

# Living with lymphoma



# 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. It is likely to be a challenging time for you. We're here to give you the information and support you need.

This booklet includes:

- ideas to help cope with difficult feelings
- tips to help manage symptoms and side effects
- suggestions for handling your day-to-day life
- sources of further information and support.

This booklet is divided into parts. You can dip in and out of it and read only the sections relevant to you at any given time.



Lists practical tips.



Is a space for questions and notes.



Signposts you to other resources you might find relevant.

**Important and summary points are set to the section colour font.**

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

Note down key contacts so that you can find them easily.

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

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Never before have I been flooded by so many emotions yet had no idea of what I was feeling. I look back on the day I was told I had cancer with complete confusion. The haze continues to be best described by Simon and Garfunkel; essentially I was surrounded within a sound of silence, where people were talking without speaking.

**Natalia, diagnosed with Hodgkin lymphoma**

# Feelings and emotions

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## **Adapting to the diagnosis**

Reactions to the news of a diagnosis of lymphoma are entirely natural. You are likely to go through many thoughts and emotions.

We say 'you' to refer to anyone affected by lymphoma, whether you are the person who has been diagnosed or you are supporting someone else with a diagnosis.

Below are some feelings you might experience. However, there is no right or wrong way to feel, nor any set order or timescale in which to experience emotions – everyone is different.

### **Shock and disbelief**

There is a lot to take in with a diagnosis of lymphoma. You might feel shocked or numb when you first hear the news – especially if you were having tests for something else when the lymphoma was found. At first, you might be in denial, thinking that this can't really be happening or that the doctors have made a mistake. You might need to go over the news several times before it sinks in.

Lymphoma can mean having to make several adjustments to your life, which may in turn mean coming to terms with the fact that your life has turned out differently to what you had planned.

### **Anger**

Lymphoma can throw you into an unfamiliar world of medical information and terminology, hospital visits and treatments.

Not knowing the cause of the lymphoma can bring confusion and anger. You might be angry about the disruption to your life and



future plans. You may feel angry with the cancer itself, with the health professionals who found it, or with those close to you.

If you are on 'watch and wait' (active monitoring), you might feel angry and frustrated that no one is treating your lymphoma. You might feel jealous or angry towards people who seem to carry on with their lives. Some people describe being 'angry at the world' as they struggle with the unexpectedness and perceived unfairness of their situation.

Sometimes anger masks fear and anxiety (see below).



Read more about 'watch and wait' (active monitoring) at [www.lymphomas.org.uk/active-monitor](http://www.lymphomas.org.uk/active-monitor).

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## **Fear and anxiety**

There is a difference between fear and anxiety. With fear, the thing you feel frightened of is specific. For example, you might be scared of having treatment.

Anxiety causes a sense of unease that can be overwhelming and vague – it happens when you feel threatened or under stress but find it hard to connect it to anything in particular.

You might feel anxious often, for example, while you are waiting for treatment and test results or if you are on 'watch and wait' (active monitoring). Your anxiety may also be triggered by programs or advertisements on television or radio, or by articles in newspapers that somehow relate to lymphoma or illness in general.

Anxiety often arises at the time of diagnosis and when treatment is discussed. Usually, it fades once treatment starts.

Common signs of anxiety include:

- being tired but unable to sleep
- feeling worried or irritable
- difficulty concentrating and inability to carry out day-to-day tasks
- muscle tension
- racing heart or palpitations (fluttering or pounding heart)
- dizziness
- quick breathing.

**Find tips on coping with anxiety later in this chapter. Let a member of your medical team know if this impacts on your day-to-day life, so that they can support you.**

### **‘If only’ thoughts**

Life with lymphoma is full of uncertainty, which often goes hand-in-hand with anxiety. Some people have ‘if only’ thoughts, for example, ‘if only I’d gone to the doctor sooner, I would not be in this situation’. These thoughts can happen when you try to take control over a situation that is, ultimately, beyond anyone’s control. Difficult as it may be, you may need to learn to cope with uncertainty.

### **Depression, sadness and loss**

Lymphoma can bring multiple losses. You might feel a sense of loss for your life as it was before the illness. You might feel sad that you have to reconsider your plans. You might worry that

your life could be shorter, which can lead to other worries, such as not being around to see your children or grandchildren grow up. These feelings of loss are a type of grief and may trigger memories of other losses you've had in the past. As well as your own sorrow, you might feel sad for your family and friends knowing that they, too, are coping with challenging feelings.

It's natural to feel low from time to time; however, if you feel very low for more than a couple of weeks and it is affecting your daily life, you may be affected by depression.

Common symptoms of depression include:

- ongoing feelings of sadness, anxiety or feeling 'empty'
- feelings of hopelessness or pessimism
- feelings of guilt or worthlessness
- loss of interest or pleasure in the things that you once enjoyed
- loss of libido (sex drive)
- restlessness and irritability
- difficulty concentrating, remembering or making decisions
- thoughts of death or suicide.

Depression doesn't mean that you can't cope or that you need to 'pull yourself together' – it's a condition and there is support available to help you through it.

**Speak to your doctor, nurse or GP if you think you may be depressed. Seek help early to lessen the risk of developing more severe depression.**



**Mind ([www.mind.org.uk](http://www.mind.org.uk)) has further information and support, including online forums, for people experiencing depression. You can also search for a depression support group on the Depression UK website [www.depressionuk.org/groups.shtml](http://www.depressionuk.org/groups.shtml)**

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### **Helplessness and loss of control**

A diagnosis of lymphoma can shatter your sense of control. You might feel that you no longer have control over things that are happening to you. Your life may be filled with appointments that tell you when and where you need to be, but you might not fully understand what's going on, leading you to feel that you do not have control. For some people, this can cause hopelessness and low mood.

### **Withdrawal or isolation**

Feeling isolated is a common experience for people affected by cancer. You might feel alone even in a crowded room. Seeing other people's lives continue as usual can be testing. Perhaps you feel that no one understands what you're going through. There may be times when you just want to be alone. Some people with cancer pretend they're OK even when they actually feel they're crumbling on the inside.

It may seem easier, or as though you have no other choice, but to withdraw from people. You might worry about how they'll respond if you tell them what's really on your mind. Feeling that you need to hide your feelings can bring a sense of isolation and low mood.

## Determination

Some people say they feel determined to get through treatment and to 'beat' their illness. Determination and positivity can be empowering and motivating and can help to give you a sense of control.

Your determination is bound to dip at times, especially when your physical energy is low or if you experience setbacks or disappointing news. A drop in determination – even if brief – can bring guilt. It's natural for motivation to dip from time to time. No one can keep it at 100% at all times. Recognise that you're only human.

## Guilt

Some people feel guilty about having lymphoma. They feel there must be something they did or didn't do to get it. You might give yourself a hard time, thinking that you should have spotted the signs or gone to the doctor sooner.

It is important to recognise that guilt is illogical yet powerful. For example, you may know that the lymphoma is not your fault, yet still feel guilty about what your family is going through. 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.



**You can read about the possible causes of lymphoma on our website at [www.lymphomas.org.uk/causes-lymph](http://www.lymphomas.org.uk/causes-lymph).**

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As well as being scary and slightly surreal, my diagnosis seemed profoundly unfair. I'm a vegetarian. I'd never smoked or taken drugs. I drink in moderation. I cycle and run regularly.

**Russell, diagnosed with non-Hodgkin lymphoma**

## Adaptation

Many people learn to adapt to their new situation, recognising that although their life has changed and may never be the same as it had been before the diagnosis, they can cope. They discover that it is possible to adapt to the changes that lymphoma brings and continue to find purpose and meaning in their life.

## Coping with difficult feelings

People find different ways of coping with difficult feelings and circumstances. While none of them can take away the situation, they can help to make it more manageable.

Explore and do what works for you. You might, for example, want to know as much as you can about your lymphoma, or you might prefer to continue with life without thinking about it very often. If this is the case, work or other activities can help to take your mind off the lymphoma.



## Notes

## **Keep in touch with friends and family**

If you're feeling low, you may have a tendency to withdraw from the people around you. This is very common and it's natural that you would want to be alone with your thoughts from time to time. Let the people close to you know if you feel this way, but do try to keep contact with them.

At times you may find the attention you get from friends and family overbearing. However, the support these relationships offer can improve your mental wellbeing and encourage you to take good care of your general health. You'll find tips on effective communication on page 91.

## **Find out about lymphoma and its treatments**

Knowing a bit about lymphoma and how it is treated can help you to regain a sense of control. It can also help you make informed decisions about your care.

Remember that there are many different types of lymphoma and that people's responses to treatment differ. Your medical team is best placed to give you information specific to your situation.

**Don't be afraid to ask for information to be repeated if this would be helpful – health professionals understand and are used to this.**

You can find out more about lymphoma, including types of lymphoma, how it is treated, and advice to help you live well on our website and in our booklets.





## Tips for finding out about lymphoma

- Prepare questions to ask your medical team. Note down the answers you get during your appointment.
- If finding out about lymphoma seems daunting, ask a friend or family member to summarise the key points for you.
- Check that information is reliable. Look for the Information Standard quality mark (shown on the back cover of this booklet). You can also ask your clinical nurse specialist (CNS) for credible information.
- Try not to 'over-read'. While it can help to understand the basics, getting caught up in the detail might be overwhelming.
- Recognise that some questions have no answers. Your medical team should give you all the information they can.



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Clinical trials are research studies involving human volunteers. The research might, for example, test a new treatment or compare different ways of using an existing treatment. Ask your medical team if you're interested in trials. You can find out more and search for a trial that may be suitable for you at [www.lymphomas.org.uk/trials-link](http://www.lymphomas.org.uk/trials-link).

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## Consider what you can control

If lymphoma has had an effect on your sense of control over your life, find ways of re-establishing it. Look for what you do have influence over to help you regain your independence and a sense of choice.



### Tips to help you regain a sense of control

- **Think about what information you're comfortable sharing with others. People might ask lots of questions but that doesn't mean you have to answer all of them.**
  - **Keep up with the things that are important in your life – whether it's a hobby or spending time with particular people.**
  - **Set daily or weekly routines to maintain structure.**
- 

I scheduled rest, exercise and chemo sessions in a diary. This gave me structure as well as a sense of being in control through a life situation that could quite easily have felt out of my control.

**Andy, diagnosed with Hodgkin lymphoma**



## Express yourself

Having an outlet for your feelings can be very beneficial. It can help you to process and make sense of them, allowing you to manage difficult emotions.

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### Tips for letting your feelings out

- **Tell someone how you feel, for example, a friend or relative. If you prefer, you can call our confidential helpline on 0808 808 5555.**
  - **Write about your feelings, for example in a journal or blog. Set aside time in a private space, free from interruptions. Express yourself freely in the knowledge that your writing is only for you – whether you share it or not is your decision.**
  - **Let off steam if you're angry or frustrated – punch a pillow, for example.**
  - **Do something creative – draw or paint, play an instrument or sing. You can search for a local choir at [www.bigbigsing.org](http://www.bigbigsing.org).**
- 

## Take it a day at a time

Be kind to yourself. Think about what you need from yourself and from others. Keep a sense of 'you' and regularly take time out for yourself. Have things in the 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 your activities and holidays. They might suggest, for example, waiting a certain number of days after having treatment.

You may feel worried about the future and whether you will recover. You might want to know how long you have to live. The doctors treating you may be able to give an idea. They base this on factors including the type of lymphoma you have, how fast it is growing, how well you cope with treatment, your general health, and any other conditions you may have. Even with all this information, nobody can say for certain how long someone will live. People often find it helps to take it a day at a time.

On the whole, the outcomes of treatment are very promising and are improving all the time. Lots of people are cured of their lymphoma or live well with it for many years.



## **Tips for living your life day by day**

- **Recognise the importance of small things – even just planning what to plant in the garden this summer, for example, can give you a sense of normality.**
  - **Plan activities around your treatment. For example, organise an outing for a time when you're less likely to experience side effects of treatment.**
  - **Show yourself patience. Imagine how you'd respond to a friend in your situation. If there are days you don't feel like doing much, allow yourself that without feeling guilty. Make time to relax – see pages 112-113.**
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## Notes

## Ask for help

It can be hard to ask for help, especially if you're someone who takes pride in being independent. Recognise that you already have a lot to deal with physically, mentally and emotionally, and that this takes a huge amount of energy. Prioritise and do not hesitate to delegate.

Consider the tasks you could ask other people to do for you, for example mowing the lawn, helping with the school drop off/pick up, shopping or preparing meals.

If you have several appointments in a week, you could organise a rota of friends to help with transport to and from the hospital.



## Tips for accepting help

- **Know that accepting help isn't forever.**
- **Remember that many people want to help and will be grateful to be told what they can do for you.**
- **Think about emotional support you'd like. Having someone to talk to about how you're really feeling can be a huge help.**

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## Connect with others who can relate to your situation

People often seek the company of others who are going through, or have been through, a similar experience to their own. While each person's situation is unique, you might find it helps to be in touch with people who can relate to your lymphoma experience.



## Tips for finding others who can relate to your experience

- Go to a support group. Find your nearest one at [www.lymphomas.org.uk/lymphoma-support-groups](http://www.lymphomas.org.uk/lymphoma-support-groups). Your nurse specialist may also be able to direct you to any cancer support groups in your area.
- Use online forums to be in touch with others affected by lymphoma [www.lymphomas.org.uk/forum](http://www.lymphomas.org.uk/forum). Macmillan also has a forum for people affected by cancer, and Shine Cancer Support hosts an online forum for people in their 20s–40s. If you're a friend or relative of someone with lymphoma, try Carers UK's forums.
- Request a lymphoma buddy – our helpline may be able to put you in touch with someone with a similar experience to yours. Visit [www.lymphomas.org.uk/lymphoma-buddy](http://www.lymphomas.org.uk/lymphoma-buddy).

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### Get professional support

The National Institute for Health and Care Excellence (NICE) recommends that your medical team assess your holistic needs and offer appropriate help. They should do this regularly, including when you are first diagnosed, when you begin treatment and when treatment ends. This is called a Holistic Needs Assessment (HNA).

**It is to be expected that a diagnosis of lymphoma has an emotional impact. However, if your level of distress continues**

**or worsens and affects your everyday life, you may find it beneficial to seek additional support, which may include a talking therapy, such as counselling or another type of psychological support.**

For some people, counselling is an opportunity to talk about the things they feel unable to talk about to others. There are many different types of counselling. What they all have in common is the counsellor's aim to provide a safe and non-judgemental space for you to feel heard and to explore your feelings.

Counselling can help you to consider:

- your thoughts and feelings
- the impact of lymphoma on your life
- what's important to you
- how you tend to respond to people and situations
- what the people and things in your life mean to you
- your resilience and inner coping resources
- resolutions and strategies to address problems.

If you're interested in counselling, speak to your doctor or nurse who may be able to refer you to a counsellor on the NHS, through your hospital or a local cancer support centre.



**You can search for a private therapist in your area on the British Association for Counselling and Psychotherapy website [www.itsgoodtotalk.org.uk/therapists](http://www.itsgoodtotalk.org.uk/therapists). You can also use the British Psychological Society's search tool at [www.bps.org.uk](http://www.bps.org.uk).**

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## Identifying worries

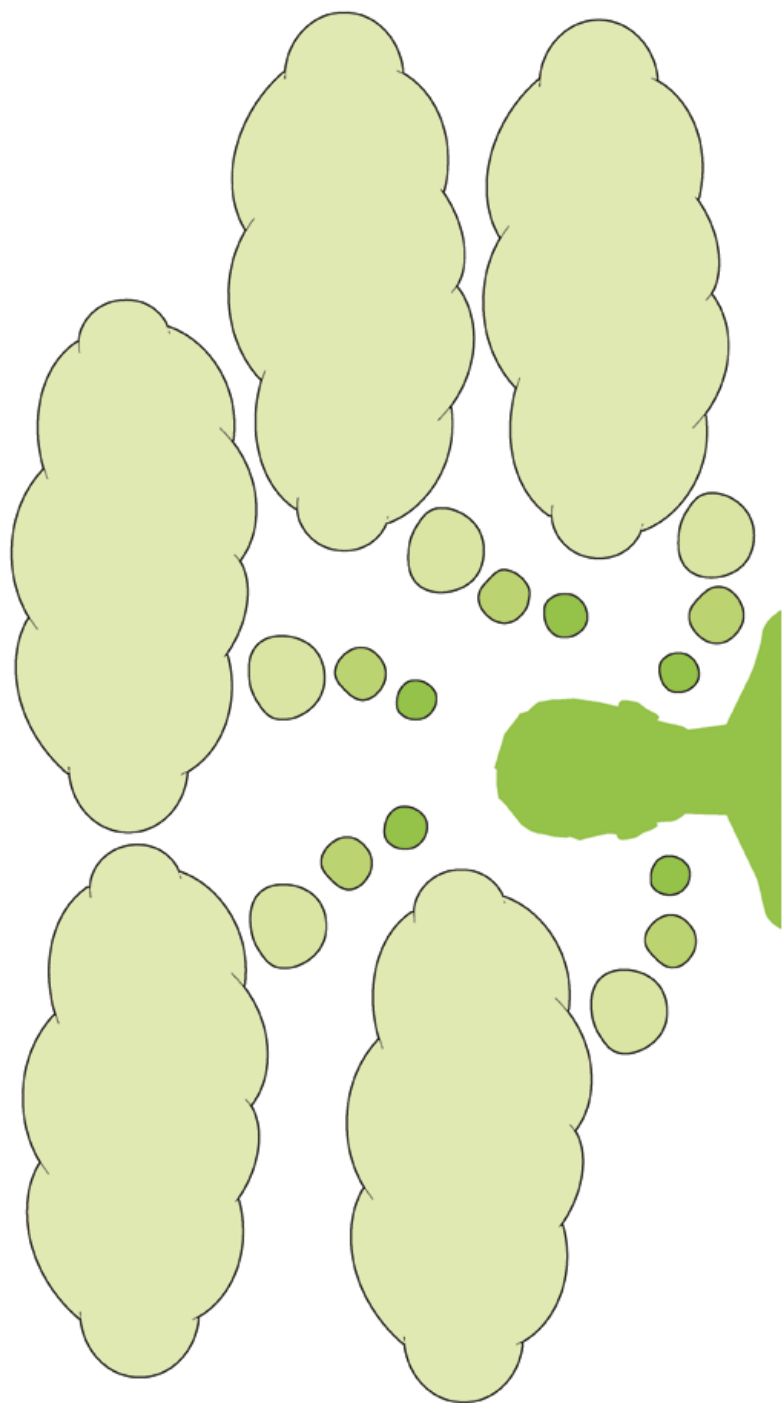
At times, your head might be full of worries. Try to recognise and 'catch' these before they spiral out of control. Write down any worries or concerns as they come into your mind. Keep a notepad by your bed in case they come up during the night.

Simply getting your thoughts on paper can take away some of their power and bring you release. There is space on the next page for you to do this. Seeing your worries in writing may help you to identify any links between them and help you to consider how to address them.

## Identify strategies

Problems can become overwhelming when they go round and round in your mind and create worry.

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. There is an example on page 27 and space for your own notes on page 28.



Use the thought bubbles to note down any worries you have

Problem	Strategy	Useful resources
<p>'It's going to be difficult to look after the children during my chemotherapy as I've been told to expect nausea and sickness.'</p>	<ul style="list-style-type: none"> <li>• Find ways to cope with side effects (eg anti-sickness medication).</li> <li>• Ask someone you trust to help with childcare, school runs and shopping.</li> </ul>	<ul style="list-style-type: none"> <li>• Your medical team for advice on managing side effects.</li> <li>• Family, friends, neighbours for help with childcare.</li> </ul>

Problem	Strategy	Useful resources



## Notes

## Challenge thinking patterns

Over the course of their lives, people develop thinking patterns. For example, you might be someone who tends to see risk in all situations, or you might be someone who is generally optimistic.

Our thinking patterns can impact and worsen how we feel. If this is the case, you can try to change them. Although this isn't easy and takes practice, it can help manage stress and anxiety.

Here are some common thinking patterns that can have a negative effect on how you feel. See if you identify with any of them. If so, consider their impact on how you feel and any alternative ways of reflecting on the same situation.

**You could consider your thinking patterns on your own, with someone close to you, or with the help of a trained cognitive behavioural therapist. Your GP may be able to refer you for professional support.**

**Catastrophising** – assuming the worst possible outcome.

- Example: I'm tired today. The lymphoma must be growing.
- Alternative: I'm tired today. There's a possibility that it's related to my lymphoma. I can speak to my nurse specialist about this. I did do a lot of walking yesterday, though, and I had a late night, which could explain my tiredness today.

**Fortune telling** – predicting the future and expecting the worst.  
This is closely related to catastrophising.

- Example: everything's going to go wrong. The treatment won't work. Even if it does, the lymphoma will probably come back.
- Alternative: the doctors told me there's a good chance of controlling my lymphoma. I'll make a note of my questions and concerns and ask my medical team about them at my next appointment.

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

- Example: I feel so worried – I just know that something will go wrong.
- Alternative: my medical team are very experienced at treating people with lymphoma. There is a high success rate of treatment for my type of lymphoma and I'll have follow-up appointments to check my response to it.

**Overgeneralising** – assuming that because something has happened once, it always will.

- Example: I didn't recognise the symptoms to begin with so I'll probably miss them if they come back in the future.
- Alternative: I didn't recognise the symptoms because I didn't know much about lymphoma. I'm much more clued up now. I know how to check myself for signs of worsening symptoms and which member of my medical team to get in touch with if I'm concerned.

**Shoulds and oughts** – giving yourself a hard time about the things you think you should be doing.

- Example: I should be feeling positive all the time. I should be on top of all the housework.
- Alternative: sometimes I feel very positive but I have days when I don't feel so positive, which is understandable given that I've been diagnosed with lymphoma. I could take care of the housework but I don't always have the energy and it's not my top priority. I could ask a family member, friend or neighbour to help keep the house clean and tidy.

### **Discounting the positive ('yes but...')**

- Example: although the nurse specialist told me that the treatment I'll have is generally very successful, she probably said that to make me feel better. I doubt it'll work for me.
- Alternative: the nurse specialist told me that the treatment I'll have is generally very successful. She has a duty to be honest. I can ask her how and when we'll know if I've responded well to the treatment and what the next steps are if the response isn't as good as expected.

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

- Example: if I tell my friends I'm feeling overwhelmed, they'll think I'm a burden and won't want to spend time with me.
- Alternative: if a friend was in my situation, I'd want to support them. When I think about it, I expect my close friends to be as supportive towards me as I would be towards them.





## Tips for challenging unhelpful thinking patterns

- Once you've identified a thinking pattern, consider what evidence you have for it. Are you basing your conclusions on emotions instead of facts, for example?
- Reason through your thoughts. Can you see things differently?
- Consider the worst case scenario and how you'd deal with it if it became a reality. This can remove some of its power, especially if you can come up with a plan.

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**Remember that your medical team is there to support you physically, mentally and emotionally. Trust that they will be honest with you in the information they provide, and let them know if you are struggling with anything.**

### Further information and resources

#### **British Association for Behavioural and Cognitive**

**Psychotherapies** (BABCP) has an online search tool to help you to search for a cognitive behavioural therapist (CBT) at [www.babcp.com](http://www.babcp.com).

**NHS Choices Moodzone** offers support with mild stress, anxiety and low mood. They have exercises, tips and audio guides at [www.nhs.uk](http://www.nhs.uk).



## Notes



## Notes



I decided straightaway that a positive attitude was important. I looked upon starting treatment as a way of improving my health. The hospital environment can seem mundane or like no-one understands, so it helps to meet and connect with people in a similar situation.

**Ellie, diagnosed with Hodgkin lymphoma**

# Coping with symptoms and treatment

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## Coping with symptoms of lymphoma

Some symptoms of lymphoma can cause discomfort. A lot of the time, they go away once you start treatment, but they can continue during and for a little while after treatment.

### Sweats

Sweats (particularly drenching night sweats that leave your bed clothes soaking wet) can be a symptom of lymphoma that often stop once you have had treatment. They can, however, carry on for a while during and after treatment as a side effect of some treatments including prednisolone (a steroid), rituximab (an antibody), and some chemotherapy drugs. In women, some types of chemotherapy may lead to menopausal symptoms, including night sweats or hot flushes.

**Keep cool by wearing light layers that you can easily remove. Natural fabrics like cotton are good choices for clothes and bed sheets because they tend to keep you cooler than synthetic (man-made) fabrics.**



### Tips for coping with sweats

- Put a soft towel underneath you in bed to save your bed sheets from getting wet.
  - Drink plenty of fluids, around 2–3 litres a day of cold drinks, to replace the fluids you lose through sweating. Avoid alcohol and caffeinated drinks.
  - Use a fan to keep your bedroom cool at night.
-

## Itching

Itching as a symptom of lymphoma is likely to improve once you start treatment. It's best not to scratch as this can leave lasting marks. Cut your nails short and wear cotton gloves in bed in case you scratch during your sleep.

Do not bathe or shower more than once a day as water and shower gel can dry your skin and cause itching. Keep baths and showers short and use lukewarm water. Hot water can trigger itching. Avoid bubble baths, perfumed soaps and perfumed shower gels; instead, use a moisturising liquid (emollient). When you get out of the bath or shower, pat your skin dry with a towel. It can be helpful to moisturise soon after getting out using a water-based cream such as E45. You may also find that applying un-fragranced lip balm helps to soothe dry lips.

Pay attention to which materials worsen your itching. Choose loose-fitting clothes made of natural fabrics like cotton. Wool and man-made fabrics can make your skin itch.

Certain products may also dry and further irritate your skin, so they are best avoided. These include alcohol-based products (such as wet wipes and antibacterial hand gel) and perfumed or lanolin-based products, including fragranced deodorants and antiperspirants.



## Tips for coping with itching

- If your itching is very intense, rub in some cream, apply cool packs or tap or press your fingers on your skin instead of scratching.
  - Moisturise 3–4 times a day using an anti-itch moisturiser, which your doctor can prescribe.
  - Use a non-biological washing detergent made for babies' clothes – this is softer on your skin than regular detergent.
  - Avoid swimming pools because chlorine can irritate.
  - Use an electric razor rather than wet shaving, or avoid shaving altogether.
  - Make time to relax – stress and anxiety can make itching harder to cope with. See page 112-113.
- 

## Coughing and breathing difficulties

You might experience a cough or difficulties breathing if you have enlarged (swollen) lymph nodes in your chest. These symptoms should go away once you start treatment. However, coughing can also be a side effect of treatments for lymphoma that reduce your blood counts.

Bleomycin can cause pulmonary fibrosis (scarring of the lungs), which can lead you to develop a cough.



You may also be at an increased risk of developing infections, including pneumocystis pneumonia (PCP) or shingles if you are immunosuppressed (have lowered immunity), are on chemotherapy or steroid treatment. Your medical team will tell you if this is the case and will prescribe preventative medication.

Seek medical advice if you:

- are short of breath
- cough up thick, yellow or green mucous
- have a cough that gets worse or is painful
- have a temperature.

You might have developed a chest infection and need antibiotics.



## **Tips to soothe a cough**

- **Drink plenty – it helps to loosen the mucous in your chest.**
  - **Make a hot honey and lemon drink – the NHS states that these are often as effective as over-the-counter medicines.**
  - **Sleep with an extra pillow – coughs are often worse when you are lying flat.**
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## Coping with side effects of treatment

### Changes in appetite

You might worry about weight loss or weight gain if you experience a change to your appetite. Any changes to your body can be a visual reminder of your lymphoma and can impact your self-esteem.

### Decreased appetite

If your appetite has decreased, try eating little and often. Choose high-energy foods (such as omelettes, cheese and biscuits) over those that are filling but provide less energy (like salads and soups).

If you lose weight due to a smaller appetite, you can boost your calorie (energy) intake by adding butter, oil or cheese to foods like bread, pasta, potatoes, vegetables and sauces. Sugar, honey or syrup can be added to drinks or puddings. By choosing full-fat options (for example whole milk) over low-fat alternatives, you also increase your energy intake. If you continue to lose weight, ask to be referred to a dietitian.

It can be difficult if people keep encouraging you to eat when you don't feel like eating. Let them know that you're doing your best and how they can help you – for example, by preparing small snacks for you to graze on throughout the day.



**Macmillan has information about the building-up diet to help you if you lose your appetite during treatment**  
**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

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I struggled with food and lost weight. My throat felt like I was trying to swallow razor blades. I avoided bread and found that soup or mashed potato was easier to eat. My hospital team offered me high calorie drinks for energy.

**Elisabet, diagnosed with Hodgkin lymphoma**



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## Tips for if you have a small appetite

- Drink at least 30 minutes before your meal to avoid filling up just before you eat.
  - Eat when you are hungry instead of sticking to set meal times.
  - Serve your food on a smaller plate if you find a large plate off-putting.
- 

## Increased appetite

Some treatments may make you feel hungrier than usual. Your appetite should go back to how it was once you finish treatment.

Steroid treatment can temporarily change your metabolism (how quickly your body uses energy) and how you store fat, even if your appetite doesn't increase. This should return to normal once you stop taking steroids.

If you are thinking of dieting, speak to your doctor. The general advice is to avoid dieting while you are having treatment as it can make it harder for your immune system to recover from treatment. It is also important that any doses calculated based on your height and weight continue to be correct. Focus instead on eating a healthy and balanced diet (see page 126).

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## **Tips for if you have increased appetite**

- **Eat plenty of foods that are filling without being high in calories, for example, fruits, vegetables and soups.**
  - **Drink plenty – it's easy to mistake thirst for hunger.**
  - **Avoid cooking with too much oil, which can add calories and lead to weight gain.**
- 

## **Nausea and vomiting**

Nausea (feeling or being sick) is a common side effect of many treatments for lymphoma. Plain-tasting and non-greasy carbohydrates can help to ease nausea. Choose foods such as toast, crackers, breadsticks, pretzels, rice and pasta.

You can bypass some of your taste buds by sipping slowly through a straw if your treatment affects your sense of taste.

**You may find that eating a cracker or plain biscuit when you first get up in the morning helps to settle your stomach if you feel nauseous upon waking.**

Some people find that food smells make them feel nauseous. Microwaving your food can help to limit these smells. You could also wait until your meal cools to room temperature before eating it as hot foods tend to produce stronger smells.

It's important to stay well hydrated if you vomit (are sick). Drink plenty of water or squash between your meals – carry a bottle of water when you are out and about to help with this.

If you are unable to eat or drink due to nausea, tell your doctor or nurse.



## **Tips to reduce nausea**

- **Ginger may reduce nausea. Try ginger beer, ginger tea, ginger biscuits, ginger cake or root ginger.**
  - **Eat little and often.**
  - **Choose cool, citrus flavoured, fizzy drinks. These tend to be more soothing than still or hot drinks and can help to settle your stomach.**
  - **Ask your doctor if they can prescribe anti-emetics (anti-sickness medication). Ask for support in finding one that helps you.**
-

## Digestive changes

Lymphoma, and some of its treatments, can cause digestive problems including diarrhoea, constipation and flatulence (wind). You might feel uncomfortable talking about digestive changes, but remember that your medical team are very used to these conversations and that they want to help you.

**Your medical team can give you advice that's suited to your individual situation to help you cope with digestive changes. This might include tweaking or changing your medication.**

## Diarrhoea

Diarrhoea means passing looser, watery stools (poo) more frequently or in larger amounts than is usual for you. You might also feel the need to go to the toilet urgently or suddenly, feel bloated or sick, experience abdominal (stomach) cramps and have a fever (in adults, this is a temperature of over 38°C or 99.5°F).

**Tell your doctor straightaway** if you have **any** of the following symptoms:

- blood in your stools (poo)
- very dark brown or black stools
- persistent or severe stomach ache
- stomach cramps
- persistent vomiting (throwing up 2–3 times a day)
- weight loss
- dehydration (dark yellow urine is a sign of dehydration)
- painless passing of a lot of watery diarrhoea.

Having diarrhoea takes up a lot of energy, so rest is important. You should replace the water and mineral salts you lose through diarrhoea to prevent dehydration. Drink plenty – aim for at least 2 litres a day, sipping little and often. Choose plain water or water mixed with broth. You could also buy an oral rehydration solution (ORS), available in pharmacies, chemists and supermarkets without a prescription. These come as powders in sachets that dissolve in water. Avoid fruit juices, caffeinated drinks, very hot or very cold drinks, fizzy drinks (including beer), alcohol and milk.

**Seek medical advice before taking antidiarrhoeal medicines (other than ORSs). Their suitability depends on the cause of the diarrhoea.**

You might not feel like eating very much when you have diarrhoea. This is OK, but you should begin eating again as soon as you feel able to. Choose:

- low fibre foods, such as potatoes, white rice, dry white toast, soup, peeled and boiled vegetables
- potassium-rich foods, such as bananas, potatoes, fish, bread, chicken, beef and turkey.

Avoid foods that could worsen your symptoms. This includes foods that are fatty, greasy and spicy, dairy products and high-fibre foods, for example, raw fruit and vegetables, beans, nuts and wholegrain cereals.



## **Tips to soothe sore skin around your bottom after diarrhoea**

- **Take a warm, soothing bath. You could also ask your nurse or doctor if they can recommend a cream.**
  - **If you can, wash your bottom after going to the toilet. If this is not possible, use fragrance-free toilet wipes, which are softer on the skin than toilet paper and can be flushed down most toilets.**
  - **Wear breathable, cotton underwear and loose clothing to reduce irritation.**
- 

## **Constipation**

Constipation means being unable to regularly pass stools, or being unable to completely empty your bowel. It is a side effect of some chemotherapy drugs, antiemetics (anti-sickness medications) and pain relief medications (especially morphine-based ones, such as codeine).

**Seek medical advice if you have not opened your bowel for a day or two longer than is usual for you. Early treatment is often much simpler than if you leave it longer.**

You may be able to lessen constipation with your diet. Some foods and drinks can help by acting as natural laxatives.



Choose:

- cereal, such as oats, barley and rye
- fruits and root vegetables, such as carrots and potatoes
- dried prunes, dried apricots and figs
- golden linseeds
- liquorice
- fruit juices that are high in sorbitol (a type of sugar), including orange, apple, prune and raspberry
- coffee.



## Tips to ease constipation

- **Eat at around the same time each day to encourage regular bowel movements.**
  - **Take light exercise, such as a gentle walk, to help soften your stools (poo).**
  - **When you need to go the toilet, go as soon as you can as waiting can make constipation worse.**
  - **Stay well hydrated, especially if you increase the amount of fibre in your diet.**
-

## **Flatulence (wind)**

As well as passing wind more frequently than is normal for you, feeling full and bloated can also be symptoms of flatulence. Some treatments and some anti-sickness medications can create extra gas in your digestive system and increase flatulence. While this isn't a serious medical problem, it can be embarrassing and uncomfortable.

There are some medications to help with flatulence; however, it's important to seek medical advice before taking them. This is particularly important if you are currently having treatment for lymphoma because some medicines can interact in unwanted ways.

Your diet can have an impact on flatulence. Lower your intake of high-fibre foods (such as wholemeal bread, bran, cereals, nuts and seeds). Avoid cabbage, apples, sprouts, onions, beans, cauliflower and fizzy drinks (including beer and pop).



### **Tips to ease flatulence**

- **Eat and drink slowly and chew your food well. This limits the amount of air you swallow.**
  - **Eat smaller meals frequently during the day as this may help your digestion.**
  - **Aid your digestion by adding ginger to your diet. You could also try drinking peppermint tea or fennel tea.**
  - **Avoid smoking as this can worsen flatulence.**
-

## Bladder problems

The chemotherapy drugs cyclophosphamide (particularly in a high dose) and ifosfamide (Mitoxana®) can very rarely cause irritation and bleeding from the lining of the bladder and the kidneys. If you experience bladder problems, drink plenty of fluids. You may be given fluids and other medicines to help prevent these problems. Discuss your symptoms with your doctor as they may need to arrange tests to make sure that your symptoms are not due to an infection.

For comfort and reassurance, wear a disposable waterproof pad (sanitary towel or incontinence pad) to protect your underwear. You can buy these from pharmacies, chemists, supermarkets or online. It's worth asking if your hospital can give you some. Alternatively, a thin panty liner may be enough.

If you are worried about having an accident in the night, a mattress protector or plastic sheet can prevent damage to your bed and make cleaning easier.



## **Tips to stay prepared if you have bladder problems**

- **Plan ahead before you travel. Pack a change of underwear and find out where toilets are.**
- **Carry a ‘Just can’t wait’ card produced by the Bowel and Bladder Community. The card states that you have a medical condition and need to use the toilet urgently. Find out more about the card and how to get it at [www.bladderandbowel.org](http://www.bladderandbowel.org).**
- **Wear bottoms that are easy to remove quickly – clothing that doesn’t have fiddly zips, buttons or other fastenings (like jogging bottoms) can be helpful if you have to go to the toilet urgently.**

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## **Hair loss**

Hair loss is a side effect of some treatments for lymphoma. It is usually temporary and can range from slight thinning through partial loss to complete loss. Changes to your hair may affect your self-esteem and confidence. It can also be a visual reminder of undergoing treatment.

Many people ask about scalp cooling as a way to prevent hair loss. Unfortunately, this technique is not helpful for people with lymphoma.

Your medical team will speak to you about your risk of hair loss before you begin treatment. If you plan to disguise your hair loss, explore options for how you’d like to do so before you begin

treatment. Try out wigs and other headwear options. If time allows, order these before you begin losing hair so that they are ready as soon as you need them. This also gives the wig specialists time to match your wig to your natural hair as closely as possible.

Give yourself as much time as you can to pick the option you're most comfortable with and to get used to it. You might also want to prepare your friends and family for your change in appearance by letting them know that you expect to lose some hair.

**Be aware that you may not know the extent of your hair loss or thinning in advance. If you are very likely to lose your hair, however, you might want to prepare yourself by cutting it short before your treatment starts. You could also shave any facial hair you have.**

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

**Pat, diagnosed with follicular lymphoma**



If you are considering a wig, ask your nurse specialist or another member of your medical team if they can put you in touch with a local wig maker. Options for wigs include real or synthetic (man-made) and even partial use of your own hair.

Other headwear options include hats, headscarves, turbans and bandanas. Clothing and accessories, such as jewellery and brightly coloured tops, can divert attention away from your head. However, you might choose to go with the change and not to try to distract from it.



**Macmillan have a step by step guide on how to tie a bandana [www.macmillan.org.uk](http://www.macmillan.org.uk).**

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I abandoned my wig in favour of a bandana. Sometimes, I just accentuated my eyes with make-up instead.

**Kate, diagnosed with Hodgkin lymphoma**

If you are thinking of using 'spray-on hair' (a product that uses tiny fibres to cover hair loss), check with your hospital consultant first that it is safe for you. It's always advisable to do a patch test before you use it.

When you begin losing hair, look after your scalp with gentle hair-care products, like baby shampoo. Leave your hair to dry naturally and avoid heat-styling tools, hair dyes, perms and chemical straightening. You can soothe a sore scalp by massaging in a mild, unperfumed moisturiser, and protect it from sun, wind and cold by wearing a hat.

If you lose hair during the night, a towelling turban or hairnet can help to catch hairs. If hairs scatter across your bed sheets, use a sticky tape to pick them up.

## **Once your hair begins to grow back**

Your scalp might itch as your hair begins to grow back. If your scalp is dry, frequent moisturising can help.

Ask your hospital how long you should wait after finishing chemotherapy treatment before you colour, chemically straighten or perm your hair. There may be traces of chemotherapy in your hair strands, which could react with the chemicals used in the styling processes. Ask your hairdresser about natural products like vegetable-based and wash-in-wash-out dyes. These are often suitable alternatives to permanent dyes.

You should also wait several months after your hair has started to grow back before you have woven-in or glued-in hair extensions. Your new hair may be weak and extensions can pull on it and cause it to break.

Your fingernails and toenails contain the same protein as your hair and may also be affected by chemotherapy. They might become dry, marked or discoloured and break easily while you are having treatment. You can improve the appearance using nail varnish; avoid quick-drying types as these can dry your nails even more. Check with your medical team if you are considering using newer nail technologies, such as gel manicures.



## Tips to help during hair loss

- Sprinkle talcum powder into your hair. Leave it a while then brush it out. This absorbs grease and helps to ease tenderness. Do this from time to time instead of washing your hair.
- 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.
- Ask your nurse specialist about help towards the costs of a wig – you may be entitled to a free or subsidised synthetic wig on the NHS.
- If you buy a wig privately, you shouldn't have to pay value added tax (VAT) as you have 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.
- A pillowcase made from 100% cotton can help to reduce scalp irritation.

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### Further information and support

We have listed a few national organisations that you might find useful if you experience hair loss, but there are many more. Ask your nurse specialist about local organisations that may be useful to you, too.



I prepared for chemotherapy by cutting my hair. I thought I might as well try out different colours and styles, so bought a number of wigs. In the end, my hair didn't fall out, but my hair, eyebrows and eyelashes became thinner.

**Caroline, diagnosed with follicular lymphoma**



**Alopecia UK** offers information, advice and support to people with alopecia (hair loss), [www.alopaciaonline.org.uk](http://www.alopaciaonline.org.uk).

**Hats 4 Heads** offer a mail-order service for people who have lost their hair through illness, [www.hats4heads.co.uk](http://www.hats4heads.co.uk).

**Look Good Feel Better** is a charity that runs free skincare and make-up workshops across the UK, [www.lookgoodfeelbetter.co.uk](http://www.lookgoodfeelbetter.co.uk).

**My New Hair** is a charity set up by hairdresser Trevor Sorbie to help people affected by medical hair loss, [www.mynewhair.org](http://www.mynewhair.org).

**Raoul** is a wig manufacturer and supplier to the NHS and private sector producing real and synthetic wigs, [www.raoulwigmakers.co.uk](http://www.raoulwigmakers.co.uk).

**Toni and Guy** are hairdressers who have formed a partnership with Macmillan to offer specialist hair care for people affected by cancer, [www.toniandguy.com/charity/strength-in-style](http://www.toniandguy.com/charity/strength-in-style).

**Wig Bank** has new and donated wigs for sale or hire,  
[www.wigbank.com](http://www.wigbank.com).

## **Fatigue**

Fatigue is extreme tiredness that doesn't go away when you rest or sleep. Many people with cancer experience fatigue (often called 'cancer-related fatigue'). It can make daily tasks difficult – for example, you might lack the energy to shower or dress. It can also affect cognitive processes such as memory and attention (see page 63).

As there is no known cure for fatigue, its management focuses on finding effective strategies for dealing with it. However, if there is an underlying cause to your fatigue (such as anaemia or depression), you may be given medicine to treat it.

## **Keep a fatigue diary**

A fatigue diary allows you to track your energy levels each day to see if there is a pattern to your fatigue. This can help to identify triggers to fatigue, which can make it easier to plan activities and rest periods.

You'll find an example template of a fatigue diary on the next page.

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

Keep the diary for a couple of weeks then review it to see if you can identify any triggers to your fatigue. Plan your activities according to when you're likely to have most energy.

Fatigue diary

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

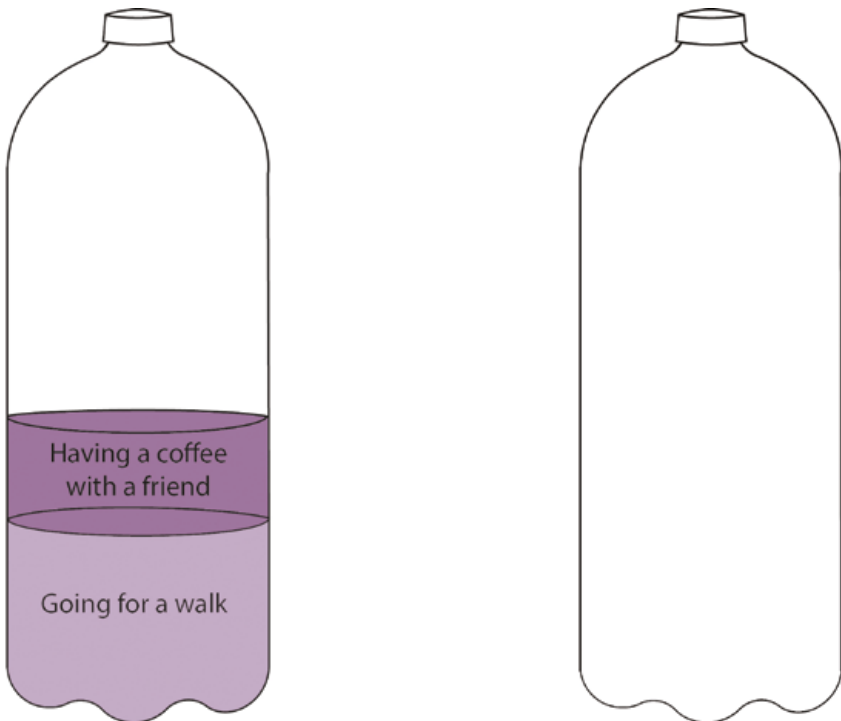
 Relaxation

 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. Consider how much energy you're starting with and how much energy each activity takes up to help plan your day. Use the bottle diagram below to help you.

If you don't have enough energy to do everything you'd like to, think about which tasks or activities are your priorities. Think about which things can wait for another day and what can be delegated.



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

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## **Pace yourself**

Think about the ‘three Ps’: plan, prioritise and pace yourself:

- Work out when you have the most energy and prioritise the most important activities or work for then.
- Set realistic goals.
- Break tasks down into manageable chunks.
- Plan regular, short rest breaks. Try not to sleep during these breaks as this can disrupt your night-time sleeping pattern.
- Ask for help from others so that you can use your energy for the tasks that only you can do or for the tasks that you most enjoy.

If you work, you may need to reduce your hours or stop working for a while. Depending on the kind of work you do, you could speak to your employer about:

- working from home for all or some of your hours
- changing your working pattern to avoid a busy commute
- delegating some of your tasks to colleagues.

See page 138 for more about managing work while you’re unwell.

## **How to explain fatigue to other people**

Fatigue can be difficult to explain. People have described it using words such as ‘paralysing’ and being ‘drained of energy’.

Christine Miserandino is a writer and advocate for people with a condition called lupus. She talks about energy capacity using spoons to describe her own illness-related fatigue.

Miserandino describes her experience using 12 spoons, which represent units of energy. She asks a friend to list some daily activities. For each of these, she takes away a spoon (a unit of energy). Using this analogy, she shows that energy needs to be rationed so as not to use it all up too early in the day. She explains that she can 'borrow' a spoon from the next day, but will be short on spoons (lower on energy) the next day. You can read Miserandino's full story at [bit.ly/spoon-energy](http://bit.ly/spoon-energy).



## **Tips for coping with fatigue**

- **Have a healthy diet and get enough calories (energy) through food and drink (see page 126).**
  - **Take light exercise, such as walking, a few times a week. Be sure to rest afterwards (see page 132).**
  - **Gradually build up the time you spend on activities that take energy. This should help to increase the length of time you're able to do them before you become tired.**
  - **Build relaxation into your day (see page 113).**
  - **Keep to a regular sleep pattern (see page 117).**
-



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Find more suggestions in Macmillan's booklet: *Coping with fatigue*. You can download or order a copy at [www.macmillan.org.uk](http://www.macmillan.org.uk).

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Fatigue is really hard to explain – it's a tiredness that sleep doesn't cure, and can make it really difficult to concentrate. It can make me feel very isolated when I need to rest instead of go out. Planning, prioritising and pacing helps. I plan rest days either side of a busier day, and choose to focus my energy on the essential things.

**Rachel, diagnosed with Hodgkin lymphoma**

### **Cancer-related cognitive fatigue (CRCF) ('chemo brain')**

The word 'cognitive' relates to thinking. Cancer-related cognitive fatigue (CRCF) means a change to your thinking processes. You might also hear it called 'cancer-related cognitive disorder', or 'mild cognitive impairment'. It's also sometimes called 'chemo brain', but the changes can happen with other types of treatment – not just chemotherapy.

People with CRCF often describe being in a 'mental fog' or feeling detached from the world. You might have difficulties recalling names and dates, concentrating on everyday tasks, planning and multi-tasking. Following the thread of a conversation or finding the right word might be hard, too.

The symptoms may come and go, and can worsen when you are busy or tired. They are often mild and usually get better with time. Usually, they improve within a few weeks of finishing treatment, although, for some people, they go on for longer. Most people find ways of managing CRCF so that it doesn't impact severely on their daily life.

**Tell your doctor or nurse about your symptoms so that they can check for and treat any underlying causes such as anaemia or infection.**

If your symptoms affect your daily life, your medical team might be able to refer you for specialist help – for example cognitive behavioural therapy (CBT). CBT is a talking therapy that helps to order your thought processes and suggests coping methods that are suited to your individual needs.



Sometimes I can't take anything in. I cannot find the right words, which makes stringing a sentence together challenging. I often find part-way through a sentence I can't recall what I was talking about.

**Adam, treated with radiotherapy and chemotherapy for Hodgkin lymphoma**





## Tips

### ...to help with focus

- Try to do just one thing at a time.
- Be patient with yourself – particularly if you are learning something new that needs a lot of attention.
- Find somewhere quiet to help you focus on a task or conversation – a quiet living room is probably better than a busy coffee shop, for example.

### ... to help with remembering

- Write things down – leave yourself reminders on sticky notes.
  - Use a calendar on your wall or on your phone to keep track of appointments.
  - Let people know you are having difficulties with your memory.
  - Add to the shopping list as soon as you notice that you're running low on something.
  - Use maps, GPS or navigation systems to find places if you find it hard to remember how to get there.
  - Keep your mind active with puzzles like crosswords, word searches and Sudoku.
-



The International Cognition and Cancer Taskforce is a group of patients and health professionals that aims to understand more about the impact of cancer treatments on cognition and to advise doctors on how best to help patients experiencing chemo brain. Find out more at [www.icctf.com](http://www.icctf.com).

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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. My GP could not identify the cause. A later diagnosis made it easier to understand what was happening. I was then able to make better judgements or defer making decisions if appropriate.

**Gerry, diagnosed with follicular lymphoma**

### **Anaemia (low haemoglobin)**

Anaemia means that there is too little haemoglobin (a chemical that carries oxygen) and too few red cells (that carry haemoglobin) in the 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. Treatment for anaemia depends on its cause.

Symptoms of anaemia include:

- fatigue (extreme tiredness)
- feeling weak and lethargic (lacking energy)
- feeling short of breath when doing things
- feeling your heart fluttering or pounding (palpitations)
- feeling dizzy or faint
- headache or sometimes aching bones
- a paler complexion than is normal for you.

There is no specific dietary advice for treatment-related anaemia, although a balanced diet is recommended.

**Let your medical team know if you notice any of the symptoms of anaemia. They are likely to suggest a blood test to check your haemoglobin level.**

### **Neutropenia (low neutrophils)**

Neutropenia means having a low number of neutrophils (a type of white blood cell). If you have lymphoma, you may be more at risk of neutropenia because of the lymphoma itself, or because of treatment.

Neutrophils are important in fighting infections, so a lowered number of this type of cell puts you at greater risk of developing infections. You are less likely to be able to fight infections without antibiotics and you may also need to be admitted to hospital to treat the infection.

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

- fever (a temperature of over 38°C or 99.5°F in adults)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or mouth
- redness and swelling around skin sores, injuries to intravenous lines
- diarrhoea
- a burning or stinging sensation when passing urine
- unusual vaginal discharge or itching
- unusual stiffness of the neck and discomfort around bright lights.

Usually, neutropenia caused by chemotherapy does not need treatment as neutrophil counts recover quickly without treatment. If you are at an increased risk of infection, your doctor might prescribe a preventative treatment.

To reduce your risk of infection, keep good hygiene and minimise your contact with germs. Avoid flossing if you are neutropenic as it can cause bleeding between your teeth and allow infection in. Check with your medical team before having any dental work. You should also ask your consultant whether you should have the flu and pneumonia inoculation (jab) before you begin treatment.

**Stay away from people with infections (such as cold and flu) and avoid public places at busy times (for example, public transport during rush hour, swimming pools and cinemas).**

Take care to protect your skin so as not to give an entrance to bacteria, which could cause infection. Take measures such as using an electric shaver rather than a razor, wearing protective gloves when gardening, and keeping your shoes on outdoors. If you cut, scratch or graze yourself, use warm water, soap and an antiseptic to clean the wound and then leave it alone; don't pick at scabs or wounds.

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## **Tips to reduce food-borne infections**

- **Wash your hands before eating.**
- **Use food within its 'use by' date.**
- **Avoid unwrapped goods (like loose bakery products).**
- **Store food at the correct temperature.**
- **Disinfect food preparation surfaces and utensils with antibacterial cleaner.**
- **Follow any advice given by your medical team.**



**Find more tips to help you avoid food-borne infection at**  
**[www.lymphomas.org.uk/neutropenia-infection](http://www.lymphomas.org.uk/neutropenia-infection).**

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Food type	Avoid	Choose
<b>Dairy</b>	<ul style="list-style-type: none"> <li>• unpasteurised milk</li> <li>• unpasteurised cream</li> <li>• yoghurts that are labelled 'probiotic' or 'bio'</li> <li>• soft unpasteurised cheeses (such as Brie, goat's cheese, paneer and Camembert) and blue-veined cheeses (such as Stilton and Roquefort)</li> </ul>	<ul style="list-style-type: none"> <li>• pasteurised milk, soya milk, ultra-high temperature-treated milk (UHT milk)</li> <li>• pasteurised or UHT cream</li> <li>• yoghurts that are not labelled as 'pro-biotic' or 'bio'</li> <li>• tubs of ice cream or frozen yoghurt, wrapped bars or lollies</li> <li>• hard cheeses (such as cheddar), processed cheeses, cottage cheese, halloumi and mozzarella</li> </ul>
<b>Eggs</b>	<ul style="list-style-type: none"> <li>• raw or lightly cooked eggs, such as soft-boiled eggs</li> <li>• dishes that contain raw or slightly cooked eggs, such as homemade mayonnaise and hollandaise sauce, and homemade ice cream and mousses</li> <li>• eggnog</li> <li>• soufflés</li> <li>• soft meringue</li> </ul>	<ul style="list-style-type: none"> <li>• well-cooked eggs, such as scrambled or hard-boiled eggs</li> <li>• shop-bought mayonnaise</li> <li>• shop-bought ice cream</li> </ul>

Food type	Avoid	Choose
<b>Meat and poultry</b>	<ul style="list-style-type: none"> <li>• raw or undercooked meat and poultry, such as meat that is still pink, including steak</li> <li>• ready-cooked hot chicken from supermarkets</li> <li>• smoked meats, such as Parma ham, salami</li> <li>• pâté</li> </ul>	<ul style="list-style-type: none"> <li>• well-cooked meat (with no pink or red colour inside)</li> <li>• tinned meat</li> <li>• vacuum-packed cold meats, such as ham, beef and turkey</li> <li>• tinned meat pâté or pasteurised meat pâté in a jar</li> </ul>
<b>Fish</b> If you are severely neutropenic, check with your medical team that it is safe for you to eat fish	<ul style="list-style-type: none"> <li>• raw or undercooked fish, like sushi</li> <li>• raw or lightly cooked shellfish, such as prawns, clams, crab, mussels, oysters, scallops</li> <li>• caviar</li> </ul>	<ul style="list-style-type: none"> <li>• freshly cooked fish, fish fingers or fish cakes</li> <li>• tinned fish, such as tuna or salmon</li> <li>• vacuum-packed smoked fish</li> <li>• frozen fish (except shellfish)</li> <li>• well-cooked prawns, for example in a curry</li> </ul>
<b>Fruit and vegetables</b>	<ul style="list-style-type: none"> <li>• unwashed fruit</li> <li>• unwashed vegetables</li> <li>• any fruit or vegetable with damaged skin or mould</li> <li>• salad from salad bars</li> </ul>	<ul style="list-style-type: none"> <li>• good-quality fresh fruit and vegetables, including mushrooms, if they are well washed and freshly prepared (except if you are severely neutropenic)</li> <li>• tinned fruit or dried fruit</li> <li>• cooked berries</li> <li>• frozen or tinned vegetables</li> </ul>

## **Thrombocytopenia (low platelets)**

Thrombocytopenia means that you have fewer platelets than you should have. Platelets are blood cells that stop bleeding from cuts. 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 may have nosebleeds, bleeding from the mouth or gums, blood in your urine or bleeding from your bowel. Women may also have heavy menstrual periods. 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 bleeding**

- **Avoid high-impact sports (such as running) and contact sports (such as rugby).**
  - **Avoid blowing your nose hard or often.**
  - **Use a soft-bristled toothbrush (for example, a child's toothbrush).**
  - **Avoid flossing your teeth if it causes you 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). Symptoms depend on which nerves are affected, but it is fairly common to experience pins and needles, numbness or a burning sensation, pain and increased sensitivity to touch and temperature. If you have PN, you may have difficulty with tasks that need fine movements, such as doing up buttons or tying shoelaces.

Usually, the symptoms of PN go away once you finish treatment for lymphoma, although they can go on for longer. Improvements in symptoms may continue for up to a year after treatment; further improvement after this time is unlikely.

Tell your doctor if you think you might have PN. They can look at how to prevent further nerve damage, which may involve tweaking your medication.

### **Note that you must tell the Driver and Vehicle Licensing Agency (DVLA) if you are diagnosed with PN.**

Damage to your nerves may stop you from receiving all the signals (like pain and temperature) that you otherwise would. Without these, you may not realise you've hurt yourself. Protect yourself by wearing gloves for gardening, washing up and using the oven. Minimise the risk of tripping over by wearing well-fitting flat or low-heeled shoes with covered toes, and keep your house clutter-free.

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. You may find that the cold weather worsens your symptoms, in which case, gloves and thick socks can help.

Losing feeling in your toes can increase your risk of hurting yourself while cutting your toenails – ask your nurse specialist whether they can help you access a podiatrist (a health professional who deals with conditions of the feet).

Although there is no conclusive evidence to support its effectiveness, some people find acupuncture helps to relieve symptoms of PN. Acupuncture involves putting fine needles into certain places called ‘acupuncture points’ on your body.



**Find out more about acupuncture at [www.nhs.uk/conditions/acupuncture](http://www.nhs.uk/conditions/acupuncture). If you're interested in acupuncture, ask your medical team if it's safe for you.**

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### **Further information and support**

**The Foundation for Peripheral Neuropathy** is an American organisation. Their website gives information about PN, including a section on healthy living with the condition, [www.foundationforpn.org](http://www.foundationforpn.org)

**The Neuropathy Trust** provides information and supports people affected by PN and neuropathic pain, [www.neurocentre.com](http://www.neurocentre.com).



## Tips for coping with peripheral neuropathy

- **Avoid alcohol as it can affect nerve function.**
  - **Check the temperature of baths, showers and washing up bowls using a thermometer, or ask someone else to check for you.**
  - **Wear slip-on or Velcro shoes if it's difficult to tie shoelaces.**
- 

### Skin problems

Skin problems can also be a symptom of some types of lymphoma, especially Hodgkin lymphoma and a type of skin lymphoma called T-cell lymphoma.

Some treatments for lymphoma can cause skin problems such as dryness, pruritus (itching), rash, soreness and photosensitivity (sensitivity to sunlight).

If you are photosensitive, the skin on your head may be particularly vulnerable. Protect your scalp by wearing a hat or high factor sun cream when you are out in the sun, and avoid being out in strong sunlight (11am–3pm in summer months).



## **Tips for coping with sensitive skin**

- **Use 100% cotton sheets and pillowcases. If you are staying in hospital overnight, ask if you can bring your own bedding.**
  - **Use a cool (not freezing) compress to relieve painful skin.**
  - **Ask your doctor if there is medication, such as a steroid treatment, that could help if you have severe photosensitivity.**
  - **Find tips on coping with skin dryness and itching on page 40.**
- 

### **Oral mucositis (sore mouth)**

Oral mucositis (sore mouth) is a side effect of some treatments for lymphoma. It happens when the mucous membrane (soft tissue that lines the inside of your mouth) becomes inflamed (swollen, red and painful). This can cause symptoms such as pain when swallowing or mouth ulcers (sores). You can reduce your risk of developing a sore mouth by avoiding smoking and alcohol. It also helps if you avoid spicy foods, acidic fruits, garlic, onions and vinegar.

Sore mouth usually gets better once you finish your treatment and your blood counts return to their pre-treatment levels. This is usually around 2–3 weeks after chemotherapy, and 6–8 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 special mouthwash that contains anaesthetic to help soothe a painful mouth.

**If your mouth is sore, eat soft foods, such as mashed potato, scrambled eggs or soup. Avoid spicy or citrus foods, which can make a sore mouth worse. Serve your food cool or warm as hot food can make irritation to your mouth worse.**

If your mouth feels sore, it's also quite likely to be 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.

Flossing can damage an already sensitive lining of your mouth and allow harmful bacteria into the bloodstream. If you regularly floss, do it gently if you decide to continue flossing during your treatment. If you do not floss regularly yet, it is not a good idea to begin while you are having treatment for lymphoma.



## Tips for coping with sore mouth

- Use mouthwash after eating to prevent infection. Choose a mouthwash that doesn't contain salt or alcohol.
  - Clean your teeth twice a day using a soft-bristled brush. Try using children's toothpaste, which is milder than regular toothpaste.
  - Suck an ice lolly to soothe pain.
  - Relieve a dry mouth by rinsing out your mouth 5–6 times a day with a bland solution: ½ teaspoon of bicarbonate of soda (baking soda) mixed with a cup of water.
- 

### Reduced fertility

Some treatments for lymphoma can reduce your fertility. This is more likely with certain chemotherapy drugs, high-dose chemotherapy used before a stem cell transplant, radiotherapy to the pelvis, and some antibody therapies.

**Your medical team should advise you on whether your fertility is likely to be affected. Talk to them about this before you begin your treatment and discuss your options for preserving your fertility.**

Sperm banking is the main option for men who wish to preserve their fertility. Testicular tissue cryopreservation (freezing) may also be possible, but this new technique is considered experimental at the time of writing.

The most common option for women is to store eggs. Embryo storage may also be an option if you have a long-term partner, but be aware that if either of you withdraws consent to use the embryos, they must be destroyed.



**Read more about fertility preservation at**  
**[www.lymphomas.org.uk/reduced-fertility](http://www.lymphomas.org.uk/reduced-fertility) and**  
**[see what services are available in your area at](http://www.hfea.gov.uk)**  
**[www.hfea.gov.uk](http://www.hfea.gov.uk).**

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Many people go on to have a family after having treatment for lymphoma. Your medical team should advise you on how long you should wait after finishing treatment before you try for a baby. Most people are advised to wait for up to 2 years. An important reason for this is to give your body time to recover from treatment. Another is that the chances of relapse (lymphoma returning) are usually highest within the first 2 years after going into remission. Women are often advised not to wait too long beyond the recommended timeframe, in case of early menopause (see page 81).

Generally, you are advised to first try for a baby naturally. However, as some women may have fewer eggs after chemotherapy treatments, it is sensible to seek advice from a fertility specialist earlier than if you had never had treatment for lymphoma.

If you have difficulties conceiving, assisted reproductive techniques (ARTs) can help. For men, these techniques include in-vitro fertilisation (IVF), intracytoplasmic sperm injection (ICSI), intrauterine insemination (IUI) and artificial insemination by donor (AID). For women who have enough eggs, it may be possible to have fertility treatment using the eggs remaining in the ovaries.

If you have a low number of eggs, you can use eggs or embryos that you stored before you had treatment. If you did not store any eggs or embryos, you might consider using donor eggs. These eggs can be fertilised with your partner's sperm or sperm from a donor. For women who have problems conceiving, using ovarian tissue may be an option, though this is considered experimental at the time of writing.

**There is strong evidence that there is no increased risk of birth defects if you conceive after treatment for lymphoma. There is also evidence that babies born to people who have had cancer are not at an increased risk of developing lymphoma themselves.**

Some chemotherapy drugs can cause long-term damage to your heart or lungs. For women, pregnancy could place an additional strain on the system. 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 are already pregnant, you can read about treatment for lymphoma during pregnancy at [www.lymphomas.org.uk/lymphoma-pregnancy](http://www.lymphomas.org.uk/lymphoma-pregnancy).**

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## **Early menopause**

The menopause (last menstrual cycle or period) marks the end of a woman's fertility. In the UK, most women reach the menopause between the ages of 47 and 53.

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 is higher with certain treatments, particularly those given at a high dose. This includes some chemotherapy treatments, and radiotherapy given to the ovaries.

## **Your doctor should talk to you about how your lymphoma treatment could affect your fertility before you begin treatment.**

An early menopause significantly reduces your chances of conceiving a child naturally. If you would like to become pregnant in the future and treatment is likely to affect your fertility, it is important that you get specialist medical advice before you have treatment for lymphoma.

An early menopause can have some long-term effects caused by low levels of the hormone oestrogen.

These include an increased risk of developing:

- osteoporosis (thin, brittle bones) – see NHS Choices for more information, [www.nhs.uk](http://www.nhs.uk).
- cardiovascular disease, including heart disease and stroke – British Heart Foundation have more information about these conditions, [www.bhf.org.uk](http://www.bhf.org.uk).
- possibly Alzheimer's disease and other forms of dementia – find out more about these through Alzheimer's Society and Dementia UK, [www.alzheimers.org.uk](http://www.alzheimers.org.uk) and [www.dementiauk.org](http://www.dementiauk.org).

It may be possible to prevent these risks if the missing oestrogen is replaced, for example, with hormone replacement therapy (HRT). Your doctor can advise you on whether this is an option, based on your individual situation.



## **Tips to minimise the long-term effects of an early menopause**

- **Eat a healthy diet, with plenty of foods that contain calcium.**
  - **Exercise regularly.**
  - **Maintain a healthy weight.**
  - **Stop smoking if you smoke.**
  - **Limit your alcohol and caffeine intake.**
-

## Coping with hospital visits

You may have several trips to hospital, either as an inpatient or as an outpatient. These visits can be difficult for a range of reasons.



### Tips to make hospital visits easier

- In case of an unplanned hospital stay, have a list of what to pack ready. Alternatively, you could pack an overnight bag so that it's ready to go.
- Take something to pass the time in the waiting room such as a novel, puzzle book or some mindfulness colouring.
- If you arrive early for an appointment, you could let the Ward Sister know that you'd like to go for a walk or a coffee and that you'll be back in time for your appointment. Tell them when you return.
- Speak to your medical team if you have any worries, for example, if you are claustrophobic and feel anxious at the thought of entering an MRI scanner.



I had met my partner (now wife) just 12 months before I was diagnosed and I made a deliberate decision to see the doctors on my own. Once I knew the diagnosis, I explained everything to her. She said we would work through it together. She came to all my chemotherapy sessions and consultant appointments and has been brilliant throughout.

**Douglas, diagnosed with follicular lymphoma**

# Relationships, family and friends

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## Changes to relationships

When emotions run high, relationships are often affected. Fear is a powerful emotion that can lead to withdrawal. Both you and those close to you may fear what lies ahead. Family and friends might be afraid of saying the ‘wrong thing’ and of upsetting you, and you might worry about burdening them with your feelings. Most people want to show support, they just might not know how best to do so – finding ways to express yourself can be hugely beneficial to you both (see page 91).

There might be times when you feel angry or resentful because people around you seem to carry on with their lives as normal. You may find it hard to accept help – for example, relying on someone for transport or to walk your dog. Remember that these changes needn’t necessarily last forever.

Sometimes, people say or do annoying things. You might get irritated by their well-meant advice, clichés or platitudes. 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 may, 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.

**You might need to take the lead in approaching others.**

**Say hello – let them know you’re still you.**

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**

## Your partner

It doesn't matter how long you've been together or what else life has thrown at you, a cancer diagnosis affects a relationship. There may 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 as much as possible. You may 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 the unfamiliar, can cause anxiety, frustration and tension, which can lead to a breakdown in communication. Find tips to help with communication on page 91.

## Sex during treatment

Generally, sex during treatment is considered to be safe and can enhance your wellbeing, but check with your medical team about any precautions you should take, especially if you are having

chemotherapy or your platelet count is low. During chemotherapy, you should 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 79).

**Note that some types of chemotherapy may cause impotence in men and vaginal dryness in women. Both of these are temporary. Ask your medical team for help if these problems affect you.**

Don't worry if you have sexual difficulties and lowered libido during treatment for lymphoma. This is not uncommon and 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 may also affect your desire.

Let your partner know how you feel and that a lowered interest in sex does not mean that you no longer find them attractive. Remember that there are other ways to express your affection, like cuddling. Although it might feel awkward to talk about these issues, it's often much easier once you start. Being open with your partner about your feelings can help to develop emotional closeness, which can in turn build physical intimacy. Above all, try not to worry – sex drive usually returns once you've recovered from treatment.



**Macmillan produces information about relationships and sex. See [www.macmillan.org.uk](http://www.macmillan.org.uk).**

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Lymphoma devastated our relationship. Neutropenia isolated me. I was angry and exhausted. Our bond was broken. Following treatment, my partner moved out but was clear that he did not want us to break up. Over 2 years, and with the support of Relate counselling, we rebuilt our relationship.

**Eva, diagnosed with diffuse large B-cell lymphoma**



## Family and friends

People are often unsure how to react to the news of a cancer diagnosis in someone they know. Some might withdraw. Others may ask questions, which can be difficult and tiring to handle. Think how much you're comfortable with sharing. For example, you could simply say: 'I've been unwell but I'm having treatment and I'm doing OK'. 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 wear this hat'.

My wife organised a day diary to ensure all medical appointments were noted. She helped me organise my huge volume of medication, sorting out pills according to the time they needed to be taken using colour coding.

**Colin, diagnosed with diffuse large B-cell lymphoma**

## Support from friends and family

Most of the time, people want to be there for you and they'll be glad for some guidance from you about how best to help you.

Lots of people want to help but don't know how– remember that the situation is new for them, too. Think about what would best help you and offer some ideas. For example, you could ask for help with:

- transport to and from hospital appointments
- housework, shopping or preparing meals
- childcare
- organising social activities.

As well as help with practicalities, let your friends and family know what you need from them emotionally – whether it's to talk about how you feel or to chat about other things, like sport or the latest TV drama.



## Tips for sharing information about your lymphoma

- **Have a key contact – this person can pass information between you and groups of friends or colleagues to save you from having to repeat it.**
  - **Send a group email with your news and updates. This approach can save you from having lots of similar conversations.**
-



- **Consider using social media. This can be a great way to update a lot of people quickly, but keep in mind that anything you post will remain online for years to come.**
  - **Instead of explaining the illness yourself, you could direct people to information on our website so that they can learn more for themselves.**
- 

## 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 so that you can work through any difficulties. It can also help to prevent hurt feelings and misunderstandings. On the next page is a tool that may help you to communicate well with those around you.



We had a rota for Skype and phone calls from friends and family. If I was feeling well, we had longer chats. If I was tired, we kept the calls brief. I knew they were thinking of me without being worn out by long chats.

**Elaine, diagnosed with follicular lymphoma**

'I' statements can be a helpful way of expressing yourself while lowering the risk of angry, hurt or defensive responses. 'I' statements focus on your feelings, as opposed to the other person's behaviour. Using 'I' statements can take blame out of your communication.

I statements	
'It really annoyed me yesterday when you kept telling me to sit down and rest', rephrased using 'I' statements:	
Say...	Example
How you feel/felt	I felt frustrated yesterday
When	when you insisted that I rest.
Why?	I know you only said it because you care but...
What you'd like	I want to do things when I have the energy, as I did yesterday. It helps me to feel more like myself. I'd really like you to trust me to tell you when I feel tired and need to rest.
How you feel/felt	
When	
Why?	
What you'd like	

## Talking to children about lymphoma

Talking to children about lymphoma is challenging. It's also something you're likely to worry about getting right. You might be concerned about frightening or upsetting children. You may also feel that you do not have the emotional resource and energy to cope with their responses.

Research shows that children cope better if they understand what is 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.

Help your child understand the situation by being honest. Use language that is appropriate to their age and development. This encourages expression of fears and anxieties as opposed to making them feel they mustn't talk about 'it' for fear of upsetting 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 cancer. Without permission to talk, children may try to cope with difficult feelings on their own, which can heighten fear 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, which could overwhelm them. Let your child know that it is OK to come back and ask questions and talk to you as often as they want to. Some hospitals allow children to visit the treatment unit. This can help to lessen their fears as it is often not as bad as they expect.

Reassure children that there is nothing they have done that has caused your lymphoma and that they cannot catch lymphoma from you.

You know your child best; trust your intuition and be guided by how much or little he or she wants to know. Don't assume you know how much information they would like.



You may find our storybook, *Tom has lymphoma*, useful in explaining lymphoma and its treatment to younger children. Download or order a free copy from our website [www.lymphomas.org.uk/tom-has-lymphoma](http://www.lymphomas.org.uk/tom-has-lymphoma).

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## Tips for talking to children about lymphoma

- Consider whether you'd like someone with you when you talk to your child – perhaps a partner or friend. Some hospitals have a nurse or social worker who could facilitate.
  - Choose a time when you're feeling calm and when you feel emotionally able to deal with questions. Give some thought to the conversation but try not to overthink it as this could put unnecessary pressure on you.
-



- If you have more than one child, speak to your children at the same time so that they do not feel that their siblings know more.
- Tell children how you feel, for example, tired or in pain. Prepare them for changes such as hair loss as a treatment side effect.
- Reassure children that their routines and activities will stay the same as far as possible, but that there may be some changes, for example, a friend's parent may be taking them to school on some days.
- Let your children's school know about the situation, so that they can offer support.
- Remember: the information will be a lot for children to take in. Revisit it from time to time so that they can ask questions and talk about their feelings.

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

**Sue, whose husband was diagnosed with follicular lymphoma**

My four 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**



### Further information and resources

**Macmillan** has advice on talking to children about cancer. They also publish a booklet called *Talking to children and teenagers when an adult has cancer*, which you can download or order online, [www.macmillan.org.uk](http://www.macmillan.org.uk).

**Marie Curie** has information about talking to children about your illness, [www.mariecurie.org.uk](http://www.mariecurie.org.uk).

### When someone you know has lymphoma

When someone close to you is diagnosed with lymphoma, you're likely to need to deal with the news yourself. At the same time, you might also want to provide practical and emotional support to the person you care about.



It's a lot to cope with and it's entirely natural to experience some powerful feelings in this situation, for example, 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.

Take care of yourself, physically and emotionally, before trying to take care of someone else.

- Lead a healthy lifestyle – eat and drink healthily, and exercise regularly.
- Take some time out for yourself – build relaxation into your day-to-day life, whether it's a walk, bath or a hobby. See page 113 for more on relaxation.
- Consider taking some formal respite – a short break or holiday. Carers UK can provide ideas and information about possible funding, [www.carersuk.org](http://www.carersuk.org).
- Continue with other aspects of your life – keep up with hobbies and spend time with people other than the person you care for.
- Connect with other carers – you might find it helps to be in touch with others who can relate to your experience. Carers UK have an online forum where you can share thoughts, feelings and tips with others.
- Find an outlet for your thoughts and emotions – this could be through a journal, private blog, artwork or singing. Alternatively, you might find that doing something physical helps, such as gardening or sports.

**We are 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 pages 23 and 162 for more information.**

If you'd like some additional support, you might consider talking to a trained professional, such as a counsellor. See page 24 for more about counselling.

### **Providing emotional support**

Don't underestimate the power of simply being there. Sometimes people with cancer worry that they'll be a burden on others so they say that they feel fine, even when they don't. If the person says they are 'OK' or 'fine' when you ask how they are, you could say that you mean you're asking how they are feeling or coping. If you get the same answer again, accept that they may not want to talk in depth, or that they really do feel OK at the moment. By asking how they are from time to time, you show that you're willing to talk if and when they're ready to.

**Remember: you can show your support in ways other than asking how someone feels – for example, simply offer the person a cup of tea and sit with them for a while.**



### **Tips to help show that you're listening**

- **Use non-verbal cues, such as eye contact, touch and nodding.**
  - **Paraphrase or repeat back what you've heard.**
-



- **Ask questions to check your understanding of what the person says.**
  - **Stay with the topic of conversation even when it's challenging and even if the person cries.**
  - **Listen without trying to find a practical solution – the person may just want to offload. Instead of trying to find a fix, you could say something like, 'that sounds really tough'.**
  - **Avoid comments that may seem as though you're brushing off the person's feelings, for example, 'you'll be fine'. It can also be unhelpful to compare the person's situation to someone who is 'worse off'.**
- 

### **Offering practical support**

The type of practical support you offer depends on the needs of the person you're trying to help and what you can realistically offer. We give some suggestions, but take guidance from the person you're caring for.

You could be involved in medical appointments. For example, you might offer transport and moral support. You could talk through any questions the person wishes to ask during their appointment. Note these down as memory prompts for them to take into their consultation.

If they want you to go into the consultation with them, agree beforehand which of you will lead the conversation and how much information they'd like to get. Don't be afraid to ask health professionals to slow down or to explain medical terms if you don't understand them. You could offer to note down any important information given during the consultation, so that the person can focus on talking with their health professional.

You could also help to monitor the health of the person with lymphoma. Their medical team will tell you what to look out for and what action to take. Make sure you know the signs of infection. These include, but are not limited to:

- fever (a temperature of over 38°C or 99.5°F in adults)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or mouth
- redness and swelling around skin sores, injuries to intravenous lines
- diarrhoea
- a burning or stinging sensation when passing urine
- unusual vaginal discharge or itching
- unusual stiffness of the neck and discomfort around bright lights.

Keep a thermometer to hand so that you can easily check their temperature.

The person you care for is likely to be on the look-out for the return or worsening of symptoms of lymphoma, particularly after

their treatment. If you spot any symptoms that they seem not to have noticed, mention them so that they can seek medical advice.

Naturally, people with cancer often become anxious if they think they have found a symptom of lymphoma or another form of cancer. You might help to lower their anxiety by talking through their concern and encouraging them to think about other possible causes of the symptom. For example, fatigue could be the result of a particularly busy day. Nausea could be an expected side effect of their treatment.

**If you or the person you care for is worried, seek guidance from their clinical nurse specialist.**

### **Helping the person to get information about lymphoma**

There is a lot of information online. A simple way of checking that health and social care information is trustworthy is to look for the Information Standard quality mark (see page 17).

Keep in mind that the extent of medical information you and the person with lymphoma would like may differ. Some people want very little information, while others prefer to have it bit by bit. There are other people who want to find out all they can.

You may have read a lot about lymphoma and wish to share your knowledge with the person you care for. Check whether they'd like this information before you give it to them. They might still be adjusting to their diagnosis or already feel overloaded with information.

## **Support for you as a carer**

It's advisable to register as a carer with your surgery. Your GP can often provide you with information and signpost you to sources of support and advice.

If you're in paid employment, speak to your human resources (HR) department about carer's leave. Note that you have a right to request flexible working and a right to take reasonable time off in emergencies.

## **As a carer, you may be entitled to financial support from the state and from local organisations.**

A carer's assessment involves a conversation between you and a trained professional to look at how caring impacts on your day-to-day life, including your emotional wellbeing. Based on this, you may be entitled to various types of help from your local council. This could include financial assistance or equipment to make some of the practicalities easier. You can request a carer's assessment through the local council of the person you care for. Find out more through NHS Choices and Carers UK, [www.nhs.uk](http://www.nhs.uk) and [www.carersuk.org](http://www.carersuk.org).

If you provide care for at least 35 hours a week, you may qualify to receive a weekly payment. You don't need to be living with the person you care for; however, you do need to meet certain eligibility criteria, including that the person you care for needs to receive certain benefits. Note that you are not usually eligible if you are claiming state pension. Find out more at [GOV.UK](http://GOV.UK).



## Tips to help you to help the person with lymphoma

- If the person with lymphoma won't accept help or doesn't want to talk, offer again at a later date – their wants and needs might change over time.
  - Find out what they are struggling with. This may give some ideas for what help to offer.
  - Be specific in your offers to make them easier to accept, for example, 'I'm popping to the supermarket. Can I pick anything up for you?'
  - See page 91 for tips to help with effective communication.
- 

### Further information and support

**Carers Trust** offers information, advice and support to carers. This includes an online forum, [www.carers.org](http://www.carers.org).

**Carers UK** provides information, advice and support to carers. This includes an online forum and a helpline, [www.carersuk.org](http://www.carersuk.org).

**Macmillan** has information for carers, [www.macmillan.org.uk](http://www.macmillan.org.uk).

**Turn2us** is a charity that helps people gain access to welfare benefits, charitable grants and support services, [www.turn2us.org.uk](http://www.turn2us.org.uk).



I lost my sense of invincibility. Before my diagnosis I never thought I could be sick. I was strong, fit and healthy, and felt in complete control of my life. Within a short space of time I could barely get out of bed and brush my teeth. I was struggling physically and my career, which I had worked so hard for, was interrupted and there was nothing I could do about it.

**Ceinwen, diagnosed with diffuse large B-cell lymphoma**



# Self-esteem

**Feelings of vulnerability** 106

**Body image** 106

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## Feelings of vulnerability

Many of us believe that our body is infallible and that nothing can go wrong with it. A cancer diagnosis can shatter this belief and shake you. You might lose trust in your body and in your ability to cope.

After treatment, people who have had cancer often feel more vulnerable to other illnesses. Uncertainty about the future can make you feel anxious and vulnerable.

## Body image

Body image is how you feel about your physical appearance. Lymphoma and its treatment can affect the way you look and therefore how you feel about yourself. For example, you might experience a change in weight, hair loss, or look more tired than usual. Although these are often temporary, they can still be difficult to cope with. While it may not be realistic to accept changes to your body overnight, trust that you can adapt over time. Find resources to help you cope with change to your body from Macmillan at [www.macmillan.org.uk](http://www.macmillan.org.uk).

**Boots and Macmillan have teamed up to provide beauty advisors who can give you hair and make-up advice after cancer treatment.**

## Self confidence

Feeling vulnerable and less confident about yourself and your body can have a significant effect on your confidence and wellbeing. It can affect how you feel physically and emotionally, and also what you feel able to do.

Recognise the significance of what you have been through. Almost certainly, life will have changed to some degree – perhaps in terms of your daily routine, your work, and your relationships.

**Allow yourself time to process any loss and to think about how your life has changed. It can help to talk to someone about this. This could be someone close to you or a trained counsellor.**

Sometimes people find it difficult to think beyond their lymphoma and begin to see themselves and the illness as one. Remind yourself of other elements of yourself, your different roles and interests. For example, you might be a father, a friend, an 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.

When it comes to getting back to your day-to-day activities, start small. You don't have to do everything all at once. In fact, if you experience fatigue, pacing yourself can help (see page 61). Set yourself a small number of goals you'd like to achieve each day. At the end of each day, think about what you have, rather than what you haven't done.

Pay attention to your 'inner voice'. It's human nature to judge oneself. You may find that your self-judgements are often negative, for example, 'I didn't achieve a single thing today' or 'no one will find me attractive anymore'. You can think of these as the voice of your inner critic, which is often unhelpful. Write down the messages – first using 'I' ('I'm boring', 'I'm not interesting') and then using 'you' ('you're boring', 'no one finds you interesting'). This can help to begin to bring some distance between you and your inner critic.

Once you have written down your inner critic's messages, challenge them. Respond to each with what a compassionate inner nurturer or inner friend might say back. Think about what someone who loves and respects you would say.

Write these responses down using 'I'. For example, in response to 'you're boring', you might say: 'Actually, Jim invited me for coffee so clearly he doesn't find me boring. I also helped him with a dilemma he had so I contributed something valuable to our friendship.'

As you become more aware of your inner critic, instead of absorbing the critical messages, you should be able to more easily respond with compassion. This takes practice.



## Tips for re-building your self-esteem

- Recognise that adjusting to lymphoma and life beyond it takes time.
  - Stay in touch with friends. Relationships can be very beneficial to your emotional wellbeing.
  - Challenge negative thoughts. Think, what evidence do I have to support this thought?
  - Keep up your activities – leisure interests can give you a sense of normality and can help to boost your confidence.
  - Set yourself some goals. They can give you something to focus on and achieving them can build your confidence.
-



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

**Reem, diagnosed with Hodgkin lymphoma**

# Relaxation and managing stress

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At times, you may find that worries dominate your thoughts. This can be exhausting and can impact greatly on your emotional wellbeing. Find strategies to help contain your worries.

## **‘Box’ (contain) your worries**

It can be really difficult to focus when you have worries rushing around your head. You could try to ‘box’ or compartmentalise these, setting aside designated ‘worry time’.

Write down the worries as they come to you. You could keep a notepad by your bed to jot down any worrying thoughts that come to you during the night. Tell yourself that you will return to them and give them your full attention later. You can then look at those you can do something about and those you cannot. Make a plan to deal with anything you can do something about (see page 25). For those that are beyond your control, develop ways of relieving stress and anxiety (see page 113).

**This type of compartmentalisation does not work for everyone. Even if it does, it might only work on some days or with some issues and it definitely takes practice.**

## **Make time for yourself**

Living with lymphoma adds more to your ‘to do’ list – attending medical appointments, considering treatment options, taking medication. It can be hard to make time for yourself with all that’s going on but it’s important that you try to prioritise some time for yourself.



You could put together a list of the things that help you relieve stress, for example:

- going for a walk
- seeing friends
- having a bath
- watching a film.

Build these in to your daily routine, and draw on them during particularly difficult times.

## Relaxation techniques

When you face a stressor (something stressful), your ‘fight or flight’ mechanism kicks in – an evolutionary survival mechanism that gives you a surge of energy to either fight with or run from danger. Adrenaline (a hormone) is pumped into your bloodstream. Once it’s there, it causes physiological changes such as faster heart rate, sweating and difficulty concentrating.

Having lymphoma is fraught with stressors – from awaiting scan results to having treatment. Develop relaxation techniques to make coping with stressors more manageable.

**It’s a good idea to practise relaxation techniques regularly so that you can call on them more easily during times of need.**

## Breathing techniques

Breathing techniques can be helpful in tense or stressful situations. For example, you might feel anxious while awaiting scan results or

nervous about having chemotherapy. Some people find being on 'watch and wait' (active monitoring) particularly stressful.

There are various breathing techniques. One exercise that many people find helpful is called '7/11 breathing':

- Find a comfortable position – 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're unable to 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 aims to help you release physical tension. It involves tensing and relaxing different groups of muscles. PMR can be useful at various times – for example, to help you to relax before bed, or before, during or after a stressful situation.

Below is an example of a PMR exercise. Pay attention to the contrast in feeling between tensing and relaxing the different muscle groups.

- Get comfortable, sitting or lying.
- Clench your fists tightly for 5 seconds.
- Release the tension.

- Shrug your shoulders up towards your ears. Hold for 5 seconds then release.
- Pull your chin in towards your chest. Clench your teeth and frown. Hold for 5 seconds. Move your chin back to its natural position and relax the muscles in your face.
- Clench your buttocks. Hold for 5 seconds. Release the tension.



**There are lots of PMR exercises online, for example, at [www.nopanic.org.uk](http://www.nopanic.org.uk).**

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## **Meditation**

There are many different types of meditation, all of which encourage relaxation. Although inconclusive, there are some research findings to suggest that meditation can promote mental wellbeing in people with cancer. Some studies suggest that it may 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 – including to the physical sensations you experience, your breathing and the world around you. Many people find that mindfulness helps them to manage stress and anxiety by allowing them to take control of thoughts before they become all-consuming.

**Mindfulness need only take 5–10 minutes of your day. Search online for apps like Headspace and Smiling Mind.**

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

**Find out more about mindfulness on the Mental Health Foundation website at [bit.ly/10-min-mindfulness](https://bit.ly/10-min-mindfulness), including a short podcast that gives you an exercise to try at home.**

## **Visualisation**

Visualisation is a technique where you ‘see’ a relaxing image or scene in your mind, such as a mountainous landscape or a beach. Make this as vivid as possible, imagining in detail 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 CDs and podcasts. Although the evidence is inconclusive, some studies report benefits of visualisation in people with cancer including an improvement in mood and pain reduction.



**There are lots of visualisation resources available online, for example a podcast on the Moodjuice website at [bit.ly/visualisation-exercise](https://bit.ly/visualisation-exercise).**

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## **Distraction with music**

Music can help to relax and to take you away, mentally, from the present situation. You could create a playlist of songs to help you at challenging times such as while you’re having treatment.

## **Further information and resources for relaxation**

**Moodjuice** has information and tips to help manage issues such as sleep problems, anxiety and depression, [www.moodjuice.scot.nhs.uk](https://www.moodjuice.scot.nhs.uk).

**NHS Choices** has a 'moodzone' that offers support with mild stress, anxiety and low mood. They have exercises, tips and audio guides, [www.nhs.uk](http://www.nhs.uk).

## Sleep

While sleeping difficulties are not uncommon in the general population, having lymphoma can have a particularly negative impact on sleep. You might have problems falling asleep or staying asleep for reasons including stress, pain, or a side effect of your treatment (for example, steroids might make you too alert to sleep).

**Speak to your doctor before taking any natural or over-the-counter sleep remedies. Some can react with treatment for lymphoma in unwanted ways.**

### Further information and resources

**NHS Choices** have information about sleep, including tips for getting a good night's sleep and information about sleeping pills, [www.nhs.uk](http://www.nhs.uk).

**Mental Health Foundation** has information about sleep, including podcasts, [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk).



## Tips for getting a good night's sleep

- Speak to your doctor or nurse specialist to help identify the cause of your sleep problems. They might be able to tweak your medication or prescribe something to help you sleep.
  - Help set your body clock. Get some natural light during the day and unwind before bed.
  - At night, keep your room dark, and avoid 'blue light' (given off by mobiles, tablets and laptops), which can disrupt your body clock.
  - Go to bed and get up at the same time each day.
  - Avoid stimulants before bed, including caffeine and sugar. Choose warm milky drinks, camomile tea and non-sugary foods such as crackers or oatcakes.
  - Make your bedroom 'sleep ready' – neither too hot, nor too cold. If you can hear noise that's beyond your control, try earplugs.
  - Manage worries – a racing mind can keep you awake. Have a pen and paper by your bed to note down any worries. Make a commitment to deal with these in the morning. See page 112 for tips for dealing with worries.
-

## Complementary therapies

Complementary therapies aim to improve mental and physical wellbeing. While they cannot cure your lymphoma, many people find them relaxing. Some people also find that they help them to cope with stress and anxiety. Research suggests that complementary therapies may also help to:

- control symptoms such as nausea (feeling sick)
- reduce your sense of pain
- reduce fatigue
- lessen feelings of anxiety
- improve your overall psychological wellbeing.

There are many different types of complementary therapies, for example, acupuncture, aromatherapy, and hypnotherapy. Massage and aromatherapy are particularly popular with people living with cancer.



**You can read more about complementary therapies on NHS Choices at [www.nhs.uk/livewell/complementary-and-alternative-medicine](http://www.nhs.uk/livewell/complementary-and-alternative-medicine).**

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### Massage

People with lymphoma often ask whether it is safe to have a massage – they worry that it could spread the lymphoma throughout their body. There hasn't been much research into massage specifically for people with lymphoma, but, as far as we are aware, there is nothing to indicate that gentle massage is

unsafe. Do check with your medical team, however, before you have a massage for the first time.

If your platelet count is low (see page 72), you may bruise easily. Tell the massage therapist that you have lymphoma and ask them to use a light touch. You should avoid areas of the body that are the focus of any active treatment (such as radiotherapy) and remember that your skin might be sensitive – ask the person massaging you to use a plain (or ‘carrier’) massage oil.

## **Aromatherapy**

Aromatherapy uses essential oils (which come from plants). It is often used alongside massage. More research is needed to look specifically at the effects of aromatherapy on improving quality of life for people living with cancer. However, there is some evidence that it may help to lessen anxiety and pain levels in the short-term.

## **Further information and resources**

**Cancer Research UK** has information about complementary therapies, their possible benefits and their side effects for people living with cancer, [www.cancerresearchuk.org](http://www.cancerresearchuk.org).

## **Complementary and Natural Healthcare Council (CNHC)**

regulates complementary healthcare practitioners in the UK. Their search tool can help you find a therapist near you. Note that it isn't a requirement for therapists to become a member so there may be suitably qualified therapists who are not on the register, [www.cnhc.org.uk](http://www.cnhc.org.uk).



**The Council for Soft Tissue Therapies (GCMT)** is a group of organisations working together to produce a set of standards. You can find a reputable massage therapist in your area on their website, [www.gcmt.org.uk](http://www.gcmt.org.uk).

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

- **Check qualifications and professional organisation membership – you can usually find this information in the therapist’s leaflets or on their website. You could also ask to see training certificates.**
  - **Find out about their experience – how long have they have been practising for and have they treated people with cancer?**
  - **Check that they have appropriate insurance – does it cover them to treat people with lymphoma?**
  - **Ask if your medical team can suggest a therapist. Some hospitals offer complementary therapies or can give you a list of recommended places to contact. Some hospices and cancer charities also give complementary therapies for people with cancer, which are often offered at a reduced rate or free of charge.**
-

## Talking about your experience

Making contact with others who can relate to your experience can be very beneficial to your emotional wellbeing. Some people find it easier to talk more openly to others affected by the illness than to family and friends. You might also like to consider talking to a trained counsellor – see page 24.

**See page 23 for information about the support we offer and how we can help put you in touch with others affected by lymphoma.**

Our support groups offer a warm welcome in a relaxed setting and an opportunity to meet others who understand. Anyone affected is welcome, whether you're someone who has been diagnosed with lymphoma, a family member, carer or friend. It can help to share experiences and to know you're not alone.

**Sharon, Information and Support team**



## 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

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## Diet and nutrition

Although there aren't any foods that cure lymphoma or stop it from growing, eating well helps your body recover from treatment. A healthy diet may also help you tolerate higher doses of chemotherapy and protect you from infection.

The diagram on the next page shows the Eatwell Guide, a resource developed by the government to show how much of what you eat overall should come from each food group.

The key points are to eat:

- plenty of fruit and vegetables
- plenty of carbohydrates (starchy) foods
- some meat, fish, eggs, and pulses
- some milk and other dairy foods
- small amounts of foods high in fat and added sugar.

**If you struggle to eat and drink during your treatment, speak to a member of your medical team for advice. They may offer you nutritional supplements or refer you to a dietitian who can give you support tailored to your individual nutritional needs.**

## ‘Wonder foods’ and other frequently asked questions

You may hear news stories about foods or drinks that can prevent or ‘cure cancer.’ Be wary of these claims. In this section, we address some frequently asked questions about food, drink and cancer. Speak to your consultant to find out if there are any foods you should avoid; they can offer advice based on your specific treatment.

# 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

Each serving (150g) contains

Energy	1376	11.3	0.5g	0.0g
Protein	10.0g	1.1g	0.0g	0.0g
Carbohydrate	10.0g	1.1g	0.0g	0.0g
Fat	10.0g	1.1g	0.0g	0.0g
Salt	10.0g	1.1g	0.0g	0.0g

of the daily reference intake

Choose foods lower in fat, salt and sugars

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

Choose wholegrain or higher fibre versions with less added fat, salt and sugar

Water, lower fat milk, sugar-free drinks including tea and coffee all count.

Limit fruit juice and/or smoothies to a total of 150ml a day

Choose unsaturated oils and use in small amounts

Dairy and alternatives

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

Eat less often and in small amounts

Per day 2000kcal = ALL FOOD + ALL DRINKS

### **Is it safe to eat grapefruit?**

Grapefruit can block CYP3A – a protein that helps break down drugs so that they can be absorbed into your bloodstream and take effect. Your doctor may advise you against eating grapefruit or drinking grapefruit juice while you are having treatment for lymphoma. Other fruits that may block CYP3A include Seville oranges, blackberries, pomegranates and some grape varieties.

### **Is it safe to drink green tea?**

Scientists think green tea could prevent some cancers and stop cancer cells from growing but far more research is needed.

Researchers also reported that green tea could stop the drug bortezomib (Velcade®, a newer drug approved for use in mantle cell lymphoma) working as well as it could. These findings come from animal studies so it's unknown whether they apply also to humans.

### **Is it OK to drink alcohol while I'm having treatment?**

Check with your consultant whether it is safe to drink alcohol. Alcohol can interact with some drugs and may affect how well they work. It should be OK to have the occasional drink between chemotherapy cycles when you feel well enough, but get medical advice first. Remember that you may feel the effects of alcohol more quickly now than you did before you had treatment. Visit [www.drinkaware.co.uk](http://www.drinkaware.co.uk) for more information about alcohol.



## Should I 'go organic'?

'Organic' means food produced with restricted use of man-made fertilisers and pesticides. Some people choose to eat organic food if they are concerned about the residues (traces) of pesticides and herbicides left in food. These levels are closely monitored to ensure that they stay well below the level that is thought to pose a health risk.

At the moment there is no quality evidence that organic foods can prevent cancer or stop it from recurring. Some studies have looked at the risk of non-Hodgkin lymphoma developing after exposure to pesticides and herbicides in agriculture workers, but further research is needed to clarify the risks.

## Will nutritional supplements help me?

If you can eat a healthy balanced diet, you don't need to take an additional vitamin or mineral supplement. If eating is difficult, though, you may need to take a general multivitamin and a mineral supplement to ensure that you get all the nutrients you need.

**Some vitamins and minerals react with some cancer treatments. Speak to your pharmacist, doctor or dietitian before starting to take any supplements.**

### **Should I avoid certain foods if my immune system is suppressed (lowered)?**

If your immune system is suppressed, you are more at risk of infection. Your immune system is suppressed if you are neutropenic (see page 67) or if you have human immunodeficiency virus (HIV). Speak to your medical team for advice about which foods to avoid to help prevent infection.

### **Will sugar make my lymphoma worse?**

Some studies show that cancer cells use energy more quickly than healthy cells do, but there is no evidence that eating sugar makes lymphoma or any type of cancer grow. There are also no findings to show that if you do not eat sugar, your lymphoma will go away. Eating a lot of sugar can have other health risks, though, including obesity, which is linked to the development of other types of cancer.

### **Can the herb Echinacea help me?**

Some people believe that Echinacea (purple cornflower) can boost immunity, fight cancer and improve side effects of chemotherapy and radiotherapy. There is currently 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 – see pages 70-71.

### **Is it safe to diet while I am having treatment for lymphoma?**

Generally, doctors advise that you should not diet during treatment as it can make it harder for your immune system to

recover. If you have steroids, you may find that these stimulate your appetite and cause fluid retention, both of which can lead to weight gain. Your weight should return to normal once you stop taking steroids, although it may require a combination of exercise and reducing your calorie intake. See page 44 for tips if your appetite has increased.

To find out more about food controversies, visit Cancer Research UK at [bit.ly/food-controversies](https://bit.ly/food-controversies).

## Smoking and drugs

### Smoking

Smoking increases your risk of developing infections, especially in the lungs. If you are currently having treatment for lymphoma, the risk increases further. Some chemotherapy drugs, including bleomycin, increase the risk of pulmonary fibrosis (scarring in the lungs), which can lead to breathing problems. Chemotherapy can also increase the likelihood of developing late effects (see pages 149-153). If you smoke, stopping can help to lower these risks.



**Get advice and support to help you quit smoking at**  
**[www.nhs.uk/livewell/smoking](https://www.nhs.uk/livewell/smoking).**

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### Recreational drugs

During treatment for lymphoma, your body is already working hard to break down and process treatment. Even after treatment, leading a healthy lifestyle that is free from recreational drugs is a good idea. This helps to put you in the best position to maintain good health.

**If you take recreational drugs, let your medical team know. They could make your treatment less effective and might affect your test results.**

### **Cannabis for medicinal purposes**

Cannabis may help with some of the side effects of treatment (including nausea, vomiting and sleep difficulties), but research findings are mixed and studies have only been carried out in laboratories using animals.

**You might think that cannabis is worth a try. Be aware, however, that it carries health risks, including the possibility of interacting with other medicines or treatment you're having in unwanted ways.**

Buying cannabis or cannabis oil on the black market is strongly discouraged as it may contain toxic (poisonous) chemicals. There have also been reports of people paying for cannabis online without then receiving the product.



**Cancer Research UK has more about cannabis and cancer [bit.ly/cannabis-cancer-cruk](https://bit.ly/cannabis-cancer-cruk).**

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## **Exercise**

Exercise can have a positive impact on physical and mental health. It can also lower fatigue, reduce your risk of infections and increase your muscle and bone strength. A further benefit is its potential to shorten your recovery time after treatment.

**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 but ideally, you should do some physical activity every day if you're able to. If you're not, build up gradually.**

For some people, exercise is a social activity. Others see it as a welcome time to be alone ('me time'). There are many different types of exercise; it's important to find a type that you can safely enjoy. Remember, you don't have to work out at the gym to get exercise. Find ways of building physical activity into your everyday life, for example:

- Go for a walk.
- Take the stairs instead of the lift or escalator.
- Do some housework or gardening.
- Push a shopping trolley or carry the shopping bags.



**NHS Choices gives more ideas for easy exercises you can do at home at [www.nhs.uk/livewell](http://www.nhs.uk/livewell).**

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I carried on with my life at a slower pace, and I treasure it. 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**

## **What precautions should I take when exercising?**

Although rest is essential to your recovery, evidence shows that it is both safe and beneficial to exercise during and after treatment.

We strongly recommend that you speak to your doctor about the type and intensity of exercise that's safe for you. They may advise you to avoid certain 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 72), due to the risk of bruising and bleeding.

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

Swimming has many health benefits, but it should be avoided at certain times. This includes if you:

- are neutropenic (see page 67), in order to avoid infection from public pools and changing rooms
- are having radiotherapy, as chlorine can irritate the area of skin that received treatment
- have a central line or PICC line (a tube inserted into a vein deep inside you to give treatments and take blood) in place, as swimming could dislodge it.

**Ask your medical team whether swimming is safe for you.**

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

There is growing support for the possible role of exercise in lowering the risk of cancer relapse (return). However, whether exercise can prevent recurrence of lymphoma, or any other type of cancer, is unknown.

## Further information and resources

**Lymphoma Association video** in which Fitness Instructor Andy (in remission from lymphoma) talks about exercise at [bit.ly/exercise-video](http://bit.ly/exercise-video).

**Active Nation** gives information about physical activities and where you can participate in these at [bit.ly/active-nation](http://bit.ly/active-nation).

**Macmillan** produce a *Get active, feel good* booklet and DVD and a review in 2012 that outlines recommendations in relation to physical activity for people with cancer. See [bit.ly/exercise-review](http://bit.ly/exercise-review).

**Trekstock** produces videos that help you to get back into exercise after cancer at [bit.ly/trekstock-exercise](http://bit.ly/trekstock-exercise).

**Walking for health** is a scheme of guided walks across England run by Macmillan and The Ramblers. See [bit.ly/walk-health](http://bit.ly/walk-health).



## Tips for exercising during and after treatment

- Build up the number of times and the length of time you exercise for gradually.
- Alternate exercise with rest to give your body time to recover.
- Find a type of exercise you enjoy, so it's easy for you to stick with it. Exercising with a friend can also make it more enjoyable – you might find that mutual encouragement helps you to stick with it.

I used to be very active and enjoy running. I found it difficult having to start again with light exercise such as walking. I had to accept that I would be slow – which was difficult as I've always been competitive, but I improved bit by bit.

**Georgia, diagnosed with Hodgkin lymphoma**

## Driving

In general, it should be safe for you to drive while you are having treatment for lymphoma. However, some treatments may make you feel drowsy, nauseous or may affect your concentration. It is also unsafe to drive if you are taking some anti-emetics (anti-sickness medicines).

Even if it is generally safe for you to drive, you might feel tired on days that you have treatment. If possible, arrange for someone to drive you to and from your appointments.

You may need to tell your car insurance company if your treatment affects your ability to drive. Check the latest advice at [www.gov.uk/lymphoma-and-driving](http://www.gov.uk/lymphoma-and-driving).

**Note that you must inform the DVLA if you have peripheral neuropathy (nerve damage), a side effect of some treatments for lymphoma – see page 73.**



## Finances

Having lymphoma can put a strain on your finances, particularly if your income is reduced. Travelling to and from hospital can be costly.

**Some hospitals offer free parking for cancer patients – check whether yours does.**

You may be entitled to financial assistance through the government. Some of these are means-tested (dependent on your income) and others are not. Possible sources of financial support include:

- Disability Living Allowance (DLA), a tax-free benefit for people who are disabled or have mobility difficulties.
- Help with the cost of some NHS services such as prescriptions and wigs.
- Housing benefit, to help meet rental payments if you are on a low income.

Financial support can be complex so it's best to seek professional guidance about what you're eligible for. You could try:

- **Citizens Advice Bureau (CAB)**, who have benefits advisors. Find your nearest CAB at [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk). Some CABs have a partnership with Macmillan – ask at your local CAB for more information.

- **Government website** – has information about the various benefits that may be available to you, [www.gov.uk](http://www.gov.uk).
- **Macmillan** has information about financial support if you are living with or caring for someone with lymphoma. They also have some online tools to help you get an idea of the financial support you might be entitled to, [www.macmillan.org.uk](http://www.macmillan.org.uk).

**In addition to benefits offered by the state, there may be organisations local to you that provide grants. Benefits advisors at your local CAB and your nurse specialist are good people to ask.**

## **Work**

You're likely to need to take some time out of work while you're having treatment for lymphoma and probably for a little while after finishing treatment. It's best to be upfront with your employer about this – speak to your HR department or your line-manager and ask how they can support you.

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 while you are having treatment and afterwards (under the Equality Act 2010).

You could consider reducing your hours or changing them so that you avoid the tiring 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.

**Even once you finish treatment, you are still entitled to reasonable adjustments to allow you to continue in your work.**

As someone who has had a cancer diagnosis, you are covered by this law for the rest of your working life. For example, if in months or years to come, you experience cancer-related fatigue and feel a break or flexible working arrangements could help you, your employer needs to consider your requests and accommodate them unless there is a good business reason not to.

Going back to work can help you to feel that life is getting back to normal. Keep in mind that you will probably need to pace yourself. It can take months to feel physically strong again and you may experience side effects for quite some time after treatment. The emotional effects of what you have been through can also make it difficult to concentrate fully.

You could have a phased return (which is a reasonable adjustment), starting with shorter days or weeks. You might also have 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 you will manage your work and finances if you're unable to work. Find out whether you are entitled to any benefits. You can also contact the Business Debtline, a confidential, independent, free service that advises on debt and cash flow problems for people who are self-employed, [www.businessdebtline.org](http://www.businessdebtline.org).

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**

### Further information and support

**Macmillan** provides information about work and cancer, including a guide to your rights at [bit.ly/work-cancer-macmillan](http://bit.ly/work-cancer-macmillan), [www.macmillan.org.uk](http://www.macmillan.org.uk).

**Turn2us** helps people gain access to financial support, including welfare benefits and charitable grants, [www.turn2us.org.uk](http://www.turn2us.org.uk).

**Working with Cancer** is an organisation that provides coaching, information, advice and support to help people with cancer get back in to work or to find work, [www.workingwithcancer.co.uk](http://www.workingwithcancer.co.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 your situation. Your doctor will need to write a letter to tell them about your lymphoma. Your education provider should be as flexible as possible, within the limitations set out by exam boards.



**CLIC Sargent has information about taking time out of school for treatment and about reasonable adjustments to help you to continue your education, training and employment**

**[www.clicsargent.org.uk/content/education](http://www.clicsargent.org.uk/content/education)**

You might like to read our *Young person's guide to lymphoma* if you're in your teens to early 20s. Download or order a copy from our website.

## Holidays and travel

There is no reason that you shouldn't get away. In fact, many people plan a trip away as something to look forward to after their treatment ends – just be sure to discuss your travel plans with your consultant before you book to check they are safe. Keep in mind that after radiotherapy, your skin could be more sensitive to sun damage for a while, so it might not be the best time to visit a very hot country.

While doctors are usually happy for you to travel within the UK while you are having treatment, most advise against travelling abroad. This is because of the increased risk of infection, possible delays in accessing medical treatment and language differences.

If you're planning a trip abroad, you may 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 what you need. Find your nearest travel clinic at [www.travelvaccinations.co.uk/travel-clinics](http://www.travelvaccinations.co.uk/travel-clinics).

**Check whether vaccines are safe for someone who has lymphoma – most are but some 'live' vaccines are not (see page 160). If you are travelling to an area where a live vaccine is strongly recommended, ask your doctor for advice.**

It's important to get the right insurance in place before you travel. It's highly advisable to get medical cover, too. This could save you from paying for any unplanned treatment you might need while you're away and cover flights should you need to return home early.

At the time of writing, the European Health Insurance Card (EHIC) entitles UK residents to get emergency care while travelling in Europe. The EHIC does not replace travel insurance: you should get both. Find out more at [www.ehic.org.uk](http://www.ehic.org.uk).



**Read more about travel insurance at**  
**[www.lymphomas.org.uk/travel-insurance](http://www.lymphomas.org.uk/travel-insurance).**

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## Tips for staying safe when travelling abroad

- 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 your situation to security staff.
  - Choose clean accommodation and be especially careful with your personal hygiene.
  - Use insect repellents and mosquito nets to protect yourself from mosquitos.
  - Ensure that the water you drink is sterilised – the easiest way is to boil it. Note that bottled water isn't always sterilised.
-



Life after treatment is not life without lymphoma. Cancer is as much a mental as a physical condition, so dealing with the emotional and psychological impact is still a part of life after treatment.

**Kate, diagnosed with Hodgkin lymphoma**



# Life after treatment

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## Feelings after treatment

You may experience a sense of facing the unknown after treatment. Whether your lymphoma is being controlled or you are in remission, it can bring emotional challenges. You might go through a whole range of feelings, including:

- Isolation – you may feel 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.
- Shock and anger – now that you're through treatment, the significance of what you've been through might hit you. You may feel angry about the disruption lymphoma has caused you and your loved ones, and by the unfairness of the situation.
- 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, you're likely to worry about it relapsing (returning). You might feel more anxious in general. Your self-esteem and confidence may be lower than they were before you had lymphoma (see page 104-109).
- Sadness – it's natural that you'd feel low when you reflect on what has happened to you. Feeling very low for more than a couple of weeks could be a sign of depression (see pages 10-12).

My nurse called me and told me I was in complete remission. I had told my mum that if I was told the good news I'd do a celebratory dance. I didn't feel like that at all. I was relieved but also overwhelmed. My initial reaction was to cry.

**Ruchi, diagnosed with Hodgkin lymphoma**



Many describe a need to find 'a new normal' after treatment for cancer. You might feel uncertain about your next steps, wondering where to go from here. Until now, your focus was probably on appointments and test results. Now that treatment is over, you might feel abandoned.



For the first few months after treatment, I had extreme mood swings and felt really frustrated. I got irritable and depressed – it felt like I had a spring wound up in me that got tighter and tighter, as though it might explode. Looking back, I think I tried to get back into a normal routine too quickly, before I was emotionally ready.

**Blair, diagnosed with diffuse large B-cell lymphoma**

Adjusting to life after treatment takes time. Find out how we can support you on pages 162-163. You may also be interested in our Live your Life programme (see page 163).

I am someone who cannot sit still. 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 plan it.

**Kat, diagnosed with double-hit lymphoma**



## **Others' responses to the end of your treatment**

Friends and family members are probably relieved that you've finished treatment. They might think you're fine now. Perhaps they tell you to celebrate.

Friends and family often quickly move on after treatment has finished. However, it often takes the person who has had treatment a lot longer to recover, both physically and emotionally. 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 perhaps also coping with side effects.

Some people may assume that you have the same energy levels that you had before your treatment. Let them know if you are tired. Remind them that it's likely to take a while for your energy levels to recover.

**Think about if and how *you* would 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.**

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## **Tips to help you express your feelings**

- **Be honest. Bottling up your emotions can make them harder to deal with in the long-term. See tips for effective communication on pages 91-92.**
  - **Talk with someone about your feelings. You could also speak to a member of our helpline team, a trained professional or others affected by lymphoma.**
- 

## **Late effects**

Late effects are side effects that develop weeks, months or years after treatment. Your doctor can give you information about the possible late effects of your treatment. We've listed some of the more common late effects, but this doesn't mean you'll get any of them.

**Most people recover well from treatment, but a few go on to develop late effects. It's important to know what to look out for to catch any problems early.**

### **Heart problems**

Chemotherapy drugs called 'anthracyclines', like doxorubicin, may increase your risk of heart problems. The risk increases with higher doses or more courses of treatment with anthracyclines. Heart problems can also happen after radiotherapy to the chest.

Heart problems become more common 10 years or more after your treatment but can occur sooner. Your risk stays increased for several years. You can reduce this risk by taking measures to improve your heart health such as eating a healthy diet, taking regular exercise, limiting your alcohol intake and not smoking.



**British Heart Foundation has information on keeping your heart healthy.**

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### **Second cancers**

If you develop a different type of cancer after lymphoma, it is called a 'second cancer'. Chemotherapy can increase your risk of some types of cancer, particularly if you have high-dose therapy. Second cancers that have been linked to chemotherapy treatment include leukaemia, lung and skin cancer. Cancer Research UK has more information about these types of cancer, including symptoms to look out for.

With radiotherapy, the type of second cancer you are most at risk of depends on the area of your body that has been treated with radiotherapy. Ask your medical team which cancers you are at a higher risk of developing. Make sure you know the symptoms of these cancers. Cancer is usually more treatable when it is diagnosed early.

**Ask your lymphoma nurse specialist or your GP about cancer screening programmes, which are designed to find cancers early.**

### **Blood problems**

Your blood counts can take a while to return to their normal levels depending on the type and intensity of treatment you have had.

In addition, myelodysplastic syndromes (MDS) are a group of blood disorders, which lead to a drop in the number of healthy blood cells you have. MDS can happen as a late effect of radiotherapy and chemotherapy.

Anaemia (page 66), thrombocytopenia (page 72) and neutropenia (page 67) are types of MDS. If you notice signs of blood problems, seek medical advice.

### **Lung problems**

Radiotherapy to the chest and some types of chemotherapy can cause damage to your lungs. The damage is a result of fibrosis (scarring).

A chemotherapy drug that can cause lung problems is bleomycin. This drug is often used to treat Hodgkin lymphoma as part of the ABVD regimen (combination of drugs). The targeted drug brentuximab vedotin may also contribute to lung problems, particularly when given together with bleomycin.

It's particularly important not to smoke if you have had treatment with bleomycin or with radiotherapy to the lungs.

**If you need to have an operation in the future, make sure you tell the anaesthetist that you've had bleomycin.**

### **Thyroid problems**

Radiotherapy to the neck or upper chest can affect your thyroid gland, which may then make less of the hormone thyroxine. This is called 'hypothyroidism' and can slow your metabolism (the speed at which your body uses energy), resulting in you feeling cold and tired, and gaining 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 but remains increased after this time. Hypothyroidism is usually picked up early by regular thyroid function blood tests. If you have hypothyroidism, your doctor can prescribe thyroxine tablets to treat it.

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

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



## Eye problems

If you've had radiotherapy to an area that includes your eyes, you might have dry eyes. Ask your doctor if there are any treatments that could help. You are also at increased risk of developing cataracts (cloudy patches in the lens of your eye that reduce your vision) in the future. Have regular check-ups with your optician as your prescription may change slightly during treatment and for a short while afterwards.

## Dental problems

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



## Tips to help you stay well after treatment

- **Ask your medical team exactly what treatment you've had and what your individual risks are.**
  - **Find out what symptoms you should look out for and what to do if you notice any of them.**
  - **Attend your follow-up appointments as these allow doctors to monitor your health and find problems early (see page 157).**
  - **Carry your medical alert card if you've been given it (see page 159).**
  - **Lead a healthy lifestyle (see page 126).**
-

## Other medical matters

Once you finish treatment, there are things to be aware of that can help you to live well.

### Signs of recurrence

A key concern for many people after treatment is being able to spot the signs of a possible recurrence (lymphoma coming back). Ask your medical team what to look out for. Be aware of the most common symptoms of lymphoma and get in touch with your medical team as soon as possible if you notice:

- **Swollen lymph nodes** – a lump or several lumps, usually painless, often in the neck, armpit or groin.
- **Fatigue** – exhaustion for no reason, or feeling washed out after doing very little.
- **Unexplained weight loss** – losing a lot of weight quite quickly without dieting.
- **Sweats** – sometimes described as ‘drenching’ when they happen at night because they can make your nightclothes and bedsheets soaking wet.
- **Fevers and infections** – some people get fevers (a temperature of over 38°C or 99.5°F in adults). Fevers often occur together with night sweats and weight loss, but they can occur separately. In addition, repeated or persistent infections (that you can’t shake off) can be a symptom of lymphoma.
- **Itching (pruritus)** without a rash.

Check once a month for swollen lymph nodes. Press firmly with three fingers. If you notice a swollen node, check again in a week. If the swelling is still there, see your GP.



## **Tips for spotting signs of recurrence and other cancers**

- **Go for any follow-up appointments you are offered (see page 157).**
  - **Take up any health screening programme invitations you are offered. In the UK, these include checking for signs of breast, cervical, bowel and prostate cancer. Find out more at [www.nhs.uk/livewell/screening](http://www.nhs.uk/livewell/screening).**
- 

I have check-ups every four months and feel I am doing wonderfully well. The best piece of advice I was given about what would alert me to anything 'suspicious' was 'listen to your body'.

**Pat, diagnosed with follicular lymphoma**



## Treatment summary

At the end of your treatment, both you and your GP may receive a treatment summary. This is an overview that covers:

- your diagnosis, including type and stage as well as date of diagnosis
- treatment you have had and when you had it
- treatment aim (to cure or control your lymphoma)
- possible side effects and late effects
- alert symptoms that require referral back to your hospital team
- key contacts, including an out-of-hours telephone number
- follow-up or management plan
- other information and lifestyle recommendations (for example, to quit smoking).

**Although it's not standard practice across the whole NHS to provide a treatment summary, many hospitals do now offer them so it's worth asking for one.**

## Follow-up appointments

**The purpose of follow-up appointments is to monitor your recovery, help you to manage any ongoing side effects or late effects of treatment, and check for signs of relapse (the lymphoma coming back).**

Follow-up appointments consist of both conversations and physical tests. Your doctor or nurse might do:

- physical examinations (such as 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
- scans, if your medical team need to assess how well your lymphoma has responded to treatment or to help check for any signs of relapse.

How often you're followed up depends on the type of lymphoma and treatment you've had. The table on the next page gives a rough guide.

Situation	Length of time you are followed-up
Hodgkin lymphoma and high-grade non-Hodgkin lymphoma	Usually 2–5 years after finishing treatment
Low-grade non-Hodgkin lymphoma	Rest of your life. Some hospitals discharge you to your GP for follow-up after 5 years; self-management is also being introduced
Treatment with maintenance rituximab	Frequently during the rituximab period; less frequently afterwards
Treatment as part of a clinical trial	As directed by the trial protocol (which outlines how the trial should run)

Some hospitals offer self-management programmes or supported management programmes, where you book your own follow-up appointments. Research suggests that most recurrences of lymphoma are picked up by the person directly affected by it.

The idea behind this approach is that you know your own body best and, with guidance, you will know when you need to be checked out.

**Self-management is only appropriate for certain people: those in long-term remission, those who have long-term stable low-grade lymphoma, and those whose risk of relapse is low. Ask your hospital whether they offer this approach if you are interested.**



## Tips to manage anxiety about follow-up appointments

- **Note down any questions you'd like to ask to help you remember them. You could run through these with a friend or family member beforehand to get them clear in your mind.**
- **Consider which anxiety or stress-relieving techniques are helpful to you (see page 112).**
- **Let your friends and family know that you have an appointment coming up and how they could help. This could include showing you some patience and understanding if you are quiet or irritable.**
- **If you have questions or concerns, contact your medical team any time.**
- **Get in touch with a member of our helpline team to talk about how you're feeling.**

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### Medical alert card

A medical alert card is a card or letter that has important information about your lymphoma and the treatment you've had. It's important that anyone treating you (including doctors, dentists and anaesthetists) is given this information.

Always have your medical alert card with you. Keep some spare copies in case you lose the original.

## **Vaccinations**

Most vaccinations are safe for people who have had lymphoma. Your doctor can give you specific advice, but as a rough guide:

- you may be told to wait 6–12 months after finishing treatment before having a vaccination
- it's advisable to have the annual winter flu jab
- if you've had your spleen removed or you have had a stem cell transplant, you need additional vaccines
- if you're going abroad, you might need specific vaccinations.

Live vaccines, such as the shingles vaccine, may pose a risk to someone with lymphoma. Discuss the shingles vaccine with your doctor or specialist nurse before having it.

## **Steroids**

If steroids were part of your treatment, your ability to make enough steroids naturally could be affected, but this is rare. Your doctor will check to see whether you're making enough of your own steroids when you finish treatment and you'll be given steroid replacement treatment if necessary. You'll also need to carry a medical alert card with this information on (see page 159).

## **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 the spleen, you won't be able to fight infections as well as you used to. You should always carry a medical alert card.



You'll also need to take precautions, which may include taking low-dose antibiotics each day for the rest of your life to protect you from infection, and keeping an emergency supply of antibiotics in case you get an infection.

**You might need regular vaccinations such as the flu jab. If you travel overseas, you may need extra vaccinations. Seek advice from your doctor.**

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

Some people who've had treatment for lymphoma need irradiated products if they have a blood or platelet transfusion. Irradiation of blood products involves treatment with X-rays to kill donor white blood cells that could attack your own cells.

You'll need irradiated blood if:

- you've had Hodgkin lymphoma
- you were treated with certain drugs, such as fludarabine or bendamustine
- you have had a stem cell or bone marrow transplant.

Your doctor will determine if you need irradiated products and you'll be given a card that states it – always keep this with you. Although the hospital that treated you will know, other hospitals will need to be informed.

# Further information and support

Whether it's you, or a loved one who's been diagnosed, lymphoma can take a great deal of adjustment. Going through tests, scans and treatment can have an impact physically, practically, socially and emotionally.

## How we can help

For more information about any of the topics covered in this booklet, visit **[www.lymphomas.org.uk/about-lymphoma](http://www.lymphomas.org.uk/about-lymphoma)**.

If you'd like to talk to someone about anything to do with lymphoma – including how you feel, get in touch:



Call our Freephone helpline on 0808 808 5555, Monday to Friday, 9am to 5pm. You can also use Live Chat on our website or text message on 07786 202030



Come to one of our support groups. Find your nearest one at [www.lymphomas.org.uk/lymphoma-support-groups](http://www.lymphomas.org.uk/lymphoma-support-groups)



If you're over 16, join our online forum to chat with others who are affected by lymphoma



Join us on Facebook or follow us on Twitter



Check out our YouTube channel to watch personal experience and medical information videos at [bit.ly/living-lymphoma-videos](https://bit.ly/living-lymphoma-videos)



Follow us on Instagram

## **Live your Life – living with and beyond lymphoma programme**

Our Live your Life workshops are designed for people who have been diagnosed with lymphoma as well as for their carers. They are designed to:

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

To find out more, head to [www.lymphomas.org.uk/living-with-lymphoma](https://www.lymphomas.org.uk/living-with-lymphoma).

## Other useful organisations

We list a few organisations below that you may find helpful. You can find more useful organisations on our topic-specific webpages. If you can't find what you need, please get in touch with our helpline team. Our online forums may also provide suggestions of useful organisations.

**Cancer Research UK** has information about cancer and about research findings. They also have online forums on their website. Speak to a nurse on 0808 800 4040  
[www.cancerresearchuk.org](http://www.cancerresearchuk.org) | online contact form

**Health and Social Care (HSC) Online Northern Ireland** has information about cancer services in Northern Ireland and signposts to other organisations that offer help and support.  
[online.hscni.net](http://online.hscni.net)

**Hospice UK** supports the work of over 200 hospices and allows you to search for a local hospice.  
020 7520 8200 | [www.hospiceuk.org](http://www.hospiceuk.org) | [info@hospiceuk.org](mailto:info@hospiceuk.org)

**Macmillan cancer support** gives practical, medical, emotional and financial support to people affected by cancer. They also run a HOPE course, developed in partnership with Coventry University, which is a self-management course for people affected by cancer.  
0808 808 00 00 | [www.macmillan.org.uk](http://www.macmillan.org.uk) | online enquiry form

**Maggie's cancer centres** are for people affected by any cancer type. They offer practical, emotional and social support to people with cancer and their families and friends. 0300 123 1801 | [www.maggiescentres.org](http://www.maggiescentres.org)  
[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**NHS Choices** has information about cancer and related conditions. NHS Livewell has digital tools to help you live well. [www.nhs.uk](http://www.nhs.uk) | [www.nhs.uk/LiveWell](http://www.nhs.uk/LiveWell)

## Helpful books

You might find it helpful to read about the non-medical aspects of cancer. Here are a few books that you might be interested in reading, but there are many more.

Goodhart F and Atkins L. *The cancer survivor's companion*. 2013. Piatkus: London.

Holland GC and Lewis S. *The human side of cancer: living with hope, coping with uncertainty*. 2001. Harper Collins: New York.

Silverman D. *Your brain after chemo. A practical guide to lifting the fog and getting back your focus*. 2009. Da Capo Press: Cambridge.

## References

The full list of references is available on request. Please email [publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk) or call 01296 619409 if you would like a copy.

Go to [www.lymphomas.org.uk/legal](http://www.lymphomas.org.uk/legal) for permitted use and reproduction of this booklet.

## How you can help us

We continually strive to improve our resources for people affected by lymphoma and we would be interested in any feedback you might have about this information. Please visit our website at [www.lymphomas.org.uk/feedback](http://www.lymphomas.org.uk/feedback) or email us at [publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk) if you have any comments. Alternatively please phone our helpline on 0808 808 5555.



**We produce more information about lymphoma.  
Visit our website at [www.lymphomas.org.uk](http://www.lymphomas.org.uk).**

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## Tell us what you think

We continually strive to improve our resources for people affected by lymphoma and are interested in your feedback. Share your comments at **[bit.ly/LA-feedback](https://bit.ly/LA-feedback)** or email us at **[publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk)**. You can also call our Freephone helpline on **0808 808 5555**.

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If you or someone close to you has been diagnosed with lymphoma, this booklet is for you. It describes some of the feelings and emotions you may have and suggests ways to help you manage these. It also gives tips for coping with symptoms and side effects of treatment, and for dealing with the practicalities of living with and beyond lymphoma.

The Lymphoma Association provides specialist information and emotional support to anyone affected by lymphatic cancer. Get in touch today to see how we can help you.

Lymphoma Association

3 Cromwell Court, New Street, Aylesbury, Bucks HP20 2PB

General enquiries 01296 619400

**Freephone helpline 0808 808 5555**

**[information@lymphomas.org.uk](mailto:information@lymphomas.org.uk)**

**[www.lymphomas.org.uk](http://www.lymphomas.org.uk)**

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