

# Living with and beyond lymphoma

Coping practically, physically  
and emotionally

Feelings and emotions

Coping with symptoms and side effects

Relationships, family and friends

Self-esteem

Managing stress and anxiety

Day-to-day living

Life after treatment





This book has been researched and written for you by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We could not continue to support you, your clinical team and the wider lymphoma community, without the generous donations of our incredible supporters. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.



To make a donation towards our work, please visit [lymphoma-action.org.uk/Donate](https://lymphoma-action.org.uk/Donate)



Your lymphoma type

---

Your treatment

---

**Key hospital contact**

Name: \_\_\_\_\_

Role: \_\_\_\_\_

Contact details: \_\_\_\_\_

Job title/role	Name and contact details
GP	
Consultant haematologist/oncologist	
Clinical nurse specialist (CNS) or key worker	
Treatment centre or clinic reception	
Hospital out-of-hours number	
Hospital ward	

# About this book

If you or someone close to you has been diagnosed with lymphoma, you are not alone. Around 19,000 people are diagnosed with lymphoma each year in the UK. Whoever you are, whatever you're feeling, we're here to support you.

This book aims to help you:

- cope with difficult feelings
- manage symptoms and side effects
- handle your day-to-day life
- find further information and support.

Important and summary points are written in the chapter colour.



Lists practical tips.



Gives space for questions and notes.



Lists other resources you might find useful, some of which are online. If you do not have internet access, please contact our Helpline team (see page 174).

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

# Contents

 Feelings and emotions	7
 Coping with symptoms and side effects	35
 Relationships, family and friends	93
 Self-esteem	109
 Managing stress and anxiety	115
 Day-to-day living	129
 Life after treatment	149
 Information and support	174



**For quite a while, I was able to put my diagnosis to the back of my mind, but over time I have realised that emotionally it has affected me far more than I really acknowledge.**

Dwayne, diagnosed with mycosis fungoides, a type of skin lymphoma

# Feeling and emotions

<b>Adapting to a diagnosis of lymphoma</b>	<b>8</b>
<b>Coping with difficult feelings</b>	<b>18</b>
<b>Dealing with worries and concerns</b>	<b>24</b>
<b>Professional support</b>	<b>31</b>

# Adapting to a diagnosis of lymphoma

You are likely to go through many thoughts and emotions when you find out that you have lymphoma. In this section, we cover some of the feelings people often tell us they experience, but there's no right or wrong way to feel. You are likely to feel different emotions at different times. This is entirely natural, and there is support available.



**We hear from people who are, understandably, struggling with a range of emotions. Upset, scared, worried; many people feel it isn't real, particularly if they feel well. For some, it brings a sense of relief to receive a diagnosis, enabling them to focus on the next steps for managing their lymphoma.**

Nicola, Lymphoma Action helpline team member

## Shock and disbelief

A lymphoma diagnosis is a lot to take in. You might feel shocked or 'numb', especially if your lymphoma was discovered during tests for something else. Some people think the diagnosis can't really be true, that the doctors have made a mistake. This natural coping mechanism is known as 'denial'. As long as it doesn't continue for too long, it can give you time to adjust to the reality of a distressing situation.

**You might need to go over the news a number of times before it really sinks in. You might also need to process small amounts of information at a time.**

## **Anger**

Lymphoma can throw you into an unfamiliar world of medical information and hospital appointments. You might feel confused, angry, and upset with the unfairness of the situation. You might question why you developed lymphoma.

Some people feel angry that having lymphoma has disrupted their life and future plans. You might feel angry with the cancer, or with the health professionals who told you the diagnosis. If you are on active monitoring ('watch and wait'), you might feel angry and frustrated with your medical team because they are not recommending treatment at the moment. Some people feel angry towards their friends and family, while others describe a general 'anger at the world'. They feel jealousy or anger towards people who don't have lymphoma and others who do not seem to be facing challenges in their lives.

Anger can disguise emotional pain such as fear, panic, frustration, anxiety and a sense of helplessness. It can sometimes be easier to show anger than other uncomfortable feelings.

## Fear and worry

After initial shock and disbelief, people often say they feel fearful and worried. For many people, just the thought of having treatment for cancer can be extremely daunting. You might be fearful about the potential symptoms or side effects you'll experience. Ask your medical team what to expect.

Your fear and worry might be higher at particular times, such as before you go for a treatment session, or while waiting for a scan.

Many people also worry about their finances, work and family life, particularly if they need to change their working arrangements.

Although treatment for lymphoma has a high success rate, you might have troubling thoughts about dying, or not being around to see your children or grandchildren grow up.

Fear is natural but it can be overwhelming, particularly if you try to cope with it alone.



**If you'd like to talk about how you're feeling, call our Helpline freephone on 0808 808 5555 (see page 174). You might also feel more in control if you find out a bit about lymphoma – see page 20 for tips.**

## Anxiety

Anxiety is a powerful sense of unease. It can be a reaction to the unknown and to the stress of uncertainty. For example, you might feel anxious while waiting for treatment and test results, or if you are on active monitoring ('watch and wait'). Media stories can also trigger anxiety. For example, you might feel unsettled by a TV programme or magazine article about lymphoma or illness in general.

Common signs of anxiety include:

- tiredness, but difficulty sleeping
- feeling worried or irritable
- difficulty concentrating
- inability to carry out day-to-day tasks
- tense muscles
- a fast heart beat
- fluttering or pounding heart (palpitations)
- dizziness
- quick breathing.

Many people feel anxious about what the outcome of their lymphoma will be. The doctors treating you are best placed to give an idea based on factors such as the type of lymphoma you have, how fast it's growing, how well you respond to treatment, your general health, and any other conditions you might have. Even with all of this, nobody can say for sure how

long someone will live. Some people find it helps to take a day at a time. Show yourself patience; if there are days you don't feel like doing much, allow yourself that without feeling guilty. Recognise the value of small things too – even planning what you'd like to plant in the garden or watching a film can help to give a sense of normality and headspace away from thoughts of lymphoma.

Sometimes, anxiety can lead to 'if only' thoughts. For example: 'If only I'd gone to the doctor sooner, I wouldn't be in this situation'. These thoughts can happen when you try to take control of a situation that is, ultimately, beyond anybody's control.

**Although it's not easy, it can be helpful to adapt and learn to live with uncertainty.**



**See pages 115 to 127 for tips on managing stress and anxiety.**

## **Low mood**

The challenges of living with lymphoma can significantly affect your mood. You might feel a sense of loss for the life you had before you were ill, or for plans you'd made that you are now reconsidering. These feelings of loss are a type of grief and might trigger memories of other losses you've had. You might also feel sad for your family and friends, knowing that they, too, are coping with difficult feelings.

The diagnosis can also shatter your sense of control. It might seem that you no longer have influence over things that are 'happening' to you; that you have lots of appointments that tell you when and where you need to be, without fully understanding them. This can lead to a sense of hopelessness and low mood.

It's natural to feel low from time to time, and it can take a while to process all the changes that are happening in your life. If you feel very low for more than a couple of weeks and it affects your day-to-day life, it could be a sign of depression.

Depression can affect people in different ways. For example, you might feel:

- anxious, sad or 'empty'
- hopeless, helpless and pessimistic
- guilty or worthless
- a loss of interest in activities you once enjoyed
- unable to concentrate or remember things
- difficulty in making decisions
- as though you want to harm yourself, which could include thoughts of ending your life.

You might experience physical symptoms such as aches, pains, a change in appetite, sleeping more or less than usual, slow movement and speech, or loss of sex drive (libido).

Speak to your clinical nurse specialist or GP if you think you might be affected by depression. Seeking help early can help to lessen the risk of developing more severe depression.



For more information about depression, visit [mind.org.uk/Depression](https://www.mind.org.uk/Depression)

## Feeling emotionally fragile or vulnerable

Even though we know it's not true, many of us have a feeling that nothing can go very wrong with our body; that serious illness or injury only really happens to other people. Being diagnosed with cancer can shatter this belief. You might lose trust in your body and in your ability to cope. You might feel uncertain and anxious about the future. Some people worry about developing other illnesses.



**I lost my sense of invincibility. Before my diagnosis I never thought I could be sick.**

Ceinwen, diagnosed with diffuse large B-cell lymphoma

## Loneliness and isolation

Even when you're in the company of others, you might feel lonely and isolated. It might feel as though people don't understand what you're going through, and it can be hard to see their lives going on as usual while you struggle. There are lots of possible reasons for feeling lonely. For example, you might:

- Find that friends seem to contact you less often. This could be through fear of 'saying the wrong thing' and upsetting you, or because they're struggling with their own emotions.
- Be unable to continue all your usual activities, which can leave you feeling 'cut off' and isolated from your everyday world.
- Hide your true feelings and pretend to feel OK. This might be because you worry you'll burden people or say something that makes them feel uncomfortable. It might also feel too painful to talk about how you really feel.
- Avoid other people because you don't want to answer their questions. You might prefer to be alone with your thoughts or want to forget about the situation for a while.



Supportive relationships can be very beneficial to emotional wellbeing. Most of the time, it's helpful to be honest. If you need some space away from friends and family for a while, let them know but try not to withdraw completely. See page 99 for tips on effective communication and page 22 for suggestions to help maintain a sense of 'you'.

Life after treatment can also bring a sense of loneliness as you adjust to seeing less of the health professionals who have been taking care of you. You might also feel isolated if friends and family expect you to quickly go 'back to normal', or assume you'll want to celebrate, without realising that this is still a difficult time for you.

## **Determination**

Some people feel determined to get through treatment and to overcome cancer. Determination and positivity can be empowering and motivating and can bring a sense of energy and control. Nonetheless, there'll be times when your motivation dips, especially when your physical energy is low or you experience setbacks. This is natural; you are only human and no one can keep their motivation high all the time.

## **Guilt**

Some people feel guilty about having lymphoma. Guilt can be irrational yet powerful. You might give yourself a hard time, thinking that there must have been something you did, or didn't do, to get it. You might blame yourself for not spotting the signs of lymphoma or seeing the doctor sooner. You might feel guilty that your friends and family are having a difficult time too.

It's human nature to look for someone or something to blame, or at least to explain things. Unfortunately, most of the time, no one can say why lymphoma develops.

**To find out more about the possible causes of lymphoma, visit [lymphoma-action.org.uk/Causes](https://lymphoma-action.org.uk/Causes)**



## Adapting to life with lymphoma

It can take a while to adapt to living with lymphoma. Your life is likely to have changed and, in some ways, might never be the same as it was before you were diagnosed. In time, most people adjust to these changes.

Staying involved in your life can help you adjust to your new situation. For example, continuing with activities and hobbies when you can, and keeping up with friendships. You can also let your medical team know that you'd like to take an active role in conversations and decisions about your health and care options.

Give yourself permission and time to process difficult feelings; this is an important part of managing your emotions and adapting to life with lymphoma.



# Coping with difficult feelings

People find different ways of coping with difficult feelings and circumstances. While none of these can take away the situation, they can help to make it more manageable. We outline some ideas below, but it's important to consider what helps **you**, regardless of what works for other people.



**In my experience, walking is a good mood-lifter, as is any time spent outside.**

Corrin, diagnosed with diffuse large B-cell lymphoma



## Express yourself

It's important to acknowledge your feelings and to have an outlet for them rather than pushing them away. If you allow yourself to make sense of difficult emotions, you are more likely to be able to manage them.

Some people find it hard to talk about their feelings, particularly feelings about having cancer. If talking feels difficult, you could find another outlet – for example, music, drawing or keeping a journal.

Releasing your thoughts and emotions can help you to feel calmer and less overwhelmed. However, focusing on your feelings can bring intense emotions to the forefront of your mind. Set aside a limited amount of time in one session to reflect and think about how you'll take care of yourself afterwards. For example, you could arrange to catch up with a close friend, or go for a walk while listening to music.



## Tips for releasing your feelings

- Talk to someone about how you feel, for example, a friend or family member. You can also get in touch with our Helpline team (see page 174).
- Acknowledge your feelings. You could keep a private vlog (video blog) or write about your feelings in a journal, diary or private blog.
- Release pent-up feelings. Do something creative such as music or art. You could 'let off steam' about feelings of anger and frustration by scrunching or punching a pillow.

## Find out about lymphoma

For some people, finding out more about lymphoma and its treatment helps to demystify it. Be careful not to overwhelm yourself with too much detail too quickly though – go at your own pace. Remember, too, that some questions have no answers.

There are many types of lymphoma, and it affects everyone differently. Some types behave more like long-term conditions. Your medical team should give you any information they can.



### Tips for finding out about lymphoma

- Find out about lymphoma on our website or in our books.
- Get in touch with our Helpline team to talk about lymphoma.
- Talk to your health professionals. Your clinical nurse specialist (CNS) or key worker is often a good first point of contact.
- Prepare questions to ask your medical team and note down the answers you get. Ask for information to be repeated or explained in a different way if it might help.
- If you feel daunted at the thought of finding out about lymphoma, you could ask a friend or family member to do it for you.

## Keep in touch with the people close to you

It is common to withdraw from other people when you feel low, especially if you feel they're treating you differently because of your lymphoma. For example, you might find their attention overbearing. Keep in mind that the people around you care. Try to find ways of letting them know when you'd like some time to yourself, but then reconnect with them afterwards.

See page 99 for tips on effective communication.



## Consider what you can control

Find ways to re-establish a sense of control in your life. Look for what you can influence to help you regain your independence.

**I now have a part-time job that's helping me to gain back some structure and confidence. Everyday tasks can be a struggle but I can feel that I am getting mentally stronger every day. Doing things and getting out there is the best way for me to build my confidence.**

Adam, diagnosed with Hodgkin lymphoma





## Tips to help regain a sense of control

- Keep some structure in your life. For example, stick to a daily or weekly routine.
- Think about what information you're comfortable with sharing. People might ask lots of questions, but that doesn't mean you have to answer all of them or share a lot of detail.
- Keep up with things that are important to you, such as a hobby or spending time with people you care about.

### **Be kind to yourself**

Think about what you need from yourself and other people. Keep a sense of 'you' by taking time out for yourself. Have things in your diary to look forward to in the short, medium and longer-term. You could discuss with your medical team when would be a good time to schedule certain activities and holidays. They might suggest, for example, waiting for a certain number of days after having treatment.

### **Accept help**

It can be hard to ask for help, especially if you like to be independent. Recognise that what you're going through takes a huge amount of physical, mental and emotional energy.

Accepting help could help to prevent you from becoming overly tired. This can be helpful when undergoing treatment and during your recovery. It can also help you to save your energy for the tasks and activities that matter most to you.



## Tips for asking for and accepting help

- Think about tasks other people could help with, such as the school run, preparing meals or mowing the lawn.
- Tell other people how they can help. Keep in mind that, in general, people want to help and are likely to be pleased if you let them know what you'd most appreciate help with.
- Have a rota for friends and family to help. For example, if you've got lots of appointments in one week, each person could help with one journey to and from the hospital.
- Know that accepting help isn't forever. It might be, for example, just while you're recovering from treatment.

## Connect with other people who are affected by lymphoma

Many people find it helps to be in contact with others who can relate to their situation. It can be an opportunity to share thoughts, emotions, experiences, tips and ideas. You could do this through Lymphoma Action's support services; see page 174.

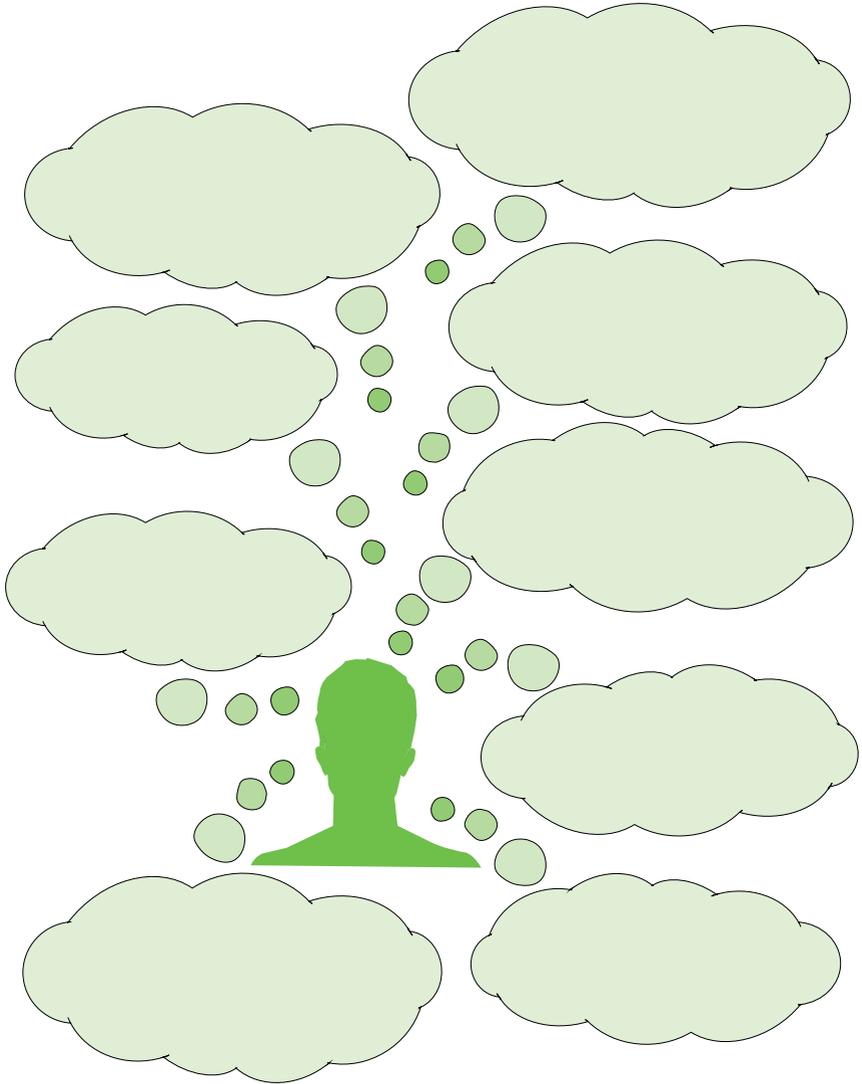
# Dealing with worries and concerns

Worries can feel overwhelming when they go round in your mind. Getting your thoughts on paper can take away some of their power and bring a sense of release. Writing down your worries might also help you identify any links between them and consider how to address them. You could use the 'thought bubbles' opposite to note down your worries.

You might also find it helpful to consider the worst case and how you'd deal with it if it became a reality. This can help you to realise that, with support, you **do** have the resources to cope with such eventualities. Even without an 'answer' to the worst case, just confronting it can help to remove some of the power of a niggling thought.

- Try to pin-point what underlies your worry.
- Break down each problem.
- Think about which aspects you can do something about and develop a plan.

An example of this approach to breaking down a problem and developing an action plan is shown on page 25.



**Figure: Use the thought bubbles to note down any worries you have**

Problem	Strategy	Resources
It'll be difficult to look after the children during my chemotherapy; I've been told to expect sickness.	<ul style="list-style-type: none"> <li>• Find ways to cope with side effects (see next chapter).</li> <li>• Ask for help with shopping and childcare.</li> </ul>	<ul style="list-style-type: none"> <li>• My medical team for advice about managing side effects of treatment.</li> <li>• Family, friends and neighbours.</li> </ul>

## Thinking patterns (ways of thinking)

During our lives, we develop particular ways of thinking. For example, you might be someone who often sees the risk in situations, or you might be someone who is generally optimistic.

You might have a long-standing belief that you should be positive. There is no evidence to suggest that thinking positively affects the progress of cancer. In fact, putting pressure on yourself to think or feel a certain way can have a negative impact on your emotional wellbeing. Research does, however, suggest that challenging unhelpful thinking patterns (or 'thought traps') can improve your quality of life. On the next few pages, we outline some common thinking patterns. You might relate to some of them.

**Catastrophising** – assuming the worst outcome.

Example: 'I'm tired today...'

- Catastrophised thought: 'which must mean the lymphoma is growing.'
- More balanced thought: 'I did a lot of walking yesterday and went to bed late. There is a possibility the tiredness is related to the lymphoma. I can talk to my clinical nurse specialist about this.'

**Predicting the worst** – expecting a negative outcome or focusing on the negative.

Example: 'I'm having treatment...'

- Expecting the worst: 'but it won't work. Even if it does, the lymphoma will probably come back.'
- More balanced thought: 'My doctors have told me that the treatment is likely to be effective. I can ask questions at my next appointment.'

**Emotional reasoning** – making judgements based on feelings rather than factual information.

Example: 'I don't know what my outcome will be but...'

- Emotional reasoning: 'I just **know** things will go wrong because I feel so worried.'

- More balanced thought: 'my medical team are very experienced. Treatment for my type of lymphoma is usually successful, and I'll have follow-up appointments to check my response.'

**Overgeneralising** – applying a conclusion too broadly (for example, assuming that because something happened once, it will happen again).

Example: 'I didn't recognise the symptoms of lymphoma before...'

- Overgeneralising: 'so I'll probably miss them if they come back.'
- More balanced thought: 'because I didn't know much about lymphoma. I've got more information now about what to look for. I know what symptoms to check for and how to contact my medical team if I'm concerned.'

**Shoulds and oughts** – putting yourself under pressure to feel or act in certain ways.

Examples: 'The house could do with being cleaned.'

- Thinking in 'shoulds' or 'oughts': 'I should stay on top of the housework. I must make a start on cleaning straightaway.'
- Replaced with more balanced thoughts: 'I don't have the energy to clean today, and it isn't a priority. I could ask a friend or family member to help with the cleaning.'

**Discounting the positives ('yes, but...')** – filtering out positives or overlooking achievements.

Example: 'My clinical nurse specialist told me that my treatment has a good success rate...'

- Discounting: 'but she probably only said that to make me feel better. I doubt it'll work for me.'
- More balanced thought: 'She has a duty to be honest. I can ask her how and when we'll know if I've responded to treatment and what the next steps are if it's not as good as expected.'

**Labelling** – applying critical labels about behaviours or characteristics.

Example: 'I didn't do everything I had planned to yesterday.'

- Labelling: 'I'm useless. What a waste of a day!'
- More balanced thought: 'I spent a couple of hours resting because I was fatigued. This is what my body needed so it was sensible. I still washed the dishes and had a phone conversation with a friend in the morning. I can do more when my energy levels are higher.'

**Mind reading** – assuming you know what other people are thinking.

Example: 'If I tell my friends how I really feel...'

- Mind reading: 'they'll think I'm a burden and won't want to spend time with me.'
- More balanced thought: 'they are likely to want to support me. I know I would if a friend was in my situation. I could start by sharing a bit about how I'm feeling with one or two close friends.'

### **Consider your thinking patterns**

You might already be aware of your thinking patterns, or it might take some practice to spot them. Sometimes, people who are close to us notice our patterns more easily than we can ourselves so you could ask someone to help you.

**Once you've identified your thought patterns, try to 'catch yourself' when you start thinking in these ways. Challenge your patterns by responding with more balanced thoughts, as in the examples.**



**Visit [getselfhelp.co.uk](https://getselfhelp.co.uk) to download free worksheets to help you identify your thought patterns.**

If you find it difficult to adapt your thinking patterns, you could ask your GP if they can refer you to a cognitive behavioural therapist (a professional who specialises in working with unhelpful thinking patterns).

## **Professional support**

It's to be expected that a diagnosis of lymphoma will have an emotional impact. There is support available to help you cope.

### **Holistic needs assessment (HNA)**

Your medical team should work with you to identify your physical, emotional and social needs. This is sometimes called a holistic needs assessment, or HNA. You should have one regularly, including when you're first diagnosed, when you start treatment, and when you finish treatment. Your medical team can use your HNA to create a care and support plan specific to you.

### **Talking therapies**

Living with lymphoma is highly likely to affect your mood. If your mood is lowered to the extent that it affects your everyday life, talk to your medical team so that they can help you find the support you need. This could include a talking therapy, such as counselling.

There are different types of talking therapies that can help you consider:

- your thoughts and feelings
- how lymphoma impacts your life, for example, your work, studies or interactions with others
- what's important in your life
- how you tend to respond to people and things, relating this to your current situation
- what the people and things in your life mean to you
- your feelings of resilience and inner coping resources
- ideas and strategies to address problems.

If you'd like to try a talking therapy, speak to your GP. They might be able to refer you on the NHS, or they might know of other wellbeing and counselling services in your local area.



**Search 'talking therapy' at [nhs.uk](https://www.nhs.uk) for more information about talking therapies, including a short video about the different types available.**

**You'll also find a list of organisations that you might find useful at the back of this book (pages 170 to 173).**



# Notes



**Sometimes the treatment itself is harder than the cancer and its symptoms. I struggled to cope and felt hopeless at the beginning of my treatment, so I searched for what made me happy and held on to this with all my strength.**

Reem, diagnosed with Hodgkin lymphoma

# Coping with symptoms and side effects

<b>Coping with symptoms of lymphoma</b>	<b>36</b>
<b>Coping with hospital visits</b>	<b>42</b>
<b>Coping with side effects of treatment</b>	<b>44</b>

# Coping with symptoms of lymphoma

Much of the time, symptoms of lymphoma ease once you begin treatment; but they can continue during, and for a while after, treatment.

As well as affecting your physical health, symptoms can affect your overall mood and quality of life. In this section, we offer suggestions to help you cope with some of the more common symptoms. Your medical team can offer advice specific to you.



**I kept a copy of my treatment plan from my CNS. I found this is a good way of keeping a sense of control over my treatment.**

Corrin, diagnosed with diffuse large B-cell lymphoma

## Swollen lymph nodes

Usually, swollen lymph nodes start to get better once you start treatment, but it can be worrying if you notice a new or bigger lymph node. You might also feel self-conscious about swollen lymph nodes. See page 110 for more about body image.



## Tips for coping with swollen lymph nodes

- Remember that lymph nodes naturally go up and down over time. Lots of things can cause them to swell, including infections (like a common cold or throat infection) and some medicines.
- Ask your medical team about how to check your lymph nodes. Try to become familiar with what's normal for you.
- Try not to 'overcheck' your nodes as this can lead to unnecessary worry and can make it harder to notice actual changes in sizes of lymph nodes. Stick to checking around once a month.
- **If you notice any new, or bigger, lumps that last more than a week, contact your medical team.**



- **For a video that demonstrates how to check your lymph nodes, search 'know your nodes' at [lymphoma-action.org.uk](https://lymphoma-action.org.uk)**
- **Search 'lymph nodes' at [bad.org.uk](https://bad.org.uk) to download or print an illustrated leaflet on how to check your lymph nodes from the British Association of Dermatologists.**

## Sweats

Sweats, particularly those that leave your bed clothes and sheets soaking wet, often stop once you begin treatment for lymphoma. However, they can continue for a while during and after treatment.



### Tips for coping with sweats

#### During the day...

- Wear clothes that are made of natural fabrics, such as cotton, as these tend to keep you cooler.
- Wear light layers of clothes so that you can easily remove a layer if you need to.
- Avoid spicy foods, sugary drinks and caffeine.
- Drink plenty of cold, non-caffeinated fluids (around 2 to 3 litres a day) to replace those lost through sweating.
- Exercise earlier rather than later in the day, to help ease night sweats.

#### At night...

- Keep your bedroom cool: use a fan, adjust your thermostat or open your window.
- Keep your bed sheets from getting too wet by placing a soft towel underneath you in bed. You could also consider a mattress protector or waterproof sheet made from a soft fabric.

## Itching

Itching caused by lymphoma usually settles once you start treatment. Difficult as it can be, try not to scratch as it can worsen the itch and could leave lasting marks. Keep your nails very short and wear cotton gloves in bed in case you scratch while you're asleep.

Avoid common skin irritants that could worsen the itch, such as chlorine, and products that are lanolin or alcohol-based. Some soaps, perfumes and cosmetics can also cause skin irritation. Generally, there is less risk from products that are fragrance-free.

Try cooling itchy areas with a cool pack. Avoid applying this directly to your skin as this can cause ice burn. Instead, you could wrap a cool pack or bag of frozen peas in a dry towel and hold this to your skin.

Applying cream could also help soothe an itch – ask your medical team if they can recommend one. Some people find that pressing or tapping the skin around the itch helps to reduce it.



You could try an oatmeal bath to help relieve the itch. You can buy oatmeal bath products, such as colloidal oatmeal, made from ground oats. You can make your own oatmeal bath by grinding uncooked, unflavoured oats into a fine powder using a food processor or coffee grinder. Add a cupful (around 240g/8oz) of the oatmeal powder to your bath. Alternatively, you can fill a pair of tights or a sock with oats, tie a knot and put it in your bath. Use lukewarm water as hot water can worsen skin irritation. The water should turn milky and feel silky. Be careful getting in and out of the bath as the oatmeal will make it slippery.



## Tips to help reduce itching

- Use an unscented or anti-itch moisturiser a few times a day, including after bathing or showering. Ask your doctor or nurse specialist if they can prescribe one.
- Wear loose-fitting, soft clothes. Cotton and bamboo are less itchy than wool and man-made fabrics.
- Eat a healthy diet and drink plenty of water to help keep your skin healthy. You could also consider using a humidifier to hydrate your skin.
- Make time to relax; stress and anxiety can make itching worse and make it harder to cope. See pages 115 to 127 for ideas on managing stress and anxiety.

If your itching is intense and disrupts your sleep or daily life, ask your medical team for advice. They might prescribe medication to help. For some people, light therapy (phototherapy) helps to reduce itching. This treatment uses a machine to deliver carefully controlled amounts of ultraviolet (UV) light to your skin. If light therapy is suitable for you, your doctors might be able to refer you for it.

## **Coughing and breathing difficulties**

If you have swollen lymph nodes in your chest, you might experience a cough or difficulties breathing. These can include:

- a dry cough
- shortness of breath
- noisy breathing
- pain behind the breastbone
- a feeling of pressure in the chest.

These symptoms should go away once you start treatment.

If you have lowered immunity (immunosuppression), you are at an increased risk of developing infections, including chest infections. This can also cause coughing and breathing difficulties.

Seek medical advice if you:

- become short of breath
- cough up thick, yellow or green phlegm (mucus)
- have a cough that gets worse or is painful
- have a fever (temperature above 38°C/99.5°F).

These could be signs that you have developed an infection and need antibiotics.



## Tips to help soothe a cough

- Drink plenty of fluid to help loosen the mucus in your chest.
- Sleep with an extra pillow under your head or back to prop yourself up; coughs are often worse when you lie down.
- Try a hot honey and lemon drink. This is generally as effective as cough medicines that you can buy in a pharmacy. Boil a cup of water and add the juice from half of a lemon. Stir in 1 to 2 teaspoons of honey.

## Coping with hospital visits

Going through tests and treatment for lymphoma means having several trips to hospital. You might need to stay in hospital overnight for some of these.



**I kept a list of every single dose I was going to receive and I ticked each one off, dose by dose.**

Nicola, diagnosed with diffuse large B-cell lymphoma



## Tips to make hospital visits easier

- Take something to stop you from getting bored while you're in the waiting room – for example, a book, phone, tablet or some mindfulness colouring.
- If you arrive early, you could go for a walk or a coffee while you wait. Let the ward or department staff know where you're going and tell them when you get back.
- Speak to your medical team in advance if you're worried, for example, if you're claustrophobic and feel anxious about having a scan.
- In case you need to stay in hospital unexpectedly, keep a list of what to pack, or have an overnight bag ready.

**Search 'staying in hospital' at [nhs.uk](https://www.nhs.uk) for more tips.**



# Coping with side effects of treatment

Your medical team is best placed to advise you on coping with any side effects you experience. In this section, we outline some general suggestions that you might like to discuss with them.

## Prehabilitation ('treatment ready')

Your medical team might suggest a prehabilitation programme before you start treatment. However, in some cases, you might need to start treatment straightaway. Prehabilitation is the process of getting ready for treatment. This means getting your body in the best condition possible to cope well with treatment.

Prehabilitation involves:

- good diet and nutrition (see page 130)
- taking physical activity (see page 136)
- looking after your mental wellbeing (see pages 116 to 127)
- ensuring good general health.

Depending on your circumstances, prehabilitation could include helping you to stop smoking or to reduce your alcohol intake. It can also involve managing any other medical conditions, such as anaemia (see page 73) and diabetes.



**The NHS website has advice, information and tools to help you make healthy lifestyle choices: [nhs.uk/live-well](https://www.nhs.uk/live-well)**

The benefits of prehabilitation can include:

- a shorter stay in hospital
- fewer side effects of treatment
- a quicker recovery
- fewer post-treatment complications
- improved overall physical and mental wellbeing.

Some treatments are only suitable for people who are well enough. Effective prehabilitation might enable them to be used in people who would not otherwise have been able to have them.

Your medical team can work with you to identify your individual prehabilitation needs and advise you on how best to meet these. Sometimes, this is called a 'personalised prehabilitation care plan' (PPCP).

## **Fatigue (extreme tiredness)**

Many people with cancer experience fatigue. This is often called 'cancer-related fatigue' (CRF). It can make daily tasks difficult; for example, you might lack the energy to shower or dress. It can also affect thinking (cognitive) processes such as memory and attention (see page 70).

Fatigue can be difficult to describe. People often talk about 'all-encompassing' feelings of 'weakness' and 'exhaustion'. Some people use words like 'debilitating', 'paralysing', and being 'drained of energy'.



**I remember saying to my husband, 'When I say I'm tired, I mean I can't function – I can't even make sense of what I'm saying, so I might as well sleep'.**

Nicola, diagnosed with diffuse large B-cell lymphoma

Fatigue usually gets better gradually after you finish treatment, but it can last several months, or sometimes longer. There are lots of things you can do to reduce the impact of fatigue on your life.



**The most overwhelming feeling throughout the process was fatigue. I remember not having the strength to reach out and put on my glasses.**

Kathleen, diagnosed with Burkitt lymphoma

## **Keep a fatigue diary**

A fatigue diary keeps track of your activity levels each day so that you can look for any effects on your energy and notice patterns. This, in turn, might help you to spot any triggers to your fatigue and make it easier to plan activities and rest.

You'll find a template of a fatigue diary on the next page. It might be helpful to think about which activities fit into each category. You can also download a copy from our website at [lymphoma-action.org.uk/fatigue](http://lymphoma-action.org.uk/fatigue)

**Remember that activity can be cognitive or emotional, not just physical.**

- If you're having treatment, put a cross in the boxes on the days you have treatment.
- Use a colour-coded system to indicate your level of activity, relaxation and sleep.

After a couple of weeks, you might start to notice any patterns. This can help you to plan, prioritise and pace your activities.



**It's hard when there's so much I want to do but I've learnt not to over-commit and to schedule rest in. I have learnt to measure my time in terms of quality, not quantity.**

Nicola, diagnosed with diffuse large B-cell lymphoma

Week 1

\_\_/\_\_/\_\_

	Morning - am											Afternoon/Evening - pm												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Week 2

\_\_/\_\_/\_\_

	Morning - am											Afternoon/Evening - pm												
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11
Monday																								
Tuesday																								
Wednesday																								
Thursday																								
Friday																								
Saturday																								
Sunday																								

Colour each square to keep track of what you have been doing (you can do half or quarter squares, too)



High energy activity



Moderate activity



Low energy activity



Relaxation



Sleep

## Choose where to spend your energy

We all have a limited energy supply. Imagine your energy capacity for each day as a bottle or tank. Some days, it has more energy in it than others. To help plan your day, think about how much energy you're starting with and how much energy each activity takes up. You could use the diagram below to help.



**Figure: Use the empty bottle on the right to plan your day as in the example on the left**

If you don't have enough energy to do everything you'd like to, think about which tasks or activities are your priorities. You could ask for help with some things, or do them on another day.



## Pace yourself

It's important to pace yourself. Consider when your energy is usually highest and use this time for your most important activities. Ask friends and family for help so that you can save your energy for the tasks you most enjoy, or that only you can do. If you work, consider how you might be able to organise your day so that you work when your energy levels are higher. See page 142 for more about managing work.

Set yourself realistic goals. Breaking your to-do list into smaller tasks can make it more manageable. Make sure you rest, too. Plan breaks into your day so that you can sit or lie down for a short while between activities.

People often ask whether it's helpful to nap during the day. During treatment, a nap might help give your body the additional rest it needs. However, with long-term cancer-related fatigue, napping in the day could disrupt your night-time sleep pattern. In this case, a rest without sleeping might be better.



**Visit [lymphoma-action.org.uk/Fatigue](https://lymphoma-action.org.uk/Fatigue) for more information, including videos of people sharing their experience of coping with cancer-related fatigue.**



## Tips for coping with fatigue

- Take regular light physical activity, such as walking, and allow time to rest afterwards. For many people with CRF, exercise can be the most effective strategy for reducing fatigue. See pages 45 to 51.
- Eat a healthy diet that gives you the energy you need.
- Build relaxation into your day.
- Have a regular sleep pattern.
- Consider trying a complementary therapy like massage, yoga or acupuncture. Check with your medical team first to make sure it's safe for you.
- Speak to your medical team – they might be able to suggest local services that can help to manage cancer-related fatigue.

See pages 129 to 147 for more about these lifestyle factors.



**I tried to get outside and walk a bit, even in the early days. It was slow and there were times I felt like I was going backwards and that my energy levels weren't getting any higher, but I was getting better and needed to be patient.**

Owen, diagnosed with angioimmunoblastic T-cell lymphoma



**Search 'coping with fatigue' at [macmillan.org.uk](https://www.macmillan.org.uk) to order or download a free booklet on cancer-related fatigue.**

## Nausea and vomiting (sickness)

Nausea (feeling sick) or vomiting (being sick) are common side effects of many treatments for lymphoma. They can be worse if you are stressed and anxious.

Tell your medical team if you feel sick. There are lots of anti-sickness medications (antiemetics) they can prescribe. These are usually more effective if you start them early.

Even if you don't feel like eating, try not to skip meals, because hunger can make nausea worse. Some people find it helps to eat little and often. See page 55 for more tips to help with reduced appetite.

You might find it easier to eat plain-tasting foods and non-greasy carbohydrates. Choose foods like toast, crackers, breadsticks, rice and pasta. If you feel sick when you first wake up, try eating a cracker or plain biscuit to help settle your stomach.

It's also important to drink plenty of fluids, particularly if you vomit. You might find cool water or citrus-flavoured, fizzy drinks more soothing than hot drinks. Try to drink throughout the day but avoid drinking too much just before meal times so you don't fill yourself up.



If you feel too sick to eat or drink, tell your doctor or CNS. Let them know about any other problems that arise from your nausea too, for example, if you're finding it hard to take necessary pills or other medications.

Your treatment might affect your sense of taste. If drinks taste unpleasant, you can bypass some of your taste buds by sipping slowly through a clean straw. If your treatment gives you an unpleasant taste in your mouth, try brushing your teeth or using a mild, alcohol-free mouth rinse between meals. Sugar-free mints and lemon sweets can also help.

Some people find that the smell of foods makes them feel sick. If this is the case, you could try microwaving your food to help limit these smells. You could also wait for your meal to cool before you eat it because hot foods often have stronger smells.

Other smells might also trigger nausea – for example, perfumes, aftershaves, shower gels or hand creams. If this affects you, try using fragrance-free products. You could also ask friends, family and colleagues to avoid wearing strong fragrances around you.



## Tips for coping with nausea

- Include ginger in your diet. For example, you could try ginger beer, ginger tea, ginger biscuits, ginger cake or root ginger.
- Eat foods you like, but avoid your favourites, in case you start to associate them with sickness.
- Try wearing acupuncture (travel sickness) bands on your wrists.
- Try behavioural techniques, such as distraction and relaxation. Visit [nopanic.org.uk/relaxation-technique](http://nopanic.org.uk/relaxation-technique) for an example.

Some people ask whether cannabis or cannabidiol (CBD) oil can help with nausea and vomiting. In the UK, cannabis and products made from cannabis are not licensed to treat nausea or vomiting caused by chemotherapy. Very rarely, specialist doctors can prescribe medical cannabis on a case-by-case basis, but only if other treatments haven't been effective and if it is suitable for you.

Home-grown cannabis and cannabis bought illegally contain lots of active chemicals in unpredictable amounts. It is not safe to use instead of medical cannabis. This is because you can't control the dose you're getting and it could be contaminated with other chemicals.

## Changes in weight and appetite

You might worry about weight loss or weight gain if you experience changes to your appetite. Any changes to your body can be a visual reminder of your lymphoma and can have a significant impact on your self-esteem (pages 109 to 113).

### Reduced appetite

If your appetite is smaller than usual, try eating little and often. It can be difficult if people keep encouraging you to eat when your appetite is low. Let them know that you are trying but find it difficult to eat your usual amounts. You could also suggest ways they could help you, such as preparing small snacks for you to graze on throughout the day.



Choose high-energy foods, such as omelettes, cheese and biscuits. Full-fat products, for example whole milk, full-fat yoghurt, nut butters and avocado, provide more energy (calories) than low or reduced fat ones.

You can also boost your calorie intake by adding:

- butter, oil or cheese to foods like bread, pasta, potatoes, vegetables and sauces
- sugar, honey or syrup to drinks or puddings.

If you continue to lose weight, you could ask a member of your medical team if they're able to refer you to a dietitian.



**Search 'building up' at [macmillan.org.uk](https://www.macmillan.org.uk) to download a free book by Macmillan Cancer Support called *The building-up diet*.**

## Increased appetite

Some treatments can make you more hungry than usual, but your appetite should return to normal once you finish treatment.

Steroids are often used as part of lymphoma treatment. They can increase your appetite. They can also affect your metabolism (how quickly your body uses energy), so you might gain weight even if your appetite doesn't increase. Your weight should return to normal once you stop taking steroids.

**In general, it's best to avoid dieting during treatment as it can make it harder for your immune system to recover.** Your height and weight are also important in calculating treatment doses. Instead of dieting, focus on eating a healthy diet, being active and giving your body the energy it needs to recover. There's more information about diet and nutrition on pages 130 to 134.

If you're concerned about weight gain, speak to a member of your medical team.

## Bowel problems

Lymphoma, and some of its treatments, can cause changes to your digestive system. These usually improve once you finish treatment but they can be difficult to live with while you are experiencing them. If you are on active monitoring ('watch and wait'), bowel problems might be a sign that treatment should begin, so let your medical team know if you have any such problems, including:

- diarrhoea: passing loose, watery poo (stools) more frequently or in larger amounts than is normal for you
- constipation: pooing less often than usual, or finding it hard to poo
- wind (flatulence): passing wind more frequently than is normal for you
- feeling full or bloated.

### Diarrhoea

Having diarrhoea uses a lot of energy, so rest when you can. It's also important to replace the water you lose through diarrhoea, so stay hydrated. Aim to drink at least 2 litres (3.5 pints) of liquid each day, sipping throughout the day. Choose plain water, weak squash or herbal tea. Avoid drinks that might make the problem worse, such as fruit juice, caffeinated drinks, very hot or very cold drinks, alcohol and milk.

You could also use an oral rehydration sachet to replace lost water and mineral salts. You can buy these in supermarkets, chemists and pharmacies.

**Seek medical advice before taking oral rehydration sachets or any other medicines to treat diarrhoea (antidiarrhoeal medicines).**

You might not feel like eating when you have diarrhoea. Try to eat as soon as you feel able to.

Certain foods can help control diarrhoea, but speak to your medical team before making changes to your diet. They might recommend eating more foods that are high in potassium, such as avocados, bananas, bread, white and sweet potatoes, fish, chicken, beef and turkey. Low-fibre foods can also help; these include potatoes, cornflakes, white rice, dry white toast, soup, peeled and boiled vegetables and tofu (bean curd).

Avoid foods that could worsen your symptoms. This can include fatty, greasy and spicy foods, dairy products and high-fibre foods, such as raw fruit and vegetables, beans, nuts and wholegrain cereals.



## Tips for coping with bowel problems when you're out

- Planning ahead can help you to feel more confident if you're experiencing bowel problems.
- Carry spare clothes and a plastic bag to store any soiled or damp clothes.
- Take a body spray and wipes with you to freshen up.
- Wear clothes that are quick and easy to take off when you need the toilet, rather than clothes with fiddly zips, buttons or other fastenings.
- Find out in advance where toilets are.
- Consider wearing a disposable waterproof pad (incontinence pad) to protect your underwear. Carry spares with you.

**Search 'just can't wait' at [bladderandbowel.org](https://www.bladderandbowel.org) to download a free 'Just can't wait' card. This states that you have a medical condition and might need to use the toilet urgently. It's also available as an app.**



## Constipation

Constipation can be a side effect of some chemotherapy drugs, anti-sickness medications (antiemetics) and pain-relief medications.

**Speak to a member of your medical team if you haven't been for a poo for a day or two longer than is usual for you. It's often simpler to treat constipation if you seek help sooner rather than later.**



### Tips to help constipation

- Drink plenty of fluids, including fruit juices that are high in sorbitol (a type of sugar), including orange, apple, prune and raspberry.
- Avoid alcohol.
- Increase the amount of fibre you eat – for example, choose oats, wholemeal or granary bread, pulses, dried fruit and vegetables.
- Add linseed to your diet.
- Eat liquorice.

Try to get into a regular pattern of going for a poo; it can help to eat at around the same time each day. Light exercise, such as a gentle walk, can help to soften your poo and make it easier to go. When you need to go to the toilet, go as soon as you can. Waiting can make the constipation worse.

## Wind

Some treatments and some anti-sickness medications can create extra gas in your digestive system and increase flatulence (wind). While this isn't a serious medical problem, it can be embarrassing and uncomfortable.



### Tips to help lessen wind

- Lower your intake of high-fibre foods such as wholemeal bread, bran, cereals, nuts and seeds.
- Avoid foods and drinks that can increase the production of wind. These include cabbage, apples, sprouts, onions, beans, cauliflower and fizzy (carbonated) drinks, including beer and pop.
- Avoid sugar-free sweets and other foods that contain artificial sweeteners.
- Reduce the amount of air you swallow. Eat and drink slowly, and chew your food well. If you smoke, try to give up.
- Eat smaller meals or snacks throughout the day rather than three larger ones.
- Take regular, gentle exercise, such as walking.

Some medications can help with wind but seek medical advice before taking them. This is particularly important if you're having lymphoma treatment because some medicines can interact with lymphoma treatments.

## Urinary and bladder problems

Some treatments for lymphoma can cause bladder problems such as:

- weeing more than usual in the daytime or at night
- a burning sensation when you wee
- blood in your wee.

These treatments include radiotherapy to the pelvis, some types of chemotherapy, and some types of immunotherapy. In some cases, medicines can be prescribed to help prevent urinary and bladder problems.

If you experience urinary or bladder problems, tell your medical team. They might need to arrange tests to check if you have an infection.

It usually helps to drink plenty of fluids. Avoid caffeinated drinks, alcohol, spicy foods, and tobacco.



For reassurance, you might choose to wear a disposable waterproof pad (incontinence pad) or thin liner to protect your underwear. A mattress protector can prevent damage to your bed and make cleaning easier if you might have an accident overnight.

## Hair loss

Some treatments for lymphoma can cause full or partial hair loss, or hair thinning. Although it's usually temporary, it can still be very distressing and can affect your self-identity, esteem and confidence. It can also be a visual reminder of going through treatment.



**If I touched my face, part of my beard fell out. If I ran my hand through my hair, I'd dislodge enough to make a wig for a small dog. My daughter shaved it off. It took me a long time to accept hairless me.**

Roger, diagnosed with high-grade non-Hodgkin lymphoma

**Whether or not to cover your hair loss is a very personal decision. If you choose to, there are lots of options.** Give yourself as much time as possible to think through them so that you can choose something that's right for you and have time to get used to the idea.

Hair extensions (clipped or woven into your hair) aren't recommended because they could damage your hair, which is likely to be more fragile during treatment.

## Preparing for hair loss

Your medical team can tell you if your treatment is likely to affect your hair. However, they won't be able to say for certain.

You might have heard of scalp cooling as a way to prevent hair loss. Unfortunately, this technique is not suitable for people with lymphoma or other blood cancers because it could make your treatment less effective.



If you are likely to lose your hair, you might want to prepare yourself by cutting it short before your treatment starts. If you have a beard or moustache, you might choose to shave these.

Some people let friends and family know that they expect to lose some hair. Your eyebrows, eyelashes, facial hair, underarm and pubic hair might also be affected by treatment. You might also lose nasal hair, although this is not common. If it happens, it can make your nose run more than usual.



**I knew I would lose my hair, but it was still a shock. When I started to lose it, I asked my hairdresser to cut it all off, which was easier for me to deal with.**

Pat, diagnosed with follicular lymphoma



## Wigs

You can get wigs made from artificial (synthetic or 'man-made') or real hair, or a combination of both. It might be possible to have a wig made from your own hair.

**You might be able to get a synthetic wig free of charge on the NHS or local care service. To find out more, search 'wigs' on the NHS website for the nation where you live: [nhs.uk/nhs-sites](https://www.nhs.uk/nhs-sites)**

If you'd like a wig but don't meet the criteria for a free one, ask your clinical nurse specialist if there is a subsidised wig scheme at your hospital that you are eligible for. They might also be able to recommend a wig supplier. If you are black or Asian, a specialist supplier might be appropriate for you.

If you buy a wig privately, you shouldn't have to pay value added tax (VAT) if you've lost your hair because of cancer. Ask the company for a VAT exemption form when you buy the wig. You won't be able to claim it back at a later date.

- **Visit [mynewhair.org](https://www.mynewhair.org) for a list of UK salons that can help you buy, fit or style a wig.**
- **For support on all aspects of hair loss and hair care, before, during and after cancer treatments visit [cancerhaircare.co.uk](https://www.cancerhaircare.co.uk)**

## Other head covering options

Hats, headscarves, turbans, bandanas and zandanas (pre-made bandanas) are all possibilities.



**Search 'tie bandana' at [macmillan.org.uk](https://www.macmillan.org.uk) for a guide on tying a headscarf or bandana.**

If you're thinking of using 'spray-on hair' (hair loss concealer), check with your medical team first to make sure it is safe for you.

**Always do a patch test before using a product to check for any allergic reactions, even if you've used it before.**

A towelling turban or hairnet can help to catch hairs if you lose hair overnight. You might find hairs scattered on your bed sheets when you wake up. You could try using sticky tape to pick them up.



## Tips for looking after your hair and scalp

- Be gentle with your hair and scalp when you start to experience hair loss.
- Limit how often you wash your hair. From time to time, instead of washing it, you could sprinkle talcum powder into your hair. Leave it a while then brush it out. This absorbs grease and helps to ease tenderness.
- Use a pillowcase made from 100% cotton to help to reduce scalp irritation.
- Use a wide-toothed comb or a baby brush. They are often gentler than other types such as paddle brushes, round brushes and rat tail combs.
- Use lukewarm water and a mild shampoo and conditioner to wash your hair.
- Avoid hairdryers and other heat-styling tools. Pat your hair with a towel and let it dry naturally.
- Comb or brush your hair gently but avoid plaiting it or tying it tightly. Soft hair ties or ribbons are gentler than elastic bands.
- Soothe a sore scalp by massaging in a mild, unperfumed moisturiser.
- Protect your scalp from sun, wind and cold by wearing a hat or other head covering.

## Once your hair starts to grow back

Hair often starts to grow back from a few weeks after finishing treatment, but it might differ to your pre-treatment hair. For example, it might grow back curlier, softer, or a slightly different colour.



**My hair had gone and I was surprised that my usually straight hair came back curly. And I seem to have more hair now too!**

Stephen, diagnosed with mantle cell lymphoma



Your scalp might be itchy as your hair starts to grow back. If your scalp is dry, frequent moisturising can help.

Ask your hospital how long you should wait after finishing treatment before you colour, chemically straighten or perm your hair. Traces of chemotherapy in your hair strands could react with the chemicals used in the styling processes.

Natural, temporary dyes might be better than permanent chemical products. If you'd like to dye your hair, you could ask your clinical nurse specialist if a wash-in, wash-out vegetable-based hair dye is suitable for you. These are milder and less damaging to your hair and scalp than chemical ones.

Your new hair might be fragile so you should wait several months after your hair has started to grow back before you have woven-in or glued-in hair extensions.

Your fingernails and toenails contain the same protein as your hair and could also be affected by chemotherapy. They might be dry, marked or discoloured and break more easily than usual. You can improve the appearance using nail varnish, but avoid quick-drying types as these can dry your nails even more. Use acetone-free nail varnish remover because those with acetone are likely to dry your nails out more. Check with your medical team if you are considering using nail technologies, such as gel manicures.

## **‘Chemo brain’ (cancer-related cognitive impairment)**

The word ‘cognitive’ relates to thinking. It includes things like memory, attention and concentration.

Cancer-related cognitive impairment (CRCI) means a change to your thinking processes. You might also hear it called ‘cancer-related cognitive disorder’, or ‘mild cognitive impairment’. Although it’s often called ‘chemo brain’, it can also affect people having other types of cancer treatment, or people who haven’t had treatment at all.

People with CRCI often describe feeling ‘hazy’ or being in a ‘mental fog’. You might have difficulties recalling names and dates, concentrating on everyday tasks, planning and multi-tasking. Following a conversation or finding the word you want to use might be hard too.

Most people find ways of managing CRCI so that it doesn’t impact severely on their daily life. See page 72 for tips.

Often, symptoms of CRCI are mild. They can come and go, and might get worse when you’re busy, tired or anxious. If you experience CRCI, speak to your nurse specialist for advice about whether it’s safe to drive.

Usually, symptoms improve between about 6 months and 2 years of finishing treatment. However, for some people, they go on much longer. If you have anxiety or depression, you might find the effects of CRCI more troublesome. It can help to manage your anxiety and depression before starting treatment. Speak to your GP for advice.

**Tell your doctor or nurse if you're experiencing CRCI so that they can check for and treat any underlying causes such as anaemia or infection.**

### **Getting specialist help**

If CRCI affects your daily life, your medical team might be able to refer you for specialist help, such as cognitive behavioural therapy (CBT). This is a talking therapy that helps you to order your thought processes and find coping methods that work for you.

Memory and attention adaption training (MAAT) is a type of CBT developed to help people affected by CRCI. It focuses on finding different ways ('compensatory strategies') to manage your difficulties. Other methods of CBT use 'brain training' techniques, which focus on challenging your brain and practising skills like using your memory. Ask your medical team for more information if you're interested in these techniques.



## Tips

### ...to help with focus

- Try to do just one thing at a time.
- Be patient with yourself, particularly with things that need a lot of attention.
- Find somewhere quiet to focus on a task or conversation.

### ...to help with remembering

- Note things down. Leave yourself written reminders or set up alerts on your phone.
- Make visual links to help you remember things.
- Use a calendar on your wall or on your phone to keep track of appointments.
- Add to the shopping list when you start to run low.
- Use maps, GPS or other navigations systems if you find it hard to remember how to get to places.

### ...to help with CRCI in general

- Consider letting people know about your difficulties. For example, it might help to ease pressure if it's hard for you to find the words you want during conversations.
- Find ways of managing stress (see pages 115 to 126) and fatigue (see page 50), as these can also affect your thinking processes.
- Try keeping your mind active with puzzles like crosswords, word searches and Sudoku.



**With cancer-related cognitive impairment, I felt as though I was encased in a deep sea diver's suit, as an observer watching myself interacting with others from a distance.**

Gerry, diagnosed with follicular lymphoma

## Anaemia

Anaemia means that there is too little haemoglobin (a chemical that carries oxygen) and too few red cells (that carry haemoglobin) in your blood. Many people with lymphoma are affected by anaemia at some point during their illness, either because of the lymphoma itself or as a side effect of treatment. There are various treatments for anaemia, depending on its cause.

Symptoms of anaemia include:

- feeling fatigued (extremely tired), weak and low in energy
- feeling short of breath when doing things
- feeling your heart fluttering or pounding (palpitations)
- feeling dizzy or faint
- a paler skin colour than is normal for you
- headache or aching bones.



Tell your medical team if you have any symptoms of anaemia. They might suggest a blood test to check your haemoglobin level. If you have anaemia, they can advise you on how best to manage it.

## Neutropenia

Neutropenia means having a low number of neutrophils (a type of white blood cell). Neutrophils help your body to fight infections. Lymphoma and its treatment can cause neutropenia. If you have neutropenia, you have a higher risk of infection than usual. Your medical team might prescribe antibiotics or antiviral medicines to reduce this risk.

If you have neutropenia and you develop an infection, it can be very serious. This means you'll need urgent treatment, usually in hospital.

**Contact your medical team immediately if you have any signs of infection, including but not limited to:**

- fever (temperature above 38°C)
- hypothermia (temperature below 35°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or sore mouth

- blocked nose
- shortness of breath
- redness and swelling around skin sores, or injuries to intravenous chemotherapy lines
- diarrhoea or vomiting
- a burning or stinging sensation when weeing, or weeing more often than usual
- unusual genital discharge or itching
- unusual stiffness of the neck, and discomfort around bright lights
- any new pain.

Neutrophil levels usually return to normal without treatment. If your neutrophil count is very low, you might have treatment to help it recover faster.

To reduce your risk of infection, keep good hygiene and stay away from people with infections such as colds and flu. Avoid public places at busy times (for example, public transport during rush hour, swimming pools and cinemas), where infections can be easily spread.

### **Protect your skin from wounds**

Take care to protect your skin from cuts, grazes and scratches. This lowers the risk of giving bacteria a way into your body. For example, use an electric shaver rather than a razor and take care while flossing. Wear gloves if you are gardening, and wear shoes outdoors.

If you do cut, scratch or graze yourself, wash your hands and clean the wound with tap water. Pat the wound dry with a clean towel and place a sterile dressing on it. Avoid picking at scabs because this can increase the risk of infection.

## **Follow food safety guidelines**

Foodborne illness ('food poisoning') can happen if you eat or drink food that's contaminated, for example with a virus or bacteria.

The World Health Organization (WHO) outlines five key steps to food safety, as shown opposite:



**For more detail about the WHO's advice, visit [who.int](https://www.who.int) and search 'food handling'.**

Although it's best to avoid takeout foods when you're neutropenic, this doesn't mean that you can't enjoy a treat from time to time. For example, you could have a well-cooked pizza. Many supermarkets now stock a range of international foods you could cook at home. Takeout drinks should be OK. However, doctors advise against having drinks from draft as the pumps can contain lots of bacteria; cans or bottles are better.

You might have heard of a 'neutropenic diet' (sometimes called a 'clean', 'low-bacterial' or 'low microbial' diet). The aim is to cut out foods that are more likely to contain infection-causing bacteria and fungi. However, there is limited scientific

research supporting neutropenic diets, and advice varies between hospitals. Your medical team are best placed to advise you on any foods or drinks to avoid.

Step	How
<b>Keep clean</b>	Wash your hands thoroughly and make sure that food preparation surfaces and utensils are clean.
<b>Separate</b>	Separate raw meat, raw poultry and raw seafood from other foods. Use separate utensils to prepare them.
<b>Cook your food thoroughly</b>	This is especially important when cooking meat, eggs and seafood. Make sure that foods like soups or stews are warmed to at least 70°C. Reheat cooked food thoroughly.
<b>Store foods at safe temperatures</b>	Generally, this means: <ul style="list-style-type: none"><li>• below 5°C for cold or perishable food</li><li>• above 60°C for hot food.</li></ul> Once food is cooked, don't leave it at room temperature for more than 2 hours; put it in the fridge.
<b>Use safe water and raw ingredients</b>	Wash fruit and vegetables before eating them, choose pasteurised (heat-treated) and do not eat or drink products that have passed their expiry date.

## Thrombocytopenia

Thrombocytopenia means having fewer platelets than you should have. Platelets are fragments of blood cells that help your blood clot. People with lymphoma sometimes have thrombocytopenia because of the lymphoma itself or as a side effect of treatment.

Thrombocytopenia can increase your risk of bruising and bleeding. You might have nosebleeds, bleeding from your mouth or gums, blood in your urine or bleeding from your bowel. Women might also have heavier periods than usual. Let your medical team know immediately if you develop any of these symptoms so that they can give you treatment if you need it.



### Tips to lower the risk of bruising and bleeding

- Avoid high-impact sports (such as running) and contact sports (such as rugby).
- Avoid blowing your nose hard.
- Wear protective gloves if you are gardening.
- Use a soft-bristled toothbrush, for example, a child's toothbrush, and avoid flossing your teeth if it causes your gums to bleed.

## Peripheral neuropathy (PN)

Peripheral neuropathy (PN) is damage to the nerves of the peripheral nervous system (the network of nerves outside of the brain and spinal cord). You can think of it a bit like a faulty wire, interfering with the signals between one part of your body to another.

Symptoms of PN depend on which nerves are affected. It's fairly common to get 'pins and needles' (pricking, tingling or numbness of the skin), a burning sensation, pain and increased sensitivity to touch and temperature. You might also have difficulty with 'fiddly' tasks that need fine movements, such as doing up buttons or tying shoelaces.

Damage to your nerves can stop you from receiving all the signals (like pain and temperature) that you'd usually get. Without these, you might not realise you've hurt yourself.



Protect yourself by wearing gloves for activities and tasks such as gardening, washing up and using the oven. Reduce the risk of tripping over by wearing well-fitting flat or low-heeled shoes with covered toes, and try to keep the floors in your house clutter-free.

Losing feeling in your toes can increase your risk of hurting yourself while cutting your toenails – you could ask your GP whether they can help you access a podiatrist (a health professional who deals with conditions of the feet) to help keep your feet in good health. This might be available on the NHS or you could find one privately.

Usually, the symptoms of PN go away once you finish treatment for lymphoma, although they can go on for longer. You might see an improvement in your symptoms for up to a year after treatment, but further improvements after this time are less likely.

Tell your doctor if you have symptoms of PN. They can advise you on how to prevent further nerve damage. They might make changes to your medication. Having PN might also affect what treatment you have in the future.



**After the third cycle of R-CHOP chemotherapy, I told my medical team I was struggling with numbness in my feet and hands. They tweaked my treatment to stop it from getting any worse.**

Nigel, affected by peripheral neuropathy during treatment for high-grade non-Hodgkin lymphoma





- **If you drive, you should tell the Driver and Vehicle Licensing Agency (DVLA) if you are diagnosed with PN. You can download a form to do so on the UK government's website:**  
**[gov.uk/peripheral-neuropathy-and-driving](https://gov.uk/peripheral-neuropathy-and-driving)**
- **Some people find acupuncture helps to relieve symptoms of PN. Acupuncture involves having fine needles put into specific places, known as 'acupuncture points', on your body. Find out more at:**  
**[nhs.uk/conditions/acupuncture](https://nhs.uk/conditions/acupuncture)**

Your medical team can give you advice on managing PN. They might prescribe pain relief medication or refer you to a pain specialist.



## Tips for coping with peripheral neuropathy

- Avoid alcohol because it can affect how well your nerves function.
- If your sense of temperature is affected, use a thermometer to make sure baths and washing up water are at a safe temperature.
- If your symptoms affect your fingers and toes, flex and stretch them for a few minutes throughout the day. You can also try gently massaging them.
- If cold weather makes your symptoms worse, wearing gloves and thick socks might help.
- Wear slip-on shoes, or ones with an easy fastening if tying shoelaces is difficult.
- Avoid putting pressure on parts of your body for too long. For example, don't sit with your legs crossed or lean on your elbows for lengthy stretches of time.

## Skin problems

Some treatments for lymphoma can cause skin problems such as dryness, itching (pruritus), rash, soreness and sensitivity to sunlight (photosensitivity). These usually clear up once you finish treatment.

Skin problems can also be a symptom of some types of lymphoma. Although treatment aims to resolve such problems, your skin might not return completely to normal.

If your skin is dry, try using coconut oil or an oat-based product in the bath. You could also ask your CNS if they can recommend a suitable moisturiser for you.

**See page 40 for more tips on coping with dry and itchy skin.**



Use a high factor sun cream when you are out in the sun. Avoid being out in strong sunlight (11am to 3pm in summer months) and protect your scalp by wearing a hat. Search 'sun safety' at [www.cancerresearch.org.uk](http://www.cancerresearch.org.uk) for more information about sun safety.

Contact your medical team if you develop a severe sunburn-like rash after being in the sun.



## Tips for coping with sensitive skin

- Use bedding that's made from 100% cotton. If you need to stay in hospital overnight, ask if you can take your own.
- Use a cool (though not freezing) compress to relieve painful skin.
- If you shave, use an electric shaver rather than a razor. Wash or shower first, to loosen the hair and make it easier to cut.

## Oral mucositis (sore mouth)

Oral mucositis is a side effect of some treatments for lymphoma. It happens when the soft tissue that lines the inside of your mouth (the mucous membrane) becomes swollen, red and painful. You might develop mouth ulcers.

Sore mouth usually gets better once you finish your treatment and your blood counts return to their pre-treatment levels. This is usually around 2 to 3 weeks after chemotherapy, and 6 to 8 weeks after radiotherapy. Your medical team might prescribe treatments to help prevent or treat sore mouth. They might also prescribe a pain relief medication or mouthwash to help soothe the pain.

Sore mouth can increase your risk of infection. To help prevent infection:

- Rinse your mouth after eating. Use warm water or warm water mixed with salt.
- Clean your teeth twice a day using a soft-bristled brush. You could use children's toothpaste, which is milder than regular toothpaste.
- Floss gently, to avoid damage to your gums.

If your mouth is sore, try eating soft foods, such as mashed potato, scrambled eggs or soup. It might also help to wait until it's cool or warm before eating it, as very hot or very cold food can irritate your mouth. Avoid foods that could worsen the pain, such as spicy foods, acidic fruits, garlic, onions or vinegar.

If your mouth is dry, try sipping fluids, eating moist foods and chewing gum or sucking a sweet. You could also ask your medical team about artificial saliva treatments.



## Tips for easing a sore mouth

- Suck an ice lolly or ice cube to soothe pain.
- Rinse your mouth frequently throughout the day with a bland solution. For example, half a teaspoon of bicarbonate of soda (baking soda) mixed into a cup of water.
- Try not to smoke or drink alcohol. Visit: [www.nhs.uk/live-well](http://www.nhs.uk/live-well) for tips to help manage these.

## Fertility

Many people go on to have a family after having treatment for lymphoma.

If your treatment could affect your fertility and you think you might want to have a family in the future, tell your medical team. They can discuss options for preserving your fertility and might refer you to a fertility specialist.



**Cancer, fertility and me is a website resource designed to help women think about their fertility preservation options. Visit: [cancerfertilityandme.org.uk](https://cancerfertilityandme.org.uk)**

Your medical team should advise you on how long to wait after finishing treatment before you try for a baby. Most people are advised to wait for up to 2 years. This is important to give your body time to recover from treatment. Women are often advised not to wait too long, in case their treatment is going to bring on an early menopause (see page 88).

Generally, it's advised that you first try for a baby naturally. However, some women have fewer eggs and some men have fewer sperm after chemotherapy so it's a good idea to seek advice from a fertility specialist.



**If you are pregnant, you can read about treatment for lymphoma during pregnancy at [lymphoma-action.org.uk/Pregnancy](https://lymphoma-action.org.uk/Pregnancy)**

Some chemotherapy drugs can cause long-term damage to your heart or lungs. For women, pregnancy increases the strain on your body. Your hospital specialist can advise you on whether to have your heart function and lung function tested before you try to conceive, and whether you should have additional monitoring during your pregnancy.



**If you have difficulties conceiving, you might be interested in assisted reproductive techniques (ARTs). You can learn about these on the Human Fertilisation and Embryology Authority website: [hfea.gov.uk](https://hfea.gov.uk)**



**My medical team told me that high-dose chemotherapy and total body irradiation would make me infertile. I was offered support at the hospital, but found the greatest support in talking to others who have been through this themselves.**

Kat, diagnosed with double-hit lymphoma, a rare type of fast-growing (high-grade) B-cell lymphoma



Visit [lymphoma-action.org.uk/Reduced-fertility](https://lymphoma-action.org.uk/Reduced-fertility) to find out more about fertility preservation.

You can also search for fertility preservation services that are available in your area at [hfea.gov.uk](https://hfea.gov.uk)

## Early menopause

The menopause (last menstrual cycle or period) happens when the ovaries stop making the hormones that cause a woman's period. It also marks the end of a woman's fertility, although generally women will become infertile some years before the menopause. In the UK, most women reach the menopause between the ages of 45 and 55.

For some women, treatment for lymphoma can cause an early menopause. You are more likely to have an early menopause if you are near to the age of natural menopause when you have treatment. The risk also depends on what treatment you have. Your medical team should tell you if your treatment is likely to lead to early menopause.

The symptoms of menopause can be uncomfortable and can impact on your overall sense of wellbeing. Some are similar to symptoms of lymphoma, so you might worry that they are a sign of relapse. **Seek advice from your GP or medical team if you're unsure.**

As well as periods stopping, you might experience:

- hot flushes
- night sweats and waking
- mood changes
- problems with memory and concentration
- headaches
- muscle aching and stiffness
- loss of interest in sex, and vaginal dryness or irritation, which can make having sex painful.



## Tips for reducing symptoms and long-term effects of menopause

- Eat a healthy diet with plenty of calcium, which is found in milk, cheese, yoghurts and dark, leafy green vegetables such as broccoli and spinach.
- Take regular physical activity.
- Maintain a healthy weight.
- Limit your intake of caffeine and alcohol, and don't smoke.

An early menopause can have long-term effects caused by low levels of the hormone oestrogen. These include an increased risk of developing other conditions:

- Osteoporosis (thin, brittle bones), which can mean it's easier to have a bone fracture. Search 'osteoporosis' at [nhs.uk](https://www.nhs.uk) for more information.
- Possibly cardiovascular (heart) disease, including heart disease and stroke, but the evidence for this is less clear. Visit [womens-health-concern.org](https://www.womens-health-concern.org) to find out more.

It might be possible to reduce these risks by replacing the missing oestrogen with hormone replacement therapy (HRT).



**After my stem cell transplant, I didn't have any periods so I wanted to have confirmed by blood tests that I'd had the menopause. There was a time when I felt like less of a woman because I could no longer have children. It felt like a lost opportunity, and I felt sad. I didn't experience judgement from others, merely curiosity. It helped to be honest and straightforward with them.**

Juliet, affected by early menopause after treatment for Hodgkin lymphoma

If you are experiencing symptoms of menopause, tell your medical team. They might offer you hormone replacement therapy (HRT) if it is suitable for you. They can also suggest treatments to help relieve symptoms of menopause and might refer you to a health professional who specialises in menopause.

Speak to your medical team before taking any herbal remedies or complementary medicines. The dose, purity and safety can vary and, importantly, could interact with other treatments you've had or are currently having.



**Relationships can change. Those that matter continue as before; others may change beyond recognition.**

Kathleen, diagnosed with Burkitt lymphoma

# Relationships, family and friends

<b>Changes to relationships</b>	94
<b>Your partner</b>	95
<b>Telling people about your lymphoma</b>	98
<b>Effective communication</b>	99
<b>Talking to children about lymphoma</b>	101
<b>When someone close to you has lymphoma</b>	105

## Changes to relationships

There are likely to be changes in some of your relationships after a diagnosis of lymphoma. Some interactions might feel strained. Family and friends might be afraid of saying the 'wrong thing' and upsetting you. You might worry about burdening people with your feelings. Other relationships might grow stronger as you offer one another support and find your way through challenges together.



**I was open about my lymphoma and answered questions honestly. It's important to demystify cancer and show that it's not as bad as the media sometimes makes it out to be.**

Kate, diagnosed with Hodgkin lymphoma

Practical changes can also be difficult to adjust to. For example, you might find it hard to accept help with transport to medical appointments, or if a friend offers to walk your dog. Most people want to help – let them know how they can best support you. We've got more tips for accepting help on page 23.

There might be times when you feel angry or resentful because people around you seem to carry on with their lives as normal. These feelings are natural but can be very painful, particularly if you have no outlet for them.

**Finding ways to express yourself can be hugely beneficial (see page 19) and can help you to adapt to your situation.**

Sometimes, people say or do things that you find patronising or annoying. You might get irritated by their well-meant advice. Some people might not seem to grasp that you are unwell if you look healthy. At the same time, many people with lymphoma say that people are over-cautious with them. Friends and acquaintances might, for example, pretend not to see you and cross the road to avoid conversation. This is probably out of concern not to say the wrong thing, but it can bring about a great sense of isolation. Keep in mind that people are not acting out of malice.

It might help to take the lead in approaching others.  
Say hello and let them know you're still you.



## Your partner

It doesn't matter how long you've been together or what else you've dealt with, a cancer diagnosis affects relationships. There might be times when you and your partner are in different places, mentally and emotionally. For example, one of you might want to quietly process what's happening while the other wants to talk things through. You might also have different ideas about what's best for you; maybe your partner asks you to 'take it easy' but you find this restricting and want to carry on with your daily routine as far as possible. These differences, in addition to each of you finding your way through such an

unfamiliar situation, can cause anxiety, frustration and tension and lead to a breakdown in communication. Find tips to help with communication on page 99.

## Sex during treatment

Sex during treatment is generally safe, but ask your medical team if there are any precautions you should take. This is especially important if you're on treatment or your platelet count is low (thrombocytopenia – see page 78).



If you're currently having chemotherapy, use a condom to avoid passing chemotherapy to your partner, to protect against infection and to prevent pregnancy (which is not recommended during treatment for lymphoma – see page 86).

Some types of chemotherapy can cause difficulty getting or keeping an erection ('impotence' or 'erectile dysfunction') in men and vaginal dryness in women. Both of these are temporary, but can be made worse by psychological factors, such as how you feel about yourself. Ask your medical team for help if these problems affect you. You might feel awkward but doctors are used to talking about sensitive issues and should offer suggestions to help.

**Don't worry if you have sexual difficulties or lose interest in sex when you're on treatment. This is not uncommon.**

It can happen for various reasons including changes to body image and self-confidence, anxiety, stress, fatigue and feeling generally unwell. If you feel less connected to your partner emotionally, this can also affect your sexual desire.

Let your partner know if your sex drive is lowered and explain that this doesn't mean that you no longer find them attractive. Remember that there are other ways to express affection, whether through physical touch or in other ways. Keep in mind that sex drive usually returns once you've recovered from treatment. Being open with your partner about your feelings can help to develop emotional closeness, which, in turn, can help with physical intimacy. Although it might feel awkward to start a conversation on the topic with your partner, you might find it becomes easier once you start.

**Visit [sexualadviceassociation.co.uk](https://sexualadviceassociation.co.uk) for information and resources to help improve sexual health and wellbeing.**



## Telling people about your lymphoma

People are often unsure how to react when they find out someone they know has cancer. Some might withdraw. Others might have lots of questions, which can be difficult and tiring to handle. Consider how much you're comfortable sharing. For example, you could simply say: 'I've been unwell but I'm having treatment and I'm doing OK'. Or you could go into more detail: 'The last couple of months have been really tough as I've been having treatment for lymphoma. I've felt stressed and low at times. Some of my hair fell out because of the chemotherapy, which is why I sometimes wear a head covering.'



**I decided to speak openly about what I was going through. It makes conversation so much easier. No one is in any doubt about what, or what not, to talk about.**

Paul, diagnosed with non-Hodgkin lymphoma



## Tips for sharing information about your lymphoma

To save you from having to repeat information and lots of similar conversations, you could:

- Have a key contact, who passes information between you and groups of friends or colleagues.
- Send group messages with updates.
- Set up a private blog.
- Use social media – although be aware that your posts will remain online for years to come.
- Let people know that they can find out more about lymphoma on our website. They can also get in touch and speak to a member of our helpline team (page 174).

## Effective communication

When life is challenging, communication can become strained. Often we take our feelings out on those who are closest to us. In general, honesty and openness is helpful in allowing an opportunity to talk through difficulties. It can also prevent assumptions, hurt feelings and misunderstandings.

## 'I' statements

'I' statements focus on you and your feelings instead of another person's behaviours and actions. They can help you express yourself while lowering the risk of angry, hurt or defensive responses and the perception of blame. The table below gives examples. When using 'I' statements, think about:

- how you feel or felt and why
- how you'd like things to be different, possibly with an idea for how this could happen.

Statement	Rephrased to an 'I' statement
You're always telling me I need to rest.	I felt frustrated yesterday when you told me to rest.  I know you care but I want to do things when I have the energy to. It helps me to feel more like myself.  Can we agree that you'll trust me to tell you when I need to rest?
It was embarrassing that you told our friends I'm not well enough to see them.	I was upset you'd told our friends I wasn't feeling well enough to see them. I was worried they might not contact me so much in the future.  We could let them know I appreciate their care and that I'll contact them when I have more energy.



**Search 'communication' at [relate.org.uk](https://relate.org.uk) for communication tips.**

## Talking to children about lymphoma

Talking to children about lymphoma is tough. It's also something you're likely to worry about getting right. You might be concerned about frightening or upsetting them. Perhaps you feel you don't have the emotional resource and energy to cope with their responses.

There's no one 'right' way of telling a child about a parent or relative's diagnosis. However, research shows that children cope better if they understand what's happening. Even very young children pick up on anxieties and frustrations within their home. It can be very troubling for them if they don't know why these tensions are there.



You know your child best. Trust your intuition and be guided by how much or little he or she wants to know. It's also a good idea to let your child's school know about the situation, so that they can offer support.

Help your child understand the situation by being honest. Use language that is appropriate to their age and development. This encourages them to express their fears and anxieties instead of giving them the message that they must not talk

about 'it' for fear of upsetting you. It's also important for children to know that nothing they did, or didn't do, has caused your lymphoma, and that they can't catch it from you.

Talk about your lymphoma to help your child feel more secure and trusting of you. Let them know it's OK to talk about the situation.



**When my husband was diagnosed, our daughter coped well but my son found it very difficult. That first week was difficult for all of us. We were a bit lost and things seemed pretty desperate. Eventually we adjusted into the new routine.**

Sue, whose husband was diagnosed with follicular lymphoma

If they feel they can't talk and ask questions, a child might try to cope with difficult feelings on their own. This can heighten their fears as they start to imagine the worst possible outcome.



Giving young children information little and often can be more helpful than giving lots of information at once. Let your child know it's OK to come back and ask questions and talk to you as often as they want to.

Some children find it helpful to do something creative while they try to understand the situation and to express their feelings. For example, you could offer drawing, painting, plasticine or modelling clay.

Some hospitals let children visit the treatment unit. This can help to lessen their fears. Often, the hospital environment is not as bad as they might expect.



**My 4-year-old knew I was having tests and even helped with biopsy dressings. She found it helpful to feel and name my nodes. We told her the name of my cancer and showed her photos of me having my medicine. She met my hospital team, too, which seemed to have a calming effect.**

Lynda, diagnosed with non-Hodgkin lymphoma



## Tips for talking to children about lymphoma

- Consider if you'd like someone with you, for example, a partner or friend. Some hospitals offer a nurse or social worker to be there.
- Choose a time when you're feeling calm and when you feel able to deal with questions. Try not to put yourself under pressure to have all the answers, though. It's OK to say something like, 'I don't know the answer to that, but shall we talk about it and I can try to find out more?'
- Help prepare children for likely changes. For example, let them know that you are likely to be more tired or that you could lose your hair. Think about how their daily routine might change – for example, who will pick them up from school on the days you have treatment.
- Tell them how you feel, for example, tired or in pain. Let them know that this isn't linked to how you feel about them.
- If you have more than one child, speak to your children at the same time so they all have the same information.



**Visit [lymphoma-action.org.uk/Children](https://lymphoma-action.org.uk/Children) for more tips, including short animations that explain lymphoma to children. Macmillan Cancer Support also have tips on talking to children and young people about cancer. They publish a set of free books. Search 'children and young people' at [be.macmillan.org.uk](https://be.macmillan.org.uk)**

## When someone close to you has lymphoma

When someone close to you is diagnosed with lymphoma, it's a lot to cope with. As well as dealing with the news yourself, you might be keen to offer practical and emotional support to the person who has lymphoma. It's entirely natural to experience some powerful feelings in this situation, such as worry, fear and anger. You might also feel resentful of the impact of the illness on your life, which can in turn lead you to feel guilty. If the person with lymphoma is your partner, you might feel sadness and loss as you re-think your future plans, whether in the short or longer term.



**At Lymphoma Action, we're here to support you as well as the person with lymphoma. Our helpline, support groups, online forums and buddy scheme are open to you, too. See page 174 for more information.**



## Tips when someone close to you has lymphoma

### To take care of yourself...

- Eat and drink healthily, take exercise and build relaxation and enjoyable activities into your life.
- Connect with others who can relate to your situation. For example, Carers UK have an online forum where you can share thoughts, feelings and tips.
- Find an outlet for your thoughts and emotions, such as writing, drawing or making music. You might find it helpful to talk to a counsellor. See page 31.
- If you're a carer to the person with lymphoma, let your GP surgery know so that they can offer support. If you're employed, speak to your HR department about any adjustments that could help you, such as flexible working hours or a temporary change in duties.



## Tips when someone close to you has lymphoma

### In taking care of the person who has lymphoma...

- Don't underestimate the value of simply being there. Be willing to listen without trying always to find a practical solution.
- Respect the person's privacy. There might be times when they don't want to talk or to share much information.
- Let the person be them. Take them away from thoughts of lymphoma by talking about things they're interested in. You could help organise social activities for when they feel well enough.
- Offer practical help. For example, you could offer transport and support at hospital appointments, or prepare meals for them.



**Search 'caring' at [lymphoma-action.org.uk](https://lymphoma-action.org.uk) for information about caring for someone who has lymphoma. We also produce a book specifically for carers. Visit [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books)**



**Self-esteem issues have been the longest lasting effect of cancer treatment for me. I felt terrible that my hair was all patchy, and my face had swollen up. When I was given a wig, it was the first time I felt good about my appearance since treatment began. I wish I could go back and tell myself that I was beautiful with or without hair.**

Georgia, diagnosed with Hodgkin lymphoma

# Self-esteem

**Body image** 110

**Self-confidence** 111

# Body image

Body image is how you feel about your physical appearance. Lymphoma and its treatment can affect the way you look. For example, you might experience a change in weight, hair loss, or look more tired than usual. All of these changes can affect how you feel about yourself.

If your body image suffers, it can have a knock-on effect on other areas of your life, such as your social and sexual relationships and your feelings of competence in your work. Unsurprisingly, your self-confidence might also be affected.



Recognise the significance of what you have been through, physically and emotionally. It might not be realistic to accept changes straightaway, but trust that you will adapt over time.

Remember, too, that changes to your body and the way you look are often temporary and that there are resources to help you cope.



**Boots and Macmillan Cancer Support have a partnership to provide local support for people living with cancer. Search 'information pharmacist' at [macmillan.org.uk](http://macmillan.org.uk) to find out more.**

# Self-confidence

Lymphoma will almost certainly have changed your life to some extent. You might feel a sense of loss and feel 'thrown', which can lower your self-confidence. Allow time to think about these changes. You could talk about them with a friend or a counsellor (see page 31).

Sometimes, people find it difficult to think beyond their lymphoma. They begin to see themselves and the illness as one. Remind yourself of other aspects of yourself, your different roles and interests. For example, you might be a father, friend, employee. You might enjoy watching sports or a particular comedian. Think about your likes, dislikes and values, too. These are all important elements that make up your identity.

## Your 'inner voice'

Pay attention to your 'inner voice'. It's human nature to judge yourself. However, you might notice that your self-judgements are often negative, for example, 'I didn't achieve a single thing today' or 'no one finds me attractive'. You can think of these as the voice of your inner critic – a voice that is often unhelpful.

To bring some distance between you and your inner critic, you could write down these messages. First, use 'I' ('I'm boring', 'I'm not interesting') and then use 'you' ('you're boring', 'no one finds you interesting').

Once you have written down your inner critic's messages, challenge them. Respond to each with something kind that a friend might say. Write these responses down using 'I'. For example, in response to 'you're boring', you might say: 'Jim invited me for coffee so clearly he doesn't find me boring. I also helped him with a dilemma so I contributed something valuable.'

With practice, you can become more aware of your inner critic. Instead of absorbing the critical messages and accepting them as the truth, you're likely to more easily respond with balance and compassion.



## Tips for re-building self-esteem and confidence

- Think about what you have achieved, instead of what you haven't done. You could reflect on this at the end of each day.
- Stay in touch with supportive friends and family.
- Keep up with enjoyable activities to give you a sense of normality.
- Set goals. These can give you something to focus on, and achieving them can be very satisfying.
- Challenge unhelpful thinking patterns. Think, 'what evidence do I have to support this thought?'  
See pages 26 to 31 for more about thinking patterns.



**I had a very useful conversation with a friend who had come through his own cancer experience. Interestingly, we focussed on exercise, diet and outlook on life. I also decided to share my cancer with all those close to me and spoke openly about what I was going through. It makes conversation so much easier. No one is in any doubt about what, or what not to talk about.**

Paul, diagnosed with non-Hodgkin lymphoma

# Managing stress and anxiety

<b>Boxing (containing) your worries</b>	<b>116</b>
<b>Talking about your experience</b>	<b>117</b>
<b>Making time for yourself</b>	<b>117</b>
<b>Relaxation techniques</b>	<b>118</b>
<b>Sleep</b>	<b>122</b>
<b>Complementary therapies</b>	<b>124</b>

Some people question whether stress can cause cancer or make it worse. Scientific evidence does not support this idea, but finding ways to manage stress can certainly benefit overall emotional wellbeing.

For many of us, the 'default' or natural state is a wandering mind – thinking about the past or the future. At times, your worries and concerns might be right at the forefront of your mind, seemingly taking over your thoughts. This can be exhausting. You might not be able to get rid of these worries entirely, but there are strategies you can use to try to manage them.

## **Boxing (containing) your worries**

It can be impossible to relax or to focus on anything else when you have worries going around in your head.

You could try to 'box' or compartmentalise these, setting aside fixed 'worry time' to think about them.

Write down any worries as they come to you. If you often have worrying thoughts at night-time, keep a notepad by your bed. Make an agreement with yourself that you'll return to them and give them your attention later. When you do come back to them during your 'worry time', you can look at which ones you can do something about and make a plan to deal with them (see page 26). For those that are beyond your control, develop ways of relieving stress and anxiety. This strategy takes practice and doesn't work for everyone. Even if

it does help, it might only work on some days or with some issues.

## Talking about your experience

Talking to other people who can relate to your experience can be very beneficial. Some people find it easier to talk openly to people who have personal experience of lymphoma than to family and friends. Others prefer to speak with a trained counsellor (see page 31). You might also be interested in connecting with others through our support services, including our support groups and Buddy service. Find out more on page 174.

## Making time for yourself

Living with lymphoma might sometimes feel as though your life is filled with medical appointments, treatments, tests and medications. It can be hard to make time for yourself but it's important that you try to prioritise it.

You could list things that help you relieve stress and try to build them into your day-to-day life. For example:

- doing something active, like going for a walk, gardening or painting
- socialising, for example, meeting friends or catching up with a relative on the phone
- relaxing and enjoying some peace, for example, taking a bath or listening to soothing music
- watching a film or reading a book.

# Relaxation techniques

There are various techniques you can try to relax your body and encourage a calmer state of mind. We outline some of these on the next few pages.

## Breathing techniques

Breathing techniques can be helpful in tense and stressful situations. Many people say they help them to feel more calm and in control, and to think more clearly. You could try a breathing technique to help if you feel uneasy – for example, about having chemotherapy, waiting for scan results or being on active monitoring ('watch and wait').

An exercise that many people find helpful is '7/11 breathing':

- Find a comfortable position, either sitting, standing or lying.
- Breathe in through your nose while counting silently to 7.
- Breathe out through your mouth while counting silently to 11.
- Repeat until you feel calmer. A few minutes is often enough.

Don't worry if you can't breathe in for the count of 7 and out for the count of 11 at first. The main thing is to breathe out for longer than you breathe in. This slows the rate you take oxygen in and, in turn, helps your body stop preparing for 'fight or flight'.

## Progressive muscle relaxation (PMR)

Progressive muscle relaxation (PMR) aims to help you release physical tension. It involves tightening (tensing) and relaxing different muscle groups. PMR exercises can help you relax before bed, or before, during or after something you find stressful. An example is below:

- Find a comfortable sitting or lying position.
- Clench your fists tightly for 5 seconds, then let go.
- Shrug your shoulders up towards your ears. Hold them here tightly for 5 seconds, then release.
- Pull your chin towards your chest. Clench your teeth and frown. Hold for 5 seconds then move your chin back to its natural position and relax the muscles in your face.
- Close your eyes tightly. Hold for 5 seconds, then gradually let them open.
- Clench your buttocks. Hold for 5 seconds, then release the tension.

At the end of the exercise, pay attention to the feeling of release. Breathe out, get up slowly and gently stretch.

**You can find out more about PMR online, for example, at [nopanic.org.uk/relaxation-technique](https://nopanic.org.uk/relaxation-technique)**



## Meditation

Meditation techniques aim to help you relax. There are many different types. Research suggests that meditation might improve mental wellbeing in people with cancer and could also reduce sleep disturbance and fatigue.

Mindfulness is a popular type of meditation. It encourages you to slow down and pay attention to the present moment; the 'here and now'. This includes your breathing and other physical sensations, such as the feel of your feet on the ground, the breeze against your skin, the temperature of the air, and any sounds you hear.

**Many people use mindfulness to feel calmer, to help take control of their thoughts, and to prevent worries from taking over their mind.**

Although mindfulness takes practice, even doing it for a short time each day can be helpful.



- **Search 'mindfulness' at [mentalhealth.org.uk](https://www.mentalhealth.org.uk) to find out more.**
- **You can also download mindfulness apps, such as Calm, Headspace, and Smiling Mind.**

Yoga is another popular type of meditation. It is often described as a 'mind–body' exercise, combining breathing with stretches and controlled movements. Many people say that yoga improves their overall mental wellbeing. Some research also suggests that it might help people cope with symptoms of cancer and side effects of treatment, including anxiety, fatigue, quality of sleep and mood.

**Search 'yoga' at [nhs.uk](https://www.nhs.uk) to find out more.**



## Visualisation

Visualisation is where you use your imagination to picture a relaxing image or scene, such as mountains, a beach or woodland. Imagine it in as much detail as possible, including what you might see, smell, hear and feel if you were actually there. You can work with a therapist to guide you through visualisation, or you can use resources such as podcasts and apps.

Some studies suggest that visualisation might improve mood and sleep quality in people with cancer.

## Music

Some people use music to relax or to take them away, mentally, from an unpleasant situation. For example, music might help to distract you from a medical procedure you feel nervous about.



**I really struggled with the thought of chemo. Then I found a CD that comforted me. Two weeks later, I walked back into the hospital and told my nurse I was going to close my eyes and listen to my music.**

Reem, diagnosed with Hodgkin lymphoma

Although more research is needed, some studies have found that benefits of music for people living with cancer might include lowering anxiety and managing pain.

**If music is helpful to you, you could make a playlist to use at challenging times. Ask your medical team if you can listen to it during scans or other procedures.**

## Sleep

Many people experience sleep difficulties, including struggling to fall or stay asleep, waking early or having nightmares. Having lymphoma can increase the likelihood of such difficulties. Side effects of treatment, pain, stress and anxiety can lower the quality of your sleep, which can, in turn, add to fatigue.



## Tips to help your sleep

### **Help to set your 'body' (internal) clock:**

- Get into a routine of going to bed and getting up at the same time each day.
- Get some natural light during the day.
- Relax before bed. For example, have a bath, read a book or listen to music.

### **Close to bedtime, avoid:**

- Foods and drinks that temporarily increase how alert you feel ('stimulants'), like chocolate and other sugary foods, sugary drinks, coffee and tea.
- Alcohol.

### **Make your bedroom into a 'sleep-ready' environment:**

- Have it at a comfortable temperature.
- Keep it dark. You could use blackout curtains or blinds, or wear an eyemask. Minimise 'blue light' from mobile phones, laptops and tablets. Most devices have a filter you can set to lower the amount of blue light they give off.
- Filter out noise that prevents you from sleeping. For example, use ear plugs or try playing soft music.
- Keep a pen and paper nearby to write down any thoughts that are going around in your head. See page 24 for more on dealing with worries.

If you have ongoing sleep difficulties, ask a member of your medical team for advice specific to your situation.



- **Search 'sleep' at [mentalhealth.org.uk](https://www.mentalhealth.org.uk) to download or order a guide on how to sleep better.**
- **Search 'sleep' at [nhs.uk](https://www.nhs.uk) for more information about sleep, including possible treatment options for sleep difficulties.**

**Do not take sleeping tablets or other remedies, including herbal ones, without speaking to a member of your medical team to check that they are safe for you.**

## Complementary therapies

Complementary therapies are used alongside treatment for lymphoma. They do not cure your lymphoma, but some types of complementary therapy might improve your mental and physical wellbeing. There are many different types of complementary therapies, such as aromatherapy, reflexology and massage. Many people find them relaxing and use them as a way of managing stress and anxiety.

Some studies suggest that complementary therapies might help people who are living with cancer. For example, acupuncture could help to reduce sickness (nausea), pain and symptoms of peripheral neuropathy. Massage might help reduce pain, fatigue and anxiety.



**Find out more by searching 'complementary therapy' at [cancerresearchuk.org](https://www.cancerresearchuk.org)**

Speak to your medical team if you're interested in trying a complementary therapy. They might:

- Advise whether it is suitable – for example, whether it could interact with another treatment you're having.
- Tell you about any reputable, local services. Some local charities and hospitals offer complementary therapies free of charge to people affected by cancer.
- Advise you on anything you should tell a complementary therapist before having treatment. For example, if you have a low platelet count, you might bruise easily, so your medical team might suggest asking your therapist to use a gentle touch.

Avoid having complementary therapy to any areas of your body that are being treated with radiotherapy. Remember, too, that your skin might be sensitive. Plain ('carrier') oils, which are made from plants, are likely to be more suitable than other types.



**Many hospices offer complementary therapies, free of charge. Find your local hospice at: [hospiceuk.org/about-hospice-care/find-a-hospice](https://www.hospiceuk.org/about-hospice-care/find-a-hospice)**



## **Tips for choosing a complementary therapist**

- Check the therapist's qualifications and professional organisation membership. This is usually in their leaflets or on their website. You could also ask to see training certificates.
- Find out about their experience – how long have they been practising and have they treated people with cancer?
- Check they have appropriate insurance. Does it cover them to treat people with lymphoma?



I felt all the certainties of life that I had taken for granted were now gone and the future looked very uncertain to me. Having a cough or cold made me anxious that the lymphoma had come back. Life seemed really challenging at that point and I felt like an outsider. I told my medical team how I felt and they organised for me to see a psychologist, which really helped.

Hayley, diagnosed with Hodgkin lymphoma



Notes



**Lymphoma hasn't stopped me living my day-to-day life. I try to do what I can when I can: I travel. I sing (I'm a professional singer). I do anything – but when I can't do it, I just accept it and stop. Some tasks were difficult as I live on my own. My medical team referred me for physiotherapy, which was really helpful – so do ask for support if you need it.**

Andrew, diagnosed with follicular lymphoma

# Day-to-day living

<b>Diet and nutrition</b>	<b>130</b>
<b>Alcohol, smoking and drugs</b>	<b>135</b>
<b>Physical activity (exercise)</b>	<b>136</b>
<b>Driving</b>	<b>139</b>
<b>Finances</b>	<b>140</b>
<b>Work</b>	<b>142</b>
<b>Study</b>	<b>144</b>
<b>Holidays and travel</b>	<b>145</b>

# Diet and nutrition

Eating well helps your body recover from treatment and can improve your general wellbeing.

The Eatwell Guide (opposite) has been developed by the government. The key points are to eat:

- at least five portions of a variety of fruit and vegetables each day
- plenty of carbohydrates (starchy foods) each day
- some protein, such as meat, fish, eggs, tofu, beans and pulses each week
- some milk and other dairy (or dairy alternative) foods each week
- only small amounts of foods that are high in fat and added salt and sugar.

Staying hydrated is also important for good health. Aim to drink six to eight non-alcoholic drinks (roughly 1.2 litres) each day and more in hot weather.



If you struggle to eat or drink, ask your medical team for advice. They might offer you nutritional supplements or refer you to a dietitian.

You can also download the guide on the government website. Search 'eatwell guide' at gov.uk



# Eatwell Guide

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

Check the label on packaged foods

Energy	Fat	Salt
100kcal	10g	0.5g
200kcal	20g	1g
300kcal	30g	1.5g
400kcal	40g	2g
500kcal	50g	2.5g
600kcal	60g	3g
700kcal	70g	3.5g
800kcal	80g	4g
900kcal	90g	4.5g
1000kcal	100g	5g

Typical values for solid per 100g (80%)/100kcal  
Choose foods lower in fat, salt and sugars



**Fruit and vegetables**  
Eat at least 5 portions a variety of fruit and vegetables every day

**Potatoes, bread, rice, pasta and other starchy carbohydrates**

**Dairy and all types of eggs**  
Choose lower fat and lower sugar options

**Beans, pulses, fish, eggs, meat and other proteins**  
Eat more beans and pulses; 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat

**Oil & spreads**  
Choose unsaturated oils and use in small amounts

Eat less often and in small amounts

Source: Public Health England in association with the Welsh Government, Food Standards, Scotland and the Food Standards Agency in Northern Ireland © Crown copyright 2016

## Frequently asked questions about diet and lymphoma

In this section, we cover some common questions about diet and lymphoma. Speak to your medical team for advice specific to your situation.

**Can any foods cure lymphoma?** Unfortunately, there are no foods that can cure cancer. Be wary of news stories or other claims saying that it can.

Cancer Research UK advise against following diets that claim to treat cancer ('alternative cancer diets'). There isn't scientific evidence to say they work, and they could make you very unwell or lead to nutritional deficiencies.

**Should I follow an organic diet?** 'Organic' foods and drinks are produced with restricted use of man-made fertilisers and pesticides. Some people choose to follow an organic diet if they're concerned about the traces of pesticides and herbicides in products. These levels are closely monitored to ensure they stay below the level considered to put health at risk. At the moment there is no quality evidence that organic foods can prevent cancer or stop it from coming back.

**Is it safe to eat grapefruit?** Grapefruit can block a protein called CYP3A4, which helps break down some medicines in your body. Your doctor might advise you against eating grapefruit or drinking grapefruit juice while you're having

treatment for lymphoma. Other fruits that might block CYP3A include Seville oranges, blackberries, pomegranates and some varieties of grapes.

**Is it helpful to drink green tea?** Scientists think there is a possibility that green tea might reduce the risk of some cancers and stop cancer cells from growing, but far more research is needed.

**Will nutritional supplements help me?** There's no evidence that dietary supplements can prevent or cure cancer. If you eat a healthy balanced diet, you don't usually need to take an additional vitamin or mineral supplement. However, if eating is difficult, your medical team might advise you to take a general multivitamin and a mineral supplement to help you get the nutrients you need.

Some vitamins and minerals react with some cancer treatments, so speak to your pharmacist, doctor or dietitian before you start taking any supplements.

**Should I avoid certain foods if my immune system is suppressed (lowered)?** If you have lymphoma, or your blood counts are low after treatment for lymphoma, your immune system might not work as well as it should. This increases your risk of developing an infection. Speak to your medical team for advice on how to reduce your risk of developing a food-related infection. We also have tips on page 76.

**Will sugar make my lymphoma worse?** Some people ask whether sugar 'feeds' cancer and makes it grow. All of the cells in our body get their energy from sugar. Cancer cells usually grow more quickly than healthy cells, so they often use a lot of energy.

There is no evidence, however, that eating sugar makes lymphoma or any type of cancer grow. Eating a lot of sugar can have other health risks, including obesity, which is linked to the development of other types of cancer. There is no evidence that cutting out sugar will make your lymphoma go away.

**Can the herb Echinacea help me?** Some people believe that Echinacea (purple cornflower) can boost your immune system, fight cancer and improve side effects of chemotherapy and radiotherapy. There is no evidence to support these claims.

**Can I eat out?** There's no reason that you shouldn't enjoy a meal out, although if you are neutropenic, you should take precautions to minimise the risk of developing an infection (see page 77).

**Is it safe to diet while I am having treatment for lymphoma?** Generally, doctors advise that you should not diet during treatment because it can make it harder for your immune system to recover. Instead, focus on eating a healthy, balanced diet (see page 130).



**For more information about media claims related to foods and nutrients and their link to cancer, search 'food controversies' at [cancerresearchuk.org](https://www.cancerresearchuk.org)**

## Alcohol, smoking and drugs

A healthy lifestyle includes not smoking, taking recreational drugs or drinking a lot of alcohol.

### Alcohol

Ask your CNS or consultant whether it's safe to drink alcohol while you're having treatment. Alcohol can interact with some drugs and affect how well they work. It's usually OK to have the occasional drink between chemotherapy cycles when you feel well enough, but check with your medical team first. Also, remember that you might feel the effects of alcohol more quickly than you did before you had treatment.

### Smoking

Smoking increases your risk of developing infections, especially in the lungs. If you are currently having treatment for lymphoma, the risk increases further.

To limit the risk of damage to the lungs, it's particularly important not to smoke if you've had radiotherapy to the

lungs. Some drugs used to treat lymphoma can also affect your lungs, including the chemotherapy drug bleomycin and the targeted drug brentuximab vedotin (see page 164).



**If you smoke, stopping can help to lower these risks. Advice and support to help you quit smoking is available at [nhs.uk/livewell/smoking](https://www.nhs.uk/livewell/smoking)**

## Recreational drugs

During treatment for lymphoma, your body is working hard to break down and process treatment. Recreational drugs could have an effect on your lymphoma treatment and increase your chances of side effects, so it's important to let your medical team know if you take them.

Even after treatment, leading a healthy lifestyle that is free from recreational drugs helps to put you in the best position to maintain good health. See page 54 for information about cannabis for medicinal purposes.

## Physical activity (exercise)

Exercise can have a positive impact on physical and mental health. For some people, it's a social activity, while for others, it provides time to be alone ('me time').

Although rest is also essential to recovery, it is both safe and beneficial to exercise during and after treatment. It can lower fatigue, reduce your risk of infections and increase your bone and muscle strength. It can also help you to recover more quickly after treatment.



**I do dog training, swimming and walk as much as I can.  
Exercise is a vital part of feeling well.**

Linda, diagnosed with follicular lymphoma

The UK recommendations on exercise for people with cancer are the same as they are for people who do not have cancer. For adults, this is 30 minutes of activity 5 days a week. Ideally, you should do some physical activity every day. If you're not able to do this at first, you can build up the amount gradually.

Aim to include physical activity in your everyday life, for example:

- go for a walk
- take the stairs instead of a lift or escalator
- do some household chores or gardening
- push a shopping trolley or carry shopping bags.



It's important to find exercise that is enjoyable and safe for you. Make sure you give your body time to recover, so alternate activity with rest.



**I used to be very active and enjoy running. I found it difficult to accept, having to start again with light exercise such as walking, but I improved bit by bit.**

Georgia, diagnosed with Hodgkin lymphoma

Your medical team might recommend avoiding some types of exercise at certain times. For example, you'll probably be advised to avoid contact sports like rugby if you have low platelets (thrombocytopenia, see page 78), due to the risk of bruising and bleeding. If you have peripheral neuropathy (see page 79) that affects the feeling in your hands and feet, cycling on a stationary exercise bike might be safer than cycling on the road.

## **Is it safe to go swimming?**

Swimming has many health benefits, but you should avoid it if you:

- are neutropenic (see page 74), in order to avoid infection from public pools and changing rooms
- are having radiotherapy, because chlorine could irritate the skin in the area being treated
- have a central line or PICC line (a tube inserted into a vein deep inside you to give treatments and take blood), due to risk of infection.

Talk to your medical team about whether swimming is safe for you.

## **Can exercise prevent a relapse (return) of my lymphoma?**

Scientists don't know for certain whether exercise can lower the risk of lymphoma, or any other type of cancer, coming back. However, there is growing support for the possible role of exercise in lowering this risk.

## **Driving**

Having cancer doesn't mean that you can't have a driving licence. In general, it should still be safe to drive while you're having treatment for lymphoma. However, some treatments might affect your ability to drive safely – for example, if they make you sleepy, nauseous or affect your concentration. It's also unsafe to drive if you are taking some anti-sickness medicines (antiemetics). If you have peripheral neuropathy (symptoms that affect the feeling in your hands and feet), inform the DVLA.

Even if it is generally safe for you to drive, there might be days when you feel tired, particularly after treatment. If possible, ask someone to drive you to and from your appointments. If there is nobody available to do this, speak to your CNS for advice. Ask if your hospital offers a transport service.



You have to inform the DVLA if you have peripheral neuropathy (nerve damage), a side effect of some treatments for lymphoma (see pages 79 to 82).

You might also need to tell your car insurance company if your treatment affects your ability to drive.



**Check [gov.uk/lymphoma-and-driving](https://www.gov.uk/lymphoma-and-driving) for the latest advice.**

## Finances

Living with lymphoma can put a strain on your finances, particularly if your income is reduced.

Travelling to and from hospital can also be costly. Some hospitals offer free parking for people who have cancer, so it's worth checking whether yours does.

**Under the Equality Act 2010, a diagnosis of cancer automatically meets the government's definition of disability. This applies also to people whose treatment has been successful.**

There is a range of government financial support that you might be entitled to. Some of these depend on your earnings and any savings you have.



**Financial support can be complicated, so it's best to seek professional guidance to find out what you're eligible for. You could try:**

- **Citizens Advice, who have benefits advisors. Find your nearest branch at [citizensadvice.org.uk](https://citizensadvice.org.uk). Some have a partnership with Macmillan; find out more from your local branch.**
- **The government website, which has information about benefits. Visit [gov.uk](https://gov.uk)**
- **Macmillan Cancer Support, who offer information about financial support for people who are living with or caring for someone with lymphoma: [macmillan.org.uk](https://macmillan.org.uk)**



In addition to state benefits offered through government schemes, there might be charities and other local organisations that provide grants (one-off payments). Benefits advisors at your local Citizens Advice and your clinical nurse specialist are good people to ask.

## Work

You're likely to need to take some time out of work during treatment, and probably for a little while after finishing treatment. Speak to your HR department or line-manager about this. Ask how they can support you.

If you are able to, you might choose to carry on working through your treatment. Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working during and after your treatment. Under the Equality Act 2010, this applies forever, not just while you are having treatment or for a limited time after finishing. For example, if in months or years to come, you get cancer-related fatigue and a break or flexible working arrangements could help you, your employer needs to consider your requests and agree to them or work with you to come to an alternative, workable solution, unless there is a good business reason not to.



**Search 'equality act' at [gov.uk](https://www.gov.uk) for more information.**



**I work for a charity. They have been brilliant and kitted me out with a desk riser and a special chair so I can stand and work.**

Kevin, diagnosed with non-Hodgkin lymphoma



You could consider reducing or changing your working hours to avoid the rush-hour commute. Depending on the type of work you do, you might be able to work some or all of your hours from home.

Going back to work can help you to feel that life is getting back to normal. However, keep in mind that you'll need to pace yourself. It can take months to feel physically strong again and it's possible to get side effects for quite some time after treatment. The emotional effects of what you have been through can also make it difficult to concentrate.



**Physically, going back to work was hard and I found it difficult even to walk up the stairs. But mentally it did me so much good and helped me recover far more rapidly.**

Carol, diagnosed with Hodgkin lymphoma

You could have a 'phased return' (which is an example of a reasonable adjustment), starting with shorter days or weeks. You might also take fewer responsibilities to start with. Be patient with yourself. Build up gradually and allow yourself plenty of time to rest and recover.

If you are self-employed, consider how to manage your work and finances if you're unable to work. Find out whether

you're entitled to any benefits (see page 140). You can also contact the Business Debtline, an independent, free service that advises on debt and budgeting for small businesses and people who are self-employed. Visit [businessdebtline.org](http://businessdebtline.org)



**Macmillan Cancer Support have information about work and cancer, including a guide to your rights at work. Search 'work and cancer' at [macmillan.org.uk](http://macmillan.org.uk)**

## Study

You are likely to need to take time off from your studies, particularly during treatment. Talk to your school, college or university about this. They might ask your hospital team to provide a supporting letter to tell them about your lymphoma. Your education provider should be as flexible as possible, within the limitations of the exam boards.



- **Teenage Cancer Trust has more information and advice about returning to school, college or university: [teenagecancertrust.org](http://teenagecancertrust.org)**
- **If you are in your teens to early 20s and are affected by lymphoma, you might be interested in our *Young person's guide to lymphoma*. You can download this book or order it, free of charge from our website.**

# Holidays and travel

Many people plan a trip away to look forward to for after their treatment ends. There's no reason you shouldn't get away; just be sure to discuss your travel plans with your consultant before you book to check they are safe.

Most doctors advise against travelling abroad if you're having treatment for lymphoma. This is because of the increased risk of infection, possible delays in getting medical treatment and any language differences that could cause communication difficulties.

Keep in mind that for a while after treatment, your skin might be more sensitive to sun damage. For this reason, you might be advised to wait a while before visiting a hot country.



If you're planning a trip outside of the UK, you might need vaccinations. Some vaccinations need to be given well in advance (at least 8 weeks) in order to work properly, so seek advice early.

Your GP or local travel clinic can advise you on which vaccinations you need. Check with them that these are safe for someone who has, or has had, lymphoma. Most are, but some 'live' vaccines are not (see page 159). If a live vaccine is strongly recommended for people travelling to the area you plan to visit, ask your doctor for advice.



**Search 'travel vaccinations' on the NHS website: [nhs.uk](https://www.nhs.uk) to find out more.**

It's also important to get the right insurance in place before you travel. Ideally, this should include medical cover, which could save you from paying for any unexpected tests or treatment you need while you're away. It could also cover the cost of travel tickets if you need to return home early. For this reason, it can be helpful if others travelling with you have their cover provided by the same insurer – some companies insist on this approach.



**Search 'travel' at [lymphoma-action.org.uk](https://www.lymphoma-action.org.uk) for more information about safety when travelling outside of the UK.**



## Tips for staying safe when travelling outside the UK

- If you're taking medication, pack extra. Split it between bags in case a piece of your luggage is lost. Your GP can write a letter to explain the situation to security staff.
- Choose clean accommodation and be especially careful with your personal hygiene.
- Use insect repellents and mosquito nets where necessary to protect yourself from mosquitos.
- Make sure the water you drink is sterilised. The easiest way is to boil it. Note that bottled water isn't always sterilised.



**Before my diagnosis, I was careful about things, but this experience has made me far less cautious. If I want something, I buy it, if I want to do something, I start planning it.**

Kat, diagnosed with double-hit lymphoma

# Life after treatment

<b>Feelings after treatment</b>	<b>150</b>
<b>Other people's responses to the end of your treatment</b>	<b>152</b>
<b>The recovery package</b>	<b>153</b>
<b>Follow-up</b>	<b>154</b>
<b>Relapse</b>	<b>157</b>
<b>Precautions</b>	<b>158</b>
<b>Late effects</b>	<b>162</b>
<b>Live your life workshops</b>	<b>169</b>

# Feelings after treatment

Finishing treatment can bring emotional challenges. You might experience a sense of facing the unknown, and it's not uncommon to go through a whole range of feelings.

For example:

- Isolation – feeling alone as you no longer see hospital staff so frequently. Friends and family might not realise that this is still a difficult time for you and expect you to want to celebrate.
- Shock and anger – now that you're through treatment, the significance of what you've been through might hit you. Some people feel that the situation is unfair and feel angry about the disruption lymphoma has caused to their life and to the lives of those close to them.
- Irritability – you might feel that others who have no experience of lymphoma don't understand you. Things that wouldn't usually bother you might do now.
- Anxiety – even if you are in complete remission and have been for some time, it's natural to worry about the lymphoma coming back. You might feel more anxious about other aspects of your health, too, or about life in general.
- Your self-esteem and confidence might be lower than they were before you had lymphoma (see pages 109 to 113).
- Sadness – it's natural to feel saddened by what's happened to you. For some people, this can develop into feeling very low frequently. If you feel low for more than a couple of weeks, this could be a sign of depression (see pages 12 to 14), for which there is support available.

- Uncertainty – many people describe needing to find ‘a new normal’ after treatment. You might feel uncertain about your next steps, wondering where to go from here. Until now, your focus might have been on appointments and test results. When treatment is over, it’s not uncommon to feel lost and abandoned.



**The past 12 years has been a rollercoaster of emotions and at times it feels like someone’s story. The first 5 years after treatment is a blur. Since then I’ve felt everything from denial to anger, and now I’m finally at acceptance. I’m grateful for my health and the journey I’ve been on. Lymphoma has played a huge part in this and it has certainly made me stronger than I ever thought I could be. I’m immensely proud of what I have achieved in the past 12 years and looking forward to many more adventures to come.**



Blair, in remission from diffuse large B-cell lymphoma



**Adjusting to life after treatment takes time. Find out how we can support you on page 174. You might also be interested in our Live your Life programme (see page 169).**

## Other people's responses to the end of your treatment

Friends and family members are probably relieved that you've finished treatment and might want or expect you to celebrate. However, it often takes the person who has had treatment a lot longer to recover, both physically and emotionally. Think about if and how you'd like to mark the end of treatment. You might plan a trip, or perhaps treat yourself to a gift. The important thing is that **you** decide.



**I didn't feel like celebrating after finishing treatment. Weirdly, although I didn't miss the treatment, I missed some of the routine of going into hospital and seeing my team who had been so supportive.**

Kate, diagnosed with Hodgkin lymphoma

You might need to remind people that you have been through a great deal. Let them know that you appreciate their care and that you are still processing your experience and possibly also coping with ongoing side effects. Remind them, too, that it's likely to take a while for your energy levels to recover.



**See pages 18 to 19 for tips on expressing yourself and talking about your feelings. Remember that we are here to support you even after treatment (see page 174).**

# The recovery package

The recovery package aims to support you in your adjustment to life after lymphoma. It includes:

- **Holistic needs assessment (HNA)**, a questionnaire designed to help you and your medical team work together to identify and address any practical, financial, physical, emotional and social needs you have.
- **Treatment summary**, which your medical team completes. This outlines your diagnosis, treatment and its possible side and late effects. It should also tell you what symptoms you should look out for and who to contact if you notice them, including an out-of-hours number. The summary should outline your follow-up plan and any lifestyle recommendations, for example about diet and exercise.
- **A cancer care review**. This is a discussion between you and your GP or a practice nurse. It's an opportunity to check-in about any medical needs and to talk about any points from your holistic needs assessment. You might also want to find out about any financial support you're entitled to, including prescription charge exemptions.
- **Health and wellbeing events**, designed to help people affected by cancer and their families live well. Our Live your Life workshops are an example (see page 169).

**If your medical team don't offer you the recovery package, ask them about it.**

# Follow-up

Follow-up allows your medical team to check your recovery, helps you to manage any ongoing side effects or late effects of treatment, and checks for any signs of the lymphoma coming back (relapsing). It also gives you an opportunity to ask any questions or raise any concerns. As well as talking about your lymphoma and treatment, you might want to discuss other aspects of your life, such as finances, returning to work, immunisations or travel.

Follow-up appointments might also involve:

- a physical examination – for example checking for swollen lymph nodes, your weight, blood pressure and heart function
- blood tests, which can help to give an overall picture of your health.

You might also have a scan to help your medical team see how well your lymphoma has responded to treatment and to check for any signs of relapse. However, scans aren't usually part of routine follow-up.

**How often you're followed-up depends on the type of lymphoma and treatment you've had.**

You might be offered a self-management programme, which allows you to book your own follow-up appointments as-and-when you need them.

Self-management is only appropriate for certain people who are aged 18 and over. In general, this applies to those who:

- are in long-term remission (no evidence of lymphoma from tests and scans)
- have long-term stable low-grade lymphoma
- are at only a low risk of relapse.

Some people find the idea of self-management daunting at first. Most recurrences of lymphoma are picked up by the person directly affected by it, rather than on a routine appointment or test. The idea behind self-management is that you know your own body best and, with guidance, you will know when you need to get checked out. Such programmes can give you a greater sense of control, increased confidence and an improved quality of life.

If you are interested in self-management, ask your clinical nurse specialist whether it is appropriate for you and whether your hospital can offer it.

**We have more information at**  
**[lymphoma-action.org.uk/Self-management](https://lymphoma-action.org.uk/Self-management)**





**Self-management is a two-way relationship between you and your clinical team. The team support you to independently manage your health while living with and beyond lymphoma, but they are always there in the background. If you notice any changes and are worried, you can call or e-mail your team to discuss your concerns. If needed, the clinical team will book an urgent appointment and see you in person quickly.**

Dr Gilly Howard-Jones, Lymphoma nurse specialist



## **Tips for dealing with anxiety before a follow-up appointment**

- To help you remember any questions you'd like to ask, write them down before your appointment. You could run through these with a friend or family member beforehand to get them clear in your mind.
- Let your friends and family know that you have an appointment coming up and how they could support you, including showing you some patience and understanding if you are quiet, tired or irritable.
- Consider which anxiety or stress-relieving techniques are helpful to you (see pages 115 to 127).
- Get in touch with a member of our helpline team to talk about how you're feeling. (See page 174).

# Relapse

If lymphoma comes back, it can cause the same symptoms as before, or different symptoms. Ask your medical team what to look out for. Be aware of the most common symptoms. Get in touch with your medical team straightaway if you notice:

- **Swollen lymph nodes:** a lump or several lumps, often in the neck, armpit or groin. The lumps are usually painless.
- **Fatigue:** exhaustion for no obvious reason, or feeling washed out after doing very little.
- **Unexplained weight loss:** losing a lot of weight quickly without trying to.
- **Sweats:** sometimes described as 'drenching' when they happen at night because they can soak your nightclothes and bedsheets.
- **Itching** (pruritus) without a rash.
- **Fevers and infections:** some people get fevers (a temperature of over 38°C or 99.5°F in adults). Fevers often come with night sweats and weight loss, but they can occur separately. Repeated or persistent infections (that are difficult to shake off) can also be a symptom of lymphoma.

**Check for swollen lymph nodes no more than once a month. See page 37 for more information about swollen lymph nodes.**



**I am able to not think about lymphoma on a daily basis, while at the same time being fully aware of the possible symptoms of it spreading. A useful analogy is driving a car: there is no point in thinking that you might have an accident whenever you start to drive, but safety measures need to be consciously employed.**

Gerry, diagnosed with follicular lymphoma

## Precautions

Depending on the treatment you've had for lymphoma, there are precautions you might need to take to prevent infections or if you need medical care in the future.

## Vaccinations

Most vaccinations are safe for people who have had lymphoma, but it's important that you take advice from your doctor about your specific situation.

As a general guide:

- You might need to wait 6 to 12 months after finishing treatment before having a vaccination.
- You are recommended to have the annual winter flu vaccination if you have lymphoma.

- If you've had your spleen (part of your immune system) removed or you've had a stem cell transplant, you'll need additional vaccines. Your medical team can give you advice about these.
- If you're going to another country, you might need other vaccinations.

Live vaccines, such as the shingles vaccine, are made using living viruses or bacteria. They can be unsuitable for people who have lymphoma or have recently been treated for lymphoma. Check with your doctor or specialist nurse before having any live vaccines.

## **Steroids**

If you have had steroid treatment, there is a small risk that your body won't be able to make enough steroids naturally. However, this is rare, and usually only if you've had steroids at a high dose and over a long time period. If you experience issues, your doctor might check to see whether you're making enough of your own steroids when you finish treatment.

**If you're on steroids for 3 weeks or longer, you should be given a steroid warning card.**

In the case of an emergency, a steroid card lets doctors know that you are on, or have recently had, steroids. It tells them the dose and if you need to keep taking the medication. Keep the warning card with you for all the time you're on steroids and for 2 years after your treatment ends.

If you have an operation or any dental work in the future, let the anaesthetist or dentist know beforehand that you've had steroid treatment so that they can take any necessary precautions to ensure you recover well.

## **After spleen removal or radiotherapy to the spleen**

Your spleen is part of your immune system. If you no longer have a spleen, or you've had radiotherapy to your spleen, you won't be able to fight infections as well as you used to.

You might need to take low-dose antibiotics each day for the rest of your life to protect you from infection. Keep an emergency supply of antibiotics in case you get an infection.

It's a good idea to carry a card that lets people know you don't have a spleen in the case of an emergency situation. Some people prefer to wear a piece of medical ID jewellery that has this information on.



**MedicAlert produces medical ID jewellery:**  
**[medicalert.org.uk](https://www.medicalert.org.uk)**

Take precautions to lower your risk of infection. This includes:

- Avoiding contact with people who are ill.
- Taking care to prevent scratches and cuts, for example, by wearing gloves when doing manual work such as gardening.
- Having any vaccinations your medical team recommend.
- Taking any antibiotics you've been prescribed.

**Contact your medical team if you have any signs of infection (see pages 74 to 75).**



**Having no spleen impacts my ability to fight infection. I'll take penicillin twice a day for the rest of my life. I don't get many infections, maybe because people don't come and see me if they've got anything infectious. If I get a bug, it takes me longer to recover - so a cold takes about 3 weeks. It's not been the problem I thought it would, and now I'm going to carry on enjoying life.**

Jackie, who had a splenectomy

## **If you need a blood or platelet transfusion**

Some people who have had lymphoma need irradiated blood products if they have a blood or platelet transfusion. Irradiation involves treatment with X-rays to kill donor white blood cells that could attack your own cells. This can prevent a rare but serious complication called 'transfusion-associated graft-versus-host disease' (TA-GvHD).

You might need irradiated blood if you:

- have had Hodgkin lymphoma
- were treated with certain drugs, such as fludarabine or bendamustine
- have had a stem cell transplant or CAR T-cell therapy.

Your doctor will tell you if you need irradiated products. If you do, you'll be given a card that states it. Keep this with you to inform hospital staff if you ever need a transfusion.

## **Late effects**

Late effects are side effects that can develop weeks, months or years after treatment. Your medical team should tell you about the possible late effects of your treatment. We list some of the more common late effects in the next few pages, but this doesn't mean that you will necessarily experience them.

Most people recover well from treatment without experiencing late effects. However, it's important to know what late effects to look out for to catch any problems early.

## Other ('second') cancers

Being treated for lymphoma increases your risk of developing a different type of ('second') cancer. However, most people who are treated for lymphoma do **not** go on to develop another cancer.

Second cancers that have been linked to chemotherapy treatment include leukaemia, lung cancer and skin cancer. With radiotherapy, the type of second cancer you are most at risk of depends on the area of your body treated.

**Ask your medical team what cancers you might be at a higher risk of developing. Make sure you know the symptoms of these because cancer is usually more treatable if it's diagnosed early.**

You can also ask your clinical nurse specialist or your GP about cancer screening programmes, which are designed to find cancers early.

## Heart problems

Chemotherapy drugs called 'anthracyclines', such as doxorubicin, carry a risk of affecting how well your heart

pumps blood around the body. This risk increases with higher doses or more courses of anthracycline treatment. Heart problems can also happen after radiotherapy to the chest, and after a stem cell transplant.

Heart problems become more common 10 years or more after your treatment but can develop sooner. Your risk stays higher for several years.



Take measures to reduce your risk of developing heart problems. This includes eating a healthy diet, taking regular exercise, limiting your alcohol intake and not smoking.



**Visit [bhf.org.uk](https://www.bhf.org.uk) for information about heart problems and advice on good heart health.**

## Lung problems

Radiotherapy to the chest and some types of chemotherapy can cause scarring (fibrosis) to your lungs. This includes the chemotherapy drug bleomycin, which is often used to treat Hodgkin lymphoma as part of the ABVD and BEACOPP regimen (combination of drugs). The targeted drug brentuximab vedotin could also contribute to lung problems, particularly when given with bleomycin. It's particularly important not to smoke if you've had any of these treatments.

Damage to the lungs can cause shortness of breath. If you're affected, you might not be able to do as much exercise as you used to. Speak to your GP or medical team for advice.



If you've had bleomycin and you need to have an operation in the future, make sure you tell the anaesthetist about your treatment.

## Hormone problems

Treatment for lymphoma can affect the glands that make hormones in your body. This can cause problems with thyroid function, diabetes and reduced fertility. In children, it could affect growth. We have more information about lymphoma in children on our website.

### Thyroid function

The thyroid gland produces a hormone called thyroxine. If you've had radiotherapy to the neck or upper chest, you might develop an underactive thyroid, known as 'hypothyroidism'. The thyroid gland then makes less thyroxine than it should, which can make you feel tired, sensitive to the cold and constipated. You might also gain weight easily.

Hypothyroidism is not an immediate effect but can happen years after having radiotherapy. The risk is higher in the first 5 years after treatment and stays increased after this time.

Doctors can diagnose hypothyroidism by a simple blood test. It is easily treated with thyroxine tablets.

If you think you might be affected by thyroid problems and you're no longer being followed-up at your hospital, speak to your GP.

Tell any doctors treating you that you have had treatment for lymphoma so that they are aware of your increased risk of thyroid problems.



**British Thyroid Association have more information about hypothyroidism. Visit [btf-thyroid.org/hypothyroidism-leaflet](http://btf-thyroid.org/hypothyroidism-leaflet)**

## **Diabetes**

If you've had radiotherapy to your tummy (abdomen), you have a slightly higher risk of developing diabetes. This is because radiotherapy can affect a gland called the 'pancreas'. The pancreas controls your blood sugar levels by producing a hormone called insulin.



**Visit [diabetes.org.uk](http://diabetes.org.uk) for more information about diabetes, including things you can do to reduce your risk of developing it.**

## **Reduced fertility**

Women's ovaries and men's testicles can be affected by some treatments for lymphoma. This can lead to reduced fertility. See page 86 for more information.

## **Eye problems**

Eye problems are a less common late effect of treatment for lymphoma. They might include dryness and cataracts (cloudy patches in the lens of your eye that reduce your vision). In some people, steroids can cause high pressure inside your eye (glaucoma), which can affect your vision.

Have regular check-ups with your optician and tell them what lymphoma treatment you've had.

## **Dental problems**

Radiotherapy to the head and neck increases your risk of tooth decay. Have regular check-ups with your dentist. Follow their advice to keep your teeth healthy.



## Tips to stay well after treatment

- Ask your medical team exactly what treatment you've had; you should be given a written treatment summary (see page 153).
- Speak to your medical team about your individual risks. Find out what symptoms you should look out for and what to do if you notice them.
- Go to any follow-up appointments you're invited to. These allow doctors to monitor your health and find any problems early (see page 154).
- Take up any health screening programme invitations you're offered. In the UK, these might include screening for breast, cervical, bowel and prostate cancer. The NHS has more information about screening. Visit [nhs.uk/conditions/nhs-screening](https://www.nhs.uk/conditions/nhs-screening)
- Lead a healthy lifestyle (see chapter on day-to-day living; pages 129 to 147).

# Live your Life workshops

Our free, 1-day interactive Live your Life workshops are facilitated by people who have been diagnosed with lymphoma. They give practical advice and support to help you live well with and beyond lymphoma.

The workshops are designed to help you:

- take control of your life with and beyond lymphoma
- find ways of dealing with the physical challenges of finishing treatment and the after-effects
- address the emotional aspects of living with and beyond lymphoma
- make sure you know where to go for further help and support.



**The workshop helped me talk through my worries and concerns. It helped me to see that I wasn't alone and what I could do to help myself.**

Janet, Live your Life workshop attendee



**For more information about Live your Life, visit [lymphoma-action.org.uk/live-your-life](https://lymphoma-action.org.uk/live-your-life)**

# Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. You can find more useful organisations on our website. If you don't find what you're looking for, please get in touch with our Information and Support Team.

**Active Nation** has information about physical activities and where you can participate. 0800 020 0135

**Alopecia UK** offers information, advice and support to people with alopecia (hair loss). 0800 101 7025

**British Association for Counselling and Psychotherapy** has an online tool to help you search for a private (non-NHS) therapist. 01455 883300

**Cancer Hair Care** offers a free advisory service led by cancer hair care NHS clinical specialists. 01438 311 322

**Cancer Research UK** has information about cancer, research findings, online forums and a service that allows you to speak to a Cancer Research information nurse. 0300 123 102 (general enquiries); 0808 800 4040 (cancer nurse).

**College of Sexual and Relationship Therapists** supports people with relationship and psychosexual challenges. 020 8106 9635

**Counselling Directory** is a nationwide database of qualified counsellors and psychotherapists. 0333 325 2500

**Fruit Fly Collective in collaboration with Guy's and St Thomas' NHS Foundation Trust** has a set of resources, including a video and a comic book, to help talk to children about cancer.

**Hats 4 Heads** offers a range of headwear for people who have lost their hair through illness. 0845 576 4287

**Health and Care Professionals Council (HCPC)** regulates complementary therapy practitioners and has an online register you can search. 020 7582 5460

**Hospice UK** supports UK hospices to provide the services they offer. Their website has an online tool to help you find your nearest hospice. 020 7520 8200

**Living Life to the Full** has free online courses covering low mood, stress and resilience. 01360 661 078

**Look Good Feel Better** provides practical support, including make-up workshops and skincare sessions, for people struggling with the side effects of cancer treatment. 01372 747 500

**Macmillan Cancer Support** gives practical, medical, emotional and financial support to people affected by cancer. 0808 808 00 00

**Maggie's Cancer Centres** offer practical, emotional and social support to people with cancer and their families and friends.  
0300 123 1801

**Mental Health Foundation** has tips and resources to help you look after your mental health. 020 7803 1100

**Mind** has advice and support to anyone experiencing a mental health problem. 0300 123 3393 (infoline).

**My New Hair** is a charity that helps people affected by medical hair loss. Their network of salons can help you buy, fit or style a wig.

**NHS website** has information about a wide range of health issues, including cancer and related conditions. The Livewell area of the website has free resources. You can also find a range of health and wellbeing apps in their apps library.

**Professional Standards Authority for Health and Social Care** has registers of practitioners that you can search online.  
020 7389 8030

**Relate** offers relationship information and support, including face-to-face and remote counselling. 0300 0030396

**Samaritans** offers support, 24 hours a day, 365 days a year, to anyone who wants to talk, or anyone in crisis: call 116 123 or email [jo@samaritans.org](mailto:jo@samaritans.org).

**Sane** has a helpline and online forum for anyone affected by mental health problems. 0203 805 1790

**Shine Cancer Support** supports adults in their 20s, 30s and 40s diagnosed with cancer. They have videos, podcasts and personal experiences on their website. They also organise support events around the UK and have an online forum on Facebook. 07804 479413

**The British Psychological Society** has information about psychology and how to find a psychologist. 0116 254 9568

**The Foundation for Peripheral Neuropathy** is an American organisation that has information about the condition.

**Trekstock** produces videos that help you to get back into exercise after cancer. 0207 388 1200

**Turn2us** helps people access financial support. 0808 802 2000

**Walking for Health** is a scheme of guided walks across England run by Macmillan and The Ramblers.

**Wig Bank** has new and donated wigs for sale or hire.

**Working With Cancer** advises people affected by cancer on issues relating to work at any time during or after cancer treatment.

# 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 or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)



Come to one of our **Support Groups**. Find one near you at [lymphoma-action.org.uk/SupportGroups](http://lymphoma-action.org.uk/SupportGroups)



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



Visit [lymphoma-action.org.uk/TrialsLink](http://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 covered in this book, we have lots more information on our website.**

**We also produce a number of books, which are available free of charge. In particular, you might find the following books helpful:**

- *Introduction to lymphoma*
- *Hodgkin lymphoma*
- *High-grade non-Hodgkin lymphoma*
- *Low-grade non-Hodgkin lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Young person's guide to lymphoma*

**Find our full range of books and information at [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books) or call us on 0808 808 5555.**

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](https://lymphoma-action.org.uk/HealthInfo)

## How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit [lymphoma-action.org.uk/Volunteering](http://lymphoma-action.org.uk/Volunteering)

We continually try to improve our resources and are interested in any feedback you might have. Please visit our website at [lymphoma-action.org.uk/BookFeedback](http://lymphoma-action.org.uk/BookFeedback) or email us at [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) with any comments. You can also call us on 0808 808 5555.

## References

The full list of references is available on request. Please email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619400 if you would like a copy.

# Disclaimer

Although we make reasonable efforts to ensure the content of our publications is accurate and up-to-date at the time of going to press, we make no representations, warranties or guarantees, whether express or implied, that the content is accurate, complete or up-to-date, particularly in relation to medical research which is constantly changing.

The content of this publication has been developed for people living in the UK and is provided for general information only and primarily for personal and educational use. It is not intended to amount to advice on which you should rely. You must obtain professional, medical or specialist advice before taking, or refraining from, any action on the basis of the content of this publication. Lymphoma Action cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information referenced in it.

©Lymphoma Action 2020. All rights reserved. No part of this publication may be reproduced or transmitted without permission. Go to [lymphoma-action.org.uk/Legal](http://lymphoma-action.org.uk/Legal) for permitted use and reproduction of this book.



# Notes

# 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:

- Professor Richard Anderson, Professor of Clinical Reproductive Science, The Queen's Medical Research Institute, University of Edinburgh.
- Charlotte Bloodworth, Haematology Clinical Nurse Specialist, University Hospital of Wales, Cardiff.
- Nikie Catchpool, Consultant Occupational Therapist and Macmillan Professional, Bath Centre for Fatigue Services.
- Dr Gilly Howard-Jones, Lymphoma Nurse Specialist, University Hospital Southampton NHS Foundation Trust.

Special thanks to Adam, Andrew, Blair, Carol, Ceinwen, Corrin, Dwayne, Georgia, Gerry, Hayley, Jackie, Janet, Juliet, Kat, Kate, Kathleen, Kevin, Linda, Lynda, Nicola, Nigel, Owen, Pat, Paul, Reem, Roger, Stephen and Sue for sharing their experiences. Quotations from their stories are featured throughout the book.

With thanks to The Constance Travis Charitable Trust, The MG Grimes Charitable Trust, The PF Charitable Trust and Gilead Sciences Ltd for part-funding this book. As per our policy, they have no influence over our content.

This book gives tips to help you manage the physical, practical and emotional aspects of living with and beyond lymphoma.

Lymphoma Action is the UK's only charity dedicated to lymphoma, the 5th 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)

Lymphoma Action  
3 Cromwell Court  
New Street, Aylesbury  
Bucks HP20 2PB  
General enquiries 01296 619400

© Lymphoma Action 2020  
6th edition produced December 2020  
Next revision due December 2023  
ISBN 978-1-9160205-8-0

Registered company in England and Wales  
(03518755). Registered charity in England and  
Wales (1068395) and Scotland (SC045850).  
LYM0060LivingLymphBk2020ed6

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