

Live your Life

Living with and beyond lymphoma

Module 1: Know your lymphoma





Remember that you're not alone – your medical team will keep checks on your health at your follow-up appointments, but it's still a good idea to check your lymph nodes. It's about having an awareness while focussing on living your life.

Martha Wilson, Clinical Liaison Nurse Specialist

Module 1: Know your lymphoma

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Notes

You can use this space to make any notes from module 1 of the Live your Life workshop.



Action plan to help me live well.

Action	How often
Keep a diary of my symptoms and concerns	Weekly

What is lymphoma?

Lymphoma is a type of blood cancer. It develops when lymphocytes (a type of white blood cell) grow out of control. They divide in an abnormal way or don't die when they should.

- Lymphocytes are part of your immune system. They move through your body in your lymphatic system and help you fight infections.
- Your lymphatic system runs throughout your body carrying a fluid called lymph.
- Lymph passes through lymph nodes (glands), which spread throughout your body.

Lymphoma commonly develops in the lymph nodes in the neck, armpit or groin. It can also develop in lymph nodes and tissues deeper inside your body, or in the bone marrow (the spongy part in the middle of some of your bigger bones, where blood cells are made). Less commonly, lymphoma starts in other areas of your body, such as the breast, stomach, bowel, skin, brain or liver.



Search 'what is lymphoma' to find out more at lymphoma-action.org.uk

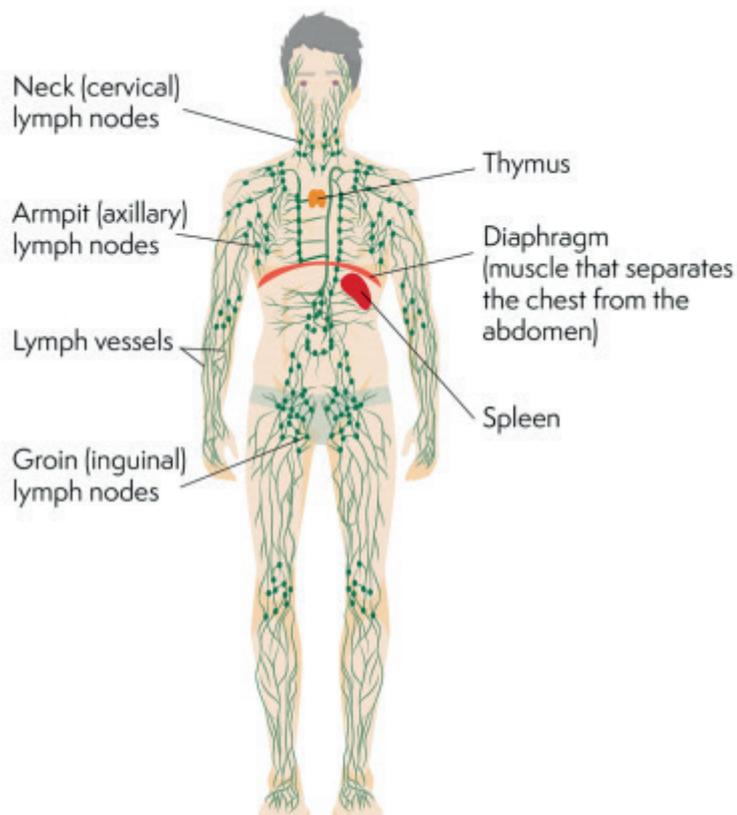
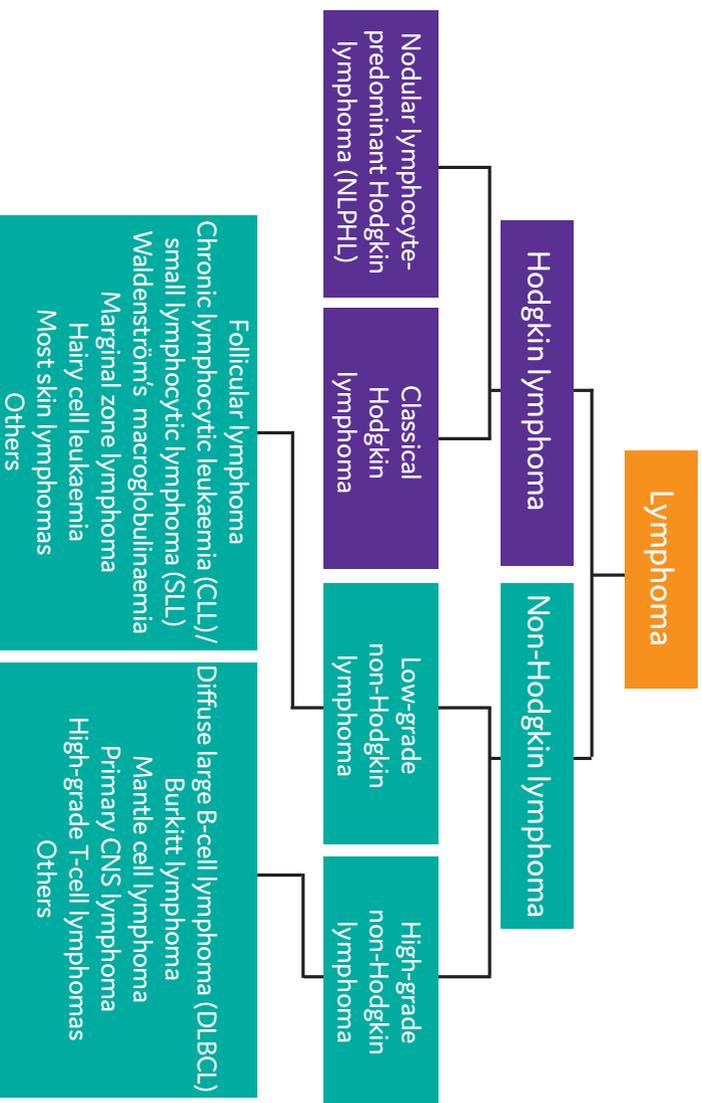


Figure: The lymphatic system

Types of Lymphoma

There are over 60 different types of lymphoma, which are sorted into groups or subtypes.



Stages of lymphoma

Staging in adults is the same for Hodgkin lymphoma and non-Hodgkin lymphoma. There are four main stages, numbered 1 to 4. Sometimes, they're written in Roman numerals as I, II, III and IV.

- **Stage 1:** only one group of lymph nodes is affected, anywhere in the body.
- **Stage 2:** two or more groups of lymph nodes are affected, all on the same side of the diaphragm (either all above or all below).
- **Stage 3:** lymph nodes on both sides (above and below) of the diaphragm are affected.
- **Stage 4:** lymphoma is either in organs outside the lymphatic system or in the bone marrow.

All stages of lymphoma can be treated. Depending on the type of lymphoma you have and its stage, you might have treatment with an aim of curing the lymphoma or keeping it under control (full or partial remission).

**We've got more information on our website.
Search 'types', 'staging' and 'treatment' at
lymphoma-action.org.uk**



Common symptoms of lymphoma

Look out for any changes to your symptoms, including new ones that develop. We outline the common symptoms of lymphoma below. However, it's important to note that these can have other causes, and not everyone experiences them.

 An illustration of a woman with long brown hair, wearing a yellow tank top. She is looking at her left armpit with a concerned expression, and her right hand is raised to her head. A small, dark, circular lump is visible on her left armpit.	<p>Swollen lymph nodes – a lump or lumps in the neck, armpit or groin are a common symptom of lymphoma. They are usually painless.</p>
 An illustration of a woman with dark hair, wearing a green shirt. Above her head are three 'z' symbols, indicating she is tired or sleeping.	<p>Fatigue – feeling exhausted for no obvious reason or feeling washed out after doing very little.</p>
 An illustration of a person sleeping in a bed. The person is covered with a dark green blanket. There are several white sweat droplets on the blanket. A window in the background shows a night sky with a moon and stars.	<p>Sweats – that make your nightclothes and bed sheets soaking wet, usually at night, although they can happen during the day.</p>



Unexplained weight loss – losing a lot of weight quite quickly without trying to.



Itching (pruritus) – without a rash. This can be particularly bothersome in hot weather.



Infections – getting infections more often than usual or having difficulty shaking them off. You might develop a cough if you have an infection that involves your airways (such as your lungs, nose and throat).

Doctors sometimes talk about 'B symptoms'. This means you have unexplained weight loss, night sweats and fever (a temperature above 38°C or 100.4°F).



For more information about symptoms of lymphoma, visit lymphoma-action.org.uk/Symptoms, where you can also watch a video about the common symptoms.

If you're on active monitoring (watch and wait) or have finished treatment

It's natural to worry about your lymphoma coming back or getting worse after treatment or during active monitoring. We often hear from people that they worry about symptoms that probably wouldn't have concerned them before. Remember that symptoms could be completely unrelated to your lymphoma and might just be a sign of a cold or other minor illness.

It can be difficult to get the balance between keeping checks on your health and worrying over minor symptoms. However, it's a good idea to be aware of what to look out for if your lymphoma does progress or come back (relapse). Ask your medical team for specific advice about symptoms to look out for.

If your lymphoma relapses, it might come back where it was before or it could affect another part of your body.

Your medical team might monitor your health more closely for a while, run any tests or checks, or arrange for you to have a scan.

Contact your medical team if you have any of the symptoms listed below.

- swollen lymph nodes that don't go away within 2 to 3 weeks
- night sweats
- unexplained weight loss
- worsening fatigue
- itching
- diarrhoea
- ongoing or unexplained pain
- rashes (if you have skin lymphoma)
- frequent infections.



You can use this space to write down any other symptoms and signs you've been told to look out for.

Monitoring your health

It can take a bit of time to get the balance between keeping checks on your health and not worrying unnecessarily.

For example, lymph nodes can become swollen for lots of reasons, such as if you are fighting an infection such as a cold.

Ask your medical team for advice about anything specific to look out for.

Know your nodes

Lymph nodes go up and down naturally over time. Although it's sensible to check them from time to time, doing it too frequently (more than about once a month), could cause unnecessary worry. It also makes it more difficult to notice changes.



If you'd like further information about how to check your lymph nodes, you could:

- **ask a member of your medical team to show you at your next appointment**
- **watch our 'Know your nodes' video on our website at lymphoma-action.org.uk/live-your-life-materials**
- **search 'lymph nodes' on the British Association of Dermatologists website at bad.org.uk to download an illustrated leaflet.**



How to check your nodes

Find a relaxed and comfortable position – lymph nodes can be difficult to feel if your muscles are tense. Take off any clothes you need to. A good time to check can be in the shower. Use three fingertips with a firm pressure to feel in a circular motion:

- in front of and behind your ears
- along both sides of your jawline
- above your collarbone
- down both sides of your neck
- in and around your armpits– leave your arm down and relaxed so that you can push deep into the centre of them
- the front and back borders of both armpits
- along both groin creases
- the tops of your inner thighs.

You could set yourself an alert or reminder in your calendar to check your nodes at the frequency your medical team suggest.

If you notice anything that you think could be a symptom related to your lymphoma, contact your clinical nurse specialist or hospital clinic and ask for a check-up. You can contact your GP if you have any other health or wellbeing concerns.

Late effects of treatment

Late effects are side effects that can develop weeks, months or years after treatment. Most people recover well from treatment without experiencing late effects. Your medical team should tell you about the possible late effects of your treatment. Your risk depends on several factors, including your lymphoma type and the treatment you've had, your age, family history and lifestyle. Possible late effects can include other ('second') cancers, heart disease, lung disease, hormone problems, dental problems and eye problems.

It's important to know what late effects to look out for to be able to notice any problems early. Speak to your medical team for advice. You might also be offered appointments at a late effects clinic once you finish your schedule of routine follow-up.



Tips for monitoring your health

- Take up any follow-up appointments and health screening invitations you're offered.
- Have regular check-ups with your dentist and optician.
- Get to know what is normal for you – if you think something isn't right, contact your GP or clinical nurse specialist.

Speak to your medical team about your individual risks, symptoms to look out for and what to do if you notice them.



Search 'late effects' on our website for more information.



You can use this table to note any changes to your health.

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

Personalised care and support

It takes time to recover after treatment for lymphoma, but there is support available. The NHS is committed to offering tailored care and support to each individual living with and beyond cancer. This is known as a personalised care and support plan.

Personalised care should include the following:

Holistic needs assessment (HNA), to help you and your medical team identify and address any practical, financial, physical, emotional and social needs you might have.

Treatment summary, which outlines:

- your diagnosis
- your treatment, its possible side effects and late effects
- what symptoms you should look out for and who to contact if you notice them, including an out-of-hours number
- your follow-up plan and any lifestyle recommendations, for example, about diet and exercise.

Cancer care review, which is a discussion that you have with your GP or a GP surgery practice nurse. It's an opportunity to talk about any medical needs you might have and to talk about any points raised in your HNA. You could also find out about any financial support available to you, including prescription charge exemptions.

Health and wellbeing events, to help people affected by cancer and their families live well. Our Live your Life programme is an example of this.

Ask your medical team for information about personalised care for you. Some hospitals offer enhanced supportive care. This is a holistic approach to supporting you as an individual, from the point of diagnosis and throughout your experience of lymphoma. It also considers physical, social, psychological and spiritual needs. You could ask your team for more information about this.

You can find out more about personalised care on the NHS website: [england.nhs.uk/personalisedcare](https://www.england.nhs.uk/personalisedcare)



Follow-up appointments

After finishing treatment for lymphoma, you have an end-of-treatment appointment with your medical team. Follow-up appointments monitor your recovery from treatment, check for any signs of recurrence and check for any signs of late effects developing.

A key part of follow-up is to give an opportunity for you and your medical team to talk about:

- how you're feeling, physically and emotionally
- whether you've noticed changes in your symptoms, including any new ones
- your adjustment to life after treatment – for example, whether you've been able to return to the things you used to do before treatment, if you'd like to.

They can signpost you to any further sources of support that could be helpful to you. You might also have a physical examination. For example, your doctor or nurse might feel your body to check for enlarged lymph nodes. At some appointments, you might have a blood test.

Sometimes, at the end of treatment, you have a scan to check how well your lymphoma has responded. This scan also helps to provide a new baseline or a 'new normal' so that if any issues arise in the future, your medical team can see what your body looked like at the end of your previous treatment.

After this point, scans aren't part of routine follow-up as there's no evidence that they help to detect relapse. Some scans give off radiation, so having scans only when they're considered to be helpful and safe keeps your exposure to radiation as low as possible.

How often you have appointments depends on your hospital's usual practice and your lymphoma type.

If you notice any changes in your symptoms, don't wait for your next appointment – contact your medical team.



**For more tips, visit our website:
lymphoma-action.org.uk/top-tips-appoint**



Tips for follow-up appointments

- **Prepare your questions in advance** so that you can use the appointment to get all the information you'd like. You could take your questions with you written on paper, phone or a tablet to help you remember them.
- **Take something with you for when you're in the waiting room** such as, a book, phone, tablet or an activity such as puzzles or mindfulness colouring.
- **Consider taking a family member or a friend with you** because as well as helping to remember key points, they can provide emotional support. If they can't be there in person, you could ask whether you could have them on the phone during the appointment.
- **Note down the information you get during your appointment** and if a family member or friend has come with you ask them to take notes for you so you can focus on talking to your doctor or nurse.
- **Think about how to manage stress or anxiety** if you find the lead-up to appointments difficult.
- **Remember that a key purpose of routine follow-up appointments is to support you** and to ensure that you have what you need to help you live well, with and beyond lymphoma.



There's space below to note down questions you might like to ask at your next follow-up appointment.

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 peer support services such as **Support Group, online support meeting** or **closed Facebook support group**. Find one at lymphoma-action.org.uk



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



lymphoma_action



If you're interested in finding out more about any of the topics in this book, we have lots more information available 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:

- *Introduction to lymphoma*
- *Living with and beyond lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Caring for someone who has lymphoma*

We also have some wellbeing videos available to watch. Search 'wellbeing videos' on our website.

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 for more information.

Useful organisations

We list some organisations below that you might find helpful. You can find more useful organisations on our website. If you don't find what you're looking for, please get in touch through our Helpline Services (see page 112).

Cancer Research UK has information about cancer, including about treatment and coping strategies.

www.cancerresearchuk.org

Citizens Advice provide free advice on matters such as housing, consumer, money and legal issues.

www.citizensadvice.org.uk

Every mind matters – NHS is a website from Public Health England with tips and advice for good mental health.

www.nhs.uk/every-mind-matters

GOV.UK is the UK government website. It outlines the financial benefits that people affected by cancer and their carers might be entitled to.

www.gov.uk

Look Good Feel Better helps people to manage the visible side effects of cancer treatment with free group and self-help skincare and make-up workshops

www.lookgoodfeelbetter.co.uk

Macmillan Benefits Advice Service offers financial advice, including welfare benefits, housing, work and debt to people with cancer and their carers.

Macmillan Cancer Support provides support for people affected by cancer from diagnosis through treatment and beyond.

www.macmillan.org.uk

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

www.maggies.org

Mental Health Foundation has information about mental health, including resources designed to introduce techniques to support mental wellbeing.

www.mentalhealth.org.uk

Mind offers support and advice in relation to mental health. You can email their infoline at info@mind.org.uk or call on 0300 123 3393.

www.mind.org.uk

NHS website has health information.

www.nhs.uk

NHS inform is a health information service from NHS Scotland covering health and welfare, and including self-help resources that are free to access.

www.nhsinform.scot

Relate is the UK's largest provider of relationship support. Their services include information, workshops and counselling.
www.relate.org.uk

Samaritans offer emotional support to anyone who is struggling with difficult feelings. Their service runs 24 hours a day, all year round. Call 116 123 or email jo@samaritans.org
www.samaritans.org

Shine Cancer Support offers support for people in their 20s to 40s who have been diagnosed with cancer.
www.shinecancersupport.org

Shout offers support to anyone struggling to cope. They have a free and confidential text service available 24/7. Text 85258
www.giveusashout.org

Teenage Cancer Trust offers information and support for young people living with cancer and for their families.
www.teenagecancertrust.org

Working with Cancer helps employees, employers, the self-employed, job seekers, people who are self-employed, and carers to manage cancer and work.
www.workingwithcancer.co.uk

Young Lives vs Cancer offers clinical, emotional and practical support to children and young people with cancer, and to their families.
www.younglivesvscancer.org.uk

About our information

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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Acknowledgements

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

- Charlotte Bloodworth, Advanced Nurse Practitioner in Haematology, University Hospital of Wales, Cardiff.
- Martha Wilson, Clinical Liaison Nurse Specialist for teenagers and young adults, The Christie Hospital NHS Foundation Trust.

With thanks to the Elisabeth Kübler-Ross Foundation (www.ERKFoundation.org), Elisabeth Kübler-Ross Family Limited Partnership®, for permission to reproduce the change curve that appears on page 35 of this book.

Special thanks to Callum, Jeff, Kat, Louise, Nuala, Pam and Penny for sharing their experiences. Quotations from their stories are featured throughout the book. We would also like to thank health professional Martha Wilson for sharing her thoughts.

With thanks to AbbVie, Bristol Myers Squibb, Incyte, Janssen, Kyowa Kirin, St. James's Place Charitable Foundation and Takeda UK Ltd for part-funding this book. As per our policy, they have no influence over our content.

This book is part of Lymphoma Action's Live your Life peer-led, self-management workshops, but can also be used on its own. It is designed to support you to live well with and beyond your lymphoma, and includes lots of information, suggestions and places for you to write your own notes.

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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© Lymphoma Action 2021
2nd edition produced December 2021
Next revision due December 2024
ISBN 978-1-914948-02-2

Registered company in England and Wales
(03518755). Registered charity in England and
Wales (1068395) and Scotland (SCO45850).
LYM0248LiveYourLife2021ed2

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