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# Self (autologous) stem cell transplants

This page is about stem cell transplants that use your own stem cells (autologous stem cell transplants). Most stem cell transplants for lymphoma are autologous transplants. We have separate information on stem cell transplants using stem cells from a donor (allogeneic stem cell transplants).

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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 'self' (autologous) 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. 'Autologous' means something that comes from you, as opposed to something that comes from someone else. It is sometimes called an 'autograft'.

If you have lymphoma, you might have a stem cell transplant if you need high-dose anti-cancer treatment. High-dose 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.

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

## Who might have an autologous stem cell transplant?

Most people with lymphoma do **not** need a stem cell transplant. Autologous stem cell transplants are used in certain circumstances with the aim of curing your lymphoma (especially **Hodgkin lymphoma** or **high-grade non-Hodgkin lymphoma**) or making your **remission** from lymphoma last longer than would otherwise be possible.

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 autologous 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 medical team feel a stem cell transplant is the best option for you.

You might have an autologous stem cell transplant:

- If you respond to initial treatment but your lymphoma comes back (relapses), especially if it comes back very quickly. This option might be suggested if you have Hodgkin lymphoma, follicular lymphoma, Burkitt lymphoma, diffuse large B-cell lymphoma (DLBCL), T-cell lymphoma, primary central nervous system lymphoma or Waldenström's macroglobulinaemia.
- If your lymphoma doesn't respond to your first treatment (**refractory**), particularly if you have Hodgkin lymphoma, DLBCL or Waldenström's macroglobulinaemia.
- As part of your first treatment if you have a type of lymphoma with a high risk
  of relapse (for example, fast-growing mantle cell lymphoma or primary central
  nervous system lymphoma) or other factors that suggest you might be at high
  risk of relapse.

### What does an autologous stem cell transplant involve?

In an autologous stem cell transplant:

- you have tests and scans to make sure you are well enough to have the treatment
- your own, healthy stem cells are collected from your blood and stored
- you have high-dose anti-cancer treatment in hospital (this is also called 'conditioning treatment')
- your stored stem cells are given back to you to replace the 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.

### What are the risks of an autologous stem cell transplant?

The most serious risks of autologous stem cell transplants are:

- a high risk of infection
- side effects of your high-dose anti-cancer treatment
- rarely, graft failure.

You are also at risk of developing late effects (health problems that may develop months or years after your treatment).

#### Risk of infection

After an autologous 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. Your blood counts start to rise after a few weeks but it can take many months for your immune system to recover.

While you are in hospital, 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. Infections can be treated, particularly if they are caught early.

When you go home, your medical team should tell you what signs 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.

I felt nervous about leaving the hospital environment where I had been in isolation with people gowned up to protect me from germs.

Now I was going home and in reality it was once I had got home that the recovery started and I could take my own steps to avoid infection.

Jamie, who was diagnosed with Hodgkin lymphoma and had an ASC

### Side effects of conditioning treatment

You are likely to experience side effects from your high-dose anti-cancer treatment ('conditioning' 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).

I began to feel better, but it was slow and not every day was better than the last. There were times I felt I was going backwards and my energy levels weren't getting any higher. But I was getting better and I just needed to be patient.

Owen, who was diagnosed with angioimmunoblastic T-cell lymphoma and had an ASCT.

#### 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. Graft failure is serious but it is very rare after an autologous stem cell transplant. Your medical team monitors your blood counts closely. If your graft does fail, you might be treated initially with **growth factors** or hormones. These encourage the stem cells in your bone marrow to produce more cells. You might need a second stem cell transplant.

#### 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 medical 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.

### Follow-up after an autologous 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 for your blood counts to build up to normal levels.

After you go home, you are usually seen in the clinic every week at first to check your blood counts are recovering well. You might need **blood transfusions** if they are low.

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

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

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 might be offered a revaccination programme. You should also have the annual winter flu jab and the pneumococcal pneumonia vaccination.

### Recovery after an autologous stem cell transplant

Although you might be allowed home a couple of weeks after an autologous stem cell transplant, it takes 3 to 6 months 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.

I was back to work five days a week, but realised I was struggling. I felt very tired and had some digestive problems and also could not achieve the closure to my lymphoma experience I wanted. I realised I needed to adjust my work life balance.

Owen, who was diagnosed with angioimmunoblastic T-cell lymphoma and had an ASCT.

When you first go home, your blood counts are likely to be low. Follow any precautions your medical team recommend 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 day if you are worried.
- 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**.

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. Many people feel well enough to **return to work** between 3 and 6 months after their transplant. You may find it helpful to start with shorter days or weeks and gradually build them up as you feel able to.

Your medical team should advise you on other factors to consider during your recovery. We also have an online **Community Forum** where you can ask questions and get support from other people affected by lymphoma or a 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 <a href="mailto:publications@lymphoma-action.org.uk">publications@lymphoma-action.org.uk</a> or call 01296 619409 if you would like a copy.

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