

## Lymphoma and the end of life

You might be reading this because doctors have said that you, or someone you love, is nearing the end of life from advanced lymphoma. It is about what someone in the final stages of life might experience and gives suggestions to help you get the practical, social and emotional support you need.

You might find this information upsetting. Our Information and Support Team are here to support you.

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## How do I know when to stop active treatment?

Deciding to end active **treatment** can be deeply emotional. You might or might not want to talk to friends and family members about it. Ultimately, the decision is between you and your **medical team**. In some cases, doctors are unable to offer further treatment. This could be because the lymphoma does not respond to treatment, or you might not be well enough for more treatment.

Some people choose to write an **advance decision** ('living will'). This allows you to write down treatments you would or wouldn't want in future, in case you become unable to communicate your preferences at the time that you need to. You are also entitled to 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'd like to dress or what music you enjoy listening to.

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

There are many factors to think about when deciding whether or not to continue with active treatment.

Your medical team considers lymphoma-specific factors, such as:

- the **type of lymphoma** you have and its **stage**
- how fast your lymphoma is growing
- the size of any lumps of lymphoma
- what parts of your body are affected by lymphoma
- your **symptoms**
- results of **genetic tests** – these can be useful with some types of lymphoma and can help guide your doctor on treatment choices.

Your medical team also considers personal factors, such as:

- your age and general health
- any **other medical conditions** you have
- any other medication you need
- the support you have at home
- anything else that is important to you – talk to your medical team about any other factors you'd like them to take into account.

## 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 your lymphoma comes back (**relapses**). The lymphoma cells can become resistant to treatment. This means that reducing or getting rid of your lymphoma (**remission**) might not work, or might last only a short time before you relapse again.

Your doctors carefully consider your specific circumstances and the type of lymphoma you have before they advise whether or not to have more treatment. They should talk you through the reasons for their advice. If you have questions, or you'd like them to explain something again, ask them. They are used to going over information and understand that it's a lot to take in.

## 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 can carry significant health risks. Some treatments could be life-threatening if you are frail or have other health problems.

The **side effects** of stronger treatments can be severe and can make you feel very unwell. You might have stretches of time in hospital that 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 give thought to your own priorities.

Together, you and your medical team should discuss the potential risks and benefits of further treatment. People often think about things they're looking forward to, for example, a wedding. They base their decision on what is likely to help them feel as well as possible for 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 as comfortably and feeling as well as possible towards the end of their life.

## Can I enter a clinical trial?

If your doctors advise that there is no further treatment for your lymphoma, you might wonder whether you could benefit from a clinical trial (medical research study). **Clinical trials** for lymphoma often test a new treatment, or how current treatments could be used differently. Some clinical trials focus on improving quality of life.

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 one time. Each trial has strict **eligibility criteria**. Very often, people who have had another, previous cancer diagnosis cannot be accepted onto the trial. People with very **low blood counts** might also be unable to take part. This is to make sure that the results are scientifically meaningful and also to keep participants safe.

As you near the end of your life, it's unlikely that there will be suitable trials for you. Finding out that there are none available to you can be distressing. You might feel that you have nothing to lose and want to take part even if you don't meet the eligibility criteria. As difficult as it can be to accept, your doctors cannot enter you into a trial unless you meet the criteria.

## How does lymphoma lead to the end of life?

There are a number of things that can happen to your body as you near the end of your life. These changes usually happen because of the impact lymphoma has on your organs and because of how advancing cancer affects your body overall. Gradually, your body slows down and stops functioning as it should.

When lymphoma affects a particular organ, it can stop that organ from doing its job. The problems you develop depend on which parts of your body are affected by lymphoma.

We outline some possible changes to your body that you might have in the final days of your life. 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.

### Bone marrow failure

Lymphoma often involves the **bone marrow**, where blood cells are made. Lymphoma can affect the bone marrow to such an extent that you are unable to make new blood cells. This can lead 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.
- **A 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:** a shortage of platelets (**thrombocytopenia**) increases your risk of bleeding and bruising. Bleeding can be internal (inside your body, such as in your gut), as well as external. Internal bleeding can cause serious complications and lead to death. Thrombocytopenia can also increase your risk of bleeding in the brain. This can cause a **stroke** (a serious medical condition that happens when the blood supply to your brain is cut off).

To help you stay active and comfortable when your bone marrow is not functioning well, your doctors might offer you **blood or platelet transfusions**. These transfusions replace some of the blood cells that your bone marrow can no longer make. However, these cells work for a limited period of time before you need another transfusion.

## Chemical imbalance

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

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 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) 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.

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

## Involvement of other organs

The symptoms you have depend on which organs your lymphoma affects.

### 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 can be difficult for your **immune system** to deal with.

### Lymphoma that affects the liver

If you have lymphoma in your liver, the amount of healthy tissue in your liver 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

- producing bile (needed to digest food).

If this happens, it can cause a range of problems, including:

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

The **palliative treatment** you are offered to lessen these symptoms depends on which organs are affected and how they are affected. Very often, **steroids** are given as a part of this.

### **Hyperviscosity (thick blood)**

'Viscosity' means the flow or thickness of blood. In advanced lymphoma, lymphoma cells produce abnormal proteins that can cause your blood to thicken (hyperviscosity). Dehydration makes hyperviscosity worse.

If your blood is too thick, it has difficulty passing through small blood vessels. This can affect the functioning of your heart and can 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 and

- loss of control over movements.

As well as looking at your symptoms, there are various tests doctors use to diagnose hyperviscosity. One of these is to measure the level of abnormal protein (paraprotein) in your blood. A higher level indicates a higher likelihood of hyperviscosity.

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## What symptoms might I have towards the end of life?

In addition to general [symptoms of lymphoma](#), your symptoms at the end of life depend on which of your organs are affected by lymphoma. You might experience some or all of the following symptoms.

### Sweats and itching

Drenching sweats, fevers and itching (common symptoms of lymphoma) can get worse over time. Your doctors might give you a cream to alleviate the itching and you could try using a fan to help cool you down.

### Weight loss

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

### Loss of appetite

Losing your appetite is very common towards the end of life. Nutrition becomes less valuable as your body gradually loses the ability to absorb food and turn it into energy. As well as losing weight, you will probably feel weaker and less able to concentrate. You might not want to eat or drink, especially if food makes you feel sick (nauseous) or if swallowing is painful. In some cases, your medical team might offer special drinks and feeds.

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 moisten your mouth and protect your lips with a lip balm.

### Fatigue and drowsiness

Lymphoma takes up a lot of your body's resources. Towards the end of your life, you have less energy and need more rest. Even following a conversation can be tiring.

Lymphoma can cause drowsiness and fatigue by:

- stopping your **organs from getting the oxygen** they need
- causing **chemical imbalances**
- 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 increasingly drowsy as time goes on and spend more time sleeping. It might be 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.

## Shortness of breath

Some people become short of breath or find it more difficult to breathe in the final weeks of life. Anaemia can cause this 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.

Lymphoma in your lungs or the surrounding area can also cause breathing difficulties. You might be given an oxygen cylinder to help you breathe more easily. In the final days of your life, your breathing might become louder or irregular. This can happen as your throat muscles begin to relax. It can also happen because of a build-up of fluid in your throat. Your medical team can give you medication to help clear your throat of phlegm.

## Confusion and agitation

You might become confused and agitated as you approach the end of your life. This can happen for various reasons, including **chemical imbalances in the blood** and side effects of certain 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 calmer.

## Withdrawal and loss of interest

As your energy levels become lower, you might lose interest in what's going on around you. Some people are less keen to see family and friends. You might find it easier to see one 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 and 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.

## Incontinence (loss of bladder and bowel control)

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 soft tube put into their bladder to drain urine away (catheter). In severe cases of diarrhoea, a rectal tube might be fitted to take away excess waste.

As you gradually eat and drink less, your body has less waste to remove and so incontinence 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 medications they can offer, either on their own or in a combination. If the pain relief medicine you are given is not effective, let a member of medical staff know so they can try another. **Morphine** is the drug most often used to treat pain in cancer. It can also help with other problems, such as **difficulty breathing**.

## 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. Your eyes can be closed for you gently. 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.

## How can my medical team help?

Your medical team should offer you and your family support as you come towards the end of your life. This includes giving you information and answering any questions you have.

To help you live comfortably in your final days, your medical team might ask **palliative care** colleagues to be involved in your care. Often, these people are based in the community and work closely with your GP. Together, they can support you to live as high a quality of life as possible. They can also offer you and your family **emotional support**.

The Department of Health (DoH) aims to support people in making decisions about their end of life care. They want to make standards in end of life care consistent by 2020. As part of this, they have published their key commitments to make sure that people have opportunities to:

- have honest discussions with healthcare professionals about their needs and preferences
- be able to make informed decisions about their care
- have a personalised care plan
- involve family members and carers in their care plan, if they'd like them to be involved
- get help and advice at any time by being given a main point of contact.

You can read more about the **government's commitment to end of life care** on the GOV.UK website. You can also read an independent report about choice in end of life care (**full review or executive summary**).

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## Your emotions towards the end of your life

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

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 shared common feelings and observed that these often occurred in a pattern. We outline some of these below.

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

Some of the feelings that people have in relation to the end of life are outlined below. You might experience some, or perhaps all of them, though they don't necessarily happen in a particular order.

## **Shock**

Being told that you will die from your illness can be a shock, even if you have had lymphoma for a long time and know your treatment hasn't worked. You might feel confused and unable to take information in. You might feel numb at first and feel very little. People around you might think that you seem very calm.

Shock is a survival mechanism; it is a short-term way of protecting yourself from pain. When people are in shock, they might not be able to give attention to their emotions. Some people instead busy themselves with making practical arrangements.

## **Denial**

Denial is a very common reaction to difficult news. You might not accept that you are coming towards the end of your life. You might, however, be taking in this information at a deeper level, without conscious awareness. For example, you might talk about going on holiday next year, but not make any booking arrangements.

Regardless of whether or not you have people around you, you can still feel very isolated. You might push away the people who are close to you while trying to deny what is happening.

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

Denial is not a state to be rushed or 'snapped' out of. Moving beyond it happens if and when you are ready to do so.

## Anger

Anger is a common response to anxiety, fear and loss. As well as feeling angry about the loss of your life, you might feel angry about other things that have happened in the past. You might feel angry that you've lost control of your life and that you're leaving the people you love behind. Some people feel envious of the people around them who will live on, for example family members and health professionals.

## Bargaining

Some people try to make bargains with a higher power, such as a god or the universe. This can take the form of deals or bargains, such as 'if you let me get better, I will lead a healthy life'. Similarly, some people have 'if only' thoughts, for example: '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

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 and can be a part of accepting your situation.

Some people also have episodes of ongoing low mood (**depression**). Let a member of your medical team know if you feel very low. Palliative care nurses are often trained in **counselling** or can arrange counselling for you through your GP. Some counsellors offer a service where they can visit you at home. If you are in a hospice or hospital, it might be possible for a counsellor to visit you at your bedside.

## Reflections on life

Nearing the end of life is often a time of reflection. If you are the person who is dying, you might think about the way you've lived your life, your interactions with other people, and whether you did all that you wanted to. As a family member or friend, you might reflect on your past and current relationship with the person who is dying. Some people are reminded of their own mortality when someone they love is nearing the end of their life.

## Guilt

Some people feel guilty as they, or someone they love, nears the end of life. If you are the person who is dying, you might think about any regrets you have. If someone close to you is dying, you might think about things you wish you had said or done for the person.

Guilt is a natural, human emotion that can be extremely painful. Try to think about all the things that you have done. If possible, reassure yourself that you did enough and that we make the best decisions we are able to at any given time.

## Acceptance

Some people reach a point of acceptance that they are reaching the end of their life. This can bring a sense of relief and freedom from fear.

Although it's not the case for everyone, some people experience gratitude as they near the end of their life. You might reflect on memories of your life with warmth, fondness and appreciation. You might feel grateful for the people and opportunities you have had and feel a sense of peace.

Not everyone reaches acceptance, however. Close family members and friends might not come to a point of acceptance, or at least not until a long time after a loved one has died.

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## Emotional support

Knowing that you are nearing the end of your life can be extremely hard to cope with. As well as getting support to manage symptoms (**palliative care**), it's also important to get the emotional support you need.

You can speak to your medical team about how you're feeling so that they can offer support. Your clinical nurse specialist is often a good person to approach.

Find ways to **express your feelings**. You could talk with a family member or friend about how you feel. If it feels too hard to talk to people who are close to you, you might prefer to contact our **Information and Support Team**. Some people find it helps to talk to a **counsellor**, who's trained to help you explore your thoughts and feelings. If you are able, art and music can also be an outlet for your feelings.

You might also find the following resources helpful:

- Cancer council NSW is an Australian charity that supports people affected by various types of cancer. Their website has information about end of life. They also produce a booklet called *Facing end of life: A guide for people dying with cancer, their families and friends*, which is free to download. It covers practical and emotional aspects of nearing the end of life, as well as common questions that people often have about dying and how to tell others the news.
- Cancer Research UK lists support you might be able to access to **help you if you are dying with cancer**.
- **Compassion in dying** has information to help you prepare for the end of life, including talking about it, planning and recording your wishes.
- Dying Matters is a coalition of organisations. It aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life. Their website has a series of **podcasts about death and dying**.
- Healthtalks.org has videos where people share their **personal experiences of living with a terminal illness**.
- Macmillan Cancer Support produce *End of life: a guide. A booklet for people in the final stages of life, and their carers*. You can download this for free as a PDF, e-book or audiobook.
- Maggie's Cancer Centres offer free practical, emotional and social support to people affected by cancer. You can find your nearest centre by using their **online search tool** or on their **online centre**. They also have section on their website that signposts to **sources of support towards end of life**.
- Marie Curie offers care and support through terminal illness. Their website has information about **what to expect at the end of life**, and **emotional experiences and concerns**.

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## 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 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. They might not want to accept this and try to change your mind. Some people say that they find it very difficult to cope with the emotions of those close to them. Try to help them understand 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.

## How much time do I have left?

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, though, 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 do have 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 to help you choose **where you would like to be cared for** at the end of your life.

## Where can I get the information I need?

Your medical team can give you information and answer any questions you have. Don't be afraid to ask for the same information again if you can't remember it all or didn't understand the first explanation. Medical professionals are used to giving information and shouldn't mind answering your questions. You have a right to understand your situation and to take an active part 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 relative or a friend to appointments to help with this.

If you have any questions about your care or treatment, get in touch with your medical team. If you are unable to find their contact details, call the hospital switchboard and ask for a member of your medical team.

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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).

## 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.

## Acknowledgements

- Charlotte Bloodworth, Lymphoma Nurse Specialist, Cardiff and Vale NHS Trust.
- Claire Tune, Lead Counsellor, Phyllis Tuckwell Hospice Care.
- Lymphoma Action Information and Support Team.
- We would like to thank the members of our Reader Panel who gave their time to review this information.



Content last reviewed: September 2019  
Next planned review: September 2022  
LYMweb0216EndofLife2019v2

✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

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