



saving the lives of people with blood cancer

ANTHONY NOLAN

## Essential facts for transplant recovery

## Coming home

Life after a stem cell transplant comes with its own set of challenges and leaving hospital for the first time can be a happy but daunting experience. Many patients are relieved and excited about going home, but others worry about coping without their hospital support.

Some find their recovery is relatively straightforward, but for others it can be very difficult, both physically and mentally.

You're probably more aware of your body now and how to spot the signs of side effects, so try not to worry. Remember, your team will only send you home when they're sure it's safe and you're ready.



You can also download or order our free information booklets, and find links to other organisations who offer support at [anthonymolan.org/patientinfo](http://anthonymolan.org/patientinfo)

Your recovery is likely to affect many parts of your life, which is why we have sorted our online recovery information into three sections: **Body, Mind and Life.**

You can also follow our **Patient and Families Facebook page** to receive news and updates from us. Search for [facebook.com/anthonymolanpatients](https://www.facebook.com/anthonymolanpatients)

Find support from other patients and their families by joining our **Patients and Families Forum** at [anthonymolan.org/forum](http://anthonymolan.org/forum)

You can speak to someone in the Anthony Nolan Patient Services team by calling **0303 303 0303** or emailing [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)

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

It's important that 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 what to do if there's a sudden change in your temperature or side effects develop
- information on looking after your central line, also known as a CVC or Hickman line
- your medication and information on how to take it
- advice about your diet and some gentle exercises you can do at home
- the times of your first outpatients appointments.

**Hospital phone number:** \_\_\_\_\_

**Other details:** \_\_\_\_\_

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## Getting support

## FAQs

More information on all the topics raised here is available in our range of information booklets and on our website - [anthonymolan.org/patients](http://anthonymolan.org/patients)

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

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'.

Some GvHD can be a good thing because it shows your immune system is active and can attack any remaining or returning disease. However, too much GvHD can cause side effects.

Your medical team will check for GvHD regularly and give you appropriate treatment if you need it.

You can find out more about GvHD at [anthonymolan.org/GvHD](http://anthonymolan.org/GvHD)

### Q. I find eating and drinking challenging, is this normal?

Almost all transplant patients experience side effects that make eating and drinking more difficult. It's a perfectly 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 [anthonymolan.org/diet](http://anthonymolan.org/diet)

### Q. Why do I always feel so tired?

Fatigue is common after transplant. It can leave you feeling physically and emotionally drained, making it hard to concentrate on even simple things. It's important that you and your family recognise that it's different to just feeling tired. It's likely to improve over time but you can also learn to cope with it by managing your energy levels too.

You can find out more about managing fatigue at [anthonymolan.org/fatigue](http://anthonymolan.org/fatigue)

### Q. Can I prevent infection completely?

It's impossible to remove all risk of getting an infection. Aim to find a balance between being sensible and too controlling. It's safer to avoid certain

activities like travelling on public transport and people who are ill, but it shouldn't stop you enjoying life too.

You can find out more at [anthonymolan.org/infections](http://anthonymolan.org/infections)

### Q. Can I do anything else to help my recovery?

Living well by following a healthy diet, keeping physically active and sleeping well will aid your recovery. We have lots of information on our website which can 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@anthonymolan.org](mailto:patientinfo@anthonymolan.org)

'I found that being prepared, knowing what could potentially happen and where I could get advice and support made it so much easier for me to cope during my transplant and recovery.'

Sam, who had a stem cell transplant in 2017

If you have any questions or comments about this resource or would like information on the evidence used to produce it, please email: [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org). The information contained in this booklet is correct at the time of going to print (June 2022). We plan to review this publication by June 2025.

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## 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 will 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.

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 that 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 doesn't mean that your transplant hasn't worked. It's a natural part of your recovery that cannot always be avoided.

## You may also need

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

### 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 will also be advised to regularly see other specialists such as a dentist, optician and gynaecologist.

### 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.

## 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 will 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

During your transplant your immune system is replaced, which means all vaccines you previously had will no longer work. This means you need to be re-vaccinated.

You'll be unable to have vaccines based on live viruses or bacteria because they are unsuitable for people with a potentially weakened immune system. This includes the TB (tuberculosis) and MMR (measles, mumps and rubella) vaccines.

Your medical team or GP will schedule and give you new vaccinations to you. For some vaccines this normally happens at six months to a year after transplant, but others are given after two years.

Your family should also consider having the seasonal flu vaccine every year. It can be given through their GP or local pharmacy.

## My Transplant Tracker

My Transplant Tracker is Anthony Nolan's free mobile app that helps you take control of your recovery after a stem cell transplant.

You can save your clinical data and blood cell counts, track your medical appointments and medications, set yourself recovery goals and track your progress over time.

Search for '**Anthony Nolan**' in the Apple iOS or Google Play app stores.

