

Lymphoma and the end of life

This information is about what someone with lymphoma in the final stages of life might experience. You might be reading it because doctors have said that you, or someone you love, is nearing the end of life. We give suggestions to help you get practical, social and emotional support.

We also have information about **bereavement, loss and grief**, if you, or someone close to you, is nearing the end of life.

You might find this information emotionally difficult to read. Our **Information and Support Team** 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.

Stopping active treatment for lymphoma

Stopping active treatment for lymphoma can be a difficult decision and deeply emotional.

In some cases, doctors are unable to offer further treatment. This could be because the lymphoma does not respond to treatment (**refractory lymphoma**), or you might

not be well enough for more treatment. There are also instances where the person with lymphoma decides they do not wish to have any more treatment.

From the point of diagnosis onwards, you should be offered symptom and pain relief. This is known as '**palliative care**' and it is separate to active treatment given to **treat your lymphoma**.

Factors in considering whether to have further treatment

There are many things to think about when deciding whether or not to have more active treatment. Your medical team considers **lymphoma-specific factors** and **personal factors**.

Lymphoma-specific factors

- the **type** and **stage** of your lymphoma
- how fast your lymphoma is growing
- the size of any lumps of lymphoma
- which parts of your body are affected by lymphoma
- how your body reacted to treatment in the past
- your **symptoms**
- results of **genetic tests** – these can be useful with some types of lymphoma and can help guide your doctor on the suitability of treatments for you.

Personal factors

- your age and general health, including any **other medical conditions** you have
- any medication you are taking
- the support you have available to you at home from the people around you, such as family members, friends and neighbours
- anything else that is important to you – talk to your medical team about any other factors you'd like them to think about.

You can read more about **what to expect from end of life care** on the NHS website.

You might also be interested in reading about the **Government's commitment to end of life care**. In this, they say that people nearing the end of their life should be able to:

- have honest discussions with care professionals about their needs and preferences
 - make informed choices about their care
 - develop and document a personalised care plan
 - discuss their personalised care plans with care professionals
 - involve their family, carers and those important to them in all aspects of their care as much as they want
 - know who to contact for help and advice at any time.
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Whose decision is it for me to stop active treatment?

The decision as to whether to have or continue active treatment for lymphoma should be yours. Your medical team can advise you about **whether further treatment is likely to work**. Together, you and your medical team should discuss the potential risks and benefits of further treatment.

When deciding whether to have further treatment, some people think about things they're looking forward to, for example, a family wedding. They base their decision on what is likely to help them feel as well as possible for the rest of the time they have left to live.

Lasting power of attorney

You might have a **lasting power of attorney** (LPA) – a legal document that sets out one or more people ('attorneys') that you have chosen to help you make decisions. Anyone can be an attorney – they do not need to have legal experience. Usually, an attorney is a family member or close friend. There are two types of LPA: **health and welfare** and **property and financial**. Your attorneys can also make decisions on your behalf if you become too unwell to do so yourself.

Advance decisions and advance statements

Some people choose to write an **advance decision** ('living will'). This allows you to list treatments you would or wouldn't want to have in the future. It is useful in case you become unable to communicate your preferences at the time that you need to. You can also set out any wider preferences about your care by making an **advance statement**. This can include anything that's important to you, for example, how you

like to dress or what music you enjoy listening to. You can find out more about [Advance Care Plans](#), including answers to frequently asked questions.

In some parts of the UK, there is a [Message in a Bottle scheme](#) where you keep important information about yourself and your lymphoma on a form. You keep this in a small plastic bottle, usually in your fridge – members of the emergency services know to check there for it.

You can read more about [choice in end of life care](#) on the UK Government's website.

Is further active treatment likely to work?

Your medical team are best-placed to talk through with you whether treatment is likely to help you.

In general, treatment is less likely to work each time lymphoma comes back ([relapses](#)). The lymphoma cells can become resistant to treatment. This means that reducing or getting rid of your lymphoma ([remission](#)) might work only for a short time, or not work at all.

When might further treatment not be suitable?

Further treatment often means using stronger treatments. The [side effects](#) of stronger treatments can be severe and can make you feel very unwell. Some treatments could be life-threatening if you are physically weak or have other health problems. Doctors are not allowed to give you such treatments if they are likely to make you more unwell.

You might have stretches of time in hospital that stop you from enjoying the things that matter to you. Many people choose a higher quality of life over a longer life. This is a highly personal choice. It means different things to different people, so it's important to give thought to your own priorities.

How does lymphoma lead to the end of life?

We outline some possible changes to your body that you might have in the final days of your life in this section. You might have some, all or none of these – nobody can predict exactly what you will experience. Please note that you might find this information upsetting to read.

There are a number of things that can happen to your body as you near the end of your life. The problems you develop depend on how aggressive the lymphoma is and which parts of your body it affects. When lymphoma affects a particular organ, it can stop that organ from doing its job.

These changes usually happen because of the impact lymphoma has on your organs and because of how cancer affects your body overall. Gradually, your body slows down and stops functioning as it should. You might have less energy, lose weight and spend more time sleeping.

As you near the end of life, you might experience:

- **bone marrow failure**
- **imbalance of chemicals**
- **lymphoma involvement of other organs**
- **hyperviscosity (thickness of blood).**

Bone marrow failure

Lymphoma can affect the **bone marrow**, where blood cells are made. This can affect your ability to make new blood cells, leading to complications such as:

- **Infection:** a shortage of white blood cells (**neutropenia**), heightens your risk of **infection**. It is quite common for people with severe bone marrow failure to die from an infection, for example a chest infection. If the infection gets into your bloodstream (**sepsis**), you could lose consciousness. Sepsis can lead to multiple organ failure and death.
- **Shortage of oxygen to your organs:** a shortage of red blood cells (**anaemia**) can stop your organs from getting enough oxygen to function properly. This can cause shortness of breath, weakness and **fatigue**.
- **Bleeding and bruising:** a shortage of platelets (**thrombocytopenia**) increases your risk of bleeding and bruising. Bleeding can happen from inside your body, such as your gut (internal bleeding) as well as from the outside of your body (external bleeding). Internal bleeding can be very serious and lead to death. Thrombocytopenia can also increase your risk of bleeding in the brain. If this affects the blood supply to your brain, it 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**. These replace some of the blood cells that your bone marrow can no longer make. However, these replacement

cells work only for a short time. Although it might be possible to have more transfusions, there are potential risks and complications of having them.

Imbalance of chemicals

When you are well, your body regulates the levels of salts and chemicals in your bloodstream, to keep them in balance.

Advanced lymphoma can disrupt this balance. Tissues affected by lymphoma can produce abnormal levels of chemicals and waste products. Normally, your liver and kidneys cope with excess levels of chemicals by removing waste. 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 lowered consciousness. You might feel confused, disoriented and drowsy. Your responses to things around you (such as noise, light and people) might slow down or stop entirely.
- **An increase in salts and chemicals** can also stop your organs from working properly. High levels of calcium in the blood (**hypercalcaemia**) is a common problem for people with advanced cancer. It can cause confusion and agitation. In some cases, it stops your heart from beating regularly and can lower your blood pressure, which might lead to loss of consciousness (fainting).

To help reduce the symptoms of hypercalcaemia, you might be given fluids into a vein (intravenously). Your doctors might offer you a drip (infusion) of the drug bisphosphonate. This helps move the calcium in your bloodstream back into your bones.

Involvement of organs

The symptoms you have depend on which parts of your body your lymphoma affects, for example, your **lungs**, **liver** or **other organs**.

Lymphoma that affects the lungs

If lymphoma affects your lungs, you are likely to have difficulties breathing. You also have an increased risk of getting a chest infection, which your **immune system** might struggle to fight off.

Lymphoma that affects the liver

Lymphoma in your liver can affect how much healthy tissue you have in your liver. This stops your liver from doing important jobs such as:

- removing unwanted or waste products from your blood
- making the proteins needed to help blood clot
- regulating your blood sugar levels
- producing bile, which you need to digest food.

If your liver is not functioning well, it can cause a range of problems, including:

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

Lymphoma that affects other organs

Other organs can be affected by swollen (enlarged) lymph tissue pressing against them. As the tissue presses on parts inside your body, it puts pressure on them. This can cause blockages and pain.

For example, pressure on the:

- food pipe (oesophagus) can block the passage of food
- blood vessels can block the passage of blood
- kidneys can block the passage of wee (urine).

Doctors can offer **palliative treatment** to lessen these symptoms. Very often, **steroids** are part of this.

Hyperviscosity (thickness of blood)

'Viscosity' means the flow or thickness of blood.

Although unusual, hyperviscosity can result in death. However, in some types of lymphoma, the lymphoma cells make unhealthy proteins (paraproteins) that can cause your blood to become thicker (hyperviscosity). If you are dehydrated, this makes hyperviscosity worse.

Blood that is too thick has difficulty flowing through small blood vessels. This can affect the functioning of your heart. It can also lower the blood supply to organs, such as your brain. When you don't get enough blood to your brain, you might have symptoms such as:

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

You might experience bleeding to the back of the eye, heart attack or stroke.

In extreme cases of hyperviscosity, you might be offered plasma exchange (**plasmapheresis**).

Symptoms towards the end of life

Your symptoms at the end of life depend on which of your organs are affected by lymphoma. Some of these are outlined in the section about **how lymphoma can lead to the end of life**.

General symptoms of lymphoma might worsen over time. You might also experience some or all of the following:

- **loss of appetite**
- **fatigue and drowsiness**
- **changes in breathing**
- **confusion**
- **withdrawal and loss of interest**
- **feeling cold**
- **loss of bladder and bowel control (incontinence)**
- **pain**
- **inability to close your eyes.**

Loss of appetite

A lowered appetite is very common towards the end of life. Nutrition becomes less valuable as your body gradually becomes less able to absorb food and turn it into energy. As this happens, you lose weight, feel weaker and less able to concentrate.

You might not want to eat or drink if your appetite is lowered, if food makes you feel sick (nauseous) or if swallowing is painful. In some cases, your medical team might offer you drinks and food through a drip. This helps to prevent discomfort caused by dehydration, thirst, dry mouth or eyes.

Your mouth can become dry when you are not drinking. If this happens, the people looking after you can help you stay comfortable by helping you to take sips of water. They can also protect your lips with a lip balm or dab your mouth with a damp sponge. In some hospitals, doctors might offer ice chips to suck on to help with hydration.

Fatigue and drowsiness

Lymphoma takes up a lot of your body's resources. Towards the end of your life, you have less energy and you need more rest. It can become difficult to do the things you once found easy, such as focussing on a conversation.

Lymphoma can cause drowsiness and fatigue by:

- causing a **shortage of oxygen to your organs**
- causing an **imbalance of chemicals**
- causing a shortage of red blood cells (**anaemia**)
- stopping your body from fighting infections.

Side effects of medication, such as pain relief medicines, anti-sickness medicines (anti-emetics) and anti-anxiety tablets, can add to weakness and fatigue.

You are likely to become more drowsy as time goes on. As you spend more time sleeping, it might also become difficult to wake you. In the final hours of your life, you are likely to continue to hear people around you and be able to feel their touch, but you might lose full consciousness.

Changes in breathing

You might become short of breath or find it more difficult to breathe. Your breathing might also become noisy (sometimes known as 'rattling').

Anaemia can cause breathing changes by limiting the amount of oxygen your tissues and organs get. To make up for this, you breathe deeper and faster, which takes more effort and can make you feel more tired.

Lymphoma in your lungs or the surrounding area can also cause breathing difficulties. You might be offered an oxygen cylinder to help you breathe more easily if your oxygen levels in your blood are too low. In the final days of your life, your breathing might become louder or irregular. This can happen as your throat muscles start to relax. It can also happen as it becomes harder for you to re-absorb or swallow the normal fluids in your chest or throat, causing a build-up of fluid in your throat. At this stage the dying person is unaware, but it can be distressing for relatives to see and hear this change in breathing.

Your medical team can give you medication to help clear your throat. In some cases, you might be offered **morphine** to help with breathlessness.

Confusion

You might become confused and restless as you near the end of your life. Some people also experience hallucinations (seeing or hearing something that isn't really there). This can happen for a number of reasons, including **chemical imbalances** in the blood and side effects of some medicines.

Your medical team should offer you support based on the reasons for your confusion and agitation. They might offer medication to help you feel calm.

Withdrawal and loss of interest

As your energy levels become lower, you might lose interest in the people and things around you. You might find it easier to see one person at a time.

Feeling cold

Your blood circulation gradually slows down towards the end of life as your heart works less efficiently. 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. The people caring for you can give you extra blankets or heat pads to help keep you warm.

Loss of bladder and bowel control (incontinence)

It is very common to lose control of your bladder and bowel in the final stages of life.

Your nurses can give you pads to keep you comfortable and to prevent your skin from irritation and to protect your clothing and bed linen. Some people have a catheter fitted, a soft tube put into your bladder to drain away wee (urine). In severe cases of diarrhoea, a rectal tube might be fitted into your back passage to take away excess waste.

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

Pain

You might feel pain in the last weeks of your life. This depends on which areas of your body are affected by lymphoma and how it affects them.

Your medical team will do all they can to ease your pain. There are many **palliative medications** they can offer, either on their own or in a combination. If the pain relief medicine you are given is not effective, if you are able to, you can let a member of medical staff know so they can try another. **Morphine** is the drug most often used to treat pain in cancer.

If you are too unwell to communicate, your doctors should be able to tell that you are in pain or distress – they can do this through measuring your pulse or blood pressure, or checking for signs of restlessness or discomfort.

Inability to close your eyes

As your muscles become weaker, you might not be able to close your eyes. Even when you are asleep, your eyes might stay open. The people caring for you can gently close your eyes for you. They can be moistened with a soft, damp cloth to keep them free from waste and crust and to reduce dryness. Artificial tears, given as drops into your eye, can also be effective in reducing dryness.

FAQs about lymphoma and the end of life

Each person has their own, unique **feelings and questions about the end of life**. We address some of the questions people often ask below.

How will I feel emotionally towards the end of my life?

There is no 'normal' way to feel at the end of life – it is a very personal experience. How you feel can depend on various things. This might include, for example, whether you are in pain, your personality and outlook on life, whether you have a religious or spiritual faith, and how satisfied you feel with the life you have had. Having your **physical, social and emotional needs addressed towards the end of your life** can also have a significant impact on how you feel.

You can read more about feelings towards end of life in our separate information about **bereavement and grief**.

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

It can be tough to tell the people you're close to that you are not continuing with active treatment. Some people say that they find it very difficult to cope with the emotions of people close to them, particularly if they seem not want to accept this and try to change your mind. You could explain to them how you reached your decision. They might need to talk about it more than once.

You might find it helpful to talk through what you'll say with your clinical nurse specialist or a member of our **Information and Support Team**. You could also ask your doctor to be there to help explain the situation to those close to you. Although these conversations can be very emotional, **open communication** can help to avoid misunderstandings and further distress. They can give you and the people you love an opportunity to say what you'd like to say.

You might be interested in **Marie Curie's Talkabout online magazine**, which aims to support conversations about death, dying and grief.

Can I enter a clinical trial?

As you near the end of your life, it's unlikely that there will be suitable **clinical trials** for you. Finding out that there are no trials available to you can be distressing. You might feel that a trial would be worth a try and want to take part even if you don't

meet the strict 'rules' for entry (**eligibility criteria**). As difficult as it can be to accept, your doctors cannot enter you into a trial unless you meet the criteria.

How much time do I have left to live?

It might be possible for your doctors to give you a rough idea of how much more time they expect you 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 much longer you will live for. Many people choose to take a day at a time, enjoying the time they have left as much as possible.

Will I be in pain when I die?

Your medical team will do all they can to **lessen any pain** you feel in your final days. No one can say for certain how you'll feel but death from lymphoma is usually comfortable and painless. If you are in pain, however, medication is available to relieve this.

What options do I have about where I die?

There can be a lot to think about in relation to where you want to spend the final hours of your life. You might choose to die at home, or you might prefer to be in a **hospice** or hospital. In some cases, the NHS offer funding towards a care or nursing home as part of their **continuing healthcare scheme**.

Marie Curie has information on **choosing where you would like to be cared for** at the end of your life.

Where can I get the information I need?

Medical professionals are used to giving information and shouldn't mind answering your questions. Don't hesitate to ask them to go over it again or explain it in a different way if this might help. You have a right to understand your situation and to be involved in making decisions about your care and treatment.

You might want to take notes or record consultations to help you remember what's said. Some people find it helpful to take a close friend or family member to appointments to help with this.

If you have any questions about your care, speak to a member of your medical team.

You might also be interested in our useful organisations webpage, which includes [organisations and resources relevant to end of life](#).

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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 or call 01296 619409 if you would like a copy.

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