

# Practical advice for parents and carers of children with lymphoma

This page covers common practical concerns of parents and carers looking after children and young people with lymphoma.

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Treatment of lymphoma in children is usually successful and most children lead a full life after lymphoma. This page gives you practical advice on supporting your child during this difficult time. We have separate information about [lymphoma in children](#), which explains what lymphoma is and how it is treated.

We use 'your child' throughout this information to refer to any child, teenager or young person up to 18 years old with lymphoma that you are looking after.

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## What happens after my child has been diagnosed?

Your child's [medical team](#) will find out as much as possible about the lymphoma and plan the best treatment for your child. Everyone is different so treatment is planned individually. [Waiting for test results](#) can be very difficult. You may feel relieved when treatment starts and you have a plan of appointments to take your child forward.

There are some things you can do during this time to help you and your child understand what happens next:

- Talk things through with your doctors and nurses and **ask all the questions** you have.
  - Read the information you have been given about your child's **type of lymphoma**, their **treatment** and what **side effects** they might have.
  - Find out how things are arranged at the hospital where your child will be treated and what facilities are available: consider schooling, access to a TV and Wi-Fi, if there are common rooms, and whether there is a kitchen where you can make a snack. Ask to have a look round the hospital facilities before your child's treatment starts.
  - Ask what support is available, such as help from social workers, outreach nurses, play specialists and support groups.
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## What should I tell my child?

Telling your child that he or she has lymphoma is difficult. You may be tempted to withhold information that seems frightening. Experts working in this field generally say it is best to be honest with your child. Experts also advise that parents and carers should use the words 'cancer' and 'lymphoma' openly. Your child will know that something is wrong because of visits to the doctor and various tests they need to have.

As soon as you know the diagnosis, it is best to tell your child. You may find it helpful to talk to your child's doctor or nurse specialist before doing this. It can help if you have some information about the illness and the recommended treatment before talking to your child. It may also be a good idea to practise what you are going to say.

You may want to tell your child yourself or you may want the doctor or nurse specialist to explain what's going on. It might be helpful to have someone else there who can support you and your child. Choose a time that is quiet and when you or the doctor will be around for some time afterwards. This way your child can come and ask questions as they arise.

Whenever you are with your child, remember he or she will pick up on your tone of voice and your facial expression. Even if you feel anxious, try to reassure your child that children with lymphoma do get cured. Hard as it may be, remember a smile may be more reassuring than words.

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 advice helpful. Our [animations](#) aimed at children might also help them understand what lymphoma is and what might happen.

## **Explain to your child that there are many different cancers and treatments**

If your child has recently been diagnosed with lymphoma, they will be experiencing things for the first time. For example, they may see other children who are unwell, who are [losing their hair](#), or who have had operations. They may find this confusing and unsettling. Everyone's experience of lymphoma is different. Your child may have different [symptoms](#) of their illness and different [side effects](#) of treatment from other children even if they have the same type of lymphoma. Explain to your child that his or her treatment may not be the same as that of some of the other children and that you and the medical team will explain what is happening. Encourage your child to ask all the questions they have and reassure them that their questions will be answered honestly.

## **Children of different ages need different information about their illness**

**Young children** between the ages of 2 and 7 will vary in how much they understand about illness, particularly their own. It is important for you to tell your child that the lymphoma has not been caused by anything they have done. Use simple, clear explanations about their treatment. Play specialists on hospital wards are trained to help parents and carers explain things to their children (including the ones without lymphoma), often through pictures, paintings and play.

**Older children** aged 7 to 12 are less likely to think that their illness has been caused by something they've done. At this age children understand that they need treatment to get better, and that they need to cooperate with the doctors and nurses. Explain that the treatment will help the healthy cells to do their job properly and get rid of the 'out-of-control' cells. Sometimes it is difficult for a child to accept that they have lymphoma, especially if they were generally well to start with.

[Tom has lymphoma](#) is a storybook designed to help you explain lymphoma to your child. Our animation explaining high-grade lymphoma is designed for children with a family member who has lymphoma, but you might find it useful to share with your child.

**Teenagers** can deal with more complex explanations. Let them guide you on how much information they want. Some teenagers cope well and get very involved in understanding their treatment. Some may require a lot of family support. Others might want to spend all their time with their friends and be as independent from their parents or carers as possible.

Some teenagers might want you to talk to their doctors but others might want to talk to them themselves. Let them take the lead if they want to.

Your teenager might feel embarrassed and self-conscious about having treatment especially as it might change their appearance. Your teenager might not admit to being bothered about such changes, but many are.

It is important to be sensitive to the changing feelings and moods of your teenager. Teenagers' feelings towards their situation and their need for support are likely to change throughout their treatment and afterwards. Like everyone else, they will have good days and bad days.

Try to discuss your child's illness with them in a calm and confident manner, and express your confidence in the medical staff treating them. If you don't know the answer to your child's question, you should say so and ask your child's doctor or nurse to help. Your child will lose confidence in you if you avoid the subject or give incorrect information.

Our [\*Young person's guide to lymphoma\*](#) booklet has more information relevant to this age group.

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## Where will my child be treated?

UK guidelines recommend that children and young people with cancer are treated in a 'Principal Treatment Centre' or PTC. A PTC is a hospital where specialists regularly treat children and young people with lymphoma. These hospitals have all the facilities they need to diagnose and treat children and young people with cancer. However, PTCs are at large teaching hospitals, often in cities, so you might need to travel if there is not a PTC local to you. If travel is a problem, some of your child's treatment or check-ups might take place in a hospital nearer your home. If your medical team is spread between a local hospital and the PTC, this is called a 'shared care' arrangement.

## Who will care for my child at the hospital?

Your child will be cared for by a team of health professionals with different areas of expertise. This is sometimes called a '**multidisciplinary team**' (MDT). A member of the team will be your contact ('key worker') who will address your questions or concerns. This is often a clinical nurse specialist (a nurse trained to specialise in a certain area) trained to work with children.

The medical team should talk to you about your child's lymphoma and its treatment. You should also be told about possible side effects and what to do when you have a problem or a question.

## What does consenting to treatment mean?

If your child is under 16, parents or carers might need to agree to certain treatments. You do this by signing a written agreement known as a 'consent form'. You are told all about the treatment and its risks and benefits before you sign. Ask any questions you have to help you understand what is happening. Keep asking until you are sure you understand. You can ask the same question more than once. Your child's medical team have heard all your questions before and want you and your child to be as comfortable as possible with what is happening.

Some children under 16 may be able to consent to their own treatment if their doctors consider them to be capable of doing so.

Young people aged 16 or over are considered to be capable of deciding on their own medical treatment unless there is significant evidence to suggest otherwise, just like for adults. They can sign their own consent form.

## Will my child need to stay in hospital overnight?

How much time your child needs to spend in hospital depends on the type of chemotherapy that your child is receiving. However, at least part of the treatment is likely to be given as an outpatient, meaning they can be at home overnight. If it is difficult for you to arrange hospital visits each day, talk to the hospital social worker. There are specialised social workers, often funded by charities, who work with families of children who have cancer. They may be able to advise you on getting help with travel costs or arrangements for your other children. Hospital social workers are experienced in supporting parents or carers who are in a situation similar to yours.

Most children with lymphoma have to stay at hospital overnight sometimes. This might be to have treatment or might be for monitoring if they are having troublesome side effects, such as serious or persistent infections. A family member should be able to stay with your child if they need to stay in hospital overnight. It is natural that children want their parents or carers to spend as much time as possible

with them. If you do need to leave, reassure your child that you will return as soon as you can.

If your child feels well enough, visits from friends and relatives can help them pass the time in hospital. The hospital environment and seeing your child feeling unwell can be distressing, though, so it is important that friends and relatives know in advance what to expect.

Any relatives or friends with a cold, flu or any other infection should be asked not to visit your child until they have recovered. Different hospitals have different rules and guidelines about visitors. Ask what the policy is at your hospital.

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## What changes can I expect at home?

Young children can have increased needs when they are ill and sometimes take up old behaviours like thumb-sucking or wetting the bed. Older children can become jealous of their brothers and sisters who don't have lymphoma. They could also be angry as they struggle to cope with their emotions.

Whatever your child's age, maintaining a routine that is as familiar as possible will help your child to adjust and cope.

Talk to your child's siblings about what is happening. If your child is in hospital, include your other children in hospital visits when you can. This will help your child's siblings understand what is happening so they don't feel left out or confused or develop unnecessary fears. This will also help them to be more understanding if the child with lymphoma receives special attention after returning home.

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**Remember your child's lymphoma diagnosis affects the whole family, so make time with their siblings as well.**

Bev, whose daughter Ellie was diagnosed with Hodgkin lymphoma at 15

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## What should I do if my child becomes unwell at home?

There is always the possibility that your child will become unwell at some stage during their treatment. This might be frightening if you are at home. Before treatment starts, you should be given advice and guidance on what to do when this happens. You should telephone the hospital immediately for advice on what to do if you are at all unsure.

You should not give your child any other drugs or medicines during treatment without first checking with the hospital specialist. Make sure the specialist knows about any other medicines your child is taking. Even some vitamins and herbal supplements can interact with some treatments for lymphoma, so check with your specialist before starting anything new.

Your child should not have any **vaccinations** or immunisations during treatment and for some time afterwards unless it has been agreed on by your child's medical team. The time period where vaccinations are not recommended differs according to your child's circumstances, so check with your child's specialist.

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## What should my child eat during treatment?

Maintaining a normal **diet** during treatment can be difficult. Your child might be feeling sick or find it difficult to eat if they have a sore mouth. It is important to keep your child's diet as balanced as possible during this time. There are many things you can do to help your child have the best possible diet:

- Include many fresh, carefully washed fruit and vegetables.
- Make sure that your child drinks plenty of fluids.
- Offer small meals frequently.
- Give your child soft foods, such as eggs, soup, milk puddings, fish and chicken, or ice cream.

Don't give your child any unusual foods or herbal remedies without checking with your specialist.

If you are worried about your child's weight, contact your key worker. They can give you advice or reassurance, and might be able to put you in touch with a dietitian for further advice.

Your child might develop **neutropenia** (low level of white blood cells) during treatment. Neutropenia is a common side effect of many lymphoma treatments. If your child has neutropenia, you need to be particularly careful about **food safety**. Your medical team can advise you if there are any foods your child should avoid while they are at greater risk of infection.

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## What happens when my child goes back to school?

Your child's schooling is likely to be affected by their illness, at least in the short term. Tell your child's school what is happening to him or her and ask how the school can support your child's education during their illness.

The [GOV.UK website](#) has more information about your child's rights to education while they are ill.

The hospital can help support your child's schooling by continuing lessons on hospital wards where possible.

The hospital social worker or oncology community nurse may be able to arrange a visit to your child's school to make sure the staff are prepared for any problems that might occur when your child goes back to school.

When your child returns to school:

- Keep the head teacher and class teacher(s) up-to-date about your child's illness and any side effects of the treatment so they can support your child.
- Advise the teachers of the risk of infection to your child; ask that they inform you if there is serious illness at the school. The risks from measles and chickenpox can continue for up to 12 months after finishing treatment.
- Ask the teacher to prepare the class for your child's return by explaining a bit about your child's illness.

Young children can be very insensitive and can find it difficult to cope with a change in the appearance of a friend. Ask the teacher to prepare the class for any [hair loss](#) or weight change in your child before he or she returns to school. The teacher should explain that these side effects will gradually go away.

It can help to explain to your child that not everyone understands as much about lymphoma as they do so they are prepared for any insensitive comments that might come their way. Encourage your child to talk to you about how they are getting on at school and whether they are having any difficulties so that you and the teachers can support them.

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## How can I look after myself at this time?

When you first learn that your child has lymphoma, your reaction might include a mixture of feelings, including shock, fear, numbness and disbelief. Some parents and carers find it difficult to take it in all at once. Sometimes it is a relief to find out at last what is wrong with your child's health. You might feel very angry and wonder why this has happened to your family – such feelings are natural. There is no evidence to suggest that you could have done anything to prevent your child developing lymphoma.

It can help to know that your child is having the best treatment available. [Treatments](#) offered are similar throughout the UK; however, if you are concerned, you can seek a second opinion and most specialists will be supportive of



your decision. If you would like to seek a second opinion, discuss it with your child's hospital specialist or your GP.

Having a seriously ill child can put a great strain on a **relationship**. It will help if you and your partner talk to each other about your child's illness to prevent misunderstandings and so that you can support each other.

It is important that you make time for yourself and your partner to do some of the things you enjoy. This can help create a sense of balance in your life. It might help you find the strength to continue to care for your child and your family during this very demanding period in your life.

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**Take each day at a time! Find the pleasure in little things, like time out watching a film.**

Bev, whose daughter, Ellie, was diagnosed with Hodgkin lymphoma at 15

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## Practical concerns

When your child has cancer, helping them to get better is your top priority. However, you are likely to have **practical concerns** too. Taking time off work to look after an ill child can cause financial difficulties. If you have other children, it can be difficult juggling childcare and hospital appointments. Ask your key worker what help is available. They can recommend resources to help you during this time. The **GOV.UK website** has useful information about benefits you might be able to claim.

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## Further information and support

This is a difficult time, but you do not have to carry the weight of your child's lymphoma diagnosis on your own. There are many people and **organisations** that can help you support your child through treatment and beyond. Many children's cancer centres have parents' groups where you can meet other parents and carers of children with cancer and talk about your fears and concerns. Your child's medical team will be able to give you more specific guidance.

Our **Information and Support team** are always happy to discuss anything that is concerning you (Helpline freephone 0808 808 5555; Live Chat on our website or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)).

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## References

The full list of references is available on request. Please email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or call 01296 619409 if you would like a copy.

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