

When someone close to you has lymphoma

 A book for family and friends



About this book

If someone in your life has lymphoma, this book is for you. Living with lymphoma can bring physical, practical and emotional demands – not only for the person who's been diagnosed, but for family members and friends.

For simplicity, we use the word 'carer' to mean anyone who's looking after someone with lymphoma, whatever your relationship to them.

We give tips to help you with some of the challenges you might face as a carer. You'll find suggestions for further support and information, as well as quotes from others who have experience of caring for someone who has lymphoma.

If you would like a copy of this book in large print, please contact us (page 77).

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

We would like to thank our incredible supporters whose generous donations enable us to offer our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work please visit lymphoma-action.org.uk/Donate



You might like to use this space to note key information in relation to the person you care for.

Type of lymphoma

Current treatment

Key hospital contact

Name: _____

Role: _____

Contact details: _____

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Are you a carer?

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“ We know that family, friends and carers can be hugely impacted by a loved one's diagnosis of lymphoma. Often, they're the ones seeking out information and providing practical and emotional support, as well as coping with their own feelings and managing other aspects of their day-to-day life. If someone close to you has lymphoma, we're here for you, as well as the person you're supporting.

Ropinder Gill, Chief Executive

Are you a carer?

A carer regularly looks after someone who has an illness or disability without being paid for it. You are a carer if you look after a family member or a friend who has lymphoma.

You don't necessarily have to live with the person. For example, you might support them by visiting them regularly or going with them to medical appointments.

You might help on a practical level by providing transport for the person to go to an art class, and this is likely to benefit their emotional wellbeing too. For example, it could enable them to do an enjoyable activity, help to build their confidence and give a sense of achievement. It could also provide a chance for some social interaction 'away from' their lymphoma.

“ My wife and I did practical things for our daughter, like housework and washing. We took her to hospital appointments and looked after her children to minimise the effect of chemo on them. We also took her dogs for two long walks a day.

Brian, carer to his daughter

Below are examples of the types of support a carer might offer. They're listed in separate categories, but in reality, many will fit into more than one.

Practical	Physical/daily living
<ul style="list-style-type: none">• Preparing meals.• Helping with housework.• Organising medicines into pill boxes.• Arranging appointments.• Providing transport to and from appointments.	<ul style="list-style-type: none">• Helping with personal care, such as getting dressed and showered.• Running errands.
Social	Emotional
<ul style="list-style-type: none">• Organising social activities.• With their consent, putting together a rota for others to help update family and friends about the person's health.	<ul style="list-style-type: none">• Talking to the person about how they feel.• Going to a medical appointment with the person to give company, support and to take notes of any points the person might be too tired or not ready to hear.

The importance of recognising that you're a carer

We all need support from time to time. Being a carer can bring added strains. It's important to identify yourself as a carer for a number of reasons. One way of getting practical and sometimes financial support is through a carer's assessment (see page 55). This can help you to become aware of your rights and entitlements. For example, you might be eligible for help with transport costs, or to receive money as direct payments to put towards the costs that come with caring.

According to research carried out by Carers UK:

- there are around 5.7 million carers in the UK
- it takes an average of two years for people to identify themselves as carers
- the value of unpaid care in England and Wales is around £162 billion per year.

Recognising your role as a carer can also help you to understand why you feel as you do – for example, worn out or worried. Making sense of your emotions can help to make them feel less overwhelming and more manageable.

See page 54 for more about financial support for carers.

Letting your GP know that you're a carer

It's a good idea to let your GP know that you're a carer and to ask them to add this to your medical records.

Your GP practice can then offer support, for example:

- flexibility with appointments, including arranging home visits if it's difficult to attend the surgery
- supporting you with balancing the needs of the person you care for with your own needs
- giving you guidance to help support you and the person you care for
- signposting to local services that provide support and advice, including carers' networks.

The Carers UK's website has more information about letting your GP know you're a carer, what to tell them and how they could help. Search 'your GP' at [carersuk.org](https://www.carersuk.org)



Notes

“ *We can give you guidance on caring for someone with lymphoma and on taking care of your own wellbeing.*

Aileen Chadwick, Macmillan Haematology
Clinical Nurse Specialist

Telling friends and other people that you're a carer

Some people feel unsure of how to let others know about their responsibilities as a carer. You might feel nervous about how they'll respond, or worry that telling them could feel awkward. Some people fear possible negative perceptions and judgements from others. For example, you might feel uncomfortable with saying that you're taking time out of paid work to care for the person with lymphoma, perhaps thinking that they might not realise how much you do.

You might like to prepare a few things to say. For example, if you come across someone you know when you're not planning to, such as in the supermarket. Think about what you're comfortable with telling them. Be respectful of the privacy of the person you care for too – you could check with them what information they're comfortable with you sharing about their health.



Your feelings

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“ It was a lonely, isolating and utterly numbing time. I felt helpless watching the person I love become a shell of himself, withstanding treatment, infection and pain. Lewis is now in remission and we are slowly finding independence from each other.

Sophie, carer to her partner

There's no typical way to feel after learning that someone you love has been diagnosed with lymphoma. This section outlines some of the feelings we commonly hear about from carers. **You might experience many different emotions, even within the same day.** Some carers describe their emotions as seeming to 'come out of nowhere', or 'just under the surface' and easily triggered.

As well as managing your own emotions, you might feel as though you've taken on or 'absorbed' those of the person with lymphoma. Some people describe feeling a sense of pressure to be 'strong' or upbeat for the person who has lymphoma, or of taking extra care not to upset them. This can be exhausting and can lead to a general sense of emotional heaviness.

Finding out about the diagnosis

Many people don't know much about lymphoma before someone they know is diagnosed. The words 'lymphoma' and 'cancer' can cause fear, and the uncertainty of the situation can be very hard to manage.

For some people, finding out a bit about lymphoma and its treatment helps to demystify it. Be careful not to overwhelm yourself with too much detail too quickly though – go at a pace that feels right for you.

“ *Trying to attend appointments together was critical, as nobody retains all of the information thrown at them. You need someone else to hear what is said and what the plan is.*

Paula, carer to her husband



Tips for finding out about lymphoma

- Find out about lymphoma. We have lots of information on our website and in our books.
- Speak to our Helpline team.
- If you have consent from the person you care for, talk to their health professionals for further information and to ask questions. If you don't understand something, ask if they can explain it as many times as you need them to.
- Check that sources of information are up-to-date and credible. One easy way to check at a glance is to look for the PIF TICK quality mark (shown on the back cover of this book). Find out more about PIF TICK at pifonline.org.uk/pif-tick

Fear

After the initial shock and disbelief, people often say they feel fear soon after finding out about the diagnosis of lymphoma in someone they love. For some people, this continues over time. For others, it might fade but heighten again at various points, such as before the person goes for a scan.

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

“ The Clinical Nurse Specialist team of the person with lymphoma can support you – they can signpost you to sources of psychological and emotional support.

Aileen Chadwick,
Macmillan Clinical Nurse Specialist

Be kind to yourself. Some carers believe they should set aside or ignore their fears, as though they're insignificant or less valid than those of the person who has lymphoma. Even if you genuinely feel optimistic, there are bound to be times when you feel less positive. Putting pressure on yourself to feel a certain way and ignoring how you truly feel can have a negative impact on your overall wellbeing and capacity to cope well.

If it feels difficult to talk about your fears with someone you know, please get in touch with our Information and Support team (see page 77).

“ My feelings of being a carer were initially of shock and fear for the responsibility of looking after someone, who I thought would never be in need of looking after until they were older. Then I seemed to fall into the role. Things seemed to come naturally but there was always the doubt, ‘am I doing the right thing by the person I’m caring for?’ But, with support from family, medical teams and charities, those doubts were allayed. Day-to-day living goes on, which can be hard to understand and accept, but you find a way whether that is realising and accepting that you can’t do everything that is on your list or actually asking for help, which personally for me was very hard.



Paula, carer to her husband

- tense muscles
- a quick heart beat
- heart palpitations (fluttering or pounding heart)
- dizziness
- quick breathing.

Life with lymphoma comes with many uncertainties and it can be difficult not to have definite answers. Your anxiety might heighten if the person you care for doesn’t tell you as much about their health or feelings as you’d like them to (see page 34).

One situation in which many people experience anxiety is if doctors recommend watch and wait (active monitoring). Doctors might recommend this approach if active treatment for the lymphoma isn’t needed straightaway. There are good reasons for this approach, but it can still be difficult to accept that the person has cancer but that they’re not having treatment at the moment.

We have more information about active monitoring on our website, including a video and podcast. We also produce a book about the approach. Search ‘active monitoring’ at lymphoma-action.org.uk



Anxiety

Anxiety can cause a powerful sense of unease. It happens in response to feeling stressed and can be a reaction to the unknown. Although anxiety is part of human nature, carers often experience heightened or ongoing anxiety. Common signs of anxiety include:

- tiredness, but difficulty sleeping
- feeling worried or irritable
- difficulty concentrating
- inability to carry out day-to-day tasks

Media stories can also trigger anxiety. For example, you might find a TV programme or magazine article that relates to lymphoma or another illness unsettling. Recognising this can be helpful and might help you decide whether you want to restrict your exposure to certain things.

Low mood

Everyone feels low from time to time. The practical and emotional demands of being a carer can intensify this. You might feel sad, anxious, panicky, tired, angry or frustrated, and your self-esteem could be affected too.

Your mood might also be lowered if other areas of your life are affected. Perhaps you don't have so much time or energy for leisure activities since becoming a carer. You might also have made changes to your working life or other commitments. All of this can lower your mood.

It's important to acknowledge how you feel and it can help to talk about it.

If your low mood continues for more than a couple of weeks and impacts on your life, it could be a sign of depression. When the demands of caring increase or go on over time, carers might be more likely to experience issues with their wellbeing, including depression. Depression can affect people in different ways. You might feel:

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

You might also have physical symptoms, including:

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

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

Stress

Research suggests that levels of stress are higher among carers. In addition to your own day-to-day life, you might be managing lots of other tasks for the person you care for. Trying to balance all of this can heighten stress to an unhelpful level.

Different people have different ways of managing stress. Taking care of your general health can improve your general wellbeing and help you to cope with everyday things that can cause stress.

You can also try self-help techniques. We outline one example, called '7/11 breathing', on the next page. There are many more online, for example, [nopanic.org.uk](https://www.nopanic.org.uk) has more self-help resources including relaxation techniques.

7/11 breathing

7/11 breathing aims to calm your body and mind. It slows the rate you take oxygen in and stops your body preparing for the evolutionary mechanism of 'fight or flight', which gives a rush of energy to either fight or escape danger.

Before starting 7/11 breathing, sit, stand or lie in a comfortable position. Breathe in through your nose while counting silently to 7. Then breathe out through your mouth while counting silently to 11. Repeat these two steps until you feel calmer. Often, a few minutes is enough. If you find 7 and 11 counts difficult, you could start by breathing in for 3 counts and out for 5.

For more information about stress and ideas to help manage it, search 'stress' on the Mental Health Foundation website: [mentalhealth.org.uk](https://www.mentalhealth.org.uk) or talk to the Clinical Nurse Specialist team of the person you care for.

If your stress levels stay high over time, speak to your GP for advice. One approach you might be interested in talking to them about is cognitive behavioural therapy (CBT). This can help you adapt how you think, with the aim of lowering stress levels. Search 'CBT' on the NHS website to find out more.

Although there is no specific medication for stress, if it's appropriate, your GP might prescribe medication to help you manage some of your symptoms of stress.

Uncertainty

Feeling uncertain can be a big part of caring for someone with lymphoma. Much of the time, lymphoma is successfully treated or managed. Nonetheless, many people want to know for definite what the outcome will be. The doctors treating the person you care for are best-placed to give information about their likely outlook. However, it's impossible for anyone to be absolutely certain.

Some carers feel self-doubt, questioning whether they're doing enough to help. Uncertainty can make it hard to adapt to your situation, to feel hopeful, and to manage anxiety.

It's common to wish for more control over things that you're unable to control. However, it can be more helpful to develop your ability to live with uncertainty.

Tips for living with uncertainty

- **Make and try to keep plans** in spite of uncertainty. For example, you could plan a day out for after treatment. This can help you and the person you care for to continue living and enjoying life.
- **Set realistic goals** to help with motivation and provide a sense of achievement.
- **Consider meditation techniques**, such as mindfulness. These encourage you to slow down and live in the present moment rather than thinking about what has been and what is to come – see page 48.
- **Think about what you can control**, such as finding out about lymphoma and looking after yourself.
- **Get emotional support** – see page 43.

“It can be helpful to set some goals. For example, you could plan something to look forward to during treatment, and perhaps a short break or holiday for after treatment.

Aileen Chadwick,
Macmillan Clinical Nurse Specialist

Loss, resentment and guilt

It can bring major life changes when someone you love is diagnosed with lymphoma. Perhaps you're unable to do all the things you'd planned to, either alone or with the person you care for. Not only are you coping with the news of the person's diagnosis, you're also adjusting to the idea that your future plans, at least for the time being, are affected. Some people feel disappointed that life hasn't turned out as they'd hoped.

You might feel lonely, lost and isolated, particularly if the situation impacts on your work or social life. [According to Carers UK's State of Caring 2022 survey, over a quarter of carers feel lonely often or always.](#)

It's common to feel a sense of grief for the life you lived before you became a carer. For some people, these feelings can develop into anger and resentment which, in turn, can bring the pain of guilt.

Sometimes, people feel guilty if they set aside thoughts of their caring role and take time out for themselves. Keep in mind that relaxation and having fun can be an essential part of coping.

“ *We hear from many people who are supporting someone with lymphoma and struggling with their own, sometimes unexpected feelings. Some people experience a sense of loss and resentment, which can be difficult to talk about, but it's an understandable response; carers are immersed in their loved one's journey, treading a different path alongside them.*

Sharon, Information and Support team member

Expressing yourself

It can be hard to talk about feelings, particularly those linked to cancer. If talking feels difficult, you could find another outlet. For example, through music, drawing or keeping a journal.

Releasing your thoughts and feelings can help you to feel calmer and less overwhelmed. However, focusing on them can also bring intense emotions to the forefront of your mind. Set aside a limited amount of time in any one reflective session and think about how you'll take care of yourself afterwards – for example, arrange to phone or spend time with a close friend.

Some people find it helpful to keep a diary, particularly when the person they care for is having treatment. This can be helpful in processing thoughts and feelings.

Talking about how you feel

Being honest with yourself about how you feel can be more beneficial than dismissing it. You can call our helpline to talk about how you feel (see page 77).

Some people find it helps to speak confidentially to a trained professional, such as a counsellor, to help work through complex emotions. See page 51 for more about talking therapies such as counselling.



Your relationship with the person you care for

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“ *I would be surprised if anyone said their relationship didn't change. I went from being the person who was protected to the person who needed to protect. I never resented my husband for getting ill but my word, I did resent the illness. I suffered with anger, frustration and disbelief that this could happen to us. Life doesn't go back to normal, it becomes a new normal. We're ten years on now. I would not deny that I feel a sense of loss for the life we had before, but it's made us work harder as a team and changed our outlooks on life.*

Paula, carer to her husband

As you both adjust to living with lymphoma, there are likely to be changes to some aspects of your relationship. You might grow closer, but there might also be times when the relationship feels strained.

In general, hard as it might at first seem, effective communication about the situation and your feelings can ease tension. It can also allow you both a chance to support one another through a difficult time.

Changes in roles within the relationship

Lymphoma can change the way things work in a relationship. These might involve practicalities, such as which of you does most of the driving. There might also be a 'switch' in roles, like which of you is most often 'the problem solver' or 'the one to cheer the other up'. Although it can take time to adjust, changes within your relationship don't necessarily have to be negative. Some people say that they find new ways of working and being together.

If the person you care for is one of your parents (or a parental figure), you might feel a sense of role-reversal. Perhaps it feels strange to help with things like medication reminders when they were the one to take care of your health during your childhood.

“ *One important message I have is the need to care for carers. Family and friends have to master their own fears. Cancer impacts upon whole families, friends and communities. Relationships can change.*

Kathleen, diagnosed with Burkitt lymphoma



If your partner is the person with lymphoma, the two of you might re-think who does what in terms of day-to-day tasks. Perhaps you now deal with the food shopping or finances, whereas your partner has usually handled these.

It can take a lot of energy to adapt to such changes. It can also be emotionally painful to see someone you care for struggling with things they once did easily. Try to be patient, both towards yourself and the person you care for.

Tips for re-thinking who does what

- **Respect the person's independence.** Ask which tasks are most important to them to keep doing.
- **Agree on tasks you could take on** so that they can save their energy for the things they'd most like to do.
- **Remind yourselves that the changes aren't necessarily forever.** It could be, for example, just while they're recovering after treatment.
- **Agree a trial timeframe** before reviewing together how the arrangement is working.
- **Talk to each other** as effective communication can help to prevent misunderstandings and bring a sense of teamwork during a challenging time (see page 70 for tips).

Feeling excluded or 'shut out'

There might be a gap between what you'd like to know about the health of the person you care for and what they're willing to share. Without information to let you know otherwise, you might start to feel anxious about the worst possible outcome. This can be highly stressful.

Consider possible reasons behind the person's choice not to involve you more. Limiting how much they tell you could be a way of trying not to burden or upset you, or an attempt to keep a sense of their independence and control.

Show that you're willing and ready to talk if and when they'd like to, but accept that there might still be a difference between your wishes and what they're comfortable sharing. As they begin to make sense of their situation and to process their feelings, they might gradually feel more at ease with telling you more.

If it feels appropriate, set aside some time to talk openly with the person about how you feel. Give some thought about how best to communicate what you'd like to say. Below, we outline a technique that can help to avoid angry and hurtful exchanges. If talking feels daunting, a good first step might be to let them know how you feel in writing.

'I' statements

'I' statements can be helpful in expressing yourself while lowering the risk of angry, hurt or defensive responses and the perception of blame.

These statements focus on you and your feelings instead of the other person's behaviours and actions. The table on the next page gives some examples of 'I' statements.

Statement	Rephrased to an 'I' statement
You never talk to me.	I want you to know that I'm happy to listen if you want to talk.
You always keep your appointments secret. It worries me.	I respect your privacy but wonder if you'd be comfortable with letting me know about upcoming appointments? If there are any you'd like me to come to, I could do that.
You never tell me anything. It makes me so angry.	When I don't know what's going on, I feel anxious and confused. I'd really like it if you'd give me more information. I'd like to support you.

Coping with changes in the person's mood

Lymphoma can affect energy levels, emotions and general mood. For example, steroids are often a part of treatment for lymphoma, and one of their common side effects is on mood. For the time they're taking them, the person might be irritable, 'flat', low in mood and short-tempered.

It can be exhausting if you feel as though you're dealing with the person's emotions in addition to your own. There might be times when you feel as though you're on the 'receiving end' of their feelings or 'taking the brunt' of them.

There might also be times when feelings are disguised. Fear and anxiety might be expressed as anger, for example. Hurtful as it can be, keep in mind that you are not the cause of changes in the person's mood.

Some people find it helpful to allow some space, even for a short while. This could be just spending half an hour in different rooms, or until you both feel calmer.

If you notice a significant impact on the person's mood, you could gently suggest that they speak to a member of their medical team. Their clinical nurse specialist or keyworker is often a good first point of contact. If it's appropriate, their doctors might adjust their medication to help reduce changes in mood.

“ I tried to just keep calm and to tell myself that it was the medication and not me. ”
Amanda, carer to her brother

Coping with changes in the person's appearance

Despite knowing that they're still the same person, changes to the person's appearance can be upsetting. If treatment is likely to affect how they look, it might help to mentally prepare for this. If it feels OK to do so, you could ask them what's expected. For example, they might lose or gain weight, or experience treatment-related hair loss. Talking in this way might also give the person an opportunity to talk about how they feel about any possible changes.

Feeling that you are now the person's carer

There might be times when caring for someone who has lymphoma feels very intense. It's important to pay attention to other aspects of yourself too. Remind yourself of what makes you 'you'. For example, you might be a partner, dad, friend and teacher. Maybe you enjoy reading, playing an instrument and a particular comedian. Think about your interests and beliefs too, your likes and dislikes, and your personal values.

Remember that the person is likely to need a mental break from their situation too. Think about things you can do together that take you both away from talk and thoughts of lymphoma. Start a conversation about a TV drama or their favourite sport. Watch a film, go out or play games together. Talk about places you've visited together or what you'd like to do in the future.

“ Jo began to lose his hair which was a really big thing! For him, losing his gorgeous long curls felt like losing his identity. For us, it made the cancer seem visible.

Nichola, carer to her son



Taking care of yourself

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“ There can be many stresses on the carer, such as running a house, visiting the person who has lymphoma, and holding down a job. There can be emotional tugs and challenging feelings, hidden behind a face of love, comfort and support. Even after treatment, there is a transition back into ‘normal life’ for the carer too.

Geoff, diagnosed with lymphoma and cared for by his wife

According to the Office of National Statistics (ONS), carers are less likely to consider themselves to be in good health compared with people who aren't carers.

This can happen when you feel unable to cope with the various demands caring can put on you, including those that are physical, social, psychological and financial.

Your wellbeing is just as important as that of the person with lymphoma. Staying well can also help you to take care of them.

Your physical health

A healthy lifestyle is an essential part of your overall wellbeing. It includes:

- **eating a healthy diet**, with fruit, vegetables, carbohydrates, protein and dairy (or dairy alternatives) with plenty of non-alcoholic fluids
- **taking regular physical activity** – for adults, this means at least 150 minutes of moderate activity (such as brisk walking, swimming or cycling) or 75 minutes of intense activity (like climbing stairs or running) weekly
- **keep within the recommended limits if you drink alcohol** – search 'alcohol units' on the NHS website for guidance
- **not smoking or taking recreational drugs**
- **following medical advice and keeping up-to-date with health checks**, including those offered through screening programmes

- **getting enough sleep** – search 'sleep' on the NHS website for tips to help you get a restful night
- **building rest into your daily life**, particularly if your caring role involves physical tasks, like lifting the person or helping them to wash.

For more guidance on following a healthy lifestyle, visit [nhs.uk/live-well](https://www.nhs.uk/live-well)

Your emotional wellbeing

You might not get much of a break from caring tasks or from related thoughts and concerns – your own or those of the person who has lymphoma. The intensity of the situation, particularly over time, can lead to high levels of anxiety and stress.

'Burnout' is the term used to describe emotional, physical and mental exhaustion that can happen as a result of ongoing heightened stress. It can happen in response to feeling overwhelmed and worn out. Over time, your physical and mental health can be affected, and you might feel as though you have little energy to give to the person you care for.

“ *My job: I didn't choose it. I didn't have any training for it. I don't get paid. I don't have a job description or contract of employment. Until recently, I did three 8-hour shifts a day, 7 days a week. There were no breaks or holidays. I can't resign or retire, even though I'm over 70. And the strangest feature is that I've never known my start date. What is this job? I am, of course, a carer.*



Gill, affected by non-Hodgkin lymphoma and a carer to her husband

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

An example of breaking down a problem and developing an action plan is given below:

Problem	Strategy	Resources
It's difficult to fit my paid work in with my caring role.	<p>I could:</p> <ul style="list-style-type: none"> • discuss a change in working hours with my employer • speak to my manager about delegating some of my tasks. 	<ul style="list-style-type: none"> • Carers UK has information about rights and support at work. • Macmillan Welfare Benefits Service provide advice about financial support.

Find signposting to sources of support on pages 77 to 80.

Think about how you can look after yourself emotionally. Try to make time for yourself, away from your caring role. Dealing with any practical concerns can also relieve stress and significantly improve your mental wellbeing.

Identify strategies to deal with your concerns

Problems can become overwhelming when they go round in your mind. Getting your thoughts down on paper can take away some of their power and bring a sense of release. Seeing your worries in writing might help you to identify any links between them and to consider how to address them.

Give yourself a break

Breaks are an important part of looking after yourself. As well as giving you time to 're-charge' your energy, it can bring enormous mental benefits too. In turn, the person you care for is likely to benefit from you feeling more refreshed and able to care for them.

“ *41% of carers haven't taken a break in the last year. Of those, 26% of carers haven't tried to take a break because they felt it was too difficult.*

Carers UK, 2022

There are different ways to take a break. Even just short breaks or 'pauses' in your day-to-day life are important. For example, try to give yourself an hour in the day that is just for you – you might sit and read or watch a programme during this time, or go for a walk.

You could also consider taking a short break (respite) with the support of an organisation that can help to organise this. This could be anything from a few hours to a couple of weeks out of your caring responsibilities. Respite can involve:

- replacement care, where support care assistants come to help look after the person with lymphoma in their home
- help with your household jobs
- a short stay in a care home for the person with lymphoma
- having someone to be with the person who has lymphoma while you take some time out
- leisure activities away from your caring duties
- a holiday, with or without the person you care for.

Time out for yourself is a vital part of mental and physical wellbeing. Spend time with friends, watch a film, take up or return to a hobby. Try also to free yourself of feeling obligated to do things you'd rather not – save your time for those things that you really have to do and the things you'd like to do.

- Carers UK has information about taking a break, including the practicalities of arranging it, paying for it and ensuring care for the person with lymphoma. Search 'taking a break' at [carersuk.org](https://www.carersuk.org)
- Carers Trust also has information about taking a break, including a list of organisations that help with funding and some of the practical arrangements. Search 'getting a break' at [carers.org](https://www.carers.org)

“ I’ve started volunteering for charity, which gets me out of the house for a few hours each week. I’m out meeting new people, learning new skills, and not thinking about what the future might hold. I believe my partner also appreciates that I’m not fussing over him 24/7! I have doubled my daily steps in the last few months by taking on an extra dog walk or two when my husband is fatigued – my physical wellbeing and outlook has improved as a result. I also have close friends who I can talk to when I need to.

Astrid, carer to her husband

You could also consider relaxation techniques, such as mindfulness, to help provide a mental break. Mindfulness is a type of meditation (relaxation) that encourages you to slow down and take note of your body and thoughts, as well as to the world around you. The idea is that focusing on the present moment can lower stress levels and improve mental wellbeing.

Search ‘mindfulness’ on the NHS website for more about this technique. You can also find mindfulness apps that are freely available online.

Nature

Spending time in nature can bring significant benefits to mental wellbeing. This can include being in a garden, park, at the beach or in a forest. Nature can help to manage stress and anxiety by giving you a sense of belonging in the world. If you spend time with other people in nature, it can also provide an opportunity to socialise.

Some people enjoy spending time in woodland, noticing their natural surroundings, sights and sounds, and taking some deep breaths. This is known as forest bathing. The idea is that this can help to bring a sense of calm, and lower stress.

Gardening can also be a helpful way of spending time in nature, with the added benefit of getting some exercise. If you don’t have a garden, or would like to make it a social activity, you could volunteer or join a community gardening group.

- Forestry England UK has tips on forest bathing for beginners. Search ‘forest bathing’ at forestryengland.uk
- The RHS has an online search tool to help you find a community gardening group near you: rhs.org.uk/get-involved/community-gardening/find-a-group

Challenge the pressure you put on yourself ('shoulds', 'oughts' and 'musts')

Feeling that you 'should' or 'ought' to do something or feel a particular way can have a significant negative effect on your mood. Such thoughts can be powerful yet unrealistic. They can become truths or realities in our mind, without us ever really questioning them.

When we're unable to meet our expectations, we can feel as though we've failed. This often leads to guilt and lower self-esteem.

Think about the 'shoulds', 'oughts' and 'musts' you feel. Consider whether they are true, then try replacing them with more encouraging statements.

Examples of 'should' statements replaced with more realistic thoughts are given below.

Should statement: 'I should feel positive for the person with lymphoma. They mustn't see me get upset'.

Replaced with more realistic thoughts: 'I really want to support the person. However, nobody feels positive 100% of the time. I am human and it's natural that I will feel upset, scared and anxious sometimes as I love this person and feel concerned about their health.'

Support from a counsellor or other therapist

There are many different types of therapy that aim to support your emotional wellbeing. Many of these involve talking to a trained professional such as a counsellor. However, there are other types of therapy. For example, you could consider working with an artistic or creative therapist to do something like drawing, painting, sculpting or using music to explore your feelings.

Working with a therapist could help you to consider:

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

The relationship between you and your therapist is extremely important – if you can trust them with how you feel, you are more likely to find your time together helpful.



- On our website's useful organisations webpage, you can find a section on emotional wellbeing. This includes organisations that offer or signpost to therapists.
- Find out more about some of the different types of therapy on the Mind website. Search 'types of talking therapy' at mind.org.uk
- Search 'how to find therapy or counselling' on the Mind website for more information about accessing these services for free or at a reduced cost.

If you think you might be interested in working with a therapist, speak to your GP. They might be able to give you a referral on the NHS. They might also know of other wellbeing and counselling services available to you in your local area.

You can also refer yourself to an NHS talking therapy service. Visit nhs.uk and search 'talking therapies' for more information and to watch a short video about the services on offer.

Other places to access therapy

If you are interested in trying a therapy, you could look into the following options:

- Local hospices, as some offer support, free of charge, to carers. This can include support groups and counselling sessions. Find your nearest hospice at hospiceuk.org/about-hospice-care/find-a-hospice

- If you are able to pay for it, you can search for a private therapist in your area using the British Association of Counsellors and Psychotherapists online tool at: bacp.co.uk/search/Therapists
- The support of a psychologist. These professionals work in various ways to improve mental health. The British Psychological Society gives more information about the role of psychologists and has an online search tool to help you find one at: bps.org.uk/public/find-psychologist

Connect with other carers

Many people find it helps to be in contact with others who can relate to their situation. It can be an opportunity to share thoughts, feelings, tips and ideas.

You could connect with other carers through:

- **online forums**, for example, Carers UK's online Carers Connect forum.
- **support groups**, such as those offered by Carers UK. Lymphoma Action support groups welcome carers, as well as people diagnosed with lymphoma.
- **requesting a Lymphoma Action buddy** by contacting our Information and Support team, who might be able to put you in touch with another carer. See page 77 for more information.

The healthtalk.org website has people's experiences of health conditions and situations, including a section on caring: healthtalk.org

Organisations such as Carers UK, Carers Trust, Turn2us and your local Citizens' Advice can give you more detailed information about your eligibility based on your circumstances.

“ Overall, the medical care has been excellent, but when issues have arisen, I've found it extremely helpful to connect with others on Lymphoma Action's Facebook for carers monthly online support meetings. All of this helped me not to feel so alone, guilty and frustrated, and to manage my expectations.

Astrid, carer to her husband



Carer's assessment

A carers' assessment is an opportunity to talk through your needs with someone who is trained to carry out the assessment. In Scotland, the assessment is known as an 'Adult Carer Support Plan'. There's no minimum number of hours you must provide care for each week to have your needs assessed, and it doesn't matter whether or not you live with the person who has lymphoma.

Through this, the person carrying out the assessment can help you to consider how caring impacts on your day-to-day life, practically, physically, socially and emotionally. They can signpost you to any support groups and networks for carers in your local area and tell you about any sources of support you are eligible for. Such support might include:

- practical help at home, such as help with cleaning or shopping
- having someone take on your caring responsibilities for a while, so that you can take a break (see page 46 for more on taking a break)
- advice on how to lift the person in ways that are safe for both of you
- helping you to access financial support.

Getting practical support

As a carer, you might be entitled to various types of practical support, including financial support. We outline some of these in the following pages.

- The Carers UK website has information about carers' assessments relevant to people living across the UK. Search 'carer's assessment' at carersuk.org
- You can also search 'carer's assessment' on the NHS website to find out how this could help you.

If you don't meet the criteria for an assessment, you should be signposted to other local services to help meet your needs.

Help with the cost of public transport

If you take a bus, train or coach with the person you care for to help them get around, you could be entitled to free or reduced-price travel. Search 'public transport' on the Carers Trust website at carers.org to find out more. You can also ask your local council about any schemes running in your local area.

Carer's Allowance

One of the most common entitlements for carers is called Carer's Allowance. This is a weekly, taxable payment paid directly into your bank account.

To receive Carer's Allowance, you don't need to live with, or be related to, the person who has lymphoma. However, to be eligible for it, you need to meet certain criteria, including not earning over a certain amount a week.

If you live in Scotland, you might also be entitled to an additional payment, called a 'Carer's Allowance Supplement'. The Scottish Government's website at mygov.scot has more information.

Find out more about Carer's Allowance at: gov.uk/carers-allowance

Your rights (legal entitlements) at work

If you are in paid employment, be aware of your rights at work. For example:

- If you've worked for your employer for at least 26 weeks, you can request flexible working. For example, a change in your working pattern to avoid a rush-hour commute. Note that there are exceptions, for example, if you work for the armed services.
- You might be entitled to paid carer's leave, designed to allow you time off for planned appointments and unexpected emergencies.

Marie Curie has more information about carers' rights at work. Search 'carer's rights at work' at mariecurie.org.uk



Supporting the person who has lymphoma

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“

I tried to listen and I was prepared to offer advice, but I also thought it was important to keep opinions to myself and stay quiet sometimes. I wanted to try to keep things as normal as possible to help the person undergoing treatment and to make this as smooth as possible.

Brian, carer to his adult daughter

The type of support you give the person with lymphoma will depend on several factors. For example, your relationship with them, their needs, and what you can realistically do within the limitations of your time, energy and other commitments. We give a few suggestions in this section.

Involvement in medical appointments

You could offer to help arrange medical appointments for the person. As well as making phone calls or online bookings on their behalf with their consent, you could note these on a calendar or in their diary. If they use a mobile phone or other electronic device to help with scheduling, you could set up reminders to alert them to upcoming appointments.

Before an appointment, you could offer to talk through any questions or concerns they'd like to raise with their health professionals. You could write these down so that they can take the list with them to their appointment as a memory prompt.

Even if the person can travel alone, you could offer to take, or simply be with them on journeys to and from their appointments. If they'd like you to go into their medical appointments with them, discuss with them beforehand which of you will lead the conversation and check what

information they'd like to get from it. You could offer to take notes of the key points discussed. Although they should receive a letter outlining these from the hospital, they might find it helpful to have a summary to take home straight after the appointment.

Health professionals might use terms that are unfamiliar to people who don't have medical training. To help ensure that the person with lymphoma understands the information they're given, encourage them to ask for clarification if they need to. You could ask if they'd like you to go into their appointments with them, to support with this.

Health professionals are there to help and shouldn't mind going over things in a different way, or if you ask them to slow down or repeat things.

Help to keep a check on the health of the person who has lymphoma

You can help the person you care for to look out for any signs and symptoms that might need medical attention. Their medical team can tell you what changes to look out for and what to do if you spot them.

Signs of infection

Having lymphoma increases the risk of getting infections. It also makes it harder to get rid of an infection without antibiotics. **You can help the person you care for by looking out for signs of infection.**

Common signs of infection include:

- fever (temperature above 38°C/100.4°F in adults)
- hypothermia (temperature below 35°C/95°F)
- shivering, which is more likely to be a sign of infection in people who are on steroid medication
- chills and sweating
- feeling generally unwell, confused and disoriented
- earache, cough, sore throat or mouth
- redness and swelling around skin sores or intravenous ('IV') lines used to give chemotherapy
- diarrhoea
- a feeling of burning or stinging when weeing
- unusual vaginal discharge or itching
- unusual stiffness in the neck and feeling discomfort with bright lights.

Keep a thermometer at hand so that you, or the person with lymphoma, can check their temperature. If the reading is over 38°C/100.4°F, call their medical team.

Possible symptoms of lymphoma

Often, the person with lymphoma is on the look-out for the return or worsening of symptoms of lymphoma, particularly after treatment. The common symptoms of lymphoma are outlined below.

Swollen lymph nodes



The most common sign of lymphoma is a lump or lumps, usually in the neck, armpit or groin. These lumps are swollen lymph nodes, sometimes known as 'glands'. Usually, they're painless.

Fatigue



Fatigue is different to normal tiredness. It means feeling exhausted for no obvious reason or feeling washed out after doing very little.

Unexplained weight loss



Losing a lot of weight quite quickly without trying to can be a symptom of lymphoma.

Sweats



Lymphoma can cause sweats at any time of the day. Those that come at night can make nightclothes and bed sheets soaking wet. They are often described as drenching.

Infections



Getting infections more easily and having difficulty getting rid of them can be a symptom of lymphoma.

Itching



Itching (pruritus) without a rash can be a symptom of lymphoma. It can be very uncomfortable, particularly when you get hot.

Fever



Some people get fevers (temperatures above 38°C or 100.4°F). Fevers often come together with night sweats and weight loss, but they can happen separately. They can also be a sign of infection.

You might notice a symptom that the person you care for seems not to have noticed. If this happens, gently point it out so that they can seek medical advice.

Search 'symptoms' on our website for more information and to watch a video animation.





Feeling anxious about health

It's understandable that someone who has had a diagnosis of lymphoma might feel anxious if they suspect that their symptoms are coming back or getting worse. Some people also worry about the possibility of developing other illnesses or types of cancer. If this happens a lot, it might help to talk through the person's concerns with them and encourage them to seek medical advice.

A general sense of anxiety about future health can be difficult to manage. Many people start to feel more confidence in their body and their health over time. You could try to help the person consider ways of living with uncertainty (page 26). However, if their anxiety impacts on their day-to-day mental wellbeing, their GP should be able to suggest further support, which might include a talking therapy (page 51).

Help with getting information about lymphoma

The medical professionals looking after the person who has lymphoma are best-placed to answer questions and give information about their individual situation. You could talk through what information they'd like and how to get it.

We have information about lymphoma on our website, including about types of lymphoma, its treatment, coping with side effects and other aspects of day-to-day living.

Some people prefer to know just the basics about their lymphoma and its treatment. If this is the case for the person you care for, reassure them that they can let their medical team know and that they should respect this. If you'd feel comfortable doing so, you could offer to do some research on their behalf, sharing just the 'top level' information with them.



“ My wife, Brenda, found out as much information as she could from Lymphoma Action, and we were given one of the charity's leaflets at the hospital when I was diagnosed. It was really hard for me to take in information at that point though. My brain was still in shock.

Malcolm, diagnosed with follicular lymphoma

Remember that there's a lot of health and social care information online and not all of it is trustworthy. See page 18 for tips on finding out about lymphoma.

What if the person won't accept my help?

Some people feel uncomfortable accepting help and it might not fit with how they see themselves. For example, for someone who's always considered themselves to be fit, healthy and highly independent, it could feel strange and unfamiliar to agree to have help. If the person is hesitant in accepting help, you could try giving them opportunities to say 'yes', such as:

- 'I'm going to the shops this afternoon. Can I pick you up something for dinner?'
- 'I haven't got anything planned for this weekend. How about I come round and help out with the housework, then we have a cup of tea together?'

If it feels appropriate, you could gently but directly acknowledge and empathise that it's difficult for the person to accept help. For example, you could say something like: 'I get the sense that it's uncomfortable for you to accept help. I think I'm similar in that I like to do things for myself. I expect it's really difficult with all you're adjusting to. I don't want to be pushy, but I'd really like to support you. Maybe you could have a think about if and how I could help?'

Tips if the person is reluctant to accept help

- Try to find out what they find difficult as this could help with making specific offers of help.
- Give the person opportunities to say 'yes' by making offers to help with specific things.
- If they say 'no' to your offers, ask again at a later date as their needs might change over time and they might be more willing to accept help after having some time to consider it.
- Try not to over-do it with your offers. Recognise that the person might not be comfortable with taking as much help as you'd like to give.

Offering emotional support

It's human nature to want to make things better for the people we care about. It can be hard not to be able to 'fix' or provide a solution to a situation. While you can't take the person's lymphoma away, you can offer valuable emotional support.

“ *The support and love from family and friends during this time has certainly helped me to face my diagnosis and treatment with optimism and positivity.*

Jamie, diagnosed with non-Hodgkin lymphoma

Show that you're listening

Sometimes, people with lymphoma tell us that they pretend to feel fine or 'put a brave face on' because they don't want to upset or burden the people around them. This pretence can feel exhausting and isolating. By listening to the person and allowing them to feel heard, you can help to ease this pressure.

Give the person opportunities to talk. You could ask them directly how they're feeling. If this doesn't feel right, you could try a more subtle approach. For example, you could ask about something practical, such as if they have any upcoming hospital appointments and how the last one went. Some people find it easier to talk about factual matters. You might then find that the conversation progresses to them telling you more about how they feel, if they want to.

Pay attention to what the person says, without thinking about what to say next.

You can show your interest and attention through:

- asking questions so that they can tell you more if they want to
- summarising or repeating back what they say, to check their meaning
- non-verbal communication, such as good eye-contact and nodding
- touch, such as gently placing a hand on the person's arm or shoulder to express warmth.

There might be times when the person simply wants to 'offload'. Let them express how they feel, without trying to do something about it. It can be really hard not to fill gaps, but silences can be helpful in giving you both time to process what's been said. Sometimes, just being with someone and letting them feel whatever they feel is deeply beneficial.

As difficult as it can be to see someone you love upset, keep in mind that feelings, including those that are painful, are natural. Tears are a healthy expression of human emotion and can help to release tension. Remember that the cause of the person's upset is the situation and not you.

We asked people with lymphoma what they'd like to say to the people close to them. Here's what they told us:

- 'We know you can't make it right, sometimes we just need a hand to hold.'
- 'Sometimes we can be irritable and short tempered, but we really appreciate your calmness and how much you care.'
- 'Sometimes it can be hard to concentrate on reading or watching TV or films. Having videos of scenery with commentary are lovely as it can be a struggle to read.'
- 'We want to be able to support you too!'
- 'Look after yourself and have your own space and support too.'

Showing that you care if you don't live with the person

Even if it's not possible to see the person, you can find other ways to communicate that you care. You could send a text message, email or card to let them know you're thinking of them. Talking on the phone or via video calls can also provide an opportunity to connect, regardless of how far away they are geographically.

What if I can't get the person to talk?

Sometimes, it can be hard to know if someone doesn't want to talk or whether they just don't know how to begin. They might be unsure whether you'll be ready to hear what they have to say.

Opening a conversation might feel more manageable while you're going for a walk or in the car together, rather than sitting down face-to-face.

When you ask how they feel, the person might say they're "OK" or feel 'fine'. If this is their response, you could ask how they really feel. This can help to show willingness to hear about difficult emotions. If you get the same answer again, it might be that the person really does feel OK at the moment, or perhaps they just don't want to talk in much depth just now. Let them know you'll be there to support them if they want to talk more at a later date.

Tips for allowing the person to express their emotions

- **Respect the person's wishes.** Tell them that you'd like to listen but that you understand if they'd prefer not to talk. You could agree that if you ask questions that they don't want to answer, they can say so without fear of offending you.
- **Don't change the topic of conversation.** Allow the person to be open with their feelings.
- **Avoid saying things like 'you'll be fine',** as this can give the impression of not taking the person's feelings seriously.
- **Be empathic.** Try to imagine how you'd feel in their situation. You can show empathy and a willingness to listen by saying something like, 'That sounds really tough. Do you want to talk more about it?'

Notes



Notes



Information and support

If you'd like to talk to someone about anything to do with lymphoma, contact us.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm on 0808 808 5555. You can also use Live Chat on our website.



Find an **Online Support Meeting** at lymphoma-action.org.uk/OSM Find one near you at lymphoma-action.org.uk/SupportGroups



Join our **Closed Facebook Group** at facebook.com/groups/LymphomaActionSupportUK

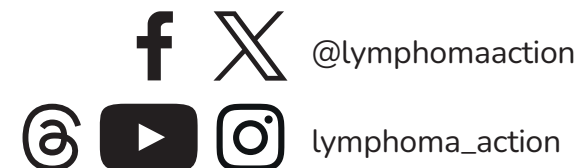


Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details.



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials.

See our website for full details of our services. For our latest news and updates, follow us on social media:



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

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

- *Introduction to lymphoma*
- *Living with and beyond lymphoma*

Find our full range of books and information, including accessible information at lymphoma-action.org.uk/Books or call 0808 808 5555 for more information.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo



Other organisations

We list organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you're looking for, please contact our Helpline team (page 77).

Carers UK gives guidance, information and support to carers. They also host an online community forum and meet-ups for carers.

Carers Trust has information and advice for carers.

Cancer Research UK has information about cancer, treatments and research.

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

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

Macmillan Cancer Support provides support for people affected by cancer from diagnosis through treatment and beyond. They also have a welfare rights advice service that you can call on 0808 808 00 00.

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

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

MIND offers mental health support. Call their Infoline on 0300 123 3393.

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

NHS website has health information and tips for carers.

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

Working with cancer helps employees, employers, the self-employed, job seekers and carers to manage cancer and work.v



Visit lymphoma-action.org.uk/Useful-Organisations for a list of other organisations you might find helpful.

Our information is evidence-based, approved by experts and reviewed by users. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo

How you can help us

Volunteering is at the heart of what we do. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

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

References

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

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This book gives tips to manage the physical, practical and emotional aspects of being a carer, if someone close to you has lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**

(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



www.lymphoma-action.org.uk



Live Chat via our website

(Mon to Fri, 10am to 3pm)

Inform | Support | Connect

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



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