

Talking to your child about your lymphoma

A diagnosis of lymphoma can have a significant impact on you and your family, and it can feel a daunting topic to talk to a child about. This information gives tips and suggestions of approaches you might consider using when talking to a child about your lymphoma. It also suggests resources you might find helpful.

We use 'parent' to mean parent, carer or guardian; however, this information might also be relevant if you're talking to another relative, such as a grandchild.

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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.

Should I tell my child I have lymphoma?

Many people feel unsure whether to tell a child they have been diagnosed with lymphoma. You might see the importance of it but worry that doing so will scare or upset them. It's only natural to want to protect the people you love. There can be a difference in how much you want to tell a child and the amount of information they ask for. Although these conversations can be difficult, research shows that children cope better if they have an understanding of what is happening.

No matter their age, children often notice subtle changes. For example, they might have a sense that there is sadness, anxiety or tension at home. Feeling that something is wrong but not knowing what the cause is can be very unsettling. Overhearing a conversation might increase worry and confusion. Children can start to blame themselves for things like changes in your mood if they have no other explanation.

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

Claire Tune, Lead Counsellor at Phyllis Tuckwell Hospice Care

Starting the conversation

Take some time to prepare yourself mentally before starting the conversation. Make sure you know enough about your **lymphoma** to explain it as children often ask lots of questions. Your medical team can give you information to help you understand your diagnosis. We also have lots of information **about lymphoma** in our **books and information** and you can contact us if you'd like further **information or support**.

While it's good to give some thought as to what you might say, try not to over-think it, as this can build pressure and anxiety. Remember it's OK to say that you don't know the answer to something but that you can try to find out.

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. Some people prefer to tell their child on their 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 you've given the other more information. You know your children best – trust your instincts.

- Talk to your child when you're feeling calm. Try not to leave it too long after your diagnosis, in case your child hears the news from someone else before you've spoken to them about it.
- Find somewhere comfortable where you can be together without interruption. This might be out on a walk or sitting down at home – wherever feels best.
- Think about when you'll start the conversation. For example, earlier in the day rather than close to bedtime.
- Let your child know that it's OK to **express how they feel**.

It's natural to get upset when talking to your child about your diagnosis. Let your child know it is OK to express their feelings and that they can talk about them with you.

Claire Tune, Lead Counsellor at Phyllis Tuckwell Hospice Care

Keep a sense of normality

A diagnosis of lymphoma is likely to cause some changes in your **day-to-day life**. As far as possible, tell your child in advance so that they know what to expect. For example, tell them if someone else will be collecting them from school and if there are likely to be more people in the house than usual once they return home. Let them know the reason too - for example, explain to them that you have a hospital appointment or that you feel exhausted and would like to save your energy to read to them before bed.

- **Keep a routine.** This helps to give a sense of familiarity, control and emotional safety, which is especially important after unsettling news.
- **Allow your child to do their usual activities.** This can help give them something else to focus on, and might provide an outlet to express and cope with their feelings. It can also be helpful in giving you some time to yourself or with a partner or friend, knowing that your child is safe and having fun.
- **Keep ground rules.** This can be difficult if you don't have much energy or feel guilty for doing so. However, it can be more unsettling to a child if day-to-day rules are not upheld as ground rules are an important part of consistency and routine.



It was important to me that we still spent time together, so we would do colouring books and play games like travel Scrabble. Katherine, whose daughter was 7 when Katherine was diagnosed with non-Hodgkin lymphoma

Read [Katherine's full story](#) in the personal experiences section of our website.

What information should I give my child?

Be guided by how much or how little your child wants to know and what they already know. For example, they might not have ever heard of lymphoma. Perhaps they know the word cancer but don't really understand what it means. If your child **does** know a bit about it, the word 'cancer' can be frightening.

I found it helpful to work as a team with my family to explain the situation to my niece when I was diagnosed with lymphoma – we could agree on an approach and take a consistent approach in the way we spoke about it.

Kiki, whose niece was 5 when Kiki was diagnosed with non-Hodgkin lymphoma

- Break information down into chunks. Having lots of information at once can be overwhelming.
 - Let your child know that it's OK to come back and ask questions and that they can talk to you when they want to. There might be times when you don't feel able to answer, for example, because you're tired. Try to acknowledge their question and let them know that you will set aside time to talk about it with them.
 - Reassure them that there is nothing they have done that has **caused your lymphoma** and that it's not possible to 'catch' lymphoma.
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Explaining lymphoma to a child

Lymphoma can be difficult to understand, particularly for a child. You could explain that:

- Everyone's body is made up of millions of tiny cells.
- Sometimes, if something goes wrong, the cells can grow out of control and form a lump.
- The lump of cells is bad and can make you unwell.
- The name of the illness is 'lymphoma'.

You can also explain that you might need medicine (**treatment**) to control or get rid of the cells. This medicine might make you feel tired or sick because it is so strong.

If you have treatment, you could say:

- The doctors are giving me treatment to get rid of a bad lump of cells.
- The treatment is strong to help it get rid of the lump of cells that have gone wrong, but it might make me feel unwell or tired at times.

Cancer is a very emotive subject, especially for children. Go at the child's speed and give the information as and when they need to know – or when they ask for it.

Sharon, whose granddaughter was 9 when Sharon was diagnosed with non-Hodgkin lymphoma

You might also find our videos helpful. We made these to watch with your child if someone in the family has lymphoma. The videos explain what lymphoma is, its treatment and how the illness might impact upon the child's day-to-day life.

There are some key differences between **high-grade (fast-growing)** and **low-grade (slow-growing) lymphomas**, so it's important to watch the right video for your lymphoma type.

Tips on approach

There are **resources** you can use to help when you speak to your child about lymphoma. You can also speak to our helpline team for support.

- **Use language that is suited to your child's age and developmental level** to help them understand the situation. Resources such as our storybook, **Tom has lymphoma**, might provide a useful starting point. We also have a set of four **Easy Read booklets** about lymphoma that use large print and pictures to explain what's happening.
- **Use the proper words** to help avoid confusion if they hear you talking about your lymphoma to other people.
- **Be honest** so that you build trust and security. Honesty can also encourage your child to express any fears and anxieties instead of them feeling they mustn't talk about it for fear of upsetting you. Trying to cope with difficult feelings on their own can heighten a child's fear as they begin to imagine various scenarios and the worst possible outcome.
- **Reassure your child** that you have a team of doctors and other health professionals who are looking after you and doing all they can to help you get better. Take care not to make promises you can't keep though.
- **Talk about how you feel.** For example, let your child know if you are sad, worried, tired or in pain. This sets an example so that your child feels more able to express their own feelings. Reassure them that no matter how you're feeling, it doesn't affect how much you love them.

We always explained the situation, which meant that when I was tired or angry, Sophie understood that it was because of the illness and not because of anything to do with her.

Eleni, whose daughter was 5 when her aunt was diagnosed with non-Hodgkin lymphoma

Emotional wellbeing

Taking care of **your emotional wellbeing** can have a positive effect on **your child's emotional wellbeing**.

Your wellbeing

A lymphoma diagnosis itself can feel overwhelming, without the additional challenges of coordinating the practicalities of family life. You might struggle with the **emotional impact of lymphoma** on you and those close to you.

Parents are often concerned with what approaches to take, and some feel guilty for being unwell or being unable to do all that they usually do with their children. These are difficult feelings and it's important to take care of your own **emotional wellbeing**.

Contact us for support and speak to a member of your medical team to find out about any support available locally to you – a clinical nurse specialist is often a good first point of contact. You might also be interested in finding out about talking therapies, such as **counselling**.

Your child's wellbeing

We all respond differently to challenges, and the same is true of children.

Older children and teens might try to hide their feelings to protect you, or behave in ways that seem challenging. It's also possible for **stress** and anxiety to cause physical symptoms or trigger existing conditions, for example headaches, stomach aches or eczema.

To help your child adjust emotionally, encourage them to keep honest and open communication.

Claire Tune, Lead Counsellor at Phyllis Tuckwell Hospice Care

Sometimes, it can help to have someone outside of the immediate family to talk to, such as a close friend. Your child might also be interested in a talking therapy, such as counselling. Schools and colleges often have their own wellbeing services, including counselling. The NHS website has more information about **talking therapies** and how to access them. Macmillan Cancer Support also have cancer support specialists who can help you find **counsellors in your area**.

Some people find it uncomfortable to know that their child is talking about their difficulties with someone else. However, for some children, it's an important part of being able to say what is on their mind, making sense of, and coping with the situation.

We had a referral through Macmillan Cancer Support for our son to have some counselling from a service that specialises in counselling for children affected by cancer. This helped him massively.

Natasha, whose children were 8 and 13 when their dad was diagnosed with lymphoma

For some people, creativity is helpful in self-expression. Such activities can feel less overwhelming and more emotionally safe than talking directly about feelings. For example, drama, dance, art, painting and music, individually or as a group activity. There are also trained professionals who offer support in working creatively to express and process thoughts and feelings.

Children often express themselves through play and arts and crafts, especially when they do not have the verbal ability to articulate their feelings. Many young people struggle to initiate communication and feel self-conscious or uncomfortable talking about feelings. 'Diluting' the situation, perhaps when in the car or doing a small task together, can potentially be a more comfortable, familiar way of checking-in with them.

Sandra Richardson, Counsellor working with children and young people

Mind has more information about **arts and creative therapies**, as well as **information about accessing them**.

Sometimes, older children start to take on more of the household chores or taking care of physical or emotional needs of the person who has cancer. This can have a significant impact on their social, physical and emotional wellbeing, and it's important that they are offered appropriate support. The **NHS has information about help for young carers**. **Carers Trust** can also help young people **find local support**.

Prepare your child for changes

Preparing children for changes can help them to 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.

We explained that although their dad doesn't look poorly now, he is poorly and he needs to start some treatment. The treatment is going to make him look sick and feel sick.

Natasha, whose children were 8 and 13 when their dad was diagnosed with lymphoma

It can also be helpful to tell staff at your children's school and any activities or clubs they're part of about the situation. For example, your child's teacher might notice changes in your child's behaviour or concentration. Having some information about what's going on allows them to offer your child support.

It can be difficult for both you and your child if you need to stay in hospital. You could tell them a bit about what it is like in hospital, to help them understand it better. Tell your child who will look after them when you're in hospital, for how long and why.

We explained how people are in hospital because they are ill, but still had to make sure she was quiet and well behaved, so that she didn't disturb the other people. We were always made to feel she was welcome and the nurses would spoil her with biscuits!

Katherine, whose daughter was 7 when Katherine was diagnosed with non-Hodgkin lymphoma

Further support and information

Our Information and Support Team are **here for you** if you'd like to talk about any aspect of lymphoma, including how you're feeling and talking to children about your diagnosis.

It's often the first thought: should I tell my child? when is the right time and how to tell them? It can be so hard to know how to manage this. We're here to talk this through.

Sharon, Lymphoma Action helpline team member

CancerCare is an American organisation that produce a **book about talking to children when a loved one has cancer** that is free to download.

Daisy's Dream offers support and information to families affected by life-threatening illness or bereavement.

Hospice UK is a charity that supports hospices across the UK to deliver high quality care. You can use their online tool to find your nearest hospice and about the support they offer to children and young people. This might include support groups and social activities.

London Cancer and Fruitfly collective have produced a **video to support parents and carers in talking to children about cancer**. **Fruitfly collective** also has a set of free resources to help children cope when a parent has cancer, and to help families talk about cancer.

Macmillan Cancer Support has information and resources to help with **talking to children and young people about cancer**.

Marie Curie has information about **practical ways to support children** when someone close to them is unwell.

Riprap is a website for teenagers who have a parent or guardian with cancer. It offers an online community and personal stories.

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

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All our information is available without charge. If you have found it useful and would like to make a donation to support our work you can do so on our website lymphoma-action.org.uk/Donate. Our information could not be produced without support from people like you. Thank you.

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