Recovery after treatment

It can be difficult to know what to expect when you finish treatment for lymphoma. This page is about your recovery from the side effects that may have affected your body during treatment. We also have information about exercise and healthy eating after treatment.

On this page

The recovery package

How soon will I feel better?

Symptoms to look out for

Late effects of treatment

The recovery package

Adjusting to life after lymphoma treatment can be hard. After months of hospital appointments, you might feel anxious or isolated when treatment ends and unsure about what to expect in the future. To help you adjust, the National Cancer Survivorship Initiative (NCSI) has developed the recovery package.

The recovery package uses a combination of strategies to identify your individual needs, help you prepare for the future and support you to live well after treatment. It is being rolled out across the NHS and should be available to every patient with cancer by 2020.
The recovery package should include:

- An assessment to identify your physical, emotional and social needs. This is sometimes called a holistic needs assessment, or HNA. Your medical team can use it to create a care and support plan that’s specific to you and your recovery.

- A treatment summary completed by your hospital team. This should contain information about the treatment you had, any long-term effects it might have, what symptoms of your lymphoma relapsing (coming back) to look out for after treatment and who to contact if you notice them. Your GP should be given a copy of this as well.
A cancer care review. This is a discussion between you and your GP or practice nurse. As well as your medical needs, it should cover things like the financial impact of cancer, whether you’re exempt from prescription charges, and the possible late effects of cancer and cancer treatment. It’s also an opportunity for you to find out what information and support services are available to you now you’ve finished treatment and how you can access them.

A health and wellbeing event, such as Lymphoma Action’s Live your Life workshops, designed to help you prepare for the future and live well after treatment. These events are full of practical advice on how to stay healthy and active with and beyond cancer. They’re also a good opportunity to meet other people in a similar situation to you.

If the recovery package isn’t available in your area, you should still be supported by your medical team. Ask your key worker what support is available and who you should contact if you have any concerns. They may also have information on local facilities and groups that could help.

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How soon will I feel better?

It takes time to recover after treatment for lymphoma and you might have side effects that continue after your treatment ends. How quickly you feel stronger depends on a range of factors, including:

- the treatment you had: recovery from more intensive (stronger) treatments (for example, a stem cell transplant) usually takes longer
- what side effects you experienced during treatment
- your age
- your general fitness
- whether you have other health conditions
- how you feel in yourself.

If you are returning to work, studies, or other responsibilities such as caring for others, remember that you won’t be back to your full
strength straightaway. Be realistic with your goals and try not to overstretch yourself.

You’ll probably notice that different effects of cancer and its treatment get better at different times.

**Difficulty eating**

You may have found eating and drinking difficult during your treatment, especially if you had a **sore mouth or mouth ulcers** (known as ‘oral mucositis’). Oral mucositis usually gets better quite quickly after finishing treatment: around 2–3 weeks after **chemotherapy** and around 5–7 weeks after **radiotherapy**. If you’re struggling to eat or drink in the meantime, there are **things you can do** that might make it easier.

**Changes in weight**

You may have lost or gained weight during your treatment, due to possible changes in your appetite, taste, digestive system and metabolism.

If you have lost weight, it should begin to build up as you become more active and your appetite improves. If you have gained weight because of your treatment, it can be harder to lose. You should aim to return to a healthy weight gradually over a few months.

Gradually my sense of taste recovered. Interestingly, I found that after treatment I did not like spicy Indian food as much as I used to. I also found I really liked peppermint tea, which I disliked beforehand.

— Elisabet, treated for Hodgkin lymphoma in 2010
During your treatment, you might have changed the way you eat to help you cope with nausea and vomiting and changes in your appetite and bowel habits. When treatment ends, it is important to return to a healthy diet. This will help you recover mentally and physically and can also reduce your risk of other health conditions in later life.

It’s not unusual for people to put on more weight than they’d like in the year or so after lymphoma treatment ends. An increase of around 1½ stones is typical. The reason for this weight gain isn’t clear but it’s likely to be a combination of the effects of the cancer itself and changes in diet and activity levels during and after treatment.

You are more likely to put on weight if:

- you had advanced stage lymphoma before treatment
- you had ‘B symptoms’ before treatment
- you had a complete response to treatment.

Changes to your body shape and weight can affect the way you feel about yourself. Speak to your specialist nurse or GP for advice on gaining or losing weight in a safe and healthy way. Ask them what your goal weight should be and how best to reach and maintain this. You could also ask for a referral to a dietitian, who can offer guidance about what to eat to help you reach your goals.

**Hair loss (alopecia)**

If you lost your hair during treatment, it should start to grow back soon after treatment ends. Most people have a full head of hair within about 3–6 months of finishing chemotherapy and 6–12 months of finishing radiotherapy. How quickly it grows depends on several factors, including your ethnicity, the treatment you’ve had and how you responded to it, and your general health.

Your new hair may be slightly different at first – for example, curlier, finer, softer or a different colour. It may also be more fragile than it used to be. As your body recovers from treatment, stronger hair begins to grow. With time, most people’s hair returns to how it was before treatment. For a small number of people, the changes may be permanent.
Caring for your new hair

- Brush your hair gently to avoid damaging it.
- Use a low heat setting on your hairdryer.
- Have your hair cut regularly to remove damaged strands.
- Wait 6–12 months after finishing treatment before you colour, chemically straighten or perm your hair, or have woven-in or glued-in hair extensions.

Blood and bone marrow problems

Lymphoma and treatments for lymphoma can affect your bone marrow. This can lower your red blood cell count (anaemia), white blood cell count (neutropenia) or platelet count (thrombocytopenia).

Bone marrow problems usually recover within about 6 weeks of your treatment finishing but it can take longer, particularly after stronger chemotherapy regimens (combinations of drugs). Your immune system might be lower than usual for several months after cancer treatment.

Low blood counts can increase your risk of developing infections or make you more prone than usual to bruising or bleeding (for example, nosebleeds, bleeding gums or heavier periods). While you’re waiting for your blood counts to recover, there are things you can do to reduce your risk of infection and bleeding.

My hair gradually grew back but was far darker than it used to be.

– Pam, treated for extra-nodal marginal zone lymphoma in 2016

If you feel uncomfortable with changes to your hair, you might want to think about things you could wear. There are many different types and styles of headwear including headscarves, wigs, turbans, hats and headbands.
It is important to have any vaccines your medical team recommends to protect you from infection. You may need to repeat vaccines you’ve already had because cancer treatment can affect your immunity.

Fatigue

Cancer-related fatigue is one of the most common – and troublesome – effects of cancer and cancer treatment. Almost everybody with cancer is affected by it.

Fatigue often lasts for months after treatment has ended. It usually improves gradually. The time it takes for it to get better varies from person-to-person. For some people, fatigue can last a year or more. In a few people, it may persist for several years, although it usually gets less troublesome over time. For some, energy levels might never be quite the same as they were before.

Fatigue can be very distressing but there are lots of strategies you can try to help you cope with it.

If you have fatigue that starts or gets worse months after treatment, tell your medical team.

Problems with memory and confusion (‘chemo brain’)

‘Chemo brain’ describes changes in memory, thinking processes and concentration that affect some people with cancer. Despite its name, it doesn’t only affect people who have had chemotherapy.

For some people affected by ‘chemo brain’, the effects only last a few weeks. Most people get better between 6 months and 2 years after finishing treatment. However, about a third of people have symptoms that last longer, sometimes for many years. If you are affected by ‘chemo brain’ there are lots of strategies that can help you cope with symptoms.
Numbness and tingling

Some treatments for lymphoma can affect your nerves, causing pain, loss of sensation and tingling, often in the hands and feet. This is known as **peripheral neuropathy**.

For some people, peripheral neuropathy gets better within a few days of finishing treatment. For others, it takes longer. Symptoms usually get better within 6–12 months but they can last longer. For a small number of people, peripheral neuropathy doesn’t go away.

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It was around 6 months before I started to get sensation back. In fact, it hadn’t been painful when it was numb, but as it was improving I started to feel pain. This lasted for about 2–3 months.

— Pam, treated for extra-nodal marginal zone lymphoma in 2016

If you have peripheral neuropathy, talk to your medical team about **medicines that can help**. There are also **things you can do yourself** to help you cope with symptoms and avoid any injuries due to the lack of feeling in your fingers or toes.

Early menopause

For some women, lymphoma treatment causes **early menopause**. If this happens, you may have menopausal symptoms such as hot flushes, fatigue, weight gain, vaginal dryness, sleep problems and irritability.

Speak to your GP if you think you may be experiencing early menopause. There are **treatments** that can reduce your symptoms and prevent long-term effects. There are also **things you can do yourself** to help you cope.
Symptoms to look out for

It is natural to worry about your lymphoma coming back (relapsing) after treatment and people often feel anxious in the lead-up to their follow-up appointments.

If lymphoma relapses after treatment, it usually causes signs and symptoms. These might be the same as before but they can be different. Lumps might appear in the same place or they can develop in new places. Sometimes more general symptoms (fevers, night sweats or itching for example) start up again or start for the first time. Symptoms of relapse also depend on what type of lymphoma you had before. Your doctor should tell you what to look out for after your treatment ends.

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

- enlarged lymph nodes (appearing as lumps in your armpit, neck or groin for example)
- drenching night sweats
- unexplained weight loss
- worsening fatigue
- itching
- rashes (if you have a skin lymphoma)
- diarrhea
- persistent or unexplained pain.

If anything is worrying you between your appointments, let your medical team know. They should be able to reassure you or offer you an earlier appointment if necessary.
Late effects of 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


Further reading

- The emotional impact of lymphoma
- Side effects of lymphoma treatment
- Late effects of lymphoma treatment
- What happens if lymphoma relapses?
- Follow-up appointments
- Exercise
- Diet and nutrition
- Glossary

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