Autologous
stem cell
transplant

Lymphoma action

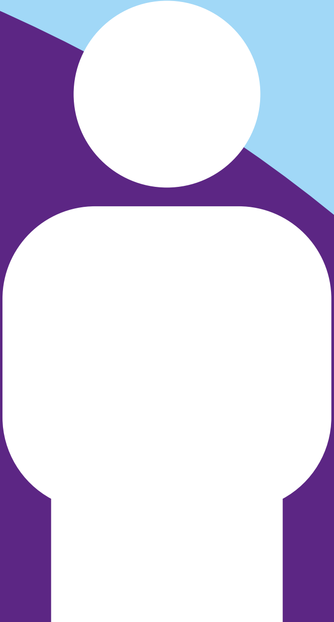
Autologous stem cell transplant

A transplant that uses your own stem cells

What is a stem cell transplant?

Having a stem cell transplant

After a stem cell transplant



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Patient Information Forum

The stem cell transplant pathway

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Your lymphoma type

Key contact

Name: ______________________________

Role: ______________________________

Contact details: ______________________________

Job title/role	Name and contact details
GP	
Consultant haematologist/ oncologist	
Clinical nurse specialist or key worker	

About this book

Some people with lymphoma need high-dose anti-cancer treatment followed by a stem cell transplant, which allows their body to make healthy blood cells again after treatment. This book explains what a stem cell transplant is and what to expect if you, or someone you know, are having one.

This book is about stem cell transplants that use your own **stem cells** (known as **autologous** stem cell transplants or 'autografts').

Important and summary points are written in the chapter colour.

★ Lists practical tips and chapter summaries.

✎ Space for questions.

➚ Lists other resources you might find useful.

This book uses some scientific words. Words that are in **blue** are explained in the glossary on pages 120 to 125.

The information in this book can be made available in large print.

Contents

By the time of the transplant I was feeling better and stronger. I was in no doubt that the transplant was the right course of action, but I was very anxious about it and knew it would be challenging.
Owen, who was diagnosed with angioimmunoblastic T-cell lymphoma and had an autologous stem cell transplant

What is an autologous stem cell transplant?

What are stem cells?

Every day, your body makes more than 300 billion new blood cells to replace cells that die off naturally. These new blood cells develop in your **bone marrow** (the spongy tissue in the centre of some of your large bones). They develop from ‘haematopoietic’ (blood-making) **stem cells**, which are undeveloped cells that can divide and mature into all the different types of blood cell your body needs. We call them ‘stem cells’ in the rest of this book.

Stem cells can develop into three main types of blood cell:

- **white blood cells**, such as **neutrophils** and **lymphocytes** (the cells that are abnormal in lymphoma), which fight infection
- **red blood cells**, which carry oxygen around your body
- **platelets**, which help your blood to clot if you have an injury.

Stem cells are constantly dividing to make new blood cells. This means they are very sensitive to the effects of chemotherapy and radiotherapy, which target cells that are dividing rapidly.

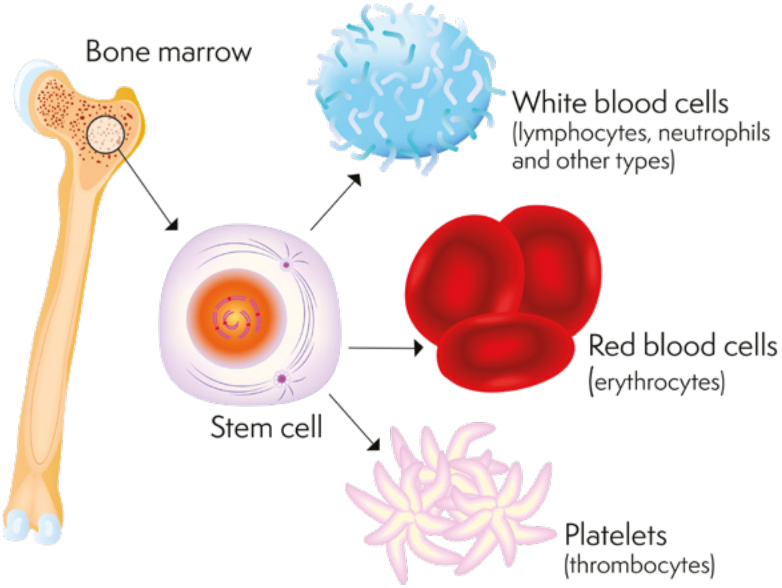


Figure: A stem cell and the blood cells it can produce

What is an autologous stem cell transplant?

A stem cell transplant is a procedure that replaces damaged or destroyed stem cells in your bone marrow with healthy stem cells.

If you have lymphoma, you might need high-dose anti-cancer treatment followed by a stem cell transplant (see page 59). High-dose treatment aims to destroy the lymphoma cells but it also damages or destroys your stem cells. This damage stops you making enough new blood cells. A stem cell transplant allows you to recover and begin to make new blood cells.

There are two different kinds of stem cell transplant:

- **autologous** stem cell transplant that use your own stem cells
- **allogeneic** stem cell transplants that use stem cells from a donor.

This book is about **autologous stem cell transplants**.

Most stem cell transplants used to treat people with lymphoma are autologous stem cell transplants.

'Autologous' means something that comes from you, rather than something that comes from someone else. In an autologous stem cell transplant, your own stem cells are first collected and stored. You are then given high-dose anti-cancer treatment, after which your own, stored, healthy stem cells are given back to you.

Other names for a stem cell transplant include:

- bone marrow transplant (if the healthy stem cells are collected from your bone marrow – although this is unusual nowadays; see page 56)
- high-dose therapy and stem cell rescue or support
- peripheral blood stem cell transplant (if the healthy cells are collected from your bloodstream; see page 51).

Who might need an autologous stem cell transplant to treat lymphoma?

Most people with lymphoma do not need a stem cell transplant. However, in some cases, an autologous stem cell transplant is more likely than standard chemotherapy to cure your lymphoma or make your remission (no evidence of lymphoma) last longer than would otherwise be possible.

Stem cell transplants are used for many types of lymphoma in a variety of situations. You might have an autologous stem cell transplant:

- as part of your first treatment if your doctor thinks your lymphoma is likely to come back (**relapse**)
- if your lymphoma relapses after a previous treatment
- if your lymphoma didn't respond to previous treatment (**refractory lymphoma**).

If you have Hodgkin lymphoma or high-grade non-Hodgkin lymphoma

Autologous stem cell transplant after relapse

Most people treated with a stem cell transplant have Hodgkin lymphoma or a fast-growing (high-grade) non-Hodgkin lymphoma that has relapsed (when your lymphoma comes back) after the first course of treatment. This might include people with Burkitt lymphoma, diffuse large B-cell lymphoma (DLBCL), T-cell lymphoma or primary central nervous system lymphoma.

The aim of treatment in these situations is to provide long-term remission or cure.

Autologous stem cell transplant during remission

Some people with high-grade non-Hodgkin lymphoma might be offered a stem cell transplant when they are in remission after their first course of treatment. This is usually if they have a type of lymphoma with a high risk of relapse, such as fast-growing mantle cell lymphoma or primary central nervous system lymphoma, or other factors that suggest they might be at high risk of relapse.

The aim of treatment in this case is to reduce the risk of relapse and to increase the chance of cure.

If you have low-grade non-Hodgkin lymphoma

Stem cell transplants are sometimes used for people with slow-growing (low-grade) non-Hodgkin lymphoma, such as follicular lymphoma or Waldenström's macroglobulinaemia. Advanced low-grade non-Hodgkin lymphomas are more difficult to cure than other types of lymphoma. They are very likely to come back (relapse) after treatment.

The aim of stem cell transplants for low-grade lymphomas is to make your remission last as long as possible. Some people with low-grade lymphoma might be cured in this way, but cure is less common for low-grade lymphoma than for other lymphomas.

Is an autologous stem cell transplant suitable for you?

An autologous stem cell transplant is an intensive form of treatment and you have to be well enough to have one. It can take around 3 to 6 months to recover physically, and 6 to 12 months for your immune system to recover. This might vary depending on your individual circumstances, for example your age and fitness levels. It isn't suitable for everyone with lymphoma, even if the lymphoma has relapsed or has not responded to treatment.

Your medical team consider lots of different factors before recommending a stem cell transplant. These include the type and **stage** of your lymphoma, the symptoms you have, how fit and well you are, any other health conditions you have, your individual outlook and your own personal preferences.

- Autologous stem cell transplants work best if your lymphoma responds to chemotherapy and is either in **complete remission** (no evidence of lymphoma on tests and scans), or in as good a **partial remission** as possible (usually this means your lymphoma has reduced by at least half).

- If your lymphoma has relapsed after chemotherapy, or if it did not respond to your first course of chemotherapy (refractory lymphoma), you are likely to have a different course of chemotherapy to reduce your lymphoma as much as possible before having a stem cell transplant. If your lymphoma does not respond to this chemotherapy, you are unlikely to be able to have a stem cell transplant. Your doctor can discuss other options with you.

If your doctor recommends a stem cell transplant, they should discuss the process with you and give you information about what is involved. They will explain why they think it is the best option for you and what the possible benefits are. They will also tell you about the possible risks of having a stem cell transplant, including the low risk of dying.

A stem cell transplant is a big decision. Your team will give you time to consider whether it is the best option for you.

> **I managed to canvass the opinion of as many doctors as I could about the merits of the stem cell transplant and they were unanimous in their opinions that this was the best course of action for me.**
> Richard, who was diagnosed with primary central nervous system lymphoma and had an autologous stem cell transplant

Ask as many questions as you want to.

Questions to ask your medical team

- What is a stem cell transplant? How does it work?
- Why are you recommending one for me?
- What is the chance it will be successful?
- What are the risks of a stem cell transplant?
- Do you think the benefits outweigh the risks for me?
- What does the transplant involve?
- What happens if it doesn't work?
- What are the alternatives?

Summary

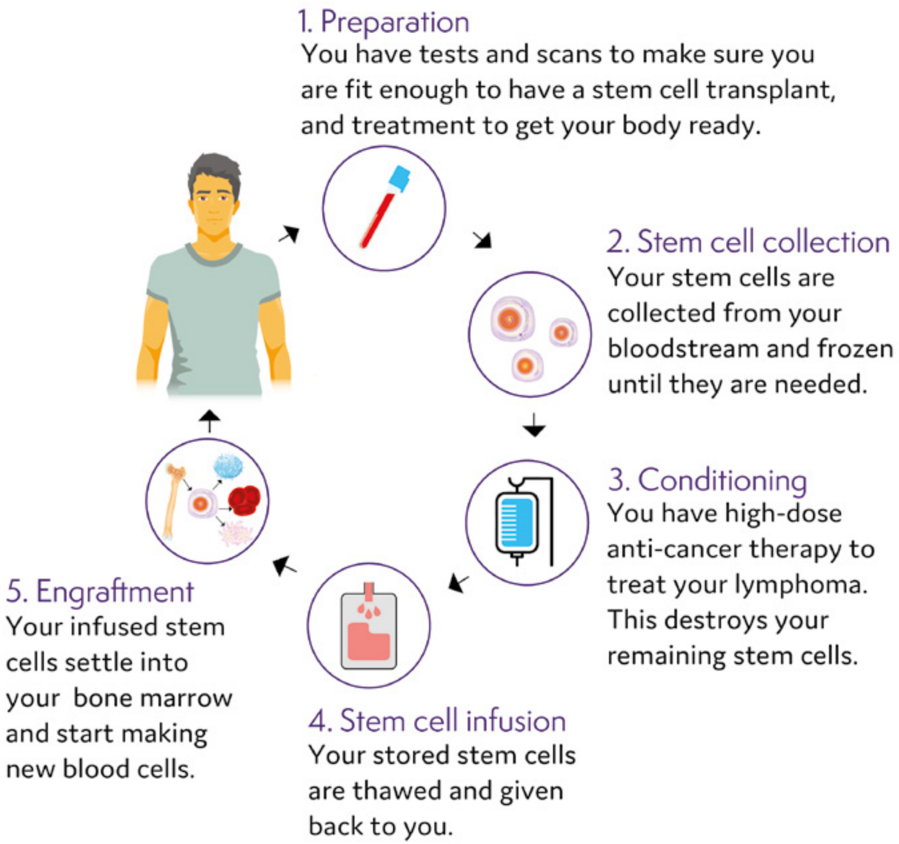
- Stem cells are immature cells that make all the different types of blood cell your body needs.
- Stem cell transplants give some people with lymphoma a better chance of having a long-lasting remission or cure.
- Stem cell transplants are used to treat some people who have lymphoma that has relapsed, didn't respond to treatment or who have a high chance of relapse.
- Stem cell transplants are a very intensive treatment. It can take many months to recover.

The autologous stem cell transplant process

An autologous stem cell transplant involves several different stages. The whole process takes weeks or months and it can take many months to recover afterwards.

You can find more information about each stage in different chapters of this book.

Although autologous stem cell transplants are an intensive form of treatment, they are safer and more effective now than ever before. There are lots of effective treatments that can help support your body while you and your blood counts recover.



1. Preparation
You have tests and scans to make sure you are fit enough to have a stem cell transplant, and treatment to get your body ready.

2. Stem cell collection
Your stem cells are collected from your bloodstream and frozen until they are needed.

3. Conditioning
You have high-dose anti-cancer therapy to treat your lymphoma. This destroys your remaining stem cells.

4. Stem cell infusion
Your stored stem cells are thawed and given back to you.

5. Engraftment
Your infused stem cells settle into your bone marrow and start making new blood cells.

Figure: The autologous stem cell transplant process

Don't be afraid to talk to people; they are part of this whirlwind that is lymphoma. They can help you think through decisions now and in the future.

Jules, who was diagnosed with Hodgkin lymphoma and had an autologous stem cell transplant

Preparing for a stem cell transplant

Where will you have your transplant?

Usually, autologous stem cell transplants are carried out in a hospital. However, if you are well enough, you might be offered an 'ambulatory stem cell transplant', where you will be treated as an outpatient.

Transplant units in hospitals

Stem cell transplants are carried out by specialist transplant units, usually in larger hospitals. There are around 50 transplant units throughout the UK. Your nearest unit might be some distance away, at a different hospital from the one where you've had the rest of your lymphoma treatment. Before your transplant, you are likely to have the opportunity to visit the transplant unit and meet the key people involved in your care.

Most people stay at the transplant unit for a few weeks to have a stem cell transplant.

> **I felt reassured to be in the haematology ward because the doctors and nurses there really understood my illness and treatment.**
> Richard, who was diagnosed with primary central nervous system lymphoma and had an autologous stem cell transplant

Ambulatory stem cell transplants

Some transplant units offer stem cell transplants as an outpatient for people who are well enough to have one. This is called an 'ambulatory stem cell transplant'. Many units ask that you have a relative or close friend who is able to be with you at all times to be eligible for an ambulatory stem cell transplant.

If you have an ambulatory stem cell transplant, you might be able to stay at home – or, if you live far away from the hospital, at accommodation arranged by your transplant unit. This might be a room at a nearby hotel or a facility owned by the hospital.

You travel to the unit every day for treatment, blood tests and check-ups but you go home (or to your arranged accommodation) at night. Some transplant centres might offer partial ambulatory care, where they plan to admit you on a certain day after you receive high-dose chemotherapy. **You can contact your transplant unit at any time of the day or night if you need to.** If necessary, you are admitted to the unit.

An ambulatory stem cell transplant is not suitable for everyone. If it is an option for you, your transplant team will discuss it with you and explain exactly how it works in your unit.

Your transplant team

Lots of health professionals with specialist knowledge in different areas of care and support are involved in stem cell transplants. This might include haematologists, specialist nurses, counsellors, physiotherapists, dietitians, radiologists, pathologists and many more. This is your transplant team. You might see some members of your team regularly but others are only involved in your care occasionally.

You will be assigned a clinical nurse specialist, key worker or transplant co-ordinator who will be your main contact at the transplant unit. This is usually a nurse trained to look after people who are having a stem cell transplant. They discuss your treatment with you and answer any questions you have.

If you are referred from another hospital, you might have two key contacts: one from your local hospital and another at your transplant hospital. The two key contacts will communicate with each other to co-ordinate your care.

Make sure you have a name and contact details for your key worker. You can write these at the front of this book on page 3.

Information and consent

Your transplant team will give you lots of information as you get ready for your transplant. This might include:

- why they feel a transplant is the best option for you
- the possible risks and benefits of having an autologous stem cell transplant
- the exact treatment you need and when you're likely to have it
- what side effects to expect in the short term
- information about any late effects or long-term effects you might be at risk of developing
- the names and contact details of key people involved in your care
- details about the transplant unit
- guidelines about visitors, and what visitors can and can't bring in
- what to bring with you for your hospital stay.

Keep all the information you're given in a file or folder so you can refer to it when you need to.

You are likely to have more than one appointment with your key worker and transplant team to give you a chance to discuss your transplant in detail before you decide whether or not to go ahead with it.

You have to give formal written consent before you can have your stem cell transplant. Your key worker will explain the process to you. Your transplant team will talk you through the consent forms that you need to sign.

Read the forms carefully and make sure you understand everything on them. Ask any questions you have, however simple they might seem.

Signing the forms says that you agree to have the treatment and that you have been informed about what is involved, including the possible risks and side effects.

Your transplant team might also ask for consent to collect information about your transplant for research purposes. This can include your diagnosis, the treatment you had and your outcome. The information is anonymous and helps scientists make sure stem cell transplants are used in the most effective way in the future.

Questions to ask your key worker

- Where will I be treated?
- How long will I be in hospital?
- Is there anywhere my family can stay when they visit if it's too far from home?
- Can the treatment centre provide any extra support, such as counselling or complementary therapies?
- What do I need to think about before my transplant?
- How can I prepare for my transplant?
- When might I be able to return to work or education?

What is salvage therapy and will you need it?

Depending on the type of lymphoma you have and how well it has responded to treatment, you might need to have a course of therapy before you can be considered for a stem cell transplant. This might be chemotherapy, **targeted therapy** or a combination of the two. It is sometimes called 'salvage therapy'. You might also hear it called 'reinduction therapy'.

Salvage therapy aims to reduce your lymphoma as much as possible to give you the best chance of responding to a stem cell transplant. How much the lymphoma reduces by is different for everyone.

If you need salvage therapy, the exact treatment you have depends on:

- the type of lymphoma you have
- what treatment you've had before
- how you responded to previous treatment.

Your medical team will tell you what salvage therapy they recommend for you and how you have it. Most people have salvage therapy as an outpatient.

Your medical team will assess how well you respond to the salvage therapy before planning your stem cell transplant. If your lymphoma doesn't respond well enough, a stem cell transplant might not be suitable for you. If this is the case, your medical team will discuss other treatment options with you.

Tests and procedures to get you ready for your transplant

Before having your stem cell transplant, you need tests to make sure it is the best option for you and that you are well enough to have it. Some people might have treatment to help preserve their fertility (see page 30), if they have not already done so. Most people have a **central line** (also known as a central venous catheter) fitted (see page 31).

Lymphoma staging tests

Before your stem cell transplant, you have tests and scans to check the stage of your lymphoma. These tests find out how much lymphoma is in your body, where it is, and how much it has been reduced by any treatment you have had already.

These staging tests are likely to be the same as the tests you had when you were first diagnosed with lymphoma. They might include a **CT** or **PET/CT** scan and possibly a **bone marrow biopsy**. If you have lymphoma in your brain or spinal cord (your central nervous system), you might also have a **lumbar puncture**.

Blood tests

Blood tests you are likely to have include:

- a **full blood count** (FBC) to check your levels of red blood cells, white blood cells and platelets
- blood typing to find out your blood group
- tests of your liver, kidney and thyroid function
- tests of glucose and iron levels
- tests to find out how well your blood clots
- tests for certain viruses, such as hepatitis and human immunodeficiency virus (HIV), to make sure the laboratory can store your stem cells safely

- tests for infections that might be dormant (inactive) in your body – this lets your transplant team be aware of any flare-ups that could happen when your white blood cell count is low.

Organ function tests

Some lymphoma treatments can damage your organs, particularly when given in high doses. You have tests before your transplant to check the health of your major organs, like your lungs, heart and kidneys. Your transplant team can give you more information about the particular tests they recommend.

Lung function tests

Lung function tests usually include breathing tests to make sure your lungs are working well, and a chest X-ray. Some people have blood tests to make sure there is enough oxygen in their blood.

As you might expect, breathing tests involve a lot of breathing in and breathing out. You might be asked to breathe into machines that take measurements. Sometimes this means breathing normally and sometimes you are asked to breathe as deeply as you can, blow as hard as you can or do breathing exercises. Sometimes your lung function is tested while you exercise. You should not have any side effects from these tests, but you might feel tired or light-headed afterwards.

Heart tests

Heart (cardiac) tests usually include:

- an **electrocardiogram** (**ECG**), which is a trace of your heart's rhythm and electrical activity
- an **echocardiogram** or 'echo', which is an ultrasound scan of your heart to check if it is filling and emptying correctly.

Both tests are painless. You have to take your top off and lie down on an examination couch or bed.

An ECG only takes a few minutes. A nurse or ECG technician attaches small sticky sensors to your chest, arms and legs. They then connect the sensors to a machine that produces a trace showing the activity of your heart.

An echocardiogram takes around 30 to 40 minutes. A healthcare professional puts gel on your chest or on an ultrasound probe. It might feel a bit cold. They then move the probe across your chest. The probe sends signals to a machine that displays pictures of your heart.

Some centres might use a **'multigated acquisition' (MUGA) scan** instead of an echo. For this, you have two injections of a harmless radioactive tracer. The injections can go straight into your central line if you have one (see page 31). You then have a scan to take pictures of how the tracer moves through your heart and blood vessels. A MUGA scan takes about an hour.

Kidney tests

Blood tests can give a good indication of how well your kidneys are functioning. Sometimes, you might also need to collect all your urine for 24 hours for further tests of your kidney function.

Some people might have a **glomerular filtration rate** (GFR) test. You first have an injection of a harmless radioactive dye. You then have blood samples taken for a few hours to measure how well your kidneys are filtering out the dye. The blood samples can be taken from your central line if you have one. You shouldn't drink caffeine for 12 hours before the test or alcohol for 24 hours before the test.

For more information about tests and staging, visit lymphoma-action.org.uk/Tests

Fertility preservation

The high-dose therapy used in a stem cell transplant can damage your testes or ovaries. Some people are able to have children after a stem cell transplant, but many are not. It is likely that your lymphoma team will have discussed this with you before your previous lymphoma treatment. Your transplant team should also discuss this with you and explain the risk of fertility being affected with your particular treatment.

If you think you might want to have children in the future, talk to your transplant team about whether you are eligible for treatment to help preserve your fertility, such as collecting and freezing your sperm or eggs. Your transplant team can refer you to a fertility specialist if this might be an option for you.

Visit the Fertility Network at fertilitynetworkuk.org for advice and support about fertility issues.

Having a central line fitted

A central line (also called a central venous catheter or CVC) is a long, thin, flexible tube that is inserted through a small vein in your arm or chest and ends in a large vein deeper inside your body. A central line is used to give medicine directly into your bloodstream through your veins (**intravenous** medicines) and to take blood samples. It means you don't have to have a needle put into your arm every time you need treatment or a blood test.

If you don't already have one, you have a central line fitted before your high-dose anti-cancer therapy starts. It stays in place until your treatment is over. You can have all your intravenous treatment through it and your blood tests taken from it.

There are two common types of central line:

- A peripherally inserted central catheter (PICC line) usually goes in through a vein at the front of your elbow.
- A tunnelled central line (for example, a Hickman® line) usually goes in through your upper chest. It runs in a tunnel under your skin and then enters a vein in your neck.

Both types sit in a large vein near your heart.

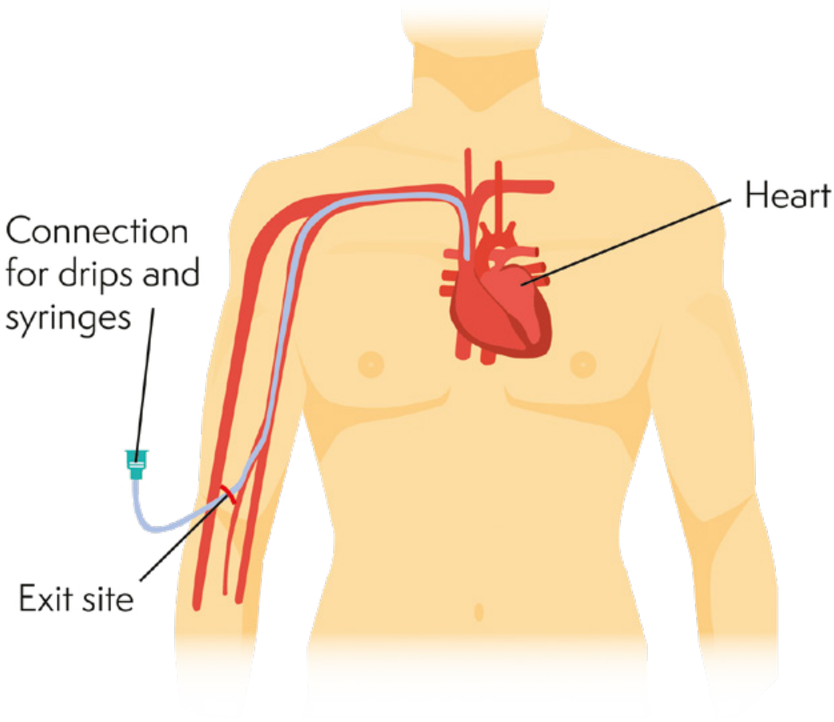


Figure: A PICC line

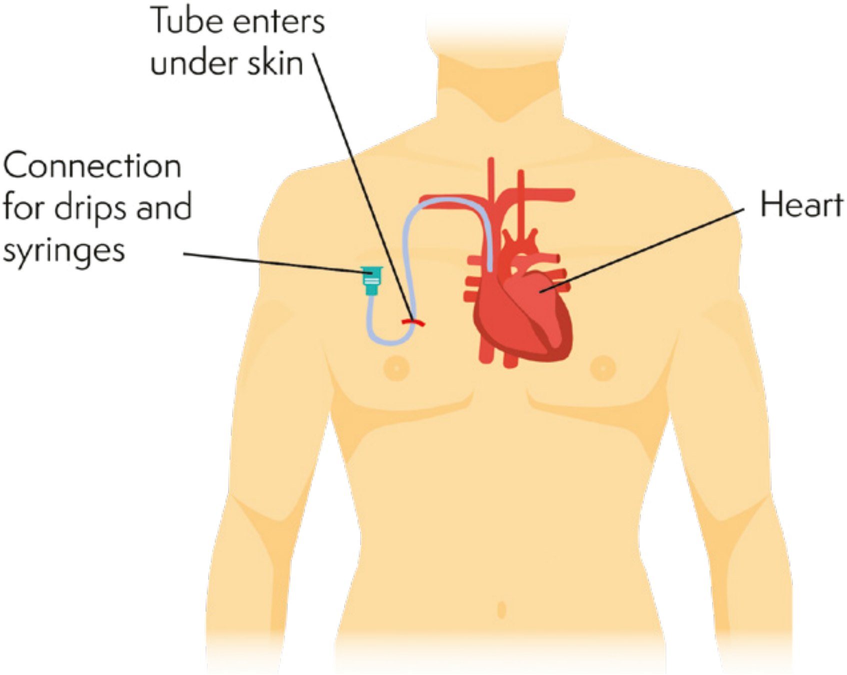


Figure: A tunnelled central line (for example a Hickman® line)

You have your central line fitted under a local anaesthetic. Some people also have a sedative to relax them. You have a chest X-ray or ECG during the procedure to check the central line is in the right position.

Looking after your central line

Your central line should stay in place for the whole of your treatment. Your transplant team show you how to care for it and what to look out for.

Every week between treatments, your dressing is changed and your line is flushed with a small amount of sterile fluid to stop it getting blocked. You might have this done at hospital, or your team might show you or your carer how to do it yourselves.

You can have a shower or a bath with a central line in but you must keep the end dry.

Ask your nurse for waterproof dressings or tape to stop the line getting wet.

Check your central line regularly. **Call your key worker if you have any problems or if you need advice.**

You usually have your line removed when you don't need any more blood or platelet **transfusions**. This is generally around 6 to 8 weeks after your transplant, although some centres might remove your line when you are discharged after your transplant.

Contact your key worker or hospital contact immediately if:

- you have any pain, tenderness, redness or swelling where your line goes in
- your neck, shoulder or arm on the side where you have the line are painful, red or swollen
- you have a high temperature (above 38°C)
- you have any other symptoms of infection, such as shivering, chills or feeling generally unwell
- your line has moved.

Things to plan before your transplant

You should be given a timetable of when things are expected to happen. This can help you make arrangements with your employer, college or university. You might also need to arrange extra support for anyone who depends on you, particularly if you have older relatives or young children. In some circumstances, your transplant team might be able to plan your treatment to fit in with important events in your life.

Lymphoma and its treatment can be difficult to cope with emotionally and psychologically. You might be offered psychological support or counselling before, during or after your stem cell transplant. You can ask your medical team if this support is available.

Support and visitors

It can be helpful to share the information you are given about your treatment with the people close to you. This helps them prepare for what to expect during and after your transplant. It also helps them understand your needs and how to support you while you recover. You might find it useful to show them this book.

Many people have stem cell transplants some distance from home. Think about how you, and your visitors, are going to travel to and from the transplant unit. Ask your key worker for information about local or hospital accommodation for your family if they need it. Check your hospital's visiting policy before making any plans.

Think about who you'd like to visit you while you are recovering. Explain to them that there might be days when you don't feel well enough to have visitors at all. Let them know that it could take you a while to get better, even many months.

> **We set up a WhatsApp group for friends and family where my husband posted regular updates. The support I felt from all the comments was really helpful, particularly when I was not up to having visitors.**
> Linda, who had an autologous stem cell transplant for transformed follicular lymphoma

Work and study

It usually takes at least 3 to 6 months for people to be ready to return to work or study after a stem cell transplant. Everyone is different, and you might need some more time before returning to work or study.

If you are employed, arrange an appointment with your manager or HR department to talk about your treatment and the time you're likely to need off work.

If you are at college or university, talk about your situation with your tutor. They can offer advice about how to manage your studies during and after treatment. If you take time out of your studies, you might be able to get a refund of your tuition fees. Ask your student finance office to check.

> **I began a phased return to work at the beginning of January 2019, and initially worked from home. It was good to be getting back to normal, and I was keen to do so as quickly as possible. I thought it would bring closure to my lymphoma experience.**
> Owen, who was diagnosed with angioimmunoblastic T-cell lymphoma and had an autologous stem cell transplant

Financial and social support

Recovery from a stem cell transplant takes several months. Think about what support you will need when you come home, particularly if you live alone. If you care for someone else, you need support both for you and the person you care for. You might also need financial assistance.

Financial and social support can be complex. Your key worker might be able to help you access any support you're entitled to. Some hospitals provide a social worker for further advice. You might have to wait some time for an appointment with an adviser, so plan ahead.

- **Citizens Advice (citizensadvice.org.uk) have benefits advisers you can contact by phone, online, or in person at your local centre.**
- **Macmillan Cancer Support (macmillan.org.uk) have information about financial support on their website.**
- **Maggie's (maggies.org) have benefits advisers for people affected by cancer.**

Visiting the dentist

Book a check-up with your dentist before you start the high-dose anti-cancer treatment for your transplant. This is important to make sure you don't have any dental problems that could become worse during your treatment or that could be a potential source of infection when your blood counts are low.

If possible, have any dental work you need before you start your stem cell transplant. You should not have dental treatment when your blood counts are low because you are more likely to bleed and you have a higher risk of developing infections.

Preparing for hair loss

High-dose anti-cancer therapy is likely to cause temporary hair loss. Some people choose to prepare for this by cutting their hair short or shaving it off completely.

Whether or not to use a head covering is a very personal decision. If you want to cover your hair loss, there are lots of different headwear and cosmetic options. Try some out beforehand to see what works for you. Think about ways to prevent heat loss and to protect your skin from the sun.

If you think you might want to use a wig, ask your key worker if they can put you in touch with a local wig supplier.

- **mynewhair (mynewhair.org) offers advice for people affected by hair loss and has a database of salons that fit and style wigs.**
- **Search ‘scarves and bandanas’ at macmillan.org.uk for a step-by-step guide to tying a bandana.**
- **Visit lookgoodfeelbetter.co.uk to find free skincare and make-up workshops for people with cancer.**

Things to consider before your transplant

- Make sure you know all the key dates for your treatment: when it starts, when you expect to go into hospital and how long you are likely to be in hospital.
- Think about practical considerations like transport, accommodation and childcare (if necessary).
- Arrange for someone to look after things at home while you are in hospital.
- Talk to your employer, college or university about the time you need to take off and any adjustments you might need afterwards.
- Consider what help you will need when you are recovering from your transplant. What could friends and family do to help you?
- Find out what financial and social support might be available to you and anybody you care for while you are in hospital and during your recovery.
- Visit the dentist.
- Think about how you'd like to deal with hair loss.

What to pack for hospital

Hospitals have rules about what you can bring with you. The rules are there to help keep your room clean and reduce the risk of infection. However, a long stay in hospital can be isolating. Bringing some distractions and home comforts with you can make it easier. Ask what your hospital recommends and consider the following suggestions for what to take with you.

Even if you are having an ambulatory stem cell transplant, have everything you need ready in case you have to be admitted to hospital.

Clothes

Lightweight, loose, soft clothing and machine-washable slippers can make you feel more comfortable. Choose tops that button up the front, as they make it easier to examine you and access your central line. Short-sleeved or sleeveless tops might be more comfortable if you have a PICC line.

Toiletries

Ask what toiletries your hospital suggests. Some units recommend antibacterial soaps, shower products and skin care. You might have dry, sensitive skin after your treatment so choose gentle, moisturising products. Your own supply of soft toilet roll or wipes can be useful.

You might have a sore mouth. Pack some lip salve and a toothbrush with very soft bristles (for example, a toothbrush for 0 to 3 year olds).

Ask your key worker if there is anything else you can bring with you to help with side effects.

Things to pass the time

Find out whether you are able to connect to the internet and what devices are allowed. There will be times when you feel too tired to concentrate so take a variety of things to pass the time, including some that are not demanding. Audio books or relaxation recordings might be useful if you find it hard to concentrate. You are likely to have a television in your room, but you might have to pay for it.

Things to cheer up your room

You can put up photos, drawings and cards. You are not allowed flowers or plants because they are a potential source of infection.

You might be allowed to take your own bedding and soft towels if you have someone who can take them home to wash every day.

Hospital checklist

☐ Soft, comfortable clothes and pyjamas
☐ Gentle toiletries and moisturisers
☐ A toothbrush with very soft bristles
☐ Lip salve
☐ Soft toilet roll or wipes
☐ Things to pass the time, such as books, audiobooks, games, your tablet, phone or laptop
☐ Things to brighten up your hospital room
☐ Soft towels and bedding (if your hospital allows this)

Questions to ask your key worker

- What do I need to think about and prepare before my transplant?
- What facilities are available at the hospital? Is there a TV?
- Will I need to be in isolation?
- Can I have visitors?
- Can I use my mobile phone in hospital? Is Wi-Fi available?
- Is there anything I can or can't bring to make myself more comfortable in hospital?
- What can I bring to help with side effects?

Summary

Before your stem cell transplant:

- you usually visit your transplant unit and meet your transplant team
- you are likely to have salvage therapy to reduce your lymphoma as much as possible
- you have tests and scans to check that a stem cell transplant is suitable for you and that you are well enough to have one
- you might be referred to a specialist to help you preserve your fertility
- you have a central line or PICC line fitted if you don't have one already
- you have time to plan the practical aspects of your treatment and recovery.

Just before the fourth chemotherapy, they took me in to harvest my stem cells. I was given growth factors which increased my production of stem cells. I was connected to a machine while the cells were harvested, followed by the final chemotherapy.

Stephen, who had an autologous stem cell transplant as part of his treatment for mantle cell lymphoma

Stem cell collection

About stem cell collection

Your stem cells are usually collected a few weeks or months before your high-dose anti-cancer treatment. This is sometimes called 'stem cell harvesting'.

Mobilising your stem cells

Stem cells are made in your bone marrow but they are usually collected from your bloodstream. Before they are collected, you have treatment to encourage the stem cells to move from your bone marrow into your bloodstream, where they can be collected more easily. This is called **mobilisation**.

Chemotherapy and **growth factors** are the most commonly used treatments to mobilise your stem cells. You may need other treatments as well.

Chemotherapy

Most people have salvage chemotherapy before a stem cell transplant (see page 25). As well as reducing your lymphoma, this encourages stem cells to move into your bloodstream. Your medical team should be able to explain how long this might take. After you finish your salvage chemotherapy, you also have growth factor injections.

If you don't need salvage chemotherapy to reduce your lymphoma, you are likely to have growth factors on their own to mobilise your stem cells. Occasionally you might have a single day of **'priming' chemotherapy**, which you would receive immediately before your stem cells are collected.

Growth factors

Growth factors are hormones that occur naturally in your body. They stimulate your bone marrow to make stem cells and help them move into your bloodstream.

To mobilise your stem cells ready for collection, you have treatment with a growth factor called 'granulocyte colony stimulating factor' (**G-CSF**). You have G-CSF as an injection just underneath your skin (a **subcutaneous** injection), usually into your stomach, the top of your leg or the top of your arm.

Most people do not need to go to hospital for the injections. Your transplant team can show you, or someone else, how to do them at home, or they can arrange for a nurse to do them for you.

> **If you have never given yourself an injection before, don't worry. They will show you how or you can ask a local nurse to do it for you. But trust me, it's no big deal and very easy. If I can do it, you can.**
> Leo, who had an autologous stem cell transplant as part of his treatment for diffuse large B-cell lymphoma

You usually start your G-CSF injections a few days after finishing your salvage or priming chemotherapy, if you have it. You have the injections once a day for around 7 to 10 days. If possible, you should have your injection at the same time each day.

It is important to remember your G-CSF injections. If you miss a day, it might make it more difficult to collect enough stem cells.

Use a diary, app or write a note and place it at the front or back of this book to keep track of when you have your injection every day. You might find it helpful to set an alarm to remind you.

Most people don't experience many side effects from G-CSF treatment. The most common side effects are muscle and bone aches and pains, and feeling or being sick. Some people might have a high temperature. Tell your transplant team if you experience these. They can advise you on medicines you can take or things you can do to help.

When you are on G-CSF treatment, you might have regular blood tests to see how your blood counts are responding. Most transplant units check your white blood cell count and how many cells have a protein called CD34, which is found on blood stem cells. The CD34 count is a good indicator of whether your bone marrow is starting to produce more stem cells.

When you have enough stem cells in your bloodstream, you go into the transplant unit for your stem cells to be collected.

Other treatments to mobilise stem cells

Chemotherapy followed by G-CSF injections produces enough stem cells in the bloodstream for them to be collected successfully in most people. However, a few people need additional treatments.

If your blood tests show that there aren't enough stem cells in your bloodstream to collect, you might be given a drug called plerixafor (also known as Mozobil®). Plerixafor blocks a protein on the surface of stem cells that normally keeps them in the bone marrow. Blocking this protein helps stem cells be released into the bloodstream.

You have plerixafor as a **subcutaneous** injection 6 to 11 hours before your stem cell collection. The most common side effects are diarrhoea, feeling sick and skin reactions where the injection was given. Tell your transplant team if you experience any side effects.

Collecting your stem cells

You go to hospital to have your stem cells collected but you usually go home the same day. You might have to go back to the hospital for several days in a row until enough stem cells have been collected.

Collecting your stem cells involves passing your blood through a machine that separates the stem cells from the rest of your blood. Your blood – minus your extra stem cells – is then returned to your body. This process is called apheresis. The machine is called a 'cell separator' or 'apheresis machine'.

Preparation for collection

Before your stem cells are collected your veins will be assessed to decide whether you need a special type of tunnelled central line to collect the stem cells. If you don't have a central line, you have a thin, flexible, plastic tube put into a vein in each of your arms. These tubes (or the ports on your central line) are connected to the cell separator machine. You might hear these tubes called 'cannulas'.

A new sterile kit is used in the machine for each person so you are not exposed to infection.

Wear comfortable clothes with short sleeves so it is easy to access your arms.

The collection process

During the collection process, you rest on a bed or chair. A constant flow of blood is taken from the tube in one arm and passes through the machine. The machine collects the stem cells and returns the rest of the blood to your bloodstream through the tube in your other arm. If you have a central line that is suitable for stem cell collection, the blood will be taken and returned through that instead. Only a small amount of blood – less than 220ml or around one-third of a pint – is out of your body at any time.

The collection process takes 2 to 4 hours in total, although you should expect to be at the hospital for the whole day. You have to keep fairly still during this time and cannot move around much.

Bring something to keep you occupied. Listening to music, podcasts or audio books is a good option. Some centres might let someone stay with you to keep you company. Check your hospital's visiting policy.

> **Nurses provided things like tea and coffee all day and really took care of everyone.**
> Leo, who had an autologous stem cell transplant as part of his treatment for diffuse large B-cell lymphoma

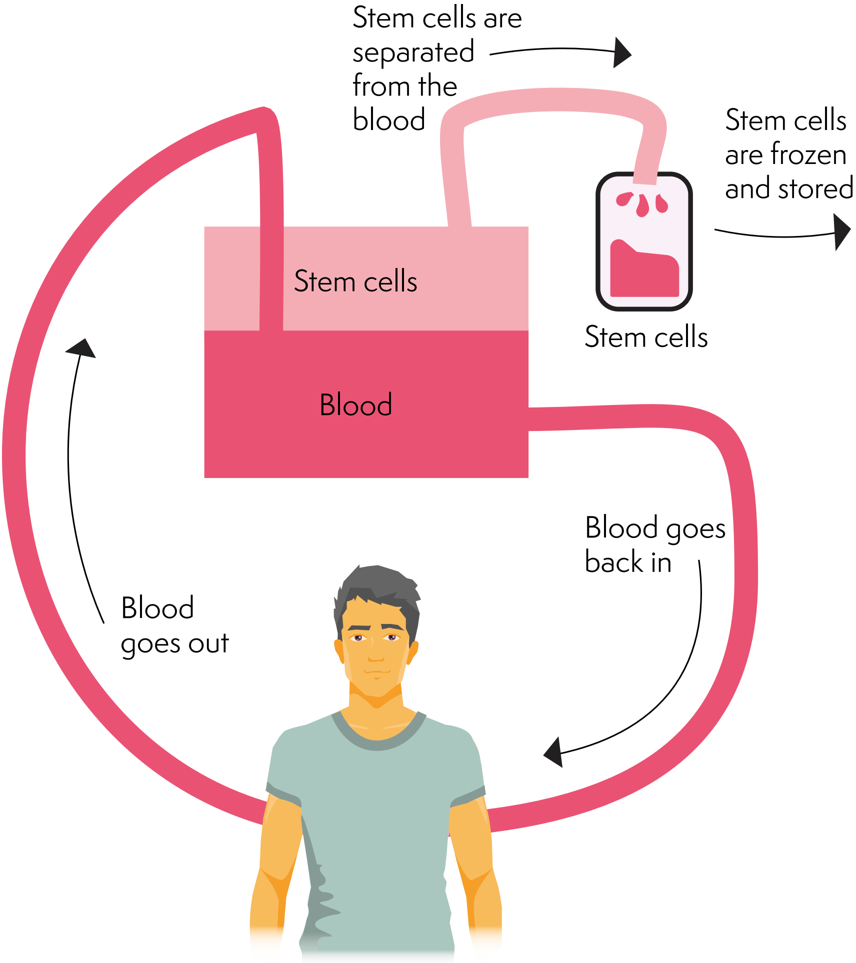


Figure: Stem cell collection

A blood thinner (‘anticoagulant’) is added to your blood as it passes through the cell separator to prevent your blood from clotting in the machine. The blood thinner can cause your blood calcium level to drop. This might cause side effects such as:

- tingling in your lips, nose or fingertips
- shivering or twitching
- nausea or stomach cramps.

These side effects are usually mild. Tell your transplant team if you experience these side effects. They might slow down the machine or give you calcium supplements, either as oral tablets or as an injection into one of your lines.

After the collection

You are likely to feel tired and perhaps a bit shaky after your stem cell collection. You shouldn’t drive afterwards. If you can, arrange for someone to take you home. Tell your medical team if you have any problems arranging a lift – they might be able to make alternative arrangements for you.

Storing your stem cells

After collection, your stem cells are mixed with a preservative and are then frozen, usually within 48 hours of being collected. They are then stored until you are ready for your transplant – usually a few weeks or months after stem cell collection. Very occasionally, your stem cells are stored in case you need a stem cell transplant in the future. Frozen stem cells can be stored for many years.

> **I had stem cells harvested while I was in remission. I had an autologous stem cell transplant about 6 years later.**
> Gary, who had an autologous stem cell transplant as part of his treatment for follicular lymphoma

What happens if you don't have enough stem cells?

After your stem cells have been collected, they are tested to make sure there are enough for a transplant. If there are not enough, you have another dose of G-CSF to boost your stem cell count. You might also have plerixafor (see page 51). You then go back to the transplant unit the next day to have more stem cells collected. It can take up to 4 days to collect enough stem cells for a transplant.

Some people don't have enough stem cells in their bloodstream to have a stem cell transplant even after several treatments. If this is the case for you, your doctor will discuss your options with you.

Very rarely, stem cells can be collected directly from the bone marrow. Your transplant team carry out this procedure in an operating theatre. You have a general **anaesthetic** first to enable your team to harvest enough cells. You then have a needle inserted into the back of the left and right side of your hip bone. The liquid bone marrow is drawn out with a syringe, similar to a bone marrow **aspirate**. The needle is inserted several times to get enough bone marrow stem cells. The injection sites will be sore afterwards but you can take painkillers to help. You can usually go home the same day or the next day.

Summary

- Before your stem cells are collected, you have treatment to boost the number of stem cells your body makes and move the stem cells into your bloodstream.
- When you have enough stem cells in your bloodstream, they are collected using a cell separator machine.
- Stem cell collection can take several hours. You might have to visit the hospital more than once before enough stem cells are collected.
- You might need other treatments if your transplant team can't collect enough stem cells.

Before my stem cell transplant I took my daughter to a Build-A-Bear and she chose a teddy with a recording of my voice saying goodnight to her for when I was having my stem cell transplant. I was away from home for a long time receiving my initial high-dose LEAM chemotherapy for my conditioning treatment.

Katherine, who had an autologous stem cell transplant as part of her treatment for T-cell lymphoma

High-dose anti-cancer treatment (conditioning)

What is high-dose anti-cancer treatment?

When you are ready for your stem cell transplant, you have high-dose anti-cancer treatment. This is called **conditioning**. Conditioning therapy aims to kill any lymphoma that is left in your body after your salvage therapy (page 25), and to reduce or destroy the stem cells left in your bone marrow. This makes room for the stored, healthy stem cells that are given back to you afterwards.

Conditioning usually involves high-dose chemotherapy.

Where do you have treatment?

In the UK, most people stay at the transplant unit to have conditioning therapy. You usually go into the unit just before your conditioning treatment starts and stay there to have your transplant. You go home when your blood counts are at a safe level. This is generally 2 to 3 weeks after your transplant but it can be longer. You are likely to stay in a room on your own while you are waiting for your blood counts to recover. This is to reduce the risk of getting an infection.

If your transplant unit offers ambulatory stem cell transplants (see page 21), you may be able to have your conditioning therapy as an outpatient. You travel to the unit every day for your treatment and go home or to nearby accommodation at night. You go back to the unit every day for checks, blood tests and any treatment you need for side effects. You can be admitted to the unit if you have any problems that need closer monitoring.

High-dose chemotherapy

Conditioning involves high-dose chemotherapy and supportive medication. The exact chemotherapy you have, and the time it takes to have it, depends on several factors, such as:

- the type of lymphoma you have
- what treatment you've had before and how you responded to it
- your general health
- the usual practice at your hospital.

Your transplant team should explain to you what conditioning treatment they recommend and why. They will tell you what the treatment involves and what side effects you might experience.

Several combinations of chemotherapy drugs can be used for conditioning treatment before an autologous stem cell transplant.

One of the most common conditioning treatments for people with lymphoma in the UK is a combination of chemotherapy drugs called **BEAM**:

- carmustine (also known as **B**iCNU® or **B**CNU)
- **e**toposide
- **a**ra-C (also called cytarabine)
- **m**elphalan.

You might have a different regimen depending on what your medical team recommends and what your centre offers. For example, some centres might use **l**omustine or **t**hiotepa instead of BCNU (**LEAM** or **TEAM**).

You usually have high-dose chemotherapy over 6 days. Different drugs are given on different days. You have the drugs through a drip into your central line. You also have extra fluid through your drip to protect your kidneys. An infusion machine might be used to make sure the drugs are given at the correct rate.

You might need to go to the toilet more often than usual when you are on a drip because you have a lot of fluid coming into your body over a relatively short time. You should still try to drink plenty of water.

We cover the most common side effects of conditioning therapy on pages 82 to 89.

Search ‘BEAM chemotherapy’ at macmillan.org.uk for more information.

Questions to ask your key worker

- What high-dose therapy will I have?
- What are the likely side effects of my treatment?
- Is my treatment likely to reduce my fertility? Is there a way to preserve my fertility?
- Where will I have my treatment?

Summary

- High-dose chemotherapy aims to kill any lymphoma that is left in your body after your induction therapy.
- Most people with lymphoma have a high-dose chemotherapy regimen called BEAM. You have it through your central line over 6 days.
- Most people stay in hospital to have their high-dose therapy.

Trevor had nine bags of stem cells altogether and it was quite a performance. One person would open the drum (at which point a cloud of steam would appear) and pull out a frozen bag of stem cells that looked a lot like a slice of frozen smoked salmon. They would defrost it in a water bath for a few minutes then hand it over to a nurse to be hung on the drip stand.

Sue, whose husband Trevor had an autologous stem cell transplant for follicular lymphoma. Since his transplant, Trevor has competed for Ireland in the European Transplant Games in Oxford.

Stem cell infusion

Having your stem cell transplant

You usually have your stem cell infusion 1 to 2 days after finishing your conditioning treatment, although you might have it sooner, depending on what chemotherapy drugs you've had. The process of being given your stem cells is called a **stem cell infusion**.

Your transplant team refer to the day of your transplant as **day zero**. They measure your recovery time from this day.

What happens on transplant day?

On the day of your transplant, you have medication (such as paracetamol and antihistamine) to help stop you reacting to the preservatives used to freeze your stem cells. You then have the stem cell infusion through a drip into your arm or into your central line, just like a blood transfusion.

> **The transplant is a bit of an anti-climax after all the preparation beforehand, as the procedure is just like a blood transfusion.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Some people find the day of their infusion quite emotional. If you find it hard to cope with your emotions, tell your nursing team. They can suggest techniques that might help.

A stem cell infusion is a very straightforward procedure that takes around an hour, depending on the number of bags of stem cells you need to have. You might have a single bag of stem cells or several bags, depending on how many bags have been collected. Each bag is defrosted just before you have it.

Your nurse checks your pulse, blood pressure and oxygen levels regularly during your infusion. They stay with you until your infusion is finished.

Side effects from stem cell infusions are rare. Some people have mild side effects such as:

- feeling sick or being sick
- a bad taste or burning feeling in your mouth
- high blood pressure
- allergic reaction
- infection.

Some of these are related to the preservatives used when stem cells are frozen. You are closely monitored for signs of any side effects or reactions and treated for them straightaway. If you have side effects, your infusion might be slowed down.

Sipping a flavoured drink or sucking sweets can help with the bad taste.

Tell your nurse if you feel unwell during your stem cell infusion.

The preservative used to store your stem cells has a distinctive smell; some people say it smells like sweetcorn or garlic. You or your visitors might be able to smell it on your breath or in your room for a few days after your stem cell infusion. It gradually fades away.

Summary

- The day of your stem cell infusion is sometimes called day zero.
- You have your stem cell infusion 1 to 2 days after your conditioning treatment ends.
- You have medication to prevent any reactions to the infusion.
- The infusion is similar to a blood transfusion. It usually takes around an hour.
- Your nurse monitors you closely throughout the infusion.

There will be times when you feel awful and you have to be prepared for the fact that you might not start to feel better for several days – not until your bloods start to recover.
Linda, who had an autologous stem cell transplant for transformed follicular lymphoma

Waiting for the stem cells to engraft

What is engraftment?

Once they are inside your body, your new stem cells make their way from your blood to your bone marrow and start making new blood cells. This process is known as **engraftment** because the stem cells 'graft' onto your bone marrow – they settle into the spaces in your bone marrow and start dividing to make new cells.

While you are waiting for your stem cells to engraft, you have very low levels of different types of blood cells:

- **neutropenia** is a low level of **neutrophils** (a type of **white blood cell** that fights infection)
- **anaemia** is caused by a low level of **red blood cells**, which carry oxygen around your body
- **thrombocytopenia** is a low level of **platelets**, which help your blood clot.

As engraftment happens, your blood counts gradually return to a safe level. You have regular blood tests to check this.

It generally takes 2 to 3 weeks for your new stem cells to engraft, although this can vary a lot from person-to-person.

Your stem cells have officially engrafted when your neutrophil count is higher than half a billion neutrophils per litre of blood for 3 days in a row. This is written down as 0.5×10^9/L.

Your transplant team might just call it a neutrophil count of 0.5. This is still lower than a normal neutrophil count (usually between 2.0 and 7.5).

> **You start counting the days until the transplant is due to take hold and your immune system starts growing again.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Some people develop a high temperature, a rash, diarrhoea or fluid retention at around the time of engraftment. This is called ‘engraftment syndrome’. It is treated with steroids. These symptoms can also be caused by many other factors, including chemotherapy, and are not necessarily a sign that engraftment is happening.

Waiting for engraftment

A team of nurses and doctors support you while you wait for your blood counts to recover. Some hospitals have other therapists, such as counsellors, complementary therapists, physiotherapists and dietitians who can also work with you during this time.

Your transplant team monitor you closely. They try to disturb you as little as possible, but you need regular observations of your temperature, pulse and blood pressure, including at night.

You also have lots of blood tests to check on your recovery and to look out for any side effects or complications from your transplant.

Treatment for symptoms and side effects

You have lots of different treatments while you wait for your blood counts to recover. This is known as 'supportive care'. These treatments help support your body while your blood counts are low and treat the side effects of your conditioning treatment.

Treatments you might have include:

- antibiotics
- antifungals
- anti-sickness medication (antiemetics)
- painkillers
- nutritional supplements
- intravenous fluids and electrolytes
- blood products (red blood cells or platelets).

> **It was difficult to keep up with all the things they were treating and it seemed that it was all about antibiotics and meds.**
> Tony, whose wife had an autologous stem cell transplant for transformed follicular lymphoma

Communicating with the people who are caring for you is a critical part of your care. Your team can't help you if they don't know how you're feeling.

Your transplant team are used to people being worried and asking questions. A stem cell transplant is a complicated process. It's not unusual to need to ask the same questions several times to understand and take in the answer.

What to tell your medical team

- Talk to your team about anything that is on your mind.
- Tell them about any side effects you are experiencing.
- Tell them if any medicines you're having to treat side effects such as nausea, diarrhoea or pain aren't working.
- Ask them any questions you have. If you don't understand the answer, ask them to explain again.

> **The key thing I have learnt is to never be afraid to ask questions, even if they may sound daft. It's your life, so correct information is paramount.**
> Leo, who had an autologous stem cell transplant for diffuse large B-cell lymphoma

Managing low blood counts

When your blood counts are low, you have a high risk of developing an infection. You will also have **anaemia** and have a higher risk of bleeding than normal due to a low platelet count.

Risk of infection

While your neutrophil count is very low, you have a very high risk of developing an infection. The risk gradually gets lower as your neutrophil count rises, but you remain at increased risk of infection until your neutrophil count returns to normal. This can be a few months after your transplant.

You can get infections from the bacteria that normally live in and on your body, for example, in your digestive system and on your skin. These are usually harmless, but they can cause infections when your immunity is low after a stem cell transplant. Infections can also come from outside sources, such as other people, food or your environment.

While your neutrophil count is low, you need to take precautions to reduce your risk of infection as much as possible (see page 78). You might also have treatment to prevent infections.

Despite being in an isolation room, I picked up every infection, had diarrhoea and flu and I struggled to eat or drink anything. My medical team explained that once my white cell count came up I would feel better. Within three days of my white cell count lifting, I could feel a real turn around and started to eat and drink again.
Stuart, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Tell your nurse if you feel unwell in any way at all.

Reducing your risk of infection if you are staying in hospital (see page 20)

- If you are staying in hospital, you are likely to be in a room on your own (see page 89).
- Your transplant team monitor you closely for any signs of infection (see page 101). They take your temperature and pulse, check your oxygen levels, and clean your central line regularly.
- You might be given antibiotics to prevent common infections.
- Hospital staff and visitors must wash their hands before entering your room. They might also need to wear gloves, gowns or aprons, and face masks.
- People shouldn't visit you if they are unwell. Children might not be allowed to visit at all – although some hospitals allow them to if they are well.
- Anybody who provides food for you should take care to follow food safety guidelines and wash their hands before preparing your meals. You might be put on a special diet that cuts out foods that are likely to contain infection-causing bacteria or fungi. Advice varies between hospitals.
- Wash or shower every day, wash your hands frequently and clean your teeth regularly.

Reducing your risk of infection if you are staying at home (see page 21)

- **Follow the guidelines given to you by your transplant team.**
- Take your temperature and check for signs of infection regularly. Contact your medical team **immediately** if you have a high temperature (above 38°) or any signs of infection (page 101).
- Take all the medicines you have been prescribed.
- Look after your central line. Your medical team will show you how to do this.
- Brush your teeth and rinse your mouth regularly with mouth wash.
- Make sure your environment is clean. If you are staying in accommodation arranged by your transplant centre, it should be cleaned and the bedding changed every day. If you have your transplant at home, make sure your home environment is clean.
- Ask friends and family not to visit you if they are at all unwell.
- If you are staying at home and you have any pets, wash your hands after touching them. Don't let them lick your face and make sure you don't come into contact with their wee or poo.

Although taking precautions reduces your risk of infection, you cannot avoid all sources of infection. Most people have an infection of some kind after a stem cell transplant.

Look out for signs of infection (page 101), so you can be treated promptly.

Anaemia

Anaemia is when you don't have enough **haemoglobin** in your blood. Haemoglobin is the protein in red blood cells that carries oxygen around your body. While you are waiting for your stem cells to engraft, your body can't make enough red blood cells and you develop anaemia.

Anaemia can make you feel very tired. You might look pale and feel short of breath. Some people have palpitations (a feeling that your heart is pounding or skipping a beat). You will have regular blood tests to check your haemoglobin level.

Most people need blood **transfusions** to treat anaemia while they wait for their blood counts to recover. This involves having red blood cells from a donor given to you through your central line. It takes a couple of hours for a bag of red blood cells to be transfused.

Most people do not feel anything when they are having a blood transfusion. A few people have a mild reaction and might develop a high temperature, chills or a rash. You have your temperature, pulse and blood pressure checked before, during and after the transfusion. Serious reactions to blood transfusions are extremely rare.

Tell your nurse if you feel unwell during or shortly after a blood transfusion.

A blood transfusion increases your red blood cell count for a few weeks but if your bone marrow still isn't producing enough of its own red blood cells, you might develop anaemia again. You might need several blood transfusions while you wait for your stem cells to engraft. You might still be slightly anaemic after you go home. Some people come back to hospital for another transfusion.

Risk of bleeding

While you are waiting for your stem cells to engraft, you also have low **platelet** levels (called **thrombocytopenia**). Platelets help your blood clot. A low platelet level means you have a higher than usual risk of bleeding and bruising.

Your transplant team observe you for any signs of bleeding until your platelet levels recover.

Tell your nurse if you notice any signs of bleeding, such as blood in your wee or poo, bleeding gums, nosebleeds or, in women, heavy periods.

If you are bleeding or your platelet count is very low, you might need a platelet transfusion. This is a bit like a blood transfusion, but the liquid is yellow and there is only a small amount of it. You have platelet transfusions though your central line. It takes about half an hour per bag. The number of bags you have depends on your platelet count and your treatment plan. Very rarely, you might have a reaction to the platelet transfusion, which might make you feel flushed or shivery.

Platelet transfusions aim to increase your platelet count enough to stop any bleeding or to reduce your risk of bleeding. Because the platelets get used up, the effect only lasts for a few days. If your platelet count is still very low, you might need another platelet transfusion.

Coping with side effects of your conditioning therapy

While you are waiting for your stem cells to engraft, you are likely to experience side effects from your conditioning therapy. The side effects you are at risk of developing depend on the exact treatment you have. Your transplant team can give you more information on what to expect and how to cope with any side effects you experience.

> **You worry about the physical side effects, and how you're going to cope, but the hospital staff make it clear they have lots of treatments to help.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

The most common side effects of conditioning treatment include hair loss, sore mouth, diarrhoea, change in taste, loss of appetite, feeling sick and, sometimes, being sick. These effects can be severe.

Tell your transplant team about any side effects you develop. They can offer treatments and advice that can help. Tell your transplant team if the medicines they give you for side effects don't seem to be working. There are often other options.

Sore mouth

It is very common for people to develop a sore mouth or mouth ulcers after conditioning therapy. It typically develops 4 to 10 days after your high-dose treatment finishes. It can be very painful but it heals quickly once your neutrophil count starts to recover.

> **The staff come to the rescue with painkillers and thick shakes instead of solid food.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Tips to help with sore mouth

- Brush your teeth regularly using fluoride toothpaste and a toothbrush with soft bristles. A toothbrush designed for toddlers is ideal.
- Use mouthwash at least four times a day. Your transplant team can give this to you.
- If your mouth is too sore to brush your teeth, ask your nurse for oral sponges to use instead.
- Avoid very spicy, rough or sharp foods.
- Use lip salve to keep your lips moist.
- If you wear dentures, take them out if you develop mouth ulcers. Clean them regularly.
- Drink plenty of fluids.
- Ask for painkillers if you need them.

If your mouth is very sore and you're struggling to eat, your nurse or dietitian might give you nutritional drinks. Some people need a feeding tube (also called a 'nasogastric tube') for a few days. This is a soft tube that goes through your nose and down into your stomach. You can have liquid food through it that goes directly into your stomach.

Loss of appetite

Many people lose their appetite for a while after conditioning therapy. You might not feel like eating much or you might feel full very quickly. Food might taste different or you might be sensitive to particular smells and tastes.

> **I had not been eating in hospital as everything tasted horrible, whereas when I got home I could graze on a little of what I fancied eating. This really helped me build up gradually.**
> Stephen, who had an autologous stem cell transplant as part of his treatment for mantle cell lymphoma

Tips to help with poor appetite

- Eat small portions of food throughout the day instead of large platefuls.
- Eat what you like when you feel like it. Check with your nurse first what foods are safe for you to eat.
- Ask family and friends to bring in snacks that you enjoy.
- Avoid foods and drinks that irritate your mouth.

If you have difficulties eating, they are usually temporary. You might need nutritional drinks to support you until you can eat normally again.

Diarrhoea

Most people have diarrhoea at some point after a stem cell transplant. It can be caused by your conditioning therapy, an infection in your gut, or some medicines (such as some antibiotics).

If you have diarrhoea, your transplant team will treat any underlying causes if possible. They might give you medicine to help reduce the diarrhoea. If you have severe diarrhoea, you might have fluids through your central line to stop you becoming dehydrated.

In many transplant units, you have your own toilet and shower. If you have diarrhoea, it is important to wash your bottom thoroughly after going to the toilet.

If you find it hard to get to the toilet in time, you might find it reassuring to use incontinence pads or sanitary towels to give you some protection. Family members might have to provide these for you, but ask your nurse about the best solution for you.

> **It’s tough, but one day you wake up and you can eat your breakfast that bit more easily, and you are going to the bathroom less frequently, and the next day it’s slightly better again.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Nausea and vomiting

You have medicine to prevent you feeling sick (nausea) or being sick (vomiting) but some people still experience these side effects. They are caused by your conditioning therapy.

Sickness can usually be controlled by anti-sickness drugs (anti-emetics). There are lots of different anti-sickness drugs available and you might have to try a few to find what works best for you. Some people have continuous anti-sickness drugs given into their central lines through a syringe attached to a small pump.

Tell your nurse if you feel sick, even if you have already had treatment for it. There may be other medicines you can have.

Fatigue and poor concentration

You are likely to feel very tired at first and might spend a lot of time sleeping. You won't have the energy to do very much and you might find it hard to concentrate on reading or even on watching television. You might feel too tired for visitors. Fatigue improves slowly, but you are likely to feel more tired than normal for some time after you go home.

Some people experience cancer-related cognitive impairment, or 'chemo brain'. You might have trouble remembering things or concentrating. Some people describe it as a 'mental fog' or feeling slightly detached from the world around them.

Visit lymphoma-action.org.uk/Fatigue and lymphoma-action.org.uk/ChemoBrain for more information on fatigue and chemo brain.

It might take 3 to 6 months for your energy levels to pick up. After this time, most people are able to go back to work and do the things they enjoy, but it is common to be able to do less than before your transplant. You might become tired more easily and need to rest or sleep more.

For some people, reduced stamina or poor concentration is a longer-term problem. If this affects you, tell your transplant team. You might still be anaemic or have another medical condition causing fatigue or poor concentration.

Tips to help with fatigue and chemo brain

- Don't overdo things – pace yourself and rest when you need to.
- Take regular, light exercise.
- Write things down to help you remember.
- Try relaxation techniques, such as breathing exercises.
- Keep to a regular sleep routine.

Staying in protective isolation

Most people having a stem cell transplant in the UK stay in a single room in hospital while they wait for their blood counts to recover. The room is cleaned regularly and sheets and pillowcases are changed every day. You cannot have plants or flowers in the room as they increase the risk of you getting an infection.

Your nurses and doctors come in and out regularly, but you are on your own a lot of the time. It can be difficult being alone when you feel ill and tired.

It is common to experience a range of different emotions while you are in protective isolation. Many people feel low and anxious. You won't be able to do as much as usual and your sleep is likely to be disrupted. You may feel as though you've lost control over your life.

Having company when possible, and plenty of things to distract you, can really help. You might also benefit from relaxation techniques such as mindfulness. Some units offer complementary therapies such as massage or aromatherapy. Talk to your transplant team about therapies that might be suitable.

Tell your transplant team if you are struggling with your feelings. They can offer advice and support. They may be able to refer you to a counsellor.

Home comforts and distractions

You might not feel like doing much. Try to have a variety of things to keep you occupied that don't require too much effort, such as music or audiobooks to listen to, books and magazines to read, or a tablet loaded with films or games. Think about hobbies you can easily take with you, such as jigsaws, scrap books or crafts.

Break up the day with small tasks, like showering, eating, and mouth care. Your transplant team might suggest things you can do to help with your care. For example, you could keep a record of your fluid intake.

Visitors

Visitors can provide welcome distraction and support. However, there will be times when you don't feel well enough for visitors. Ask them to send cards, letters and emails instead. Photographs and children's drawings can also give you a boost.

Check with your unit about their guidance for visitors, particularly in the early days after your transplant when your risk of infection is highest. Some units do not allow children to visit. Find out the rules in advance.

Tell your visitors what you can and can't eat so they can bring in the right things.

> **You will feel like you cannot do anything to help as a family member, but just being there is enough.**
> Tony, whose wife had an autologous stem cell transplant for transformed follicular lymphoma

Keeping active

Exercise can help your mood and physical recovery after a stem cell transplant but it is important not to overdo it. Your team can give you advice on ways to keep active while you are waiting for your blood counts to recover.

Try to get dressed if you can. As your blood counts start to rise, you might be able to go for short walks outside your room. Even if you can't leave your room, you might be able to do some stretching exercises or work with exercise bands or light weights.

What if the stem cells don't engraft?

Graft failure occurs if the transplanted stem cells fail to settle in your bone marrow and make new blood cells. This means your blood counts do not recover. Graft failure is serious but it is **very rare** after an autologous stem cell transplant.

Your transplant team monitors your blood counts closely. If your graft does fail, you might be treated initially with growth factors or hormones. These encourage the stem cells in your bone marrow to produce more cells. You might need a donor (allogeneic) stem cell transplant if your blood counts don't improve.

Summary

- Engraftment is when your new stem cells settle into your bone marrow and start making new blood cells.
- It takes 2 to 3 weeks or more for your blood counts to recover after a stem cell transplant.
- Most people stay in protective isolation during this time. This can be challenging but taking plenty of things to distract you and keeping in touch with loved ones can help.
- While your blood counts are low, you need to take precautions to reduce your risk of infection as much as possible.
- Not all infections can be prevented. Look out for signs of infection, so you can be treated quickly.
- You are likely to experience side effects from your conditioning therapy. You have treatment to help with these.
- Tell someone if you have side effects or if your medicines don’t seem to be working.
- You probably won’t feel like doing much a lot of the time, but take plenty of things to occupy you for when you feel like it.
- Be as active as you can.
- Encourage family and friends to keep in touch and visit you when you feel up to it.

Finishing cancer treatment was perhaps the easy part. My whole body and mind had tired. The Macmillan counsellor said it can take years to get back to my original mojo level as everyone is different. I'm getting there.

Imtiaz, who had an autologous stem cell transplant as part of his treatment for central nervous system (CNS) lymphoma

Going home and follow-up

Getting ready to go home

Most people who have an autologous stem cell transplant in hospital go home 2 to 3 weeks after their stem cell infusion (day zero). However, it can be longer, particularly if you develop a serious infection or other complications. You are discharged from hospital once you feel well enough and when your neutrophil count has returned to a safe level.

Your transplant team needs to be sure that you have enough support at home or are able to care for yourself before they discharge you. Social services might work with your hospital team to make sure you have the right care when you go home.

> **Week 3 and the blood counts had already started to rise very slightly. It was sunny outside and sunny inside the room. The doctor said Trevor might be able to go home at the end of the week and he was definitely starting to feel brighter.**
> Sue, whose husband Trevor had an autologous stem cell transplant as part of his treatment for follicular lymphoma

Most people are ready to go home when the time comes, but it might feel daunting to leave the ward, where doctors and nurses have been checking on you day and night. You should be given a list of names and telephone numbers of people to contact if you are unwell, have a problem or need advice.

People often expect to feel better just because they are going home. Your family and friends might also expect that being discharged from hospital means you have recovered. Remember that you might go home as little as 2 weeks after a very high dose of treatment – much higher than you have had in the past. It can take a while to recover from it.

Don't be surprised if you still feel exhausted and don't have much of an appetite after you go home. You might also still have a sore mouth or find that things taste different. You are still likely to be anaemic and have a low platelet count for a while.

Tips for when you go home

- Arrange for someone to give you a lift home and help you with your bags.
- Make sure you know who to contact if you have any problems.
- Don't expect too much of yourself. Give yourself time to recover.

About your follow-up

You have very frequent follow-up appointments when you are first discharged from hospital or from ambulatory care. The appointments might be at your transplant unit or they might be at a hospital closer to home if you live far from the unit. Both hospitals should have up-to-date records of your treatment and progress. Your GP should also get this information.

You are usually seen in clinic every week at first to check your blood counts are recovering well. You might need blood transfusions if your red cell count or platelet count are low.

You then have appointments each month. Around 3 months after your transplant you are likely to have a **CT scan** or **PET/CT scan** to see how the lymphoma has responded to the treatment. If you had lymphoma in your bone marrow, you might also have a **bone marrow biopsy**.

You have regular tests to check on your recovery. Gradually, you are seen less often. Your follow-up appointments are to check that your lymphoma has not come back (relapsed) and to look out for late effects (side effects that develop months or years after treatment – see page 109).

Things you can do to help you recover

The time it takes to recover from an autologous stem cell transplant varies from person-to-person, but most people take 3 to 6 months to begin to feel back to normal.

You might still have low blood counts when you go home. It can take a few months for these to build up to normal levels. You have regular blood tests to check on your recovery.

You might go home with your central line still in if you still need blood transfusions. The central line is removed when your blood counts have recovered.

This section gives you some tips about looking after yourself while you recover.

Take steps to reduce your risk of infection

Even though you aren't discharged until your neutrophils are at safe levels, your **immune system** is still lower than usual for some time after your transplant. This means you have a higher risk of infection than usual.

There are some steps you can take to try to keep this risk as low as possible:

- Avoid people who have infections and places with a high risk of infection, such as cinemas, busy shops, or public transport during rush hour.
- Ask your transplant team for advice about using public swimming pools and gyms.
- If you have young children, ask their friends' parents to alert you to any infections that are going round.
- Shower regularly and wash your hands after using the toilet, before preparing or eating food, before taking medicines, and after being outside.
- Take good care of your teeth and gums.
- Wash your clothes and bedding regularly.
- Make sure your fridge is set at 5°C or lower.
- Keep your fridge and food preparation surfaces clean. Follow food storage, freezing and cooking instructions carefully.

- If you have pets, wear gloves to clean them out or ask friends or family to do it for you. Wash your hands after stroking or handling pets.
- Use a condom for at least 3 months after your transplant to reduce the risk of infection.
- Keep a thermometer handy so you can easily check your temperature.
- Take all the medicines you've been prescribed.
- Find out what vaccinations you should have (see page 108).

Even if you take all these precautions, you might still pick up an infection. It's not unusual for people to be readmitted to hospital after they've been discharged. Remember that the earlier you notice an infection, the sooner you can be treated for it.

> **I felt nervous about leaving the hospital environment where I had been in isolation with people gowned up to protect me from germs. Now I was going home and in reality it was once I had got home that the recovery started and I could take my own steps to avoid infection.**
> Jamie, who was diagnosed with Hodgkin lymphoma and had an autologous stem cell transplant

Contact your transplant team immediately if you have any signs of infection, including, but not limited to:

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

Try to reduce your risk of bleeding

If your platelet level is low, you might bruise or bleed more easily than usual. Take care to avoid injury and contact your medical team immediately if you notice any signs of bleeding.

Tips to reduce your risk of bleeding

- Take care to avoid injuring yourself when preparing food, gardening or doing DIY.
- Wear protective gloves when gardening.
- Use a water-based lubricant during sex. (You might be advised to avoid sex completely if your platelet count is very low.)
- Avoid high-impact sports or contact sports.
- Tell your transplant team if you notice any blood in your wee or poo, you have nosebleeds or unusual vaginal bleeding.
- Tell your team if you notice any bruising or develop a skin rash.

Know the signs of anaemia

You might be anaemic for some time after you go home. This can make you feel lethargic.

Contact your transplant team if you feel very tired, dizzy or short of breath. If your haemoglobin is very low, you might need a blood transfusion (see page 80).

Look after your skin

Your skin might be dry and sensitive after an autologous stem cell transplant. Your skin might also be more sensitive to the sun than usual, making you more prone to sunburn. High-dose conditioning therapy can also increase your risk of developing skin cancer later in life. To reduce this risk, you will always need to be careful to protect your skin from the sun.

Tips to look after your skin

- Moisturise often, especially after a bath or shower.
- Use mild, unperfumed skin-care products and cosmetics.
- Use an electric razor rather than wet shaving, or avoid shaving altogether.
- Use mild washing powder suitable for sensitive skin.
- Wear a hat and high factor sun cream (SPF 30 or 50) when you are out in the sun.
- Avoid the sun when it is at its strongest (11am to 3pm in summer months).

Eat well

> **My eating was an issue until around 3 months after my high-dose chemo. I was given nutritional supplements after the feeding tube came out.**
> Linda, who had an autologous stem cell transplant for transformed follicular lymphoma

Eating well can help you recover faster. It also reduces your risk of developing other illnesses in the future. Once your appetite has come back, you should try to eat a healthy, balanced diet. This should include:

- plenty of fruit and vegetables
- starchy foods (carbohydrates) such as potatoes, bread, rice or pasta
- some meat, fish, eggs, pulses or other proteins such as tofu
- some low fat milk, cheese, yoghurt or other dairy foods or dairy alternatives
- small amounts of unsaturated oils and spreads
- small amounts of foods high in fat and sugar
- 6 to 8 glasses of fluid per day
- no more than 14 units of alcohol a week.

Search 'healthy eating' at macmillan.org.uk for more information, including recipe ideas specifically tailored for people with cancer.

Stay active

Exercise after a stem cell transplant helps your recovery, gives you more energy and helps you to feel better generally. However, it is important not to do too much too soon.

Take things gradually and set yourself achievable goals. You might find that you get tired more easily than you used to or become short of breath sooner. Don't expect too much of yourself. Small amounts of exercise, such as a short walk each day, can make a difference.

Avoid contact sports and high-impact exercise until your platelet count has returned to normal. You are at increased risk of bruising and bleeding, and your body is less able to heal itself while your platelets are low.

> **I am a fairly fit person and used to run and cycle. Once I was out of hospital, I started walking, increasing the distance I went each day very slowly. Within two to three months of the stem cell transplant I felt pretty much back to normal.**
> Stephen, who had an autologous stem cell transplant as part of his treatment for mantle cell lymphoma

Ask your key worker what exercise is safe for you and what precautions you might need to take.

Stop smoking

If you're a smoker, stopping smoking can help you recover faster. It also reduces your risk of picking up lung infections and reduces your risk of developing late effects of your treatment (see page 109).

It can be very hard to quit smoking, especially when you're already going through a stressful time. You're much more likely to quit successfully if you get help and support, either from your GP, a local Stop Smoking service or online.

The NHS has an online service that provides free online, telephone and email support to help you quit smoking. Find out more at nhs.uk/better-health/quit-smoking

Coping with difficult feelings

Most people going through a stem cell transplant find it difficult emotionally. You might feel different things at different times. Your feelings might be very strong, sometimes overwhelming, making it hard to think about anything else or continue with day-to-day life.

Sometimes people feel very low a lot of the time. This might be depression. Depression can affect people in different ways.

If you are struggling with anxiety or think you might be depressed, talk to your transplant team. There is support available.

> **I think I will always make art about my recovery. It was something that helped to give me a focus and make meaning out of something so surreal and life changing. My lymphoma experience does not define me, but it had a huge impact on my life and I want to pay homage to that.**
> Sarah, who had an autologous stem cell transplant as part of her treatment for Hodgkin lymphoma

- Our Helpline (freephone) offers a listening ear if you need to talk. Call us on 0808 808 5555, email information@lymphoma-action.org.uk or Live Chat via our website at lymphoma-action.org.uk
- Our Helpline Team might be able to put you in touch with someone else who has had a stem cell transplant via our Buddy Service.
- Find an Online Support Meeting near you at lymphoma-action.org.uk/SupportGroups
- Ask your medical team if they can refer you to a specialist, such as a counsellor or clinical psychologist.

Day-to-day living

Having a stem cell transplant affects everybody differently. It can take at least 3 to 6 months for people to return to work or study. Everybody is different, and you might need longer. You may find that it affects you in ways you didn't expect. You might need to make changes to your everyday life to help you cope. Some people call this finding their 'new normal'.

We have more information on day-to-day living, including about work and study, sex, travel and holidays, in our book *Living with and beyond lymphoma.* Download a copy at lymphoma-action.org.uk/Books or order a free copy at lymphoma-action.org.uk/Shop

Vaccinations

When you have a stem cell transplant, you lose your immunity to diseases you were vaccinated against before your transplant. This includes the vaccinations you had as a child. Around 3 months to a year after your transplant, you will be offered a revaccination programme. You should also have the annual winter flu jab and the pneumococcal pneumonia vaccination. If you're going abroad, you might need specific vaccinations.

You can't have live vaccines for at least 2 years after a stem cell transplant. The exact time varies depending on how you recover and whether you need any more treatment.

Live vaccines are made using bacteria or viruses that are weakened but still alive. There is a risk that you could develop the infection if you have a live vaccine shortly after your transplant.

Live vaccines include those for measles, mumps and rubella. The nasal spray flu vaccine is also a live vaccine, but the injection is not.

If you are going abroad, check what vaccinations you need. You may not be able to have them all. Make sure you seek medical advice at least 8 weeks before your trip – some vaccinations have to be given well before you travel in order to work properly.

Ask your doctor or specialist nurse for advice before having any vaccines.

Long-term and late effects of treatment

Although most side effects of conditioning therapy go away soon after treatment has ended, some can last longer. These are long-term side effects. High-dose conditioning therapy can also cause side effects that occur months or years after your treatment has ended. These are called **late effects**.

The late effects you might be at risk of depend on what treatment you've had. Ask your key worker what to look out for.

Fatigue

Most people experience fatigue after a stem cell transplant. It usually gets better gradually but it can last for months after your treatment has ended. For some people, it can last a year or more, although it usually gets less troublesome over time. A few people find their energy levels are never quite the same as they were before their transplant.

See page 88 for tips on how to cope with fatigue.

> “
>
> **I began to feel better, but it was slow and not every day was better than the last. There were times I felt I was going backwards and my energy levels weren’t getting any higher. But I was getting better and I just needed to be patient.**
>
> Owen, who was diagnosed with angioimmunoblastic T-cell lymphoma and had an autologous stem cell transplant

Lowered immunity

Your immune system should recover after an autologous stem cell transplant, but some people remain susceptible to infection for many months or even years after treatment. You might find that you catch colds easily, or that you take longer to shake them off. See page 101 for tips on reducing your risk of infection.

Heart problems

Heart problems are more common in people who have been treated for lymphoma than in the general population due to the effects of chemotherapy and previous exposure of radiotherapy to the chest. Heart problems might start 10 years or more after your lymphoma treatment but they can develop sooner. Your risk of heart problems stays higher than usual for several decades after your treatment.

People who have been treated for lymphoma also have a higher than usual chance of developing 'metabolic syndrome' – a combination of diabetes, high blood pressure and obesity. Metabolic syndrome also increases your risk of developing heart disease.

You can lower your risk of developing heart problems by making lifestyle choices that aim to keep your heart healthy. These include maintaining a healthy weight, eating well, staying active and not smoking. You should also have your blood pressure, blood sugar level and cholesterol level checked regularly.

Lung problems

High-dose chemotherapy or radiotherapy can cause scarring (fibrosis) of your lungs. If the damage is mild, it can be seen on X-rays or scans, but it doesn't cause any symptoms. If there is more serious damage, you might get short of breath. You can still exercise, but you might not be able to do as much as you used to before feeling out of breath.

If you smoke, quitting reduces your risk of developing lung problems – and other late effects – after a stem cell transplant.

Other cancers

High-dose chemotherapy and radiotherapy can increase your risk of developing another cancer in the future. However, this risk is still small. **Most people who have been treated for lymphoma never develop another cancer.**

The type of cancer you might be at risk of depends on lots of factors, including the type of lymphoma you have, the exact treatment you've had, how old you were when you were treated and how old you are now.

Lifestyle factors also affect your risk. You should do what you can to reduce your risk. Consider not smoking, eating a healthy diet and maintaining a healthy weight. Protect your skin from the sun. Talk to your doctor about what to look out for in the future.

Ask your transplant team what cancers you might be at higher risk of developing. Make sure you know the symptoms of these cancers. Cancer is usually more treatable if it is diagnosed early.

Peripheral neuropathy

Some chemotherapy drugs can damage the nerves that carry information about touch, temperature and pain. The drugs can also cause damage to the nerves involved in muscle movement. This nerve damage is called **peripheral neuropathy** (PN).

Neuropathy most often affects the nerves in your hands and feet, causing symptoms such as numbness and tingling in your fingers and toes. You might feel it in other places, too. Sometimes it affects the nerves of the internal organs, which is known as ‘autonomic neuropathy’. This can cause symptoms such as abdominal cramps and constipation.

For most people, peripheral neuropathy starts to get better after you finish treatment, but it can take weeks or months. For some people, it never goes away completely.

Tell your key worker if you have symptoms of peripheral neuropathy. They can suggest things to help with symptoms.

> **I struggled with peripheral neuropathy on my hands and feet. I have found ways to help with this, like using thermal socks and using a heat pack on my hands.**
> Stuart, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

You must notify the Driver and Vehicle Licensing Agency (DVLA) if you have peripheral neuropathy.

Reduced fertility

Some people are not able to have children naturally after a stem cell transplant. Your transplant team should have discussed options to preserve your fertility before your stem cell transplant (see page 30).

If you are planning to have a baby after your stem cell transplant, you should wait at least 6 months after finishing your treatment before trying to become pregnant or make your partner pregnant. Women might be advised to wait longer, to give their body time to recover. Some people prefer to wait 2 years, when the chance of your lymphoma coming back is usually lower.

Early menopause

High-dose therapy can cause early menopause in women. During treatment, your periods might become irregular or they might stop altogether. A few months (or sometimes years) after finishing your treatment, they might return to normal. However, for many women, periods never come back.

The Daisy Network (daisynetwork.org) and Menopause Matters (menopausematters.co.uk) offer support and information for people experiencing early menopause. They also have forums where you can connect with other people with a similar experience.

Early menopause can cause symptoms such as hot flushes, mood changes, vaginal dryness and a lack of interest in sex. Early menopause also increases your risk of developing brittle bones (osteoporosis).

If you have early menopause, you are likely to be offered **hormone replacement therapy**. This can help with the symptoms of menopause and reduce your risk of developing osteoporosis.

Other late effects

Other late effects you might be at risk of include:

- low thyroid function
- eye problems
- tooth decay.

Your transplant team can tell you more about these.

Visit lymphoma-action.org.uk/LateEffects for more information about late effects of lymphoma treatment.

Questions to ask your key worker

- What late effects might I develop?
- How will I be monitored for these effects?
- How can I reduce my risk of being affected?
- What signs should I look out for?
- Are there any screening programmes I should take part in?

What happens if your lymphoma comes back?

If your lymphoma comes back (relapses) after an autologous stem cell transplant, your treatment options depend on lots of factors. These include the type of lymphoma you have, the treatments you've had and your general health.

> **Unfortunately my transplant didn’t work, but there were still other treatment options available for me. Touch wood, things have worked out OK in the end.**
> Jason, who had an autologous stem cell transplant as part of his treatment for Hodgkin lymphoma

Many people can have more treatment. This might be radiotherapy, **targeted treatment**, **CAR T-cell therapy** or a donor (**allogeneic**) stem cell transplant. You might be asked if you’d like to take part in a clinical trial.

Your specialist can give you more information about your options.

Visit lymphoma-action.org.uk/TrialsLink to find out more about clinical trials, or to search for a trial that might be suitable for you.

> **A scan after my autologous stem cell transplant showed I still had active lymphoma in my chest. I had radiotherapy but this did not shrink the lymphoma completely. I then took part in clinical trials of three different drugs before finally going into remission.**
>
> Carol, who had an autologous stem cell transplant as part of her treatment for Hodgkin lymphoma

Summary

- You might feel scared about going home after a stem cell transplant. You are likely to feel tired, weak and unwell to start with. It takes time to recover after a transplant.
- You might still be on treatment when you first go home.
- You have regular follow-up appointments to check your recovery, monitor your lymphoma and look for any late effects of your treatment.
- After a stem cell transplant, you are at higher risk of developing certain health problems. Make sure you know what signs to look out for and what steps you can take to keep your risk as low as possible.
- Expect to have good days and bad days as you recover. Talk about how you feel. If you think you might be depressed, or if other people are worried about your mood, ask for help.

Glossary

Allogeneic	the use of someone else's tissue
Anaemia	shortage of red blood cells or haemoglobin in the blood
Anaesthetic	drugs given to make a part of the body numb (local anaesthetic) or temporarily put the whole body to sleep (general anaesthetic)
Aspirate	a sample of fluid that has been sucked out of the body
Autologous	the use of a person's own tissue
Bone marrow	the spongy material at the centre of larger bones that contains stem cells
Biopsy	a test that involves removing a sample of tissue and looking at it under a microscope
CAR T-cell therapy	treatment that uses your own, genetically modified T cells to recognise and kill lymphoma cells

Central line	a flexible tube inserted into a large vein in the chest that allows chemotherapy to be given and blood to be taken; also known as a ‘central venous catheter’ (CVC)
Conditioning	high-dose anti-cancer treatment given before a stem cell transplant
Complete remission	no evidence of lymphoma on tests and scans after lymphoma treatment
CT scan	short for computed tomography: a scan that uses X-rays to take pictures of ‘slices’ through your body
Day zero	the day you are given your healthy stem cells
ECG (electrocardiogram)	a method of recording the electrical activity of the heart muscle
Engraftment	the process of new stem cells settling into the bone marrow and starting to produce blood cells
Full blood count	a blood test that measures the level of red blood cells, the different types of white blood cells and platelets in your blood

G-CSF	granulocyte colony-stimulating factor: a growth factor that stimulates your bone marrow to make blood cells
Growth factors	hormones (chemical messengers) that stimulate your bone marrow to make stem cells
Haemoglobin	the protein inside red blood cells that carries oxygen around your body
Hormone replacement therapy (HRT)	treatment with female hormones to reduce the symptoms and long-term effects of menopause
Immune system	the system in your body that fights off and prevents infection
Intravenous	into a vein
Late effects	side effects that might develop months or years after treatment
Lumbar puncture	a test that involves looking at a sample of the fluid taken from your spinal cord under a microscope
Lymphocytes	specialised white blood cells that are part of your immune system

Mobilisation	the process of moving stem cells from your bone marrow to your bloodstream
Neutropenia	shortage of neutrophils in the blood
Neutrophils	a type of white blood cell that is important in fighting infections
Partial remission	a reduction in the amount of lymphoma in your body after treatment
Peripheral neuropathy	damage to the nerves of your peripheral nervous system, which carries signals and messages between different parts of your body
PET scan	positron-emission tomography: a scan that uses a radioactive form of sugar to look at how active cells are
Platelets	tiny fragments of cells in your blood that help your blood clot
Priming chemotherapy	preparing the bone marrow for stem cell mobilisation using growth factor injections
Red blood cell	blood cells that carry oxygen around your body

Relapse	when your lymphoma comes back
Refractory lymphoma	when your lymphoma doesn’t respond to previous treatment
Stage	a measure of how much of your body is affected by lymphoma
Stem cell infusion	stem cells given to you through a drip into a vein
Stem cells	undeveloped cells that can mature into many different cell types; ‘haematopoietic’ stem cells can mature into different types of blood cell
Steroids	anti-inflammatory medicine that also regulates the body’s metabolism and immune response
Subcutaneous	relating to the fatty tissue under your skin
Targeted treatments	treatments that disrupt particular processes or proteins in lymphoma cells to stop them growing or dividing
Thrombocytopenia	shortage of platelets in the blood

Transfusion	blood or blood products given to you through a drip into a vein
White blood cell	a cell that helps your body fight infections; several different types exist including lymphocytes and neutrophils

Useful organisations

Anthony Nolan has extensive information about stem cell transplants and an online transplant community.
0303 303 0303 anthonynolan.org.uk

Blood Cancer UK provides a range of information about blood cancers, including stem cell transplants.
0808 2080 888 bloodcancer.org.uk

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.
0808 808 0000 macmillan.org.uk

Information and support

If you'd like to talk to someone about anything to do with lymphoma, get in touch.

Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm on 0808 808 5555. You can also use Live chat on our website.

Find an **Online Support Meeting** near you at lymphoma-action.org.uk/support-you/online-support-meetings

Join our **Closed Facebook Group** at facebook.com/groups/LymphomaActionSupportUK

Our **Buddy Service** can put you in contact with someone in a similar situation to you. Call our Helpline for details

Visit lymphoma-action.org.uk/TrialsLink to find clinical trials that might be suitable for you.

Find out more through our videos, webinars and podcasts at lymphoma-action.org.uk

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We produce many other publications that give information about lymphoma. Visit our website at lymphoma-action.org.uk or call 0808 808 5555 for more information.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo

How you can help us

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this book. Please visit our website at lymphoma-action.org.uk/Book-Feedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.

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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We would like to thank our incredible supporters whose generous donations enable us to offer all our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work please visit lymphoma-action.org.uk/Donate

This book explains what an autologous stem cell transplant is and what to expect if you, or someone you know, is having one to treat lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years. We're here for you.

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