

Recovery after lymphoma treatment

On this page we outline support available to help with some of the physical and emotional challenges you might experience after [treatment for lymphoma](#). You might also be interested in our peer-led self-management [Live your Life programme](#).

We have separate information about the [emotional impact of lymphoma](#), [living with and beyond lymphoma](#) and [day-to-day living](#).

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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.

Adjusting to life after treatment

People often tell us that finishing treatment for lymphoma can bring a range of emotions. You might feel positive some or a lot of the time. However, you might also experience more challenging feelings, for example **feelings of uncertainty**, **changes in relationships** and **coping with side effects**.

For me, finishing treatment is where I felt my journey began. I had so much to process in terms of what had just happened. I think I just put all of my trauma in boxes throughout my treatment just to get through it. I am learning how to filter out the emotions I can control and those I can't, while being gentle with myself.

Jacqueline, who was treated for non-Hodgkin lymphoma

It can take time to adapt once you finish treatment. In time, many people describe finding a 'new normal'.

You might be interested in **others' personal experiences of adjusting to life after lymphoma**.

It was difficult for me to work, so some of my role had to be given to others. As I live on my own, I organised for someone to come and stay with me for three weeks when I went home. At the end of treatment, fatigue was extreme. Despite going to bed early, I still needed to have an afternoon nap. I tried to go out for short walks each day around the block. I also really enjoyed going out for coffee so that I could be around people.

Penny, who was treated for CNS lymphoma

You should be offered **personalised care and support** from your medical team to help you live well after treatment.

Think about how you can look after yourself. You might find our **health and wellbeing resources** helpful. We also have a **useful organisations** webpage, which includes a **section on emotional wellbeing** and **talking therapies**.

Your doctor or nurse might suggest that you consider a talking therapy. In my experience, people may be a little hesitant at first, but usually find it very helpful. If you're interested in accessing this type of support, you can ask your GP practice or a member of your medical team for more information.

Dr Johnny Marshall, National Association of Primary Care

As you adjust to life after treatment, it can be helpful to:

- **Recognise how you're feeling** – you might want to talk to someone about this, for example, our [Helpline Team](#). You might want to try a **talking therapy** such as [counselling](#).
- **Connect with other people who have been treated for lymphoma** – for example, through our [closed Facebook support group](#) or [Buddy Service](#).
- **Be patient with yourself** – give yourself time to adjust to life after treatment.
- **Build up slowly** – for example, set yourself small, manageable goals and try to be understanding towards yourself if there are times you don't meet them.
- **Try to get a balance between activity and rest** – you could ask your clinical nurse specialist (CNS) for guidance about [exercise and physical activity](#) that is suitable for you.

My medical team had given no promises about how long recovery would take, but it has taken longer than I would have thought to regain my strength. I said this to a haematologist recently, and he explained that I had been very ill and they had put my body through some really intense treatment, so I needed to be kind to myself.

Penny, who was treated for CNS lymphoma

Uncertainty

Some people describe feeling 'lost' or alone after treatment. You might have a sense of facing the unknown and a general feeling of uncertainty. You might feel unsure about what to expect in the future or worried that your [lymphoma could return \(relapse\)](#).

Some people come to feel a sense of safety in having a lot of hospital appointments. They feel some comfort in seeing their health professionals frequently. We often hear that they then feel unsettled or anxious once appointments become less frequent. Some people feel abandoned or unsupported once treatment finishes, which can come as a shock. Remember that you can contact your medical team before your next appointment if you have any concerns.

Feelings of uncertainty can have a powerful impact on your emotional wellbeing. You might feel high levels of **anxiety**. Some people experience low mood, which can lead to **depression**.

Let your **Clinical Nurse Specialist** (CNS) know how you're feeling. They can offer reassurance and can often signpost to local sources of support.

You can also contact our **Helpline Team** to talk in confidence about how you're feeling and to find out about the **support we offer**.

Health professionals recognise how difficult it can be to live with uncertainty and want to offer support. As a GP, I would like to emphasise that we are here to give you support through treatment and beyond – for the rest of your life.

Dr Johnny Marshall, National Association of Primary Care

Relationships

Lymphoma and its treatment can have an effect on **relationships** with family and friends. Some people describe positive changes, such as feelings of closeness. However, there might be challenges too, leading to some relationships feeling more strained.

There might be differences in how you and others think you should approach your recovery. For example, they might ask you to take life at a gentler pace than you would like to. Or you might feel pressured to 'get back to normal' as soon as possible.

I found it helpful to set expectations. For example, some people might not understand that you're still coming to terms emotionally with everything you have been through. I lost contact with a number of friends – some didn't seem very patient and wouldn't take precautions when meeting up while I was waiting to recover some immunity. I found I made close friends in unexpected places too, though.

Elaine, who was treated for follicular lymphoma

Although it's not always easy, finding ways to **communicate effectively** and with honesty can be of great benefit to relationships.

We have more information about **the impact of lymphoma on relationships**.

Will I have side effects after finishing treatment?

For some people, **side effects of treatment** can continue for a while after finishing treatment. If you have any concerns, speak to a member of your medical team.

Side effects can go on long after treatment has finished. It is important to flag any ongoing symptoms to your medical team so that they can give you advice or signpost you to specialist support if needed.

Charlotte Bloodworth, Lead Haematology Clinical Nurse Specialist

Changes in weight are quite common after treatment for cancer. This could be because of the lymphoma itself. It might also happen because of changes to your **diet** or levels of **physical activity**. If you want to gain or lose weight, speak to your CNS or GP. They can give you advice on how to do this in a safe and healthy way.

If you are struggling with side effects, whatever these are, speak to your medical

team for advice and to find out how they can support you. This might include self-help strategies or a referral for specialist support.

Your GP will understand that any side effects you experience can have a major impact on your health and wellbeing. As GPs, we would wish to support you in addressing what matters to you as best we can through offering self-help strategies, treatments and referral for specialist support.

Dr Johnny Marshall, National Association of Primary Care

Healthy living after treatment

Your medical team can give you advice about **living well after treatment**. This includes about any health and safety precautions to take, such as if and when to have certain **vaccinations** and **how to lower your risk of infection**.

The general guidance is to have a **healthy lifestyle**, which includes:

- **eating well**
- doing **exercise** that's suitable for you
- looking after your mental wellbeing, including **managing stress**
- keeping a **healthy weight**
- limiting your **alcohol intake**
- **not smoking**.

You can find more information about these and other healthy lifestyle factors on the **NHS website**.

Your GP surgery is also there to support you to live well after treatment. On the **Patients Association** website, you can find **information and guidance**, including on **getting the most out of your GP appointment**.

It can also be helpful for you to be able to [view your GP health record](#) and access services using [NHS app](#).

How can I lower my risk of infection?

Your medical team will tell you about any precautions you should take in your [day-to-day](#) life to [lower your risk of infection](#). They should tell you any [symptoms and signs](#) to look out for that could suggest you have an infection. You'll also be given information about [what to do if you think you might have an infection](#).

You should be told about any precautions to take if your blood counts are still recovering after treatment. This includes if you have [anaemia](#) (low red blood cells), [neutropenia](#) (low neutrophils – a type of white blood cell) or [thrombocytopenia](#) (low platelets).

Preventing infection if you need medical care in the future

You might be given specific guidance to prevent infections if you need medical or dental care in the future. This can depend on what treatment you've had and how long ago you had it.

If you have had your [spleen removed \(splenectomy\)](#), or radiotherapy to your spleen, your medical team will tell you about special [precautions you should take](#). You might also be given a warning card to carry with you.

Warning cards

In some cases, you'll be given a warning card to carry with you if you:

- have recently had treatment with [steroids](#)
- don't have a spleen
- should have [irradiated blood products](#) in case you need a [blood or platelet transfusion](#).

The cards give important information about your treatment to help you and any health professionals treating you take necessary precautions.

Personalised care and support

The NHS aims to give tailored care and support to everyone with and beyond cancer. This is known as a personalised care and support plan.

A one-size-fits-all health and care system simply cannot meet the increasing complexity of people's needs and expectations.

– NHS UK

Personalised care should include:

- **Holistic needs assessment (HNA)**, a questionnaire to help you and your medical team work together to identify and address any practical, financial, physical, emotional and social needs you might have.
- **Treatment summary**, which your medical team completes. This outlines your lymphoma diagnosis and treatment, as well as its possible **side effects** and **late effects** you might get. It should tell you what symptoms to look out for and who to contact if you notice them, including an out-of-hours number to call if you need to. The summary should outline your follow-up plan and any lifestyle recommendations, for example about **diet** and **exercise**.
- **Cancer care review**, which is a conversation that you have with your GP or a GP surgery practice nurse. It's an opportunity to talk about any medical needs you might have. You can discuss any points raised in your **HNA**. You could also find out about any **financial support** available to you, including **prescription charge exemptions**.
- **Health and wellbeing events** (such as our **Live your Life programme**), to help people affected by cancer and their families live well.

You can read more about **personalised care** on the NHS website. You might also be interested in our podcast about **enhanced supportive care**, an approach that aims to help address the physical and psychological effects of living with lymphoma.

A personalised approach to care and support ensures that people's needs can be fully identified, and the appropriate support planned. It is vital that care and support is planned and arranged around what matters to people, their individual strengths and developed abilities.

- NHS England

Frequently asked questions about recovery after treatment for lymphoma

We answer some questions people often have about recovery after treatment for lymphoma. Your **medical team** can give you information specific to your situation.

How soon after treatment will I feel better?

It takes time to recover after treatment for lymphoma and it can take a while for your energy levels to build back up.

There are lots of things that can affect how soon you will start to feel better:

- the **type of treatment** you had
- how long **side effects** go on for after treatment
- your age
- your general health and fitness
- any other medical conditions you have
- how you feel **emotionally**.

How long will side effects go on for after treatment?

A lot of the time, side effects start to improve once you finish treatment. However, some people have side effects that go on for weeks or months after treatment finishes. Your CNS or GP can help you to manage any side effects you get.

I'm struggling with the emotional impact of recovering from treatment – what can I do?

The **emotional impact of lymphoma** can be significant, including during recovery from treatment. For example, you might feel heightened anxiety about the uncertainty of possible **relapse** (the lymphoma coming back) or other health issues. You might worry that other people close to you will become ill.

It can also take a while to feel comfortable being around friends again – whether this is because you are regaining confidence socially, or you are concerned about developing an **infection**. Talk to your medical team – they can continue to support you with your **physical and emotional** wellbeing after treatment.

Whatever your challenges; however you're feeling, we're **here to support you**.

Can I get back to my 'normal' routine once treatment finishes?

You might have taken time out of some of your day-to-day activities such as [work](#), [studies](#) or other responsibilities during your treatment. If you plan to go back to these, remember that you won't be back to your full strength straightaway. Be realistic with your goals rather than overstretching yourself. Find out how your workplace, school, college or university can support you. Although it can take a while to adjust, many people describe finding a 'new normal' after treatment for lymphoma.

Should I celebrate when treatment finishes?

There's no typical way to feel after treatment – while some people choose to celebrate, not everyone wants to.

Think about if, when and how you'd like to mark the end of treatment. For example, you might treat yourself to a gift. Some people plan a trip – talk to your doctors about whether your travel ideas are safe and advisable. You might also be interested in our information about [travelling safely outside the UK](#) and about [travel insurance](#).

However, you might choose not to celebrate at all, or not to do so straightaway. People around you might offer suggestions – try not to feel pressured by these or by the approaches that others have taken.

The important thing is that you decide on what feels right for you.

Where can I go for support in my recovery from treatment?

Finishing treatment for lymphoma doesn't mean that the support available to you stops. For example, you could:

- connect with others who are affected by lymphoma – you could do this through one of our [online support meetings](#) or [Closed Facebook Support group](#)
- join us at a Lymphoma Action [Live your Life workshop](#) designed for people who have recently finished treatment or are on [active monitoring](#) – get practical tips and support from others affected by lymphoma and health professionals.

Remember that your medical team can support you even after you finish treatment. A good first point of contact is often your CNS.

Will I get late effects after my treatment?

Late effects are health conditions that can develop months or even years after treatment for lymphoma. Modern treatments are designed to treat lymphoma effectively while keeping the risk to your long-term health as low as possible. Your doctor will monitor you for late effects at your **follow-up appointments**.

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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