

Live your Life

Living with and beyond lymphoma
Workbook to accompany workshops

Module 1: Know your lymphoma





I have strongly encouraged my patients to consider attending a Live your Life workshop. The day is truly inspirational and gives the individual the ability to take control by learning more about lymphoma and then self-management by addressing diet, exercise and local support.

Theresa, lymphoma clinical nurse specialist





One of the main benefits of the Live your Life workshop was an open and frank discussion about recurrence in a supportive and safe environment. Since the end of my chemo, this has been lurking at the back of my mind. It was good to talk about my anxieties and hear the thoughts and experiences of others.
Phil, diagnosed with diffuse large B-cell lymphoma

Module 1: Know your lymphoma

This module is one of a series taken from our workbook 'Live your Life - living with and beyond lymphoma'.

There are five modules in total:

- Know your lymphoma
- Coping with the emotional aspects of lymphoma
- Exercise and staying active
- Diet and nutrition
- Practical aspects of living with lymphoma

You can download all of the modules, or the complete workbook, at www.lymphoma-action.org.uk/lylworkbook



**Use this space to transfer your notes from Module 1
of your Live your Life workshop**



Action plan

Action	How often
<i>I'm going to keep a diary of my symptoms and concerns</i>	

If I am worried about any symptoms I should contact:

Name of health professional	Contact details

What is lymphoma?

Lymphoma is a cancer of lymphocytes (white blood cells that fight infection). Healthy lymphocytes travel around your body in the lymphatic system – part of your immune system. The lymphatic system includes lymph nodes (bean-sized glands that filter the fluid in your lymphatic system) as well as some organs, such as your thymus and spleen.

Lymphoma develops when lymphocytes grow out of control. Abnormal lymphocytes can collect almost anywhere in the body but they usually collect in lymph nodes, which are found throughout your body, often in groups. Lymph nodes also swell when your body is fighting infection.

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. Less commonly, lymphoma starts in other areas of your body, such as the breast, stomach, bowel, skin, brain or liver.

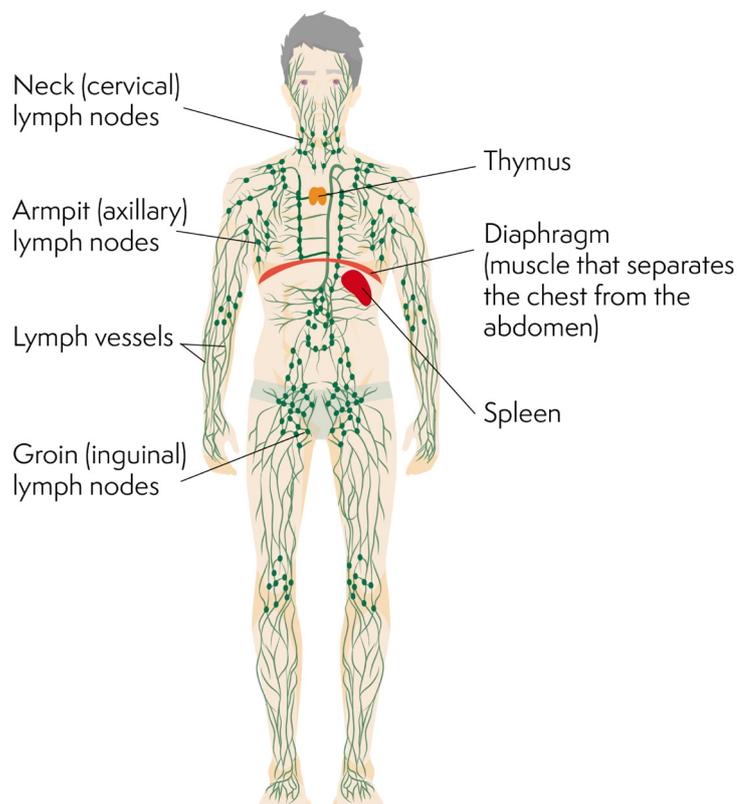


Figure: The lymphatic system



For more information on lymphoma, the lymphatic system and the immune system, visit www.lymphoma-action.org.uk/WhatIsLymphoma

Types and stages of lymphoma

There are over 60 different types of lymphoma, broadly grouped into Hodgkin or non-Hodgkin lymphoma. Within these types, there are many subtypes.

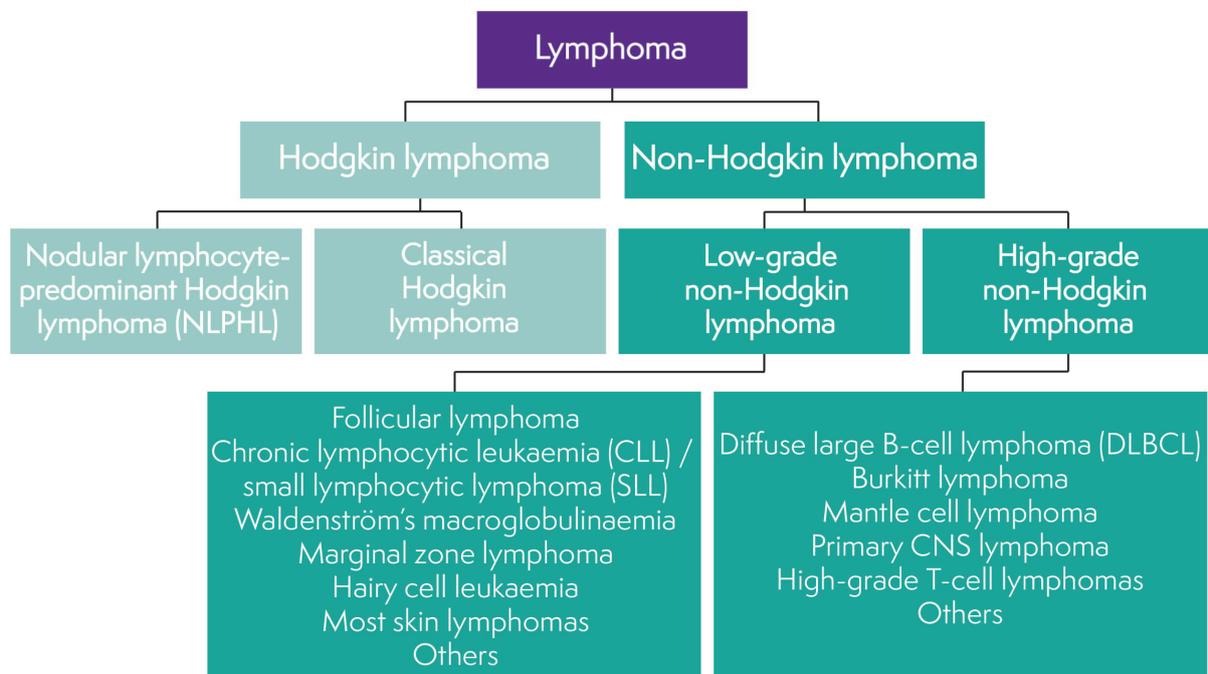


Figure: The main types of lymphoma

Most types of lymphoma are staged on a scale of 1 to 4:

- **Stage 1:** Only one group of lymph nodes is affected.
- **Stage 2:** Two or more groups of lymph nodes are affected but they are all on the same side of the diaphragm.
- **Stage 3:** Lymph nodes on both sides of the diaphragm are affected.
- **Stage 4:** Lymphoma is found in the bone marrow or in organs outside the lymphatic system.

All stages of lymphoma can be treated. Depending on the type of lymphoma you have and the stage it's at, treatment might aim to cure the lymphoma or to keep it under control (in full or partial remission).

- For more information on the different subtypes of lymphoma, visit www.lymphoma-action.org.uk/Types-Lymphoma
- For more information on the treatment of lymphoma, visit www.lymphoma-action.org.uk/Treatment or call our Information and Support team on 0808 808 5555 to order information.



Symptoms of lymphoma

The most common symptoms of lymphoma are:



Swollen lymph nodes – a lump or lumps, often in the neck, armpit or groin. They are usually painless.



Fatigue – feeling exhausted for no obvious reason or feeling washed out after doing very little.



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



Sweats – that make your nightclothes and bed sheets soaking wet, usually at night although they can happen during the day.



Itching – (pruritus) without a rash, particularly in hot weather.



Infections – getting infections more often than usual or having difficulty shaking off infections.



For more detailed information on the symptoms of lymphoma, visit www.lymphoma-action.org.uk/Symptoms

Symptoms to look out for

It is natural to worry about your lymphoma coming back or getting worse after you've finished treatment or during active monitoring. Whenever you feel ill, you might worry it's the lymphoma again. Remember that symptoms may be completely unrelated to lymphoma; you're as likely as anybody else to get coughs, colds and other illnesses. Lots of things – infections, skin conditions and immune diseases, for example – can cause lymph nodes to swell.

It can be difficult to get the right balance between monitoring your health and worrying unnecessarily over minor symptoms. However, it is a good idea to be aware of what to look out for if your lymphoma does relapse.

If your lymphoma relapses, it might come back where it was before or it could affect another part of your body. You might notice new, or bigger, lumps. You might get more general symptoms (for example, fevers, night sweats or itching – known as 'B symptoms'). Signs of relapse also depend on what type of lymphoma you had. Your doctor should tell you what to look out for.



Symptoms to look out for

Contact your medical team if you have any of the following symptoms:

- enlarged lymph nodes lasting more than a week
- drenching night sweats
- unexplained weight loss
- worsening fatigue
- itching
- rashes (if you have skin lymphoma)
- diarrhoea
- persistent or unexplained pain.



Write down any other symptoms and signs you've been told to look out for.

Know your nodes

Lymph nodes go up and down naturally over time. Checking too frequently can cause unnecessary worry and also makes it more difficult to notice any changes in size of lymph nodes.

Try not to check your nodes too often – no more than once a month.



How to check your nodes

Get comfortable and relax. It's difficult to feel lymph nodes if your muscles are tense.

Take off any clothes you need to.

Using three fingertips, gently 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
- from the centre of your armpits down the chest wall
- the front and back borders of both armpits
- along both groin creases
- the tops of your inner thighs
- behind your knees.

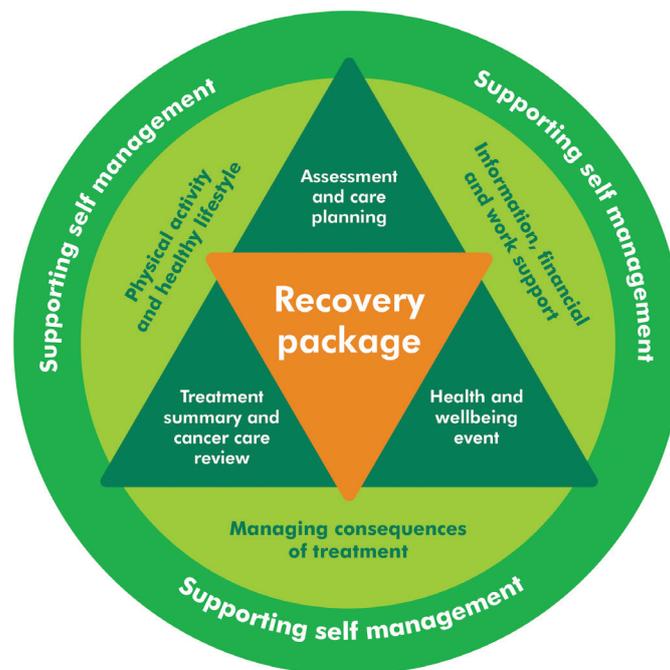
You know your body and how you normally feel. If you notice anything that you think could be a lymphoma symptom, contact your CNS or hospital clinic and ask for a check-up. If you notice anything else that is unusual for you, contact your GP.



Search 'lymph nodes' on the British Association of Dermatologists' website www.bad.org.uk to download or print an illustrated leaflet on how to check your lymph nodes.

The recovery package

When your treatment ends, you might be offered the recovery package. This is a combination of strategies to identify your individual needs, help you prepare for the future and support you to live well after treatment. It is being rolled out across the NHS and should be available to every person with cancer by 2020.



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Figure: The recovery package

The recovery package should include:

- an assessment to identify your physical, emotional and social needs
- a treatment summary
- a cancer care review to discuss your medical and financial needs, support services, and the possible late effects of your lymphoma and its treatment
- a health and wellbeing event, such as Lymphoma Action's Live your Life workshops.

If you would like a treatment summary and you haven't received one, ask your medical team for one.



For more information, search recovery package at Macmillan Cancer Support's website www.macmillan.org.uk or talk to your medical team.

Follow-up appointments

Follow-up appointments aim to monitor your recovery from treatment, check for any signs of recurrence and monitor any late effects you may be at risk of. How often you have appointments depends on your hospital's usual practice and the type of lymphoma you have.

Your follow-up appointments may involve:

- a discussion about how you're feeling, in particular, whether you've noticed any signs of recurrence, how you're coping with side effects, and any late effects of treatment you're concerned about
- a physical examination
- blood tests (not necessarily at every appointment).

CT scans or PET scans are not usually necessary unless your doctor suspects your lymphoma is growing. They do not detect relapse any earlier than a clinical review and they expose you to unnecessary radiation.

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



Getting the most out of your appointments

- Write down any questions you have so you don't forget them.
- Think about taking a friend or family member with you.
- Take notes or ask your doctor or nurse to write information down.
- Don't be afraid to talk about how you're feeling emotionally.
- Take something to pass the time in the waiting room.



Note down any questions for your medical team.

Useful organisations

Cancer Research UK provides comprehensive information on all types of cancer. Call **0808 800 4040** or visit **www.cancerresearchuk.org**

Citizens Advice provides free, independent and confidential advice on benefits, housing, consumer and other problems. Call **03444 111 444** (England), **03444 77 20 20** (Wales) or visit **www.citizensadvice.org.uk**

CLIC Sargent provides specialist support for children and young people with cancer and their families. Call **0300 330 0803** or visit **www.clicsargent.org.uk**

Depression UK is a self-help organisation for people with depression. Visit **www.depressionuk.org**

Drinkaware is an independent charity that helps people make better choices about drinking. Call **0300 123 1110** or visit **www.drinkaware.co.uk**

Macmillan Cancer Support provides support and information for people with all types of cancer. Call **0808 808 00 00** or visit **www.macmillan.org.uk**

Maggie's Centres provide free support for people with cancer and their family and friends. Call **0300 123 1801** or visit **www.maggiescentres.org**

Mind provides advice and support to anyone experiencing a mental health problem. Call **0300 123 3393** or visit **www.mind.org.uk**

Moodjuice offers information, advice and self-help resources to people experiencing troublesome thoughts, feelings and actions. Visit **www.moodjuice.scot.nhs.uk**

NHS Choices provides comprehensive health information to help you make the best choices about your health and lifestyle. Call **111** or visit **www.nhs.uk**

NHS Smokefree provides motivation, information and support for smokers who want to quit. Call **0300 123 1044** or visit **www.nhs.uk/smokefree**

Shine Cancer Support offers support for adults in their 20s, 30s and 40s who have a cancer diagnosis. Visit **www.shinecancersupport.org**

The Mental Health Foundation is a UK charity that helps people understand, protect and sustain their mental health. Visit **www.mentalhealth.org.uk**

The UK Government information service outlines what benefits you might be entitled to and how to claim them. The enquiry line is no longer available. Visit **www.gov.uk**

Working with Cancer is an organisation that helps people with cancer get back in to work or to find work. Visit **www.workingwithcancer.co.uk**

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 expert for her assistance with this booklet:

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References

These are some of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at publications@lymphoma-action.org.uk or phone on 01296 619409 if you would like a copy.

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About our information

Lymphoma is a complex type of cancer. Our award-winning information and publications can help you better understand your diagnosis, treatment and life beyond lymphoma.

Lymphoma Action's booklets give information on broad topic areas (for example they might cover all low-grade non-Hodgkin lymphomas and the types of treatment often given). They are professionally printed and bound and most are A5 size.

We offer our lymphoma information to you free of charge (UK only). If you live outside the UK, we recommend that you contact the lymphoma patient and carer organisation in your country as treatments and healthcare systems vary overseas. You can find a list of which organisations might be of help in your country on the Lymphoma Coalition website www.lymphomacoalition.org.

Lymphoma Action is committed to the provision of high quality information for people with lymphoma, their families and friends. We produce our information using nationally recognised guidelines, including the DISCERN tool for information about treatments, the NHS Toolkit for producing patient information and the Campaign for Plain English guidelines. Lymphoma Action is a certified member of The Information Standard independent quality assurance scheme, which is supported by the Department of Health.

Our publications are written by experienced medical writers, in close collaboration with medical advisers with expertise in the appropriate field. The most relevant references are listed in the publication. A full list of sources is available on request.



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



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



Get in touch with a buddy, someone affected by lymphoma



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



Like us on Facebook



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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 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.



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

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Check our website for the most up-to-date details of our services, including opening times.



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

We would like to thank our incredible supporters whose generous donations enable us to offer all 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. From everyone at Lymphoma Action and on behalf of those affected by lymphoma, thank you.

To get involved in fundraising for us or to make a donation towards our work please visit www.lymphoma-action.org.uk/Donate

This workbook complements the Live your Life workshop. It provides practical advice and information about living with and beyond lymphoma and has space for you to record information about your own lymphoma experience.

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



Helpline freephone **0808 808 5555** (Mon to Fri, 10am to 3pm)



Email **information@lymphoma-action.org.uk**



Visit **www.lymphoma-action.org.uk**



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Lymphoma Action
PO Box 386
Aylesbury
Bucks HP20 2GA
General enquiries 01296 619400

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