

LIFE AFTER TRANSPLANT:

AN ESSENTIAL GUIDE TO **GRAFT VERSUS HOST DISEASE (GVHD)**



#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@anthonymolan.org

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ANTHONY NOLAN
PATIENT EXPERIENCE
TEAM



WHAT'S IN THIS LEAFLET?

After having a bone marrow or stem cell transplant, some patients will develop graft versus host disease (GvHD). We've put together this brief guide to help you understand what GvHD is, who might get it, where and when it might occur, and who to go to for help and support.

We've included information from health professionals, and tips from patients who've been where you are now.

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

WHAT IS GVHD?

GvHD stands for graft versus host disease. The word 'graft' simply means your donor's cells, and the 'host' is you.

When you have a stem cell transplant, the cells transplanted from your donor will form your new blood and immune system.

Your immune system's job is to attack things that don't belong in your body. It keeps your body safe from infections caused by bacteria, viruses and other things that are not part of you.

When you've had a stem cell transplant, there are still small differences between your new developing immune system and other cells in your body. As a result, your growing immune system may harm some of the cells in your own body because it sees them as

'different'. This is called graft versus host disease.

Some GvHD may be a good thing because it means that your new immune system is working and is likely to be attacking any remaining disease cells. This can help stop the disease coming back. You might hear this called graft versus tumour effect.

Too much GvHD can cause unwanted complications and side effects.

'A little bit of GvHD can be useful.... it indicates that your new immune system is working and it may be attacking any residual disease.'

Dr Rob Danby, Consultant
Haematologist



WILL I GET GVHD?

GvHD can be hard to predict, so it can be difficult to work out who will get it and who won't. We know that about half of people who have a transplant will get GvHD, but it's often very mild – for example, you might only get a mild skin rash. But for some people GvHD can be more severe. There's more information in this leaflet about what can help.

WHAT ARE THE SIGNS AND SYMPTOMS OF GVHD?

GvHD can occur at any time, but particularly:

- When the immune cells start to come back and appear in your blood, usually a few weeks after your transplant.
- When your team start to reduce the medication that suppresses your immune system, usually a few months after you go home. The immune cells become more active, and notice that there's a difference in your body's cells and may mount an attack.
- If you have a donor lymphocyte infusion (DLI) – this is a top up of donor cells which can sometimes be given if your new immune system needs a boost. It kick starts the immune system, which can lead to GvHD.

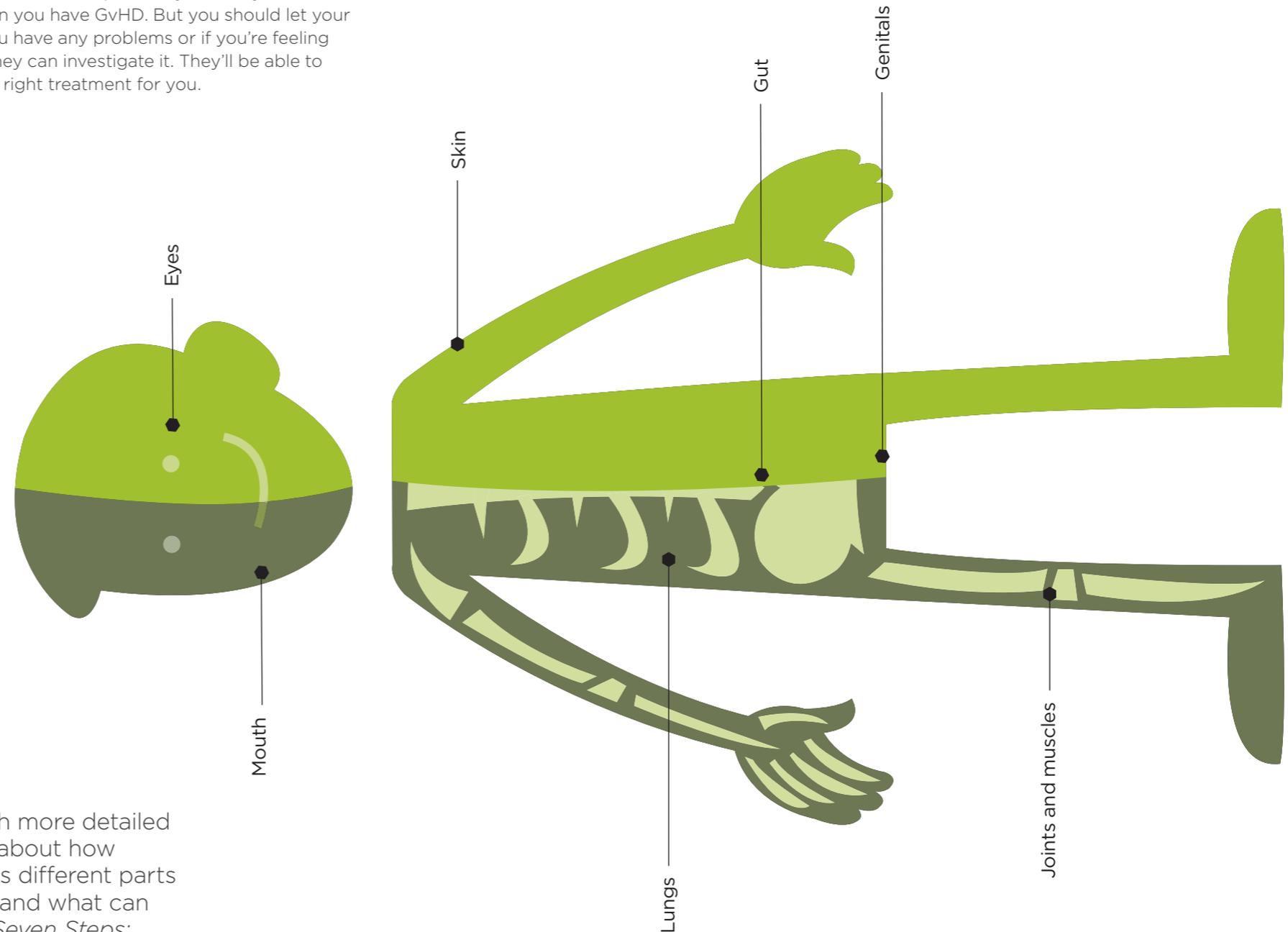
EARLY ON

In the early weeks and months after your transplant, you might hear your team call GvHD 'acute GvHD.' The first sign of acute GvHD could be a rash, or an upset stomach with nausea, vomiting or diarrhoea, or it could affect your liver tests, sometimes causing jaundice (yellow discoloration to skin).

LATER ON

You might hear this called 'chronic GvHD', this may happen later on – from around 100 days after transplant. GvHD can then affect different parts of the body. We've listed these on the next pages.

Having problems with these parts of your body doesn't necessarily mean you have GvHD. But you should let your team know if you have any problems or if you're feeling unwell so that they can investigate it. They'll be able to recommend the right treatment for you.



There's much more detailed information about how GvHD affects different parts of the body and what can help in *The Seven Steps: The Next Steps*.

‘IT’S ALL ABOUT KEEPING THINGS UNDER CONTROL AND FINDING THE RIGHT BALANCE OF MEDICATIONS. GVHD IS USUALLY VERY TREATABLE.’

Hayley, Anthony Nolan Post-Transplant Clinical Nurse Specialist

HOW WILL MY TEAM MONITOR ME FOR GVHD?

After a transplant you’ll have regular appointments and your doctor will ask you questions about how you are and any new symptoms you’ve noticed. You’ll have blood tests and a physical examination. This is to see how you’re doing generally and if your medications need adjusting.

If you have new symptoms, you might have more tests, or be referred to see a specialist.

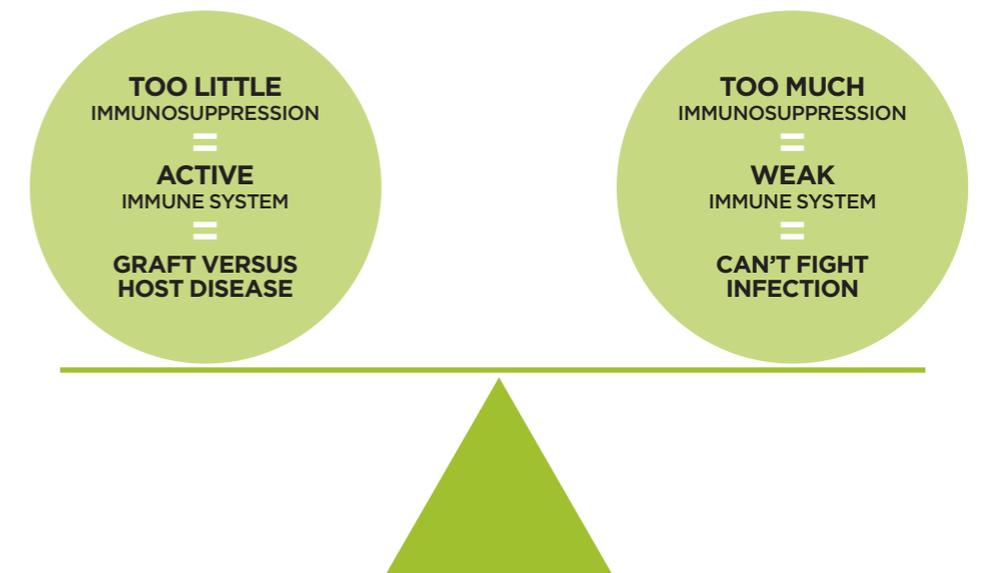
After your transplant you will be given medication called immunosuppression. The aim of this medication is to suppress your new immune system and prevent GvHD. A common medication used is ciclosporin.

Your team will keep a close eye on your medication. The amount of immunosuppression they give you is a careful balance and will vary from one person to another.

Too much immunosuppression may mean that your immune system will be too weak to fight infection. Too little immunosuppression may mean that your immune system is too active and can cause GvHD.

‘Ciclosporin puts the breaks on your new immune system, so that it doesn’t come back too fast and cause harm. When you and the new cells start to get used to each other, the ciclosporin can be reduced. If GvHD then appears, you might need a bit more time on the ciclosporin – your body and your new cells need a little longer to adjust.’

Dr Rob Danby, Consultant Haematologist



WHAT ARE THE TREATMENTS FOR GVHD?

DAMPENING DOWN THE IMMUNE SYSTEM

If you're taking medication to suppress the immune system after your transplant, such as ciclosporin, your team might increase the dose. By suppressing the immune system, they can also reduce the GvHD. If you've stopped taking the ciclosporin and GvHD has appeared, you might have to start taking it again.

TREATING THE PART OF THE BODY WHERE THE GVHD IS

You might be offered treatments just for the part of the body that's affected. For example creams for your skin, special mouthwashes, or drops for your eyes. These only treat that specific area, but not the immune system as a whole. That means you treat the GvHD without raising the risk of infection.

STEROIDS

This is medication that can be taken as a tablet to help suppress the immune system even more. They're a stronger form of immunosuppression.

'I HAD MOUTH GVHD FOR 6 MONTHS. IT EVENTUALLY RAN ITS COURSE, AND IN THE MEANTIME TABLETS AND MOUTH WASHES HELPED.'

Ailis, had a transplant in 2012

‘SOME PEOPLE FIND GVHD IS A BIT LIKE BEING ON A ROLLER COASTER – IT COMES AND GOES AND YOU HAVE GOOD DAYS AND BAD DAYS. WE TRY TO SMOOTH OUT THE UPS AND DOWNS.’

Dr Rob Danby, Consultant Haematologist

TAKING YOUR MEDICATIONS

It's really important to take your medications and use creams regularly, following your team's advice. This makes it more likely that the treatments will be effective. If you're finding it hard to keep track of all your medications you could use a diary or chart, set alarms on your phone and sort tablets into a special container called a dosette box.

Like all treatments, medications for GvHD do cause side effects; your transplant team should let you know about what side effects to expect. If you have any concerns or if you get any new symptoms while you are having treatment let your transplant team know.

OTHER TREATMENTS

A variety of other treatments are available for GvHD. Your treatment will depend on many things, such as the type of GvHD and what part of your body is affected. For more information read our booklet, *The Seven Steps: The Next Steps*.

LIVING WITH GVHD

There's no set time for how long you may have GvHD, sometimes it settles down with treatment very quickly, and sometimes it goes on for a long time. It can come and go, and sometimes it can happen in a different area to where you've had it before. Keep in touch with your team about what's going on.

GOING BACK INTO HOSPITAL

It's common for people to be readmitted to hospital after a transplant, and it can happen a number of times. If you have GvHD you might need to go back into hospital so you can have stronger medication through a drip. It can feel frustrating, but it's useful to know that your team can give you treatment that you need and keep a close eye on you.

GETTING SUPPORT

There can be lots of ups and downs during recovery from a transplant. Some people find that dealing with GvHD leaves them feeling tired and down. If you feel like things are getting too much, there is support there if you need it, as well as ways you can look after yourself.

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@anthohnolan.org**

GET CONNECTED

Find support from other patients and their families by joining our online transplant community at **anthohnolan.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 **anthohnolan.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/
anthohnolanpatients**

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GO AGAIN - WILL I EVER
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Ailis, had a transplant in 2012

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