

Lymphoma and the end of life

This information page is about what you might experience in the final stages of life when you have advanced lymphoma. Please note that you may find this information distressing.

On this page

[How do I know when to end active treatment?](#)

[Can I enter a clinical trial?](#)

[How do I tell friends and family I'm no longer receiving active treatment?](#)

[How much time do I have left to live?](#)

[How does lymphoma lead to the end of life?](#)

[What symptoms might I have as I approach the end of life?](#)

[How will I feel emotionally?](#)

How do I know when to end active treatment?

Deciding to end active **treatment** is deeply emotional and personal. Although people close to you might offer their views, the final decision is between you and your **medical team**. In some cases, doctors may not be able

to offer any further treatment. This might be because the lymphoma is not responding to treatment, or because you are not well enough to tolerate further treatment.

Throughout your treatment, you should be offered **palliative care** to maintain your quality of life. ('Palliative' comes from the word to 'palliate', which means to relieve or to lessen suffering.) If there is no further treatment for your lymphoma, your medical team should continue to offer you palliative care. The type of palliative care you receive depends on your needs and wishes. It often includes pain relief and symptom control. Your care should be holistic, which means that any physical, practical, social, emotional and spiritual needs you have are addressed.

There are many factors to consider when deciding whether to continue with active treatment for your lymphoma.

Is further treatment likely to work?

The treatment is less likely to work each time your lymphoma relapses (returns). The lymphoma cells can become resistant to treatment. This means that remission (reducing or ridding your lymphoma) might only last for a short time before you relapse again. Your doctors carefully consider whether further treatment is likely to work.

What are the risks of further active treatment?

Further treatment often means using stronger treatments. Unfortunately, as well as acting on the lymphoma, these treatments may pose significant health risks. Some treatments can be life-threatening if you are frail or have other health problems.

The **side effects** of stronger treatments can be severe. They might make you feel very unwell and stop you from enjoying the things that matter to you. Many people choose a better quality of life over a longer life. This means different things to different people, so it's important to think about your own priorities.

You and your medical team should weigh the potential risks and benefits of having further treatment. People often think about things they're looking forward to (eg a wedding). They base their decision on what is likely to help them feel as well as possible to enjoy the time they have left.

Deciding to stop active treatment does not mean that you are giving up. For many people, it is a choice to live their final days as comfortably and feeling as well as possible.

Can I enter a clinical trial?

When there is no further treatment for your lymphoma, you may wonder whether a clinical trial could benefit you. Clinical trials are medical research studies involving human volunteers. **Clinical trials** for lymphoma often test a new treatment, or how existing treatments could be used differently.

Only a small proportion of people with lymphoma are treated as part of a trial. There are lots of reasons for this. There are only a limited number of trials running at any time. Trials have strict eligibility criteria to make sure participants are safe and that the results are scientifically valid. There is not a suitable trial for everyone at any given time.

Finding out that there are no suitable trials can be distressing. You might feel that you have nothing to lose and wish to participate in a trial even if you do not meet its eligibility criteria. Please remember that your doctors cannot enter you into a trial unless you meet the criteria. Talk to your medical team about your options if there isn't a trial you can take part in.

How do I tell friends and family I'm no longer receiving active treatment?

It can be tough for the people around you to hear that you have decided to end active treatment. They might find your decision hard to accept and may try to change your mind. Be honest with them about your decision-making

process so that they can see how you have reached your decision. If you wish, you could also ask your doctor to be with you to help explain. Although the conversation may be difficult, open communication can help to avoid misunderstandings and further distress.

How much time do I have left to live?

Your doctors may be able to give you an idea of how much time you can expect to live. They base this on the **type of lymphoma** you have, how fast it is growing and how it affects your vital organs (brain, heart, liver, kidneys and lungs).

Even with all this information, nobody can say for certain how long you have left. Many people choose to take a day at a time, enjoying the time they have left as much as possible.

How does lymphoma lead to the end of life?

There are a number of things that can happen to your body as you come towards the end of your life. Usually these changes happen because of the impact lymphoma has on your organs and the effects of advancing cancer on your body overall. Gradually, your body slows down and loses its function. Death from lymphoma is usually comfortable and peaceful.

When lymphoma involves a particular organ, it can stop that organ from doing its job. The problems you develop depend on which parts of your body have lymphoma involvement. We outline some possible changes to your body that you might experience in the final days of your life. Please remember it is difficult to predict exactly what will happen to you.

Bone marrow failure

Lymphoma often involves the bone marrow. Lymphoma can cause death when it affects the bone marrow to such an extent that you are unable to make new blood cells.

- **Neutropenia: shortage of white blood cells increases your risk of infection.**

It is quite common for people with severe bone marrow disease to die from an infection (eg chest infection). Severe infection in 1 part of the body can lead to infection in the blood. When this happens, you might lose consciousness.

- **Anaemia: shortage of red blood cells prevents your organs from getting enough oxygen to function properly.** It can cause shortness of breath, weakness and **fatigue**.

- **Thrombocytopenia: shortage of platelets increases your risk of bleeding and bruising.** Bleeding can happen internally (inside your body, eg bleeding in your gut) as well as externally. Internal bleeding can cause serious complications and can be fatal. Thrombocytopenia may also increase your risk of bleeding in the brain, which can cause stroke.

To help you stay active and comfortable when your bone marrow is not functioning well, your doctors might offer you blood transfusions.

Chemical imbalance

You need a fine balance of salts and chemicals in your bloodstream to function properly. When you are well, your body regulates the levels, so that they are just right.

Advanced lymphoma can disrupt this fine balance. Tissues affected by lymphoma may produce abnormal levels of chemicals and waste products. Normally, the liver and kidneys cope with excess levels of chemicals by removing waste products. If lymphoma stops these organs from functioning as they should, it can lead to an imbalance of chemicals.

High levels of chemicals in the bloodstream often lead to a lower level of consciousness. You might feel confused, disoriented and drowsy. Your responses to things around you (such as noise, light and people around you) may become slow or stop entirely.

Increased salts and chemicals can also stop your organs from working properly. Hypercalcaemia (high levels of calcium in the blood) is a common problem for people with advanced cancer. It can lead to confusion and agitation. In some cases, it can stop your heart from beating regularly and lower your blood pressure.

Involvement of other organs

The symptoms you experience depend on which organs your lymphoma involves (affects).

If lymphoma involves your lungs, you are likely to have difficulties breathing. You also have an increased risk of chest infection, which can be difficult for your **immune system** to shake.

With liver involvement, the amount of healthy tissue in the liver progressively lessens. This stops your liver from doing important tasks such as: removing toxins from your blood; making the proteins needed to help blood clot; regulating your blood sugar levels; and producing bile, which is needed to digest food.

Liver disease can cause a range of problems, including:

- **nausea** (feeling or being sick)
- lowered appetite
- decreased levels of consciousness
- abdominal (stomach) swelling and discomfort
- jaundice (which makes your skin and the whites of your eyes look yellow)
- increased risk of bleeding
- fluctuating blood sugar levels.

Other organs may be affected by enlarged (swollen) lymph tissue pressing against them. As the tissue presses on your body tubes, it can cause blockages and pain. For example, pressure on the oesophagus (food pipe) can block the passage of food; pressure on blood vessels can block the passage of blood; pressure on the kidneys can block the passage of urine.

Hyperviscosity (thickness of blood)

'Viscosity' refers to the flow or thickness of blood. In advanced lymphoma, abnormal proteins produced by the lymphoma cells can cause hyperviscosity (thick blood). Dehydration worsens hyperviscosity.

If your blood is too thick, it can have difficulties passing through small blood vessels. This can lower the blood supply to organs such as your brain. When you don't get enough blood to your brain, you can have symptoms including:

- drowsiness or confusion
- headache
- blurred vision
- dizziness and
- loss of control over movements.

Hyperviscosity can also cause problems with the blood supply to your heart, making your heart beat irregularly.

Inability to close your eyes

As your muscles weaken towards the end of life, you may lose your ability to close your eyes. Your eyes may stay open even when you sleep. Should this happen, your eyes can be closed for you and gently lubricated to reduce dryness.

What symptoms might I have as I approach the end of life?

Your symptoms at the end of life depend on which of your organs are affected by lymphoma. You might also experience some of the more general symptoms. Your medical team can advise on how to cope with these symptoms.

Itching and sweats

Itching and drenching sweats (common [symptoms of lymphoma](#)) may worsen over time. You may be given a cream to alleviate the itching. To help

with sweats, you might be given a fan and, in some cases, medication.

Weight loss

Weight loss can happen because the lymphoma is using up your energy supplies. Loss of appetite also often contributes to weight loss.

Loss of appetite

Losing your appetite is very common towards the end of life. Nutrition becomes less valuable to you as your body gradually loses the ability to absorb food and turn it into energy. As well as losing weight, you are likely to feel weaker and less able to concentrate. You may not want to eat or drink, especially if food makes you feel nauseous or if swallowing is painful.

If it is appropriate, your medical team may offer you special drinks and feeds. Your mouth may become dry because you are not drinking; if this is the case, your carers can help you stay comfortable by moistening your mouth and lips.

Fatigue and drowsiness

As you near the end of your life, you have less energy and need more rest. Even following or holding a conversation can be tiring.

Lymphoma uses a lot of your body's energy and resources. It can also stop your organs from getting the oxygen they need to function properly. This can lead to drowsiness and fatigue. In addition:

- chemical imbalances can lead to lowered levels of consciousness
- **anaemia** and infections can cause fatigue
- medication, eg pain relief or anti-anxiety tablets, may contribute to weakness and fatigue.

You are likely to become increasingly drowsy and spend more and more time sleeping. It might be difficult to wake you. In the final hours of your life, you may lose consciousness. You will probably continue to hear people around you and be able to feel their touch. Your loved ones can talk to you, be near to you and hold your hand.

Shortness of breath

Some people become short of breath or find it more difficult to breathe in the final weeks of life. This can be caused by anaemia limiting the amount of oxygen your tissues and organs get. To make up for this, you breathe harder.

Breathing difficulties can also be caused by lymphoma in the lungs, or the surrounding area. Your doctor can arrange for equipment (eg an oxygen cylinder) to help you breathe.

In the final days of your life, your breathing may become more noisy or irregular. This can happen because of the build-up of fluid in the throat. Your medical team can give you medication to help clear your throat. It can also happen as your throat muscles begin to relax.

Confusion and agitation

You may become confused and agitated as you approach the end of your life. There are various possible reasons for this, including chemical imbalances in the blood and the effects of certain medicines.

Your medical team should offer you medication and support to help you feel calmer, depending on why you feel confused or agitated.

Withdrawal and loss of interest

As your energy levels lower, you may lose interest in what is going on around you. Some people are less keen to see family and friends. You might find it easier to see an individual person at a time.

Circulation

Your blood circulation gradually slows down towards the end of life. When this happens, you are more sensitive to cold temperatures. Your hands and feet might feel cold. The skin on your face, hands, feet and legs might look pale, slightly blue and blotchy. Extra blankets or heat pads can help to keep you warm.

Incontinence (loss of bladder and bowel control)

You may lose control of your bladder and bowel. This is very common in the final stages of life. Your nurses may be able to provide pads to keep you comfortable and to protect your clothing and bed linen. Some people have a catheter fitted (a soft tube put into the bladder to drain urine away).

As you gradually eat and drink less, your body has less waste to remove. Incontinence becomes less of a problem. In the final hours of life, your kidneys stop making urine.

Pain

You may have pain in the last weeks of your life. Whether it happens depends on which areas of your body are affected by lymphoma and what damage it causes.

Your medical team should do all they can to lessen your pain. There are many medications they can offer, either on their own or in a combination. If a pain relief medicine is not effective, let a member of medical staff know, so they can try another. Morphine is the most common drug used to treat pain in cancer. It can also help with other problems, such as difficulty breathing.

How can my medical team help me?

Your medical team should offer you and your family support as you move towards the end of your life. They can provide information and answer questions. They can also offer pain relief and **palliative care** to help you to live comfortably in your final days.

The Department of Health (DoH) aims to support people in making decisions about their care and to end the variation in end of life care by 2020. They have recently published their key commitments, to:

- offer opportunities for honest discussions
- enable people to make informed decisions about their care
- provide personalised care plans for all

- allow discussion of personalised care plans
- involve family members and carers
- provide a main contact for people at the end of their life, available day and night.

You can read more about the DoH's commitments in their paper [Our commitment to you for end of life care](#).

How will I feel emotionally?

There is no 'normal' way to feel; the end of life is a very personal experience. How you feel depends on various factors. These might include your personality and outlook on life, your background, whether you are a religious or spiritual person, and how satisfied you feel with the life you have lived.

In 1969, Elizabeth Kübler-Ross, a Swiss psychiatrist, wrote a book called *On death and dying*. She spoke to over 200 people at the end of their life about how they felt. Kübler-Ross found that many people share common feelings and observed that these often occur in a pattern. Over the years, Kübler-Ross's ideas have received widespread support.

You might experience some, or perhaps all, of the following feelings. They don't have to occur in any particular order.

If you are close to someone who is dying, you are likely to experience a range of powerful emotions too. You may move back and forth between them, or skip some entirely. Some days, you might have several emotions all at once, which can feel overwhelming.

Shock

Even if you have had lymphoma for a long time and you know your treatment has not worked, it can still be a shock to hear that you will die from your illness. You may feel bewildered and unable to take information in. You might feel numb at first and feel very little. People around you may say that you seem very calm. Some people busy themselves with making

practical arrangements when they are in shock, rather than considering how they feel emotionally.

Denial

Denial is very common. You may refuse to accept that you will soon die. However, you may be processing this information at a deeper level of consciousness. For example, you might talk about going on holiday next year, but make no booking arrangements.

Regardless of how many people are around you, you are likely to feel isolated. You might push away the people who are close to you while you try to deny what is happening.

Denial can be a useful defence to protect you from feeling emotionally pained and overwhelmed. It can help you to enjoy today without worrying about the future. However, it can also make it difficult for you and others to make preparations or to talk about things that are important.

Denial is not a state to be rushed or 'snapped' out of; you move beyond it when you are ready.

Anger

Anger is a common response to anxiety, fear and loss. As well as feeling angry about the impending loss of your life, you might feel angry about other things that have happened in the past. You might feel envious of the people around you who will continue to live after you die, for example family members and health professionals.

Bargaining

Some people try to strike bargains with a higher power, such as a god or the universe. This can take the form of 'deals' eg 'if you let me recover, I will lead a healthy life'. Similarly, some people have 'if only' thoughts eg 'if only I'd gone to the doctor sooner, I might not be in this situation'. These thoughts can be a way of trying to take control over a situation that is, ultimately, beyond anyone's control.

Grief and sadness

In Western cultures, grief and deep sadness are strongly associated with death. You are likely to experience these emotions for yourself as well as for loved ones. Sadness is natural as you approach the end of life. It can help you accept your situation. Some people might also have episodes of **depression**.

Acceptance

Not everyone reaches acceptance about the end of life. The people close to you might not reach it until a long time after you're gone. Some people do, however, reach a point of acceptance. This can help to free you from fear and allow you to die peacefully.

Further information and support

We have listed a few national organisations that you might find useful if you, or a loved one, are reaching the end of life. You may also wish to use our online forums to get in touch with others affected by lymphoma. Your nurse specialist is a good person to ask about any local organisations that may be useful to you. You can also call our helpline on 0808 808 5555 for help with finding support in your area or if you wish to talk through any aspect of lymphoma.

Carers UK offer support, advice and information for anyone who is caring for someone with an illness or disability.

Cancer Research UK has more information about the physical and emotional changes that can happen at the end of life.

Dying Matters is a coalition of members across the UK that aims to help people talk openly about dying, death and bereavement, and to **make plans for the end of life**. They have **a range of resources** and **information** on their website.

Hospice UK is a national charity that supports the work of hospices across the UK. Their website includes an **online search tool** to help you find a

hospice near to you.

Macmillan Cancer Support offer a range of information and support, including to **help support you at the end of life**.

Maggie's Centres provide practical, emotional and social support for people with cancer and their families and friends. They have a number of **centres across the UK** as well as an online community.

Marie Curie Cancer Care support people with a terminal illness and those close to them. Their website includes an online **directory of support** to help you find appropriate support.

References

These are a few of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at publications@lymphoma-action.org.uk or phone on 01296 619409 if you would like a copy.

- Payne S, Seymour J, Ingleton C, (eds). Palliative Care Nursing: principles and evidence for practice. 2004. Oxford University Press: Oxford.
- Bailey MD and Harman SM. Up-to-date 2016. Palliative care: The last hours and days of life. Available at: www.bit.do/last-hours (Accessed July 2016).
- Lee, DH. Approach to end of life care. The Ochsner Journal, 2002. 4: 98–103. Available at: www.bit.do/approach-end-life (Accessed July 2016).
- National Institute of Health and Care Excellence (NICE). Care of dying adults in the last days of life. Available at: www.bit.do/NICE-end-life (Accessed July 2016).

Further reading

- [Glossary](#)
- [Lymphoma and palliative care](#)
- [Your medical team](#)
- [Managing stress](#)

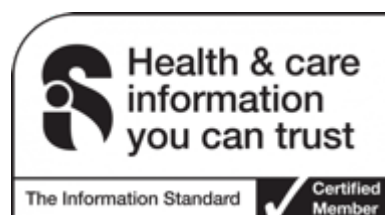
Acknowledgements

- We would like to thank the Expert Reviewers and members of our Reader Panel who gave their time to review this information.
-

Content last reviewed: September 2016

Updated: April 2018

Next planned review: September 2019



© Lymphoma Action