

Caring for someone who has lymphoma

This information is for anyone who is caring for someone who has lymphoma. It gives ideas on offering practical and emotional support, as well as tips to help you take care of yourself.

On this page

Am I a carer?

Offering practical support

Offering emotional support

Your emotions as a carer

Taking care of yourself, physically and emotionally

Getting practical support

Your rights at work

We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

Am I a carer?

If you're looking after someone who has lymphoma without being paid for it, you're taking on the role of a carer. This includes looking after a family member, partner or friend who has lymphoma, whether or not you live with them.

Although the term 'carer' can include paid carers (for example, through private services), we use 'carer' to describe people who are unpaid.

You don't need to be living with the person to be a carer. You're probably a carer if you spend a lot of time caring for the person – there's no legal definition of this, but it could mean anything from a few hours a day, to 24 hours a day, 7 days a week.

Citizens Advice, 2023

The type of care you offer depends on factors like your **relationship with the person**, their needs, and what you can realistically do within the limitations of your time, energy and other commitments. It can be **practical, emotional** or, very often, a mixture of both.

We hear many people who look after someone with lymphoma say that they don't see themselves as a carer. They think of themselves as only the person's partner, relative or friend, without really realising all they do to care for them.

Different people cope differently with caring for someone who has lymphoma. As a husband, I have been there as a 'carer', but I saw it as an extension of marital support, akin to childbirth, life and death. My wife took a similar view, saying: "you are not my carer".

Roger, whose wife was diagnosed with lymphoma

Why is it important to recognise that I'm a carer?

For some people, simply recognising that you are a carer and any **changes that it brings to your relationship with the person you care for** can be helpful emotionally. However, an additional consideration is that much of the **support that might be available to you** as a carer depends on having your needs considered through a **carer's assessment**. This can help you to access practical, financial and emotional support.

Acknowledging your role as a carer can also be helpful in making links with how you're feeling. For example, there might be times when you feel worn out, anxious or sad. This is natural at times when you have a lot to deal with and you are tired. Understanding your emotions can help to make them feel less overwhelming and help your mental wellbeing.

The **NHS website has information about a carer's assessment**, including about how to get one and how it might help you. You can also find information about the **carer's assessment** and about **telling your GP that you're a carer** on the Carers UK website.

Offering practical support

There are lots of ways you could offer practical support to someone who has lymphoma.

You could help with day-to-day life tasks such as cleaning their home, doing their shopping, or preparing meals for them. You might take their dog for a walk or pick up their children from school.

Helping the person on a **practical** level could also help them mentally. For instance, by driving them to an art class, you can also enable them to do an activity they enjoy, bring a sense of achievement, boost their confidence, offer a chance for social interaction and give the person a break from thoughts about their lymphoma.

The person with lymphoma might be interested in **technologies to make the practicalities of life easier**. These can include, for example, devices to help manage medicines and systems that use spoken commands to control appliances or electrical items in the home (such as lights and heating). There are also various tools like electric tin openers and jar openers to help if the person is fatigued or experiencing nerve damage (**peripheral neuropathy**) as a **side effect of treatment**.

You could also offer to take an active role in the person's health. This might include, for example, being **involved in their medical appointments, helping to keep a check on their health** and **getting information they would like**.

Involvement in medical appointments

If the person you care for would like you to be involved in their medical appointments, you could offer to:

- make calls or online appointment bookings on their behalf
- talk through any questions or concerns with them before their appointments
- note down the person's questions as a memory prompt for them to take with them to appointments to discuss with their healthcare professionals
- help with scheduling, by noting appointments on a calendar or in their diary
- organise reminders or set up alerts about upcoming appointments
- take, or simply be with them on journeys to and from their appointments
- **go into appointments with the person.**

I went along to medical appointments, mainly just to listen, but sometimes I picked up on things that my brother had missed or forgotten to ask.

Amanda, whose brother was diagnosed with lymphoma

Going into medical appointments with the person

If the person would like you to go with them into a medical appointment, check with them beforehand which of you will lead the conversation. Find out what information they'd like to get from it. You could offer to note down the key points. Although they should receive a summary letter from the hospital at a later date, it can still be helpful to have notes to take away straight after the appointment. We have more [tips about getting the best from your medical appointments](#). You and the person you care for might also be interested in our suggested list of [questions to ask your medical team about lymphoma](#).

Sometimes, during medical appointments, health professionals might use words that people without medical training are unfamiliar with. To help make sure that the person you care for understands the information they're given, encourage them to ask their doctors to explain anything they don't understand. Healthcare professionals are there to help and don't mind going over things, explaining things in a different way, slowing down or repeating things.

Our online [glossary](#) briefly explains what doctors mean by words you might hear when they are talking to you [about your lymphoma](#). You might also find it helpful to talk things through with a member of our [Helpline Team](#).

Looking after yourself if you are involved in the person's health

Supporting someone with their medical appointments can be a big commitment. It might feel rewarding to know that you are providing such support to the person you care for. However, for some people, it can also be tiring and stressful. To help yourself, and therefore the person you care for, you could:

- **Mentally prepare for the appointment beforehand.** You might want to give some thought to it in private or talk to someone about how you're feeling – our [Helpline Team](#) are here to support both you and the person with lymphoma.
- **Give yourself time to understand any information you're both given during the appointment.** There can be a lot to take in and you might need time to go over what you've been told.

- **Do something relaxing and enjoyable** after the appointment. For example, listen to relaxing music, have a bath, meet a friend, go for a walk, read a book or watch something.

Helping to keep checks on the person's health

Together, you and the person you care for can look out for any signs and symptoms that might need medical attention. Their medical team can give you advice about this and what to do if you notice anything that might be a possible sign of **infection** or **symptom of lymphoma**.

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**. Keep a thermometer at hand so that you, or the person with lymphoma, can check their temperature. If the reading is above 38°C or 99.5°F, contact their GP or a member of their medical team.

Possible symptoms of lymphoma

Be aware of the common **symptoms of lymphoma**. If you notice a symptom that the person you care for seems not to be aware of, gently point it out so that they can seek advice from a member of their medical team. A good first point of contact is often the person's **clinical nurse specialist** (CNS).

Helping to get information about lymphoma

The medical professionals looking after the person with lymphoma are best-placed to answer specific questions and give information about their individual situation. Their **keyworker** (often their clinical nurse specialist) is a good person to approach with questions or concerns. With the consent of the person you care for, you could also talk to their keyworker to help get any information they would like.

You can also find lots of information **about lymphoma** on our website, including the different **types of lymphoma**, **treatment**, coping with **side effects**, **emotional wellbeing** and other aspects of **day-to-day living**. Our **Helpline Team** are available to talk about any aspect of lymphoma.

Finding trustworthy information

Remember that there's a lot of health and social care information online and that not all of it is trustworthy. The [NHS website](#) is a good place to find a range of health information.

A quick and easy way of finding out whether information is high quality is to check whether it has the [Patient Information Forum \(PIF\) TICK](#), a UK-wide quality mark that indicates that the information is trustworthy. You could find out more about [our approach to producing health information](#) on our website.

Other tips include looking at:

- **when it was produced** for an idea of how up-to-date it is
- **whether a trusted organisation or relevant health professional** has been involved in producing it
- **the list of references**, if there is one, to tell you where the information was drawn from
- **how impartial and balanced the information** is, for example, is it trying to sell you something?

Some people prefer to know lots of detail about their lymphoma. Others feel more comfortable finding out just the basics. If the person you care for feels this way, encourage them to let their medical team know this and reassure them that their health professionals should respect their wishes. If you feel comfortable doing so, you could offer to do some research about their lymphoma and its treatment, sharing just the 'top level' information with them.

Offering emotional support

You can offer emotional support in various ways. Find [ways to show that you care](#), [allow the person opportunities to talk](#), [listen](#) and [pay attention to what they say](#).

Show that you care

Find ways to express your warmth and how much you care. You could send a text message, email or card to show that you're thinking of them. Talking on the phone or having a video call can also allow you to connect, regardless of physical distance.

Some of the ways of showing you care include:

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

Allow opportunities to talk

If it feels awkward to ask someone directly how they're feeling, you could ask about something practical – like whether they've got any medical appointments coming up and how the last one went. The conversation might then lead onto them telling you more about how they're feeling, if they want to.

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. Go at a pace that feels right – and remember that not everything needs to be covered in one conversation. By showing your support, the person might be more likely to come to you if they would like to talk another day.

Listen and pay attention to what the person has to say

Pay attention to what the person says, without planning what to say next. There might be times when the person just wants to offload and express how they feel, without you trying to do something about it. It can feel more comfortable to fill any gaps in the conversation. However, simply staying with the person and allowing them to feel however they feel can be deeply beneficial. Keep in mind that feelings, including those that are painful and challenging, 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, not you.

If the person doesn't seem to want to talk

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

Starting a conversation might feel less daunting in a relaxed setting, such as out on a walk together or on a car journey, rather than sitting face-to-face.

Some people find it easier to talk to someone outside of their family and groups of friends. You or the person you care for might be interested in our [Support Services](#), including our [Helpline](#), [Online Support Meetings](#) and [Buddy Service](#).

Your emotions as a carer

Many carers experience mixed feelings about supporting someone who has lymphoma. As well as managing your own day-to-day life and [coping with your feelings](#), you are supporting someone else with theirs. It might also seem that you're in a process of ongoing adjustment as you [adapt to changes](#) in practical arrangements and dealing with the emotional impact of caring.

You might feel a sense of reward in helping to meet the needs of someone you love. Some people feel closer to the person they care for. No matter how much you love and care about the person, though, there are likely to be times when you feel physically and mentally exhausted. The intensity of the situation, particularly over a time, can lead to heightened anxiety and [stress](#). This can bring difficult emotions such as sadness, resentment, and a sense of burden or 'burn out' and stress. Such feelings can in turn lead to guilt, which can be extremely difficult to handle. Carers UK has information about [coping with guilt, resentment and other difficult emotions](#).

Carer burnout

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

Signs of burnout can include:

- **physical signs**, such as feeling tired all the time, headaches, muscle pain, change in sleeping patterns and appetite, frequent illness
- **emotional signs**, such as a sense of helplessness, loss of motivation and isolation
- **behavioural signs**, such as feeling irritable, withdrawing from the people around you, procrastinating or taking longer to complete tasks, using food, drugs or alcohol to help manage your feelings.

To avoid carer burnout, take care of your [emotional wellbeing](#) and give yourself [breaks](#). Helpcare.org has more information about [caregiver stress and burnout](#), and about [burnout prevention and treatment](#).

Although there's no set way to feel, we outline some of the feelings we've heard about from people who are caring for someone with lymphoma. Try to recognise how you feel, and **consider how you can help yourself**, including the **support that might be available to you as a carer**.

Adapting to change

Caring for someone who has lymphoma is likely to affect your plans and your day-to-day routine. You might also need to change your schedule or plans in the short to medium term.

Change can be hard to cope with. As well as getting used to a different way of life on a practical level, the changes can be a reminder of the reason for making them. In addition to the sadness and concern you might feel in relation to the person's health, some people feel loss or disappointment that life hasn't turned out as they had hoped or expected.

Your relationship with the person you care for

As you both adjust to the **uncertainty** and challenges of living with lymphoma, there might be changes within your relationship. For example:

- your approach to day-to-day practicalities might differ – for example, who does most of the driving or how you divide household tasks between you.
- there might be a switch in roles – such as which of you tends to be 'the problem solver' or 'the one to cheer the other up'.
- if the person you care for is your parent (or a parent figure), you might experience a sense of role-reversal in taking care of their needs.

You might grow closer to the person you care for. Some people describe positive psychological changes, such as a sense of reward, fulfilment, new possibilities, closeness to the person, creativity or deeper meaning in life. This is often called 'post-traumatic growth'.

What the person with lymphoma needs from you can change over time. Sometimes they might not want to be reminded of their lymphoma and be treated any differently. At other times, they might really want your help.

Roger, whose wife was diagnosed with lymphoma

You might also find that there are times when you seem to take on the emotions of the person you care for. If their energy levels are lowered by the physical or emotional effects of lymphoma and its treatment, this might lower their general mood and patience. They might seem abrupt and 'snappy'. This can affect your own mood and patience. Carers UK has tips on how to deal with this and information about **your relationship as a carer and some common situations you might face**.

Through the various emotions, there are very likely to be times when your relationship with the person you care for feels strained. Some people describe a need to be strong, upbeat and positive for the person with lymphoma – this can be very draining, emotionally. Very often, being open about the challenges and working together to address them can be far more beneficial.

Keep in mind that support needs change over time. These might happen gradually or suddenly. Although it can be hard to discuss these things with the person you care for, having a plan in place to help manage any sudden deteriorations can make a stressful situation more manageable.

Micaela Plucinski, Lymphoma Clinical Nurse Specialist

Differences in what you'd like to know and what the person tells you

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 tell you. Some people describe feeling shut out or excluded. Without information to let you know otherwise, you might start to think about the worst possible outcome, which can heighten stress and anxiety.

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.

I would advocate supporting the person's independence. You might want to do everything for them but helping them to self-manage and do what they can for themselves is paramount. It fosters empowerment and helps with esteem.

Micaela Plucinski, Lymphoma Clinical Nurse Specialist

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 with sharing.

Consider whether it could help to let the person know how you feel. If it feels appropriate, set aside some time to talk openly with them, without interruptions. Below, we outline a technique (using 'I' statements) that can help to avoid angry and hurtful exchanges.

Examples of 'I' statements

Instead of saying: 'You're so secretive about your appointments', you could rephrase it as an 'I' statement:

- 'I respect your privacy but if you could be comfortable with it, maybe you'd let me know about upcoming appointments? I could come with you if you'd like me to.'

Instead of saying: 'You never tell me anything. It makes me so angry. It's not fair to make me worry', you could rephrase it as an 'I' statement:

- 'When I don't know what's going on, I feel anxious, upset and confused, and I start to really worry. I'd really like it if you would give me a bit more information because I'd like to support you.'

You might also be interested in our information about [communicating with the people around you](#).

Living with uncertainty

Uncertainty is a significant part of caring for someone with lymphoma. For example, you might worry about:

- the outcome for the person you care for
- whether the financial stability of your income is affected
- if you are doing enough for the person.

Lymphoma is often successfully treated or managed, and goes into **remission** (disappearance or significant shrinkage of lymphoma). However, many people want to know for definite what the outcome will be for the person they care for. The doctors treating them might be able to give an idea based on factors including the **type of lymphoma** and how fast it is growing. Even with all this information, however, nobody can say for certain how someone will respond to treatment, what **side effects** they will get or how long they will live.

If the situation affects your earnings, you might also feel uncertainty about your current and future financial stability. This can bring great stress and anxiety. For example, you might temporarily reduce your working hours in order to care for the person with lymphoma. Their ability to work might also have become limited. Find out about **possible sources of financial support** available to you. You might also be interested in the video that Carers UK have on **understanding your rights and getting support if you're working and caring**.

Some carers feel uncertainty and self-doubt, questioning whether they're doing enough to help. Consider how you can best help the person you care for, but recognise, too, that it's important to **take good care of yourself**.

Coping with uncertainty

Uncertainty can make it hard to adapt to your situation, to feel hopeful, and to manage anxiety. Some people describe a sense of having been 'shaken' when someone they love becomes unwell. It's common to wish for more control over things that you're unable to control. However, working towards accepting it can help you to develop your ability to live with uncertainty.

Some things you might find helpful are to:

- **Think about what you can control**, such as following a **healthy lifestyle** and taking care of your **mental wellbeing**. You might also find it helps to find out a bit **about lymphoma**, though take care not to overwhelm yourself with too much information.
- **Make and keep plans**. For example, you could plan a day out for when the person you care for finishes treatment. This can help you both to continue enjoying life. Just be sure to consider their energy levels and any safety precautions they might need to take.
- **Set realistic goals**, to give you both something to aim for.

- **Use meditation or relaxation techniques**, such as **mindfulness**. This encourages you to slow down and live in the present rather than thinking about what has been and what is to come.
 - **Get emotional support**, whether this is through talking with someone close to you, getting in touch with **our Helpline Services**, or seeking support through a trained professional, such as a **counsellor**.
-

Taking care of yourself, physically and emotionally

There's not a simple way of dealing with the demands of being a carer, but there are things you can do to help yourself. We outline some of these below, and you might also be interested in our **top tips for family, friends and carers** offered by our closed Facebook group. You might also be interested in Age UK's information about **balancing working and caring**.

A healthy lifestyle and **looking after your mental wellbeing** helps to put you in the best position to care for the person with lymphoma. You can also find support in dealing with challenging feelings and consider **sources of practical support** that might be available to you.

It's also 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, which might include flexibility with appointments, signposting to carers' support networks, and giving you guidance to help support yourself and the person you care for. Carers UK has guidance on **letting your GP know** that you're a carer, what to tell them and how they could help.

Taking care of your mental wellbeing

Good mental health can help you to feel confident and better able to cope with stress, **uncertainty** and change.

- **Tell your GP you're a carer**, so that they can **support you** as an individual with the added responsibilities of caring, and in taking care of the person with lymphoma.
- **Prioritise making some time for yourself**, away from your caring role. Find way to relax, have fun and do something you enjoy.

- **Build relaxation into your day-to-day routine**, for example, take a walk, have a bath, or use relaxation techniques. Even short 'pauses' can be beneficial – like having a cup of tea, reading a chapter of a book or listening to a podcast. You could dedicate a slot each day for this, like first thing in the morning.
- **Try to keep up with other areas of your life**, like any leisure activities you enjoy, and spending time with friends and family.
- **Have an outlet for your feelings**, such as by talking to someone close to you or connecting with other carers – Carers UK have an **online forum** where you can share thoughts, feelings and tips. You could also express your feelings through a journal, artwork or singing.

Carers shouldn't feel they are alone. The clinical team of the person with lymphoma can offer you support as well. Ask for help so that they can signpost you to support in the community or through their services.

Micaela Plucinski, Lymphoma Clinical Nurse Specialist

Getting support with challenging feelings and low mood

Caring can bring complex emotions – you don't need to cope with these alone.

Our **Helpline Services** team are here for you, as well as the person who has lymphoma. You can talk to them about any aspect of caring for someone who has lymphoma, including about how you feel.

Many people feel low from time to time, and this is particularly true of those who are coping with a caring role. If your low mood goes on over time and affects your day-to-day life, this could be a sign of **depression**.

For some people, speaking confidentially to a trained professional, such as a **counsellor**, can help to work through complex emotions. If you are interested in getting this type of support, speak to your doctor, who might be able to offer you a referral on the NHS. You can also search online for a private therapist in your area. You could try the **British Association of Counsellors and Psychotherapists** or **The British Psychological Society**.

Connecting with other carers

You might like to be in contact with other carers, for example through:

- **online forums**, such as those hosted by **Carers UK**
- **online support groups** offered by Carers UK. Lymphoma Action **Online Support Meetings** are also open to those who care for someone with a lymphoma diagnosis.

You could also ask our Helpline Team if they can connect you with another carer through our **Buddy Service**.

Take a break from your caring role (respite)

Rest is an important part of looking after yourself. There are different ways to take a break from your caring role. One option is to consider taking a short break (respite) with the support of an organisation that can help to arrange this. This could be anything from a few hours to a couple of weeks' break from your caring responsibilities. Respite can involve:

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

Carers UK has a factsheet about **finding time to relax and taking a break** and a **video about the importance of taking a break**. Their **factsheet on taking a break** includes a list of organisations that can help in arranging a break.

Carers Trust also has information about **taking a break**, including a list of **organisations you could contact about holidays for unpaid carers**.

Getting practical support for you

The practical support available to you might include help with finances and other aspects of day-to-day life. Having a **carer's assessment** can help to identify what might be on offer to you, such as the **Carer's Allowance** and **other sources of financial support**. It's important to know your **rights at work** too.

Carer's assessment

During a carer's assessment, you talk through your needs with someone who is trained to carry out the assessment. They help you to consider how caring affects your day-to-day life, practically, physically, socially and emotionally.

They can signpost you to any carers' support groups in your area and tell you about sources of support you are eligible for through your local council (or Health and Social Care Trust, if you are in Northern Ireland). This might include:

- practical help at home, such as with household chores
- having someone take on your caring responsibilities for a while, so that you can **take a break**
- advice on how to lift the person you care for in ways that are safe for you both
- financial support to go towards the costs of caring.

The NHS website has more information about the **carer's assessment**.

Carer's Allowance

One of the main entitlements for carers is the Carer's Allowance. This is a taxable payment that you can choose to have paid weekly in advance or every four weeks 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, you do need to meet eligibility criteria, which includes not earning over a certain amount a week.

Find out more about **Carer's Allowance**, including current rates, on the government's website.

Other sources of financial support

Not everyone is entitled to receive Carer's Allowance but there are various sources of financial support you might be eligible for as a carer. Organisations such as [Carers UK](#), [Carers Trust](#) and your local [Citizens Advice](#) can give you detailed information about your eligibility based on your individual circumstances.

Your rights (legal entitlements) at work

If you are in paid employment, it's a good idea to find out about your rights to flexible working and adjustments. Age UK has information about [balancing working and caring responsibilities](#) and a [guide that gives advice for carers](#).

Speak to your HR department about how they can support you. 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 some exceptions to this, for example, if you work for the armed services. The UK Government has also given its intention to make the right to request flexible working an entitlement for every employee in Britain from day one of their employment.
- You might be entitled to paid carer's leave, designed to allow you time off for planned appointments and unexpected emergencies.

Macmillan Cancer Support has information about [cancer and employment rights](#). You can also find out more about [carers' rights at work](#) on the Marie Curie website. Carers UK also has information about [managing paid work and caring](#).

References

The full list of references for this page is available on our website. Alternatively, email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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