

## Recovery after lymphoma treatment

It takes time to recover after treatment for lymphoma but there is support available to help with any physical and emotional challenges you face. We have separate information about **living with and beyond lymphoma** and about **day-to-day living**.

### On this page

**Adjusting to life after treatment**

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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](mailto:information@lymphoma-action.org.uk).

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## Adjusting to life after treatment for lymphoma

Finishing treatment for lymphoma can bring a range of emotions. Some of these are likely to be positive but others might be harder to cope with.

Dealing with challenges can have an impact on how you feel overall and on your self-esteem. Be patient with yourself. Give yourself time to adjust to life after treatment.

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**I was raring to go after treatment but I took my consultant's advice to listen to my body to help me recover. With my work, my employer encouraged me to start with an hour of work a day, which I thought this was silly – but to be honest, it was enough and it was the right thing for me to build up gradually.**  
Andrea, diagnosed with Hodgkin lymphoma

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Each person's experience with lymphoma is unique, but connecting with other people who have been treated for lymphoma can be a helpful source of support. You could be in touch with someone who might be able to relate to your experience through our peer-support [buddy service](#) or [closed Facebook support group](#). There is more information on our website about the [support we offer](#), including [wellbeing videos](#) and information about [support groups](#).

You might also be interested in [Maggie's](#), a charity that offers free cancer support and information in centres across the UK and online.

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**At the end of my treatment the consultant said I was free to go. It didn't really sink in. My cancer was gone. Stepping out of the hospital was a lovely sunny day, but I felt low. I was questioning why it was I was allowed to survive. I learnt from the nurses and counsellors that this is known as 'Survivor's Remorse' and is when you are filled with guilt for making it through. The weeks passed and I could not shake off this low feeling. I was referred to a Macmillan counsellor. I think having it explained to me helped enormously.**

Imtiaz, treated for central nervous system (CNS) lymphoma

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You might be interested in hearing [Adam talk about his experiences of recovering from treatment](#) for lymphoma.

## **Uncertainty**

You might have a sense of facing the unknown and a general feeling of uncertainty. Some people describe feeling 'lost' or alone after treatment. After getting used to regular hospital appointments, you might feel unsettled or anxious without so much contact with your medical team. You might feel unsure about what to expect in the future. Some people [worry about the possibility that their lymphoma will come back \(relapse\)](#) or get worse.

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**Weirdly, although I didn't miss the treatment, I missed some of the routine of going into hospital and seeing my team who had been so supportive.**

Kate, diagnosed with Hodgkin lymphoma

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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 get in touch with our **helpline team** to talk in confidence about how you're feeling and to find out about the **support we offer**.

## Relationships

Finishing treatment can have an impact on interactions with those around you. We often hear people say that they have a different perspective or outlook on life now having experienced lymphoma.



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**I think my perspective in life has changed. I used to take things very much more seriously, but a cancer diagnosis puts things into perspective. I feel rather humble and very fortunate.**

Neil, treated for grey zone lymphoma

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You and the people close to you might have different thoughts about what is best for you. For example, **friends and family** might want you to take life at a slower pace than you'd like to. You might feel rushed by others to 'get back to normal'. However, rather than things going back to exactly as they were before their diagnosis, many people describe finding a 'new normal' and need time to adapt once treatment finishes.

It might seem hard, but finding ways of **communicating effectively** and honestly can help to ease the strain on your relationships.

## **Side effects**

For some people, **side effects** can go on during recovery, which might feel disheartening when you have finished your treatment.

Changes in weight are fairly common after treatment for cancer. This can be for a number of reasons, including the effects of the cancer itself, changes in **diet** and changes in **physical activity** levels during and after treatment. Speak to your CNS or GP for advice on gaining or losing weight in a safe and healthy way.

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**It's been 9 years since I finished treatment. I live with some ongoing health issues that affect my day-to-day life, but there have also been lots of positive changes and my outlook on life has changed too. I would encourage people to make use of the support available.**

Andrea, diagnosed with Hodgkin lymphoma

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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.

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**It's important to let your medical team know if you have any side effects after you finish your treatment. Whether these are physical or emotional, they can reassure you and help you find the right support to help you manage.**

Dr Gilly Howard-Jones, Lymphoma Nurse Specialist

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You might also be interested in our book: **Living with and beyond lymphoma: coping practically, physically and emotionally.**

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## Keeping well after treatment

It's important to take guidance from your medical team. However, the general advice is to follow a healthy lifestyle. This includes **eating well**, doing **exercise** that's suitable for you, keeping a **healthy weight**, limiting your **alcohol intake** and not **smoking**. You can find more information about these and other healthy lifestyle factors on the **NHS website**.

### Things to consider

Treatment for lymphoma can cause temporary low counts of red blood cells (**anaemia**), white blood cells (**neutropenia**) or platelets (**thrombocytopenia**). Low blood counts can increase your risk of developing infections, make you bruise or bleed more easily (for example, with nosebleeds, bleeding gums or heavier periods) than before you had treatment. While your blood counts are building back up, take steps to **lower your risk of infection** and **bleeding**.

You might also be given guidance to **prevent infections** for if you need medical care in the future. This can depend on what treatment you've had and how long ago. Precautions might include:

- having or not having certain **vaccinations**
- taking low-dose antibiotics every day if you've had your **spleen removed (splenectomy)** or **radiotherapy** to your spleen.

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

- have recently had treatment with **steroids**
- don't have a spleen
- need **irradiated blood products** in case you need a **blood or platelet transfusion**.

Ask your medical team any questions you have. They can give you advice specific to your situation.

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## Personalised care and support

The NHS is committed to offering tailored care and support to each individual living with and beyond cancer. This is known as a personalised care and support plan.

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**Personalised cancer care means providing patients with access to care and support that meets their individual needs – from the moment they receive their cancer diagnosis – so that they can live as full, healthy and active a life as possible. This can include helping people to access financial, emotional, psychological and social support as well as providing them with information on managing their lifestyle, treatments and therapies available.**

NHS UK

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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 diagnosis and treatment, as well as its possible **side effects** and **late effects**. It should also tell you what symptoms you should look out for and who to contact if you notice them, including an out-of-hours number. The summary should outline your follow-up plan and any lifestyle recommendations, for example about **diet** and **exercise**.
- **Cancer care review**, which is a discussion that you have with your GP or a GP surgery practice nurse. It's an opportunity to check in about any medical needs you might have and to talk about any points raised in your holistic needs assessment. You could also find out about any **financial support** available to you, including **prescription charge exemptions**.
- **Health and wellbeing events**, which aim to help people affected by cancer and their families live well. An example of a health and wellbeing event is our **Live your Life programme**.

You can read more about **personalised care** on the NHS website.

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## Frequently asked questions about recovery after treatment for lymphoma

In this section, 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 finishes will I feel better?

It takes time to recover after treatment for lymphoma and it might take a while for your energy levels to build back up. How quickly you feel stronger depends on factors that include:

- the type of **treatment** you had
- whether **side effects** go on once you finish your treatment
- your age
- your general health and fitness, including any other medical conditions, if you have any
- how you feel **emotionally**.

Some people have **side effects that go on after treatment finishes**. If this is the case for you, ask your CNS or GP for advice about how to manage these.

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

You might have taken time out of **work**, studies or other responsibilities during your treatment. If you plan to return 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 time to adjust, many people describe finding a 'new normal' after treatment for lymphoma.



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**After treatment, I had to adapt to a new life. The nurses had become my friends and the cancer ward my second home. So much had happened and I had to find my way again in a world that had evolved so much since I last saw it. I gradually picked back up where I'd left off. I am now 6 years in remission. I've graduated from university, bought my first home, progressed in my career, and conceived a beautiful daughter. Looking back, I realise that I had cancer but cancer never had me. It made me realise I have an inner strength that I didn't know I had.**  
Tatiana, diagnosed with Hodgkin lymphoma

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### **Should I celebrate when treatment finishes?**

Some people mark the end of treatment. Think about if and how you'd like to. You might plan a trip, or perhaps treat yourself to a gift. 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?**

Just because you've finished treatment, it doesn't mean that the support available to you stops. For example, you could:

- Speak to your CNS about any side effects that are bothering you, and ask for advice about how to manage them.
- Connect with others who are affected by lymphoma at a **support group** or on in an **online community**.
- Attend a Lymphoma Action **Live your Life workshop** to get practical tips to help you **live well with and beyond lymphoma**.

## Will my lymphoma come back?

It's very common to worry about your lymphoma coming back (**relapsing**) after treatment and many people feel anxious in the lead-up to their **follow-up appointments**. Your doctor should tell you what to look out for after you finish treatment.

## Contact your medical team if you have any of the following symptoms:

- **swollen lymph nodes** lasting more than a week
- **drenching night sweats** lasting more than a few weeks
- **unexplained weight loss**
- **worsening fatigue** (extreme tiredness)
- **itching**
- a **rash** (if you have **skin lymphoma**)
- **diarrhoea**
- ongoing or unexplained **pain**.

**If you're worried about any symptoms, let your medical team know – don't wait until your next planned appointment.** They should be able to reassure you or offer you an earlier appointment if necessary.

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**After treatment, patients will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.**  
NHS England long-term plan

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If you have ongoing heightened anxiety levels that affect your **day-to-day life**, speak to a member of your medical team or your GP. They can offer advice and support, which might include a referral for a **talking therapy**, such as **counselling**. The NHS website has information about **anxiety, fear and panic**. You can also find a list of **organisations that offer emotional support** on our website.

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**As a GP, it's my job to listen to any concerns and offer help. I'm happy to assist in making sense of what's happening and working together with my patients to help manage both physical and emotional difficulties.**

Dr Vince Ryan, GP

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## 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**.

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**Late effects from lymphoma treatment don't affect everyone. Attending your follow-up appointments means your medical team can closely monitor your health for late effects once treatment has ended.**

Dr Gilly Howard-Jones, Lymphoma Nurse Specialist

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## References

The full list of references for this page is available on our website. Alternatively, email [publications@lymphoma-action.org.uk](mailto: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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