

Practical advice for young people with lymphoma

This page gives practical advice on issues that often concern teenagers and young adults (up to 24 years old) with lymphoma. Younger children and their parents or carers might find our storybook, [Tom has lymphoma](#), useful.

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Treatment for lymphoma in young people is usually successful and most people lead a full life after lymphoma. This is a difficult time, but you do not have to deal with this on your own. There are many people and [organisations](#) that can support you through your treatment and beyond. Your medical team will be able to give you more specific guidance.

Don't be afraid to ask for help if you are worried or to ask questions if you don't understand something.

Our Information and Support team are always happy to discuss anything that is concerning you. Call our Helpline freephone on 0808 808 5555, Live Chat on our website or email information@lymphoma-action.org.uk.

What happens after I have been diagnosed?

You might start treatment straightaway. There might be a few weeks before you start treatment while your [medical team](#) find out as much as possible about your lymphoma and plan the best treatment for you. Everyone is different, so treatment is planned individually. Waiting for treatment to start can be very difficult. You may

find that you feel relieved when treatment begins and you have a plan of appointments to take you forward.

There are some things you can do to help you understand what happens next:

- Talk things through with your doctors and nurses and **ask all the questions** you have. It might help to note your questions down before your appointment, so you don't forget them.
 - Read the information you have been given about your **type of lymphoma**, your **treatment** and what **side effects** you might have.
 - Find out how things are arranged at the hospital where you will be treated and what facilities are available: consider schooling, access to a TV, Wi-Fi and common rooms, whether there is a kitchen where you can make a snack. Ask to have a look round the hospital facilities before your treatment starts.
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Where will I be treated?

You and your medical team should decide together where the best place is for you to 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 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 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.

There are units for young people with cancer at some hospitals. They are designed specifically for teenagers and young adults. These units let young people spend time with and gain support from other people in hospital of a similar age.

You are likely to have some or all of your treatment as an outpatient, which means you visit the hospital for your treatment but you won't need to stay overnight.

You may have to have some of your treatment as an inpatient, which means you need to stay in the hospital overnight. You might also have to stay in hospital if you have any serious side effects of treatment, such as a serious infection.

Teenagers aged 13 to 18

If you are 13 to 18 years old, you should be treated in a specialised children's or young person's unit in a PTC. A family member might be able to stay with you if you need to stay in overnight.

Young adults aged 19 to 24

If you are a young adult, you might have the choice between being treated in a specialised teenage and young adult unit or on an adult ward at the local hospital. Discuss all the options with your medical team. Think about how much time you need to spend in hospital, what the facilities are like and how easy it will be for your friends and family to visit.



I felt confident in my doctor and the hospital I was diagnosed in was easier to get to than the teens and young adults unit, so I decided to stay there. I was the youngest on the ward but really appreciated the banter and support from everyone.

Natalia, diagnosed at 20

The NHS, Teenage Cancer Trust and CLIC Sargent produce a useful [leaflet about cancer services for young people](#). For more detailed information, see [NHS England's policies on children and young adult cancer services](#).

Your medical team

You are cared for by a team of health professionals with different areas of expertise. This is sometimes called a '**multidisciplinary team**' (MDT). There might be a lot of people involved in your care but you should have someone you can contact (a 'key worker') with any questions or concerns. Your key worker is often a clinical nurse specialist, or sometimes a teenage and young adult (TYA) nurse specialist. The medical team should talk to you about your lymphoma and its treatment. You should also be told about possible side effects and what to do when you have a problem or any concerns.

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 medical team have heard all your questions before and want you to be as comfortable as possible with what is happening. It can be difficult to take in everything that is happening. It might help to write down your questions and the answers, and to have someone with you at appointments who can take notes for you.

It's up to you how much you want to know about your care. It's fine if you only want to know the basics.

Consenting to treatment

If you are under 16, your parents or carers might need to agree to certain treatments. They might have to sign a written agreement known as a 'consent form'. You may be able to consent to your own treatment if your doctors consider you to be capable of doing so.

If you are 16 or over, you are considered to be capable of deciding on your own medical treatment unless there is significant evidence to suggest otherwise, just like for adults. You can sign your own consent form. Make sure you understand what is happening and you have considered all of the options if there is more than one possible treatment.

How can I look after myself?

Taking good care of yourself during and after treatment will help your body to recover.

Your medical team will give you information about **side effects** of the treatments you are having. Don't suffer in silence – there are usually treatments and strategies to help with side effects. Ask your key worker for advice. Your medical team also need to know about any side effects in case they need to adjust your treatment plan.

Remember that everyone has a different experience of lymphoma. You might have different symptoms and side effects from someone else with the same type of lymphoma.

Eating well

Some side effects of treatment, such as nausea or an irritated gut, can make it difficult to eat. You may also find that some foods don't taste as good as they used to, but your taste should return to normal shortly after your treatment is over.

Eating a well-balanced diet will allow your body to develop new healthy cells.

Tips for eating:

- Include many fresh, carefully washed fruit and vegetables in your meals.
- Drink plenty of fluids.
- Eat small portions frequently.
- Try soft foods, such as eggs, soup, milk puddings, fish and chicken, or ice cream.

Ask your medical team if there's a dietitian you can talk to if you have difficulty eating.

If your white blood cell count is low, this is called '**neutropenia**'. Neutropenia is common in people being treated for lymphoma. You will need to be particularly careful about food safety if you have neutropenia. Ask what foods you should avoid while you are at greater **risk of infection**. Make sure you talk to your medical team if you want to try any unusual foods or herbal remedies.

Some treatments can make you gain weight. Generally, you should avoid trying to lose weight while you are having treatment as your body needs proper nutrition to help it recover. Focus on a healthy diet while you are having treatment and recovering.

Exercise

Keeping active is one of the best ways to feel better. Exercise might help reduce some of the side effects of treatment and will keep you in good shape for your recovery.

Lymphoma and its treatment affect everyone differently. While you are on treatment, your energy levels will vary. Gentle daily exercise is better for you than sudden bursts of activity. Going for a walk every day is a good start. Ask a physiotherapist or nurse to recommend some exercises you can do instead of more strenuous activities. You can build up to more strenuous exercise when you are well enough.

You might need to make a few changes to your usual exercise routine, depending what treatment you are having and how it is affecting you.

Bear the following in mind:

- Some chemotherapy drugs can affect the strength of your heart so you might be advised not to do power-lifting or heavy weights.
- You may need to avoid swimming while you have a low white blood cell count or if you have a central line fitted, to avoid infection.
- **Low platelets** can make you more likely to bruise and bleed. Because of this, you will need to avoid sports where you are likely to get injured. Check with your medical team before taking part in any high-impact sports, such as football, rugby or mountain biking.

Alcohol, recreational drugs, smoking

Drinking alcohol, taking recreational drugs or smoking makes it much harder for your body to recover.

Alcohol and recreational drugs are broken down and processed by the liver and kidneys. Both organs already have plenty of hard work to do processing your chemotherapy drugs.

Smoking increases your chances of getting infections, particularly in the lungs. Stopping smoking can reduce your risk of some of the possible **late effects** of chemotherapy and radiotherapy, such as other cancers, heart disease and stroke. If you need advice on alcohol, recreational drugs or smoking, ask your medical team. They will keep what you tell them confidential. They can tell you where you can find relevant information and support.

Sex

If you are sexually active, you can continue to have sex during treatment. You might face some new problems. Low platelets mean you could bruise easily. Vaginal dryness can occur. If intercourse becomes uncomfortable, a water-based lubricant might help.

Contraception remains very important during treatment:

- Although treatment may affect your fertility during treatment, you may still be able to make a baby. Some chemotherapy drugs can damage eggs and sperm, which can prevent a baby from developing normally. Talk to a doctor or nurse straightaway if you suspect that you or your partner have become pregnant during your treatment.
- Ask your medical team whether you can continue to use your usual contraceptive.
- Vomiting and diarrhoea make the contraceptive pill less effective.

It's important to use a condom if you have sex. Condoms protect your partner from your treatment and protect you against infection.

The emotional and physical aspects of lymphoma and its treatment can affect your sex life. You might lose interest in sex, or feel too tired. Talk to your partner and find other ways to stay close. For many people, sex drive returns to normal once their treatment is over. However, regaining sexual desire and confidence can take time.

CLIC Sargent have more information for young people about [relationships and sex](#), which you might find useful.

Your feelings

[Coming to terms with having lymphoma](#) is difficult. You might need time to take it all in and accept your illness.

Your feelings are likely to change over time as you have good days and bad days. Your treatment can also affect your moods and you may find yourself on an emotional swing. Find ways to manage your feelings. Talking to family and friends or joining discussions about lymphoma on the Lymphoma Action [online forum](#) may help. When you feel able, exercise; doing the things you enjoy and a change of scene may make you feel more positive. Having lymphoma might change your outlook on life.

Losing control over what's happening to your body can affect your confidence. Focus on what you can control. For example, if you [lose your hair](#), wearing a hat or a wig can make you feel less self-conscious. As you go through your treatment, take things slowly and do only what you are comfortable with. For example, you could invite friends over if you are worried about going out.

If you are feeling sad or low most of the time and can't seem to escape it for over 2 weeks, you could be [depressed](#). If you feel like this, talk to someone you trust, like your doctor or your parents. You might need some counselling or other treatment to help you work through these negative feelings. It is common to have negative feelings, so don't be afraid to speak to someone about how you feel.

What should I do if I feel ill?

You are more likely to get an infection when you are having treatment for lymphoma. You should follow the advice of your hospital team to reduce the risks of getting an infection. However careful you are, you can't avoid all germs. Some infections come from germs that normally live on your body and get out of control if your white blood cell counts are low. If you have low white blood cell counts, your body is less likely to be able to fight an infection on its own. If you spot signs of an infection, contact your medical team straightaway.

Symptoms of infection include but are not limited to:

- fever (temperature above 38°C)
- hypothermia (temperature below 35°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disorientated
- earache, cough, sore throat or sore mouth
- blocked nose
- shortness of breath
- redness and swelling around skin sores or injuries to intravenous lines
- diarrhoea or vomiting
- a burning or stinging sensation when weeing, or weeing more often than usual
- unusual vaginal discharge or itching
- unusual stiffness of the neck and discomfort around bright lights
- any new pain.

Keep a thermometer handy so that you can easily check your temperature. Remember that shivering can be a sign of infection even if you do not have a fever. This is more likely if you are taking **steroids**, which can mask a high temperature.

Contact your medical team immediately if you have any of the above symptoms, no matter how minor or vague they seem.

You can phone your team at the hospital or get someone to phone for you. You should have been given telephone numbers to call at any time. If not, ask for this information. If your team advises you to go to the hospital, go at once.

It is always best to be checked over and have treatment early if it is needed. A delay can have very serious consequences.

What about school, university or work?

You may want to continue with your studies or work. It is good to keep your life as normal as possible but you must listen to your body. You are likely to need some time off during your illness, particularly during treatment.

Education

If you are at school, you or your parents should talk to the school to tell them what is happening to you. You might be able to go to school some of the time. You can also get help with your studies through hospital teaching or home tutoring. Your medical team will be able to advise you.

I'd been determined from the start to keep up my education, as it was an element of my life I felt I maintained control over. Luckily, I managed to attend about 70% of the time. When I did need to stay in hospital, I always asked school to send work to me, which was helpful, giving me something productive to do!

Ellie, diagnosed at 15

If you are at university, tell your tutor what is going on and they will be as flexible as possible. Your university handbook should include policies in case of illness.

I remember quite a few people asking me what I was going to do about university. At the time, this was not on my mind at all. I emailed the university, simply explaining the situation and saying I wouldn't be going back until the following September.

Natalia, diagnosed at 20

Your school or university will need a letter about your illness. This might be written by your hospital doctor or your GP. Your doctor may charge for this. Your school or university is required to keep this information confidential.

Work

If you are working, tell your boss or human resources (HR) department about your illness. You are not required to do this by law, but you will almost certainly need to take some time off work during treatment. Everyone is different, and it is difficult to tell how much time you will need to take off. You might be able to work from home sometimes when you are able to do your job but are not well enough to travel. By law, your employer cannot discriminate against you. They have to make reasonable adjustments to your working arrangements during your treatment and recovery.

You can decide how much you want to tell other people at work.

Getting back into work after having cancer can feel very challenging. Find out what you can do and what your rights are in our videos about **working after cancer**.

Read our webpage on **day-to-day practicalities** for more information about work, studying, finance and other issues after a diagnosis of lymphoma.

How will my illness affect my relationships?

Your illness is bound to affect your **relationships** with your friends, family and partner.

Talking to your friends

Telling your friends about your illness is difficult. You don't have to do it face to face. You might find it easier to send them a message. Your friends may feel awkward and may not know what to say to you. Tell them what is helpful and unhelpful. Let them ask questions and help them understand what you're going through.

When you are used to your treatment pattern, you can arrange things with your friends on the days when you are likely to feel better.

You may find that your friendships change as some people will be more supportive and understanding than others. Some of your friends may surprise you with their support during your illness.

Family relationships

You may feel like you can't talk to your parents about how you feel because they are already worried about you. Talk to your hospital team as they can offer extra support to your parents so they can deal with their worry better. Don't hide how you feel from your parents; they want to support you.

If you are living at home, you may find that your parents seem overprotective and controlling. They might not want you to go out with friends. Remember: they're trying to protect you. There may be good reasons for their worries. For example, if your white cell count is low, you should avoid crowded places like cinemas, clubs, busy shops and public transport to lower your risk of infection. Talk to your parents if their behaviour is bothering you. It might help to agree some rules together.

It can be difficult to deal with younger siblings at home while you are ill. They might irritate you if you are not feeling well. They could also be jealous of the attention you are getting. Perhaps you will feel jealous of them carrying on with their lives as if nothing has happened. Like all of your friends and family, they will be worried about you. If you talk to them, they may also surprise you with their support.

If you have children yourself, telling them you have a type of cancer can be one of the most difficult things you do. Find out more about **talking to children about lymphoma**.



My family were amazing and really helped me through. For example when I lost my hair, my younger sister would wear a head scarf when we went out, so that people wouldn't focus on me. Slowly I began to feel more myself again.

Hayley, diagnosed at 20

Staying close to your partner

This can be a tough time for relationships. If you have a partner, they will probably feel helpless. Let your partner know what they can do to help you. Be honest with each other and talk about how you are feeling.

Some tips for maintaining relationships during your illness:

- Tell people how you feel when you are ready to talk.
- Remember that your friends and family are worried about you.
- Let people do things for you – they will want to feel useful, even if it's in a small way.
- Do the things you enjoy with your friends and family when you can.

Download or order our booklets, [Young person's guide to lymphoma](#), and [Living with lymphoma](#) for more detailed, practical advice to help you manage your relationships during this time.

What happens when my treatment is finished?

You will probably feel a mixture of emotions when your treatment is finished. It can be a big relief for some but many people feel quite low. You may also find that life is suddenly very different as you won't have hospital appointments all the time. You will still be seen as an outpatient, though, to make sure everything is ok.

Follow-up

You will have regular **check-ups** for several years after your treatment has finished to make sure you are in remission (there is no sign of lymphoma). It is very important that you go to these appointments. If test results are good over time, you can be confident that the lymphoma has not come back. If the lymphoma has come back or you have a late effect of treatment (a side effect that doesn't show up until months or years after treatment), the sooner it is found the better. Your medical team will tell you what symptoms and side effects to look out for while you are in follow-up. If you are unsure what to look out for in the future, ask your medical team. You might find it helpful to keep a note of what they say.

After several years, you may go into long-term follow-up, where the focus is on checking for any **late effects** of treatment.

If you are worried or have any new **symptoms** in between check-ups, you don't have to wait until your next appointment. Contact your medical team. They can reassure you or arrange for you to see them earlier than planned.

In remission – medical matters

It is really important that anyone treating you in the future knows that you once had lymphoma, and what treatment you've had. You should be given a card with all the important information. Ask for it if you haven't been given one. Always carry it with you. If you have had your **spleen removed**, have been treated with **radiotherapy**, have received **steroids**, or need **irradiated blood** if you ever have a blood transfusion, you might need to carry cards that mention this. These cards mean that anyone treating you will be aware of potential problems and be able to monitor you closely or give you alternative treatments.

There are some things you will need to be careful about after treatment for lymphoma:

- Use a high-factor sun screen and avoid sunbeds. Chemotherapy and radiotherapy make your skin more sensitive to the sun.
- Get advice from your doctor before **travelling abroad**.
- Take care of your immunity. Lymphoma treatment can cause you to lose some of the immunity you had from childhood vaccines. You might need to have some vaccines again. You may have to wait until at least a year after your treatment to have some **live vaccines**. Ask your lymphoma consultant for advice about vaccinations – for example ask if you should have the yearly flu jab.
- Some drugs that treat lymphoma can affect your breathing, so if you ever need an operation, the anaesthetist will need to take special care.

- Some of the chemotherapy drugs used to treat lymphoma can affect the strength of your heart. Ask your doctor if you need to avoid activities that put extra strain on the heart, such as lifting weights.
- If you had treatment that can affect the heart and you get pregnant later in life, you may need a scan of your heart and you may need to be monitored more carefully during labour.

Your medical team will be able to advise you about these or any other issues that concern you after treatment.

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



**I went travelling for 6 months after being told I was in remission.
Don't let your cancer diagnosis stop you. Listen to the advice given
to you by medical professionals and most importantly,
enjoy yourself!**

Greg, diagnosed at 23, and family

References

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

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