be interested in if you are considering taking part in one on our website.

Questions to ask about finishing treatment

- What can I do to [stay healthy](#) after treatment?
- Is there anything I can do to reduce the risk of the lymphoma coming back ([relapse](#))?
- Are there any health issues I should look out for after my treatment ends?
- How soon after treatment finishes can I have dental treatment?
- Is it OK to have [vaccinations](#)? Should I have the winter flu jab?
- If I have experienced [treatment-related hair loss](#), when can I start using my usual hair products again? When can I dye or perm my hair?
- Is it safe for me to [travel to another country](#)?
- If I want to start a family, how long should I wait after finishing treatment?
- Do I need to state my lymphoma diagnosis on an application for a job or volunteering role?
- How can I cope with anxiety or other [challenging feelings](#)?
- Am I able to be provided with a Treatment Summary?



Questions to ask about follow-up

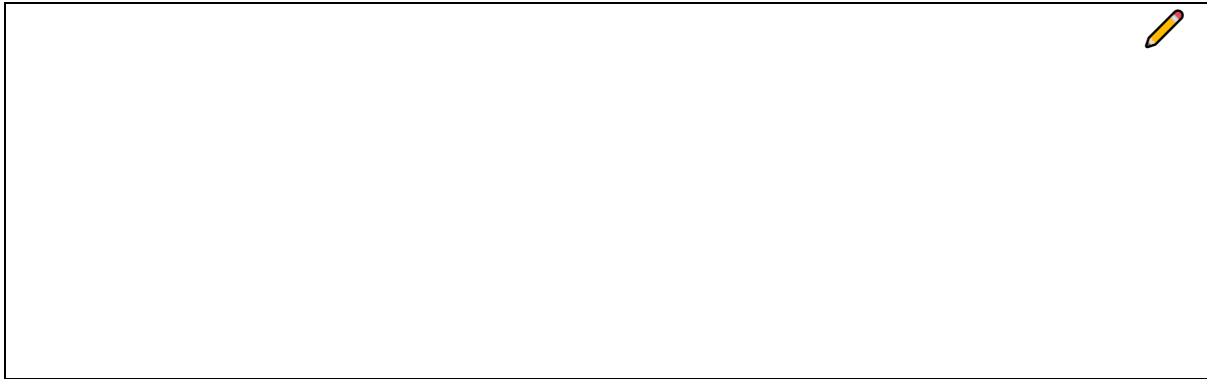
- What is the purpose of **follow-up**?
- What happens at the follow-up appointments?
- Who will I have my follow-up appointments with?
- How often will I have follow-up appointments after I finish treatment?
- Are there any symptoms I should look out for that might suggest the lymphoma has come back (relapsed)?
- Who should I contact if I am worried about anything between appointments?
- What **emotional support** is available to me between appointments?



Questions to ask about relapse

- Is my lymphoma likely to come back (**relapse**)?
- Is there anything I can do to reduce the risk of relapse?
- How will I know if the lymphoma relapses?
- Are there any symptoms I should look out for?

- What should I do if I think my lymphoma has come back?
- What treatment might I be offered if the lymphoma relapses?
- What is the likelihood of the lymphoma going into **remission** with further treatment?



Acknowledgements

- We would like to thank our Education and support services team and the members of our Reader Panel who gave their time to review this information.

Content last reviewed: September 2023
Next planned review: September 2026
LYMweb0014QsMedTeam2023v5

✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

© **Lymphoma Action**

Tell us what you think and help us to improve our resources for people affected by lymphoma. If you have any feedback, please visit 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

lymphoma-action.org.uk/Donate. Our information could not be produced without support from people like you. Thank you.

Disclaimer

We make every effort to make sure that the information we provide is accurate at time of publication, but medical research is constantly changing. Our information is not a substitute for individual medical advice from a trained clinician. If you are concerned about your health, consult your doctor.

Lymphoma Action cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information we refer to, including that on third party websites.