

Caring for someone who has lymphoma

On this information page, we define a carer as someone who looks after a person with an illness or disability without getting paid for it. You are a carer if you're looking after a relative or a friend with lymphoma. This page outlines the kind of help a carer might provide and lists sources of specialist support that are available to carers.

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Am I a carer?

A carer is someone who, without payment, looks after a family member or friend who would otherwise find it hard to function or cope. This can be for a variety of reasons, for example illness such as **lymphoma**, disability, a mental

health problem, or a combination of reasons. You might live with the person you care for, or you might visit or give support remotely, for example, giving emotional support over the phone or remotely running errands for them.

Many people who look after people close to them do not see themselves as carers. However, it is a term that's commonly used, for example by organisations that provide benefits to people who look after others. We use the word 'carer' to refer to anyone who's looking after a family member or friend with lymphoma.

As a carer, you are likely to have specific needs and concerns. For example, you might want to know what practical help you can give or how to emotionally support the person you're looking after. You might also want to know how to look after yourself and what support is available to you.

Carers provide a range of support, which can be:

- physical eg helping with showering/bathing and going to the toilet
- emotional eg providing company and listening to how the person feels
- practical eg shopping, cleaning the house and arranging medical appointments
- social, eg organising leisure activities and visits to see friends.

Offering emotional support

Sometimes people with cancer feel they need to say that they feel fine, even when they don't. This is often because they don't want to burden others. Pretending can be exhausting and can make the person feel isolated. Listening to how they feel can ease this pressure. If the person says they are 'OK' or 'fine' when you ask how they are, you could repeat the question, asking how they really are. If they give you the same answer again, it may be that they don't want to talk in depth, or that they really do feel OK at the moment.

Show that you are willing and ready to talk if and when they'd like to. You might be one of few people they feel able to talk with about how their illness is affecting them, physically and emotionally. Keep in mind, however, that as well as talking about their health, there may be times when they

want to talk about other things – like a current TV drama or their favourite sport. People with cancer often say this helps them to feel ‘normal’ or ‘like their old self’. Tell them you’ll be there whatever they’d like to talk about.

If the person does not want to talk, let them know that’s fine and that you will continue to be available if they change their mind. Be guided by them: their desire to talk may change over time or even from one day to the next. Let them know that you won’t be offended if they don’t want to answer your questions. You could agree how they can let you know, eg ‘I don’t feel comfortable talking about that’ or ‘Can we speak about something else?’ It can be hard if you want to talk, but the person you care for doesn’t want to. Let them know that you’d appreciate being able to talk and how you feel it could help. It can also be helpful to seek emotional support.

If you don’t live with the person you care for, or if it is hard to be with them face-to-face, find other ways of communicating. You could send text messages, a card, emails, talk on the phone or via Skype or Facetime.

The person you care for might experience intense feelings that affect their wellbeing, or they might find it hard to talk to people close to them. If so, you could suggest a referral to a psychologist or trained counsellor. If the person has a religious faith, you could suggest that they speak to a hospital chaplain. Health professionals, including GPs, should help you with these referrals. We also offer a range of support services that might benefit the person you care for, including a [helpline](#) and [support groups](#).

Show that you are listening

Feeling heard can be extremely helpful. Pay attention to what the person with lymphoma says without planning what to say next. Ask follow-up questions, paraphrase or repeat back what the person has said and check what they mean if you are unsure. Eye contact, touch, and nodding are all non-verbal forms of communication that can help show that you are listening.

Although the topic of conversation might be challenging at times, try not to change the subject. Avoid saying things like ‘you’ll be fine’ as this might give the person the impression of being brushed off, even if that isn’t your intention. Instead, acknowledge the difficulty of the situation. You could say

something like: 'That sounds really tough. Would you like to talk more about it?'

There may be times when the person with lymphoma simply wants to offload. Allow them to feel whatever they feel without trying to find a practical solution. As difficult as it may be to see them upset, such feelings are natural. Tears are healthy and can help to release tension. Remember that someone's expression of sadness does not mean that you have caused these feelings.

Offering practical support

The type of practical support you can offer depends on what's needed, how much time you have and what you can realistically do. It can also vary depending on your relationship with the person. Some of the ways you could help include:

- being involved with medical appointments
- monitoring the health of the person with lymphoma
- supporting the person with lymphoma to get the right information and advice.

Being involved in medical appointments

You might offer to take the person you care for to and from medical appointments. As well as transport, you could provide emotional support at what may be a particularly anxious time.

Before the appointment, talk through any questions the person would like to ask their **medical team**. Note these down along with any concerns or other points they'd like to discuss. These can act as a memory prompt during the consultation.

If the person you care for would like you to go into the appointment with them, agree beforehand which of you will lead the conversation. Discuss how much information they'd like to get from it. You could also offer to write down key points from the information given during the consultation.

Health professionals might use medical terms that are difficult to understand. Ask them what they mean. Health professionals are used to explaining things and shouldn't mind if you ask them to slow down or repeat things.

Monitoring the health of the person with lymphoma

The medical team can tell you what changes in health to look out for and how to respond to them.

You can help the person you care for by looking out for signs of infection. These include, but are not limited to:

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

Keep a thermometer nearby so that you can easily check the temperature of the person who has lymphoma. Call a member of their medical team if their temperature goes above 38°C. Remember that shivering can be a sign of infection even without a fever. This is more likely in people who are taking **steroids**.

The person you care for is likely to be on the look-out for the return or worsening of **symptoms of lymphoma**, particularly after their treatment. The common symptoms are:

- swollen lymph nodes
- fatigue
- unexplained weight loss
- night sweats
- itching.

If you spot any symptoms that the person you care for seems not to have noticed, gently point them out so that they can seek medical advice.

Naturally, people with cancer often become anxious if they think they have found a symptom of lymphoma or another form of cancer. If this happens frequently, you could try to help lower their anxiety by talking through their concerns and encouraging them to think about other possible causes of the symptom.

For example, they might feel **fatigued** because they had a particularly busy day and their **nausea** could be an expected **side effect** of their **treatment**. Agree a plan of action, eg how many days to keep a check on the symptom before seeking medical advice. If either of you remain concerned or unsure about the cause of the symptom, seek medical advice.

Supporting the person with lymphoma to get information and advice

The medical professionals looking after the person who has lymphoma are the best people to answer questions and give information about their individual situation.

If you look at health and social care information online, make sure that it's trustworthy. Check that the information is up-to-date and backed up by scientific findings. Look at who wrote the information – for example, is it a well-known and reputable organisation? Has it be written or reviewed by a lymphoma expert? Be wary of websites that try to sell something.

If the person with lymphoma asks for your advice, talk the issue through with them. Try to understand their wants and needs. This can help you to work together to find a suitable way forward. If they ask you a question that you don't know the answer to, say so. You can't be expected to know everything. Instead, think about how you can help the person get the information or advice they need, for example, by speaking to their medical team.

Keep in mind that the level of medical information you and the person with lymphoma would like may differ. You may have researched lymphoma and wish to share what you know with the person you care for. Check whether they'd like this information before you give it to them. They might still be **adjusting to their diagnosis** or already feel overloaded with information.

What if someone doesn't accept help?

Some people find it hard to accept help. This might be the case for people who have always seen themselves as physically fit and healthy, very independent, or those who link receiving help with weakness.

Be specific with your offers. This might make it easier for the person with lymphoma to say yes, eg 'I'm going shopping this afternoon. Can I pick you something up for dinner?' Or 'I'm free all day on Saturday so let me know if you'd like me to come and help with the housework'. Find out from them what sorts of things they are finding difficult – this may give you ideas for suggestions you could make about the help you can offer.

If the person declines your offers, ask again later as their needs may change. It might also take asking more than once for them to accept your offer – but try not to overdo it.

Emotional impact of being a carer

Lymphoma doesn't only affect the person who is diagnosed – it's also a time of change for you. When a friend or family member is first diagnosed with lymphoma, you might feel a whole range of emotions such as shock and disbelief, helplessness and sadness. If your partner is the person with the diagnosis, you might feel loss as you reconsider your future plans. Your financial stability might be less certain, too.

It's natural to feel worried as you are plunged into the unknown. Some people describe a need to 'be strong' or to 'stay positive' for the person with lymphoma, yet openness and working together can be far more beneficial.

Being a carer can bring mixed feelings, too. You might find your role rewarding and feel close to the person you care for. However, there may be times when you feel physically and mentally tired. You might feel **stressed**, burnt out, sad or resentful. For some people, such feelings lead to guilt, which can be difficult to handle.

Take steps to manage the challenges. By ensuring that you are fit and healthy, both physically and emotionally, you put yourself in the best possible position to care for someone else.

- **Lead a healthy lifestyle** – **eat and drink healthily**, and take **regular exercise**.
- **Take some time for yourself** – build relaxation into your day-to-day routine, whether this is taking a walk, bath, or spending time on a hobby. You might also like to consider a short break or holiday. Carers UK have **information about taking a break**.
- **Continue with other aspects of your life** – it's important to keep up with other areas of your life, like hobbies and activities.
- **Spend time with other people** – keep up with your friends and relatives.
- **Connect with other carers** – you may find it helpful to be in touch with others who can relate to your experience. Carers UK have an **online forum** where you can share thoughts, feelings and tips with other carers.
- **Find an outlet for your thoughts and emotions** – this could be through a journal, private blog, artwork or singing.

Feeling shut out

Some people with lymphoma prefer not to involve their friends and family with their health very much. They may limit how much they tell you. This might be their way of keeping their independence and sense of control. They may not want to burden or upset you, or they may choose to keep the details of their illness separate from other areas of their life.

It can be difficult to deal with if you are not given as much information as you'd like. You may feel shut out, which can bring feelings of hurt and anxiety. Consider talking to the person with lymphoma about how you feel. This can be hard, particularly if you are not used to talking about how you feel. Set aside some time to talk openly and without interruptions.

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

For example:

- 'When you shut me out, you make me really angry and upset. It's so unfair and I don't know what to do.'

Rephrased using 'I' statements:

- 'When I don't know what's going on, I feel anxious, upset and confused. I'd really like it if you would give me a bit more information about your health because I'd like to support you. I want you to know you're not alone.'

Show that you are comfortable with them being open about their health if they choose to tell you more. However, keep in mind that it is their decision how much information they share about their lymphoma.

Living with uncertainty

Uncertainty can be very hard to manage. It can make you feel as though you are not in control of your life. Trying to control things that you can't control can increase anxiety. Instead, as difficult as it may be, you can learn to live with uncertainty.

In many cases, lymphoma is successfully **treated** or managed and can lead to remission (no evidence of lymphoma) or **cure**. Many people want to know for definite what the outcome will be and it can be difficult to live without this certainty.

Some people feel worried that the person they care for might not recover. They want to know how long the person with lymphoma has to live. The doctors treating them may be able to give an idea. They base it on factors including the **type of lymphoma** and how fast it is growing. Even with all this information, nobody can say for certain how long someone will live.

Making and following-through with plans despite uncertainty can be beneficial eg, planning a holiday for after treatment. Techniques like **mindfulness meditation** can also help you to cope with uncertainty. Focus on what you can control, eg researching lymphoma and looking after yourself. Get the **emotional support** you need at this difficult time.

Neville shares his experiences of caring for his wife, Sue in this short video.

Emotional support for you as a carer

Caring for someone who has lymphoma can be tough. In addition to managing your own life, you are also supporting someone else on a practical and emotional level, as well as coping with your own feelings. Consider what friends and family can help you with – from household chores to providing a listening ear.

We offer various sources of support. Our helpline team are here for you, as well as the person who has lymphoma. You can make contact with other carers through our **support groups** and online forums. Our information and support team may also be able to put you in touch with another carer through our **Buddy scheme**. Some people also find it helpful to read accounts such as memoirs of other carers.

Caring can be tiring and stressful. For some people, it can trigger **low mood or depression**, particularly if you have experienced depression in the past. If your role as a carer impacts on your mental wellbeing, you might consider talking to a trained professional, such as a counsellor. There are many different types of counselling. What they all have in common is the counsellor's aim to provide a safe and non-judgemental space for you to feel heard and to explore your feelings. If you are interested in counselling, speak to your doctor, who may be able to refer you to a counsellor on the NHS. You can also search online for a private therapist in your area. Try the **British Association of Counsellors and Psychotherapists**, **The British Psychological Society** or **Health and Care Professionals**.

Practical support for you as a carer

As a carer, you may be entitled to financial support. [Carers UK](#), [Carers Trust](#) and your local [Citizens' Advice Bureau](#) can give you information about eligibility. If you are in paid employment, speak to your HR department about the possibility of paid [carer's leave](#). You also have a right to request flexible working and to take reasonable time off in emergencies. Carers UK have information about [rights and support for employees](#).

Carer's assessment

A carers' assessment is designed to look at your needs. It involves a conversation between you and a trained professional and should look at how caring impacts on your day-to-day life, including your emotional wellbeing.

Based on the assessment, you may be entitled to various types of help from your local council. This could include financial assistance or equipment to make some of the practical tasks of your caring role easier. They might also arrange for someone to take on your caring duties while you have a short break or attend an appointment.

You can request a carer's assessment through the local council of the person you care for – it doesn't matter how many hours a week you provide care for or whether you live with the person who has lymphoma. If the council agrees that you appear to have support needs, they will arrange for you to have a carer's assessment. If you are not eligible for support from your council, they should signpost you to any other local organisations that may be able to help you.

[NHS Choices](#) and [Carers UK](#) have more information about carers' assessments.

Carer's allowance

You may be entitled to receive a weekly payment if you provide care for at least 35 hours a week. You don't need to be living with the person you care

for; however, you do need to meet certain eligibility criteria. This includes that the person you care for needs to receive certain benefits in order for you to be eligible. You can find out more about carer's allowance and how to apply for it on the [GOV.UK](#).

Further information and support

Lymphoma Action offers a range of support services. You can get in touch with other carers through our online forums. Our [helpline team](#) may also be able to put you in touch with another carer through our [Buddy scheme](#).

Carers Trust offers information, advice and support to carers. This includes an online forum.

Carers UK provides information, advice and support to carers. This includes an online forum and a helpline. Call 0808 808 7777.

Macmillan Cancer Support has information for carers, including 2 booklets: Looking after someone with cancer and Supporting a loved one through cancer? We're here for you.

Turn2us is a charity that helps people gain access to welfare benefits, charitable grants and support services. They have a dedicated section for carers on their website.

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.

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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