

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **DEALING WITH INFECTIONS**



**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



At Anthony Nolan we take great care to provide up to date and accurate facts about stem cell transplant. 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 and 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 please get in touch with us on **patientinfo@anththonolan.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@anththonolan.org**

The information contained in this booklet is correct at the time of going to print (March 2020). We plan to review this publication within three years. For updates or the latest information, visit **anththonolan.org**

Cover image: Victor Douglas, who had a stem cell transplant in 2018

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ANTHONY NOLAN
PATIENT SERVICES



WHAT'S IN THIS BOOKLET?

One of the most common side effects after a stem cell transplant is infection and although it is an expected part of recovery, it can also be challenging. This booklet highlights when you might get infections, the symptoms to look out for and how infections are treated as well as how to look after yourself and prevent infections in both your short and long term recovery. It's been written with the first-hand advice of our remarkable patients and the expert guidance of healthcare professionals. They have shared their experience to help you through your recovery.

Unless otherwise stated, the information in this booklet applies to both autologous and allogeneic stem cell transplants. This is a general guide – we always recommend that you speak to your transplant team for specific advice and information.

If you need to ask us any questions or would like some more advice, please get in touch with the Anthony Nolan Patient Services team at:

patientinfo@anthohnolan.org or on **0303 303 0303**



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KEY FACTS



It's normal and expected to have an infection after your stem cell transplant. This can occur at any time throughout recovery, not just during the transplant admission.



You don't need to have a temperature to have an infection. If your temperature is normal or unusually low but you don't feel well, contact your transplant team to discuss your symptoms.



It's important that you balance keeping yourself safe from infection with doing the things you enjoy. Your mental health is as important as your physical health.



It's recommended that you have the flu vaccination annually for life.



You will need to have your childhood vaccinations repeated once your immune system has recovered.

HOW DO I KNOW IF I HAVE AN INFECTION?

You should always check with your transplant team on their practice for identifying infections and make sure you know who to contact if you develop an infection when you are at home. Please be aware that this is a general guide only – you should always contact your medical team if you have any concerns. Some symptoms of infection include:

- A temperature 38°C or above
- Uncontrolled shivering (also known as rigors)
- Cough
- Shortness of breath (SOB)
- Redness, pain or discharge around a Hickman, Central or PICC line or Port
- Increased vomiting and abdominal pain
- Pain when passing urine or passing urine that has an odour
- Increased diarrhoea or blood in your stools
- Generally feeling unwell

WHEN YOU MIGHT GET AN INFECTION

As your immune system recovers following a stem cell transplant, it's normal to get infections. When you get them and how well your body copes with infections will vary throughout your recovery.

During your transplant and when you're in the early stages of recovery, your white blood cell (the cells in your body that fight infection) counts will be low. That means the risk of infection is greater. How long this will last depends on how well your blood counts are recovering and the type of transplant you had.

Patients who have autografts (receiving your own stem cells) are expected to have a low white blood cell count for less time than those who have had an allograft (receiving stem cells from a sibling or unrelated donor). This is largely because, when having an allograft, medication is given to suppress your immune system which leaves you more vulnerable to infections for a longer period. These medications are very important in controlling your immune system so that the new stem cells can grow. It's a balance of allowing your new stem cells to regenerate whilst keeping you safe from infections.

As you recover and your immune system becomes stronger, the risks of infection reduce. However, it's important to remember that white blood cell counts can fluctuate and it is normal to have ups and downs after transplant, especially if you have had an allograft. It can be disappointing and daunting if you get an infection while you recover and sometimes this might mean you have to be admitted back into hospital for treatment. As frustrating as this is, remember it's a normal part of recovery.

You don't need to have a temperature to have an infection. If your temperature is normal or unusually low but you do not feel well, contact your transplant team to discuss your symptoms.

'Infection is just 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 in 2016



WHAT HAPPENS IF I GET AN INFECTION?

In most cases, if an infection is suspected then blood samples will be taken. One of the samples taken are called 'cultures' which will be sent to the microbiology lab to see if a specific infection can be identified.

Other tests that might be performed are below. Some of these are routine while some will only be taken if there are specific symptoms:

- Swabs/Oral, nasal, wound, Hickman, central or PICC line
- A sample of fluid taken from the nose/ a nasopharyngeal aspirate (NPA)
- A sample of saliva/Sputum sample
- Stool sample
- Urine sample
- Chest X-ray

TYPES OF INFECTION AND TREATMENT

Infections are caused by a number of different bugs (bacterial, viral or fungal) and the treatment for each is different. Sometimes, even after taking a sample of blood or other bodily fluid, specific infections will not always be identified, which is normal. Even without knowing the cause of infection, treatment will be started immediately.

The initial treatment will include antibiotics and then, depending on how your body responds and if anything is identified from the samples sent to the laboratory, your medical team will decide on further treatment. How your infection is treated will also depend on how well your immune system has recovered.



THERE ARE THREE WAYS THAT TREATMENT CAN BE GIVEN:

Intravenously (IV) – This will be via a drip, as an infusion or all at once in a syringe (called a push) and given through your line or cannula. This type of treatment is most common in the early stages of recovery while your counts are still recovering or if you are unwell, and will usually involve you being admitted to hospital.

Orally – As a tablet or liquid to be swallowed. This type of treatment is used more often once your immune system has recovered and if your infection is mild. It may also be used if you finish a course of IV antibiotics and your team discharges you home to carry on with treatment for a period of time.

Inhalation – Some types of lung infections require medications to be given via a nebulizer. You will need to wear a mask to receive this and, in some cases, will have to be admitted to hospital. However, it can sometimes be given in an outpatient clinic.

SPECIFIC INFECTIONS TO BE AWARE OF

These infections are more common if you have had an allograft transplant. In general, treatment of these infections will need to start as soon as possible. Get in touch with your transplant team even if you are not sure that you are experiencing signs of infections, it's always best to contact them to discuss any concerns you have.

NEUTROPENIC SEPSIS

After a stem cell transplant, you're more at risk of something called neutropenic sepsis. A neutrophil is a specific type of white blood cell that fights infection, whose numbers can drop very low after your transplant. Although it is normal to get an infection at this time, if you get an infection that your body cannot fight during this period, this is called 'neutropenic sepsis'. This can develop very quickly and can be life-threatening, so it's important that you are vigilant for signs of infection.

PNEUMOCYSTIS PNEUMONIA (PCP)

PCP is a fungus that causes pneumonia. People who have had a stem cell transplant and are on immunosuppression are at a higher risk of developing it. You will need to be put on preventative medication to be protected against this. This can be either as a regular inhalation or oral tablet. Symptoms can include a cough, difficulty breathing, high temperature and chest pain which gets worse when breathing or coughing. A diagnosis will involve a chest x-ray and sputum samples.

CYTOMEGALOVIRUS (CMV), EPSTEIN-BARR VIRUS (EBV) AND ADENOVIRUS

These are common viruses that 60-90% of the general population will have been exposed to by the time they reach adulthood. After the initial infection, these viruses remain dormant (asleep) and cause no symptoms or illness. Because people who have had a stem cell transplant have a suppressed immune system, these viruses can activate (wake up) and may need to be treated.

Regular monitoring for these viruses after transplant will be carried out via routine blood samples. If a virus is detected your team will discuss with you what treatment you need. It's important to know that you might not feel unwell or have any symptoms before it is detected by a blood test. In many cases, it is still important to treat you at this stage, even if you feel well. This is to prevent the viruses causing very severe infection.



SHINGLES

Shingles can occur when the virus that causes chicken pox 'reactivates'. Like CMV, Adenovirus and EBV, once you have experienced chicken pox, the virus remains dormant in your body forever. When you are healthy, your immune system manages to stop the virus reactivating. However, when recovering from a stem cell transplant with a suppressed immune system, the risk of developing shingles increases.

You will be on preventative medication to reduce the chance of shingles developing but you must avoid being around anyone with shingles or chicken pox until your immune system has completely recovered. If you think you might have been exposed to anyone with shingles or chicken pox, even if you have no symptoms, please let a member of your transplant team know straight away. They will take some more details from you and decide whether you need any other preventative medication.

Shingles can occur anywhere on the body. Symptoms include burning pain and itchiness, red raised lesions or blisters which develop in a line as they usually follow the path of a nerve. If you think you could be developing symptoms, **please let a member of your transplant team know immediately.** Do not touch or scratch the blisters and do not apply any creams.

If you do develop shingles, it can be very contagious if anyone comes in direct contact with the skin rash.

You should therefore avoid other people with suppressed immune systems, as well as pregnant women, as they are all at a higher risk of getting severe infections.

RESPIRATORY INFECTIONS

Developing a respiratory or chest infection is very common after stem cell transplant, especially through the winter period. The cause and treatment can vary so it's important that you tell someone if you have any symptoms such as a dry, productive or painful cough or shortness of breath (SOB). Even if you feel fine when you sit but experience unusual SOB when you walk small distances, you should let your transplant team know. A small change can be a sign that a chest infection is developing so it is better to start treatment early. Chest infections that are not treated can quickly develop into more serious lung infections.

Please remember that when you attend the outpatient department, if you think you have a chest infection, tell the reception immediately as they might decide to take you straight to a single room. This is to prevent the spread of infections to other patients.

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

Peter, recipient of a stem cell transplant.

CENTRAL VENOUS CATHETER (CVC) INFECTIONS

A central line is normally fitted shortly before your chemotherapy is due to start or before your admission for transplant. It's a thin tube that goes through the skin near your collarbone and into the large vein that leads into your heart (also called a Hickman line). Alternatively, you may have a peripherally inserted central catheter (PICC) line in your upper arm into one of the main veins either in your arm or chest. Both lines enable the nurses and doctors to take blood samples, deliver the stem cells and treatments without using a needle every time.

Although it is safe to have a CVC, there can be a risk of causing infection and you should be vigilant for signs of infection such as redness, pain, discharge from the site, temperatures and rigors. A CVC line can carry an infection even without these symptoms so if you have a temperature alone the CVC site will be swabbed, and the swab sent to the laboratory. If you do develop an infection in your CVC line, treatment can include antibiotics and sometimes the CVC will be removed.

CVC infections can develop very quickly so it's important that you contact a member of your team immediately if you have any concerns.

PREVENTION

It's important to know how to protect yourself from infections. You should be particularly vigilant when your white cell count is low, and you are on immunosuppressants. Below is a general guide for you to follow, but you should also talk to your transplant team for more specific advice.

MEDICATION

From admission for your transplant, you will be started on preventative medications to protect you from viral and fungal infections. Ask your team to explain what these drugs are so you understand what they are for. It's important that you take these medications. If you are struggling to take them then you must let your transplant team know so alternative means of prevention can be made.

HICKMAN LINE CARE

Be aware of how to keep your Hickman/central/PICC line clean and when it needs to be flushed by a nurse. You will know more than anyone when it was last cleaned, and when dressings were changed.

FAMILY AND FRIENDS

It can be difficult to know as a family member or friend what you need to do to reduce infections and the best advice is to take a common-sense approach. Always wash your hands and always say if you are not feeling well or have been in close contact with someone who is unwell. If you have children or grandchildren, it should be fine for them to be around the person who has had the transplant if they are well.

If you have any concerns at all, speak to the transplant team and they will advise you on what action to take. It's a balance of keeping people safe while they recover and not limiting them from spending time with people they love. Most of the precautions below should also be followed by family and friends to reduce the risk of infections.





PRACTICAL ADVICE

- Always wash your hands using hot water and soap or alcohol-based hand gel and dry thoroughly – particularly before eating and after going to the bathroom.
- Avoid being near anyone who has a cough, cold, is vomiting or has diarrhoea. If you do come into contact with anyone with these symptoms, wash your hands straight away.
- Have a digital thermometer at home that you can use to check your temperature. Taking it at roughly the same time every day will help you know what is normal for you and you will then be able to recognise if it changes.
- If you have any infective symptoms when attending your outpatient appointments, please let the receptionist know as they might decide to take you straight to a single room to isolate you. This will be to prevent the spread of infections to other patients.
- Avoid handling any waste from your pets or fish tanks and wash your hands after you have been in contact with pets or animals.
- Avoid handling any garden/pond waste.
- As much as possible, try to minimise contact with large crowds and traveling on public transport.
- Always practice safe sex to reduce the risk of sexually transmitted diseases.
- Ensure that your family or those that you live with are up to date with their vaccinations. For example, family members in close contact with you should receive the flu vaccine.

EATING AND DRINKING

- Follow good food hygiene practice.
- Ensure all food is cooked properly and avoid eating meat that is served rare, 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 them out of the fridge for long periods.
- Defrost food in the fridge, not at room temperature.
- Do not re-heat food more than once.
- Only eat in restaurants with freshly prepared food, avoid food that has been left out on display including from salad bars and buffets.
- Try and drink at least two litres of fluid a day.

Although you should avoid foods that cause infection, it's important that you maintain your weight and keep hydrated to keep strong in case you develop an infection. Loss of appetite is common after transplant, if you struggle to follow the dietary advice given for after your transplant speak to your dietician who will give you alternatives.

IMMUNISATIONS

Having a stem cell transplant causes loss of immunity from your childhood vaccinations. It's therefore recommended that they are repeated to protect you from preventable infections. Your transplant team will guide you as to when this should start but it will generally depend upon how well your blood counts are recovering, how much immunosuppression you are on and if you are free from infections. In most cases, your GP will be asked to administer the vaccinations.

The vaccinations will be given in several stages. The first vaccines may be started as early as three to six months after your transplant, depending on the factors listed above. They will include inactive vaccinations, which are safe to have even if your immune system is still recovering. Live vaccines may be given from around two years after transplant, if your white cell counts have recovered and if you are no longer on any medication to suppress your immune system.

Ask your transplant team for a copy of the vaccination schedule so you know what to expect. It can take time to complete all the vaccinations so please don't be concerned, it's completely normal. Until you have completed the vaccinations, you should avoid anyone known to have an infectious disease.

'The initial months of strict infection control, not meeting family or friends was tough but we took that time to learn lots of fun digital stuff! It's fantastic how apps can bring out your creativity and also help you stay connected.'

Raka, who had a transplant in 2014

WELLBEING

It can be easy to isolate yourself away, not see your family and friends or go out for fear of getting an infection. It's important to balance looking after yourself with doing the things you enjoy. Looking after your mental health is equally as important as your physical health and we recommend a common-sense approach. Below are a few tips to help find the right balance:

- See family and friends in smaller groups which will not feel so overwhelming.
- Plan trips out at quieter times of the day to avoid large crowds.
- Ask your children's school to let you know if there are any infections going around the school. Even if your children are not affected you will still need to be aware.
- If being affectionate is a normal part of your relationships, then continue to do this if there is no risk of infection. Discuss any questions you might have with a member of your transplant team that you feel comfortable with.
- Carry out jobs in the garden in short periods and wear gloves.
- You do not need to deep clean your house, cleaning it as normal is enough.



'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, recipient of a stem cell transplant.

LONG TERM

Over time, as your immune system recovers, becoming stronger and gaining immunity, the risks of infection decrease. As a result, the preventative medications will be stopped. Your appointments at the transplant centre will decrease and you will go back to seeing your GP rather than your transplant team if you develop any infections.

Although you should be able to get back to life as it was before the transplant, there are still a few things that you should be aware of:



- You might be on the antibiotic Penicillin V lifelong as protection against certain bacteria.
- You might always be a bit more susceptible to infections like colds and coughs and it might take you a bit longer than your family and friends to recover.
- It's recommended that you have the flu vaccination annually for life.
- If you develop chronic graft versus host disease (cGvHD) and remain on immunosuppressants, you will always be at a higher risk of infection.

'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.'

Dr Robert Danby, Consultant Haematologist

ANTHONY NOLAN CONTACT DETAILS

ANTHONY NOLAN PATIENT SERVICES

If you or a loved one is affected by a stem cell transplant, there are many ways we can support you:

Need to talk?

The Patient Services team at Anthony Nolan is here for you. Call us on **0303 303 0303** or email: **patientinfo@anthonymolan.org**

Get connected

Find support from other patients and their families by joining our **Patient and Families Forum** at: **anthonymolan.org/forum**

Find 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: **anthonymolan.org/patientinfo**

OTHER USEFUL CONTACTS

BRITISH ASSOCIATION FOR COUNSELLING AND PSYCHOTHERAPY

itsgoodtotalk.org.uk

01455 88 33 00

Information about counselling and therapists in your area.

CITIZEN'S ADVICE

citizensadvice.org.uk

03454 04 05 06

Advice on a wide range of issues, including financial and legal matters. Online advice is available at: adviceguide.org.uk

CLIC SARGENT

clicsargent.org.uk

0300 3300 0803

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

EXPERT PATIENTS PROGRAMME

expertpatients.co.uk

0800 988 5550 or 01925 320 000

Free self-management courses to help you take control and manage your condition.

GOV.UK

gov.uk

Information about UK government services, including benefits, employment and money matters.

IMPROVING ACCESS TO PSYCHOLOGICAL THERAPIES (IAPT)

england.nhs.uk/mental-health/adults/iapt/

Enables patients to self-refer to NHS-funded counselling and therapy services available in their local area.

MACMILLAN CANCER SUPPORT

macmillan.org.uk

0808 808 00 00

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

MAGGIE'S CENTRES

maggiescentres.org

0300 123 1801

A network of drop-in centres for cancer information and support. Includes an online support group.

MIND

mind.org.uk

020 8519 2122

Mental health charity which offers information, advice and support to anyone going through stressful situations or experiencing a mental health problem.

NHS CHOICES

nhs.uk

111

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

SAMARITANS

samaritans.org

116 123

The Samaritans are available 24 hours a day to listen and provide help for any problem you would like to talk about.

TEENAGE CANCER TRUST

teenagecancertrust.org

020 7612 0370

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

‘I FIND THAT SOME PATIENTS PUT TOO MUCH PRESSURE ON THEMSELVES TO GET BACK TO BEING HEALTHY REALLY QUICKLY. IT’S NORMAL TO GET AN INFECTION AT SOME POINT AFTER TRANSPLANT.’

Hayley, Lead Nurse, Anthony Nolan



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