

LIFE AFTER TRANSPLANT:

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



**ANTHONY
NOLAN**

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of people with
blood cancer



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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@anthonymolan.org

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ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS GUIDE?

After having a stem cell or bone marrow transplant, some patients will develop 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 have been where you are now.

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KEY FACTS

- 1 GvHD is an expected side effect of an allogeneic stem cell transplant. Up to 80% of patients will experience it.
- 2 GvHD can be controlled with medication and in most cases it will stop.
- 3 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 prevent the disease coming back.
- 4 Always report any changes to your GvHD to your transplant team immediately. GvHD can worsen quickly if not treated appropriately.
- 5 Always take your immunosuppression medication as advised. This is among the most important medication you'll need to take.
- 6 Treatment for GvHD can put you more at risk of infection, so report any change in your temperature to your transplant team immediately.
- 7 If you are being treated for GvHD and are admitted to a hospital other than your transplant centre, you must ensure your transplant team is informed. This is so they can advise on how best to manage your GvHD.

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 GvHD.

Some GvHD can be a good thing because it means that your new immune system is working and is likely to be attacking any remaining or returning disease. This can be referred to as 'graft versus leukaemia effect' or 'graft versus tumour effect'.

However, too much GvHD can cause unwanted complications and side effects. At its worst, GvHD can be life threatening.

'It's important to report any changes to your medical team. You know your body so watch out for unexpected changes and don't be afraid to ask silly questions.'

Mark, who had a stem cell transplant in 2016

WHAT TYPES OF GvHD ARE THERE?

GvHD is usually classed as 'acute' if it occurs in the first 100 days after transplant. It's classed as 'chronic' if it occurs any time after that. However it can also be 'progressive' – which is when acute GvHD progresses to chronic GvHD – or it can 'overlap', when features of both acute and chronic GvHD occur at the same time.

Once classed, GvHD is then given a grade which is used to guide treatment and to help monitor improvements. Grading is based on symptoms and the number of organs involved. Some transplant centres slightly adapt the grading system they use, so it's best to check how they measure yours.



WILL I GET GvHD?

GvHD is not yet fully understood and it can be difficult to predict who will get it and who won't. We know that up to 8 out of 10 people who have a transplant will experience GvHD. Often it's very mild but for some people GvHD can be more severe and can affect their quality of life. This guide explains what can help.

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

Debbie Anderson, Anthony Nolan Clinical Nurse Specialist

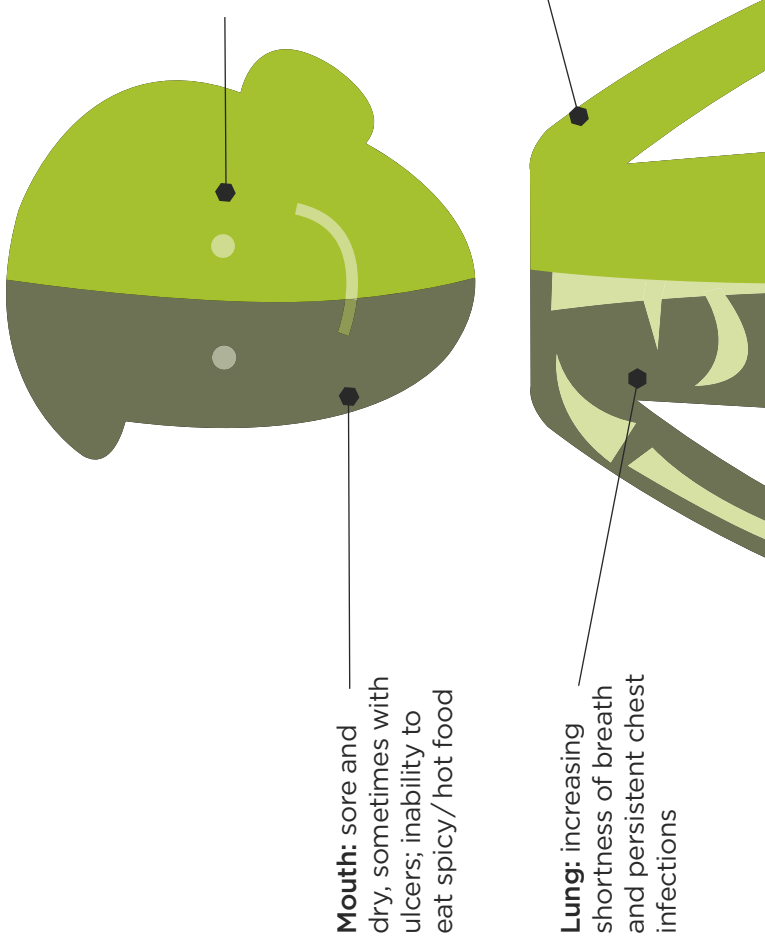
WHAT ARE THE SIGNS AND SYMPTOMS OF GvHD?

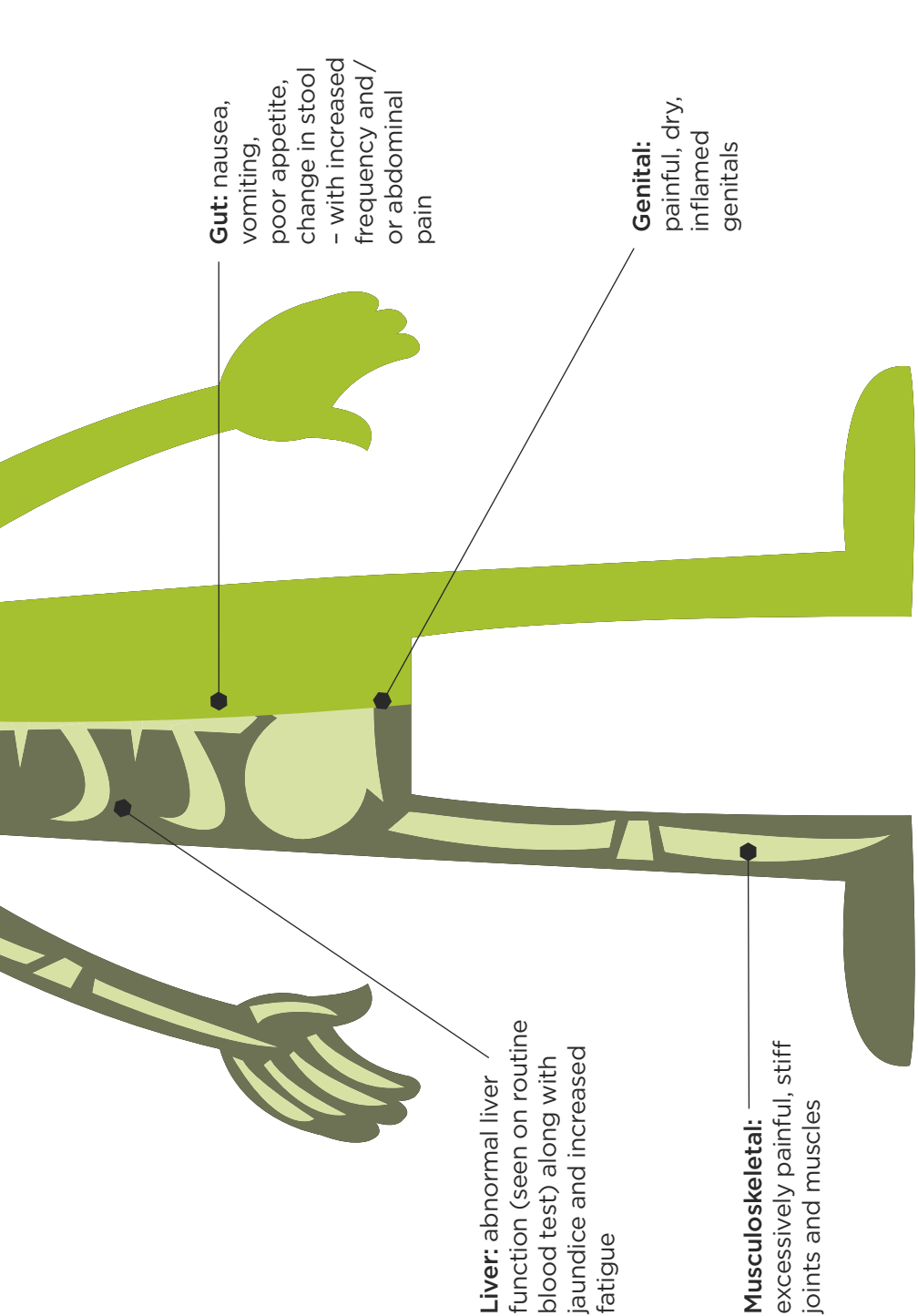
GvHD can occur at any time, so it's important to report any symptoms after transplant to your team. However the most common times to experience GvHD are:

- When your immune cells start to come back and appear in your blood, usually a few weeks after your transplant. a boost. It kick-starts the immune system, which can lead to GvHD.
- When your team starts to reduce the medication that suppresses your immune system, usually a few months after you go home. The immune cells become more active, notice there's a difference in your body's cells and may start an attack. Some symptoms are quite general and do not always mean that you have GvHD. However it is important that you report any of these symptoms to your transplant team so they can assess them.
- 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

COMMON ORGANS AFFECTED BY GVHD

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.





Gut: nausea, vomiting, poor appetite, change in stool - with increased frequency and/or abdominal pain

Genital: painful, dry, inflamed genitals

Liver: abnormal liver function (seen on routine blood test) along with jaundice and increased fatigue

Musculoskeletal: excessively painful, stiff joints and muscles

WHAT ARE THE TREATMENTS FOR GvHD?

Treatment for GvHD varies depending on the organ involved. It can be broken down into:

LOCAL TREATMENTS

This includes creams for skin GvHD, drops for eye GvHD and physiotherapy for GvHD of the joints.

ORAL TREATMENTS

You will be started on immunosuppressive medication (such as cyclosporine, mycophenolate or tacrolimus) before your transplant to suppress your immune system and allow the new stem cells to grow.

If you develop GvHD, the dose might need to be increased for a while to calm down the GvHD and control the symptoms.

Oral steroids can also be used depending on the severity of the GvHD and response to initial treatment. Steroids are a type of immunosuppression. Once the GvHD has improved, these medications will slowly be reduced again.

INTRAVENOUS TREATMENTS

These might be used if oral medications do not control the GvHD. This might require an admission into hospital for medications to be administered.

'I had mouth GvHD for six months. It eventually ran its course, and in the meantime tablets and a mouthwash helped.'

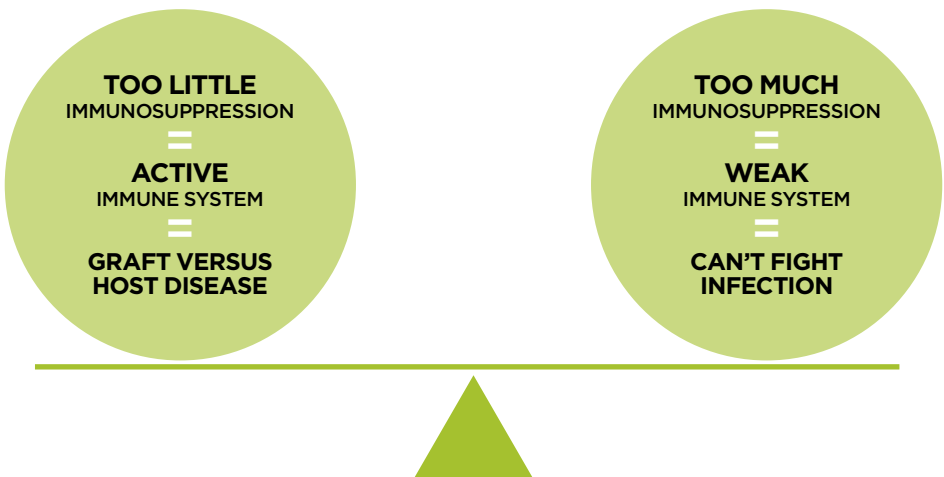
Ailis, who had a transplant in 2012

In some cases, acute or chronic GvHD cannot be controlled with these medications, and further treatment or referral to a specialist is needed. Other specialists that you might be referred to are:

- Dermatology (skin and genital)
- Gastroenterology (gut)
- Hepatology (liver)
- Oral medicine
- Ophthalmology (eyes)
- Respiratory (lungs)
- Rheumatology (musculoskeletal)
- Gynaecologist/Urologist (genital)

Tests might include biopsies (for skin or liver GvHD) or a small camera being used to look more closely at the organ (for stomach or lung GvHD). These tests can confirm the GvHD diagnosis.

If oral and intravenous medications are unable to control the GvHD, a referral for extracorporeal photopheresis (ECP) might be made.



WHAT IS ECP?

ECP is a treatment used for acute and chronic skin, liver and oral GvHD. It aims to destroy the white blood cells that cause GvHD by combining a medication called methoxypsoralen (8-MOP) with ultraviolet (UV) light.

The procedure involves being attached to a machine that removes your blood through a cannula and drip. It then separates the white cells from your blood, before returning the blood to your body. The white cells are then exposed to UV light and 8-MOP to destroy the cells that cause GvHD, and then returned to your body.

Treatment can take 1–2 hours. You might start by having two appointments per week, every fortnight. However over time (depending on your response) treatment cycles are likely to reduce. ECP for acute GvHD responds quite quickly, whereas ECP for

chronic GvHD can take six months or more before any improvement. In some cases, treatment can last 12–18 months or longer.

‘The machine itself can be a bit noisy, but you get used to it. You can still eat and drink, which isn’t a problem. You’re kept comfortable so it’s nothing to worry about.’

Sam, who had ECP to treat his GvHD

TOP TIPS FOR MANAGING GvHD

- 1 Always take your immunosuppression medication and/or oral steroids. This is among the most important medication you'll need to take. If you have nausea, vomiting or diarrhoea, or are unable to take your medication, you must tell your doctor or Clinical Nurse Specialist (CNS).
- 2 Report any change in your GvHD to your transplant team as soon as you notice it. Do not leave it until your next appointment – GvHD can quickly get worse. Call your CNS or a member of the transplant team who can offer advice over the phone and in most cases will prevent the need to come into clinic.
- 3 Depending on the organ involved, GvHD and its treatment can have knock-on effects so you might need to be referred to other healthcare professionals such as a dietician or physio. It's important that you follow their advice to prevent weight loss, manage fatigue and maintain fitness. For more info, read our booklet *An Essential Guide to Diet and Physical Activity* or online resources at **anthonymolan.org/life**
- 4 Immunosuppression leaves you more at risk of infection, so be vigilant for symptoms, especially if you are on these medications for long periods. Report any change in temperature to your transplant team immediately. For more info, see our booklet *An Essential Guide to Dealing With Infections* or online resources at **anthonymolan.org/body**

WHAT IF I'M ADMITTED TO ANOTHER HOSPITAL WITH GvHD?

GPs and local hospitals may not have had much experience of treating GvHD. So if you need to visit your GP or are admitted to your local hospital while receiving treatment for GvHD, here are some important things to remember:

- Tell them all the medications you are on and the treatment you are receiving for GvHD.
- Make sure they contact your transplant centre. Give them the relevant contact numbers or contact the transplant centre directly yourself, if necessary.
- If the doctors would like to change any of your GvHD medication, ensure they first discuss this with your transplant centre.
- Immunosuppression and steroids should never be stopped suddenly. If this is suggested by the doctors, ensure they have first spoken to your transplant centre. This type of medication should only be reduced over a number of days.
- If you are referred to a specialist within the local hospital for your GvHD (a dermatologist, for example) check that your transplant centre is aware of the referral. This is because it is important that the specialist has knowledge of GvHD.

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

Dr Rob Danby, Consultant Haematologist

LIVING WITH GvHD

In most cases, GvHD can be easily treated and resolved. However, in some cases it could begin to affect your quality of life.

You might need to be admitted to hospital, for example, which might make you feel that you are not moving forward. Feeling this way is normal and we would encourage you to speak to either your doctor or CNS about this. They could refer you for emotional support or counselling – our booklet *Your Mental Health and Stem Cell Transplant* has further details, or you can read more online at

anthonynolan.org/mind

Referral for ECP can seem daunting, due to the length of treatment. Sometimes patients delay it as long as possible – but the timing of ECP is crucial for it to be most effective. It is essential that if your doctor suggests a referral for ECP

you consider it carefully. Leaving it too long could reduce the effectiveness of the treatment.

Fatigue can be experienced by anyone who has had GvHD, especially chronic GvHD. A combination of ongoing treatments, hospital appointments and infections can all contribute to fatigue. It's important to discuss this with your doctor or CNS, who can advise you how to best manage fatigue and refer you to a physiotherapist or occupational therapist for support.

Our booklet *Managing Fatigue* has further information, or you can read more online at

anthonynolan.org/fatigue



ANTHONY NOLAN CONTACT DETAILS

If you or a loved one is affected by a stem cell or bone marrow 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**

'I THOUGHT, "HERE WE GO AGAIN - WILL I EVER GET BETTER?" BUT GvHD TURNED OUT TO BE A GOOD THING AS MY ILLNESS HAS COMPLETELY GONE AND I'M DOING GREAT NOW.'

Ailis, had a transplant in 2012

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