

# SUPPORTING YOUR FRIEND THROUGH A BONE MARROW OR STEM CELL TRANSPLANT



#BMTsupport

~~ANTHONY  
NOLAN~~

saving the lives  
of people with  
blood cancer

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# WHAT'S IN THIS BOOKLET?

We've put together this booklet for the friends of someone who's had (or is about to have) a stem cell or bone marrow transplant.

It's been written with guidance and advice from our remarkable patients and their loved ones, to help you understand what your friend might be going through, and to suggest ways you can support them.

If you need to ask us any questions, or you'd like some more advice, please get in touch with the Anthony Nolan Patient Experience team at [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org) or **0303 303 0303**.

And if you've had a transplant and you think this booklet might help your friends understand your journey better, why not share it with them online?

*If you'd like to order more copies of this guide, please get in touch with Anthony Nolan at [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org)*

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# WHAT IS A TRANSPLANT?

Your friend has just been through something huge; a bone marrow or stem cell transplant. Their blood cancer or disorder will have stopped their bone marrow from producing healthy blood cells. Having a transplant means that doctors will put new, healthy blood stem cells into your friend's bloodstream where they find their way to the bone marrow. The cells will begin to grow and make healthy red blood cells, white blood cells and platelets. This basically means your friend has an entirely new immune system.

Before your friend's even had their transplant, they'll have already been through a lot. To make sure the donor cells have the best chance of working, your friend will have had treatment that includes chemotherapy, and often radiotherapy, too. This is called 'conditioning therapy'. It prepares the bone marrow to accept the new cells.

After conditioning therapy, your friend will be at their most vulnerable, and that's when they have their transplant. The day of the transplant is sometimes called 'Day Zero'. This is followed by a period of isolation in hospital, when they're team keeps a close eye on them and hopefully their new donor cells are accepted. This is called engraftment.

The first sign that the transplant's working is when your friend starts to make new blood cells. As soon as the cells reach a safe level, and the transplant team feel that your friend is ready, they will be sent home.

This can sometimes happen within a few weeks, but could sometimes be later. That doesn't mean that the transplant isn't working; just that it's taking a bit longer.

It's understandable that you might think when your friend goes home things will get back to normal, but in reality this is just the beginning of what can sometimes be a complicated recovery. By keeping that in mind, you can give your friend the best possible support in the longer term.

# MARIE'S STORY- PART 1

## BEFORE THE TRANSPLANT

Ashling and I have been friends since secondary school, so she's been stuck with me for a long time now!

We grew up together, and even though we went to different sixth form colleges and lost touch for a time, we naturally drifted back to each other.

Ashling was diagnosed with late-stage acute myeloid leukaemia (AML) when she was 25, and it was such a shock. She'd only been feeling under the weather for a few weeks – we couldn't believe it was leukaemia. I just didn't imagine that was what it could be. It was really scary.

I knew nothing about bone marrow transplants in the beginning. Like Ashling, I like to have all the information, so I was straight onto the internet to try to find out as much as I could, talking to her, her mum and the doctors. Something that surprised me was how much preparation there was for the transplant, and just how much she has to go through in order to have one.

I guess I thought of it like an organ transplant – you whip one out and put the new one in and you start to feel better. But it was so much more complicated than that.

## IN HOSPITAL

I kept in contact with Ashling as much as I could when she was in hospital, mainly by text. It was sometimes hard to find a balance of wanting to be there – but not wanting to intrude.

I often wanted to know exactly what had been going on, all the details, but I had to remind myself that she might have already had to explain it to six other people before me. I didn't want to add to her exhaustion.

Something I found difficult was trying to find different ways to say, 'How are you?' I even got out the thesaurus! I think what helped was finding different things to share and talk about, instead of always talking about her condition. I sent her silly YouTube videos to keep her entertained, and we'd have a laugh together about those at visits, getting the doctors involved, too. (Everyone loves a cat video.)

It was such a relief when we found out that they'd found a donor for her. There was quite a wait, and a lot of worry, and trial drugs in between when she was so sick. We were all happy to have good news.





# LEAVING HOSPITAL

It can be natural to assume that your friend is 'better' when they leave the hospital, but the road to recovery is different for everyone.

Some people will find it both physically and psychologically demanding, with lots of post-transplant complications, and for others, things may be much more straightforward. One complication that can occur after a stem cell transplant is Graft vs Host Disease, or GvHD.

GvHD describes the reaction that can happen when cells from a donor (graft) are attacking your friend's body (host). During this reaction, donor cells recognise that your friend's body is 'foreign' and mount an attack against it.

For a small number of people, GvHD can be a serious and sometimes life-threatening illness, and it can have a big impact on how your friend might feel, physically and emotionally.

Fortunately, for the majority of patients GvHD is mild, causing very few problems. For more detailed information, please visit the booklet and resources section of our website.

Having some bumps along the road, with infections, setbacks and feeling unwell, is a normal part of recovery.

Even though your friend has new stem cells reproducing all the time, their immune system is still vulnerable. This is because it's had to start from scratch, just like a newborn baby.

It's very likely that your friend may be readmitted to hospital quite soon after going home. This doesn't mean the transplant hasn't worked; it's normally to manage an infection, and being back in hospital means that they can get the antibiotic treatment that's best for them.

Regular hospital appointments for blood tests, check-ups and receiving blood products, such as red blood cells or platelets, are common for all transplant recipients as well.

It's also highly likely that your friend will go home from hospital with their Hickman (central) line still in place - this is a tube threaded into a large vein where they can receive blood products, transfusions and medicines quickly and safely.

**'My friends are surprised, even now, that I'm not the same. That I can't do the same things as I could before.'**

*Martin had his transplant in 2014*

# FATIGUE

Fatigue is a very common and debilitating side effect after a transplant. It's more than the usual feeling of tiredness after lots of work or exercise, or a bad night's sleep, and it doesn't go away with sleep or rest. It can make your friend feel both physically and mentally drained, leaving them with little to no energy or motivation, and it can be hard to concentrate on anything.

**'It's good for friends to realise that if they visit, you may not feel like much interaction or conversation, but that doesn't mean you aren't glad they are there. Sometimes the greatest support can be supporting your partner.'**

*George had his transplant in 2014.*

When you're visiting your friend at home, you could volunteer to help with the simple things. Ask if you might be able to help round the house when you're there. 15 minutes of tidying up or housework is easy for you, and would be a big relief to your friend, who may even find it challenging to get up the stairs.

**'It can be difficult to ask, so it was appreciated when friends offered their help.'**

*Sarah had her transplant in 2010*

You could also do some groceries, pick up their kids from school, or ask if they need a lift to their hospital visits. Your support can make a huge difference. People worry about being a burden, so it's nice if you can reassure them that you really would love to help out.

**'Please don't get offended if we don't get back to your kind text or email straight away (or dare I say, even at all!). I promise you that we really did appreciate the thoughtful message. However, in between getting used to our 'new normal', we can forget to reply or sometimes not have the energy to, even with those close to us.'**

*Minou's two children had transplants in 2014*

# HOW YOU CAN HELP

## GIVE THEM SPACE...

Your friend has to think about a lot of things after their transplant: getting used to being back at home and not on a ward, worrying about their blood test results, what foods they can eat... the list goes on.

Contact from people who care about them is lovely, but a phone call might not always come at the best time. Texts and emails are a great way to keep in touch, as there's no pressure for them to respond at that moment.

## ...BUT DO KEEP IN TOUCH

**'Stay in touch; receiving cards was lovely. It was good to know what was going on at work, in friends' lives, in the world!'**

*Kate's husband Crispin had his transplant in 2013*

Life after transplant can be tough. Distractions are welcome, and it's good to stay connected to people.

It might be some time before your friend can return to work or go to larger social events, so it's nice to keep them up to date with what's been happening. If your friend

seems a little socially awkward, be patient with them - they're probably adjusting to having company again outside of their immediate circle.

## YOUR HEALTH

**'The most important aspect for me was to advise friends, and have them understand how important hygiene was, and not to visit if at all unwell.'**

*Sarah had her transplant in 2010*

Even if you're feeling a tiny bit under the weather, or you think it's just a cold, it's better to cancel a visit than to put your friend at risk of infection.

When you do visit, hand-washing and being mindful of dirt and germs is really important. Your friend is susceptible to catching bugs, so they may seem a bit paranoid about visitors.

Don't be offended, but do try and understand how scary it can be, and make a point of washing your hands as soon as you get to the house - put them at ease. And if you're not sure about something, just ask! Your friend will appreciate you taking the risk of infection seriously.

# MARIE'S STORY - PART 2

## AFTER HOSPITAL

After the transplant – to be honest – we expected her to have it and to be better. I wasn't aware of all the complications that could happen afterwards. It was definitely a longer road to recovery than expected.

The first time I saw her at home, she was so grey and tired. She looked worse than she had looked at any other stage in the process, even after chemotherapy. That was when she seemed the sickest.

## FRIENDS AND THEIR HYGIENE

Being mindful of hygiene wasn't fully understood by everyone. I remember speaking to another friend before Ashling arrived for coffee; she mentioned she had a bad cough. I said, 'You have to go home, you can't be around Ashling.' I think sometimes it's similar to the mentality of people going into the office with a cold; you think, 'I'll be fine, just keep going', and that's not a helpful attitude to have around a transplant patient.

When she visited my house I was always very conscious of her concerns around hygiene. I remember one of the visits; when she arrived

at the door, I said: 'I've cleaned everything in the house, so you can eat off any surface you fancy – it's a neutropenic-friendly zone!'

## FATIGUE, FRIENDSHIP, AND MUTUAL SUPPORT

Ashling suffered with fatigue after transplant, and that was something I knew about all too well, as I have multiple sclerosis (MS). It was kind of a relief, in a way, to have someone understand something I'd been trying to explain and define for friends and loved ones for years. That strengthened our friendship.

## WHAT I'VE LEARNT

One thing I've learned from having a friend go through a bone marrow transplant is the importance of patience and understanding. Because sometimes Ashling would be down, and not up for chatting at all at visits, and you just have to say to yourself; 'That's OK, that's how she is feeling today.'

Or perhaps she might cancel plans, when she just didn't feel up to it. Some friends found that hard to come to terms with, especially as she was sick for a long time after the transplant.



# FINALLY...

We hope this guide has given you a better understanding of your friend's transplant journey. If you have any more questions, or you just want someone to talk to, please get in touch with the Anthony Nolan Patient Experience team at [patientinfo@anthonymolan.org](mailto:patientinfo@anthonymolan.org) or **0303 303 0303**. They'd be happy to offer advice and support.

You can also visit the Anthony Nolan Transplant Community, and talk in person with patients and their loved ones about life after transplant, and some of the issues that can arise: [anthonymolan.org/transplantcommunity](http://anthonymolan.org/transplantcommunity)

## OTHER USEFUL LINKS

Bloodwise produces patient support booklets, including some with information on specific blood cancers and blood disorders:

[bloodwise.org.uk/all-blood-cancers/patient-information-booklets](http://bloodwise.org.uk/all-blood-cancers/patient-information-booklets)

Macmillan Cancer Care has a variety of useful tips about supporting someone with cancer, available on their website:

[macmillan.org.uk/information-and-support](http://macmillan.org.uk/information-and-support)

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**Kate's** husband Crispin had his transplant in 2013

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