

WORK AND STEM CELL TRANSPLANTS:

AN IN-DEPTH GUIDE FOR EMPLOYERS



#BMTsupport

**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer

Disclaimer

At Anthony Nolan we take great care to provide up-to-date and accurate facts about stem cell transplants. We hope the information here will help you support your employee.

Each transplant centre will do things differently, so this booklet is just a general guide and isn't intended to replace advice from a patient's doctor or transplant team.

This information is not a substitute for legal advice. If you or your employee need legal advice, please contact a solicitor. While we do everything we can to provide the highest quality information, Anthony Nolan will not accept any liability for the use, or inability to use any information provided in this leaflet.

© Anthony Nolan 2016

All rights reserved. No part of this publication may be reproduced or transmitted without permission in writing from Anthony Nolan.

All trademarks and brand names referred to are acknowledged as belonging to their respective owners.

The information contained in this booklet is correct at the time of going to print (December 2016)

Anthony Nolan is a registered charity
No 803716/SC038827

WORK AND STEM CELL TRANSPLANTS:

AN IN-DEPTH GUIDE FOR **EMPLOYERS**



saving the lives
of people with
blood cancer

ANTHONY NOLAN
PATIENT SERVICES
TEAM

CONTENTS

What's in this booklet?	6
What is a stem cell transplant?	10
Your employee's rights	12
Taking time off work	15
Going back to work	19
Dealing with the effects of a transplant at work	23
We're here to help	28
Other organisations that can help	30



WHAT'S IN THIS BOOKLET?

Working after a stem cell transplant may be a big milestone for your employee on their road to recovery.

It can be an important part of making them feel 'normal' again and a different focus away from the medical world of a transplant. Some people find that going back to work means they feel more confident, less bored and helps prevent them feeling low.

Returning to work isn't always straightforward. Your employee will be recovering physically and emotionally from a major treatment. As they recover, they might be dealing with a number of side effects that may go on for months or years. They'll need to adjust to these, and they may need to make changes to the way they work and take things gradually.

As an employer or manager you'll play a vital supporting role. Helping people who are going through, or recovering from, a transplant to remain in or return to work will have benefits for your organisation, business and other staff too. But we recognise that this can be tricky, providing the right support for them as well as balancing the needs of other staff and the organisation. Sometimes you may feel unsure about what to say or do for the best.

That's why we've put together this booklet to help you gain more insight into stem cell transplants and the impact on your employee. Whether they're just about to have a transplant, they're recovering from one or if they've had one a long time ago but still need some support. We've included the experiences of other patients, as well as guidance from specialist health professionals and the latest information on employment law. Use this alongside more general information from organisations. For example **Macmillan Cancer Support's Essential Work and Cancer Toolkit for Employers**, and their training **Macmillan at Work** - find out more at macmillan.org.uk/atwork

ACAS also produce comprehensive information for employers.

We've also made an accompanying booklet for patients and their families, **Work and finance: before, during and after a stem cell transplant**.

If you ever need to ask questions, or you need more information, please get in touch with the Anthony Nolan Patient Services team at patientinfo@anthonymolan.org or call **0303 303 0303**

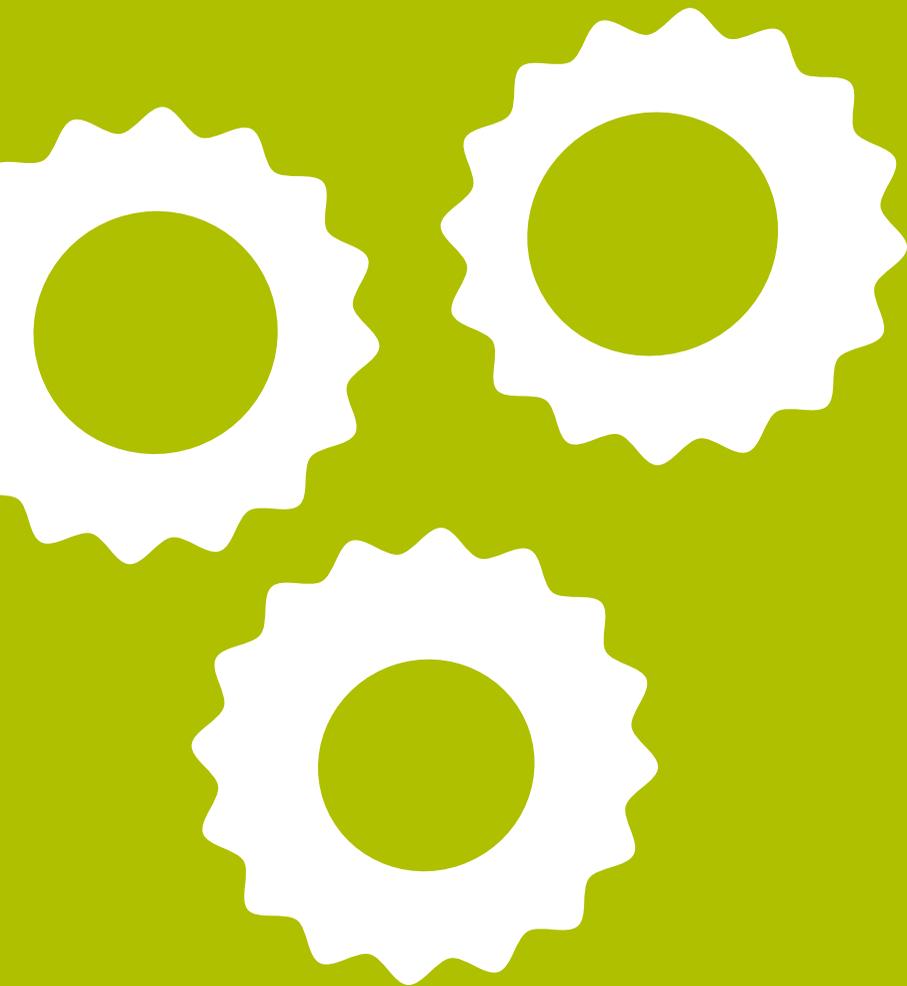




'YOU WILL BE EMPLOYING
SOMEONE WHO MAY
HAVE A DEEPER
UNDERSTANDING OF
LIFE. AND IT SHOWS
THAT CANCER DOESN'T
HAVE TO END BADLY.'

Crispin, had a transplant in 2013

1 WHAT IS A STEM CELL TRANSPLANT?



Your employee has just been through something huge; a bone marrow or stem cell transplant.

Their blood cancer or blood 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 their 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 they have an entirely new immune system.

Before your employee'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, they'll have had treatment that includes chemotherapy, and often radiotherapy, too. This is called 'conditioning therapy' which prepares the bone marrow to accept the new cells.

After conditioning therapy, your employee 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 their 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 is working is when they start to make new blood cells. As soon as the cells reach a safe level, and the transplant team feel that your employee 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.

Many people think that going home after a transplant, means that things will go back to normal. In reality this is just the beginning of what can sometimes be a complicated recovery. By keeping that in mind, you can give them the best possible support in the longer term.

2 YOUR EMPLOYEE'S RIGHTS



As someone with a blood cancer or blood disorder your employee is protected under the Equality Act 2010 in England, Scotland and Wales, or the Disability Discrimination Act 1995 in Northern Ireland.

This means that: it's illegal for them to be discriminated against at work or to be treated less favourably for reasons relating to their ill health.

As their employer, you should try and find ways to make reasonable adjustments to support them in work, both before and after their transplant.

This means that you have a duty to make reasonable adjustments to the location, working arrangement or lack of extra support that puts a disabled person at a substantial disadvantage compared to others. What counts as a reasonable adjustment varies, but examples of support could be:

- Reasonable time off for work for hospital stays and appointments
- Reduced hours
- Flexible working
- Changing their duties
- Working from home
- Workplace adaptations
- Allowing for regular breaks

MORE INFORMATION

For more information on equality law, contact **ACAS, Equality and Human Rights Commission** or **Macmillan Cancer Support** who have a **Guide to Reasonable Adjustments**.

WHAT DOES A DISABILITY MEAN UNDER EQUALITY LAW?

In the Equality Act a disability means a physical or a mental condition which has a substantial and long-term impact on a person's ability to do normal day to day activities. The Act also covers people who've had a disability in the past. Or who continue to experience debilitating effects, as a result of treatment for a past disability, such as the long term side effects of a transplant. This even applies to people who've had a transplant many years ago (even as a child), and are still experiencing 'debilitating' effects as a result of the treatment.



3 TAKING TIME OFF WORK



It's useful to know what to expect so you can make arrangements with your employee.

Your employee might have already been off work for a while before their transplant or they could have been working up to the point they went into hospital. Not everyone wants to talk about their diagnosis or treatment, but you could let them know that they can talk to you if they want to. Things may go more smoothly if you can keep in contact and it will help them know that you support them.

During the run up to their transplant, a conversation about their job and the time they need off might be part of their planning with their medical team. They may be able to tell you about their health at the moment and give you a rough estimate about when they may return to work. But it's very important to realise that things aren't set in stone and recovery varies from person to person.

SICK PAY

If they're too ill to work, your employee might be able to claim company sick pay if your organisation provides it. This is normally set out in their contract of employment, or staff handbook. They will also be entitled to Statutory Sick

Pay (SSP), if your organisation does not provide company sick pay, or if their company sick pay has run out. SSP is paid after the third consecutive day of sickness and is paid for up to 28 weeks (7 months).

They'll need to ask their GP or doctor or nurse in the hospital to give them a 'fit note' covering the time they are not fit to work (see page 20).

You can find out more about SSP, including amounts, by visiting [gov.uk/statutory-sick-pay](https://www.gov.uk/statutory-sick-pay)

'I was fully open with my employer from the start – I was immediately on the phone to my line manager when I was diagnosed with leukaemia. They were amazingly supportive.'

Crispin, had a transplant in 2013

RECOVERY

Some people find that recovery is relatively straightforward, for others it can be physically and emotionally demanding. This can vary depending on the type of transplant they've had and what long term side effects they might be dealing with.

They'll probably need to be in hospital for about three to four weeks for the actual transplant. That's from the time they're admitted to hospital for their pre-transplant treatment, to the time they're well enough to go home afterwards. But recovery afterwards can take six months to a year, or sometimes longer. It's also quite common for people to have some setbacks and need to go back into hospital after a transplant. This might be because of an infection, a side effect that needs treatment or for other reasons.

Read page 27 for tips on what might help them with particular side effects at work.

SUPPORTING CARERS

It may be that you're employing someone who is caring for or supporting someone affected by a stem cell transplant. Caring for someone affected by a transplant can take a big emotional, physical and financial toll. This may mean they need to take time off to be with them in hospital or help with their recovery at home.

If your employee is a carer, they are legally entitled to take 'reasonable' time off work to deal with an emergency affecting a dependant. Whether this is paid or not will depend on your organisation's policy. Carers also have the right to request flexible working. This includes working from home or changing hours.

Find out more about supporting carers at work, visit [carersuk.org](https://www.carersuk.org)

'I worked in an environment where I had constant contact with members of the public and because of this my consultants were reluctant for me to return too quickly after my transplant due to the risk of infection. So by the time they were happy to sign me fit to return I had been off work for over a year'

Nilush, had a transplant in 2013

4 GOING BACK TO WORK

LOOKING AFTER YOURSELF

Finding out that your employee has a blood cancer or blood disorder and needs a transplant could be a big shock for you. You might feel upset, worried or unsure what to say them. These are all normal reactions and getting some more information and support for yourself might help. The Anthony Nolan Patient Services team are here for you if you're close to someone affected by a stem cell transplant.

WHAT HELPS?

- Learning about a stem cell transplant will help you gain a better understanding of what your employee is going through and how best to support them.
- Work with your employee to decide how you'll keep in touch and review this from time to time. As they'll be feeling very unwell during and after their transplant, they could put you in touch with a friend or family member who could update you on their behalf.
- Talk to your employee about their entitlement to company and Statutory Sick Pay; point them in the direction of your work policy for guidance.
- Remember, they are protected by equality law and you are legally obliged to make reasonable adjustments to support your employee in work before and after their transplant (see page 13).
- Take advantage of **Macmillan Cancer Support's** and **ACAS's** training and information for employers.



It's important that they don't return to work earlier than their health permits, but once they're on the road to recovery your employee may want to think about making preparations for going back to work. This can be exciting, but also daunting for them and for you, especially if they've been away a long time.

PREPARING TO GO BACK

Whilst your employee is preparing to go back it will be useful for them to think about what will help with their return. Arrange a meeting with your employee and your HR department, if you have one, to agree a return to work plan. It's normally best to try and take things gradually. As part of the reasonable adjustments you'll consider to support them, a phased return to work and flexible working could help ease them back in to things.

'For me the main issue when returning to work was confidence. So in order to build this up it was essential to establish a rapport with my line manager. The key was flexibility! It's not always easy to admit that you are not coping and can't do as much as before.'

Ariane, had a transplant in 2011

WHAT HELPS?

Understanding the principles behind equality law and reasonable adjustments may help you prepare for discussions with your employee - there's more information on this on page 13.

Your employee's transplant team may be able to provide a 'fit note', advising on what changes may help.

You could also refer them to an occupational health advisor. They are health professionals who specialise in workplace health issues. They can support your employee in reviewing what adjustments they feel are needed and they can advise you on this, they can also make an assessment of their fitness for work.

If you don't have access to an occupational health adviser, then the government's Fit for Work service offer impartial advice on returning to work - visit [fitforwork.org](https://www.fitforwork.org)

Your employee may also be able to get an Access to Work grant to pay for practical support to stay in work. Find out more at [gov.uk/access-to-work](https://www.gov.uk/access-to-work)

Again, keeping in touch with your employee about their return should make things easier when they do come back. And once they do return, regular catch-ups could help make sure they continue to get support that's right for them.

'For my partner, it was a staggered return - he had days when he could just flop and rest. As I saw he could manage it, I was less anxious.'

Caroline's partner had a transplant in 2012

Some people say that they lack confidence when they return to work after a transplant. You could support them by talking about training courses that could help, or suggesting time to arrange catch-up meetings with colleagues.

It may be that their colleagues don't understand about stem cell transplants or recovery afterwards as it's still a rare treatment. With your employee's permission you could give out our leaflet, **Supporting your Friend Through a Bone Marrow or Stem Cell Transplant** to help them better understand what they've been through.

'At times I was ecstatic that I was being treated 'normally' - and at other times I was affronted that they seemed to have forgotten everything I had been through! But it's important to remember that some people have had little experience of cancer in general and don't know how to react.'

Ariane, had a transplant in 2011



5 DEALING WITH THE EFFECTS OF A TRANSPLANT AT WORK



After a transplant, the road to recovery is different for everyone, but even though they might look well it's likely that your employee will be dealing with the long-term psychological and physical effects of their treatment. Getting support from their medical team will help them feel as well as possible.

You'll need to consider reasonable adjustments to support them at work, so it's good to be aware of the main side effects that people recovering from a transplant will go through. We've listed some of the side effects here, and included tips about what might help.

'He could be fine on a Monday and do something and then on a Tuesday not be able to get out of bed.'

Employer

INFECTIONS

Your employee's immune system will be recovering in the first year to 18 months after their transplant, and sometimes longer. This means their risk of getting an infection is higher during this time. While their immune system is still recovering they should try and take extra steps to protect themselves from infection.

'My haematologist was reluctant for me to go back to work in the airport. He advised I start another project from home.'

Nilush, had a transplant in 2013

FATIGUE

Fatigue is a common problem after a bone marrow or stem cell transplant. It's more than just usual tiredness and can make people feel both physically and mentally drained, leaving them with little to no energy or motivation.

For some people, fatigue is a short-term consequence of treatment that gets better over a few months. Others can be still living with it for years after their transplant.

MEMORY AND CONCENTRATION

Some people find that they have problems with their memory, attention and concentration after a transplant. Often these problems get better in the year after their transplant, but some people find that these difficulties have an impact on their daily life and work for longer.

EMOTIONAL CHANGES

It's common for people to feel worried and down before, during and after a transplant. The treatment itself can make them feel unwell, tired and low, and their normal life will have been disrupted. Often these feelings subside over time, but in some people they hang around for longer. It's important that your employee gets support if they need it. You could point them in the direction of the Anthony Nolan Patient Services team for further support (see page 29). Or they could also speak to their GP or medical team. Find out more in our leaflet, **Life After Transplant: An Essential Guide to Emotional Wellbeing**.

'It's a bit like brain fog. I often can't think of the right words.'

Ceinwen, had a transplant in 2012.

GRAFT VERSUS HOST DISEASE

After a stem cell transplant, a person's growing immune system may harm some of the cells in their own body because it sees them as 'different'. This is called graft versus host disease. We know that about half of people who have a transplant will get GvHD. It's often very mild – for example, they might get a mild skin rash, but for some people GvHD can be more severe. 'Chronic GvHD', can affect different parts of the body and cause a variety of symptoms that might have an impact on your daily life and work.

GvHD is a side effect that can be particularly hard to understand – you've probably never heard of it and it isn't always visible. If your employee has GvHD then it may be helpful if they can explain the impact of it for you, having a letter of support from their transplant team may also help you understand it.

OTHER SIDE EFFECTS

Your employee's skin, joints, muscles, bones and eyesight can all be effected as a consequence of their transplant, or by GvHD. Depending on what work they do, you may need to change their duties or the way they work for a while.

'I work for an organic horticultural charity, I work outdoors quite a bit, carrying things around. It's a physical job and because my wrists are so weak – wheelbarrows are one thing that I struggle with. Most people are aware that I have problems and I have to explain it quite a bit.'

Alexandra, had two transplants, the first in 2005

TOP TIPS

Talk to your employee to try and understand their needs, as well as what support they feel they may need from you in returning to work. Arrange regular reviews to ensure the right support is in place – as their needs may change over time.

Here are some brief tips that might help your employee and could be considered as part of the reasonable adjustments you make to support them.

- Going back to work gradually (a phased return) and starting with reduced or part-time hours might help ease them into things.
- They might need to vary or change duties for a while to make it easier to manage side effects, like a weakened immune system or fatigue. For example, could they work in an office rather than interacting directly with the public? Could they sit down at times, instead of being on their feet all day?
- They may be able to identify times when they feel most awake, energised and able to work. It may be that they could do different shifts or hours for a while.
- See if they can factor in regular breaks, and stop and rest if they need it.
- Working from home could help reduce their risk of infection and make things more manageable if they're dealing with fatigue. Could they start or finish slightly earlier or later to avoid the rush hour?
- It's also important that your employee takes care of themselves as well as working. Taking time to rest, relax and exercise; looking after their emotions and getting more support if they need it, will help your employee at work and at home.

6 WE'RE HERE TO HELP



Finding out that your employee has a blood cancer or blood disorder and needs a transplant could be a big shock for you. You might need more information and support for yourself. The Anthony Nolan Patient Services team are here for you and your employee.

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 [anthonynolan.org/patientinfo](https://www.anthonynolan.org/patientinfo)

NEED TO TALK?

The Patient Services team at Anthony Nolan are here to answer any questions. Call us on **0303 303 0303** or email patientinfo@anthonynolan.org

OTHER ORGANISATIONS THAT CAN HELP

ACAS

Provide information, advice, training, conciliation and other services for employers and employees to help prevent or resolve workplace problems.

0300 123 1100

acas.org.uk

CARERS UK

Advice, information and support for people looking after their loved ones.

0808 808 7777

carersuk.org

CITIZENS ADVICE

Advice about benefits, work and money online and in local centres.

citizensadvice.org

GOV.UK

Government services and information, including benefits and disability information.

gov.uk

DO-IT

The UK's national volunteering database.

do-it.org

EQUALITY ADVISORY AND SUPPORT SERVICE

Advises and assists on issues relating to equality and human rights, across England, Scotland and Wales.

0808 800 0082

equalityadvisoryservice.com

EQUALITY AND HUMAN RIGHTS COMMISSION

Advice and guidance about your rights at work.

0808 800 0082

equalityhumanrights.com

MACMILLAN CANCER SUPPORT

Practical, financial and emotional support for people with cancer, their family and friends.

0808 808 00 00

macmillan.org.uk

MAGGIE'S CENTRES

A network of drop-in centres for cancer information and support. Includes free courses, emotional and practical support and an online support group.

0300 123 1801

maggiescentres.org

MONEY ADVICE SERVICE

Free and impartial money advice, set up by the government.

0800 138 7777

moneyadvice.service.org.uk

NATIONAL CAREERS SERVICE

The National Careers Service provides information, advice and guidance to help you make decisions on learning, training and work opportunities. The service offers confidential and impartial advice. This is supported by qualified careers advisers.

0800 100 900

TURN2US

Turn2us is a national charity that helps people in financial hardship gain access to welfare benefits, charitable grants and support services.

turn2us.org.uk

This publication was reviewed by

Sharon Cain, Head of HR,
Anthony Nolan

Sam Crosby, Macmillan
Telephone Welfare Rights
Advisor, Toynbee Hall,
London

Thomas Dobson, Citizens
Advice, Gateshead

Liz Egan, Working through
Cancer Programme Lead,
Macmillan Cancer Support

Hayley Leonard, Anthony
Nolan Post-Transplant
Nurse Specialist, The Royal
Marsden NHS Foundation
Trust London

Catriona Quillinan,
Anthony Nolan Post-
Transplant Nurse
Specialist Manchester
NHS Foundation Trust

Daniel Rolph, HR Business
Partner, Anthony Nolan

Michelle Rouse, Macmillan
Cancer Support

The Anthony Nolan
Patient and Families Panel



'GOING BACK TO WORK
HAS SO MANY BENEFITS
- IT'S DIFFICULT TO
QUANTIFY HOW MUCH I
ENJOYED BEING PART OF
A TEAM, BEING BACK AT
WORK WITH MY MATES.'

Crispin, had a transplant in 2013

anthohnolan.org/patientinfo
facebook.com/anthohnolanpatients
patientinfo@anthohnolan.org
0303 303 0303
blog.anthohnolan.org

Reg Charity no 803716/SC038827
878PA-EmpB/1116



saving the lives
of people with
blood cancer