

Talking to children about lymphoma

Telling your child you have lymphoma and talking about your illness can be very difficult. This page gives some guidance on what to tell your children and where to find other resources.

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Resources

This page is intended for parents or carers who have been diagnosed with lymphoma. Parents and carers may also find this page useful when explaining that another relative, such as a grandparent, has lymphoma.

Should I tell my child about my lymphoma?

It's not uncommon to feel uncertain about how to talk to children about lymphoma. You might be worried that you'll scare or upset them and it's natural to want to protect them.

Research indicates that children cope better if they understand what is happening. Even very young children pick up on the atmosphere at home and notice when something is wrong. Not knowing what's wrong can be very worrying for them if they sense tensions but don't know why they're there. They could overhear things that make them worry more and they might blame themselves for your changes in mood.

You can help your child cope with your diagnosis and any changes at home by being honest with them. Explain what is happening in a way they can understand.

It is easier for children to cope if they trust you and know they can talk to you about their feelings.

One of the mums in the playground asked how I was doing. Having told them about the diagnosis, we realised we had to tell our daughter now, in case she heard about it from someone else.

Katherine, diagnosed with lymphoma when her daughter was 6

How can I talk to my child about lymphoma?

The idea of telling your child you have lymphoma can be overwhelming. You might feel you have little emotional resource and energy to cope with their responses. Take some time to mentally prepare yourself before starting the conversation. It's helpful, though, not to leave it too long in case your child hears the news from someone else before you've spoken to them about it.

Make sure you understand your **lymphoma** before you try to talk to your child about it. Your medical team can give you information and advice to help you understand your diagnosis. You can also find out more about lymphoma on our **website** or **contact us** if you'd like information or support.

- Talk to your child when you are feeling calm.
- Find a comfortable place where you can sit together and you won't be disturbed.
- If you have more than one child, it is best to talk to them together so they have the same information.

It's natural to get upset when talking to your child about your diagnosis. Let your child know it is OK to express your **feelings** to the people who are close to you.

Who'll be there?

You might want someone with you when you talk to your child about your diagnosis and treatment. This could be a partner, family member or friend. Some hospitals have a suitable member of staff, such as a nurse or social worker, who can help you tell your child if you'd like them to. You might, however, prefer to tell your children on your own. Take whatever approach feels right for you and your family.

If you have more than one child, talking to them at the same time can help to create inclusivity. If you speak to children separately, one might worry that the other knows more than they do. You know your children best, so trust your instincts.

What should I say?

Think about how to start the conversation but don't overthink it. It's only natural that you'd want to 'get it right'. However, aiming for the perfect conversation puts unnecessary pressure on you.

Find out what your child knows already. It is very likely that your child has never heard of lymphoma. They might have heard of **cancer** but not know what it means. If they do have an understanding of it, the word 'cancer' can be frightening. Your child might think it means you are going to die.

Be guided by how much or how little they want to know. There are resources you can use to help explain what is happening.

Giving young children information little and often can be preferable to giving lots of information at once – they may not be able to process it all, which can feel overwhelming. Let your child know that it's OK to come back and ask questions and talk to you as often as they want to. Reassure them that there is nothing they have done that has caused your lymphoma and that they cannot catch it from you.



I'd just turned 40 and had two young sons. Sadly there has been a lot of cancer in our family, so despite how young they were, I knew my children would have some understanding. I didn't want them to overhear hushed conversations, but wanted to be open with them and let them ask me any questions they wanted. Generally they coped very well and just got on with life.

Caroline, whose sons were 8 and 5 when she was diagnosed with lymphoma

Be honest and keep it simple

Help your child understand the situation by using age-appropriate language and being honest with them. Honesty helps to build trust and security. It can also encourage your child to express any fears and anxieties as opposed to making them feel they mustn't talk about 'it' for fear of upsetting you. Trying to cope with difficult feelings alone can heighten children's fear as they begin to imagine various scenarios and the worst possible outcome.

Below are some ideas of how to explain lymphoma and its treatment to young children. You might also find our storybook, *Tom has lymphoma*, useful.

- Everyone's body is made up of tiny cells. Sometimes, the cells go wrong. If the cells grow out of control, they might form a lump.
- I have a bad lump or bad cells growing in my body.
- The doctors are giving me treatment to get rid of the bad lump or cells so they don't get worse.

- The treatment is strong to help it get rid of the bad lump or cells, but it might make me feel ill.
- I might need some help while I am getting better.

While you won't be able to make your child any promises, you can reassure them that doctors are doing all they can to make you better.

As well as being honest in explaining your lymphoma to your children, honesty about how you're feeling can also be helpful. For example, let your child know if you're sad, worried, tired or in pain. Knowing this might help them to express their own feelings. It could also help them to understand any changes in their lives, for example, if you can't take them to school because you're feeling **fatigued**. Explain that lymphoma can affect your **mood and feelings** but that it doesn't change how much you love them or mean that they've done something wrong.

Use the proper words

It can be very confusing and worrying for children to hear you saying words they don't know to other people. They might just need to know that 'lymphoma' is the name of your illness and '**chemotherapy**' is the strong medicine you are having.



I told her what we knew, that the treatment would make me very poorly, that the strong medicine would make my hair fall out, but that the kind of cancer I had was very treatable and the doctors were working hard to make me better. We found a couple of books really helpful, *Nowhere Hair* and *The Secret C*, and used these as a way to let her talk openly about what was happening.

Katherine, who was diagnosed with lymphoma
when her daughter was 6

Prepare your children for changes

Preparing children for changes can help them cope with them. Talk to your children about **side effects** such as **hair loss**, **sickness** and **fatigue**. Reassure them that, as far as possible, their routines and activities will stay the same, but that there may be changes to their day-to-day life. For example, there might be some days when a classmate's parent collects them from school if you need to go to a hospital appointment.

Let staff at your children's school and any activities or clubs they're part of know about the situation too. For example, your child's teacher might notice changes in your child's behaviour or concentration – having some information about what's going on can help them to understand why.

Both you and your child are likely to find the separation hard if you need to stay in hospital. Tell your child who will be looking after them, for how long and why. Talk about what it is like in hospital and what they might see if they visit.

Be prepared to be asked 'why'?

Reassure your child that there is nothing they have done that has **caused** your lymphoma. You didn't do anything wrong either. No one knows why it happened to you. Bodies are very complicated and sometimes things go wrong.

Keep communication open

Telling your child about your lymphoma is a big step. It is just as important to keep communication open after you have told them.

Don't expect to tell your child everything in one go. Be guided by your child's reactions and questions. They might need time to process their feelings before they come back to talk to you about it some more. They might want to ask lots of questions. They might just go and play as if nothing is wrong. Let them know you are there to answer their questions. Talk about your illness to give them openings to talk to you if they need to.

Let your child know it is OK to talk about cancer. They do not have to **cope with difficult feelings** on their own.

Older children and teenagers

Older children and teenagers can understand more about your illness and might ask more questions than younger children. They might bottle up their feelings to protect you, or behave in a challenging way at times. Encourage them to talk to you and ask questions. Be honest and open so they feel like they can trust you. Some children and teenagers find it helpful to have someone else to talk to, like a family member or friend. It is important to still give older children and teenagers guidance and structure in their lives so they learn how to cope with difficult situations.

If someone close to you has lymphoma: animations for children

On our webpage, we have videos that are designed to be watched with your child if they have a loved one or family member with lymphoma. The videos explain what lymphoma is, what treatment involves and how the illness might impact upon the child's day-to-day life. The first video is about Hodgkin lymphoma and high-grade non-Hodgkin lymphoma, and the second video is about low-grade non-Hodgkin lymphoma. There are important differences between **high-grade (fast-growing)** and **low-grade (slow-growing) lymphomas**, so make sure you watch the right video.

Resources

There are several resources you can use to help you in your conversations with your children.

- Our *Tom has lymphoma* storybook is about a primary-aged boy diagnosed with lymphoma. Although the story is from Tom's perspective, many parents have found it useful.
- Macmillan Cancer Support have **advice on talking to children about cancer** including how to tell them about your diagnosis, treatment and its side effects. They also publish a booklet called *Talking to children and teenagers when an adult has cancer*, which you can download free of charge or order online.
- Cancer Research UK also have a **webpage** on this topic.

- London Cancer and the Fruit Fly Collective have produced **a video** to support parents in talking to children about cancer. There is also **a comic** using the same illustrations and concepts.
- Talking to children about lymphoma if your diagnosis is terminal is one the most difficult things you ever do. Macmillan Cancer Support and Winston's Wish have collaborated to produce a booklet called *Preparing a child for loss*. It gives practical advice to guide you in these conversations.
- The **Marie Curie** website also has information on talking to children about your cancer.

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.

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.

Acknowledgements

- Helen Easson, Haematology Clinical Nurse Specialist, Royal Hallamshire Hospital.
- Claire Tune, Lead Counsellor, Phyllis Tuckwell Hospice Care.
- We would like to thank the members of our Reader Panel who gave their time to review this information.

Content last reviewed: July 2018

Updated: July 2019

Next planned review: July 2021

LYMwebLYMweb0235TalkingCYP2018v2



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