ANTHONY NOLAN

Infections after a stem cell transplant

A Guide



At Anthony Nolan we take great care to provide up-to-date and accurate facts about stem cell transplants. We hope the information here will help you to look after yourself.

Each transplant centre will do things differently, so this booklet is just a general guide. It isn't intended to replace advice from your doctor and transplant team.

Please speak to your transplant team for more details about your own situation, as they will be able to give you personalised, specific advice.

Ordering more copies

If you'd like to order more copies of this guide, or to request it in an alternative format, please get in touch with us at **patientinfo@anthonynolan.org**

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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 (October 2026). We plan to review this publication within three years, by October 2029. For updates or the latest information, visit **anthonynolan.org**

Cover image: Raj, who had a stem cell transplant to treat myelofibrosis

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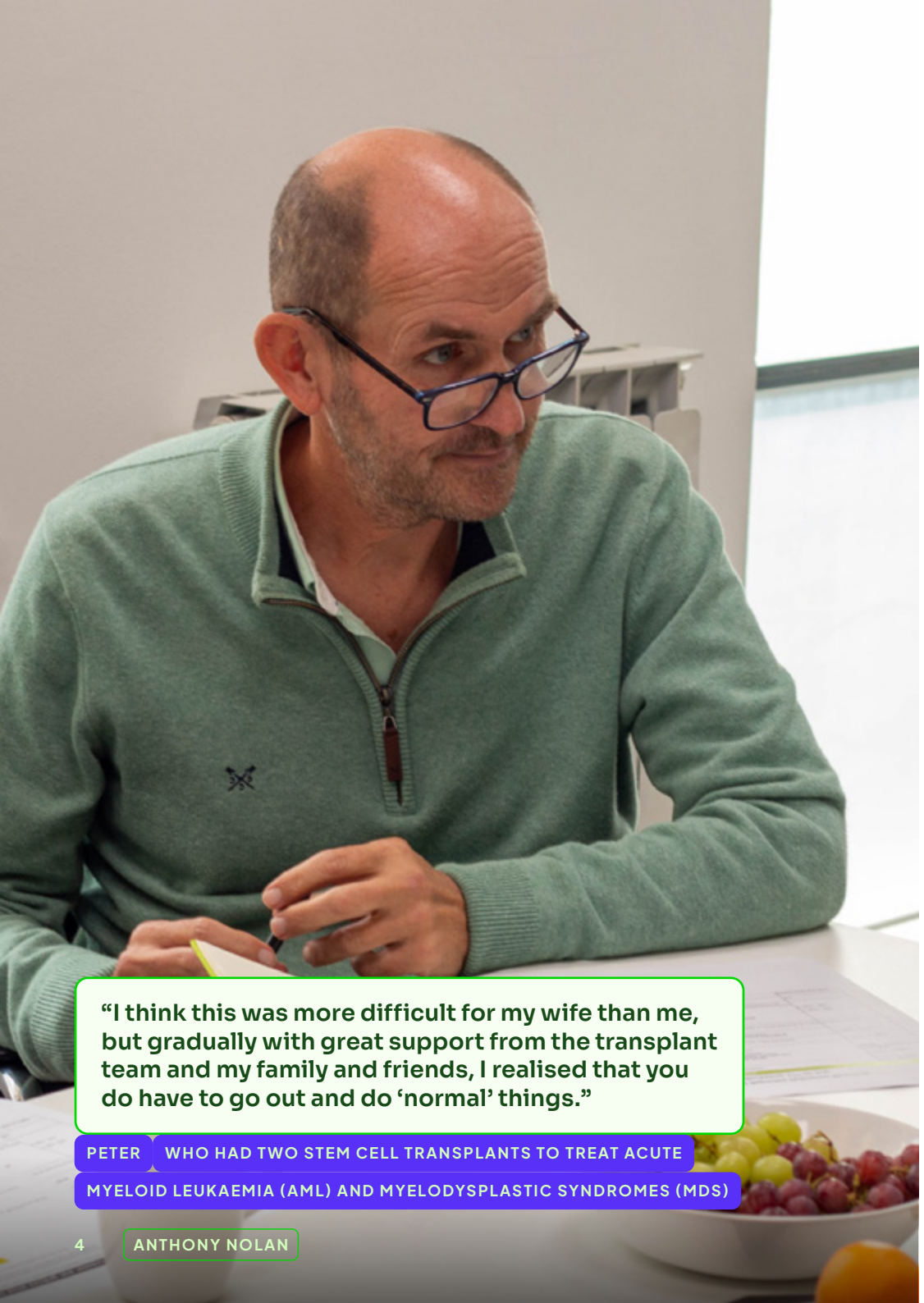
What's in this booklet?

After having a stem cell transplant, you'll be at risk of infection while you recover. Although getting infections is one of the most common aspects of recovery, dealing with this can feel challenging.

This booklet highlights why you might get infections and which signs to look out for. It also explains how doctors might treat different types of infection. We have tips and ideas on how to look after yourself and prevent infections during recovery – both in the short and long term. Unless otherwise stated, our information applies to both autologous and allogeneic transplants.

To write this booklet, we got expert guidance from healthcare professionals as well as people who have had a transplant. They shared their experiences with us to help you see that other people have come through similar difficulties.

If you need to ask us any questions, or you would like more advice, please get in touch with the Anthony Nolan Patient Services team at **patientinfo@anthonynolan.org** or **0303 303 0303**.



“I think this was more difficult for my wife than me, but gradually with great support from the transplant team and my family and friends, I realised that you do have to go out and do ‘normal’ things.”

PETER WHO HAD TWO STEM CELL TRANSPLANTS TO TREAT ACUTE MYELOID LEUKAEMIA (AML) AND MYELODYSPLASTIC SYNDROMES (MDS)

Contents

Key questions 6

Why might I get an infection? 9

What are the signs of infection? 10

What happens if I get an infection? 12

What are some common types of infections? 15

How can I prevent infections? 21

Will I be at risk of infection in the long term? 27

How can I look after my mental wellbeing? 28

Support from Anthony Nolan 30

Other useful contacts 32

Key questions

Will I have any infections after my transplant?

It's normal and expected to have an infection after your stem cell transplant. Infections can happen at any time during recovery, not just while you're in hospital for your transplant.

If my temperature rises, does that mean I have an infection?

Not all infections will cause you to have a high temperature – in fact, some can cause your temperature to drop. But even if your temperature is normal, talk to your transplant team if you don't feel well.

Should I isolate myself to avoid infection?

No. While it's important to keep yourself safe from infection, try to balance this with doing things you enjoy. During recovery, mental health is as important as physical health.

Should I have the flu vaccine?

Every year after your stem cell transplant, doctors generally recommend you have the flu vaccine. If you're not offered this, contact your GP or medical team to arrange.

What other vaccines are recommended after a transplant?

You'll need to repeat your childhood and coronavirus (COVID-19) vaccines once your immune system has recovered. You might need to wait a while before getting any live vaccines though.



“The initial months of strict infection control were tough, but we took that time to learn lots of fun digital stuff! It’s fantastic how apps can bring out your creativity and help you stay connected.”

RAKA WHOSE SON, NATHAN, HAD A STEM CELL TRANSPLANT

Why might I get an infection?

While your immune system recovers after a stem cell transplant, it’s normal to get infections.

Throughout your recovery, you might get them at different times, and your body might react in different ways. The main reason why infection is so common is a **lack of white blood cells**.

During your transplant and early stages of recovery, your white blood cell count will be low. These are the cells in your body that fight infection. With less white blood cells to fight, your risk of infection is greater.

How long this lasts might depend on the type of transplant you had:

- **If you’ve had an autologous transplant,** using your own stem cells, your low white blood cell count doesn’t usually last for a long time.
- **If you’ve had an allogeneic transplant,** using stem cells from a donor, your low white blood cell count usually takes longer to increase again. This is because you’ve had medication to suppress your immune system so the new stem cells can grow. This leaves you vulnerable to infections for a longer time than with an autologous transplant.

It can be disappointing and scary if you get an infection while you recover. Sometimes you might have to go back into hospital for treatment. This might feel really frustrating, but try to remember it’s a normal part of recovery. As you recover and your immune system becomes stronger, the risk of infection gets lower.

It’s important to remember that white blood cell counts can go up and down all the time. This is normal, especially if you’ve had an allogeneic transplant. You can get more information about types of stem cell transplants at anthonynolan.org/transplants

What are the signs of infection?

By recognising signs of infection as early as possible, doctors can help you stop it from becoming too severe.

You know your body best and you can tell when something isn't right. But you need to have the confidence to contact your medical team and get checked out.

Before leaving hospital, you should ask your transplant team how to:

- find out the best ways to check for infection
- get in contact directly if you think you have an infection.

Please be aware that this is a general guide to infections. You should always contact your medical team if you have any concerns. They'll be able to give you advice about your specific situation.

Some common signs and symptoms of infection include:

- a temperature of 38°C or higher
- uncontrolled shivering, also known as rigors
- a cough
- shortness of breath, which you might hear called SOB
- redness, pain or discharge around your central venous catheter (CVC) or port
- vomiting
- stomach pain
- pain when you pee
- smelly pee
- diarrhoea, which means runny poo
- blood in your poo
- generally feeling unwell.



"Infection is a daunting prospect post-transplant. But with the support of a specialist team to refer to when you have concerns, you do feel less afraid to face the world again."

JOANNA WHO HAD A STEM CELL TRANSPLANT TO TREAT ACUTE MYELOID LEUKAEMIA (AML)

What happens if I get an infection?

If you have a suspected infection, your medical team will most likely start by taking blood samples. Doctors will send these samples to a laboratory to see if they can identify any specific type of infection.

Aside from taking blood, they might try some other tests to check for infection. Some of these are routine tests, while others are for certain symptoms. Doctors might take:

- oral or nasal swabs
- swabs from a wound or CVC site – which you might call a Hickman, central or PICC line
- a sample of fluid from inside your nose, called a nasopharyngeal aspirate (NPA)
- a spit sample, called a saliva or sputum sample
- a poo sample
- a pee sample
- a chest X-ray.

Getting treatment for infections

Infections can be either **bacterial**, **viral** or **fungal**. Even after taking a sample, doctors can't always identify specific infection types. But this is quite normal.

Either way, treatment will start immediately if you have a suspected infection. Even if your medical team don't know exactly what the infection is.

Treatment is different for each type of infection. Depending on the infection location, you might get an external treatment like cream or eye drops. But generally, your initial treatment will usually include a dose of antibiotics. Your medical team will decide on further treatment depending on:

- how your body responds to the antibiotics
- whether they can identify anything from your sample in the lab analysis
- how well your immune system has recovered after your transplant.

Intravenous (IV) treatment

Doctors can provide IV treatment in different ways, such as:

- through a drip
- as an infusion
- all at once in a syringe – called a push or bolus – through your CVC or cannula.

Intravenous treatment is common in the early stages of recovery while your white blood cell count is still low. It's also a common treatment method if you're already unwell. Usually, you'll need to go into hospital for this type of treatment.

Oral treatment

Doctors can provide oral treatment as a tablet or liquid that you swallow. Oral treatment is more common after your immune system has recovered, or if you have a mild infection. You might also get oral treatment after you finish a course of IV antibiotics and leave hospital. You can then continue with oral treatment yourself at home.

Inhalation treatment

For some types of lung infection, doctors need to provide medication through a nebuliser. You'll need to wear a mask to receive this type of treatment. You might have to go into hospital, or you might get this treatment at an outpatient clinic.



“Managing infections post-transplant was very challenging, although I think the experience of the COVID-19 pandemic helped bring to light the precautions we can all take to manage the risks as effectively as possible.”

RAJ WHO HAD A STEM CELL TRANSPLANT TO TREAT MYELOFIBROSIS

What are some common types of infections?

The infections listed in this section are more common if you’ve had an allogeneic transplant, which means using donor stem cells.

Talk to your transplant team if you have even the slightest sign of infection. Treatment for any of these common infections should generally start as soon as possible. It’s always best to discuss any concerns you have before it gets worse.

Neutropenic sepsis

A neutrophil is a certain type of white blood cell that fights infection. After transplant, the number of neutrophils in your body can drop to a very low amount. If you get an infection that your body can’t fight during this period, this is called ‘neutropenic sepsis’. This can develop very quickly and can be life-threatening, so it’s important to look out closely for signs of infection – you can find a list on **page 11**.

Pneumocystis pneumonia (PCP)

PCP is a type of fungus that causes pneumonia. You’re at a higher risk of developing PCP if you’ve had a stem cell transplant and you’re on immunosuppression treatment. You’ll need to take preventative medication to protect yourself from PCP. You might have regular inhalation or take an oral tablet.

Symptoms include a cough, difficulty breathing and a high temperature. You might also have chest pain which gets worse when breathing or coughing. Diagnosis will involve having a chest X-ray and providing a spit sample.

Cytomegalovirus (CMV), Epstein-Barr virus (EBV) and adenovirus

These are very common types of viral infections. Around 60 to 90% of people in the UK will have been exposed to these by the time they reach adulthood. After recovering from the initial infection, these viruses remain inactive and cause no symptoms or illness. But if you've had a stem cell transplant, you'll have a suppressed immune system. In this case, these viruses can reactivate and you might need treatment.

Doctors will regularly check for these viruses after transplant by taking blood samples. If they detect a virus, your team will discuss treatment with you.

You might not feel unwell or have any symptoms before the blood test detection. It's still important to get checks and treatment at this stage, even if you feel fine. Preventative treatment stops these viruses from causing very severe infection.

"I did have a few infections. The CMV was a surprise as I felt fine. The treatment was horrible but each time I recovered and felt a bit stronger."



PETER WHO HAD TWO STEM CELL TRANSPLANTS TO TREAT ACUTE MYELOID LEUKAEMIA (AML) AND MYELODYSPLASTIC SYNDROMES (MDS)

Shingles

When the virus that causes chickenpox reactivates in your body, you might end up getting shingles. Like CMV, EBV and adenovirus, once you've had chickenpox, the virus remains inactive in your body. When you're healthy, your immune system stops the virus from reactivating. But with a suppressed immune system after stem cell transplant, your risk of developing shingles increases.

You'll usually need to take preventative medication to reduce the chance of shingles developing. But you must avoid being around anyone with shingles or chickenpox until your immune system has completely recovered. **Tell someone in your transplant team immediately if you think you've been exposed**. They'll take some details and decide whether you need any other medication.

Shingles can show up anywhere on your body. Symptoms include:

- burning pain and itchiness on your skin
- red raised lesions or blisters, which develop in a line as they usually follow the path of a nerve.

If you notice symptoms, tell someone in your transplant team immediately. Don't touch or scratch the blisters, and don't apply any creams.

If you get shingles, it can be very contagious and serious. You should avoid other people with suppressed immune systems, as well as anyone who is pregnant.

All adults who have had a stem cell transplant are eligible for a shingles vaccine called Shingrix. Ask your transplant team to arrange this with your GP. To find out more about post-transplant vaccines, go to our information on **Getting vaccinations** on **page 24**.

Respiratory infections

Developing a respiratory or chest infection is very common after stem cell transplant, especially in winter. Causes and treatments can vary, but look out for symptoms like a dry, wet or painful cough, or shortness of breath. Even if you feel fine when resting, but experience shortness of breath when walking short distances, tell your medical team.

Small changes in symptoms can signify that a chest infection is developing. And it's always better to start treatment early. Left untreated, chest infections can quickly develop into serious lung infections.

If you go to outpatients for a suspected chest infection, tell the reception staff when you arrive. They might want to take you to a private room to prevent it spreading to other patients.

Central venous catheter (CVC) infections

Shortly before your chemotherapy begins or before you go into hospital for transplant, you'll usually have a type of CVC fitted.

Most often, you'll hear this called a central line or Hickman line. It connects a thin tube that goes through the skin near your collarbone into the large vein that leads into your heart. You could also get a portacath, often called a port, which sits under the skin instead. Or you might have a peripherally inserted central catheter (PICC) line in your upper arm. This links to one of the main veins either in your arm or chest.

No matter which type you get, having a CVC in your body enables your medical team to:

- take blood samples
- deliver stem cells
- treat you without using a needle every time.

Although it's safe to have a CVC, there can be a risk of infection. Check for any **signs of infection** such as:

- redness around the site
- pain around the site
- discharge from the site
- a high temperature
- uncontrolled shivering, also known as rigors.

A CVC can carry an infection even without these symptoms. Even if your only symptom is a high temperature, doctors will normally swab the CVC site and send it to the laboratory.

If you develop an infection in your CVC line – the thin tube – the treatment might involve antibiotics. Sometimes doctors might need to remove or replace your CVC, or replace the line.

CVC infections can develop very quickly. Make sure to tell a member of your team immediately if you have any concerns.

In hospital, doctors might also insert a cannula to give you medication or fluids. This is a shorter-term solution, unlike a CVC which stays in your body in one of the main veins. But cannulas can also become infected. Staff will check for redness around the site and probably replace it after a few days, even if it looks fine.



How can I prevent infections?

It's important to know how to prevent and protect yourself from infections.

Try to be careful while your white blood cell count is low after transplant and during recovery. You'll also need to take extra care if you're on immunosuppressants.

This section offers general guidance and advice on preventing infections. For more specific advice, talk to your medical team.

Preventative medication

As soon as you go into hospital for your transplant, you'll take preventative medications to protect you from viral and fungal infections. Your team can explain the purpose of each type of these drugs.

You'll continue taking some of these as you recover, but it's important to follow the exact instructions from your doctor. If you're struggling with taking these drugs, tell your transplant team so they can try different ways to protect you.

Practical advice after leaving hospital

After your transplant, you'll spend time recovering at home. But it's very important to follow guidance to prevent infection, which might not be what you're used to:

- **Learn how to keep your CVC clean and when your line needs to be flushed by a nurse.** If you're not sure, speak to someone in your medical team. You'll know better than anyone when it was last cleaned and dressings were changed. If you struggle to keep track, try making a note in your calendar of each flush and clean date.

- **Always wash your hands using hot water and soap, or alcohol-based hand gel.** Dry your hands thoroughly too, particularly before eating and after using the bathroom. Make sure to change your hand towels often enough, especially if you live with other people.
- **Avoid being near anyone suffering with a cough, cold, vomiting or diarrhoea.** If you come into contact with anyone with these symptoms, wash your hands thoroughly straight away.
- **Have a digital thermometer at home to check your temperature.** Taking it at roughly the same time every day will help you learn what's normal for you. This will help you to recognise if it changes.
- **If you think you might have an infection when attending outpatients, let the receptionist know.** They might decide to take you straight into a private room to isolate you. This is to prevent the spread of infection to other patients.
- **Wash your hands after touching or being near pets or animals.** As well as this, you should avoid handling their poo. Someone close to you might be able to help you care for your pet while you recover.
- **Avoid handling any garden or pond waste.** You can easily pick up bacteria from dirt, mud or untreated water sources. If it's not possible to avoid, you should always wear gloves and wash your hands afterwards.
- **Try to minimise contact with large crowds and travelling on public transport.** This isn't always possible, but try to do this whenever you have the option. You could also consider wearing a facemask in this type of situation.
- **Always practise safe sex.** Doing this will reduce the risk of sexually transmitted diseases and infections. You can find out more about sex after transplant at **anthonynolan.org/sex**
- **Make sure the people you live with are up to date with vaccinations.** For example, family members in close contact with you should get the flu vaccine every year.

Guidance for food and drink safety

Getting sick from eating and drinking is common, even without having a suppressed immune system. But try to prevent this by following these practical tips during recovery at home:

- Always follow good food hygiene practice.
- Make sure you cook all food properly.
- Avoid eating rare meat, shellfish, raw or undercooked eggs, and blue cheeses.
- Wash any fruit and vegetables under running water before eating.
- Keep food refrigerated and do not leave food out of the fridge for long periods.
- Defrost frozen food in the fridge, not at room temperature.
- Do not reheat food more than once.
- Only eat in restaurants or order from takeaways with freshly prepared food.
- Check up-to-date hygiene ratings of restaurants and takeaways as much as you can.
- Avoid food that has been left out on display, including from salad bars and buffets.
- Try to drink at least two litres of water a day.

Although you should avoid foods that can cause infection, it's important you maintain weight and keep hydrated. This will keep you strong in case you get an infection. However, loss of appetite is very common after transplant. If you struggle to follow the dietary advice, speak to your dietitian about alternatives. For more information, go to **anthonynolan.org/diet**

Getting vaccinations

None of your previous vaccines will continue to work after your stem cell transplant. This includes all your childhood vaccines and COVID-19 vaccines. Doctors recommend you repeat all your previous vaccines after transplant.

Your transplant team will tell you when you should get these. Generally, it depends on:

- how well your white blood cell counts are recovering
- how much immunosuppression treatment you're on
- and if you currently have any infections.

In most cases, your GP surgery will vaccinate you in several stages. You might get your first vaccines as soon as three to six months after your transplant.

Inactive vaccines are safe to have even when your immune system is still recovering. **Live vaccines** are usually safer to get around two years after transplant – as long as your white blood cell counts have recovered and you're no longer taking immunosuppressants.

Ask your transplant team for a vaccination schedule so you know what to expect. It can take time to get every vaccine again – don't be concerned, this is completely normal. Until you've had all the vaccines you need, try to avoid anyone known to have an infectious disease.

How can family and friends help with infection prevention?

If you're a family member or friend of someone who's had a stem cell transplant, it can be hard to know how to manage the risk of infection. You should follow most of the same precautions and guidance previously listed in this section.

More generally, the best advice is to take a common-sense approach. For example, you should always:

- wash your hands
- tell them if you're not feeling well
- tell them if you've been in close contact with someone unwell
- keep up to date with vaccinations, especially if you live with the person.

It should be fine for children or grandchildren to be around the person who's had the transplant, as long as they're not unwell.

If you have any concerns at all, speak to the transplant team. They can give you advice on what to do. It's a balance of keeping the person safe while they recover, without limiting them from spending time with people they love.

For information and advice if you're caring for someone else, learn more at **anthonynolan.org/parentsfamilyfriends**



“Living cautiously is the new normal, even 10 years after my transplant. You can never be too careful, as your immune system has completely changed.”

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

Will I be at risk of infection in the long term?

Over time, your immune system will recover, become stronger and gain immunity. Along with this, your risk of infection will also decrease.

As a result, you should be able to stop taking preventative medications. You won’t need to attend as many appointments at the transplant centre. You should be able to go to your GP rather than hospital if you notice signs of infection.

But as you start getting back to your life as it was before transplant, you might be affected by some **potential long-term issues:**

- You might have to take an antibiotic called penicillin V for the rest of your life. This protects you against certain harmful bacteria.
- You might always be at higher risk of infections like colds and coughs. It might also take you a bit longer than other people to recover, even if you’ve had the same infection.
- You should get the flu vaccine every year for the rest of your life.
- You’ll always be at a higher risk of infection if you develop chronic graft versus host disease (cGvHD) and keep taking immunosuppressants. For more information on GvHD, go to anthonynolan.org/GVHD

How can I look after my mental wellbeing?

When you feel worried about getting an infection, you might feel tempted to isolate yourself.

You might want to avoid seeing your family and friends, or avoid going out. But it's really important to balance looking after yourself with doing the things you enjoy. **Looking after your mental health is just as important as looking after your physical health.**

Here are a few tips to help you find the right balance:

- See family and friends in smaller groups, which might feel less overwhelming.
- Plan trips out at quieter times of the day to avoid large crowds.
- Ask your children's school to inform you if there are any known infections going around. Even if your children are unaffected, you still need to be aware.
- If being affectionate with friends and family is a normal part of your relationships, keep doing this if there's no risk of infection. But if for example someone has a cough, it might be best to avoid affection until they feel better.
- If sex and intimacy are a regular part of your life, whether you have a partner or not, you'll be able to continue doing this safely. For advice, you can talk to a member of your transplant team who you feel comfortable with.
- If you like doing outdoor jobs, such as work in the garden, do this in short periods and always wear gloves.
- After your transplant, you shouldn't have to deep clean the place you live. Cleaning it as normal should be enough for your recovery period.



"You can make your own decisions and do things that you want to as before, like going to weddings and gatherings. Weigh up what's important to you, and if in doubt, discuss with your medical team."

DR ROBERT DANBY CONSULTANT HAEMATOLOGIST

Support from Anthony Nolan

If you or a loved one is affected by stem cell transplant, there are many ways the Anthony Nolan Patient Services Team can support you. Call us on **0303 303 0303** or email **patientinfo@anthonynolan.org**

You can also support your mental health by:

- **Using the Telephone Emotional Support Service** – this service is available for free for stem cell transplant recipients and family members. You can talk about whatever's on your mind. Find out more at **anthonynolan.org/TESS**
- **Getting connected** – find support from other people who understand by joining our Patients and Families Forum at **anthonynolan.org/forum**
- **Finding information** – our website has lots of helpful information about what it's like to go through a transplant. Download or order our booklets for free, and find links to other places where you can get support at **anthonynolan.org/patients**

Our clinical nurse specialists

Anthony Nolan funds, recruits and supports specialist nurses based in UK transplant centres. By doing this, we aim to raise the standard of post-transplant care around the country. We want people who have a stem cell transplant, and their families, to have equal access to support at all stages of recovery, for as long as it's needed.

Our clinical psychologists

Anthony Nolan also funds several clinical psychology posts based in UK transplant centres. These psychologists help people come to terms with the emotional and mental effects of their stem cell transplant.



Other useful contacts

Across the UK, there are hundreds of useful organisations offering advice and support to anyone who needs it. You can find them in person, online or even call them for a chat.

British Association for Counselling and Psychotherapy

bacp.co.uk
01455 88 33 00

Information about counselling and therapists in the UK.

Macmillan Cancer Support

macmillan.org.uk
0808 808 0000

Practical, financial and emotional support for people with cancer, and their family and friends.

Maggie's

maggies.org
0300 123 1801

Offers help to anyone affected by cancer. Talk to and get support from professionals on any topic related to your treatment or recovery.

Mind

mind.org.uk

Infoline: **0300 123 3393**
Support line: **0300 102 1234**

Provides information and helplines for people who need support with their mental health or wellbeing.

NHS Talking Therapies Programme

nhs.uk/talkingtherapies

Allows people to self-refer to NHS-funded counselling and therapy services in their local area.

NHS Vaccinations

nhs.uk/vaccinations

Provides information on the NHS vaccination schedule and offers an online booking portal.

Samaritans

samaritans.org
116 123

Offers a free, confidential helpline where you can talk about anything at all, 24 hours a day.

Teenage Cancer Trust

teenagecancertrust.org

Offers support to improve the lives of teenagers and young adults with cancer.

Young Lives vs Cancer

younglivesvscancer.org.uk
0300 303 5220

Offers a range of services for children affected by cancer and their families. Includes a helpline for emotional support and practical advice.



“I find that some patients put too much pressure on themselves to get back to healthy really quickly. It’s normal to get an infection at some point after transplant.”

RACHEL ANTHONY NOLAN LEAD NURSE AND HEAD OF PATIENT SERVICES

“Infection is a daunting prospect post-transplant. But with the support of a specialist team to refer to when you have concerns, you do feel less afraid to face the world again.”

JOANNA WHO HAD A STEM CELL TRANSPLANT TO TREAT ACUTE MYELOID LEUKAEMIA (AML)

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For further patient information:

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