

When a child has lymphoma: practicalities

This information is about some of the practical concerns you might have if your child has lymphoma. We have separate information about **lymphoma in children**, which explains what lymphoma is and how it might be treated. We also have **information for teens and young adults who have been diagnosed with lymphoma**.

We say 'your child' throughout this information to mean anyone aged up to 18 with lymphoma that you are looking after, even if you are not their parent, guardian or primary caregiver.

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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.

What happens after my child is diagnosed with lymphoma?

There's no right or wrong way to feel when you first find out that your child has lymphoma. Your reaction might include a **mixture of feelings**, including shock, fear, numbness and disbelief. Some people are relieved to get a diagnosis after having various investigations into what might be wrong.

Once lymphoma is confirmed, your child might have further **tests and scans** to help their doctors find out as much as possible about your child's lymphoma and how it is affecting them.

A **multidisciplinary medical team** (MDT) of health and social care professionals work together to plan and provide the best possible **treatment for your child**. Your child should be assigned a **key worker** – a member of their MDT who will be your main point of contact for any **questions or concerns you have**. Usually, this is a lymphoma or haematology **clinical nurse specialist**.

It can be challenging to **wait for test results**, and different people find different ways of coping. Alongside your child's medical team, **our helpline team** is here to support you and your family however you are feeling.

What treatment will my child have?

Your child's medical team should talk to you and give you written information about the **type of lymphoma** your child has. They should offer opportunities to talk to them about your child's diagnosis, **treatment** options, possible **side effects** and **late effects of treatment** (health problems that can happen months or years after the original treatment your child has had).

Remember that it's OK to ask as many or as few questions as you want to. Encourage your child to ask questions too. We have a list of suggested **questions to ask about lymphoma** that you might find helpful.

There can be a lot to take in and understand, which can be particularly difficult in times of heightened **stress** and anxiety. There might be times that you'd like information repeated or to be explained in a different way. Health professionals are used to this so don't hesitate to ask.

Before your child has treatment, it's important that both you and they understand what it involves. The hospital also needs written **consent to treatment**. For children who are under the age of 16, a parent or guardian must provide this. Make sure that you understand what treatment involves and about any possible side effects and late effects of treatment. You might want to ask about any possible long-term implications, such as about any effects on your child's **fertility**.

If your child is not old enough to give consent, you can still involve them in decisions about their care and treatment. This can help them to cope with it, both now and in the longer-term.

No matter their age, consider how you can give your child some control. This could even be which arm to have an injection in, or what they might like to do as something fun or relaxing between treatments – just check first with their medical team that any activities are suitable for your child and about any safety precautions to take.

The British Medical Association has information about **parental responsibility and consent**, including a parental consent guide.

Where will my child have treatment?

Children and young people with cancer are treated in a specialist children's cancer centre called a Principal Treatment Centre (PTC). There are **21 PTCs across the UK**.

It might be possible for your child to have some of their treatment at a hospital closer to home through a children's community nursing team. Having some appointments at the PTC and some at a local hospital is known as 'joint' or 'shared care'. The local hospital is called a Paediatric Oncology Shared Care Unit (POSCU).

Your child might have treatment as an inpatient (which means they stay overnight at hospital) or as an outpatient (which means they can go home overnight). If your child needs to go to hospital frequently and making these journeys is difficult, speak to your child's clinical nurse specialist or **hospital social worker**; it might be possible for them to help with travel arrangements, including signposting to help towards the costs.

If your child needs to stay in hospital overnight, this is either for treatment or monitoring of **side effects**, such as serious or persistent **infections**. A family member should be able to stay with them. Young Lives vs Cancer has information about **staying in hospital with your child and what you'll need**. If it's not possible to stay with your child, reassure them that you'll be back as soon as you can, and, if possible, when this will be.

It's often possible to visit a hospital before treatment starts so that you and your child can familiarise yourself with the environment and ask any **questions**. For example, you might like to find out about:

- facilities, such as a TV, WiFi access, a common room and a kitchen
- social and emotional support, for example through social activities, **social workers**, play specialists or **counsellors** – some of this support might be available at the hospital and some within the community
- educational support through hospital teachers
- **visitor policies**, such as when visiting hours are and what visitors can and shouldn't bring.

I decorated my son's room so that it didn't even look like a hospital room anymore – there were fairy lights everywhere and we tried to make it fun. He had lots of things that he could do in bed like drawing, Lego and stickers.

Laura, whose son was diagnosed with lymphoma and is now 10 years in remission

How much time will my child spend in hospital?

How often and for how long your child goes into hospital depends on factors, including:

- their treatment schedule, including the **type** and dose
- times when their medical team needs to keep closer checks on them, such as, if they develop an **infection** that needs treatment, or experience **side effects of treatment** that need to be monitored.

Your child's medical team should be able to give you information about how much time your child is likely to spend in hospital.

Social workers

A social worker can support children who have cancer and their families. They can help with a range of things; for example, they might help to:

- explain your child's lymphoma to them
- arrange travel (possibly also for any other children you have) to and from the hospital, which might include organising help towards travel costs
- organise school work for your child by liaising with their school
- apply for **financial support** that you might be eligible to receive
- put you in contact with other families who have experience of a child who has, or has had, cancer.

If you are interested in the support of a social worker, ask a member of your child's medical team for information. Some hospitals have **social workers provided through the charity Young Lives Vs Cancer**.

Talking to your child about their lymphoma

Go at your child's pace and be honest and straightforward with them. You might think it's better not to tell them things that could frighten and upset them. However, children can be highly intuitive and notice when something doesn't seem quite right. It can be confusing and unsettling if they don't know what this is, building anxiety and mistrust.

Once we had the diagnosis confirmed, we were in a better position to understand the treatment plan, and we were told that it would be quite harsh. We were warned that it'd be difficult for Sonny and that there would be long hospital stays. We spoke to Sonny and explained to him that he had a thing called 'Burkitt lymphoma' and that the doctors had taken it out but they would have to give him some really strong medicine to make sure that it had gone away completely and that it didn't come back. We told him that he'd need to be in hospital and that he wouldn't be able to go to school for quite some time.

Laura, whose son was 5 when he was diagnosed with lymphoma.

Once you know the diagnosis, tell your child. Think about where and when you'll tell them and whether you'd like someone else to be with you, for example, family or a member of your child's medical team.

Explaining lymphoma and treatment

Lymphoma can be difficult to understand, particularly for a child. Use language that's appropriate to their age and think about the questions your child might ask. You might want to talk this through with a member of your child's medical team or **our helpline team**.

Below are some suggestions to help explain lymphoma and its treatment:

- 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 to your child that they might need medicine (**treatment**) to control or get rid of the cells. This medicine might make them feel tired or unwell because it is so strong. Prepare them for any changes that might happen after treatment, for example **hair loss, sickness** and **fatigue** and let them know that these should get better in time.

General tips for talking to a child about lymphoma:

- Use words like 'cancer' and 'lymphoma' to lower the risk of confusion and misinterpretation.
- Reassure your child that there is nothing that they did, or didn't do, to cause the lymphoma. Let them know, also, that they can't pass it on to other people.
- Be honest if you don't know the answer to a question, and suggest ways you can try to get the information they would like.
- Get an idea of the **treatment your child might have**, so that you can tell them a bit about it and reassure them that there is a plan to help make them better.
- Explain that everyone is different – they might assume that what happens to other children at hospital will happen to them but this won't necessarily be the case. Even if other children they see have the same type of cancer and the same treatment as your child, different people respond differently.
- Give your child information in chunks so they're not overwhelmed by lots of information all at once and have time to think over what you've spoken to them about. Let them know that they can ask questions as and when they want to.

Consider **resources you could use to help explain lymphoma**. For example:

- Our storybook, **Tom has lymphoma** is designed to help primary school-aged children understand what lymphoma is and how it is treated.
 - Our **animations** explain what lymphoma is and how it is treated.
 - Our resources on **talking to children about lymphoma** are aimed at parents explaining a lymphoma diagnosis in the family, but you might find some of the suggestions helpful.
 - **Children's Cancer and Leukaemia Group (CCLG)** has information about **talking to children**, including siblings, friends and classmates, when a child has been diagnosed with cancer. Their **publications are available to download on their website**.
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Supporting young children

Young children often believe their actions have caused something to happen or not to happen, even if nobody has told them so. Let them know that they haven't done anything to **cause** their lymphoma, and reassure them that they can't give it to anyone else.

Give some advance notice about upcoming treatment without going into detail about the whole, longer-term treatment plan, as this could be overwhelming.

Let your child know that there will be times that they are unable to go to **school**, either because they have a hospital appointment or because they need to rest after treatment.

Keep in mind that young children might express themselves behaviourally when they are struggling emotionally. This might include undesirable behaviours, or showing signs of anger. Try to help your child find ways of expressing themselves, for example, through drawing or play, as well as talking. It can also be helpful to **let their teachers know about their situation** so that they can offer support. Sharing some of your own feelings about treatment with your child might help to normalise emotions. In turn, it can help them to tell you how they're feeling.

There is huge value for your child in simply being with them, for example, playing or watching a film together. Speak to your child's clinical nurse specialist to find out about support available to help your child deal with difficult emotions.

Lymphoma is likely to affect some aspects of day-to-day life; however, it's important to keep a sense of normality where possible.

- **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 when they can.** This can help give them something else to focus on, and might provide an outlet to express and cope with their feelings.
 - **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. Although there are bound to be times when flexibility is needed, basic ground rules are an important part of consistency and routine.
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Supporting teens

It can be difficult to get the balance between offering support while respecting the independence and privacy of a young person. Try to be led by them. There might be times when they just want your company, to talk or to do something fun, and there might be times when they'd prefer to be alone.

Speak to the young person before their hospital appointments to find out what approach they'd like to take. They might want to lead the discussions with their health professionals with you there to support, or they might prefer you to ask the questions.

As well as understanding their illness and treatment, another challenge for teens can be coping with side effects of treatment. They might feel self-conscious if treatment changes their appearance by causing hair loss or a change in weight, for example. Before a young person starts treatment, their medical team should tell them about any **side effects** they are likely to experience and offer support to manage these.

As young people try to cope emotionally with what is happening, their behaviour might change – for example, they might show anger, become withdrawn or engage in risky behaviours. Try to find **effective ways of communicating** and let them know that you are ready to talk if and when they're ready. Some young people might prefer to talk to someone outside of the family, for example a close friend or other young people who are affected by cancer. **Our helpline team** is also here to offer support.

Our **Young person's guide to lymphoma** has more information for young people aged 16 to 25, including about lymphoma and its treatment and how to look after yourself during treatment and beyond.

Our **information for children and young people who have been diagnosed with lymphoma** might also be of interest to teenagers and young adults aged up to 24 years.

Your child's education

Your child is likely to need some time out of school during and after treatment for lymphoma. Reassure them that you, the hospital and their teachers will work together to help keep them up-to-date with what's going on at school, both in terms of school work as well as any other aspects of school life.

My husband and I took it in turns to be at the hospital with Sonny so that one of us could be at home with our daughter. His school was very supportive and they did kind things to show Sonny that he hadn't been forgotten. One day, they set up a Skype call from the school to his bed at the hospital, and it absolutely made his day.

Laura, whose son was 5 when he was diagnosed with lymphoma

Talk to your child's school about what is happening and find out how they can support your child's social, emotional and educational development. It might help to tell them about your child's:

- lymphoma and treatment plan, including any side effects of treatment
- risk of infection – lymphoma and some treatments can increase the risk of infection for several months after treatment finishes. Ask them to let you know as soon as possible about any illnesses at the school, particularly chickenpox, measles and shingles.

Your child's consultant or GP can write a letter to help explain their situation.

The government website has information about **illness and your child's education**.

You can also ask the hospital how they can help to support your child's education, for example, by providing access to hospital teachers. They might also be able to arrange for a member of hospital staff (such as a **social worker** or clinical specialist nurse) to visit your child's school to help teaching and pastoral staff to support your child.

Some children might make insensitive comments, which can feel very hurtful. It can help to explain to your child that not everyone understands as much about lymphoma as they do. Encourage your child to talk to you about how they are finding school and whether they are having any difficulties so that you and their teachers can support them.

Young Lives vs Cancer has information about school, including about **talking to your child's school**, **staying in touch with friends during treatment** and **taking exams**. Children's Cancer and Leukaemia Group also has information about **dealing with school** for children diagnosed with cancer.

After treatment

Finishing treatment is a time of adjustment and finding a 'new normal'. Although it can bring relief and a sense of celebration, some people find the end of treatment difficult, having felt well-supported by the regular interactions with their child's medical team. There is no right or wrong way to feel – try to be patient as you and your family adjust.

I felt strange that I didn't want to go home, but the staff at the hospital explained that this is actually quite common, to feel scared about leaving the hospital. Having lived for so long in a hospital, it felt strange to have to go in only for the regular follow-up appointments, which gradually became fewer and more space apart.

Laura, whose son was 5 when he was diagnosed with lymphoma

Young Lives vs Cancer has tips from parents and one of their nurse educators about **dealing with mixed emotions as your child approaches the end of cancer treatment**.

Your child should be supported by their medical team in their **recovery from treatment**, including information about **keeping well after treatment**. They should be offered **personalised care and support** that is suited to their individual needs.

After treatment, your child will have **follow-up appointments**. Their medical team should tell you what the schedule for these is and about any symptoms to look out for that you should contact them about between appointments. They should also talk to you and your child about possible signs of **late effects** (health problems that can happen months or years after treatment) and what to do if you notice them.

Looking after yourself

Having a child diagnosed with lymphoma can be physically, practically and emotionally challenging.

Although you might not think of yourself as one, if you are looking after someone who has lymphoma, including a child, you are a carer. You can find out about the practical and emotional support you might be able to access in our information about [caring for someone who has lymphoma](#).

Lymphoma can cause **stress**, anxiety, and have an effect on **relationships within and outside of the family**. Try to find **effective ways of communicating with the people around you**; honest conversations can help to connect with others, and support you and them through this difficult time.

You might also find it helpful to be in touch with others who can relate to your experience of having a child who has cancer. Some hospitals have support networks where you can connect with other parents and carers about your experiences and how you're feeling – ask your child's medical team if they can signpost you to any sources of such support.

Some people feel uncomfortable with making time to relax and do enjoyable things; however, **taking care of your emotional wellbeing** can be greatly beneficial to your child. At a time of continual readjustment, getting enough rest to be able to offer reliable and consistent support to your child is key. Try to build in time to do things 'away from your child's lymphoma', for yourself, as a family, and with your partner, if you have one. Friendships can also be an important source of support.

In addition to concerns about your child's health and wellbeing, you are likely to have **practical concerns**. For example, taking time out of **work** can have a **financial impact** on your household income. The [GOV.UK website](#) has information about benefits you might be able to claim.

To help with practicalities:

- ask your child's medical team what help is available to you and your family.
- **Home Start** is a charity that offers volunteer-provided support to families across the UK, including with practicalities such as household chores and shopping.

There are many other **organisations that offer support and information dedicated to children and young people with cancer.**

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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