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Donor (allogeneic) stem cell transplants

This page is about stem cell transplants, where the stem cells come from a donor (allogeneic stem cell transplants). We have separate information on stem cell transplants that use your own stem cells (**autologous stem cell transplants**).

On this page

What is a donor (allogeneic) stem cell transplant?

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What are the risks?

Follow-up

Recovery

We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email **information@lymphoma-action.org.uk**.

What is a donor (allogeneic) stem cell transplant?

A **stem cell transplant** is a procedure that replaces damaged or destroyed **stem cells** (cells in your bone marrow that make new blood cells) with healthy stem cells. 'Allogeneic' means something that comes from a different person, as opposed to something that comes from you. An allogeneic stem cell transplant is a stem cell transplant that uses stem cells from a donor. It is sometimes called an 'allograft'.

If you have lymphoma, you might have a stem cell transplant if you need high-dose anti-cancer treatment (this is also called 'conditioning treatment'). High-dose anti-cancer treatment aims to destroy the lymphoma cells but it also destroys your stem cells. This stops you making new blood cells. A stem cell transplant allows you to have high-dose treatment and still be able to make new blood cells.

An allogeneic bone marrow transplant can also help fight the lymphoma directly. The donor stem cells build a 'new' **immune system**. The new immune cells can recognise lymphoma cells as foreign and help to get rid of them. They can also help prevent the lymphoma coming back (**relapsing**). This effect is known as the 'graft-versus-tumour effect' or '**graft-versus-lymphoma effect**'.

Some types of lymphoma are particularly sensitive to the graft-versus-lymphoma effect. These include **chronic lymphocytic leukaemia** (CLL) and **mantle cell lymphoma**.

A stem cell transplant is an intensive form of treatment. It can take many months to fully recover afterwards.

Who might have a donor stem cell transplant?

Most people with lymphoma do **not** need a stem cell transplant. Allogeneic stem cell transplants are only used in certain circumstances but they can be a very effective treatment for some people with lymphoma. In some situations, they can increase your chance of having a long-lasting **remission** (no evidence of lymphoma). However, there is a risk of serious side effects and complications. Your medical team should tell you what is involved and if there are any other treatment options.

A stem cell transplant is an intensive form of treatment and you have to be well enough to have one. It can take many months to fully recover. Your medical team consider many factors before recommending a stem cell transplant. Below we list some of the situations when an allogeneic stem cell transplant might be recommended. Not everybody with these types of lymphoma needs a stem cell transplant – and there might be other situations where your doctor feels a stem cell transplant is the best option for you.

You might have an allogeneic stem cell transplant:

- if you have lymphoma that comes back (**relapses**) after a **self (autologous) stem cell transplant**
- if your lymphoma doesn't respond to your first treatment (**refractory** lymphoma)
- if you have **adult T-cell lymphoma** (ATL) as part of your first-line treatment
- if you have **chronic lymphocytic leukaemia** (CLL) that has transformed to high-grade lymphoma (Richter's transformation) as first-line treatment
- rarely, if you have **Waldenström's macroglobulinaemia** that comes back (relapses) after previous treatment.

You should consider the possible risks and benefits of having an allogeneic stem cell transplant very carefully. Ask as many questions as you need to reach a decision. You might want to use our list of suggested **questions to ask your medical team** to help you.

Your medical team are best placed to give you advice specific to your situation. However, you might also find it helpful to speak to another person who has had an allogeneic stem cell transplant. Our Information and Support Team may be able to put you in touch with someone through our **Buddy Service**. We also have an online **Community Forum** where you can share your emotions and experiences, ask questions and connect with other people affected by lymphoma or a stem cell transplant.

What does an allogeneic stem cell transplant involve?

In an allogeneic stem cell transplant:

- you have tests and scans to make sure you are fit enough to have the treatment
- your transplant coordinator organises a search for a suitable stem cell donor
- you have high-dose anti-cancer treatment (conditioning treatment) in hospital
- the donor stem cells are given to you to replace your stem cells that have been destroyed by the high-dose anti-cancer treatment
- you stay in hospital while you wait for your blood counts to recover.

We have detailed information about each step on our page on **having a stem cell transplant**.

I waited anxiously for the donor cells to start grafting into my body. It was an amazing feeling when the counts started to climb up from zero. I started to think there would be a time when I could be outside again. They had suggested I would be in hospital for around 8 weeks, but I was able to leave hospital after just 3 weeks and 2 days.

Kat, diagnosed with double-hit lymphoma and had an ASCT

What are the risks of an allogeneic stem cell transplant?

The most serious risks of allogeneic stem cell transplants are:

- graft-versus-host disease (GvHD)
- risk of infection
- side effects of high-dose anti-cancer treatment (sometimes called conditioning treatment)
- graft failure
- late effects.

Graft-versus-host disease

Graft-versus-host disease (GvHD) is a common complication of an allogeneic stem cell transplant. It happens when the new **immune system** that grows from the donor cells (the 'graft') recognises the other cells in your body (the 'host') as foreign, and attacks them.

This effect is useful when it attacks your lymphoma cells, but it can also attack healthy tissues. This can cause serious side effects. Most of the time, GvHD causes mild-to-moderate symptoms, but occasionally, it can be severe and even life-threatening. Before and after your transplant, you are given **treatment** (immunosuppressant drugs) to reduce your risk of developing GvHD. Your transplant team monitors you closely for any signs of GvHD so they can treat it as early as possible if it develops.

GvHD is classed as 'acute' or 'chronic' depending on when you experience it and the signs and symptoms you have.

Acute GvHD

Acute GvHD typically develops within 100 days of your transplant – although it might develop later, particularly if you've had reduced-intensity conditioning treatment. Up to half of all people who have an allogeneic stem cell transplant develop some degree of acute GvHD. It mainly affects the skin, the gut and the liver. It can cause:

- a sore, itchy rash, often on the hands, feet, ears and chest, although it can spread to the whole body
- feeling sick (nausea), being sick (vomiting), tummy pain and weight loss
- diarrhoea, which can be watery or bloody
- fever
- jaundice (a build-up of a chemical called 'bilirubin', which can make the whites of your eyes and your skin look yellow).

Acute GvHD is graded from 0 (mild) to 4 (very severe) based on the symptoms you have. Grading helps your doctor to decide what treatment to give you.

Although acute GvHD is unpleasant, and can sometimes be severe, it is also a sign that your new immune system is attacking any lymphoma cells left in your body after high-dose treatment.

Chronic GvHD

Chronic GvHD generally develops more than 100 days after your transplant. It is most likely to develop in the first year after your transplant, but it can happen later. It affects around half of all people who experienced acute GvHD but it can develop even if you didn't have acute GvHD.

Chronic GvHD most often affects the mouth, skin, gut and liver. It can also affect other areas, such as your eyes, joints, lungs and genitals. The features of chronic GvHD are different from those of acute.

Symptoms of GvHD can include:

- skin rashes, flaking or itchy skin, changes in skin tone or texture, tightening of the skin
- dry or irritated eyes
- dry or sore mouth
- thinning of your hair
- indigestion, diarrhoea, nausea, vomiting or unexplained weight loss.

Your doctor should assess you for GvHD regularly as part of your **follow-up**. For each part of your body affected by chronic GvHD, they might give you a score between 0 (no impact) and 3 (severe impact) based on the impact your symptoms have on your daily life. This helps them decide on the best treatment for you.

If you have any signs of GvHD, you will have tests to find out what areas of your body are affected and how severe it is. These might include **blood tests**, **X-rays** and **scans**.

Prevention and treatment of GvHD

Before and after your transplant, you have drugs to dampen your immune system (immunosuppressant drugs) to try to prevent GvHD developing or to limit the effects of it if it does develop. They are often started during your conditioning treatment.

The most common drugs used to prevent GvHD are:

- Methotrexate, a type of chemotherapy given through a drip into a vein. You usually have it on days 1, 3, 6 and 11 after your stem cell infusion.
- Ciclosporin (sometimes spelt cyclosporin), an immunosuppressant medicine. You have it through a drip into a vein every day at first and then as oral tablets once your blood counts have recovered. You carry on taking it when you go home after your transplant. The dose is gradually reduced as your new immune system becomes less reactive to your own body tissues. This might take several years.

Some transplant centres use different drugs, particularly for people who have reduced-intensity conditioning or who only have a partially matched stem cell donor. Newer treatments are also being studied to see if they are more effective at preventing GvHD than current treatments.

If you develop GvHD, your doctor might increase your immunosuppressant drugs. If this is not effective, you might need high doses of **steroids** to suppress your immune system further. You also have treatments to help control your symptoms of GvHD. These vary depending on the parts of your body that are affected.

If steroids do not control GvHD, there are a range of other treatment options. Your doctor chooses your treatment based on your individual circumstances.

Because treatment for GvHD suppresses your immune system, it can increase your risk of developing infections. Your transplant team tries to find the right balance of medications that allows your immune system to fight infections without attacking healthy cells.

As time goes on, your new immune system usually becomes more tolerant to your host cells and you can gradually come off your immunosuppressant drugs. Sometimes GvHD can develop or flare up when your immunosuppressant drugs are reduced, so your medical team monitor you closely. If GvHD develops or comes back, you restart the immunosuppressant drugs.

Anthony Nolan produce a **booklet about GvHD**.

> **Because my neutrophil numbers remained low, I needed to be supported by G-CSF injections to avoid Graft versus host disease (GvHD) problems.**
> Kat, who was diagnosed with double-hit lymphoma and had an allogeneic stem cell transplant.

Risk of infection

After an allogeneic stem cell transplant, you have very low blood counts for a few weeks. Having a low white blood cell count, especially a type of blood cell called 'neutrophils' (**neutropenia**), puts you at very high **risk of developing an infection**. These infections can be serious but they can be treated, particularly if they are caught early. They can lead to a long stay in hospital.

While you are in hospital after having your transplant, your medical team take **precautions to reduce your risk of infection**. They also monitor you closely for any **signs of infection**. Although taking precautions can reduce your risk of infection, you cannot avoid all sources of infection. Most people develop infections after an allogeneic stem cell transplant.

In the first month or so after an allogeneic stem cell transplant, you are at highest risk of developing bacterial infections, such as bloodstream infections, pneumonia, digestive system infections or skin infections.

In the next few months, you are most at risk of developing viral infections. These might be viruses that were lying dormant in your body before your transplant that may flare up when your immune system is low. They don't always cause symptoms. You have regular blood tests after your transplant to make sure you don't have a flare-up of a viral infection called cytomegalovirus (CMV). If your blood tests show CMV is present – even if you have no symptoms – you have treatment with antiviral drugs. You might need more than one course of treatment.

Your blood counts start to rise between 2 to 4 weeks after an allogeneic stem cell transplant. However, it can take many months, or sometimes even years, for your immune system to recover fully, especially if you are still taking immunosuppressant drugs to prevent GvHD.

When you go home, your team should tell you what **signs of infection** to look out for and who to contact if you are worried you might have an infection.

Contact your medical team immediately if you have any signs of infection.

Side effects of conditioning treatment

You are likely to experience side effects from your high-dose anti-cancer treatment. We have separate information on the most common **side effects of lymphoma treatments**, including practical tips on how to cope with them. You might find the following pages particularly helpful:

- **oral mucositis (sore mouth)**
- **anaemia (low red blood cell count)**
- **thrombocytopenia (low platelet level)**
- **nausea and vomiting** (feeling sick and being sick)
- **bowel problems** (diarrhoea, constipation, wind).

Graft failure

Graft failure occurs if the transplanted stem cells fail to settle in your bone marrow and make new blood cells. This means your blood counts do not recover, or they begin to recover but then go down again. Graft failure is serious but it is rare after an allogeneic stem cell transplant, especially if your donor is a good match. Your medical team monitors your blood counts closely. If your graft does start to fail, you might be treated initially with **growth factors** or hormones. These can encourage the stem cells in your bone marrow to produce more cells. You might need a second stem cell transplant, either from the same stem cell donor or a different one.

Late effects

Late effects are health problems that may develop months or years after your lymphoma treatment. Most transplant centres have dedicated late effects services that offer screening programmes to detect late effects as early as possible. This gives you the best chance of being treated successfully if you develop any late effects.

Your transplant team should tell you what late effects you may be at risk from and what you can do to reduce your risk of developing them. For more information, see our page on **late effects of lymphoma treatment**.
You may also be at risk of developing **post-transplant lymphoproliferative disorder** (PTLD) – lymphomas that can develop in people who are taking immunosuppressant drugs after a transplant. However, PTLD is rare. Most people who have had transplants do **not** develop PTLD. Your transplant team will talk to you about your individual risk and any signs or symptoms you should look out for.

Follow-up after an allogeneic stem cell transplant

Most people go home 2 to 3 weeks after having their stem cell transplant. However, it can be longer, particularly if you develop a serious infection or other complications. Your risk of complications is highest in the first few weeks after your transplant but it can take many months – sometimes even years – for your immune system to recover fully.

After you go home, you are usually seen in the clinic every week at first to check how you are recovering. You have blood tests to check your blood counts and to measure your virus levels. Your doctor also checks for any signs of **GvHD**.

- You might need **blood transfusions** if your red blood cells or platelets are low.
- If your new immune system is not making as many cells as it should be, you might have a transfusion of white blood cells from your donor. This is called a 'donor lymphocyte infusion' (DLI). It helps boost the **graft-versus-lymphoma effect**. This can happen at any point after the transplant but it is most common during the first couple of years.

Around 3 months after your transplant, if you are recovering well, your appointments usually go down to about once a month. You might be referred back to your local hospital with less frequent visits to your transplant centre. You might have a **CT scan** or **PET/CT scan** to see how the lymphoma has responded to the treatment. If you had lymphoma in your bone marrow, you might also have a **bone marrow biopsy**.

Gradually, you are seen less often. If you don't have any complications, your **follow-up appointments** may be every 6 months until 3 to 5 years after your transplant, and then every year. Your appointments are to check that your lymphoma has not come back (**relapsed**) and to look out for any signs of GvHD or **late effects** (side effects that develop months or years after treatment).

When you have a stem cell transplant, you lose your immunity to diseases you were vaccinated against before your transplant. This includes the vaccinations you had as a child. Around 6 months to a year after your transplant, you should be offered a revaccination programme. You should also have the annual winter flu jab, pneumococcal pneumonia vaccination and any COVID-19 vaccinations.

Recovery after an allogeneic stem cell transplant

Although you might be allowed home a couple of weeks after an allogeneic stem cell transplant, it can take several months to a year or even more for you to recover completely. This can be a difficult time physically and emotionally. You might find our information on **living with and beyond lymphoma** helpful.

When you first go home, you will be on several treatments to prevent GvHD and infections. Your blood counts are also likely to be lower than normal. Follow any precautions your medical team recommends to help you stay well.

- Make sure you know how to **reduce your risk of getting an infection** and what **signs to look out for**. Your medical team should give you numbers to call at any time of the day or night if you are worried or become unwell.
- If you have low platelet levels (thrombocytopenia), you are at increased risk of bruising and bleeding. Take **precautions** to avoid injuring yourself and contact your medical team if you have any **signs of bleeding**.
- Contact your medical team if you develop any symptoms of GvHD.

It is common to have to go back into hospital for treatment in the weeks and months that follow your transplant but as time goes on, your risk of serious complications decreases.

You are also likely to be experiencing **side effects** from your high-dose treatment. You may feel unwell and very tired. Give yourself time to recover. It usually takes around a year to recover from an allogeneic stem cell transplant.

Listen to **our podcast** where John Murray, Nurse Clinician in Bone Marrow Transplant, and Angie Leather, who is Lead Nurse for Transplant and Haematology CNS, talk about the role of stem cell transplants, when they are used and the important differences between autologous (self) and allogeneic (donor) stem cell transplants. This podcast includes discussions around this often very difficult subject, and contains information on side effects and treatment outcomes that may be potentially distressing.

References

The full list of references for this page is available on our website. Alternatively, email **publications@lymphoma-action.org.uk** or call 01296 619409 if you would like a copy.

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