

Bereavement and grief

This information is for anyone affected by lymphoma who is nearing the end of life. You might be processing what has happened and grieving for the life you have lived. It is also for friends and family of someone who is dying, or has died, from lymphoma. While nobody can take away your grief, there is support available to help you cope. You can also contact our **helpline team** for emotional support.

We have separate information about what you might experience towards the **end of life**.

On this page What is grief? How does grief feel? Depression and grief How can I help myself? Frequently asked questions about bereavement and grief

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**.

What is grief?

Grief is intense sadness and a sense of loss. If you have lymphoma, you might feel a sense of loss for the life you once had. For some people, grief comes at the point of diagnosis. You might also feel deep sorrow for the **people close to you**.

If someone close to you has lymphoma, you might experience grief **before** the person dies (anticipatory grief). This can happen as you start to prepare yourself mentally and emotionally for them not being there.

How does grief feel?

Grief isn't a single feeling – it can be a whole range of feelings. It is a very personal experience, and different people feel it in different ways. Some people say they go back and forth between feeling calm and 'OK', and feeling some of the more challenging emotions, like intense sadness.

Grief can feel overwhelming and can affect you mentally and physically. For example, you might experience low energy, a sense of 'tightness' in your chest or throat, and aches and pains. You might find it difficult to concentrate, feel agitated, shocked, numb, angry, or lacking motivation and purpose. Some people experience **depression** (very low mood).

Some people also experience emotions such as relief and a sense of peace. Like all feelings, these are valid. While lots of people do experience them, however, such positive feelings might then trigger guilt and sadness.

When someone you love dies, it can bring a great sense of uncertainty. It can also bring questions and thoughts about your own mortality. The depth and intensity of loss usually fades over time. However, you might still experience feelings of loss years later.

I think this is the first time I have really stopped to look back on the death of my mum eight years ago when I was 11 years old. Sonia, whose mum died of lymphoma

Elizabeth Kübler-Ross was a Swiss psychiatrist. Based on her conversations with over 200 people, she outlined some of the feelings people often experience towards the end of their life. These have since been applied to people who are going through a bereavement. You can read more about Kübler-Ross's work in her book: **On death and dying: what the dying have to teach doctors, nurses, clergy and their own families**.

As Kübler-Ross says, however, not everyone experiences all of these feelings nor do they necessarily come in a particular order. You might have just some of them, or go back and forward between them, and there's no set time limit in which to experience them. Since the work of Kübler-Ross, others have looked at the balance between the importance of continuing a relationship with the person who has died, while also managing our life after a death – we tend to go between focusing on the loss, while continuing to adapt to a life without that person. Dr Martin Powell, Hospice CEO

In this section, we cover some of the feelings that might come with grief:

- shock and disbelief
- feeling alone
- longing
- fear
- anger
- regrets, wishes and guilt.

Shock and disbelief

The end of life can be a huge shock, even if you have known for a while that you, or someone you love, is unwell.

When someone close to you dies, you might feel disbelief that they could be with you one day and not the next. Some people describe feeling numb, as though the person hasn't really died. Although this is most typical when the person first dies, it can last for some time. It can be part of mentally processing or 'learning' that the person is no longer there.

Feeling alone

If you or someone you love is nearing the **end of life**, you might feel very alone. It might feel as though no one truly understands what you are experiencing. Perhaps you feel unable to talk to friends and family about how you're feeling. However, it can be very beneficial to find an emotional connection with other people. You might find this through **support groups, counselling** or speaking to a member of our **helpline** team.

Many people feel uncomfortable talking about death. They feel unsure of how to support someone who is nearing the end of life, or someone who is bereaved. Friends and people you know might say or do unhelpful things. For example, they might avoid you, or avoid talking to you about the person who has died. They might say clichéd things such as 'time is a healer'. Even if you know that they are not deliberately upsetting you, their words and behaviours can still feel upsetting, and you might feel alone with your feelings. Some people describe intense loneliness and feeling separate or 'cut off' from those around them. You might feel that the people around you don't really understand what you're going through.

Consider letting people know how you're feeling. You could tell them that it's OK to ask how you're feeling and to talk about your loved one. Explain that you're having a very difficult time and that, if you become emotional, it's not because of something they've said or done – the emotions are already there.

There might be times when you don't really know what you want or need from family and friends. You might want someone to listen to you, or just to be with you.

Longing

If you are nearing the end of life, you might long for the life you had, for the good health you once had, and for more time to live.

If someone close to you has died, you might yearn to be with them, perhaps wishing for more time together. You might think you see or hear them, for example, in the supermarket. A stranger with the same colour hair or someone who seems to walk in the same way might remind you of them. You might dream about the person or think of things you'd like to tell them, only to 're-remember' that they are no longer here. Although this can be distressing, it can be part of the natural process of grieving as your brain is adjusting to the fact that the person has died.

We are lucky that we have a strong community around us that have helped over the years with straightforward things like food or helping with problems. But there is no-one like your mum. I hear friends talking about what they have been doing with their mums and it hurts. Sonia, whose mum died of lymphoma

Fear

Many people feel frightened about death. It is an unknown, and you might feel anxious about being in pain. You might worry about loved ones after you have died. Trying to identify what it is you are fearful of can help to reduce some of the intensity of the fear. You might want to talk to someone close to you, a member of **your medical team**, or a **counsellor**.

Anger

You might feel angry – perhaps towards the lymphoma itself or the health professionals looking after you or your loved one. Perhaps you feel angry because your outlook on life has been deeply affected. Some people describe their worldview having been 'shattered', and feel angry in general and at the unfairness of the situation.

If someone close to you has died, you might feel angry with the people around you for seeming to move on with their lives. Some people feel anger towards themselves. They think of things they wish they had or hadn't said or done before the person died, which can lead to feelings of **regret and guilt**. Although it can be hard to acknowledge, it's also quite common to feel angry at the person who has died for leaving you, because you are in such emotional pain.

Regrets, wishes and guilt

You might go over things you feel you should or shouldn't have said or done – for example, certain life choices or an argument with a close friend. Some people think in terms of 'if only'. For example, 'if I can become well again, I'll lead a healthier lifestyle' or 'if the person I love could be well again, I'll be more selfless'.

If someone close to you has died or is dying, you might feel as though you didn't do enough for them. Very often, the reality is that, however much you did, you could not have changed the outcome. Consider, 'what would have been enough?'. You could consider all the things you did for the person, both practically and an emotionally. If possible, reassure yourself that you did enough.

Some people feel relieved that the person has died, often because their loved one is no longer having to cope with their lymphoma. It can also be a relief to have a break from **caring for someone who has lymphoma**. Some people experience guilt for feeling this relief. These are natural, human emotions. Although painful, it can be helpful in the long-run to allow yourself to feel whatever you're feeling.

Depression and grief

Low mood is very common following a bereavement. Some people experience feeling very low (depression). Different people experience depression in different ways. Some of the symptoms you might experience are:

- low mood and feeling close to tears
- lack of energy and motivation
- loss of interest and pleasure in the things you usually enjoy
- feeling anxious and worried
- agitation and inability to focus
- difficulty making decisions
- loss of appetite
- difficulty sleeping.

The NHS website has more information about **depression** and sources of support. They also have a self-assessment online tool that has questions to help you identify **whether you could be feeling depressed**.

What if depression continues?

There is no set time that is considered 'normal' to feel low after the death of a loved one.

For many people, depression after a loved one dies fades over time. For some people, however, it continues. If it goes on for a long time, your grief might be described as 'unresolved' or 'complicated'. This type of grief can affect your emotional wellbeing and limit the enjoyment you take in living your life.

People who have unresolved grief might spend a lot of time thinking about the person who has died, sometimes including about how they died. You might, for example, spend a lot of time at the cemetery where they have a memorial stone, or looking at photos of them.

Other symptoms of unresolved grief can include:

- an ongoing sense of numbness or disbelief that the person has died
- avoiding thinking about the person
- ongoing low mood
- going out of your way to avoid reminders of the person
- feeling that life has no meaning or purpose
- thoughts of ending your life, perhaps to be with the person.

As part of unresolved grief, you might have ideas about your future that include the person who has died, and are therefore impossible. For example, you might plan wedding anniversary celebrations with a husband or wife who has died.

Let someone know **if you think you might be experiencing depression** or unresolved grief. Your GP is often a good person to approach and can suggest **sources of support** to help you cope and to process your loss.

How can I help myself?

Nothing can change your situation. However, there are things you can do to help yourself **cope with difficult feelings**.

Acknowledge your feelings

Be patient and allow yourself to feel whatever you're feeling. Some people try to deny or 'block' their feelings out, pretending that they're not there. Some people try to 'dull' or 'numb' their feelings with drugs or alcohol. Often, people say that they don't 'deserve' to feel the loss as intensely as other people who perhaps had a closer relationship to the person who has died – your grief is real and valid. As painful as loss is, acknowledging your true feelings generally helps in the long term. Marie Curie has information about **how talking about the end of our lives helps us**.

Talk to someone about how you feel

There can be a great deal to process when someone you love dies. Some people find it helps to connect with others who have experienced a bereavement through **support** groups or online forums.

Talk honestly with someone about how you feel. This could be a family member or a friend or, if you have a religious faith, a member of your religious community. You could write in a journal or speak out aloud to the person who has died. If you prefer to speak to someone you don't know, our **Information and Support Team** is here to listen to you and can help you to find **sources of support**.

You might also choose to get support through **counselling**. Sometimes, specialist bereavement counselling is available through your local hospice. You can **search online for your nearest hospice** or ask your GP if they can help you to access such support.

Take care of yourself

Sometimes, people who are bereaved take less care of themselves. It can be hard, but eating well, taking some exercise and getting some rest is important to your overall **health and wellbeing**. You might also consider practical support for a little while if you find day-to-day life difficult. For example, help with shopping or with household chores. You might also consider taking some time out of work – if you are employed, ask your manager or HR department how they can support you.

You'll also find some sources of support listed on the **bereavement section of our useful organisations** webpage.

FAQs about bereavement and grief

Each person has their own thoughts and beliefs about death. In this section, we address some of the questions people often ask about bereavement, grief and loss.

I am nearing the end of life – how will I feel about this?

There can be a great deal to process as you near the **end of life**. Some people try to find meaning in their life. You might think about the things you've done and seen, the choices you've made, and what impact you might have had on the world and the people around you. It can be a very emotional experience to reflect on your life. However, it can help you to process and to start to feel calmer about dying. Some **hospices** offer a counselling service that can support you in this.

What caused the lymphoma?

It can feel extremely unfair that you, or someone close to you, has lymphoma. You might feel **angry** and a huge sense of loss for your future plans. Underneath this anger there is often a great sense of loss and sorrow.

You might wonder whether there was anything you have done to cause the lymphoma. It's human nature to look for reasons; however, in most cases, there is no known **cause of lymphoma** and there is nothing that you could have done to have changed the outcome. There is no one or nothing to blame, which can be difficult to accept.

Someone I love has died – how long will I feel such grief?

There's no set timeframe for how long grief lasts. Each person goes at their own pace. You might feel OK on one day and not the next. For most people, however, the sense of loss gradually fades. Despite still loving and thinking about the person who has died, most people adjust to the life that is different to the one they had expected. Over time, people often start to feel warmth and have fond memories when they think about the person.

Is how I feel normal?

Grief can be intense and might, at times, feel overwhelming; however, this is a natural part of bereavement.

Many people imagine that they see or hear the person who's died. People often wonder whether this is normal. In fact, the experience is very common and can happen as your brain starts to process that the person has died. It can be considered as part of **longing** for them.

Is it OK to start to feel OK again?

At first, realising that you've laughed or haven't thought about the person for a while might bring **guilt**. It's very natural to go 'in and out' of grief, between sadness and going about your day-to-day life. This is all part of processing your loss and is entirely natural.

As time goes on, you might experience a gradual 'letting go' of the person as you move into a new phase of your life. Although the person is no longer physically with you, some people feel that the person is with them in some way. This is very personal and means different things to different people. Some people describe a sense of closeness and being with the person when they think about them. People often consider their qualities and the good times they shared when they remember the person.

How can I cope with anniversaries and birthdays?

For some people, certain dates can be emotional and bring new sadness. For example, the anniversary of the person's death or their birthday. Sometimes the lead up can feel more challenging than the day itself.

Think about what would help you through these times. For example, you might plan time with a friend, or take some time off work. Some people choose to mark the occasion, such as with a family meal to remember the person who has died. Others prefer to carry on with their day-to-day life without doing anything different. Some people mark anniversaries and events for the year after the person dies. Others continue to do so over the years to come. We all have our own ways of coping. There is no right or wrong so do what's right for you.

How can I talk to children about death?

It can be extremely difficult to talk to children about the death of a loved one. How you talk to them depends on various factors – these include their age and developmental ability, their relationship with the person, how you usually communicate as a family, and any religious beliefs you and your child might have. Marie Curie has information about **talking to children about the death of a loved one.** We also list specialist sources of support in the **bereavement section of our useful organisations webpage**.

References

The full list of references for this page is available on our website. Alternatively, email **publications@lymphoma-action.org.uk** or call 01296 619400 if you would like a copy.

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