ANTHONY
NOLAN

Essential facts for transplant recovery

Coming home

Life after a stem cell transplant comes with its own set of challenges.

Leaving hospital for the first time can be a happy but also unsettling experience. Many people feel relief and are excited about going home. But at the same time there's the worry of coping without hospital support. And recovery takes different paths. Sometimes it can be (relatively) straightforward, while for others there are physical and mental challenges to face.

There's no right way to feel but try not to worry. You've probably become very aware of your body, and you know how to spot the signs of side effects. Remember, your team will only send you home when they're sure it's safe and you're ready.

FAQs

You can find more information on all the topics raised here in our information booklets and on our website **anthonynolan.org/patients**

What is graft versus host disease (GvHD) and how could it affect me?

It's important to be aware of GvHD and alert your hospital team about any side effects. Most people who've had an allogeneic stem cell transplant will get GvHD in some form. It can seem unexpected and have a big impact on how you feel post-transplant. But it's usually very treatable.

The word 'graft' means your donor's cells, and 'host' means you. After your transplant, there are still small differences between your donor's stem cells and your cells. This means your new immune system may harm other cells in your body because it sees them as 'different'. You can get side effects if lots of your body's cells are targeted in this way. GvHD can affect many body areas and can be life-threatening. It can happen within two to three weeks of transplant, or months after.

So, your medical team will check for GvHD often and will give you the right treatment if you need it. Learn more about GvHD at **anthonynolan.org/GvHD**

I find eating and drinking challenging, is this normal?

Almost all transplant patients experience side effects that make eating and drinking more difficult. For example, you might feel sick, lose your appetite or have a sore mouth. It's a normal part of recovery. Right now, your focus should be on maintaining your current weight and finding foods you can eat easily. Your medical team will have advice on how to do this. You can find out more at **anthonynolan.org/diet**

Why do I feel exhausted all the time?

Fatigue is common after transplant. It's a lot more than 'feeling tired', and it's important for you and your family to remember that. It can drain you physically and emotionally, making it hard to concentrate on even simple tasks. It's likely to improve over time, but learning to manage your energy levels can be a way of coping.

You can find out more about managing fatigue at **anthonynolan.org/fatigue**

Can I prevent infection completely?

It's impossible to remove all risk of getting an infection. So, aim to find a sensible balance. Avoid unnecessary risks but don't be too controlling. It's safer to avoid public transport and people you know are ill, but you can still go out and enjoy life. Find out more at **anthonynolan.org/infections**

Can I do anything else to help my recovery?

You'll boost your recovery by looking after yourself as well as you can. That means a combination of healthy eating, staying active and sleeping well. We've got lots of information on our website to support you.

If you have any worries or questions, or need advice, contact your medical team straight away so they can check on you.

You can also contact the Anthony Nolan Patient Services team on **0303 303 0303** or **patientinfo@anthonynolan.org**

Hospital visits

Your medical team will continue to check on you regularly to make sure your new immune system is working properly and to monitor any side effects.

Everybody's recovery journey is different, and some people will need to visit the hospital more often, for longer into their recovery.

Early recovery

After leaving hospital, you'll have one or two check-ups with your medical team every week. They will:

- assess your general health and how you're feeling
- look for signs of infections or GvHD
- check on other side effects and possibly alter your medication
- count your blood cells and check your chimerism (how many blood cells come from your donor compared to your own)
- test that your liver and kidneys are working well
- flush and clean your central line
- answer any questions or concerns you might have.

If your blood cell or platelet counts are low, you may also be given one (or more) blood transfusions. This will be more likely in your early recovery.

Ongoing recovery

As you continue to recover, you will still have regular check-ups at the hospital, but they are likely to happen less often.

Scans

Three months after your transplant, you may have a **bone marrow test** or a **PET-CT scan**. This may also happen one year after your transplant. These scans are both used to monitor your progress and to confirm your blood cancer or blood disorder has not returned.

Central line removal

Your central line can risk causing an infection, so it will be removed as soon as it's no longer needed. This is normally a few months after transplant. Removing it is normally done at the outpatient clinic using a local anaesthetic. This numbs the affected area. You may need a stitch or two to help the wound heal.

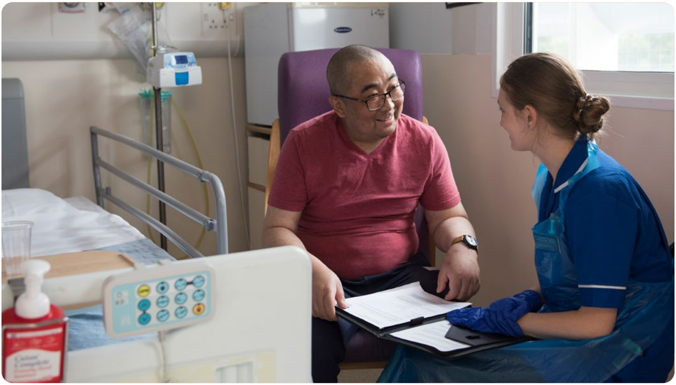
Hospital readmission

Unfortunately, you may have some setbacks in your recovery and might need to spend some time back in hospital. This does not mean your transplant hasn't worked. It's a natural part of your recovery that cannot always be avoided.

Long-term recovery

No matter how long it's been since your transplant, you'll always have someone in your medical team to contact. This is normally your clinical nurse specialist (CNS).

You'll have a full health assessment every year after your transplant. Your medical team will keep an eye on whether you're experiencing any late effects of transplant.



Vaccinations

Your immune system is replaced with your donor's during the transplant. So, you'll need new vaccinations to protect you from infections and illnesses. This includes vaccinations you had as a child.

Your transplant team will give you a schedule and ask your GP to give new vaccinations. This schedule can vary depending on where you live. Vaccinations that contain a weakened live virus, like the MMR (measles, mumps and rubella) vaccine, can only be given two years after transplant. They're not safe for people with a possibly weakened immune system. You can get other vaccines sooner, six to 12 months after transplant. This includes others usually given in childhood, flu, and COVID-19. You can also get the non-live shingles vaccine, Shingrix.

To help protect you, your family could have the seasonal flu vaccine every year. They can get it through their GP or local pharmacy. They may also be eligible to have the chickenpox vaccine, again to protect you.

You may also need...

Your medical team may decide to give you specific treatments or referrals during your recovery, depending on your situation and any side effects you have.

Specialist appointments

Alongside your general health checks, you may be referred to specialist doctors, who are experts in one treatment or part of the body. This often happens if you have GvHD that affects certain organs.

You'll also be advised to regularly see other specialists such as dentists and opticians.

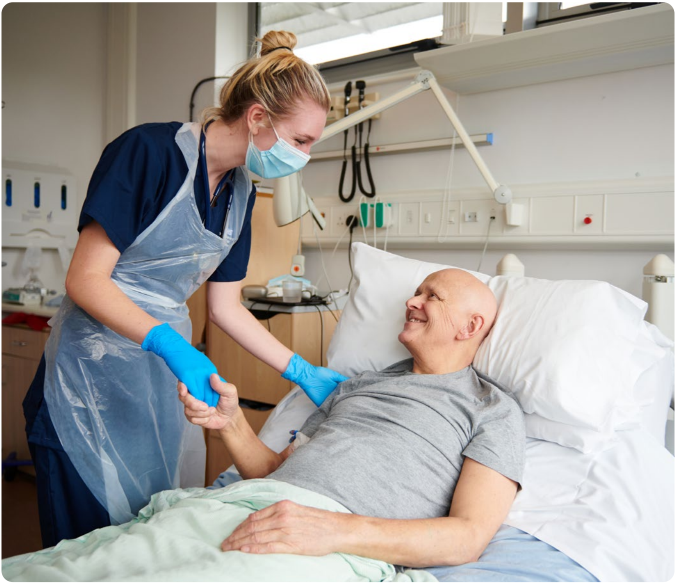
Donor lymphocyte infusion (DLI)

If your chimerism is low, you could be given a 'top-up' of your donor's cells. This simple procedure is very similar to a blood transfusion.

High dependency

At times you may need specialist care on a high-dependency or intensive care unit (ICU). These units offer essential care, support and close observation if you become very unwell.

It's common to feel frightened, down or frustrated when returning to hospital, but your medical team will give you the best possible treatment and support.



Find information

Your recovery is likely to affect many parts of your life, with physical effects on your body and changes to your lifestyle and activities. Importantly, there are also effects on your mind, emotions and mental health. We cover all of this in our online recovery information at **anthonynolan.org/recovery**

You can also download or order our free information booklets, and find links to other organisations who offer support at **anthonynolan.org/patientinfo**

> **“Be aware of what your body is telling you. Tune in to it and recognise when something feels different or off. And tell your clinical nurse specialist straight away to get things checked out.”**

SAM WHO HAD A STEM CELL TRANSPLANT TO TREAT ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)

Going home checklist

It’s important you feel prepared to go home. Your nurse will give you a ‘going home’ talk before you leave hospital and provide you with:

☐ Contact details for your team, including an out-of-hours number.

☐ Information on looking after your central line, also known as a CVC or Hickman line.

☐ Advice about your diet and some gentle exercises you can do at home.

☐ Information on what to do if there’s a sudden change in your temperature or side effects develop.

☐ Your medication and information on how to take it.

☐ The times of your first outpatient appointments.

☐ **Hospital phone number:**

☐ **Other details:**

Support

Whenever you have a question about your recovery or need some extra support, the Anthony Nolan Patient Services team will be here to help.

Need to talk?

You can speak to someone in the Anthony Nolan Patient Services team by calling **0303 303 0303** or emailing **patientinfo@anthonynolan.org**

Get connected

Find support from other patients and their families by joining our Patients and Families Forum at **anthonynolan.org/forum**

You can also follow our Patient and Families Facebook page to receive news and updates from us. Search for **facebook.com/anthonynolanpatients**

If you have any questions or comments about this resource or would like information on the evidence used to produce it, please email: **patientinfo@anthonynolan.org**.

The information contained in this booklet is correct at the time of going to print (July 2025). We plan to review this publication by July 2028. For updates or the latest information visit **anthonynolan.org**

For further patient information:

anthonynolan.org

facebook.com/anthonynolanpatients

x.com/anthonynolan

patientinfo@anthonynolan.org

0303 303 0303

Trusted Information Creator

Patient Information Forum

anthonynolan.org

ANTHONY NOLAN

Registered charity number 803716/SC038827

4247PS 07/25