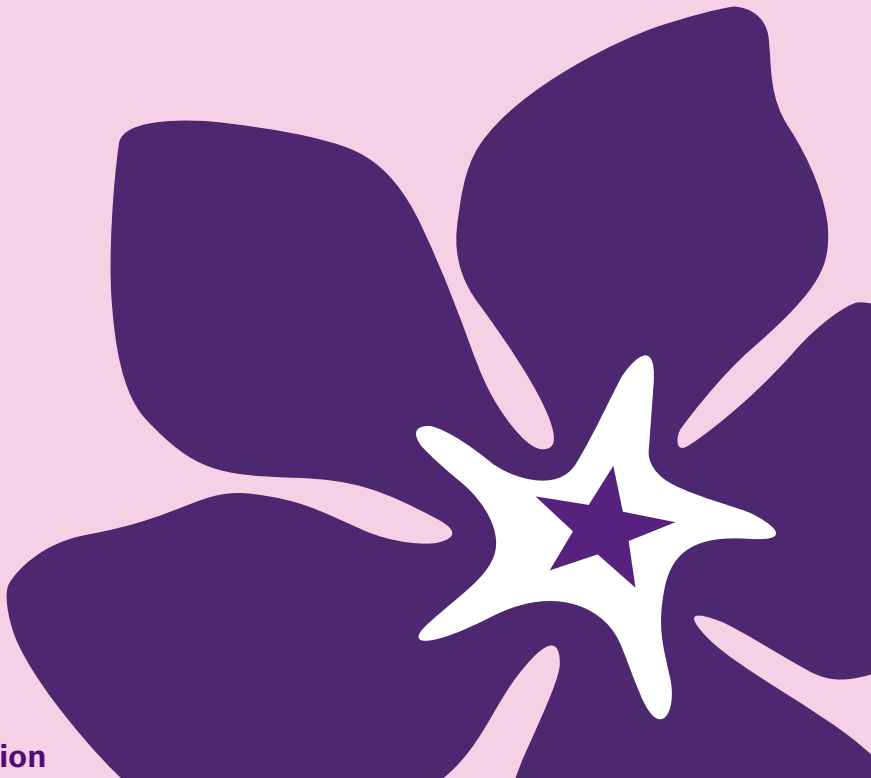
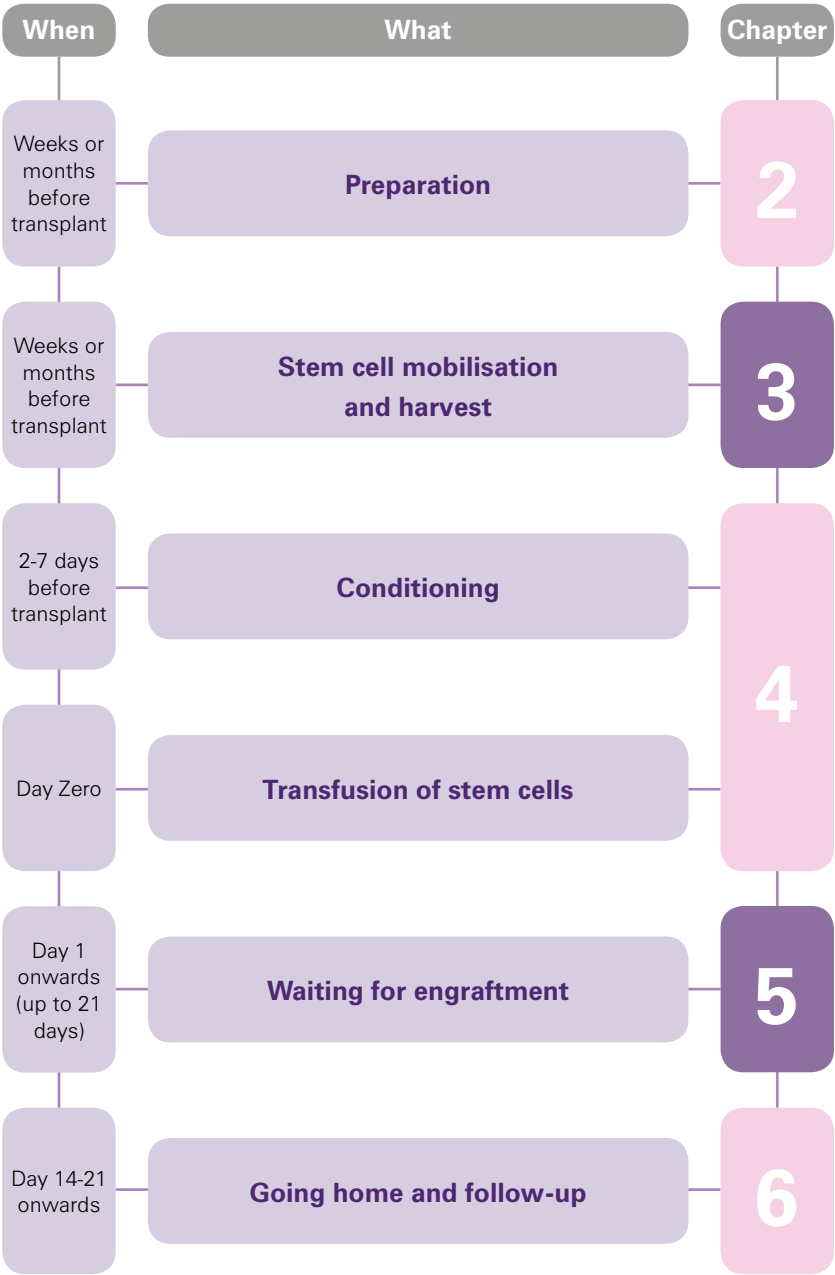


Autologous stem cell transplant



The stem cell transplant pathway



How you can help us

We continually strive to improve our resources for people affected by lymphoma and we are interested in your feedback. Share your comments at

www.lymphomas.org.uk/feedback or email us at publications@lymphomas.org.uk. You can also call our Information and Support Team on 0808 808 5555.

If you find this information useful and would like to help make it available to other people affected by lymphoma, then please consider making a donation to support our work at www.lymphomas.org.uk/donate-book. We fully rely on voluntary donations. Thank you.



We produce other booklets about lymphoma and its treatment. Please call us on 0808 808 5555 if you would like a copy of any of the following:

Lymphoma

Hodgkin lymphoma

Low-grade non-Hodgkin lymphoma

High-grade non-Hodgkin lymphoma

Living with lymphoma

Young person's guide to lymphoma

Tom has lymphoma (storybook for children with lymphoma)

All about lymphoma (EasyRead version)

Clinical trials

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We would also like to thank the members of our Reader Panel who gave their time to review this booklet.

About our information

The Lymphoma Association is committed to providing high-quality information for people with lymphoma, their families and friends. We produce our information using nationally recognised guidelines, including the DISCERN tool for information about treatments, the NHS Toolkit for producing patient information, and the

Campaign for Plain English guidelines. The Lymphoma Association is an accredited member of The Information Standard independent quality assurance scheme, which is supported by the Department of Health. For further information on The Information Standard, visit www.england.nhs.uk/tis

Our publications are written by experienced medical writers in close collaboration with medical advisers with expertise in the appropriate field. Some publications are written by professionals themselves, acting on guidance provided by the Lymphoma Association.

In some instances, our publications are funded by grants from pharmaceutical companies. These sponsors do not have any involvement in the content of a publication and have no editorial input.

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



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Introduction

Some people with lymphoma need high-dose treatment followed by a stem cell transplant, which allows their body to make healthy blood cells again after treatment.

You may be someone with lymphoma who is going to have a stem cell transplant. Perhaps someone close to you is having this treatment. You are not alone – around 700 people have an **autologous** stem cell transplant for lymphoma every year in the UK. Improvements in technology and in supportive care (treatments that don't treat your lymphoma but support your body's recovery) mean that stem cell transplants are now more successful than ever.

This booklet aims to explain what stem cell transplants are and what you might expect from your treatment. It describes stem cell transplants that use your own **stem cells**. Such a transplant is known as an '**autologous**' stem cell transplant or an '**autograft**'.

The booklet is divided into parts. You don't have to read it all at once. Stem cell transplants involve several stages and can be difficult to understand. You might like to read the bit that's relevant to you at each stage.

You can take this booklet with you to appointments with your medical team – there is space for you to make notes.

Whatever your situation, we hope the information helps you cope with the challenges ahead.

Please note that the information in this booklet is specific to procedures for people with lymphoma. If you are having an autologous stem cell transplant for another reason, your treatment may be different to that described in this booklet.

This booklet uses some scientific words. Words that are in bold are explained in the Glossary on pages 103-106.



If you would like any specific information, or would like to talk to someone about lymphoma, please call our Information and Support Team on 0808 808 5555 or visit our website at www.lymphomas.org.uk.

What is a stem cell transplant?

What are stem cells?

What is a stem cell transplant?

Who can have a stem cell transplant to treat lymphoma?

Is an autologous stem cell transplant suitable for me?

What happens in an autologous stem cell transplant?

1

What are stem cells?

You have lots of different types of cell in your body. Each type of cell is specialised to carry out a certain function. Your body makes new cells all the time to replace cells that die naturally. New cells are made when **stem cells** divide (multiply). These new cells can remain stem cells or can develop into specialised cells.

There are 2 types of stem cells:

- **Embryonic stem cells** are found at the very earliest stages of life and can make all the different types of cell in the body.
- **Adult stem cells** can only develop into certain types of new cell.

The stem cells used in **autologous** transplants for the treatment of lymphoma are a type of adult stem cell called '**haematopoietic**' (blood) stem cells. New blood cells are being made all the time from haematopoietic stem cells in your **bone marrow**. Haematopoietic stem cells can develop into all types of blood cells, including:

- **red blood cells** (erythrocytes), which carry oxygen around your body
- **white blood cells, eg lymphocytes, neutrophils** and other types which help fight infection in different ways
- **platelets**, which help your blood to clot, preventing bleeding and bruising.

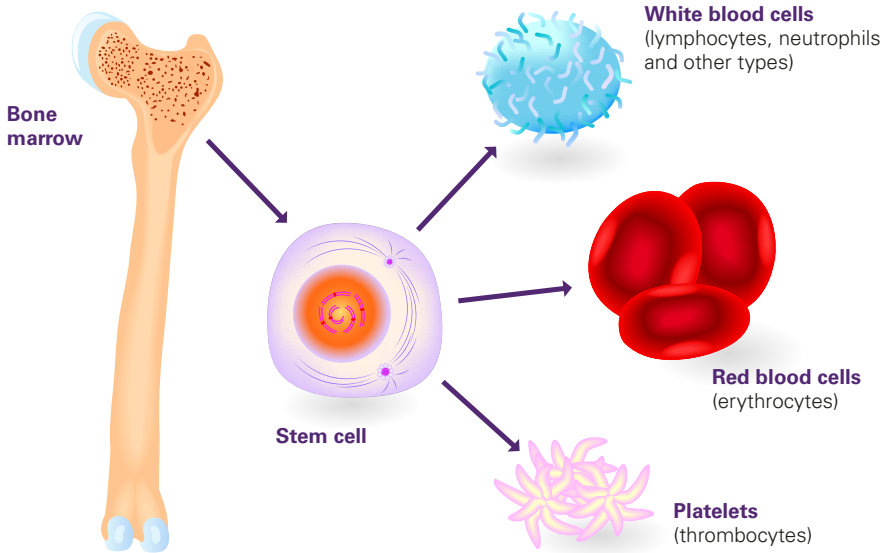


Figure 1 The different types of cell a haematopoietic (blood) stem cell can develop into

What is a stem cell transplant?

There are 2 different kinds of stem cell transplant:

- **Autologous** stem cell transplants that use your own stem cells.
- **Allogeneic** stem cell transplants that use stem cells from a donor.

Most stem cell transplants in people with lymphoma are **autologous** stem cell transplants. An autologous stem cell transplant helps your bone marrow recover after high-dose treatment.

An allogeneic stem cell transplant gives you a new immune system from a donor as well as helps your bone marrow to recover. The new immune system can help your body recognise the lymphoma cells as being abnormal.

1

This reaction is called 'graft-versus-lymphoma' effect and can help to destroy the lymphoma cells. However, the new immune system cells can attack healthy cells in your body as well, which can cause serious side effects – this is called 'graft-versus-host' disease.

'Autologous' means something that 'comes from you', not someone else. In an autologous stem cell transplant, your own blood **stem cells** are collected and stored. You are then given high-dose anti-cancer treatment, after which your own blood stem cells are given back to you.

High-dose anti-cancer treatment using chemotherapy alone or chemotherapy with radiotherapy kills cancer cells. Chemotherapy works best on cells that are dividing quickly, like cancer cells. However, blood stem cells also divide quickly. When high-dose anti-cancer treatment is given, it kills so many healthy blood stem cells that you can be left without enough to make the new blood cells you need.

A stem cell transplant gives you blood stem cells after treatment. This allows your doctor to give you high-dose treatment, while preserving your ability to make new blood cells.

This kind of treatment is sometimes called 'high-dose therapy and stem cell support' or 'high-dose therapy and stem cell rescue'.

Who can have an autologous stem cell transplant to treat lymphoma?

Clinical trials have shown that for some people an autologous stem cell transplant is more likely than standard chemotherapy to cure their lymphoma or make their remission (no evidence of lymphoma) last longer.

Stem cell transplants are used for many types of lymphoma in a variety of situations.

You might have a stem cell transplant:

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

Occasionally, your doctor might suggest you have your **stem cells** collected and stored in case you need a stem cell transplant in the future, even if a stem cell transplant isn't part of your planned treatment at that moment.

Hodgkin lymphoma and high-grade non-Hodgkin lymphoma

Most people treated with a stem cell transplant have Hodgkin lymphoma or a high-grade (fast-growing) non-Hodgkin lymphoma which has relapsed after the first course of treatment. The aim of treatment in these situations is to provide long-term remission or cure.

Some people with high-grade non-Hodgkin lymphoma might be offered a stem cell transplant when they are

1

in remission after their first course of treatment. This is usually because their kind of lymphoma has a higher risk of relapse. The aim of treatment in this case is to reduce the risk of relapse and to increase the chance of cure.

Low-grade non-Hodgkin lymphoma

Stem cell transplants are sometimes used for people with low-grade (slow-growing) non-Hodgkin lymphomas. Advanced low-grade non-Hodgkin lymphomas are more difficult to cure than other types of lymphoma. They are very likely to relapse. Stem cell transplants for low-grade lymphomas are given with the intention of making 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 me?

An **autologous** stem cell transplant isn't suitable for everyone with lymphoma, even if the lymphoma has relapsed or is refractory. You have to be well enough for such intensive treatment.

Autologous stem cell transplants work best if your lymphoma responds to chemotherapy and is in remission or in as good a partial remission (reduced by at least half) as possible. If you have relapsed, or if your lymphoma has not responded to chemotherapy the first time, you are likely to have another, different course of chemotherapy to reduce your lymphoma as much as possible before having your stem cell transplant. If your lymphoma does not respond to chemotherapy, you are

unlikely to be able to have a stem cell transplant. Your doctor can discuss other options with you.

You need to be aware that recovery from an autologous stem cell transplant takes several months.

If your doctor is recommending a stem cell transplant, they should discuss the procedure with you and give you information about what is involved. You should be introduced to your key worker or clinical nurse specialist who can offer advice and information. A stem cell transplant requires careful planning so you should have time to consider whether this is the best option for you.

→ see pages 95-101 for questions you could ask yourself and your medical team about autologous stem cell transplants

What happens in an autologous stem cell transplant?

An **autologous** stem cell transplant follows a pathway. Each stage of the pathway is described in more detail in the following sections.

Figure 2 overleaf gives an overview of the different stages of the autologous stem cell transplant process.

Although it is an intensive form of treatment, autologous stem cell transplants are safer and more effective now than ever before. In recent years, there have been major improvements in methods for collecting **stem cells**. Modern supportive care treatments are very effective in supporting your body while it recovers.

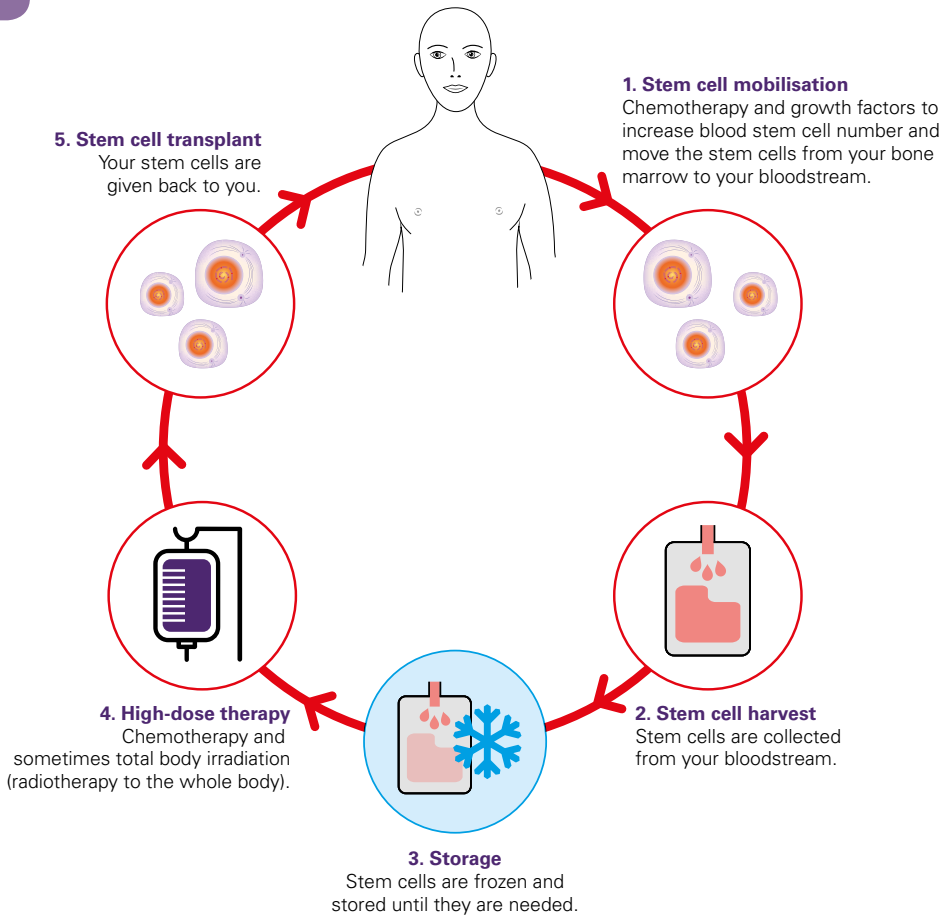


Figure 2. The autologous stem cell transplant process

Summary

1

- Stem cells can grow into different types of cell to replace cells that die naturally in your body.
- Stem cell transplants replace blood stem cells killed during high-dose therapy, so you can continue to make new blood cells.
- Stem cell transplants can give you a better chance of a long-term remission or cure of your lymphoma.
- Stem cell transplants are most commonly used to treat people who have relapsed, didn't respond to their first treatment or have a high chance of relapse because of the type of lymphoma they have.
- Stem cell transplants are an intensive treatment.
- Thanks to improvements in technology and supportive treatments, they are now safer and more effective than they used to be.

Notes

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Preparing for a stem cell transplant

Where are transplants done and who's involved?

What tests do I need?

What is a central line and why do I need one?

Why do I have chemotherapy before my stem cells are collected?

What do I need to consider before my stem cell transplant?

Where are transplants done and who's involved?

2

Stem cell transplants are only carried out by specialist transplant units that are in larger centres. Many people have to travel some distance from home for their treatment. You have the opportunity to meet the people involved in your care at the specialist centre and you can ask any questions you have.

Transplant coordinator and key worker

You should be assigned a contact person (key worker) who should discuss your treatment with you and answer any questions. Most transplant units have a member of staff called a **transplant coordinator**. The transplant coordinator is a nurse or another health professional trained to look after people preparing for stem cell transplants. They might be your key worker during this part of your treatment. They are central to your care and see you regularly.

Information and consent

You are given lots of information during the preparation stage. Keep all this information together in a file or folder so you can refer to it when you need to. The information you are given could include:

- The names and contact details of important people and details about the treatment centre.
- What to bring with you for your hospital stay.
- Guidelines about visitors, including what visitors can and cannot bring in with them.
- What side effects to expect in the short term.
- Details of any extra support your treatment centre can

- provide, eg counselling or complementary therapies.
- Information about **late effects** which are side effects that can develop months or years after your treatment.

Ask your key worker for more information if you have any questions. For example, ask whether there is anything you can bring with you to help with side effects.

2

You can jot down any notes or questions and take this booklet with you to your appointments.

As far as possible, your treatment is planned to fit in with important events in your life. You and your team spend some time planning the coming months. You should be given a timetable of when things are expected to happen. This helps you to make arrangements with your employer, or with your college or university. You might also need to arrange extra support for anyone who depends on you, particularly if you have elderly relatives or young children.

You have to give formal, written consent for the stem cell harvest and also for the treatment to go ahead. Once the process has been explained to you, you sign forms to say that you agree to have the treatment and that you have been informed about what is involved, including the possible risks and side effects.

What tests do I need?

You need tests to make sure you are well enough to have a stem cell transplant and to check on your lymphoma.

Blood tests

Blood tests include:

- Your full **blood count** (FBC) and your blood group.
- Tests of your liver, kidney and thyroid function.
- Tests of glucose and iron levels.
- Tests for certain viruses, eg hepatitis and human immunodeficiency virus (HIV). The results of these virus tests are also needed so the laboratory can store your **stem cells** safely.
- Tests for infections that might be dormant (inactive), eg many people have had chickenpox and then carry the virus without knowing it. Such infections might flare up when your blood count is low. Your doctor can prescribe antiviral medicines if needed.

Restaging tests

You might need to have restaging tests. These tests find out how much lymphoma is in your body and measure whether any chemotherapy you have had already has reduced the lymphoma. Restaging tests might include a **CT** or **PET/CT scan** and possibly a **bone marrow biopsy**.

Organ function tests

Some lymphoma treatments can damage your organs, particularly when given in high doses. You need tests before your transplant to check the health of your major organs, like your lungs, heart and kidneys. Your medical 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 blood tests

to make sure there is enough oxygen in your 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 blow as hard as you can or do breathing exercises. Sometimes your lung function is tested during exercise. There should be no side effects from these tests, but you might feel a little tired afterwards.

Cardiac tests

Heart 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 are asked to remove your clothes above the waist.

An ECG only takes a few minutes. Small sticky sensors are attached to your chest, arms and legs. They are connected to a machine that produces a trace showing the activity of your heart.

An echocardiogram takes around 30–40 minutes. A gel is put on your chest or on the ultrasound probe. The probe is moved across your chest and a nearby machine shows the pictures produced.

Some centres might suggest a multigated acquisition

(MUGA) scan instead. This involves having a low-dose radioactive injection and then standing or lying in front of a scanner.

2

Kidney tests

You have tests to make sure your kidneys are functioning well.

You might have a glomerular filtration rate (GFR) test. A harmless radioactive dye is injected into your vein and blood samples are taken for a few hours afterwards to measure how well your kidneys are filtering the dye. The blood samples can be taken from your **central line** if you have one (see next page). Some centres estimate your GFR by taking a single blood test and matching this with the results of a 24-hour urine collection. In this case, you are given detailed instructions to make sure you collect exactly 24 hours' worth of urine.

What is a central line and why do I need one?

You have a central venous catheter or **central line** inserted before your high-dose treatment starts if you do not already have one. You need lots of different treatments and blood tests during a stem cell transplant. A central line stays in place until your treatment is over and means you can have all your treatment through it. You can have blood tests taken from the line too. The central line makes giving you treatment easier and is more comfortable for you than repeated jabs.

Central lines are long, flexible tubes that are inserted into a vein and end in a vein deeper inside your body.

There are 2 common types of central line: a peripherally inserted central catheter (PICC line) and a tunnelled central line (sometimes called a Hickman® or a Groshong® line). A PICC line usually goes in through a vein in your arm at the level of your elbow. It is held in place by a piece of tape or dressing. A tunnelled central line is usually positioned on your upper chest. Part of the line runs in a tunnel under your skin, which reduces the risk of infection. Both types of central line end in a vein that is deeper inside your body.

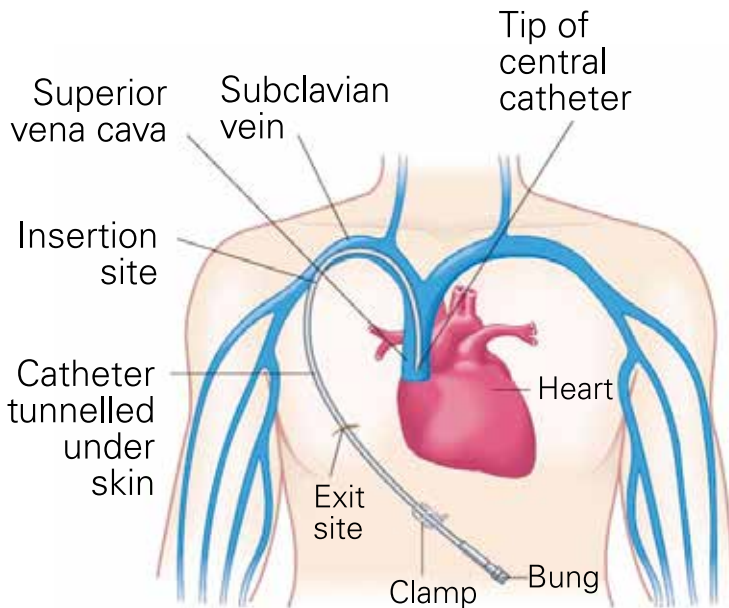


Figure 3. A central line

The line is put in during a small operation under either a local or a general **anaesthetic**. You have a chest X-ray after a central line has been put in to check that it is in

the right position. The line is then covered at the exit site (the place where it goes into your skin).

2

Your central line should stay in place for the whole of your treatment. You will be given information about how to care for it and what to look out for. The line is flushed (fluid passed through it) weekly and the dressing is changed weekly. This might be done at the hospital or you or your carer might be shown what to do on your own.

You can shower, but it is best not to bathe while the line is in as **you must not immerse the exit site or the line itself in water**. You must not go swimming while the line is in. You are told what precautions to take to avoid getting the exit site wet when showering. The line can be secured against your body with tape to avoid it getting caught. If the dressing gets wet or loose, it needs to be changed.

Check the exit site regularly. Call your key worker if you have any problems or need advice about your central line. Look out for signs of infection or that your central line might have moved or caused a blood clot to form.

Contact your key worker immediately if you have any of the following symptoms:

- pain or tenderness at the insertion site
- discomfort or swelling in your neck or arm on the side the line is in
- temperature above 38°C
- other symptoms of infection, eg fever, chills or feeling generally unwell.

Your line is usually removed when you no longer need any blood or platelet transfusions, around 6–8 weeks after your transplant.

Why do I have chemotherapy before my stem cells are collected?

2

Most people have a course of chemotherapy before their **stem cells** are collected. This is different from the high-dose chemotherapy you have after your stem cell collection.

This first chemotherapy is given to:

- Reduce any remaining lymphoma. If you have relapsed after an earlier course of treatment, or if you have residual (leftover) lymphoma, you have more chemotherapy to reduce the lymphoma as much as possible before your stem cell transplant. You might hear this referred to as ‘salvage’ chemotherapy or ‘remission induction’.
- Encourage your **bone marrow** to make more blood **stem cells** so that there are enough for collection. Suppressing your bone marrow with chemotherapy encourages it to repair itself by making more stem cells.

You also have growth factor injections a few days after the chemotherapy has finished. Growth factors boost the number of stem cells produced by your bone marrow and move them into your bloodstream.

The exact chemotherapy regimen you have depends on your individual situation and the kind of lymphoma you have. If you have residual lymphoma, your chemotherapy

2

might be given some months before your stem cells are harvested and you might have further courses of this type of chemotherapy. This is to make sure your bone marrow is clear of lymphoma and to produce a better remission before going ahead with your stem cell transplant.

What do I need to consider before a stem cell transplant?

There are things you should consider while your stem cell transplant is being planned.

Preserving fertility

High-dose therapy can damage your testes or ovaries. Some people are still able to have children after treatment, but many are not. You might be eligible to have sperm or embryo storage. Talk about this with your consultant or key worker.

Visiting the dentist

You should see your dentist for a check-up before your high-dose treatment. This is to check that you don't have any dental problems that might be made worse by treatment or that could be a potential source of infection when your **blood counts** are low. You should avoid dental treatment when your blood cell 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 therapy is likely to cause temporary hair loss. If you think you might prefer to use a wig while your hair is growing back, your key worker can advise you on how to arrange one.

Support and visitors

Share the information you are given about your treatment and what to expect with the people close to you. Explain to them that there might be days when you don't feel well enough to have visitors while you're at the hospital. Let them know that it can take you a while to get better after you come home, even many months. This might help them to understand your needs and to support you while you recover.

Many people have stem cell transplants some distance from home. The people close to you might also want to travel with you or stay nearby. Ask your key worker for information about local or hospital accommodation for your family if they need it.

Financial and social support

Recovery from a stem cell transplant takes several months and you need support in place for when you come home. If you live alone, and particularly if you are over 65, find out about what support might be available to you.

If you care for someone else, find out what support is available for that person and for you, including financial assistance. Ask your key worker whether the hospital can provide a social worker for further advice. You can also contact your local council's social services department or approach charities that offer this kind of advice.

Work and study

Explain your treatment to your employer, your college or university. It usually takes 3–6 months for people to

2

be ready to go back to work after a stem cell transplant. It could take longer. If you are a student, discuss the situation with your tutor as they are best-placed to offer you advice how to manage your studies during and after treatment.

Things to take to hospital

Hospitals have rules about what you can bring with you. The rules are made to keep your room clean and reduce the risk of infection. However, your hospital stay might feel isolating and bringing some distractions and home comforts with you can help you through this time. Ask what your hospital recommends and consider the following suggestions for what to take with you.

Things to brighten up your room

You can pin up photos and drawings. You can take your own bedding and soft towels if someone at home can wash them for you.

Things to pass the time

Ask whether you can take your mobile phone and whether you are able to connect to the internet. 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. A television set is likely to be provided in your room, but you might have to pay for it.

Things to wear

When choosing your clothes, try to get tops that button up the front, as they make it easier for doctors to

examine you and for nurses to care for your **central line** and give you your treatments. Lightweight, loose, soft clothing and machine-washable slippers can make you feel more comfortable.

Toiletries

Ask about what your hospital recommends regarding toiletries. Some units recommend antibacterial soaps, shower products and skin care. You might need gentle products. Your own supply of soft toilet roll or flushable wet wipes can be useful if you have any soreness caused by side effects.

You might have a sore mouth. Take a toothbrush with very soft bristles, eg a toothbrush for 0–3 year olds. Your medical team can recommend other products that help.

2

Summary

There is a lot of preparation before a stem cell transplant:

- You have tests to find out about your lymphoma and to check you are well enough to have a stem cell transplant.
- You have a **central line** or a PICC line inserted if you don't have one already.
- You are likely to have chemotherapy to treat any leftover lymphoma and to help your body produce more stem cells for collection.

During this stage, you can make preparations to help you through your treatment and recovery:

- Seek advice about financial support and about what happens while you are off sick from your job.
- Ask about what help might be available to those you care for while you are in hospital and during your recovery.
- Visit your dentist.
- Think about if and how you'd like to cover hair loss.
- Talk to your medical team about fertility – you might be referred to a fertility specialist.
- Think about what you might want with you in hospital and ask your medical team for advice on what to take.

Notes

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Notes

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Stem cell mobilisation and harvest

What are stem cell 'mobilisation' and stem cell 'harvest'?

Where do stem cell mobilisation and harvest take place?

Mobilising your stem cells

Collecting your stem cells

Storing your stem cells

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

What are stem cell 'mobilisation' and stem cell 'harvest'?

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Your **stem cells** are collected (harvested) in the weeks or months before your high-dose therapy. Before the harvest, you need treatment to help your body produce more stem cells and to mobilise (move) them from your **bone marrow** into your bloodstream so they can be collected more easily.

The chemotherapy you have as part of preparation for your stem cell transplant can cause more stem cells to be made in your bone marrow as well as treating your lymphoma. You also need growth factor injections to mobilise your stem cells.

There is a lot to remember and keep track of during this stage. Use the notes pages in this book to write down everything important.

Where do stem cell mobilisation and harvest take place?

You normally have both stem cell mobilisation and harvest as an outpatient. You come into hospital for chemotherapy and go home afterwards if you are well enough. You don't need to go to hospital for growth factor injections. Your medical team can show you or someone else how to do them at home or can arrange for a nurse to come and 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 in 2016

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You go into hospital to have your **stem cells** collected and should be able to go home afterwards. You might have to go to the hospital for 1–3 days in a row so that enough stem cells can be collected. In some circumstances, you might have to stay overnight, eg if you are having a central line fitted on the same day.

Mobilising your stem cells

Chemotherapy and growth factors are most often used to increase the stem cell count and to mobilise (move) your stem cells from your bone marrow into your bloodstream to make it easier to collect them. You may need other treatments as well.

Growth factors

Growth factors are hormones that occur naturally in your body and help produce blood **stem cells** in your **bone marrow**. They are sometimes used to increase your **white blood cell counts** if they fall too low during treatment for lymphoma. For stem cell transplants, growth factors are used to stimulate production of stem cells in your bone marrow and help the stem cells move into your bloodstream so they are easier to collect – this is called 'mobilisation'.

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You have daily injections of a growth factor, usually a granulocyte colony stimulating factor (**G-CSF**). The injections normally start within a few days of finishing chemotherapy. G-CSF is given as a **subcutaneous** injection – into the fatty tissue under your skin. Injections are usually given into your stomach, the top of your leg or the top of your arm.

The exact number of injections needed varies, but people normally have growth factor injections over 7–10 days. If possible, you should have your injection at the same time each day, often in the late afternoon.

It is important to remember your G-CSF injections. If you miss a day, this might slow down stem cell mobilisation and make it difficult to collect your stem cells.

Most people have few side effects. The most common side effects of G-CSF are muscle and bone aches and pains. You might find paracetamol helpful if you have pain. You may need something stronger. Your medical team can advise you which painkillers are suitable for you and can give you more information about any other side effects you might experience.

Regular blood tests are done to see how your **blood counts** are responding. As your white blood cell count starts rising, you are asked to come into the hospital for your stem cells to be collected. Most transplant centres check your white blood cell count and also check how many cells have a protein called '**CD34**' that is found on blood stem cells. The CD34 count is a good indicator of whether your bone marrow is starting to produce stem cells.

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 other treatments to achieve this.

If the results of your blood tests show that you don't have enough stem cells in your bloodstream for them to be collected, you might be given plerixafor (Mozobil™) in addition to G-CSF before your collection. Plerixafor causes stem cells to be released into the blood. It is given as a **subcutaneous** injection 6–11 hours before your stem cell collection. The most common side effects of this treatment are diarrhoea, nausea (feeling sick) and skin reactions where the injection was given.

Collecting your stem cells

You might hear your stem cell collection referred to as 'harvesting'. Stem cell collection is usually done in the haematology department at the hospital using a machine called a 'cell separator'. The process where your blood is passed through a machine to separate a part and return the rest to your bloodstream is called '**apheresis**'.

Preparation for collection

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

- The stem cells are usually collected through your central line or through a line in your arm.
- Wear comfortable clothes with short sleeves so there is easy access to your arms.

You rest on a bed or chair during the collection procedure. Bring something to keep you occupied. You need to stay reasonably still during the stem cell collection so listening to music or audio books is a good option. Some centres let someone sit with you to keep you company.

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‘Nurses provided tea, coffee etc all day and really took care of everyone.’

Leo, who had an autologous stem cell transplant in 2016.

The collection process

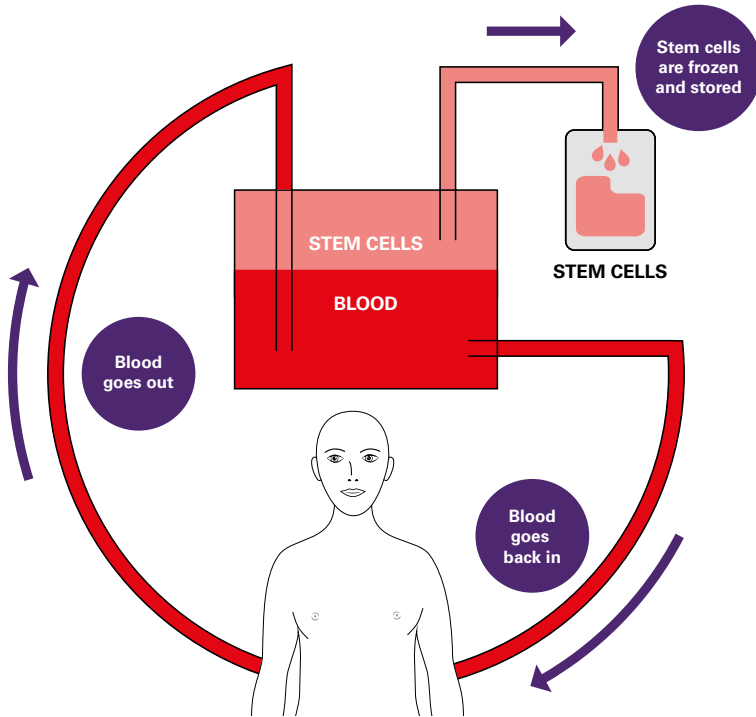
A constant flow of blood is taken from a line in an arm and passed through the machine. The cell separator collects **stem cells** and the rest of your blood is returned into your other arm. If you have a **central line**, the blood might be taken and returned through that instead. Only a small amount of blood – around 160 millilitres or a third of a pint – is out of your body at any time.

The process takes a few hours to complete.

Some people feel light-headed during their stem cell collection, but most people don’t notice much at all.

An anticoagulant (blood thinner) drug is added to your blood as it passes through the cell separator to prevent your blood from clotting in the machine. It can cause side effects like:

- mild nausea (feeling sick)
- tingling in your lips, nose or fingertips.



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Figure 4. Stem cell collection: Blood is passed through a cell separator, which separates and collects stem cells

These side effects are caused by a low blood calcium level. They don't last long – they usually stop when the machine is switched off but can continue for a few hours afterwards. If side effects are troublesome, they can be treated with calcium supplements, given as tablets or **intravenously** (into a vein).

After the collection

If you can, arrange for someone to take you home after stem cell collection as you are likely to feel tired and perhaps a bit shaky. You shouldn't drive. Tell your medical team if you have any problems with arranging a lift. It may be possible for them to arrange alternative transport.

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Storing your stem cells

After collection, your stem cells are mixed with a preservative, frozen and stored until you need them. Usually, your stem cell transplant takes place in the few weeks or months following collection. Sometimes your stem cells are stored in case you need a stem cell transplant as a future part of your treatment. Stem cells can be stored frozen for many years.

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

When your **stem cells** have been collected, they are counted to make sure there are enough of them. If there are not enough, you might be given another dose of **G-CSF**. You are then asked to return the next day to have more stem cells collected. It can take 1–3 days to collect enough stem cells for a transplant.

If enough **stem cells** are not collected in the first collection, you may have plerixafor in addition to G-CSF (page 43).



'My lymphoma was tenacious and came back. I underwent, therefore, conditioning treatment as a precursor to an autologous stem cell transplant, using stem cells harvested about 6 years beforehand while I was in remission.'

Gary, who had an autologous stem cell transplant in 2009

Some people don't have enough stem cells in their bloodstream to have a stem cell transplant even after several treatments. Should this be the case for you, your doctor will discuss your options with you. You might be able to have an **allogeneic** stem cell transplant, which uses donor cells. Very rarely, **stem cells** can be collected directly from your **bone marrow**.

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Allogeneic stem cell transplant

If you don't have enough of your own **stem cells** for an **autologous** stem cell transplant, you might be able to have an **allogeneic** stem cell transplant, where cells from a donor (someone else) are used. An allogeneic stem cell transplant has more risks than an autologous stem cell transplant. You have to be fit enough for this intensive treatment. You also have to have a suitable donor who is a close match to your tissue type. This is often a sibling (brother or sister) or a matched donor from a donor register.

We have separate information about allogeneic stem cell transplants on our website at www.lymphomas.org.uk.

Stem cell collection from bone marrow

Very rarely, **stem cells** can be collected directly from the **bone marrow**. A needle is used to remove bone marrow from the space in the centre of your hip bone. Your doctor might need to do several injections to take enough bone marrow. The procedure is done under a general **anaesthetic** so you don't feel anything. However, the injection sites are likely to be sore afterwards. You can take painkillers until the soreness gets better.

Summary

- For stem cell **mobilisation**, you have growth factor injections to boost the numbers of **stem cells** produced and help move the stem cells into your blood.
- The chemotherapy you have before your transplant also helps to boost stem cell numbers and move them into your bloodstream.
- When you have enough stem cells, they are collected (harvested) using a cell separator machine.
- The cell separator takes blood out of your arm, passes it through the machine to remove the stem cells, and returns the remaining blood to your other arm.
- You have a blood thinning drug to stop your blood clotting in the machine. This drug can cause side effects, but they are short-lived and easily treated.
- Stem cell collection can take several hours, sometimes over more than a day.
- You might need other treatments if your medical team can't collect enough stem cells. Your doctor should discuss your options with you if you don't have enough stem cells for an **autologous** stem cell transplant.

Notes

[illegible]

Conditioning and stem cell transfusion

4

What does this stage involve?

Where do I have treatment?

High-dose chemotherapy

Total body irradiation (TBI)

Stem cell transfusion

What does this stage involve?

When you are ready for your stem cell transplant, you have high-dose therapy, which your doctor may call '**conditioning**'.

Most people with lymphoma have high-dose chemotherapy. Very rarely, people also have **total body irradiation** or **TBI** (whole-body radiotherapy) just after or before their chemotherapy.

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After your high-dose therapy, your stored **stem cells** are given back to you.

Where do I have treatment?

Most people who have a stem cell transplant in the UK are admitted to hospital for their high-dose treatment and transplant. This means coming to hospital just before your high-dose treatment starts and staying there until your **blood counts** are at a safe level. Most people go home 2–3 weeks after their transplant.

You are likely to stay in a room on your own. Some hospitals offer some of the treatment as an outpatient. This means that you have your high-dose treatment, go home or to nearby accommodation, and come into hospital for daily checks and for help with any side effects. Because lots of people who have a stem cell transplant have treatment at a large centre that is some distance from home, this accommodation is usually a room at a nearby hotel or a facility owned by the hospital.

High-dose chemotherapy

High-dose chemotherapy is given over a few days. The chemotherapy you have, and the time it takes to have it, depends on several factors, eg:

- what kind of lymphoma you have
- what treatments you've had before
- your general health
- the usual practice at your hospital.

High-dose chemotherapy is usually given via your **central line**. Some of the drugs are given as injections into your line and others are given as an infusion from a drip (given slowly from a bag of fluid). An infusion machine might be used to make sure the drug is given at the correct rate.

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The machine might beep from time to time, but the flow is stopped until the glitch is sorted out. You might need to go to the toilet more often during your infusion as you have a lot of fluid coming into your body over a relatively short time. You are also encouraged to drink more than usual.

Your medical team should give you more information about your high-dose treatment, including which drugs you are having and what side effects you might experience.

BEAM chemotherapy is often used as the high-dose treatment:

- B – BCNU® or carmustine
- E – etoposide
- A – Ara-C or cytarabine
- M – melphalan.

You have these chemotherapy drugs for a week.

Total body irradiation

Most people with lymphoma have high-dose chemotherapy alone. Very rarely people also have radiotherapy to the whole body, which is known as **'total body irradiation'** (TBI).

TBI is different from standard radiotherapy – with TBI your whole body is treated at the same time and the dose is given over a shorter period. The dose and timetable for your treatment depends on your individual situation. Your medical team should give you details about the exact treatment you are having. If you are having TBI, it can be given before or after your high-dose chemotherapy.

4

Stem cell transfusion

After your high-dose treatment, you usually have to wait 1–2 days for the chemotherapy to leave your system before you have your **stem cell infusion**. Otherwise, the chemotherapy could damage the new cells. You might have your stem cell infusion sooner than this, depending what chemotherapy drugs you've had.

Stem cell infusion is a straightforward procedure, similar to a blood transfusion. In fact, many people say that having your stem cells returned feels anticlimactic after all the preparation and intensive treatment.

On the day of your transplant, your stem cells are thawed and then given to you through your **central line**. You might have a single bag of stem cells or several bags

depending how many bags have been collected. The infusion takes around 1–2 hours depending how many bags of stem cells you have. You have your pulse and blood pressure checked frequently and the nurse usually stays with you until the infusion is completed.

‘Trevor had 9 bags of 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 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 in 2014

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Tell someone if you feel unwell during the process. Side effects are usually mild and don’t last long, but if you do feel unwell, the infusion can be slowed down. You might have:

- mild nausea
- altered taste
- a flushed feeling.

The preserving agent used when freezing the cells (dimethyl sulfoxide, DMSO) causes many of these side effects. DMSO has a distinctive smell – some people say it smells like sweetcorn. You might be able to smell it on your breath and visitors might notice it in your room.

Your medical team might refer to your transplant day as ‘**Day Zero**’. They measure your recovery time starting from this day.

4

Summary

- Most people having a stem cell transplant in the UK are admitted to hospital before their high-dose therapy, which is called '**conditioning**'.
- High-dose chemotherapy is given over a period of a few days. The chemotherapy you have depends on the type of lymphoma you have and the usual practice at your hospital.
- **Total body irradiation** (TBI) is used for some kinds of lymphoma and for lymphoma in particular parts of the body. It is given over 2–4 days. TBI is given after chemotherapy and just before your **stem cell infusion**.
- Your stem cells are given back to you 1–2 days after your high-dose chemotherapy or the day after you finish TBI. The infusion takes about 1–2 hours.
- A chemical called DMSO is used to preserve the stem cells. It has a strange smell and can cause short-term side effects such as flushing and mild nausea.
- The day of stem cell infusion is referred to as '**Day Zero**'.

Notes

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Engraftment and supportive care

5

What is engraftment?

What happens while I wait for engraftment?

What side effects and supportive care might I have?

How can my medical team support me?

Being in protective isolation

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. Gradually your **blood counts** return to a safe level. This process is known as **engraftment** because the stem cells 'graft' onto your bone marrow – the stem cells and bone marrow grow together and start working normally again.

It takes around 8–12 days for the first new blood cells to appear in your blood, showing that engraftment has happened. You can only go home when your body is making enough new blood cells.

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The different types of blood cells each take a different amount of time to appear in your blood:

- **Neutrophils** appear first. These are the **white blood cells** that fight bacterial infection.
- **Platelets** are usually next. Platelets help with blood clotting and so prevent bleeding.
- **Red blood cells** appear last. They carry the oxygen in your blood.

Recovery of your neutrophil count is the most important factor in planning your discharge as you need treatments and strict measures to prevent infection while your neutrophil count is low.

What happens while I wait 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 medical team monitor you closely and you need regular checks of your temperature, pulse and blood pressure, including at night. The nurses try to disturb you as little as possible, but close observation is very important.

You have lots of treatments while waiting for your blood counts to recover. This is known as 'supportive care'. These treatments help to protect your body while your blood counts are low and treat the side effects of your high-dose treatment.

What side effects and supportive care might I have?

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As well as low **blood counts**, you are likely to have other side effects from your high-dose treatment. The side effects you are likely to have depend on the exact treatment you've had.

- High-dose chemotherapy causes the same side effects as regular-dose chemotherapy, but the side effects can be more severe and can last longer. Side effects include temporary hair loss, sore mouth, diarrhoea, change in taste, loss of appetite, nausea, and sometimes vomiting.
- **Total body irradiation** (TBI) can cause some of the same side effects as high-dose chemotherapy. TBI can also cause a skin reaction similar to sunburn. Skin reactions are most likely to show in folds of skin, such as in the groin or under the breasts.



'We were expecting the side effects to be much worse. He didn't get the sore mouth he was anticipating and only got a slight temperature, not the raging infections he could have had. He had a bad enough time of it, but it could have been worse.'

Sue, whose husband Trevor had an autologous stem cell transplant in 2014

There is more about the most common side effects in the following sections and you can find more information on all of these on our website. Tell your medical team about any side effects you develop as they can offer treatments and advice that can help. There are often several options for treatment so tell them if the medicines they give you for side effects don't seem to be working.

Low blood counts

Many of the side effects that you have supportive care for are related to low **blood counts**:

- risk of infection increases with **neutropenia** – low levels of **neutrophils** (a type of **white blood cell**), which fight infection
- **anaemia** is caused by low **red blood cells**, which carry oxygen around your body
- **thrombocytopenia** is caused by low **platelets**, which help blood clotting.

Risk of infection

You are at high risk of infection while your **neutrophil** count is very low (**neutropenia**). You're at increased risk of infection until your white blood cell count returns to normal. This can be a few months after your transplant.

Infection is a common complication of high-dose therapy and many people have an infection of some kind before they leave hospital. 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 when you have lowered immunity they can cause infections. Infection can also come from outside sources, for example from food or from other people.

Remember that most infections can be prevented and treated. Your team have a lot of information about infections and how to deal with them. Much of your supportive care is aimed at reducing the risk of infection as far as possible. You are closely monitored for signs of infection. Your temperature and pulse are checked at regular intervals, including at night. **You must tell your nurses if you feel generally unwell or if you feel feverish or short of breath.** These symptoms might indicate infection, even if your temperature is normal. Some of the other measures to reduce the risk of infection include:

- Good hygiene – your room should be cleaned every day and you must shower, wash your hands and clean your teeth regularly.
- Treatments to prevent infection – you may have antibiotics and special mouthwashes.
- Another growth factor injection can be given to boost your blood counts, usually 7 days after your transplant.
- Eating the right things (neutropenic diet) – you should avoid some foods because they are more likely to carry bacteria, eg unpasteurised cheese and takeaway food.
- Rules for visitors – people with an infection shouldn't visit. Some hospitals ask that young children don't visit at all as they are exposed to lots of infections at school or nursery.

Visitors might be asked to wear protective clothing and should always wash their hands and use an antibacterial hand rub when visiting. They might be given a plastic apron to wear. You are not allowed flowers or plants in your room to reduce the risk of infection. Some hospitals display flowers for you outside your room.

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

Anaemia

Anaemia means that there is too little haemoglobin and too few **red blood cells** (that carry haemoglobin) in your blood. The haemoglobin in your **red blood cells** carries oxygen to your body's other cells. Anaemia can make you feel very tired and sometimes short of breath. You have regular checks of your haemoglobin level as part of your blood tests. You might need **transfusions** of **red blood cells** to treat anaemia while you wait for your **blood counts** to recover. **Red blood cells** from a donor are given to you through your **central line**. It takes a couple of hours for a bag of **red blood cells** to be transfused.

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Most people do not feel anything when they are having a blood transfusion. A few people have a mild reaction to the transfusion and develop a high temperature, chills or a rash. This doesn't usually last for very long and slowing the transfusion down can help. You have your temperature, pulse and blood pressure checked during the transfusion. Severe reactions to blood are extremely rare.

If you feel unwell during or shortly after your blood transfusion, tell the nurses straightaway.

The transfused **red blood cells** gradually work less well over a few weeks, which means you might need another transfusion if your **red blood cells** are still low. You might still be slightly anaemic and have to come to hospital for **red blood cell** transfusions after you go home.

Risk of bleeding

Platelets help with blood clotting. A shortage of platelets (**thrombocytopenia**) means you are more at risk of bleeding and bruising. You are closely observed 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 urine or after a bowel movement (your poo might have obvious blood or be black in colour). Report any bleeding from your gums or mouth or if you have a nosebleed. Women should also report heavy periods.

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You might need a **transfusion** of platelets – this is a bit like a blood transfusion, but the liquid is yellow in colour and there is only a small amount of it. Platelet transfusions are given through your **central line** and take about half an hour per bag. Some people have a reaction to the platelet transfusion, which can make them feel flushed or shivery. You can be given drugs through your central line to treat this reaction.

The platelets that are given do not make the platelet count normal again. Instead, they stop any bleeding that's already occurred or lower the risk of further loss of blood. Because the platelets get used up, the effect of transfusion only lasts for a few days. You might need to have another platelet transfusion afterwards. Your platelet count takes some time to recover. Bleeding is only likely with very low platelet levels, so you are likely to go home even if your platelet count is low.

Other common side effects

Some side effects are common with most types of high-dose treatment for lymphoma. Your medical team can give you more information on these and on other side effects that you might experience.

It is common to also have emotional changes during your treatment. It is natural to experience feelings of sadness and anxiety. Talk to your medical team if you are struggling with your feelings. They can offer advice and support or may have a counsellor they can refer you to.

Fatigue and poor concentration

You are likely to feel very tired and may 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.

It might take 3–6 months to start feeling 'normal' again, irrespective of your age. After this time, most people are able to go back to whatever activity was normal for them before their transplant. Note that it is common to be able to do less than before the transplant. You might become tired more easily and need to sleep more. You might have to ensure that you get more rest than you needed before your lymphoma.

For some people, reduced stamina or poor concentration is a longer-term problem. Should it happen to you, you can discuss it with your team. You might still be anaemic or have another medical condition causing fatigue or poor concentration. There are many strategies to help people cope with these problems.

Sore mouth and loss of appetite

It is very common for people to develop a sore mouth or mouth ulcers after high-dose therapy. It is important to take particularly good care of your mouth at this time. You are given special mouthwashes and should use these regularly. Here are some suggestions about mouth care:

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- Use a toothbrush with soft bristles, eg one designed for 0–3 year olds.
- Use mouthwashes before and after meals and at bedtime, or whenever you can.
- If your mouth is too sore to brush your teeth, ask your nurses if they can provide foam swabs to use instead.
- Don't use dental floss.
- Keep your lips moist with lipsalve. Ask the hospital what they recommend.
- If you wear dentures, you might have to take them out if you develop mouth ulcers.
- Ask for drugs to help with pain.

Many people lose their appetite for some of the time. Your mouth might be sore. You could find that food tastes different too. You might not feel like eating.

You might find it easier to divide larger platefuls and eat smaller portions more often. There might be kitchen

facilities or a fridge available, so that you can eat what you like when you feel like it. You could ask family and friends to bring in snacks that you enjoy. Ask your nurses for detailed information about safe foods. Avoid drinks and foods that are irritating to your mouth.

Eating problems are usually temporary. You might be offered nutritional drinks to support you until you can eat normally.

Occasionally, people are offered a feeding tube as a short-term measure if their mouth is very sore. The feeding tube is a soft tube that goes through your nose and down into your stomach. It means you can be fed with a special liquid without the discomfort of eating.

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Nausea, vomiting and diarrhoea

You are likely to have loose stools or diarrhoea at some point following your high-dose therapy. You might also have nausea and vomiting. These problems are caused by chemotherapy or radiotherapy, both of which damage the cells of your gut.

Infection in your gut can also cause nausea and diarrhoea. Drugs given to treat infection, such as antibiotics, can cause these problems too. Remember that these problems are related to your treatment and are temporary.

You can be given drugs to help. There are several types of anti-sickness drugs to try and you might have to try a couple to find one that works for you. Some people have continuous anti-sickness drugs given into their **central lines** through a syringe attached to a small pump.

If you have diarrhoea because of your treatment, you might find that incontinence pads or sanitary towels can give you some protection and reassurance if you find it hard to get to the toilet in time. Family members might have to provide these for you, but ask your nurses about what's the best solution for you. In many units you have your own toilet and shower.

How can my medical team support me?

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Communicating with the professionals caring for you is a critical part of your care. Talk to your team about anything that is on your mind. Tell your team about any side effects or if a drug intended to prevent a side effect isn't working. Tell them if you have a problem with mouthwashes, for example, or with eating.

Your medical team are used to people being worried and asking questions. A stem cell transplant is a complicated process that involves several stages. Many people have to ask the same questions several times to understand the answers.

'The key thing I have learnt is to never be afraid to ask questions, even if they may sound daft. It's your life and correct information is paramount.'

Leo, who had an autologous stem cell transplant in 2016

Being in protective isolation

Most people having high-dose therapy and stem cell transplant in the UK spend some time in a single room while they wait for their **blood counts** to recover. 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, feeling sick and tired, and without much energy for distracting yourself.

Visitors

Visitors can provide a welcome distraction and support. There might be rules for visitors, particularly in the days just after your transplant when your risk of infection is highest. Some units do not allow children to visit. Your hospital will be as accommodating as possible about visiting.

'I took the children to visit when nobody had any coughs or colds. I told them they had to be on their best behaviour – no jumping on the bed and no touching anything as this was the time we had to be extra careful about germs.'

Sue, whose husband Trevor had an autologous stem cell transplant in 2014

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There will be times when you won't have energy for visitors. Warn people beforehand that you sometimes might be too tired to see them. Your friends and family might then want to send cards, letters or emails. Photographs and children's drawings can also give you a boost and help the hospital room seem more your own.

Some units have (or can arrange) a telephone in your room, but ask about this in advance and get information about the cost. Some units offer an internet connection. Be aware that some units have restrictions on the use of mobile phones.

Keeping active

Your medical team can give you advice on keeping active while you are waiting for your **blood counts** to recover. Exercise is important – even a small amount can help, eg stretching exercises will help to stop you getting stiff. Ask your medical team what they recommend and whether you can go for a short walk outside your room.

Home comforts and distractions

It can be boring and frustrating to have time to fill when you don't feel like doing much. Try to have a variety of things to do, eg music to listen to and books and magazines to read. Break up the day with small tasks, like showering, eating, and mouthcare. Your medical team might have suggestions for things you can do to help with your care. For example, you could keep a record of your fluid intake.

Summary

- It takes about 8-12 days (sometimes longer) for **engraftment** – where your body starts making its own blood cells again after a stem cell transplant.
- A lot of your care is to prevent infection while your **blood counts** are low. Follow any rules from the hospital and keep yourself clean.
- Not all infections can be prevented. Look out for signs of infection, so it can be treated quickly.
- You might not feel like eating very much. Ask family to bring in food that you might enjoy, but make sure this food is safe. Ask for information about safe food.
- You probably won't feel like doing much a lot of the time, but have a good supply of amusements for when you feel like doing something. Try to break up your day with small routines, like mouthcare, showering and eating.
- Be as active as you can. Stretching exercises and short walks can make a difference to how you feel.
- Encourage family and friends to keep in touch and make short visits. You might not feel like visitors some days, so get them to check with someone before they come in.
- Communication is important. Talk to the people looking after you. Tell someone about your side effects or if your medicines don't seem to be working. Ask questions.

Notes

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After your transplant

When can I go home?

How is follow-up organised?

How can I help my recovery?

How can I deal with difficult feelings?

What are the long-term and late effects of treatment?

How do I know my treatment has worked?

What happens if my lymphoma comes back after an autologous stem cell transplant?

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When can I go home?

Most people go home 2–3 weeks after the **infusion** of their **stem cells**. You are discharged from hospital once you feel well enough and your **white blood cell** count has returned to a safe level. Your medical 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 ensure you have the right care when you go home.

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‘Week 3 and the blood counts 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 in 2014

Arrange for someone to give you a lift home and help you with your bags. Most people are ready to go home when the time comes, but leaving the ward, where doctors and nurses have been checking on you day and night, might feel frightening. 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.

If you live a long way from the transplant centre, a hospital closer to home can either take over your care or can share your care with the transplant hospital. Both hospitals should have up-to-date records of

your treatment and progress. Your GP should get this information too.

You might still have low **red blood cell** and low **platelet** counts when you go home. It might be some time before these return to normal. You are likely to still be **anaemic** and you could still be at increased risk of bleeding. You might go home with your **central line** still in. The central line is removed when your blood counts have recovered.

The time it takes to recover from a stem cell transplant varies from person to person, but most people take 3–6 months to recover. You have regular blood tests to check on your recovery.

You might expect to feel better just because you are going home. Your family and friends might expect that discharge from hospital means you have recovered. Don't be surprised if you still feel exhausted, sick 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.

Remember that you may go home as soon as 2 weeks after a very high dose of treatment – much higher than what you have had in the past. It can take a while to recover from it.

How is follow-up organised?

You have very frequent follow-up appointments at the clinic soon after your discharge from hospital. The

appointments might be at the transplant unit or they might be at a hospital closer to home if you live far from the unit.

You are seen in the clinic every week at first to check your **blood counts** are recovering well. You then have an appointment each month.

Around 3 months after your transplant you are likely to have a **CT scan** or **CT/PET scan** to see how the lymphoma has responded to the treatment. You have regular tests to check on your recovery. Gradually, you are seen less often, but follow-up usually continues for several years.

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Your follow-up appointments are to check that your lymphoma has not relapsed (come back) and to make sure you are recovering well. Your doctor also monitors you for signs of side effects that only develop weeks, months or sometimes years after treatment (**late effects**).

How can I help my recovery?

It takes time to recover from an **autologous** stem cell transplant. It may be many months before you return to what feels physically and mentally normal for you. The following pages give some information about looking after yourself during your recovery.

Risk of infection and low blood counts

You are still more likely than usual to get an infection when you go home from hospital.

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

- fever (temperature over 38°C)
- shivering
- chills and sweating
- feeling generally unwell, confused or disoriented
- earache, cough, sore throat or mouth
- redness and swelling around skin sores or injuries to **intravenous** lines
- diarrhoea
- a burning or stinging sensation when passing urine
- unusual vaginal discharge or itching
- unusual stiffness of the neck and discomfort around bright lights.

There is no evidence to suggest that locking yourself away makes any difference. There are some steps you should take, especially immediately after your transplant:

- Avoid places where the risk of infection is higher, like cinemas, busy shops, or public transport during rush-hour.
- Ask your medical team for advice about using public swimming pools and gyms.
- Keep a thermometer handy so you can easily check your temperature. **Call your medical team immediately if your temperature goes above 38°C.**
- Avoid people who have obvious viral infections, especially measles, shingles or chickenpox. If you have young children, ask their friends' parents to alert you to any infections that are going round.
- Pay close attention to your personal hygiene: shower regularly; wash your hands carefully after using the toilet and before eating; take good care of your teeth

and gums; wash clothes and bedding regularly.

- Make sure your fridge is clean and set at 5°C or lower.
- Keep your food preparation surfaces clean and wash your hands before preparing food. Make sure frozen food is defrosted thoroughly before cooking if it can't be cooked from frozen. Ensure that precooked meals are thoroughly heated.
- Ask friends or relatives to clean pet housing (eg fish tanks, bird cages) and litter trays. Avoid other people's pets.
- Use a condom for at least 3 months after your transplant to reduce the risk of infection.

You are at higher risk of bleeding problems if you have low **platelets**. Take care to avoid injury and **contact your medical team immediately if you notice any signs of bleeding.**

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- Take care with food preparation and gardening, when you are more likely to injure your hands. Wear protective gloves when gardening.
- Be sure to report bleeding when passing urine or after bowel movements, or unusual vaginal bleeding. Report bruising or skin rashes.
- Ask for advice about precautions to take in relation to sexual intercourse if your platelets are low.

You might also be **anaemic** for some time after your discharge from hospital. This can add to your feeling of tiredness and lethargy. Tell someone if you feel short of breath. It might be possible to treat your anaemia; you might need a **transfusion** of **red blood cells**.

Skin care

Your skin may be dry and sensitive for many months after an autologous stem cell transplant. Moisturise often, especially after a bath or shower. Use hypoallergenic skin-care products and cosmetics, which are less likely to cause allergic reactions.

Chemotherapy and radiotherapy can each make your skin photosensitive (more sensitive to the sun), making you prone to sunburn. They can also increase your risk of developing skin cancer later in life.

To help with photosensitivity:

- Protect your scalp by wearing a hat or 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–3pm in summer months).
- Use a cool (not frozen) compress to relieve painful skin.
- If your photosensitivity is severe, your doctor might prescribe a steroid treatment.

You will always need to be careful to protect your skin from the sun.

Eating well

Most experts advise that you eat as healthy a diet as possible. There is lots of evidence that healthy eating prevents other serious illnesses and can increase your energy and strength. There is, however, no evidence to suggest that any particular diet helps your recovery or prevents relapse of your lymphoma.

Exercise

Clinical research studies have shown that 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. Don't expect too much of yourself. It is upsetting to set yourself goals that are impossible to achieve. Small amounts of exercise, such as a short walk each day, can make a difference.

Avoid contact sports (eg rugby) and other 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. Ask your consultant what type and intensity of exercise is safe for you.

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You might find that you are more easily tired or that you become short of breath. You might have to make changes to your exercise routine while you are recovering from your transplant. Although you are likely to need to take some precautions, it is important to find ways of including physical activity in your life that are safe and enjoyable for you.

Sex

You might be advised to avoid sexual activity until your **platelet** count is above a certain level as you could have problems with bruising and bleeding. If your **white blood cell** count is low, you are also at more risk of infection.

You can carefully resume sex when your **blood counts** are high enough. Ask your medical team about any precautions you should take. It is important to protect yourself from sexually transmitted infections – condoms and femidoms help prevent them.

You might be less interested in sex for a while. This is very common – you have been through a lot, both physically and emotionally. If this persists, speak to your medical team.

Sexual difficulties and lack of desire/loss of libido are common when you have lymphoma. They can arise for various reasons including changes in body image and lowered self-confidence, feeling stressed, anxious or fatigued, and feeling generally unwell. Some types of chemotherapy may cause temporary impotence in men. Your partner might worry that having sex can harm you.

Serious illness can cause changes in a relationship. You or your partner may feel that things are not the same as they used to be. Talk to your partner and find ways to be close. Once you and your partner have had time to adjust to the changes in your life, sexual desire is likely to return.

If you have concerns about changes to your sex life, talk to your medical team. They may be able to signpost you to further sources of support or refer you to a psychosexual counsellor who specialises in relationships and sexual difficulties.

Travel

You should get advice from your medical team before you travel if you've had a stem cell transplant in the last few months or if you are still having any problems. You may be advised not to go abroad for 3–6 months as you are still having regular follow-up appointments during that time and your **blood counts** might still be low. Travelling puts you in close proximity to lots of people and you might pick up an infection. If your **platelets** are low, you could have problems with bruising or bleeding.

Take information about your medical history and treatment with you in case you need help when on holiday, even if you stay in the UK. If you are taking medication, carry some in your suitcase and some in your hand luggage. You might want to take some extra supplies, should any of your baggage get lost. Ask your GP to write a letter explaining your situation in case you are stopped at customs.

You are likely to find it difficult to get travel insurance for some time after your transplant. Many companies refuse travel insurance for people who have recently had cancer treatment. Some cover part of your travel, such as loss of luggage or cancellation by the airline, but do not cover medical expenses related to problems arising from your lymphoma or its treatment. Your team may have a list of insurers that other people in a similar situation have used. There is a discussion thread on our online forum, which you might find useful.

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 use a weakened form of the organism that causes the infection. 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 shingles, measles, mumps, rubella, tuberculosis and yellow fever. If you intend to travel, check what vaccinations are required as 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 if they are to work properly.

You can have vaccinations that are not live vaccines, eg the flu jab, but they might not be as effective as usual if your **immune system** is still recovering after your stem cell transplant.

Your childhood vaccinations may not be effective after a stem cell transplant, so you may be given these again when your immune system has recovered.

Work

How long it takes before you are ready to return to work depends on how quickly you recover from your stem cell transplant. Most people feel well enough to return to work 3–6 months after their transplant.

It is important not to rush back before you feel ready. You may want to consider a gradual return to work and go back part-time initially. Consider reducing your

working hours, if possible. Discuss your return to work with your medical team and other people involved, eg your employer. Your employer must, by law, make any 'reasonable adjustments' that allow you to continue working while you are having treatment and afterwards.

How can I deal with difficult feelings?

Most people going through lymphoma treatment have emotional difficulties at times. It is natural to have strong feelings when dealing with cancer. You can expect to 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.

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It can help to talk to other people who have gone through a similar experience. Our Information and Support Team might be able to put you in touch with someone else who has had a stem cell transplant. They also offer a listening ear if you need to talk – call them on 0808 808 5555.

Alternatively, you can email them at information@lymphomas.org.uk or Live Chat via our website www.lymphomas.org.uk. The Lymphoma Association website also has forums where you can ask questions and get support from other people affected by lymphoma or a stem cell transplant.

Sometimes people feel very low a lot of the time and this might be depression. Depression can affect people in different ways. If you are struggling with feelings of anxiety or feel you may be depressed, talk to your medical team. There is support and treatment that can help.

What are the long-term and late effects of treatment?

Although most side effects of high-dose therapy go away soon after treatment has ended, some can last longer. These are long-term side effects. High-dose therapy can 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 consultant or key worker about what to look out for.

Reduced lung function

Some people find that they become short of breath more easily. This is not likely to be disabling. It doesn't prevent you from exercising, but you might find that it takes less exertion than it used to before you are out of breath. This can happen because high-dose therapy can damage your lungs. Your lung function can improve over time.

Peripheral neuropathy

Some chemotherapy drugs can cause damage to 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'.

Neuropathy most often affects the nerves in your hands and feet, causing symptoms like 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 like abdominal cramps and constipation.

For most people symptoms of neuropathy are temporary, but some people can have long-term or permanent damage.

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

Reduced fertility

High-dose treatment is likely to reduce your fertility. Some people are still able to conceive naturally, so you shouldn't assume you are infertile after a stem cell transplant. It's impossible to know how your fertility will be affected by treatment, but your specialist should discuss potential changes to your fertility with you before treatment starts. There may be options available to help preserve your fertility.

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Doctors generally advise that women with lymphoma do not become pregnant during their treatment and for some time afterwards; many recommend waiting for 2 years.

Doctors recommend that men with lymphoma prevent making their partner pregnant while they are receiving chemotherapy treatment and for at least 3 months afterwards.

Lymphoma treatments may damage sperm or eggs and could be harmful to a developing baby. If a woman is pregnant it can make it more difficult to treat the lymphoma if it comes back. Discuss such issues with

your medical team. They can give specific advice based on your individual circumstances.

Reduced fertility in women is related to age. Women closer to the average age for menopause are more likely to experience reduced fertility and may undergo an early menopause. You may find that your periods become irregular or stop altogether during treatment. Afterwards they may return to normal, but some women find that the irregularity continues.

Early menopause in young women can put them at increased risk of osteoporosis (brittle bones) compared with women who have their menopause at the expected age. Your risk of osteoporosis depends on a variety of factors, including lifestyle and family history. You can discuss this with your specialist. There are treatments available to strengthen your bones if you have an early menopause. Some women can be prescribed hormone replacement therapy.

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Reduced immunity

Your immunity should recover after an **autologous** stem cell transplant, but some people remain susceptible to infection following treatment. This is more often the case for people who have had Hodgkin lymphoma. You might find that you catch colds easily, or that you take longer to shake them off.

Heart problems

Heart problems are more common in people who have been treated for lymphoma than in the general population. Your risk of heart problems can be increased

by certain chemotherapy drugs. Heart problems commonly start 10 years or more after your treatment but can occur sooner. Your risk of heart problems remains increased for a number of years.

You can help to lower the risks of heart problems by making lifestyle choices that aim to keep your heart healthy, including maintaining a healthy weight and not smoking. You should also monitor your blood pressure and have regular checks for diabetes and cholesterol.

Other cancers

High-dose chemotherapy and radiotherapy can each increase your risk of developing another cancer later in life. However, this risk is small.

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Your individual risk depends on many factors, including what type of chemotherapy or radiotherapy you've had, your age over time and how old you were at the time of treatment.

Your risk also depends on lifestyle factors. 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.

How do I know my treatment has worked?

As part of your follow-up, your doctor checks that your lymphoma is in remission (no evidence of lymphoma) and there is no evidence of relapse (lymphoma coming back). You have tests and scans to check on your lymphoma, just as you did when you were first diagnosed.

What happens if my lymphoma comes back after an autologous stem cell transplant?

If your lymphoma relapses after an **autologous** stem cell transplant, your doctor should discuss your options with you. Many people can have more treatment. Sometimes, newer drugs are available for people who have relapsed after an autologous stem cell transplant. This might be through a clinical trial. Not everyone is suitable for every new treatment or clinical trial but your doctor can give you more information about your options.

We have a service dedicated to clinical trials in lymphoma. To find out more, visit our website at www.lymphomas.org.uk/trialslink.



'A scan after my autologous stem cell transplant showed I still had active lymphoma in my chest. I then had radiotherapy but this did not shrink the lymphoma completely. I then took part in clinical trials of 3 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 may 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 get back to normal.
- You have regular follow-up appointments after your discharge from hospital. These are to check your recovery, monitor your lymphoma and look for **late effects** of your treatment.
- You continue to have treatment during the follow-up period. The treatments you need depend on your **blood counts** and risk of infection.
- You can remain at higher risk of infection for months. Take care with food storage and preparation, practice good personal hygiene, and avoid people with infections. Monitor yourself for signs of infection and contact your medical team if you develop a fever.
- Gradually increase your activities and workload. Take good care of your diet and build up a regular exercise routine.
- Ask your medical team or your GP for advice about travel and vaccinations.
- You are likely to have mixed feelings when you leave the hospital. Expect to have good days and bad days. Talk to others about how you feel. If you think you might be affected by depression, or if those around you are worried about your mood, ask for help.

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Things to consider before having an autologous stem cell transplant

Questions to ask yourself

Questions to ask your medical team

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Questions to ask yourself

- How will I get to the treatment centre?
- Do I understand what will happen to me and who will look after me?
- Who is my key contact?
- When does my treatment start?
- When do I need to go to hospital and how long do I need to stay?
- Who will look after things at home while I'm at hospital?
- What help will I need when I'm recovering from my transplant?
- How should I look after my central line and what do I do if I have a problem?
- Have I made all the necessary arrangements at work?
- Have I made financial arrangements, such as for paying bills for when I'm in hospital and recovering?
- Is there anything I could ask friends and family to do to help me through treatment and recovery?
- Have I arranged to see my dentist before treatment starts?
- Do I have everything I want to take to hospital to make my stay comfortable and to help me pass the time?

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Questions to ask your medical team

- What is a stem cell transplant? How does it work?
- Why is this treatment recommended 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?
- Why are you using my cells and not donor cells?
- What happens if you can't collect enough stem cells?
- 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?
- What do I need to consider and prepare before my transplant?
- Where will I be treated?
- How long will I be in hospital?
- Will I need to be in isolation? Can I have visitors?
- What facilities are available at the hospital? Is there a telephone I can use? Is there a TV?
- Can I use my mobile phone in hospital? Is WiFi available?
- Is there anything I can or can't bring to make myself more comfortable in hospital?
- Is there anything I could bring to help with side effects?
- Is there anywhere my family can stay when visiting if I am far from home?
- Can the treatment centre provide any extra support, eg counselling or complementary therapies?
- When will you know if the transplant was successful?
- What happens if the transplant doesn't work?

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Conclusion

Whatever your situation, we hope that this booklet has helped you to understand more about **autologous** stem cell transplants, including what happens during an autologous stem cell transplant and during your recovery. We hope it has given you useful tips on what to think about at each stage of the process.

If you would like further information on anything you have read in this booklet, or if you would like to talk about any aspect of your lymphoma, please visit our website at www.lymphomas.org.uk. You can also call our Information and Support Team on 0808 808 5555 or email information@lymphomas.org.uk

Glossary

Allogeneic	using 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 (a local anaesthetic) or put the whole body to sleep (a general anaesthetic)
Apheresis	the process where something is removed from the blood and the remaining blood is returned to the body
Autologous	using a person's own tissue
Autograft	a transplant using the person's own tissue
Biopsy	a test which takes some tissue to be looked at under a microscope
Blood count	a blood test that counts the different types of cells in your blood, including the red blood cells, the different types of white blood cell and platelets
Bone marrow	spongy material at the centre of larger bones which produces our blood cells

CD34	A protein found on blood stem cells used to help your medical team decide when to collect your stem cells
Central line	a flexible tube which is inserted into a large vein in the chest; allows chemotherapy to be given and blood to be taken through a tube
Conditioning	refers to the chemotherapy or irradiation given immediately before a transplant
CT scan	stands for computed tomography, which is a scan that uses X-rays to give a picture of the inside of your body in 'slices'
Day Zero	the day the transplant of the stem cells takes place
Engraftment	the time when the transfused stem cells start to produce new blood cells in the bone marrow
G-CSF	stands for granulocyte colony-stimulating factor which is a growth factor that stimulates the bone marrow to make white blood cells
Haematopoietic	cells with the potential to develop into different types of blood cell
Immune system	the parts of the body that fight off and prevent infection
Infusion	the giving of a fluid other than blood into a vein

Intravenous	into a vein
Late effects	side effects that can develop months or years after treatment
Lymphocytes	specialised white blood cells in the body's immune system; there are 3 main types: B cells, T cells and the much less common natural killer (NK) cells
Lymph node	gland that forms a sieve in the lymphatic system, involved in fighting infection
Mobilisation	the process where stem cells are moved from the bone marrow to the bloodstream
Neutropenia	shortage of neutrophils in the blood
Neutrophil	a type of white blood cell that is important in fighting infections caused by bacteria and fungi
PET scan	stands for positron-emission tomography which is a scan that uses a radioactive form of sugar to look at how active cells are; often combined with a CT scan, it shows which bits of the body are affected by lymphoma
PICC line	stands for peripherally inserted central catheter which is a central line that is put in at a point further

away from the chest than most other central lines (eg in the upper arm)

Platelets

the tiny fragments of cells in your blood that help form blood clots and stop bleeding

Red blood cell

a cell that contains haemoglobin, which allows it to carry oxygen around our bodies

Stem cell

a cell that has the potential to develop into many different cell types

Subcutaneous

under your skin

Thrombocytopenia

shortage of platelets in the blood

Total body irradiation

a form of radiotherapy given to the whole body, not just part of it, used with patients who are about to undergo a stem cell transplant

Transfusion

the giving of blood or blood products (eg red blood cells, stem cells) into a vein

Transplant coordinator

a healthcare professional with particular knowledge of stem cell transplants

White blood cell

a cell found in the blood and in many other tissues that helps our bodies to fight infections; several different types exist including lymphocytes and neutrophils

Information, support and useful organisations

For further information and support, please email us at information@lymphomas.org.uk or call our Information and Support Team on 0808 808 5555 (9am–5pm Monday–Friday). We can put you in touch with others affected by lymphoma. You might also find our online forums or support groups useful.

Here is a short list of useful organisations. If the right organisation isn't listed here, please call us on 0808 808 5555.

Anthony Nolan

Matches people who need an allogeneic transplant.
Provides a range of publications and has an online transplant community.

Phone: 0303 303 0303 (general enquiries)

www.anthonynolan.org

Email: via website

Bloodwise

Funds research into the causes and treatment of blood cancers. Provides a range of publications, including information about stem cell transplants.

Phone: 0808 2080 888 (freephone support line)

www.bloodwise.org.uk

Email: support@bloodwise.org.uk

Cancer Research UK

Provides information and statistics about cancer and funds research.

Phone: 0808 800 4040 (freephone helpline staffed by nurses)

www.cancerresearchuk.org

Email: via website

Leukaemia CARE

Offers information, advice and support to people with leukaemia and other blood cancers.

Phone: 08088 010 444 (24hr freephone care line)

www.leukaemiacare.org.uk

Email: care@leukaemiacare.org.uk

Macmillan Cancer Support

Provides practical, medical, emotional and financial support to people living with cancer.

Phone: 0808 808 00 00

www.macmillan.org.uk

Email: via website

Selected references

The full list of references, including links, is available on request. Please email us at publications@lymphomas.org.uk or call us on 01296 619409 if you would like a copy.

NHS Blood and Transplant Therapeutic Apheresis Services. Patient Information Leaflet – Peripheral Blood Stem Cell Collection (PBSC). Effective July 2014. Available online. (Accessed June 2016).

NHS Choices. Stem cell and bone marrow transplants. Available online. (Accessed April 2016).

Patient.info. Stem cell transplant. Available online. (Accessed April 2016).

Bloodwise. Blood and bone marrow transplantation: the seven steps. Available online. (Accessed June 2016).

European Group for Blood and Bone Marrow Transplantation (EBMT) – Nurses Group. Haematopoietic stem cell mobilisation and apheresis available online. (Accessed April 2016).

EMA. Mozobil – Plerixafor. European Public Assessment Report (EPAR) summary for the public. Available online. (Accessed June 2016).

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'Although an autologous stem cell transplant feels very complicated, I found taking it a step at a time really helped. Don't be afraid to ask as many questions as you want to.'

Leo, who had an autologous stem cell transplant in 2016



This booklet will help you understand autologous stem cell transplants for lymphoma. It explains what they are, how they are carried out and what to expect during and after treatment.

The Lymphoma Association provides specialist information and emotional support to anyone affected by lymphatic cancer. Get in touch today to see how we can help you.

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