

Caring for someone who has lymphoma

If you look after a family member or a friend who has lymphoma without being paid for it, you're taking on the role of a carer. On this page, we suggest ways you could offer practical and emotional support to the person who has lymphoma. We also suggest tips to help you take care of your own needs, including signposting to sources of support for carers.

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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?

A carer looks after someone who has an illness or disability without being paid for it. This includes looking after a family member or friend who has lymphoma, regardless of whether or not you live with them.

The type of help you offer depends on several factors. These might include your relationship with the person, their needs, and what you can realistically do within the limitations of your time, energy and other commitments.

We suggest ways of offering **practical** and **emotional** support. However, in reality, helping in one way is likely to bring other benefits. For instance, you might offer practical support by driving the person to an art class. This might help their emotional wellbeing too. It could enable them to do an enjoyable activity, bring a sense of achievement, boost their confidence, offer a chance for social interaction and give the person **time 'away from' their lymphoma**.

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

Many people who look after someone with lymphoma don't see themselves as a carer; they consider themselves to be 'just' the person's partner or friend and might not realise all they do. If you don't see yourself as a carer, you might be less likely to consider the **support available to you**. Accessing much of this depends on having your needs considered through a **carers' assessment**.

As well as helping you to get practical, financial and emotional support, recognising your role as a carer can help you to understand why you feel as you do – for example, physically and mentally tired, worn out, anxious or sad. Making sense of our emotions can help to make them feel less overwhelming and have a positive effect on mental wellbeing.

Offering practical support

There are many practical ways you could help someone who has lymphoma. You could help with day-to-day life. For example, you could clean their home, do their shopping, or prepare meals for them. You might take their dog for a walk or pick up their children from school.

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 treatment on them. We also took her dogs for two long walks a day.

Brian, whose daughter was diagnosed with lymphoma

You could also offer to take an active role in the person's health. For example, you could **be involved in their medical appointments**, **help to keep a check on their health** or **get information they would like**.

Involvement in medical appointments

You could offer to be involved in the person's medical appointments.

Examples are given below:

- With the person's consent, make calls or online appointment bookings on their behalf.
- Note appointments on a calendar or in their diary. If they use a mobile phone or other electronic devices to help with scheduling, you could set up alerts to remind them about upcoming appointments.
- Talk through any questions or concerns with them before appointments. You could also note these down as a memory prompt for them to take with them to discuss with their health professionals.
- Offer to take, or simply be with them on journeys to and from their appointments.

If the person would like you to go with them into their medical appointments, check beforehand which of you will lead the conversation. Discuss what information they'd like to get from it. You could offer to take notes of the key points discussed during the consultation. Although they should receive a letter outlining these from the hospital at a later date, they might find it useful to have a summary to take home straight after the appointment.

I went along to 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

I carried on working during Philip's treatment but I kept him company during most of his chemo sessions.

Cyanne, whose husband was diagnosed with lymphoma

Sometimes, health professionals 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 questions. If you go into the appointment with them, you could support them in this. Healthcare professionals are there to help and shouldn't mind going over things in a different way, slowing down or repeating things.

Some people have lots of questions - that's OK. There really is no such thing as a silly question.

Aileen Chadwick, Macmillan Haematology Clinical Nurse Specialist

Supporting someone with their medical appointments can be exhausting and stressful so it's important to take care of your own wellbeing too. For example, it can be helpful to:

- 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.
- allow yourself time to digest any information you're given during the appointment. There can be a lot to take in and you might need to go over what you've been told.
- do something relaxing and enjoyable after the appointment, for example, listen to relaxing music, meet a friend, go for a walk, unwind in the bath or read a book.

Remember that our helpline team are [here to support you](#) if you'd like to talk about any aspect of caring for someone who has lymphoma. With the person's consent, you could also talk to the keyworker involved in their care; very often, this is their [clinical nurse specialist](#) (CNS)

Help to keep a check on the person's health

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 about 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](#).

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, call their medical team.

Possible symptoms of lymphoma

Very often, the person with lymphoma is on the look-out for the return or worsening of **symptoms of lymphoma**, particularly after **treatment**. As the person's carer, it can be helpful for you to also be aware of the common symptoms of lymphoma. If you spot a symptom that the person you care for seems not to have noticed, gently point it out so that they can seek advice from a member of their medical team.

Help with getting 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 clinical nurse specialist or keyworker would often be a good first person to approach with questions or concerns.

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

The questions didn't seem to come when we were in appointments. They came when we were at home. As a carer, naturally, I wanted the best and to absorb as much information as possible.

Lucy, whose husband was diagnosed with lymphoma

Some people prefer to know just the basics about their lymphoma and its treatment. 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 in doing so, you could offer to do some research about their lymphoma and its treatment, sharing just the 'top level' information with them.

I learnt a lot about my daughter's condition. Any booklet she was given were handed straight over; she simply didn't want to know! She relied on me to find out and tell her as needed, and for me to ask her various consultants anything that needed answering.

Helen, whose daughter was diagnosed with lymphoma

Remember that there's a lot of health and social care information online and that not all of it is trustworthy.

- Check when it was published for an idea of how up-to-date it is.
 - Consider where the information is coming from. For example, is it produced by a trusted organisation? Has a lymphoma expert or other relevant professional been involved in producing it?
 - Look for a list of references to tell you where the information was drawn from.
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Offering emotional support

At a time that's likely to bring challenging emotions, you can provide valuable emotional support to the person you care for.

Sometimes, people pretend to feel fine or 'put a brave face on' because they don't want to upset or burden the people around them. Pretence can be exhausting and isolating. You can help to ease this pressure by **showing that you care, being willing to listen, giving the person opportunities to talk** and **paying attention** to what they say.

Show that you care

Find ways to express your warmth and care. Even if you don't see the person very often, 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.

Be willing to listen

There might be times when the person just wants to 'offload' and express how they feel, without you trying to do something about it. Resist the temptation to fill silences – 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.

Allow opportunities to talk. You could ask the person directly how they're feeling. If this doesn't feel right, try a more subtle approach. For example, ask about something practical, such as if they have any upcoming hospital appointments and how the last one went. Some people feel safer discussing factual matters and the conversation might then progress to them telling you more about their feelings. However, there might be **times when they would prefer not to talk.**

Pay attention to what the person says, without thinking about what you might say next. Show your interest, warmth and attention through:

- non-verbal communication, such as eye-contact and nodding
- asking questions, to invite the person to tell you more
- 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.

I tried to listen and was prepared to offer advice but I also thought it was important to keep opinions to myself and keep 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, whose daughter was diagnosed with lymphoma

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

Sometimes, it's 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 in a relaxed setting, such as on a walk together rather than sitting face-to-face. When you ask how they are, the person you care for 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 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 in much depth at the moment. Let them know you'll be there to support them if they want to talk more another time.

Some people find it easier to talk to someone outside of their network of family and friends. You or the person you care for might be interested in our **support services**, including our **helpline**, **support groups** and **buddy service**.

The emotional impact of being a carer

It's natural to experience mixed feelings as a carer. It might seem that you're in a process of continual adaptation as you re-adjust to any changes in practical arrangements and deal with the emotional impact of caring. As well as managing your own day-to-day life and coping with your **feelings**, you are supporting someone else with theirs. The intensity of the situation, particularly over a time, can lead to high levels of anxiety and **stress**.

You might feel a sense of reward in helping to meet the needs of someone you love. Some people say they grow closer to the person they care for. However, no matter how much you love and care about the person, there are likely to be times when you feel physically and mentally exhausted. 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.

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**.

The keyworker (usually a clinical nurse specialist) involved in the person's care can support you too. For instance, we can give guidance on caring for someone with lymphoma and on looking after your own wellbeing. We can also signpost to sources of support, for example, in relation to finances and work.

Aileen Chadwick, Macmillan Haematology Clinical Nurse Specialist

Finding out about the diagnosis

Many people don't know much **about lymphoma** before someone they know is diagnosed. When you first find out about the diagnosis, it can take a while for the news to sink in. You might feel a whole range of emotions, including shock or numbness, disbelief, helplessness, fear and sadness. The words 'lymphoma' and 'cancer' can bring fear and send thoughts spiralling, and the uncertainty of the situation can be very hard to manage. Some people find it helps to **find out a bit about lymphoma**, its treatment and side effects; this

can help 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.

Adapting to change

Caring for someone who has lymphoma is likely to have an effect on your plans and your day-to-day routine. You might also need to re-consider your plans in the short to medium term. Perhaps you're unable to do all the things you'd planned to, either alone or with the person you care for.

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 hoped.

Your relationship with the person you care for

As you both adjust to living with lymphoma, there might be changes within your relationship. Your approach to day-to-day practicalities might differ, for example, which of you 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 parental 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, but there might be times when the relationship feels strained. 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. You might also find that there are times when you seem to 'absorb' 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' and, in turn, this could affect your own mood and patience.

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 tell you. Some people describe feeling 'shut out' or excluded, which can be very hard to cope with. 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.

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

'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. 'I' statements focus on you and your feelings instead of the other person's behaviours and actions.

Examples include:

1. 'You never tell me anything. It makes me so angry. It's not fair to make me worry.'

Rephrased 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.'

2. 'You're so secretive about your appointments'

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

3. 'You never tell me how you really feel.'

Rephrased as an 'I' statement: 'I'd also like you know that, if you do want to talk about how you feel, I'm happy to listen'.

Remember that even if the person doesn't give you much detail at first, this could change over time. As they begin to make sense of the information they're given and to process their feelings, they might feel more at ease with telling you more.

Living with uncertainty

Uncertainty is a significant part of caring for someone with lymphoma. Some carers feel uncertainty and self-doubt, questioning whether they're doing enough to help. Many of us give ourselves a hard time, feeling that we should be doing more. Consider **how you can best help the person** you care for, but recognise, too, that it's important to **take good care of yourself**.

Lymphoma is often successfully treated or managed, and goes into **remission**, which means that there is no evidence 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 personal or household income, 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.

Uncertainty can make it hard to adapt to your situation, to feel hopeful, and to manage anxiety. Some people with a spiritual faith describe their beliefs as being 'shaken' when someone they love becomes unwell. It's common to wish for more control over things that you're unable to control. However, it can be more beneficial to develop your ability to live with uncertainty, for example:

- **Make and keep plans** in spite of uncertainty. 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.
- **Consider meditation or relaxation techniques, such as mindfulness**. This encourages you to slow down and live in the present moment rather than thinking about what has been and what is to come.

- **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 try not to over-do it, as this can heighten anxiety.
 - **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 and getting emotional support

While there is no one, simple way of dealing with the demands of being a carer, there are things you can do to help yourself. A **healthy lifestyle** and looking after your **mental wellbeing** helps to put you in the best position to offer good care to 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**.

When our son was diagnosed with lymphoma, my husband and I felt like we were little fish in a big pond.

Lucy, whose husband was diagnosed with lymphoma

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' networks, and giving you guidance to help support yourself and the person you care for. Carers UK have guidance on **letting your GP know** about your status as a carer, what to tell them and how they could help.

Follow a healthy lifestyle

There are a number of steps you can take to follow a healthy lifestyle, including:

- **Eating a healthy diet**, with fruit, vegetables, carbohydrates, protein and dairy (or dairy alternatives) and drinking 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.
- **Not drinking excessive amounts of alcohol** – search 'alcohol units' on the **NHS website** for more information.

- **Not smoking or taking recreational substances.**
- **Following any medical advice you're given and keeping up-to-date with health checks**, including those offered through relevant screening programmes.
- **Getting enough sleep.** The NHS website has [tips to help you get a restful night](#).
- **Building rest into your daily life**, particularly if your caring role involves physical tasks such as lifting the person or helping them to bath or shower.

The NHS website has more [guidance on following a healthy lifestyle](#).

Take care of your mental wellbeing

Mental wellbeing is as important as physical health. Being in good mental health can help you to feel generally well, confident and able to cope with stress, uncertainty and change.

Find ways to relax

Whatever form it takes, make time for yourself, away from your caring role. Find ways to relax, have fun and do something you enjoy.

- **Build relaxation into your day-to-day routine**, for example taking a walk or having a bath. Even short 'pauses' can be beneficial, such as having a cup of tea or reading a chapter of a book. You could allocate a 'slot' dedicated to you each day, for example, an hour first thing in the morning.
- **Continue with other aspects of your life** – try to keep up with other areas of your life, such as leisure activities.
- **Spend time with friends and family**, and not just with the person you are caring for.

You could also consider using [relaxation techniques](#), such as [mindfulness](#), to help provide a mental break.

Have an outlet for your feelings

Find an outlet for the array of feelings that being a carer can bring. You could talk to a friend or relative about how you feel. If this feels difficult, look for other opportunities to express yourself, for example, you might:

- Keep a journal, for example in the form of a diary, video or private blog.

- Connect with others who can relate to your experience of caring. Carers UK have an [online forum](#) where you can share thoughts, feelings and tips with other carers.
- Find a creative outlet, such as artwork, singing, sculpting or music.

Get support in dealing with challenging feelings

Trying to cope alone with your feelings can be incredibly challenging. Over time, it might lead to low mood. If you experience low mood that continues over time and affects your day-to-day life, this could be a sign of [depression](#).

Our [support services](#) team are here for you, as well as the person who has lymphoma. You can get in touch about any aspect of caring for someone who has lymphoma, including about how you feel.

For some people, speaking confidentially to a trained professional, such as a [counsellor](#), can help to work through complex emotions. 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](#) or [The British Psychological Society](#).

Connect with other carers

You might like to be in touch with other carers to share thoughts, feelings, tips and ideas in relation to caring for someone. Even if you choose not to talk much about your caring situation, it might still be reassuring to be in the company of, and to socialise with, others who can relate to your situation.

You could connect with other carers through:

- our [online forums](#), and through those hosted by other organisations such as [Carers UK](#)
- support groups, such as those offered by [Carers UK](#); [Lymphoma Action support groups](#) are also open to those who care for someone with lymphoma as well as people living with a diagnosis
- requesting a [Lymphoma Action Buddy](#) through [our support team](#), who might be able to put you in touch with another carer.

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 of these 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 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 chores
- 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
- taking part in leisure activities away from your caring duties
- taking a holiday, with or without the person you care for

Carers UK has a [factsheet about taking a break](#) and a video about [the importance of taking a break](#). Carers Trust also has [information about taking a break](#), including a list of organisations that help with funding and some of the practical arrangements of taking a holiday.

Getting practical support

Depending on your needs and eligibility, 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 is on offer to you, such as [carer's allowance](#) and [other sources of financial support](#). It's important to know your [rights at work](#) too.

Carer's assessment

The purpose of a carer's assessment is to consider how caring affects your day-to-day life, practically, physically, socially and emotionally.

During a carer's assessment, you talk through your needs with someone who is trained to carry out the assessment. 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 over 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 being a carer.

Find out more about the **carer's assessment on the NHS website**.

Carer's allowance

One of the most common entitlements for carers is the 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, you do need to meet eligibility criteria, which is means-tested and 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

In addition to carer's allowance, 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 Bureau** (CAB) 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, 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.
- You might be entitled to paid carer's leave, designed to allow you time off for planned appointments and unexpected emergencies.

Macmillan have information about **cancer and employment rights**. You can also find out more about **carers' rights at work** on the Marie Curie website.

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

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