

# Graft versus host disease (GvHD)

## A Guide



At Anthony Nolan we do everything we can to help you look after yourself. That includes providing up-to-date and accurate information about stem cell transplants that we hope will help.

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

Make sure you speak to your transplant team for more specific details about your own situation, so they can give you personalised advice.

### Ordering more copies

If you'd like to order more copies of this guide please get in touch with us on [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)

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## What's in this booklet?

After having a stem cell transplant, you might develop graft versus host disease (GvHD).

We've put together this booklet to help you understand:

- what GvHD is
- who might get it
- where and when it might occur
- who to go to for help and support.

This booklet has been written with the first-hand advice of our remarkable patients and the expert guidance of healthcare professionals. They have shared their experiences to help you through your own experience.

If you have any questions or would like further advice, you can call our helpline on **0303 303 0303** or email us: [patientinfo@anthohnolan.org](mailto:patientinfo@anthohnolan.org)



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## Key facts about GvHD

### How do people get GvHD?

We often see GvHD as a side effect of an allogeneic stem cell transplant. This type of transplant involves receiving cells from a donor, not using your own.

### Do I need to take medication for GvHD?

You can control GvHD with medication and in most cases it will stop. A lot of people will need to take immunosuppression medication – make sure you take it exactly as advised.

### What should I do if I think I have GvHD?

You should always report any changes in your post-transplant experience to your team right away – especially changes in your temperature, which might be a sign of infection. GvHD can quickly get worse if it's not treated.

### What if I need to go into hospital?

If you go into a hospital other than your transplant centre while you have GvHD, make sure your transplant team knows. They'll need to advise on how best to manage your GvHD safely.



## What is GvHD?

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

After your stem cell transplant, your donor's cells will form your new blood and immune system. But there are still small differences between your newly developing immune system and other cells in your body.

As a result, **your new immune system may harm some of the cells in your body** because it sees them as 'different'. This is what we call GvHD.

## Why does GvHD develop?

Normally, your immune system's role is to keep your body safe from infections caused by bacteria, viruses and fungi that are not part of you. It also scans your body's own cells and removes any that don't appear to be 'normal', such as those turning into cancer cells.

If your new immune system starts targeting and attacking a lot of your body's existing cells, this can cause unwanted complications and side effects. At its worst, too much GvHD can be life-threatening.

However, some GvHD can be a good thing because it means:

- your newly formed immune system is working
- your working immune system is likely to be attacking any remaining or returning disease cells.

You might also hear this called 'graft versus leukaemia effect' or 'graft versus tumour effect'.



**"GvHD is usually very treatable – it's all about keeping things under control and finding the right balance of medications."**

DEBBIE ANTHONY NOLAN CLINICAL NURSE SPECIALIST

## Why might I get GvHD?

GvHD can affect anyone who has had a stem cell transplant using a donor's cells, also known as an allogeneic transplant. In extremely rare cases, people can get mild GvHD from a transplant using their own stem cells too.

There's generally a higher rate of GvHD among:

- people who have received stem cells from an **unrelated donor** – even if they are a perfect human leukocyte antigen (HLA) match
- people whose stem cell donor is related to them, **but not a perfect or near-perfect HLA match**, also known as a 'mismatched transplant'.

Medical professionals do not yet fully understand GvHD, making it difficult to predict who will get it and who won't. People often experience very mild symptoms, but for others, GvHD can feel more severe and can affect their quality of life.

**“Everything else became a quality of life issue rather than a life-threatening issue. I was eating 3,000 calories a day but not putting weight on, and I was having bad acid reflux. I started on medication for that. I have chronic GvHD in my gut.”**

DAN WHO HAD A STEM CELL TRANSPLANT FOR

ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)

## When am I most likely to get GvHD?

You can get GvHD at any time, so it's important to report any post-transplant symptoms to your team. However, **people most commonly experience GvHD when:**

- Your **immune cells** start to come back and appear in your blood. This is usually a few weeks after your transplant.
- Your medical team **reduces the medication that suppresses your immune system**. This is usually a few months after you go home. As your immune cells become more active, they might notice there's a difference in your body's cells and start an attack.
- You have a **donor lymphocyte infusion (DLI)**. This is a top-up of donor cells which you might get if your new immune system needs a boost.



## What are the signs of GvHD?

The signs of GvHD can vary massively. More importantly, people most often experience symptoms caused by **GvHD in certain organs or parts of the body**, such as your:

- skin
- stomach and gut
- liver
- inside the mouth (oral)
- eyes and around the eyes
- lungs and breathing function
- muscles and joints
- genital area.

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

## How will I know if I have GvHD?

As not all symptoms are specific only to GvHD, you might have a test to confirm the GvHD diagnosis. Your medical team might perform tests like:

- **A biopsy**, a procedure where a small sample of tissue is taken. Doctors might do this test for skin or liver GvHD.
- Using a **small camera** inside your body to look closely at the affected organ. Doctors might do this test for stomach or lung GvHD.

Although many GvHD symptoms are quite general and can feel mild, it's still **important you tell your transplant team as soon as possible**.

**"I had a dry mouth, but this tends to get better and mine didn't. I have GvHD in my mouth and my eyes, so I'm constantly using eye drops and having sips of water."**

**DAN** WHO HAD A STEM CELL TRANSPLANT FOR ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)

# What are the symptoms and treatments for different body parts?

Although everyone has their own experience of GvHD, there are some common symptoms and treatments for certain body parts and organs.

## Skin GvHD

Symptoms on the skin are very similar for both acute and chronic GvHD.

### Symptoms and effects on your skin:

- Dry, red and itchy skin across multiple areas of your body
- Might affect your ability to regulate your temperature
- Can lead to infection if the skin is broken

### Treatments for skin GvHD:

- Some cases need no treatment and improve naturally
- Moisturisers or steroid cream to treat mild cases
- Medication to suppress your immune system in more severe cases
- Ultraviolet light and extracorporeal photopheresis (ECP) treatment

## Gut GvHD

### Symptoms and effects on your gut:

- Sickness, diarrhoea, indigestion, cramping feelings and a lack of appetite
- Could affect your mouth, oesophagus (food pipe), stomach and bowel. Acute gut GvHD usually affects the bowel.

### Treatments for gut GvHD:

- Drinking lots of fluids to avoid dehydration
- Anti-diarrhoea medication in more severe cases
- Painkillers to ease stomach cramps
- Anti-sickness drugs to stop you feeling sick



**“After the transplant, he had GvHD of the skin pretty bad. He caught his reflection in the bath – because you have to have a bath every day, change your bed, change your clothes – and he saw he had no hair and his skin looked horrible and he was so unhappy.”**

**HOLLY MUM TO RUPERT, WHO HAD A STEM CELL TRANSPLANT FOR MYELODYSPLASTIC SYNDROMES (MDS) WITH MONOSOMY 7**



## Mouth GvHD (oral)

### Symptoms and effects on your mouth:

- Having a sore or dry mouth because you aren't producing enough saliva
- Getting ulcers because of your dry mouth
- Affecting your sense of taste, making food taste unusual

### Treatments for oral GvHD:

- Visiting your dentist regularly
- Practising good oral hygiene
- Using a prescribed, steroid mouthwash

**“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 STEM CELL TRANSPLANT**



## Liver GvHD

As it's an internal organ, you might not see or feel anything at first, but your doctor might find out something is wrong by testing your liver function.

### If your GvHD gets worse, it can have symptoms and effects on your liver:

- Jaundice (yellowing of skin)
- Itchy skin
- A swollen liver, causing abdominal pain

### Treatments for liver GvHD:

- Steroid-based drugs
- Other drugs to suppress your immune system



## Lung GvHD

Your lungs can lose some of their flexibility and elasticity because of GvHD, causing certain **symptoms and effects**:

- Shortness of breath
- Feeling wheezy
- Being prone to coughs and chest infections
- Finding exercising more difficult.

If you experience any lung GvHD symptoms, contact your medical team right away.

**Treatments for lung GvHD** will probably first involve tests to find out what's causing your problems and rule out infection. This might include a:

- lung function test
- chest X-ray
- CT scan
- bronchoscopy (a long, flexible tube with a camera that allows doctors to look inside your airways).

**“I have chronic GvHD in my lungs. They think it’s bronchiolitis, which is basically scarring of the small vessels that take oxygen from your lungs to your blood.”**

**DAN WHO HAD A STEM CELL TRANSPLANT FOR ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)**

## Eye GvHD

**Symptoms and effects on your eyes:**

- Itchy, dry and uncomfortable eyes
- Constantly watering eyes
- High sensitivity to bright light

**Treatments for eye GvHD** might include referral to an ophthalmologist (a specialist doctor for people with eye conditions), who may prescribe a combination of:

- eye drops
- anti-inflammatories
- antibiotics.

Wearing sunglasses may also help improve the symptoms and effects.

## Muscle and joint GvHD

**Symptoms and effects on your muscles and joints:**

- Restricted movement and pain in your arm and leg joints
- Finding tasks such as driving or climbing stairs more difficult
- Having swollen joints

**Treatments for muscle and joint GvHD:**

- Physiotherapy to improve your symptoms
- Doing lots of stretches and keeping your joints mobile

## Genital GvHD

### Symptoms and effects on your genitals:

- Vaginal dryness
- Narrowing of the vagina
- Ulceration (in advanced cases) causing pain and discomfort during sex
- Sensitivity or a rash on the penis (which could cause discomfort when you pee)
- Problems maintaining an erection

### Treatments for genital GvHD:

- Referral to a gynaecologist – they may prescribe a steroid cream, or a gel to combat vaginal dryness.
- Referral to a urologist – they may prescribe a steroid cream to reduce sensitivity of the penis.

In some cases, GvHD cannot be controlled with these treatments or medications. You might need further treatment or referral to a specialist. If oral and intravenous medications are unable to control the GvHD, you might also get a referral for **extracorporeal photopheresis (ECP)**. Read more about ECP on page 23.

**“It’s really important to take the medication including creams, eye drops and mouth washes regularly. It’s also helpful to keep up with other things where you can, like exercise and catching up with friends. It can improve your quality of life between what can be a gruelling schedule of clinic visits.”**

DR FIONA DIGNAN CONSULTANT IN HAEMATO-ONCOLOGY AT

MANCHESTER ROYAL INFIRMARY

## Are there different types of GvHD?

There are four types, or ‘classes’, of GvHD:

- **Acute:** starts within 100 days of your transplant.
- **Chronic:** starts more than 100 days after your transplant.
- **Progressive:** when acute GvHD progresses to chronic GvHD.
- **Overlap:** when features of acute and chronic GvHD happen together.

Once classed, medical professionals then give the GvHD a grade which they use to guide treatment and help monitor improvements. The grade is based on your 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.



“The transplant itself went smoothly but I developed chronic skin GvHD.”

ELAINE WHO HAD A STEM CELL TRANSPLANT FOR LEUKAEMIA



“I got lucky in that I never had any acute GvHD but there were some chronic signs.”

DAN WHO HAD A STEM CELL TRANSPLANT FOR ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)



“Zara had very acute GvHD. She was doing so well at first and within a week her body was starting to make the new cells but she started complaining of a lot of tummy pain.”

TARUNA MUM TO ZARA, WHO HAD A STEM CELL TRANSPLANT FOR ACUTE MYELOID LEUKAEMIA (AML)

## What is extracorporeal photopheresis (ECP)?

ECP is a treatment that aims to **destroy the white blood cells that cause GvHD**. It does this by combining a medication called methoxypsoralen (8-MOP) with ultraviolet (UV) light.

Doctors can use ECP for both acute and chronic classes of skin, liver and oral GvHD.

### How does ECP treatment work?

If you have ECP to treat your GvHD, the procedure will look something like this:

1. Doctors will attach you to a machine that removes your blood through a cannula and drip.
2. This machine separates the white blood cells from your blood, while returning the rest of the blood to your body.
3. Your white blood cells are then exposed to UV light and 8-MOP to destroy the cells that cause GvHD.
4. The machine returns the treated white blood cells to your body.

“I find it really relaxing! 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

## How long does ECP treatment take?

ECP treatment can take between one and two hours. You might start by having two appointments per week, every fortnight. However, depending on your response, your treatment cycles are likely to reduce over time.

It also depends on your class and grade of GvHD:

- ECP for acute GvHD responds quite quickly.
- ECP for chronic GvHD can take six months or more before any improvement.
- In some cases, ECP treatment can last 12 to 18 months, or longer.

If you get a referral for ECP, it might feel quite daunting due to the length of treatment. Some people want to delay it as long as possible, but the timing of ECP is crucial for it to be most effective.

**If your doctor suggests a referral for ECP, it's essential you consider it carefully.** Leaving GvHD untreated for too long could reduce the effectiveness of ECP.

**“As well as ECP treatment, I started to have some physio. That helped, so I started to think that some gentle exercise might be good for me too. My sister and my brother have played bowls for years, so me and my husband thought, ‘let’s give that a try’. My GvHD improved along with my bowls.”**

**ELAINE WHO HAD A STEM CELL TRANSPLANT TO TREAT LEUKAEMIA**

## Tips for safely managing GvHD

While everyone can have a different experience of GvHD, it might help to read our tips from healthcare professionals and people who have gone through it before:

- **Take your medication exactly as advised.** Always take your immunosuppression medication – 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).
- **Report any change in your GvHD to your transplant team immediately.** Do not leave it until your next appointment, as GvHD can quickly get worse. Call your CNS or a member of your transplant team – they can advise over the phone and in most cases will save you a trip to the clinic.
- **Keep your team updated if you go into hospital.** If you’re admitted to another hospital, you must ensure they contact your transplant centre. This will allow them to advise the hospital on how best to manage your GvHD.
- **Watch out for signs of infection.** As some treatments for GvHD and immunosuppression can put you more at risk of infection, please be wary of symptoms – especially if you’re taking these medications for long periods. Report any change in temperature to your transplant team immediately.

You can order our booklet *An essential guide to dealing with infections* or read more online at [anthynolan.org/Infections](https://anthynolan.org/Infections)

- **Be wary of related effects.** Depending on the organ involved, GvHD and its treatments can have knock-on effects. You might need to be referred to other healthcare professionals such as a dietician or physio. It's important you follow their advice to eat a healthy diet, prevent weight loss, manage fatigue and maintain fitness.

You can order our booklet *An essential guide to diet and physical activity* or read more online at [anthonymolan.org/Exercise](http://anthonymolan.org/Exercise) and [anthonymolan.org/Diet](http://anthonymolan.org/Diet)



**“It’s about finding the balance – you need to be able to live your life. I have GvHD of the lungs and my consultants are querying if I’m having a flare up of gut GvHD too. It would be life-changing to have a treatment that was able to get this under control and stable again.”**

WENDY WHO HAD A STEM CELL TRANSPLANT FOR HODGKIN LYMPHOMA

## What if I’m admitted to another hospital with GvHD?

Many GPs and local hospitals may not have had much experience of treating GvHD.

If you need to visit your GP, or are admitted to your local hospital while receiving treatment for GvHD, it’s **important to remember the following advice:**

- 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. On page 31, you can fill in all the relevant details you might need in the future.
- If the doctors would like to change any of your GvHD medication, they need to first discuss this with your transplant centre.
- You should never suddenly stop taking immunosuppression or steroid medication. If doctors suggest this, ensure they have first spoken to your transplant centre. These types of medication should only be reduced gradually, over a number of days.
- If you’re referred to a specialist in the local hospital for your GvHD – like a dermatologist for your skin, for example – check your transplant centre is aware of the referral. It’s important the specialist has some knowledge of GvHD.

## Difficult feelings while living with GvHD

In most cases, your medical team can quite easily treat and resolve GvHD. However, in cases where GvHD begins to affect your wellbeing, this in turn could affect your quality of life.

As well as coping with the effects of GvHD, certain aspects might also affect both your physical and mental health and wellbeing.

### Having long-term treatment

Some people require long-term treatment for GvHD, which can take a toll on your body and mind. You might not be able to, or feel like you want to, do all of the things you used to do.

But over time, you can slowly start to build up to things and set goals for yourself. Your treatments and medication may also decrease after time, but even if you end up having treatment for years, it will start to feel like part of your normal routine.

### Experiencing fatigue

A combination of ongoing treatments, hospital appointments and infections can all contribute to fatigue. Your doctor or CNS can advise you on how to best manage fatigue. They might also refer you to a physiotherapist or occupational therapist for support.

You can order our booklet *Managing fatigue after a stem cell transplant*, or read more online at [anthohnolan.org/Fatigue](https://anthohnolan.org/Fatigue)

### Being readmitted to hospital

This might make you feel like your condition is not improving, which can lead to poor mental wellbeing. This feeling is perfectly normal – but we would encourage you to speak to either your doctor or CNS about this. They could refer you for emotional support or counselling, a type of talking therapy.

You can order our booklet *Your mental health and stem cell transplants*, or read more online at [anthohnolan.org/MentalHealth](https://anthohnolan.org/MentalHealth)

### Coping with body image and low self-esteem

Depending on the part(s) of your body affected by GvHD, it might feel difficult seeing certain types of changes. When you're already recovering from a stem cell transplant, and might have already experienced hair loss or changes in your weight, the symptoms of GvHD on top of this can have a negative effect on your confidence and self-esteem.

Preparing yourself for how people might talk to you might make you feel more confident and help you stay in control of the situation.

Our online information has tips and advice to help you cope with these feelings – read more at [anthohnolan.org/BodyImage](https://anthohnolan.org/BodyImage)

**“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

# 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](mailto:patientinfo@anthonymolan.org)

### Get connected

Find support from other patients and their families by joining our **Patient and Families Forum** at: [anthonymolan.org/forum](http://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](http://anthonymolan.org/patientinfo)

# My appointments and contacts

If you've been referred to any specialists to help manage your GvHD, you can keep track of your appointments and their contact details here.

## Specialist consultant

Speciality: .....  
Name: .....  
Contact number: .....  
Name of hospital: .....  
CNS contact: .....

## CNS contact at Transplant Centre

Name: .....  
Contact number: .....  
Appointment dates: .....  
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**“GvHD is usually very treatable – it’s all about keeping things under control and finding the right balance of medications.”**

**DEBBIE**

**ANTHONY NOLAN CLINICAL NURSE SPECIALIST**



**For further patient information:**

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