

The emotional impact of living with lymphoma

Adjusting to life with lymphoma is an ongoing process, for the person diagnosed, and for those close to them. It's not unusual for feelings to change, even at different times within one day. This information outlines some of the feelings people often describe. However, each person has their own, individual experience of lymphoma.

If you, or someone close to you, has lymphoma, we are here to support you.

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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.

Feelings after a lymphoma diagnosis

There's no typical way to feel after being told that you, or **someone close to you**, has lymphoma – you are likely to experience a mix of feelings and emotions, some of which can be difficult to cope with.

There is such a wide range of feelings people affected by lymphoma might experience. I think it's all part of the cancer roller coaster.

People shouldn't feel guilty about their emotions and how they might change through the process.

Andrea, diagnosed with Hodgkin lymphoma

The feelings outlined below cover a range of possible responses to a diagnosis of lymphoma. You won't necessarily feel all of these, nor in a particular order or at set times:

- **shock and disbelief**
- **denial**
- **fear**
- **anxiety**
- **helplessness and loss of control**
- **anger and irritability**
- **sadness and loss**
- **guilt**
- **withdrawal or isolation.**

I have probably experienced every emotion relevant to a cancer diagnosis (except for depression) and I have watched my family and friends go through it all, too

Debbie, diagnosed with follicular lymphoma

Shock and disbelief

Shock is a very common reaction to a diagnosis of lymphoma. Some people say they feel numb or as though it isn't real.

It might take some time before you feel ready to even begin to process the news of the diagnosis. You might need to go over it a number of times as you start to adjust to the reality of it.

After the initial shock, I felt like I had lost control of everything. I likened it to being on a hamster wheel that I couldn't get off.

Andrea, diagnosed with Hodgkin lymphoma

If you are in shock or disbelief, you might not want to talk about the situation. Explain to your **family and friends** that you need some time to process the information your doctors have given you. You could consider signposting friends and family to our information, including our book: **When someone close to you has lymphoma.**

Denial

People in denial might try to carry on with their daily life as if nothing has changed. This can sometimes happen if you feel overwhelmed and unable to accept the diagnosis. Denial isn't always bad. In the short term, it can protect you from the emotional pain that can come when you think about the situation.

If denial continues over time, however, it can stop you from considering the impact of lymphoma on your life. This can stop you from **developing healthy coping strategies** and from being actively involved in making important decisions about your health care. Staying in denial might also lower your likelihood of taking good care of your **general health and wellbeing**, including seeking medical advice when you need to, for example, if you notice **signs of infection**.

A very important part of our role as a clinical nurse specialist (CNS) is to identify and support emotional and psychological wellbeing at any point during the lymphoma journey. This can be for anyone affected by a diagnosis of lymphoma. Everyone is different and will experience concerns and worries about lymphoma at different times. I would encourage you to contact your CNS to discuss these. We are able to sign post to other teams or other organisations if required. We have a vast range of supportive interventions within our local hospital and wider area that can be accessed by patients and their families/carers.

Samantha Darby, Lymphoma Clinical Nurse Specialist

Fear

Lymphoma is unfamiliar, and it affects your physical and emotional wellbeing. A natural reaction to this is fear. Many people feel scared and struggle to listen to anything more the doctor says after hearing 'lymphoma' or 'cancer'.

Words like 'cancer' and 'tumour' are very powerful and seem to reverberate in the mind, reducing all else into a kind of impenetrable verbal fog. A friend told me to concentrate on three things: exercise, eating well and being positive. Happily, the cabin fever, the anger, and the loss of direction began to recede.

Paul, diagnosed with high-grade non-Hodgkin lymphoma

To take away some of the power of the unknown, you might find it helps to **learn a bit about your lymphoma**. Your medical team can answer any specific questions you have, and our **Helpline Services Team** are also here to support you.

Anxiety

Anxiety is a natural response to feeling under stress or pressure. It can affect your mind and your body in various ways. For example, after a diagnosis of lymphoma, you might experience:

- a feeling of unease, worry or dread
- increased irritability
- difficulty concentrating
- difficulty **sleeping**
- muscle tightness (tension)
- a 'racing', fluttering or pounding heart (palpitations)
- dizziness
- quick breathing.

Heightened anxiety can also be common in people who are on **active monitoring ('watch and wait')**, where doctors recommend that you don't have treatment straightaway. For some people, the idea of this leads to increased anxiety. Ask your medical team to explain why they are recommending active monitoring for you – understanding why they've suggested you go on active monitoring might help to **manage anxiety**.

Although anxiety is a natural response to a challenging situation, it can feel very uncomfortable and overwhelming. Anxiety can affect your **day-to-day life** in various ways. It can affect your mood, concentration, ability to relax and to get a restful night's sleep.

I learned not to bottle up my own worries and concerns. It was important to talk things over with people I trusted. Friends, work colleagues and Lymphoma Action provided me with a kind ear and helpful information.

Cyanne, whose husband was diagnosed with lymphoma

If anxiety interferes with your **day-to-day life**, speak to a member of your medical team for support to help you to manage it – a clinical nurse specialist is often a good person to approach. If you are caring for someone who has lymphoma, ask your GP what support they can offer or signpost you to..

Helplessness and loss of control

It's common to feel a loss of control after a lymphoma diagnosis. Some people describe feeling passive in their lives and a sense of things 'happening to them'. For example, you might know where and when you need to be at medical appointments. However, you might not feel that you truly understand the reasons for all the **tests and scans** you're having, or why a particular **treatment** is recommended for you. **Getting the information and support you'd like** can help you to regain a sense of control.

We have separate information if you are **caring for someone who has lymphoma**. This includes about **taking care of yourself and getting emotional support**.

Anger and irritability

You might feel angry about the disruption that lymphoma causes to your life and plans. Some people feel angry with the cancer itself or towards the health professionals within their medical team.

People often question why lymphoma has happened to them. They feel it is unfair and doesn't make sense, particularly if they have been in good health up until this point in their lives.

I felt angry that lymphoma had taken everything away from me and it has only been recently that I have accepted that it is OK to be angry. But I also realised there was help and support out there.

Hayley, diagnosed with Hodgkin lymphoma

It is also common to feel irritable with the people around you. You might resent that they can carry on with their lives while you are having to make changes to yours. It can feel irritating to receive well-meant advice from family and friends. For example, people might encourage you to 'be positive' and to 'fight' your illness. If someone close to you has lymphoma, you might feel a sense of pressure to feel positive for both of you. However, there will be times when you don't feel positive or motivated, and such comments can lead to feelings of hurt. You might also feel 'detached' and emotionally distant from these people.

We often hear from people affected by lymphoma that others don't seem to understand what they're going through. For example, people might expect you to feel overjoyed once treatment is over, particularly if you are in **remission**. However, many people feel a whole range of feelings **after treatment**, which can be challenging.

I've seen pictures of people on Facebook celebrating their last chemo with 'last chemo' badges and things like that, but when I finished treatment, I didn't feel like that. I learned that getting to the end of treatment was another step in my treatment. Although I hadn't expected to, I missed the routine of going into hospital and seeing my team, who had been so supportive.

Kate, diagnosed with Hodgkin lymphoma

Sadness and loss

Some people feel a deep loss for their good health – you might feel a sense of grief and sorrow in the uncertainty of whether you can continue to live your day-to-day life as you have until now. You might also feel sad for your **family and friends**, knowing that they, too, are coping with challenging feelings. If someone close to you has lymphoma, you might also feel great sadness and loss. Some people then also feel guilty for feeling this way, and feel a sense of pressure to be positive. Memories and feelings about other losses you have had in your life could also be triggered.

Guilt

Some people feel guilty when they are diagnosed with lymphoma. They wonder if they could have caused or prevented it. Some people wonder if there were symptoms they could have recognised earlier. We also hear people say that they feel guilty for the impact on friends and family. If someone close to you has lymphoma, you might question whether you could have encouraged the person to go to their GP sooner. The reality is that there is no one to blame for the diagnosis.

It's human nature to look for someone or something to blame, or at least to help explain things. In most cases, however, the **cause of lymphoma** is not known. There is little or no evidence to suggest that anything you have or have not done has caused you to develop lymphoma.

Withdrawal or isolation

There might be times when you feel unable to be around others. You might feel that no one really understands what you're going through. Some people pretend to feel OK even when they don't really feel this way. You might worry about how people will respond if you tell them how you really feel.

It's understandable that you might want to be alone from time to time. However, maintaining healthy **relationships with family and friends** is important too. The support that these relationships offer can have a significant positive effect on your **mental wellbeing**. In turn, this can have a motivating and empowering impact in encouraging you to take good care of your general health.

During times when you'd rather be on your own, you could politely let the people close to you know that this is the case – this honesty might help to prevent hurt responses, or them worrying that they have upset you. We have more tips about **communicating with the people around you**.

It's natural to want time alone sometimes. However, withdrawing from others all or most of the time could be a sign of **depression**, where you feel very low emotionally. There are many other **possible symptoms of depression**, which can be physical and psychological. If you think you might be experiencing depression, there is a **range of support available** – speak to your GP or your clinical nurse specialist for advice.

Coping with difficult feelings

It's important to allow yourself to feel your emotions. Ignoring them can make them harder to cope with. Over time, this can have an impact on your overall wellbeing, as well as relationships with family and friends.

Although **living with lymphoma** is challenging, there is support available. Speak to your GP or your clinical nurse specialist for advice. You can also speak to a member of our **Helpline Services Team** about any aspect of lymphoma, including about how you are feeling.

You might also be interested in the **health and wellbeing resources** on our website.

Our [useful organisations list](#) has a section on emotional wellbeing.

- **Manage anxiety** – Anxiety can feel very uncomfortable and overwhelming. There are lots of things you can try that might help you, which might include self-help strategies (like [mindfulness](#)) and talking therapies (such as [counselling](#)).
- **Consider what you can control** – A lymphoma diagnosis can bring a sense of [lack of control and hopelessness](#). It can help to look for what you **are** able to control. For example, only sharing information you are comfortable sharing with others.
- **Get the information you would like** – [Find out what you would like to know about lymphoma](#), as and when you would like to.
- **Follow a healthy lifestyle** – This includes good [diet and nutrition](#), getting [physical activity](#), [managing stress](#), having enough [sleep](#), and doing the things you enjoy.
- **Build relaxation into your day-to-day life** – Many people find a [complementary therapy](#) helpful, for example [mindfulness meditation](#), as well as spending time with family and friends.

You might be interested in listening to our [podcast with counselling psychologist Angela Waind](#), who talks about emotional wellbeing, the links with physical health, and strategies to help support positive mental wellbeing.

Macmillan Cancer Support has a [free audiobook about the emotional effects of cancer](#) – you can download it in sections or listen to the whole book.

I try to fill my days and enjoy life. I would encourage people to ask their consultant any questions they'd like to, and to seek counselling if you think it could help you.

Ashley, diagnosed with skin lymphoma

Benefits of finding ways to cope with challenging feelings

Finding ways to cope with challenging feelings can help you in the longer term. Many people then go on to experience positive life changes.

Some of the positive changes people describe are:

- closer **relationships with family and friends**
- greater appreciation for life and feeling more able to live in the present moment
- feeling that life has meaning to it, which might arise from new priorities
- feeling more connected or 'at one' with yourself, the world and, for some people, a religious faith
- having a healthier lifestyle than before your diagnosis
- a changed view of yourself, for example, feeling greater resilience, gratitude, and acceptance
- exploring new possibilities.

Findings suggest that the following factors are likely to help in the development of such positive changes: expressing your emotions, **managing stress**, and feeling supported by **relationships with family and friends**.

The past 12 years has been a rollercoaster of emotions and at times it feels like someone's story. The first 5 years after treatment is a blur. Since then I've felt everything from denial to anger, and now I'm finally at acceptance. I'm grateful for my health and the journey I've been on. Lymphoma has played a huge part in this and it has certainly made me stronger than I ever thought I could be. I'm immensely proud of what I have achieved in the past 12 years and looking forward to many more adventures to come.

Blair, in remission from diffuse large B-cell lymphoma

Counselling

Counselling is a type of talking therapy that can help you consider:

- your thoughts and feelings
- how lymphoma affects your life, for example, your **work, studies** or **relationships**
- what is important in your life
- how you usually respond to people and things, relating this to your current situation
- what the people and things in your life mean to you
- your feelings or resilience and sense of ability to cope
- ideas and strategies to address challenges.

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

If you would like support in adjusting to living with lymphoma, speak to your GP or a member of your medical team. They might be able to refer you on the NHS, or they might know of other wellbeing and counselling services in your local area. You can also see our [emotional wellbeing section of our useful organisations listing](#).

Finding out about lymphoma

Understanding a bit [about lymphoma](#) can help you to feel empowered and more in control of your situation. It can help you to be actively involved in making decisions about your health and care.

We have information on our website about lymphoma, including its treatment and how to [live well, with and beyond lymphoma](#). Contact our [Helpline Services Team](#) if you can't find what you're looking for and to find out more about [how we can support you](#).

Although it is also important to acknowledge the reality of the situation, you might find work or other activities a good distraction. Some people prefer not to have lots of information, while other people want to know as much as they can about their lymphoma. There is no right or wrong way. Give yourself time to adjust to your diagnosis and to find an approach that works for you.

[Nicola, Lymphoma Action helpline team member](#)

Your medical team are best-placed to answer any questions you might have about your specific [lymphoma type](#) and recommended [treatment](#) plan. They are also used to repeating information or explaining it in a different way if this could be helpful.

Getting the balance right for you

Although it can be helpful to understand a bit about your lymphoma and its treatment, having lots of information all at once can be overwhelming. Make sure that any information you read is from a reputable source. One way of recognising

trustworthy information is to check whether the organisation producing it is an accredited **Patient Information Forum (PIF) TICK** member. This shows that they have been awarded with a health and care information quality mark by an independent organisation.

If it feels daunting to find out about lymphoma, you could ask a family member or friend if they could help you by researching the things you'd like to know about lymphoma. They can then summarise this and tell you just the key points.

Any booklets my daughter was given were handed straight over; Carol relied on me to find out and tell her as needed, and for me to be able to ask her various consultants anything that needed answering.

Helen, whose daughter, Carol, was diagnosed with Hodgkin lymphoma

Read **Helen's personal experience**.

Adjusting to life with and beyond lymphoma

It can be challenging to adjust to **life with and beyond lymphoma**. Some people describe finding a 'new normal', and many people adapt well to a new routine. For example, you might need to make some changes in your day-to-day life, either in the short or longer term.

The difficult thing, I think, is that after a diagnosis of cancer, you will always have had a diagnosis of cancer. It will always be part of you, but it is not you. I think that's the thing I initially struggled with – how cancer fitted into my identity. I now understand that I have had cancer. That's a part of me. In terms of mental health, I've become much stricter with myself in terms of making sure that I create and save time for positive things.

Kate, diagnosed with Hodgkin lymphoma

Give yourself permission rather than putting pressure on yourself to continue with things in the way that you did before you were diagnosed with lymphoma.

You might be interested in our **Live your Life** peer-led self-management programme. This is designed for people who have just finished treatment or who are on **active monitoring (watch and wait)**, to help adjust to life with and beyond lymphoma.

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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