

Live your Life

Living with and beyond lymphoma



About this book

This booklet is for people who are living with and beyond lymphoma. It is divided into chapters that correspond with the modules of the Live your Life workshop. The final chapter covers additional practical information about living with and beyond lymphoma.

The booklet includes:

- summaries of important information
- tips on dealing with some of the common effects of lymphoma and its treatment, and finding your 'new normal'
- space for you to record your own notes and experiences
- sources of further information and support.

You can dip in and out of the booklet and read only the sections relevant to you at any given time.

Important and summary points are in the chapter colour.



Lists practical tips.



Space for questions and notes.



Lists other resources you might find relevant.

The information in this booklet can be made available in large print.

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Lymphoma Action have been such an instrumental support network to me throughout my diagnosis and treatment journey in many ways, but particularly the invaluable information available which helps make sense of the disease and treatment process.

Jayne, diagnosed with follicular non-Hodgkin lymphoma

Introduction

We know that finding your 'new normal' after a lymphoma diagnosis or after finishing treatment for lymphoma can be difficult.

We hope you found the Live your Life workshop useful and informative. This booklet is designed to summarise the topics covered in the workshop and point you to sources of further help and support.

Live your Life workshops are delivered by Lymphoma Action. For over 30 years we've been informing, supporting and connecting people affected by lymphoma. If you are living with lymphoma, you can count on us to support you and your family from diagnosis, through treatment and beyond. We offer:

- **Information and Support team:** A knowledgeable and friendly team trained to provide a listening ear to you and your loved ones.
- **Support groups:** Meet people in your area who've been affected by lymphoma – whether as a patient, a friend or a family member.
- **Buddy support:** We can connect you with someone who has a personal experience of lymphoma and understands what you're going through.
- **Community forums:** Connect to other people affected by lymphoma any time of the day online – ask questions, read other people's experiences and share yours.
- **Information you can trust:** Our expert-reviewed information and publications can help you better understand your diagnosis, treatment and life beyond lymphoma.
- **Lymphoma TrialsLink:** Find out more about clinical trials and search for a trial that might be suitable for you.
- **Lymphoma Matters:** Our regular magazine, packed with useful information, the latest lymphoma news and personal stories.

We're here for you.



Get in touch today to see how we can help you.

- **Call our Information and Support team free on 0808 808 5555**
- **Visit our website: www.lymphoma-action.org.uk**
- **Like us on Facebook**
- **Follow us on Twitter**
- **Check out our YouTube channel**
- **Follow us on Instagram**



Your lymphoma type and stage

Your treatment



Use this space to record contacts so you can find them easily.

Health professional	Name and contact details
GP	
Consultant haematologist or oncologist	
Clinical nurse specialist or key worker	
Treatment centre/clinic reception	
Hospital out-of-hours number	
Hospital ward	
Support group coordinator	



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

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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.

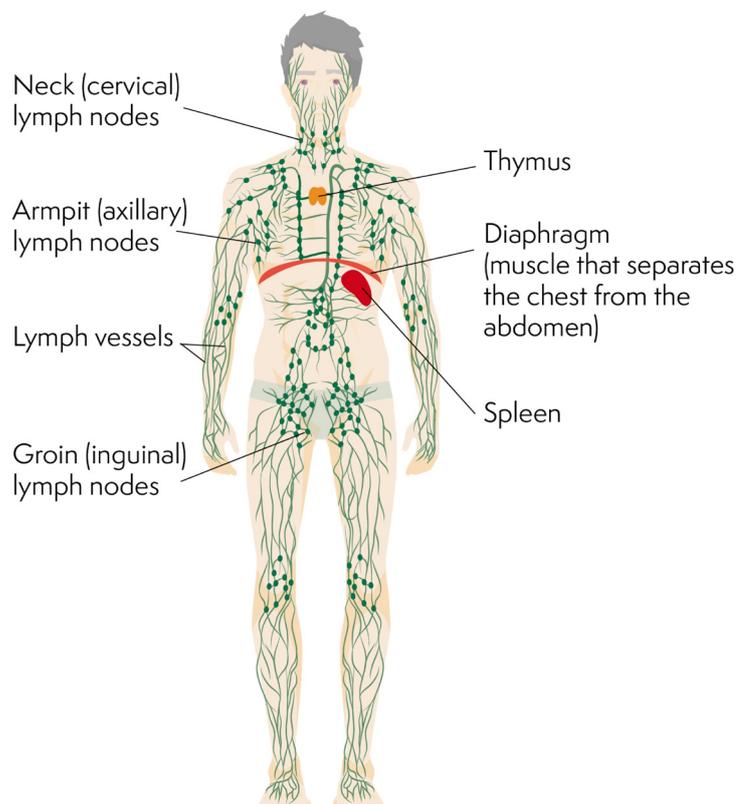


Figure: The lymphatic system



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.

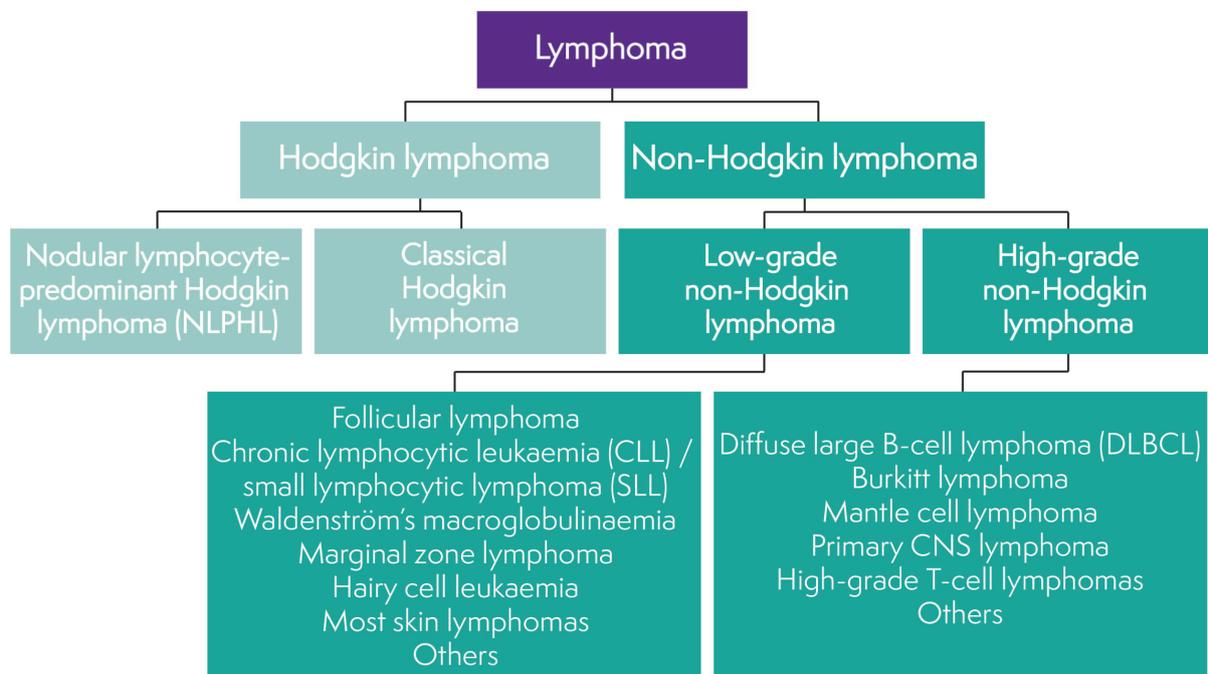


Figure: The main types of lymphoma

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.

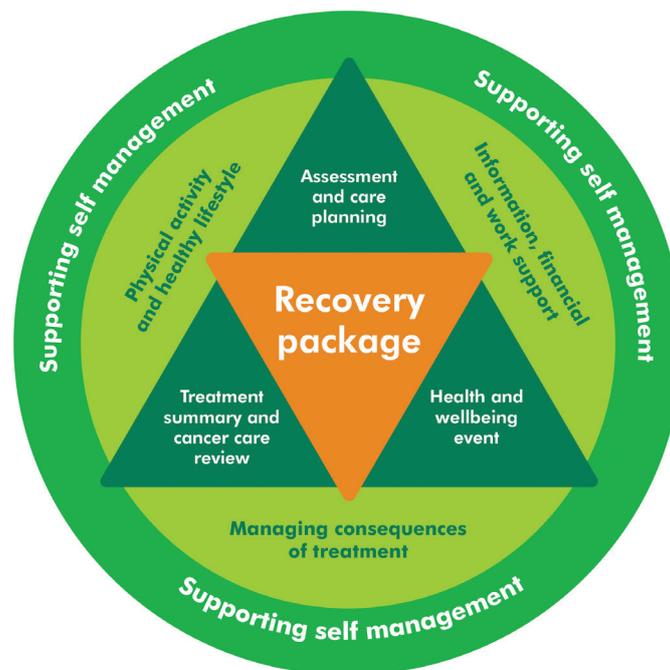
You know your body and how you normally feel. If you notice anything that you think could be a lymphoma symptom, contact your CNS or hospital clinic and ask for a check-up. If you notice anything else that is unusual for you, contact your GP.



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.



The Live your Life workshop provided a safe space for me to talk about my feelings with other people who understood how I was feeling and what I was going through – other people who speak the ‘lymphoma language’. Most important for me was being able to recognise and accept those feelings in a safe environment and discuss with others the different ways in which I could move on and find a new normal.

Dorothy, diagnosed with follicular lymphoma





Chemotherapy and maintenance treatment took its impact on my energy and wellbeing. I found myself in an emotional, dark and lonely place. It was at this crucial point, some 18 months after my initial diagnosis, that I realised I needed to put my hand up and ask for help and could not fight this battle alone. In many ways I was grieving for the person I was before cancer.

Simon, diagnosed with stage 4 nodal marginal zone lymphoma

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**Use this space to transfer your notes from Module 2
of your Live your Life workshop**



Action plan

Action	How often
<i>Example: Try mindfulness</i>	<i>Once a week going forward</i>

If I am concerned about how I'm coping or need extra support, I will talk to:

Name (family, friend or health professional)	Contact details

Your feelings

People respond differently to a diagnosis of lymphoma. It's not unusual to feel differently at various times, even within a single day. You might feel especially low at certain times during your experience of lymphoma, such as:

- when you are first diagnosed
- if you are put on active monitoring (watch and wait)
- at the start of treatment
- at the end of treatment
- before follow-up appointments
- if your lymphoma relapses.

There isn't a 'normal' way to feel, but some of the emotions you might experience are shown below.



Use the figure above to write down any other feelings you've experienced since having lymphoma.



It might be useful to track your mood on a chart or diary to help you identify things that make you feel worse and things that help you feel better.

Date	Mood score (1=worst; 10=best)	Comments
<i>Example: 16th May</i>	4	<i>Felt anxious after yesterday's blood tests</i>



- For more information on the emotional impact of living with lymphoma, search 'emotions' at www.lymphoma-action.org.uk or call our Information and Support team on 0808 808 5555.
- Macmillan Cancer Support have a range of resources and forums on feelings after cancer. Search 'emotions' at www.macmillan.org.uk
- NHS Choices offers an online mood self-assessment tool. Search for it at www.nhs.uk
- There are lots of different mood tracker apps available. Search for one that's suitable for your mobile phone.
- Find your nearest support group at www.lymphoma-action.org.uk/SupportGroups. Your nurse specialist may also be able to direct you to cancer support groups in your area.
- Use our forum to connect with others affected by lymphoma: www.lymphoma-action.org.uk/Forum

Depression

Depression is a very common experience for people with lymphoma. It does not mean you are weak. You cannot just 'shake it off' or 'pull yourself together'; depression is an illness. It is normal to need support, just as you would for a physical illness.

Depression can affect people in different ways. You may feel:

- anxious, sad or 'empty'
- hopeless, helpless and pessimistic
- guilty or worthless
- a loss of interest or pleasure in activities that you once enjoyed
- that you want to harm yourself, which might include thoughts of suicide
- that you are unable to concentrate, remember things or make decisions.

You might also have physical symptoms of depression, which can include:

- unexplained aches or pains
- loss of, or increased, appetite
- sleeping more or less than usual
- slow movement or speech
- loss of sex drive.

If you have had depression in the past, you may be more likely to experience it after a diagnosis of lymphoma.

Speak to your doctor, nurse or GP if you think you may be depressed.



Write down who you feel comfortable talking to if you're feeling low.



- **NHS moodzone offers practical advice and interactive tools, videos and audio guides on stress, anxiety and depression. Visit www.nhs.uk/conditions/stress-anxiety-depression**
- **Mind has further information and support, including online forums, for people experiencing depression. Visit their website www.mind.org.uk**
- **You can also search for a depression support group on the Depression UK website www.depressionuk.org**
- **If in crisis, please contact the Samaritans on 116 123.**

Coping with difficult feelings

Having lymphoma is challenging. There is no simple way of preparing for the range of emotions you might experience. You can, however, find ways to live well with lymphoma. Acknowledge how you feel and ask for the help you need. Counsellors, your medical team, your family and friends can all be a source of support. Just as you would use a crutch if you broke your leg, it is OK to need support if you are struggling emotionally.



Tips for coping with difficult feelings

- Express your feelings. You could try:
 - speaking to a counsellor
 - talking to family and friends
 - writing down your thoughts and emotions.
- Make relaxation and enjoyment a priority. For example:
 - do things you enjoy
 - consider complementary therapies.
- Consider what you are able to control. You might find it helpful to:
 - learn more about lymphoma
 - make healthy lifestyle choices
 - set daily and weekly routines
 - choose what information to share and who to share it with.
- **Do what feels right for you.**



Write down things that help you cope with your feelings.



- Macmillan Cancer Support have a booklet called *Talking about your cancer*, which you may find helpful. Find it at www.macmillan.org.uk
- Our Information and Support team may be able to connect you with someone with a similar experience. Call 0808 808 5555 or visit www.lymphoma-action.org.uk/Buddy

Stress

Living with lymphoma can be very stressful. Stress can have psychological effects, such as worry and anxiety, difficulty concentrating, irritability, sleeplessness and difficulty relaxing. It can also cause physical symptoms such as increased heart rate, headaches, muscle tension, dizziness, loss of appetite and nausea.



Tips for managing stress

- Try to identify things that trigger your stress and get rid of any you can.
- Set aside time for your hobbies.
- Try relaxation techniques like breathing exercises, meditation or mindfulness.
- Try complementary therapies such as massage, acupuncture or aromatherapy.
- Look after yourself: eat well and exercise regularly.
- Be kind to yourself.



Use the figure above to write down your stressors and work out which ones you can do something about.



Moodjuice has information and tips on managing stress, sleep problems, anxiety and depression at www.moodjuice.scot.nhs.uk

Relationships

Having lymphoma can put pressure on your relationships: some may become strained while others may become closer. As well as coping with your own feelings, you may feel pressure to deal with the emotions of family and friends.

People with lymphoma often say they feel other people don't understand them. You might have a sense that others expect you to get back to 'normal' soon after treatment. This can be frustrating and feel as if they have no idea what you have been through and continue to go through.

Many people with lymphoma say that others are careful not to upset them. We hear that people pretend not to see them or cross the road to avoid conversation. This is probably for fear of saying the wrong thing, but it can bring a great sense of loss and isolation. Some people find their friends react in a way they didn't anticipate: their closest friends may disappear and people they didn't expect to may make the most effort. Communication is important in maintaining relationships.



Tips on talking to your partner

- Be honest about how you feel.
- Use 'I' statements to focus on you and your feelings rather than your partner's behaviour.
- Explain what you need and how your partner can support you.
- Don't be afraid to discuss sexual intimacy.

Tips on talking to children

- You know your child best; trust your intuition.
- Be as specific and honest as possible.
- Use language your youngest child can understand.
- Talk to them about any changes to their day-to-day life.

Tips on talking to friends and colleagues

- Let people know how they can support you.
- Reassure them they don't need to feel pressured to say the 'right thing'.
- Consider asking someone to be a key contact to pass on information, or use social media to update a lot of people quickly.
- Instead of explaining lymphoma yourself, direct people to Lymphoma Action's website so they can learn more for themselves.

Mental wellbeing

Mental wellbeing describes your mental health and your ability to cope with the stress of day-to-day life. It includes:

- confidence
- self-esteem
- contentment and enjoyment
- maintaining relationships
- engagement with the world around you
- productivity
- dealing with stress.

There are five steps we can all take to improve our mental wellbeing.

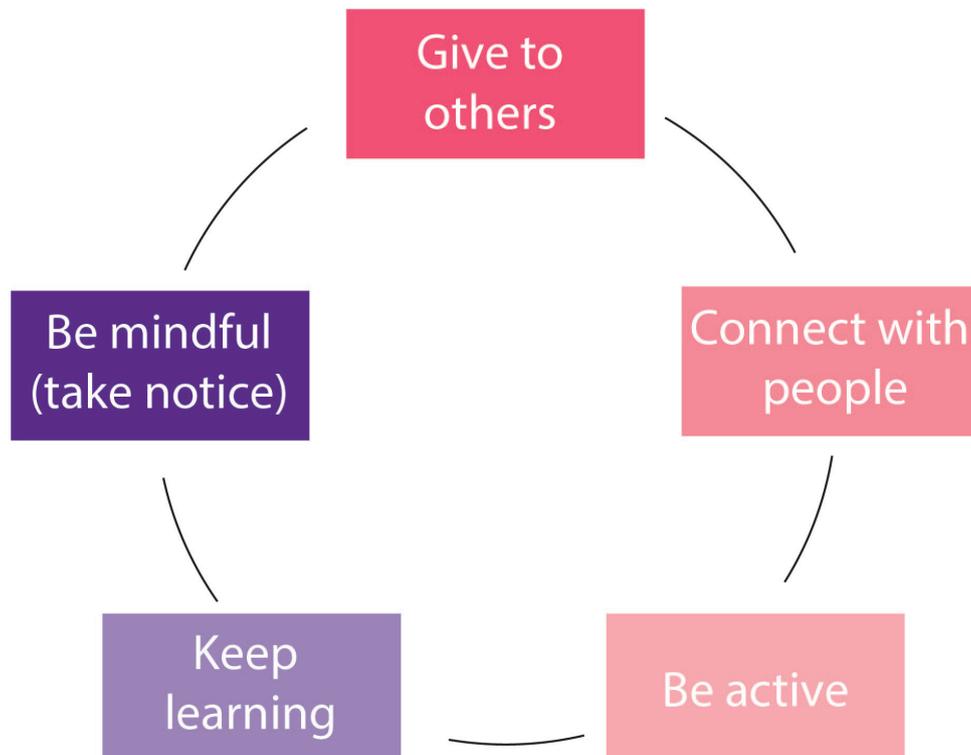


Figure: The circle of wellbeing



- For more information on the five steps to mental wellbeing, visit the NHS Choices website www.nhs.uk
- Mind also has more information on mental wellbeing, including tips on how to improve it, at www.mind.org.uk

Mindfulness

Mindfulness is a popular type of meditation. It encourages you to slow down and pay attention to the present – including the physical sensations you experience, your breathing and the world around you. Many people find that mindfulness helps them to manage stress and anxiety by allowing them to take control of thoughts before they become all-consuming.

You can be more mindful in your everyday life just by slowing down and noticing things around you, like sounds, smells and the feeling of a fabric or breeze against your skin.



Tips on how to be more mindful

- Try practising mindfulness at the same time each day.
- Take time to notice sensations, smells, sounds, tastes and sights.
- Visualise your thoughts: if your mind is too busy to focus on mindfulness, try to picture your thoughts physically leaving your mind.
- Label thoughts and feelings: identify how you feel and name the feeling.
- Focus on the present: try not to relive the past or worry about events in the future that might not happen.



Make a note of things you'd like to try to improve your mental wellbeing.



- Visit Headspace at www.headspace.com to download a meditation app or sign-up for free online meditation tools.
- Download the free Smiling Mind mindfulness app or search for their YouTube channel to watch a series of mindfulness videos.
- Find out more about mindfulness on the Mental Health Foundation website www.mentalhealth.org.uk, including a 10-minute mindfulness exercise.



I was really weak and exhausted after I finished chemotherapy so I started going for a short walk every day to give my days some structure and get me out of the house! I found getting and staying active really helped rebuild my health and fitness, make new friends, and manage some of the emotional fallout from diagnosis, treatment, and side effects. Sometimes it's difficult to know how to start being active but the Live your Life events have some great information and advice about exercise – and it's all based on the experiences of people who've been affected by lymphoma so I know I can trust it!

Freya, diagnosed with diffuse large B-cell lymphoma





It was so helpful focusing on setting and implementing personal goals to help maintain a healthy life, living with lymphoma. It was also an opportunity to consider and reflect on how lucky we are to be able to live a full life with this malignancy, something I never thought would be the case in the very early days of diagnosis.

Jayne, diagnosed with stage 4 follicular lymphoma

Module 3: Exercise and staying active

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**Use this space to transfer your notes from Module 3
of your Live your Life workshop**



Action plan

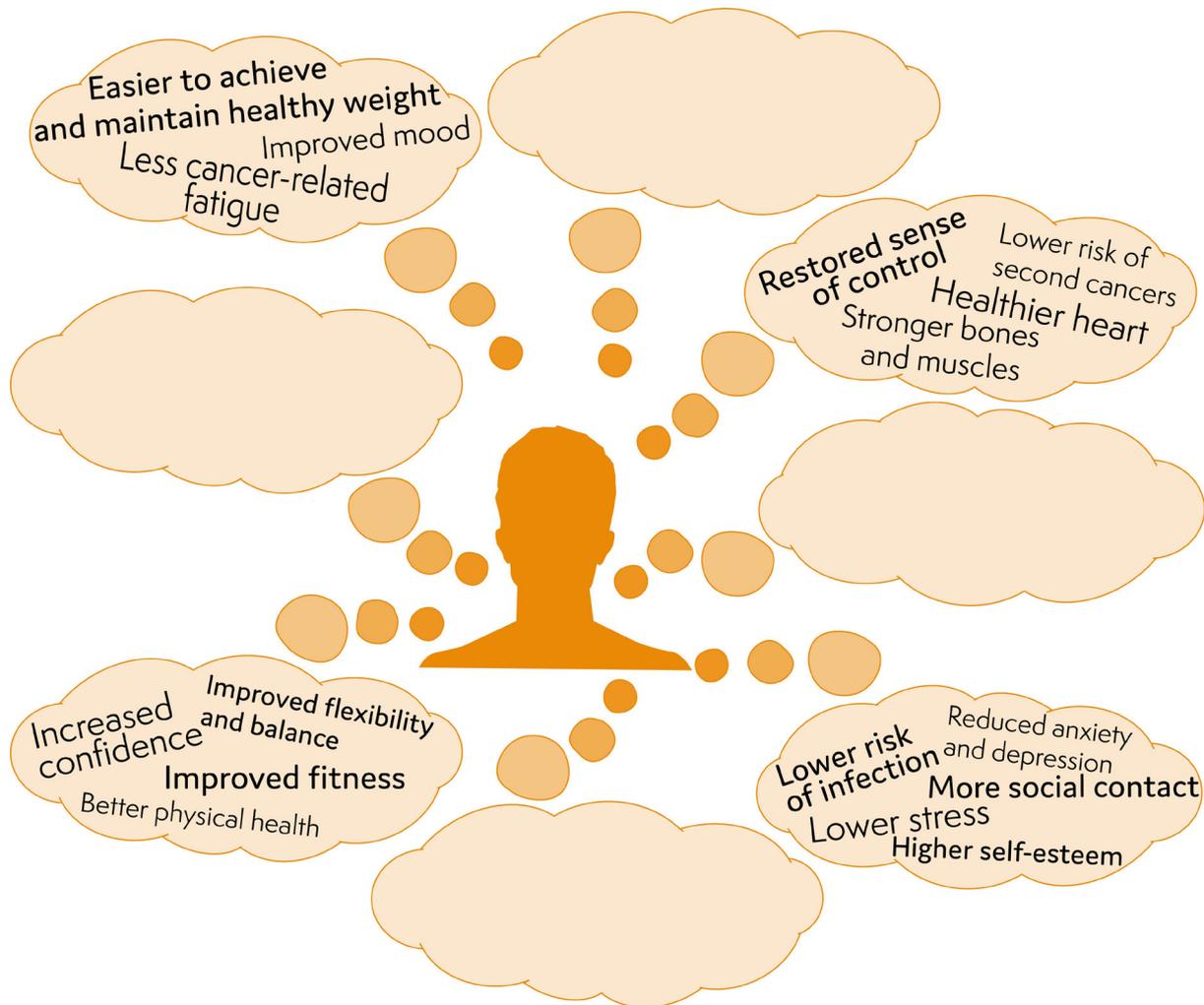
Action	How often
<i>Example: Research and join a local dance class</i>	<i>Once a week</i>

Things I'm going to check with my medical team before exercising:

What I'm going to check	Who I'll check with	When I'll check

The benefits of exercise

Exercise has the same benefits for people with lymphoma as it does for anyone – plus some additional benefits related to the effects of cancer and its treatment.



Use the figure above to write down any other benefits of exercise or activity you can think of.



Macmillan Cancer Support has more information on the benefits of being active before, during and after treatment for cancer at www.macmillan.org.uk

Exercise guidelines

In general, people who have lymphoma should aim to take the same amount of exercise as people who are well. For adults, the current recommendation is:



* Recommended for people over 65 years old.

If you prefer, you can swap 30 minutes of moderate exercise for 15 minutes of vigorous exercise – or do a mix of both. Your exercise schedule should take into account your overall fitness, treatment, and other factors that could affect your safety.

Speak to your medical team about the type and intensity of exercise that is safe for you.

Moderate exercise	Vigorous exercise	Strength exercises	Coordination and balance exercises
<ul style="list-style-type: none"> • Mowing the lawn • Vacuuming • Brisk walking • Gentle cycling • Dancing • Aqua aerobics • Hiking • Golf 	<ul style="list-style-type: none"> • Climbing stairs • Jogging or running • Aerobics • Fast swimming • Hard cycling • Football • Tennis • Rugby • Hockey • Martial arts 	<ul style="list-style-type: none"> • Digging the garden • Carrying shopping • Yoga • Chair aerobics • Push-ups • Sit-ups • Resistance band training • Weight training 	<ul style="list-style-type: none"> • Tai chi • Yoga • Pilates

- Search 'physical activity guidelines' at www.gov.uk for the Government's recommendations on exercise for different age groups.
- Search 'exercise guidelines' at www.cancerresearchuk.org to find out more about exercise after a diagnosis of cancer.

Planning your exercise

It is beneficial to exercise during and after treatment for lymphoma, but remember that you might be able to do less than you did before. Build in regular breaks and give yourself enough time to recuperate after exercise.

Exercise needs to be tailored to you, not just with regards to your lymphoma, but to any other conditions you might have as well. For example, if you have a heart condition, you should avoid over-vigorous exercise; if you have osteoporosis, you need to avoid high impact exercise and contact sports. Some of the side effects of lymphoma and its treatment might also affect the type of exercise you can do.

You might want to talk to your GP for advice before starting a new exercise programme.



Precautions

- If you're anaemic, you'll get tired and short of breath more easily than usual. Take this into account when you plan your exercise schedule.
- Peripheral neuropathy can affect your balance, coordination and your ability to feel injuries such as blisters. Choose activities with a low risk of falls or injury.
- Avoid high-impact sports if you have a low platelet count (thrombocytopenia) to lower your risk of bruising and bleeding.
- Avoid public swimming pools and gyms if you have low immunity (for example, if you have a low neutrophil count or you've had a stem cell transplant).



Use the table below to make a note of things to consider when planning your exercise programme.

Activities that are suitable for me	Precautions I need to take	Signs I should slow down or stop

Getting started

It can be daunting to think about exercise when you're recovering from a lymphoma diagnosis or treatment. It's important to remember that every little helps. You could start by making small changes to your lifestyle to help you be more active.



Tips on being more active

- Cut down the time you spend sitting down.
- Break up sedentary time with regular walk breaks.
- Take the stairs instead of a lift or escalator.
- If you can, cycle or walk instead of driving or getting the bus.
- If you're going further afield, get off the bus a stop early or park a bit further away than usual and walk the rest of the way.

The key thing is to 'find your level': the amount of exercise you can do without feeling exhausted. You can build up from this over time.



Tips on exercising

- Try to do some physical activity every day.
- Choose activities that you enjoy.
- Make it convenient – slot exercise into your daily routine.
- Start at a level that's appropriate for you.
- Increase your activity level gradually.
- Alternate activity and rest to allow your body to recuperate.



Use the table below to write down activities that you already do, however small, and think about how you can build upon them.

Activity	How I can build upon it
<i>Example: Mow the lawn once a week</i>	<i>Rake up the cuttings afterwards</i>

Staying motivated

It's easy to start out with good intentions but it can be difficult to keep the momentum going. It's important to make a positive commitment to staying active, either by putting it in writing or by telling people what you're going to do.



Tips on staying motivated

- Set realistic goals that aren't too daunting. Break long-term goals into a series of manageable, shorter-term goals.
- Share your goals with people who will encourage you to achieve them.
- Track your progress – for example, with a wearable fitness tracker, an app, an online tool or an exercise diary.
- Exercise with friends or family or join an exercise class where you can support each other – and where you'll be missed if you don't attend.
- Be flexible: if you're too busy or too tired to exercise, give yourself a break and get back on track as soon as you can.
- Reward yourself and enjoy the positive feelings exercise gives you.



- **Some hospitals, community centres, cancer centres and sports centres run exercise programmes specifically for people with cancer. Your CNS may be able to give you information on groups near you.**
- **Maggie's Centres offer a range of exercise options for people with cancer. Search for your nearest centre at www.maggiescentres.org**
- **Search 'exercise' at www.trekstock.com for information about how to continue to be active after you've been diagnosed with cancer.**
- **Walking for Health is a network of health walks with over 375 schemes across England. Find one near you at www.walkingforhealth.org.uk**
- **Visit www.beinspireduk.org/play for information and advice on how to get started in a wide variety of different sports and activities.**
- **Search 'exercise' at www.nhs.uk for information about exercise and health, including a variety of exercise plans and home fitness routines.**
- **Visit the NHS One You website for free tips, tools and support on getting healthier and more active: www.nhs.uk/oneyou**
- **There are many fitness apps tailored to different sports and devices. Search on your mobile for one that suits you.**



Ah food! It was wonderful when my appetite returned after chemotherapy and radiotherapy. I had lost a stone and a half during treatment and was still a bit of a 'reluctant' eater. The Diet and nutrition module covers the current guidelines on what to eat and drink. I still use my mental picture of the Eatwell Guide to help plan my daily meals. I do believe eating healthily has been a major factor in my recovery after treatment.

Gill, in remission and enjoying life after stage 4 follicular lymphoma





The Live your Life workshop allowed us all to explore and reflect on our diet before, during and after cancer treatment. The information on the Eatwell Guide gave me a great insight into how much diet has changed and the balance required for healthy eating.

Laura, diagnosed with diffuse large B-cell lymphoma

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Use this space to transfer your notes from **Module 4** of your **Live your Life** workshop



Action plan

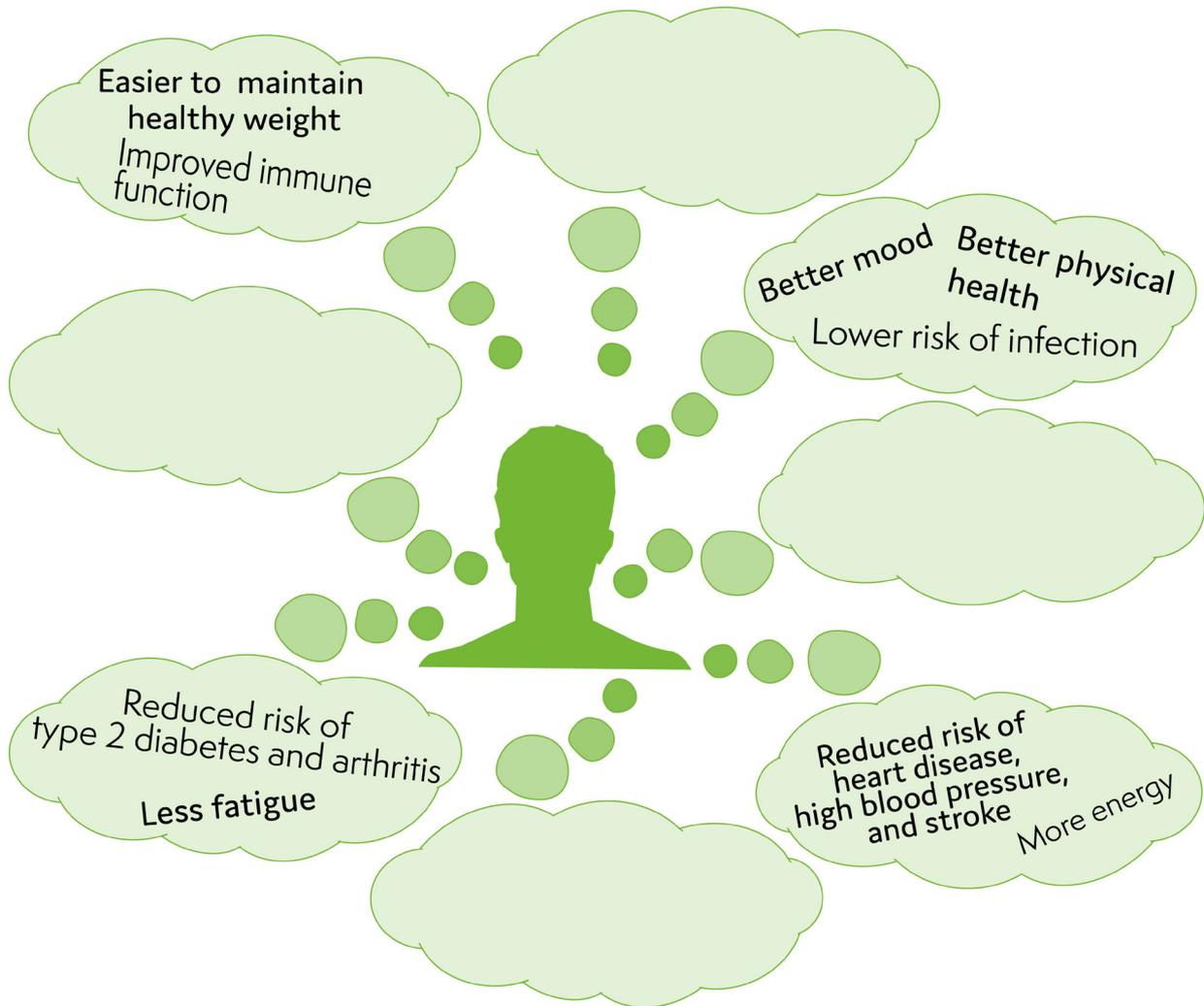
Action	How often
<i>Example: Eat 5 portions of fruit and vegetables</i>	<i>Every day</i>

People who can support me:

Who I'd like support from	How they can support me

The benefits of a healthy diet

A balanced diet is essential for good health. Although there are no foods that can cure lymphoma, eating well can help you to cope with treatment and support your recovery. A healthy diet is just as important once you complete your treatment for lymphoma as it is during treatment. The benefits of good nutrition include:



Use the figure above to write down any other benefits of a healthy diet you can think of.

What is a healthy diet?

A healthy diet is made up of different food groups.

- **Fruit and vegetables** are good sources of vitamins and minerals. Vitamins and minerals help keep your immune system, bones, teeth and skin healthy.
- **Potatoes, bread, rice, pasta and other starchy carbohydrates** are your body's main source of energy.
- **Beans, pulses, fish, eggs, meat and other proteins** are important for your body to grow and repair. You may need more protein than usual to help your body heal during and after treatment for lymphoma.
- **Dairy and dairy-alternatives** provide calcium (important for bone health), zinc (a mineral with various functions, including helping wounds heal) and protein.
- **Oils and spreads** are a source of energy and provide useful vitamins.

Fibre helps to keep your heart healthy and your digestive system working well. Although it is not classed as a separate food group, you should aim to eat 30g of fibre each day. It is found in foods that come from plants, for example fruits, vegetables, cereals and potatoes.

The Eatwell Guide shows what proportion of each food group should make up your daily diet.

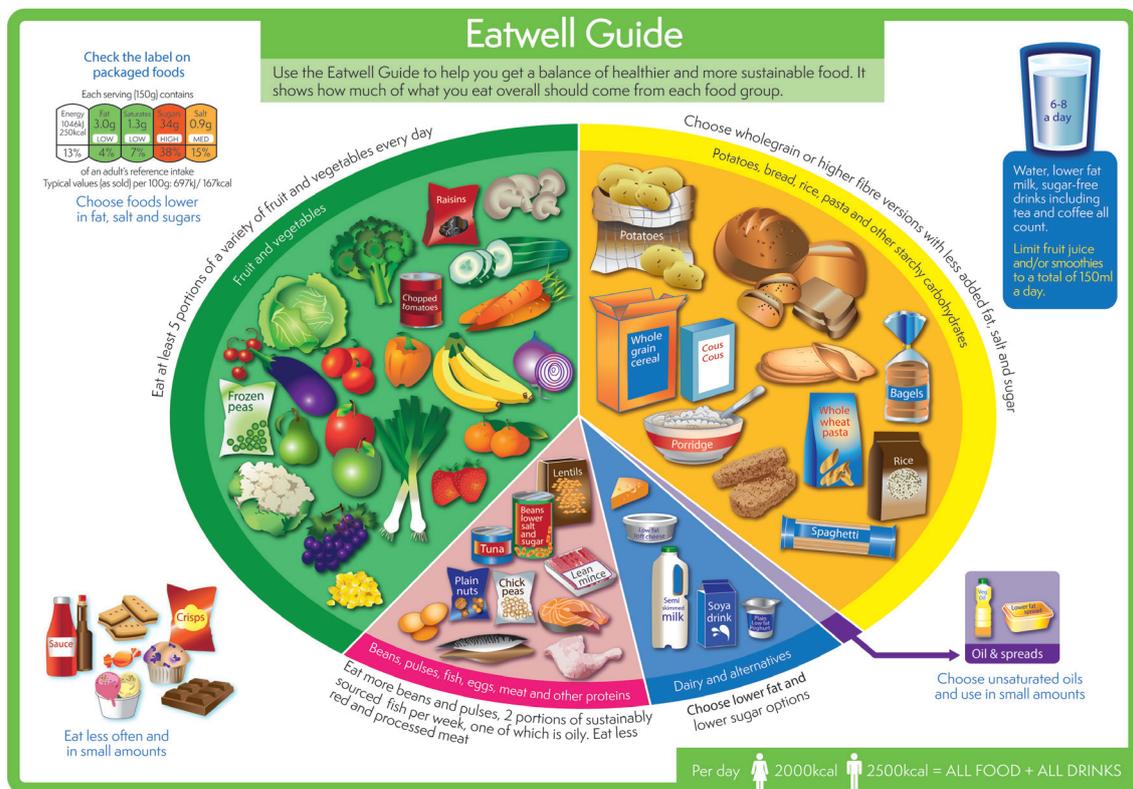


Figure: The Eatwell Guide

Eating with and beyond lymphoma

If you struggle to eat and drink during treatment for lymphoma, you may need to alter your diet to help you get enough calories. This might include dietary supplements, fortified foods or foods high in protein and fats. Your medical team can give you advice or refer you to a dietitian for support tailored to your individual nutritional needs.

If your treatment has ended, your appetite is good and your weight is normal, you should follow the same dietary recommendations as people without lymphoma.

If you are neutropenic, ask your medical team for advice about which foods to avoid and what precautions to take to help prevent infection.



Tips on maintaining a healthy diet when you are well

- Make changes to your diet gradually.
- Set realistic goals and track your progress.
- Swap unhealthy snacks for fruit or vegetable sticks.
- Swap full-fat dairy products for lower fat alternatives.
- Reduce your portion size.
- Give yourself time to register if you're full before taking second helpings.



- Search 'healthy living after cancer' at www.wcrf-uk.org to download a printable guide on healthy choices for people with and after cancer.
- Search 'healthy eating' at www.macmillan.org.uk for dietary advice and recipe ideas specifically tailored for people with cancer.
- Search 'eating well' at www.royalmarsden.nhs.uk for information about nutrition for people with cancer, including advice on how to deal with common difficulties related to eating.
- Search 'food controversies' at www.cancerresearchuk.org to find the scientific facts about foods that are alleged to increase or decrease the risk of cancer.
- Search 'cancer myths' at www.cancer.gov for information on common cancer myths and misconceptions.
- Talk to your CNS about being referred to a dietitian if you would like help with your diet.



Use this food diary to record your typical weekly diet.

	Breakfast	Lunch	Dinner	Snacks	Drinks
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

Healthy weight

Body mass index (BMI) is a measure of your weight in relation to your height.

If you lost weight during treatment, your BMI may be below the healthy range. This increases your risk of immune system problems, nutritional deficiencies, fertility issues and fatigue. Try to gain weight gradually to a healthy range.

A BMI above the healthy range can increase your risk of heart disease, stroke, type 2 diabetes and some cancers. Even if you have a healthy BMI, you are still at risk if you have too much tummy fat. Try to lose weight if your waist is more than 94cm (37ins) if you are a man, or more than 80cm (31.5ins) if you are a woman.

The best way to lose weight is through a combination of diet and exercise.



Tips for gaining weight if your BMI is too low

- Aim to gain weight gradually.
- Eat a healthy diet that provides the right amount of calories for you.
- Eat regular meals and occasional snacks.
- Choose healthy foods that are high in energy, such as unsalted nuts, dried fruit, full-fat dairy products and starchy carbohydrates.
- Don't rely on high-calorie foods full of saturated fat and sugar.

Tips for losing weight if your BMI is too high

- Aim to lose 1lb to 2lb a week by reducing your calorie intake.
- Be more active.
- Plan your menu: eat regular, healthy meals based on the Eatwell Guide.
- Use a smaller plate.
- Drink plenty of water and cut down on alcohol.
- Avoid junk food.



- Use the NHS online BMI calculator at www.nhs.uk/live-well
- Search 'NHS weight loss plan' at www.nhs.uk for a free, 12-week diet and exercise plan that promotes safe and sustainable weight loss.



Use this chart to record your BMI. Label each entry with the date to track your progress.

My height: _____ Healthy weight range for me: _____ .

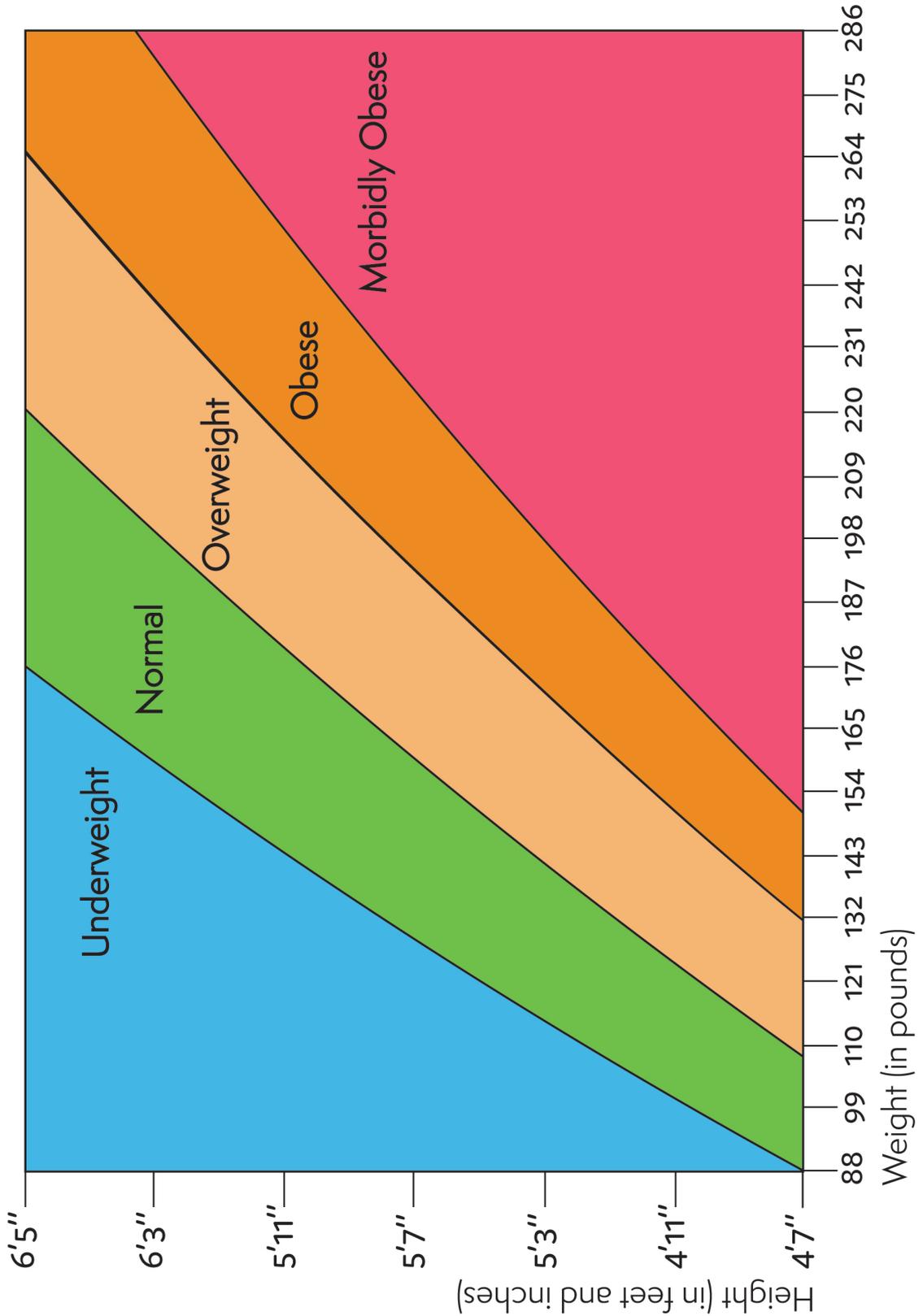


Figure: BMI chart

Alcohol

Drinking more than 14 units of alcohol a week increases your risk of weight gain, difficulty sleeping, impotence, low mood, liver disease, some cancers, heart disease and stroke. To keep these health risks low, it is safest not to drink more than 14 units of alcohol a week and to spread your units evenly over three days or more.

The guidelines are the same for men and women.

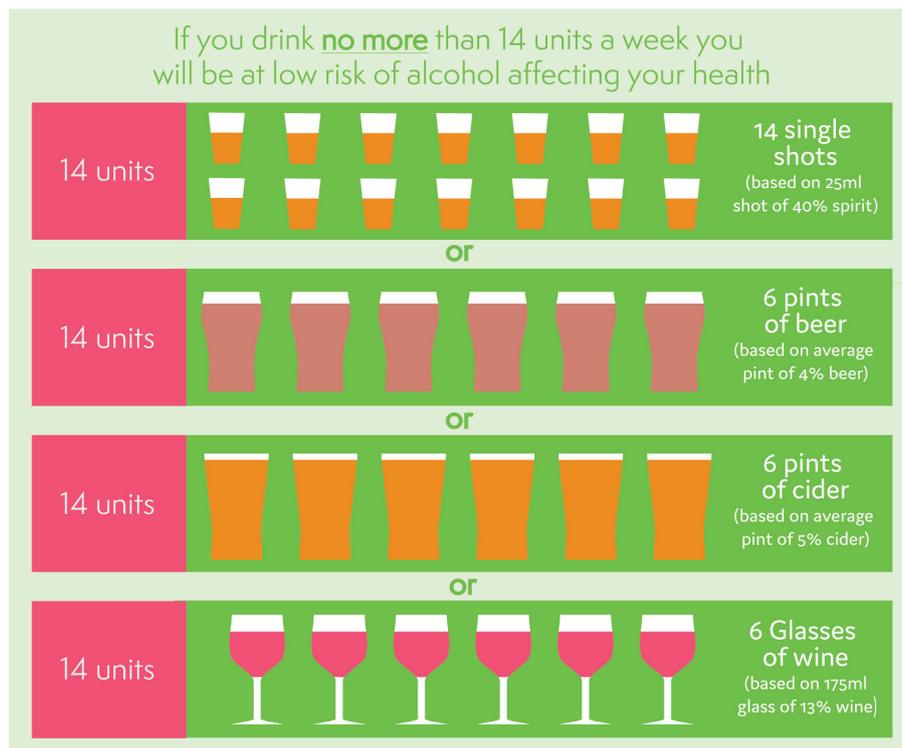


Figure: Weekly alcohol intake guidelines



Tips for cutting down on alcohol

- Have several drink-free days a week.
- On an evening out, alternate alcoholic drinks with soft drinks.
- Choose lower strength drinks.
- Swap pints for half-pints and choose smaller glasses of wine.
- Try topping-up wine with soda or beer with lemonade.



Visit www.drinkaware.co.uk for more information on alcohol and its effects, and tools and guidance on how to cut down the amount you drink.

Smoking

Smoking can slow your recovery from lymphoma and increase your risk of lung infections, second cancers and other late effects of treatment such as heart disease, lung disease and stroke. Stopping smoking reduces these risks, gives you more energy and improves your life expectancy.

Quitting smoking is hard. You're much more likely to be successful if you get help and support, either from your GP, a local Stop Smoking service or online.



Tips for stopping smoking

- Talk to your GP, join a local stop smoking service or find online support.
- Make a plan: list your reasons to quit and set a stop-smoking date.
- Tell people close to you that you're trying to quit.
- Consider using nicotine-replacement therapy or e-cigarettes.
- Find new ways to unwind.
- Avoid alcohol and other triggers.
- Keep your hands and mouth busy.
- Clear away anything that reminds you of smoking.
- **Keep trying.**



If you smoke, make a list of reasons to quit and set your stop smoking date

Reasons to quit	Stop-smoking date



- **Smokefree at www.nhs.uk/smokefree is an NHS service that provides free online, mobile, telephone and face-to-face support to help you quit.**
- **Search 'stopping smoking' on the NHS Choices website www.nhs.uk for information and advice to help you quit smoking.**
- **Search 'how to stop smoking' at www.cancerresearchuk.org for more information on the methods you can use to give up smoking.**
- **Talk to your GP or other healthcare provider about stopping smoking.**



Within a short time, I had a eureka moment. I realised I was still trying to live my old way of life, and the emotions I was feeling was a form of bereavement for that previous life. With this new perception on fighting, living and working with lymphoma, I use the knowledge and information gleaned from the workshop to create realistic personal action plans and achievable goals.

Simon, diagnosed with stage 4 nodal marginal zone lymphoma





Although many would describe my treatment as successful, life has changed. There is no point trying to 'pick up where I left off' as I am a different person both physically and emotionally. Life has changed – and, surprisingly, often for the better.

Phil, diagnosed with diffuse large B-cell lymphoma

Module 5: Practical aspects of living with lymphoma

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**Use this space to transfer your notes from Module 5
of your Live your Life workshop**



Action plan

Action	When
<i>Example: Register for screening programme</i>	

If I am worried about side effects or late effects I should contact:

Name of health professional	Contact details

Coping with side effects of lymphoma treatment

It takes time to recover after treatment for lymphoma and you might have side effects that continue after your treatment ends. Some are covered here.

Cancer-related cognitive impairment ('chemo brain')

'Chemo brain' describes changes to memory, thinking processes and concentration that affect some people with cancer. Most people get better between 6 months and 2 years after treatment ends but about 1 in 3 people have symptoms that last longer.



Tips for coping with 'chemo brain'

- Pace yourself: keep life simple and don't take on too much.
- Be organised. Do one thing at a time and don't try to multi-task.
- Put important things in one place every time you put them down.
- Write things down – in diaries, sticky notes or on your phone.
- Eat a healthy diet, exercise and keep your mind active.
- Try relaxation techniques.
- Tell your family, friends and colleagues how they can support you.

Peripheral neuropathy

Some treatments for lymphoma can affect your nerves, causing pain, loss of sensation and tingling, often in the hands and feet. This is called peripheral neuropathy. Symptoms usually get better within 6 to 12 months but they can last longer.

You may need to inform the DVLA if you have peripheral neuropathy. Ask your medical team for advice.



Tips for coping with peripheral neuropathy

- Flex, stretch and massage your fingers and toes several times a day.
- Avoid alcohol as it can affect nerve function.
- Wear gloves and thick socks in cold weather.
- Use gloves for gardening and washing up and oven gloves for cooking.
- Wear well-fitting, flat or low-heeled shoes.
- Check the temperature of baths and showers before you get in.

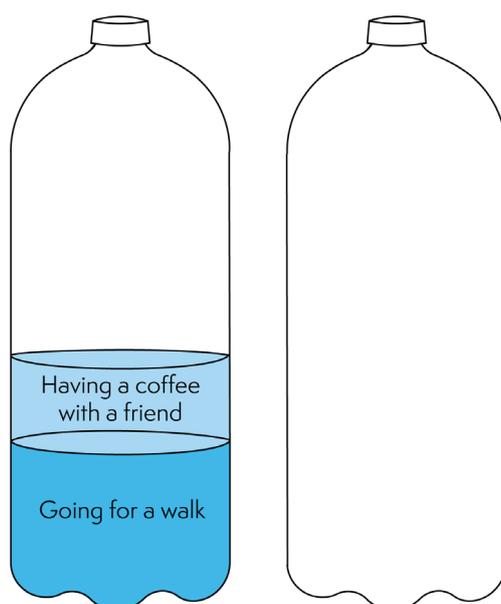
Fatigue

Cancer-related fatigue is one of the most common and troublesome effects of cancer and cancer treatment. Fatigue often lasts for months after treatment ends and it may persist for several years, although it usually gets less troublesome over time.



Tips for coping with fatigue

- Prioritise your most important activities for when you have most energy.
- Pace yourself. Don't try to do too much and plan regular short rests.
- Exercise regularly – it may seem counterintuitive but it improves fatigue.
- Eat a healthy diet.
- Try relaxation and complementary therapies.
- Keep to a regular sleep pattern.
- Ask for help when you need it.



Imagine your energy capacity for each day as a bottle. Use the diagram above to plan your day according to how much energy each activity takes.



- Visit [youtube.com/LymphomaAction](https://www.youtube.com/LymphomaAction) for videos and personal experiences about life after lymphoma.
- Search 'coping with fatigue' at www.macmillan.org.uk to download a booklet on how to deal with fatigue at work.

Late effects of lymphoma treatment

Late effects are health problems that appear months or years after treatment has finished. Your risk of late effects depends on a number of different factors, including your type of lymphoma, your treatment, your age and lifestyle. Late effects of lymphoma treatment can include:

- second cancers
- heart disease
- stroke
- lung problems
- thyroid problems
- dental problems
- eye problems.

It is important to attend all screening programmes you are called for – they are designed to pick up problems early.



Your treatment summary should tell you what late effects you're at risk of and what signs to look for. Make a note of them here.

Late effects I'm at risk of	Signs to look out for



Tips for monitoring late effects

- Get to know what is normal for you.
- Attend your follow-up appointments and screening appointments.
- Have regular check-ups with your dentist and optician.
- **If you think something is not right, visit your GP or contact your lymphoma specialist.**



For more information about side effects and late effects of lymphoma treatment, talk to your CNS, call our Information and Support team on 0808 808 5555, or search 'side effects' at www.lymphoma-action.org.uk

Early menopause and fertility

Some lymphoma treatments can reduce your fertility or cause early menopause. Your specialist should tell you if you are likely to be affected.

Early menopause can cause symptoms that are similar to lymphoma, such as night sweats or tiredness. Symptoms are more likely to be caused by menopause if you also have other symptoms of menopause, such as irregular or no periods, hot flushes or mood swings. Symptoms are more likely to be caused by lymphoma if you have other symptoms of lymphoma, such as weight loss, fever or itching.

If you're worried that your lymphoma has come back or got worse, contact your medical team straight away.

There are lots of methods to help preserve fertility, or to help you conceive if you have fertility problems. Many people go on to have a family after lymphoma treatment.

- 
- **The British Infertility Counselling Association website at www.bica.net provides information and support on infertility and assisted conception.**
 - **Find out about fertility treatment and its availability at The Human Fertilisation and Embryology Authority website at www.hfea.gov.uk**
 - **Visit www.fertilitynetworkuk.org for information, advice and support groups for people who are struggling to conceive.**
 - **Visit www.daisynetwork.org.uk for information and a friendly support network for women with premature menopause.**
 - **Visit www.menopausematters.co.uk for information on premature menopause, a forum and a list of frequently asked questions.**
 - **The British Menopause Society offers advice, reassurance and education for women of all ages at www.womens-health-concern.org**

Bone health

Some lymphoma treatments can cause bone thinning, particularly if you have experienced early menopause. To improve your bone health, follow the normal recommendations for a healthy lifestyle: eat a healthy diet, do not smoke, exercise regularly and keep to the guidelines for alcohol consumption.



Search 'bone health' at www.macmillan.org.uk for more information on how cancer and its treatment can affect your bones.

Travel

Many people plan a holiday to look forward to after treatment. It's a good idea to discuss your travel plans with your doctor before you book. Your skin could be more sensitive to sun damage for a while, so it might not be the best time to visit a very hot country.

If you're planning a trip abroad, you may need vaccinations. Some need to be given at least 8 weeks in advance so seek advice early. Your GP or local travel clinic can advise you. They can also tell you which vaccinations are safe for people with lymphoma. Live vaccines are not recommended.

Travel insurance

Travel insurance is more expensive for people with lymphoma because the insurance company considers you more likely to make a claim.

Most companies will not offer travel insurance while you are on treatment. Many will not offer cover until a set amount of time (often 12 months) after the end of your treatment. If you are on maintenance rituximab, some companies may class you as being on treatment but others may not.



Tips for finding travel insurance

- Shop around for the best deal.
- Ask other people with lymphoma who they've found insurance with – for example, on Lymphoma Action's forum: www.lymphoma-action.org.uk/Forum
- Read the small print to check exactly what your policy covers.
- Let your insurer know if your health changes before you travel.



- **For more information on travelling with lymphoma, visit our 'Living with lymphoma' pages at www.lymphoma-action.org.uk/LWL**
- **Find which vaccinations you need for your destination at the NHS Fit for Travel website www.fitfortravel.nhs.uk**
- **Search 'travel and holidays' at www.macmillan.org.uk for information, advice and booklets on travelling after cancer.**
- **Search 'travel' at www.abi.org.uk for general advice on buying and claiming on travel insurance from the Association of British Insurers.**
- **The National Travel Health Network and Centre's website www.nathnac.net also provides travel health information.**

Work and study

By law, you are entitled to 'reasonable adjustments' to allow you to continue to work or study after a diagnosis of lymphoma. This law protects you for the rest of your working life, not just while you're ill or having treatment.

Talk to your manager, HR department or education provider about any adjustments you may need. Examples of 'reasonable adjustments' include:

- reducing or changing your hours
- a phased return to your usual hours, starting with shorter days or weeks
- working from home
- adjusting the kind of work you do (for example, a less physical role)
- changes to your workplace (for example, installing a wheelchair ramp)
- special equipment or software you may need
- time off for medical appointments.

If you're at school, your school and local council should provide support, such as home tutoring or a hospital teaching service, to make sure your education doesn't suffer.

Financial support

Under the Equality Act 2010, a diagnosis of cancer meets the government's definition of disability and there's a wide range of financial support you may qualify for. Financial support can be complex so it's best to seek professional guidance.

- **Watch videos about working with and after lymphoma at www.lymphoma-action.org.uk/WAC**
- **Search 'work and cancer' at www.macmillan.org.uk for information about work and cancer for employed and self-employed people.**
- **Working with Cancer, at www.workingwithcancer.co.uk, is an organisation that helps people with cancer get back in to work.**
- **Search 'education and employment' at www.clicsargent.org.uk for information about taking time out of college for treatment.**
- **Citizens Advice have advisers you can contact by phone, online at www.citizensadvice.org.uk, by web chat or at your local centre.**
- **Click 'benefits' at www.gov.uk for information about the various government benefits that may be available to you.**
- **Your specialist nurse may also be able to help you access the support you're entitled to.**



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**



Live Chat via our website (Mon to Fri, 10am to 3pm)

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

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