

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **DEALING WITH INFECTIONS**



#BMTsupport

**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 Anthony Nolan on patientinfo@anthohnolan.org

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ANTHONY NOLAN
PATIENT EXPERIENCE
TEAM



WHAT'S IN THIS LEAFLET?

After a transplant your immune system is gradually recovering and you'll be more prone to infections. Find out more about how to protect yourself from infections in this basic guide, as well as signs and symptoms to look out for.

All the information is based on input from expert health professionals, as well as the experiences of other patients.

If you're preparing for a transplant, this leaflet could help you learn more about what to expect and how you can help yourself.

This is a general guide, the care people need after their transplant varies. Speak to your transplant team about what to expect in your particular situation.

WHAT DO I NEED TO KNOW ABOUT INFECTIONS?

It is quite common to develop infections after a stem cell transplant, as it takes some time for your new immune system to fully recover.

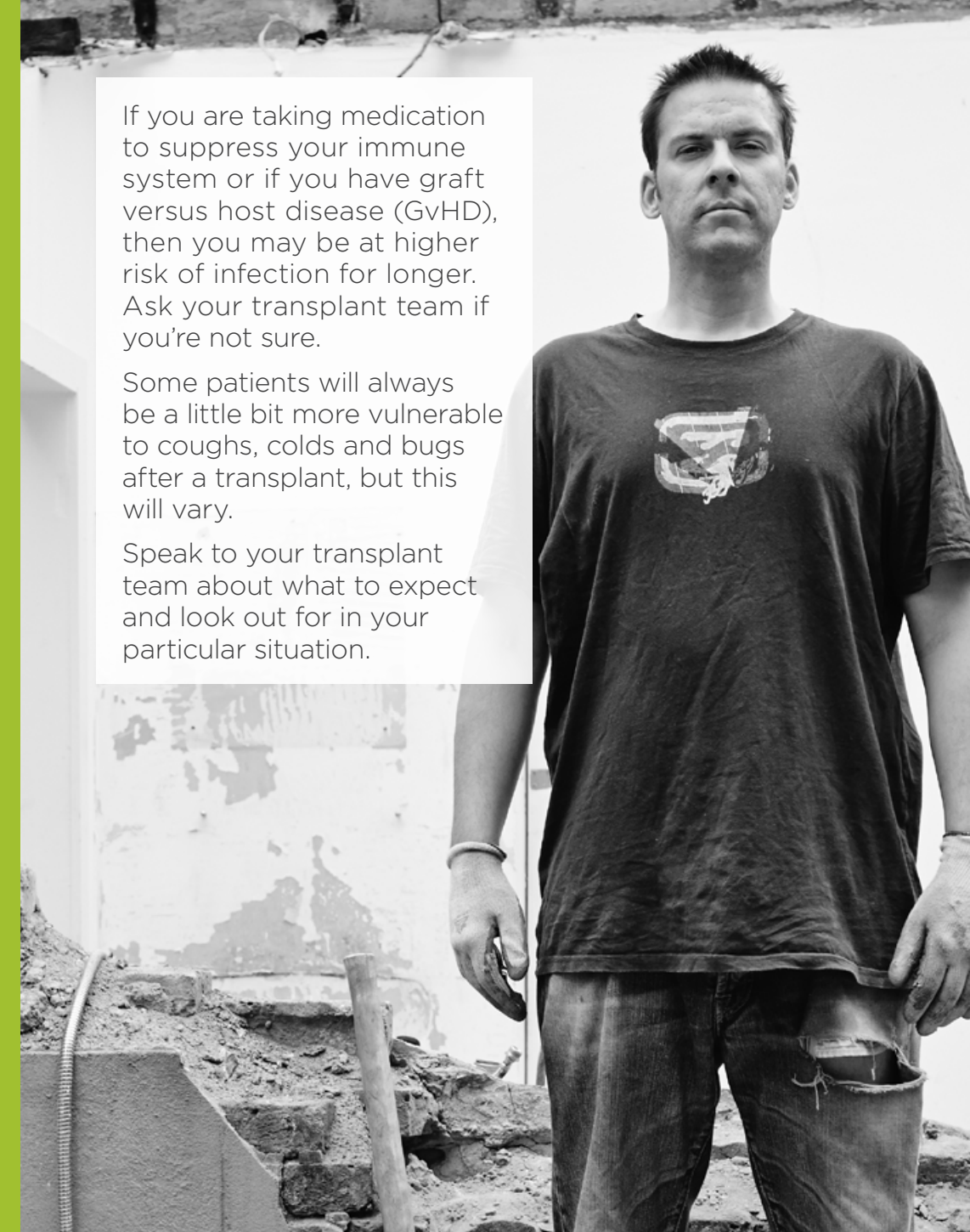


HAVING SOME BUMPS ALONG THE ROAD WITH INFECTIONS AND FEELING UNWELL IS A NORMAL PART OF RECOVERY. IT'S NATURAL TO FEEL ANXIOUS ABOUT INFECTION, BUT TRY AND BALANCE THIS WITH GETTING BACK TO A NORMAL LIFE.

If you are taking medication to suppress your immune system or if you have graft versus host disease (GvHD), then you may be at higher risk of infection for longer. Ask your transplant team if you're not sure.

Some patients will always be a little bit more vulnerable to coughs, colds and bugs after a transplant, but this will vary.

Speak to your transplant team about what to expect and look out for in your particular situation.



WHAT SHOULD I LOOK OUT FOR?

In the first 3 to 6 months...

Take your temperature regularly or if you're feeling unwell. Your team will give you more detailed advice:

You can add in your team's advice here:

SOME SYMPTOMS TO LOOK OUT FOR:

- A high temperature (fever)
- Cough
- Feeling short of breath
- Needing to pass urine more often
- Pain when you pass urine
- Diarrhoea
- Blood in urine or poo
- Redness around your central line site
- Generally feeling unwell
- Severe tiredness
- Bleeding
- Chest pain
- Severe headaches

Add any other advice you've been given about symptoms to look out for here:

Contact the hospital immediately if you have a temperature above 37.5°C, or if you suddenly feel unwell even without a temperature, or if you notice any of the signs or symptoms listed.

Don't worry about it being a false alarm as prompt treatment for a real infection is important.

Call the hospital contact number if you've been given one, or go straight to A&E for emergency treatment.

WRITE THE HOSPITAL CONTACT NUMBER HERE:

"I think it's important not to get complacent. In my case a routine chest infection developed into something more serious that needed treatment straightaway."

Pavlos, had a transplant in 2010

LATER ON IN YOUR RECOVERY

Your transplant team will give you specific advice about when it's ok to see your GP rather than them if you're worried about an infection.

If it's been many years since your transplant and you're otherwise well, then normally you can treat simple coughs and colds as anyone else would and see your GP. If in doubt, you can always get back in touch with your transplant team for advice.

In a small minority of cases, some people continue to have difficulty with their immune system for a long period of time. If you're getting continuous infections then you may be able to receive immunoglobulin infusions to help boost your immune system. Immunoglobulins are antibodies that help fight infection.

TREATING INFECTIONS

What treatment you need depends on what's causing your symptoms. Your team will do tests so they can identify the type of infection and decide on the right treatment.

You may not need treatment straightaway and your team might decide just to keep an eye on your symptoms.

If you do need treatment, this could be tablets, treatment through a drip, or through a nebuliser - a device used to give medication in the form of a mist that you inhale into your lungs. Some patients will need to go back into hospital for treatment.

'I had infections which presented really quickly, and got the right medication in as soon as possible. It was just a hiccup - no one has a completely smooth journey.'

Sarah, had a transplant in 2010

For more information about different types of infections read our booklet, *The Seven Steps: The Next Steps*.

HOW CAN I PROTECT MYSELF FROM INFECTIONS?

The first six months after your transplant:

Ask your transplant team if you need to follow this advice for longer than six months:

- Wash your hands, particularly after using the bathroom or touching anything dirty, or after being in crowded areas or on public transport.
- Try to avoid people with coughs, colds or who might have infections or other bugs.
- Avoid dirt and waste, for example changing nappies, gardening, touching household or animal waste (if you do, wash your hands!)
- Take extra care with pets, wash your hands after touching them, avoid

touching cat litter, and look after their health. Some people decide that someone else should look after their pets in the first few months after their transplant.

- Follow food safety guidelines.
- Avoid travelling to any countries or locations where food and water quality might not be up to the highest standards for the first 6-12 months after your transplant.

Do I need to clean my house every day?

It's best to use common sense and make sure your house is as clean as possible. Some people like to do a thorough spring clean before they go home from hospital, but just do what

feels best for you. Your body is generally used to the environment in your house.

Can I go out and about?

Avoid busy places and public transport at peak times for a few months while your immune system recovers. It's still important to see people and do normal things. You might want to visit friends or go shopping – and this is fine, too, but try to go at quiet times.

If you're not sure what's safe to do, ask your team for advice.

'You've been through so much, you shouldn't have to hide yourself away, and not touch your partner or hug your grandchildren. Recovery just takes a long time and you can't underestimate how heavy a treatment a transplant is – it's important to have goals of getting back to work and everyday life, but at the same time don't be too hard on yourself.'

Hayley, Anthony Nolan Post-transplant Nurse Specialist

Longer-term

With time you can be more relaxed and your confidence will grow. You don't have to be so strict with the precautions suggested for the first six months.

There are some things you can still do to protect yourself from infections in the long-term:

Get immunised:

You'll need to have a number of vaccinations to protect you from infections and illnesses, this includes the vaccinations you had as a child. You'll have these several months to a year after the transplant. You might need to have some of them more than once. Many transplant centres recommend that you have the flu-jab every year for life. Read our booklet, *The Seven Steps: The Next Steps* for more detailed information.

Look after yourself:

There's no magic potion for boosting your immune system. In general, try and keep fit and well by eating a healthy diet and exercising.

Going back to work:

Some people find they are ready to go back to work about six months to a year after transplant. This will vary depending on your recovery and the type of work you do. You're normally at much less risk of infection at this point anyway, but it's sensible to take some precautions if you can. If you have a job where you're in contact with the general public a lot, see if you can make any changes to your role where you're less exposed.



‘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 Danby, Consultant Haematologist

There can be lots of ups and downs during recovery from a transplant. Monitoring your health and dealing with infections can feel overwhelming. As time goes by, you'll find that things get easier, but if you feel things are getting too much, there is support if you need it.

Find out more, read our leaflet: [Life After Transplant: The Essential Guide to Emotional Wellbeing](#).

WE'RE HERE TO HELP

If you or a loved one are affected by a stem cell or bone marrow transplant, there are many ways we can support you.

NEED TO TALK?

The Patient Experience team at Anthony Nolan are 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 online transplant community at **anthonymolan.org/transplantcommunity**

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**

SHARE YOUR THOUGHTS

We work with a panel of people who've been affected by transplant to make sure we get our services and information right. And we'd love you to join them.

From sharing your experiences, to coming up with new ideas and giving feedback on our resources and services: we need your ideas and insight. If you're interested in joining the panel, just get in touch!

TELL YOUR STORY

Nothing inspires people to help like hearing the story of someone affected by blood cancer. If you'd like to share your story, please contact us to find out more.

SOCIAL MEDIA

You can also share stories and find out more about our work on our Patients and Families Facebook page:

facebook.com/anthonymolanpatients

This publication was reviewed by

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The Anthony Nolan Patient and Families Panel

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Hayley, Anthony Nolan Post-Transplant Nurse Specialist

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