



ANTHONY  
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saving the lives  
of people with  
blood cancer

## 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.



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.
- ☒ 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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Your recovery is likely to affect many aspects of your life, which is why we have sorted our online recovery information into three key sections: **Body, Mind and Life**. You can also download or order our free information booklets, and find links to other organisations who offer support at [anthonynolan.org/patientinfo](http://anthonynolan.org/patientinfo)

### Find information

You can also follow our **Patient and Families Facebook page** to receive news and updates from us.  
[anthonynolan.org/forum](http://anthonynolan.org/forum)  
by joining our Patients and Families Forum at

### Get connected

You can call a member of our team on **0303 303 0303** or email [patientinfo@anthonynolan.org](mailto:patientinfo@anthonynolan.org)

### Need to talk?

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



## GETTING SUPPORT

## FAQS

More information on all the topics in this leaflet are available in our information booklets and on our website [anthonynolan.org/patients](http://anthonynolan.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 on you regularly and give you appropriate treatment when you need it.

### 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.

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

Fatigue is a common problem 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.

### Q. Can I prevent infection completely?

It's virtually impossible to remove all risk of getting an infection and you're likely to have a setback at some point.

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.

### 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.

If you have any concerns about anything, contact your medical team straight away so they can check on you.

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](mailto:patientinfo@anthonynolan.org). The information contained in this booklet is correct at the time of going to print, March 2019. We plan to review this publication within three years. For updates or the latest information visit [anthonynolan.org](http://anthonynolan.org).

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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, over a longer period of time.

### 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.

### Later on

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

### Scans

At 3 months and 1 year after your transplant, you may also have a **bone marrow test** or a **PET-CT scan**. They 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 infection, so it will be removed as soon as it's no longer needed, normally a few months after transplant. Removing it is normally done at the outpatient clinic using a local anaesthetic. You may need a stitch or two to help the wound heal.

### Hospital readmission

Unfortunately, you're likely to have some setbacks in your recovery and you may 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 ok 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 a point of contact, normally your clinical nurse specialist (CNS).

You will also have a full health assessment after every year. This is where 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 the vaccines you had as a child will no longer work. 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 and MMR (measles, mumps and rubella) vaccines.

Your medical team or GP will schedule and give your 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 phone 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'

