

Work and stem cell transplant

Information for employers



**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.

This information is not a substitute for legal advice. If you 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 booklet.

Ordering more copies

If you'd like to order more copies of this guide, please get in touch with us at patientinfo@anthohnolan.org

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ANTHONY NOLAN
PATIENT SERVICES



*We have a long, hard
ahead but I look to
when no child dies
waiting for a donor*

*Shirley Walker, founder of British
Kidney Transplant Association*



What's in this booklet?

Working after a stem cell transplant can be a big milestone on your employee's road to recovery.

It can be an important part of making them feel 'normal' again and give them a different focus away from the medical world of a transplant.

But returning to work isn't always straightforward.

After a transplant, your employee will be recovering physically and emotionally from major treatment. They may need to make adjustments to the way they work and take things gradually.

We've put together this booklet to help you support your employee, before and after their transplant.

You could also give your employee our booklet for patients and their families *Going back to work after your stem cell transplant*.

If you have any questions, or need more support, please get in touch with us at patientinfo@anthonymolan.org or call **0303 303 0303**.



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Key facts



A stem cell transplant is a major treatment, and your employee will need a substantial period off work - sometimes six months to a year, and maybe longer.



You have a legal responsibility to support your employee. It's illegal to discriminate against them or treat them unfairly.



You have a legal responsibility to make reasonable adjustments to help your employee return to work.



Recovery is different for everyone - your employee may get back to work quickly or it may take a long time. They may need to go back gradually and do different duties for a while.

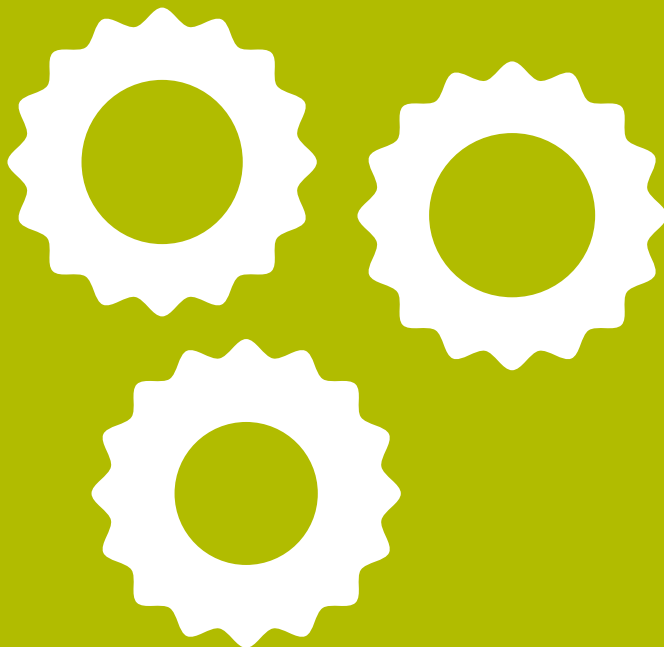


After a stem cell transplant, most people experience side effects that they need to manage at work, both in the short and long term. You have a legal responsibility to make reasonable adjustments to help them do this.



There are lots of organisations that provide information, advice and training for employers to help them support employees with long-term health conditions (see p41).

What is a stem cell transplant?



A stem cell transplant is a major treatment, used to treat blood cancer or a blood disorder.

How does a transplant work?

Blood cancer or blood disorders stop someone's body from producing healthy blood cells. A stem cell transplant puts new, healthy stem cells into someone's bloodstream.

The healthy cells then attach to the person's bone marrow and start to make new blood cells. Over time, this leads to the development of a new immune system.

Before the transplant

Before their transplant, your employee will need to stay in hospital for a few weeks for conditioning therapy. This includes chemotherapy, and sometimes radiotherapy, which prepares their bone marrow to accept the new cells.

Having the transplant

Transplant day normally happens the day after conditioning therapy finishes. People sometimes call it 'day zero'.

During the transplant, the cells will be passed as a fluid into the patient, like a blood transfusion. It takes between 30 minutes and a few hours. The transplant isn't painful and your employee will be awake the whole time.



Recovering in hospital

After their transplant, your employee will stay in protective isolation, where they are closely monitored as their new immune system develops.

During this time, they will usually stay in a single room with the door closed, and visits are strictly limited. This could be for a few weeks or a number of months.

Returning home

Before your employee can go home, their doctors will need to make sure that the transplant is working and their body is starting to make new blood cells.

Once these cells reach a safe level, and their doctors feel they are ready, your employee will be able to go home.

Once they are at home, they will start their recovery. Most people will need at least six months to recover at home, but for some people, this can take a year or longer.

During this period, it's quite common for people to have setbacks and need to go back into hospital for treatment.

You can find more about stem cell transplants on our website [anthonynolan.org](https://www.anthonynolan.org) or by reading our leaflets *Essential facts for transplant patients* and *Essential facts for transplant recovery*.



The hardest part for anyone who hasn't had a transplant to understand is that someone may look very well but is actually completely the opposite.

Mel, who had a stem cell transplant to treat CMML

Your employee's rights



In the UK, your employee's rights to work are protected under equality law. This means you have legal responsibilities to treat them fairly and support them at work.

What are my legal responsibilities as an employer?

Under the Equality Act 2010 (England, Scotland and Wales) and the Disability Discrimination Act 1995 (Northern Ireland), you're classed as having a disability if you have a blood disorder or cancer.

This includes if you had a transplant in the past – even as a child – or experience long-term side effects, such as chronic graft versus host disease (GvHD) or fatigue.

This means that, as an employer, you're legally required:

- to support your employee's return to work
- to make 'reasonable adjustments' to their role
- to consider providing an alternative job if their role can't be adapted
- not to treat them unfairly, or discriminate against them, because of their health condition.



Reasonable adjustments

As an employer, you have a legal responsibility to make reasonable adjustments to support your employee, before and after their transplant.

These could be:

- time off for hospital stays and appointments
- doing lighter or different duties
- working part-time or flexible hours
- working from home
- practical changes to their workspace, like a more comfortable chair or keyboard
- more regular breaks.

The type of reasonable adjustments you're required to provide will depend on the type and size of your organisation and your employee's role.

You can find out more from Acas at

[acas.org.uk/reasonable-adjustments](https://www.acas.org.uk/reasonable-adjustments).

More information

For more information about equality law, see the Equality and Human Rights Commission, Equality Advisory and Support Service, Macmillan Cancer Support or Acas (see p41).

Supporting your employee



A transplant has significant physical and emotional effects. As an employer, you can be an important source of support. You also have legal responsibilities to support your employee.

Talking to your employee

Try to be sensitive to your employee's needs and feelings. Make sure you make time to talk and listen to them. If you're not sure what to say, Macmillan Cancer Support has resources on talking to people about cancer that might be helpful.

Confidentiality

Your employee may ask you to keep their information confidential, and not tell your colleagues. This is their legal right, under the Human Rights Act 1998, the Data Protection Act 2018 and the General Data Protection Regulation (EU) 2016.

Check your policies

Check whether your organisation has any guidelines or policies to support your employee. Arrange a meeting to discuss them, and make sure you both have copies in writing.

This could include:

- sick pay
- absence from work, including how / how often your employee needs to be in touch while they're off, and how / when to provide a fit note
- return to work
- occupational health
- any pension provision.

Make sure the policies are up-to-date. Acas and Macmillan Cancer Support have templates for policies if you need to write one.

Employee benefits and wellbeing initiatives

Find out whether your organisation offers any employee benefits or wellbeing initiatives. If they do, tell your employee what's available and how to access it.

This could include:

- An Employee Assistance Programme (EAP) – these usually offer services like counselling and guidance for employees and managers.
- Critical illness insurance – this provides a lump sum if your employee is diagnosed with a particular illness or disability.
- Income protection insurance – this provides an income to your employee if they are unable to work long-term because of illness.

Sick pay

Your employee can claim Company Sick Pay if your organisation provides it. If not, they may be entitled to Statutory Sick Pay (SSP). To find out more, go to [gov.uk/employers-sick-pay](https://www.gov.uk/employers-sick-pay).

Planning for an absence

Before the transplant, arrange a meeting with your employee to discuss how much time they will need and how you can support them. They may want to bring a friend, work colleague or family member to the meeting.

It's likely that your employee will need an extended period of time off work, but it's difficult to know exactly how long.

Your employee can give you information from their transplant team about their health and progress, but it's important to be flexible. Recovery varies from person to person, and things can change as they progress.



I worked in an environment where I had constant contact with members of the public. My consultants were reluctant for me to return too quickly after my transplant due to the risk of infection.

Nilush, who had a stem cell transplant to treat AML



Fit notes (sick notes)

Your employee should provide fit notes (sick notes) from their medical team to cover the time they are off. Make arrangements about who they should send these to, how and how often.

The fit notes should tell you about their health and give you a rough estimate about when and how they may return to work.

Keeping in touch

Make a plan with your employee about how and how regularly you'll be in touch. They may put you in touch with a friend or family member who can update you when they're feeling too unwell.

Some people like to be contacted regularly, whereas other people may find it stressful to have to think about work. Work together to find what is best.

Try to review this, as they may want to be contacted differently at different times. As it gets closer to their return to work, they might like to have catch ups with colleagues, for example.

Supporting someone who is a carer

If your employee is caring for someone who has had a stem cell transplant, they may need to take time off work.

Carers are legally entitled to take reasonable time off work to deal with an emergency affecting a dependent. 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 their hours. Find out more at the Carers UK website (see p41).

Get information and training

Reading up about stem cell transplants will help you understand more about what your employee is going through and how to support them. Have a look at the information on the Anthony Nolan website.

You may also want to get training for you and your team about supporting employees with long-term health conditions. Working To Wellbeing and Macmillan Cancer Support both offer training programmes (see p41).

Support for you and your team

Having a colleague who is unwell can have a practical and emotional impact on you and your team. If you need support, talk to your manager or HR department.

Anthony Nolan's Patient Services team can also provide emotional and practical support to anyone who is close to someone going through a stem cell transplant (see p40).

Checklist: Supporting your employee

- Talk to your employee about what you can do to support them and whether they'd like you to keep it confidential.
- Check your policies and guidance, and make sure they're up-to-date.
- Find out whether you offer any employee benefits or wellbeing initiatives, and tell your employee how to access them.
- Arrange a meeting to explain what financial support and benefits you can offer, such as Statutory or Company Sick Pay or an Employee Assistance Programme.
- Find out about your legal obligations to your employee from Acas or Equality Advisory Support Services (EASS).
- Decide how you and your employee will keep in touch and review this regularly.
- Be flexible about the amount of time your employee may need off, and be aware that this may change.
- Read information about stem cell transplants to understand more about what your employee is going through and how to support them. Visiting the Anthony Nolan website is a good place to start, at [anthonynolan.org/patients](https://www.anthonynolan.org/patients)
- Look into training for employers from Working To Wellbeing or Macmillan Cancer Support.

Returning to work



Once your employee is on the road to recovery, they may want to think about returning to work. This can be exciting but also daunting, especially if they've been away for a long time.

Deciding when to return

Your employee should only return to work when they are physically able. Their transplant team will let them know when this is possible.

Their fit notes (sick notes) should give you an idea about when and how this might happen. They may need to have a phased return, and do lighter duties or less hours for a while.

Check your Return to Work policy

You may have a Return to Work policy that sets out the processes you need to follow. If you have an HR team, check to see if you have a policy.

Plan reasonable adjustments

As your employee is classed as having a disability under equality law, you must consider making reasonable adjustments to help them return to work (see p17).

These can help your employee get back to work quicker, support them in their recovery and help them stay in work long term.

Your employee's transplant team may be able to provide a fit note (see p22) advising on what changes may help.

Adjustments should be planned between yourself and your employee, with input from their medical team or an occupational health advisor or vocational rehabilitation practitioner.

For more information, see Macmillan Cancer Support, ACAS, Equality and Human Rights Commission or Citizens Advice (see p41).



Make a Return to Work plan

Arrange a meeting with your employee and your HR department (if you have one) to agree a Return to Work plan. You may need to get advice from an occupational health specialist. Working To Wellbeing or Fit for Work also provide advice.

Agree on a plan that suits you both. Make sure you both have a copy in writing, and that the plan is reviewed regularly.

The plan should be flexible and adjustable, so it can be changed to fit your employee's needs over time. You should aim to gradually build your employee's confidence to help them manage a sustained return to work.

Wellbeing Action Plan (WAP)

Your employee has just gone through a significant upheaval in their life and will probably have experienced a lot of ups and downs. This can have an impact on mental health.

To support your employee, you may want to consider making a Wellbeing (or Wellness) Action Plan (WAP). This sets out practical steps you and your employee can take to support their mental health as they return to work.

For more information and to download a free plan, see the **Mind** website.

Pay during a phased return

If your employee returns on reduced hours, they should be paid their normal wage for the hours they work. If you agree on lighter duties or less responsibility, you and your employee should agree what pay would be fair.

Occupational health

You may have an occupational health advisor or vocational rehabilitation practitioner that you can refer your employee to. They will help you and your employee work out what support they need. For more information, see [**Fit For Work**](#).

Employee Assistance Programme

Find out if your organisation has an Employee Assistance Programme that provides services, like counselling. If you do, tell your employee what it offers and how to access it.

Access to Work

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

Catch-up meetings

Your employee might find it helpful to have catch up meetings with you and their colleagues before they return, to get up to speed and help with their transition back to work. You should update them on any organisational changes, or things that might affect their work.

Training

If your employee has been off work for a while, they may appreciate doing some training to refresh their skills and boost confidence. Have a look into what opportunities you could offer.

Talking to your team

Your employee may or may not want you to discuss what's happened with their team or the wider organisation. If they ask you to keep this confidential, it's a legal requirement that you do.

However, you may want to discuss the benefits of telling their colleagues, such as:

- They will be able to support your employee.
- They will have more realistic expectations about your employee's performance.

Either way, it's a good idea to explain to your team that your employee may take a while to settle back in and to be supportive.

Regular check-ins and reviews

It's good practice to have regular check-ins with your employee to see how they are managing, and review their Return to Work plan and reasonable adjustments.



Checklist: Returning to work

- Your employee's medical team will let you know when and how they will be able to return to work.
- Check your Return to Work policy if you have one.
- Consider making reasonable adjustments to support them – you have a legal responsibility to do this.
- Make a Return to Work plan and review it regularly.
- Refer your employee to an Occupational Health Advisor, vocational rehabilitation practitioner or an Employee Assistance Programme if you have them.
- Find out if your employee is eligible for an Access to Work grant.
- Ask them if they'd like you to arrange catch ups with colleagues before they return or shortly after.
- Offer training to boost confidence and update their skills.
- Ask your employee how they would like you to talk to your team, and ask your team to be supportive.
- Have regular check-ins and reviews.

Managing side effects



Most people will have to manage some side effects after a transplant, even if they look well. This might be in the short term as they recover, or long term. This may change over time.

If your employee has side effects because of their transplant, you have a **legal requirement** to make reasonable adjustments to help them manage them at work (see p28).

Infections

After a transplant, your employee's immune system will be recovering for up to 18 months, and sometimes longer.

This means they have a higher risk of infections, and you may need to change the way they work to help protect them.

Your employee may also be more prone to coughs and colds, and take more time to recover than normal.

For more information, read our *Essential guide to dealing with infections* booklet.



Fatigue

Fatigue is a common problem after a stem cell transplant. This is more than just feeling tired. Post-transplant fatigue can leave someone with little energy to do even simple things and can make it difficult for them to concentrate, even after lots of rest and a good night's sleep. For some people, it's a short-term consequence of treatment, but for other people, it can last for years after their transplant.

For more information, read our guide *Managing fatigue after a stem cell transplant*.

Memory and concentration

Some people have problems with their memory, attention and concentration after a transplant. Often these problems get better after a year or so, but some people find they last for longer.

For more information, see our booklet *Cognition: How stem cell transplant can affect your memory and concentration*.

Emotional wellbeing

Most people experience feelings of worry, uncertainty and low mood at some point during a transplant. This can have an impact on someone's ability to work.

For more information, see our booklet *Your mental health and stem cell transplant*.

Graft versus host disease (GvHD)

When someone has a stem cell transplant, their growing immune system may harm some of the cells in their body because it sees them as 'different'. This is called graft versus host disease (GvHD).

GvHD can cause a range of symptoms affecting the skin, gut, eyes, lungs, mouth, liver, muscles, joints and genitals. Symptoms differ from person to person and aren't always visible.

Find out more in our *Essential guide to GvHD* booklet.

Other side effects

Your employee's skin, joints, muscles, bones and eyesight can also be affected.



Chronic fatigue and GvHD aren't usually obvious. The employee may pretend that everything is fine, not want special treatment or to be constantly viewed as an invalid. It's a tricky balance.

Mel, who had a stem cell transplant to treat CMML

Top tips: Managing side effects

- Make an effort to learn about your employee's side effects and how they affect them at work.
- Work with your employee to make reasonable adjustments to help them manage side effects.
- A phased return may help, so they can slowly build up over time.
- It might help your employee to do different or lighter duties for a while.
- To help prevent infection, think about how you can reduce your employee's contact with people. For example, working from home, in a different role or doing different hours.
- Regular breaks can help manage fatigue, and improve memory and concentration.
- It might help to change their working patterns so they can work when they have most energy.
- When allocating tasks, break them down into manageable chunks and give your employee plenty of time – they may need a bit longer than usual.
- If an employee is having memory or concentration problems, see if you can provide a quieter place for them to work.
- Try to avoid putting pressure on your employee to recover more quickly or do more than they can. It can take a while to settle back in.
- Check in with your employee regularly to see how they are doing and if they need any support. Their needs may change over time.

Anthony Nolan contact details

Anthony Nolan Patient Services

If you or someone you know 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

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

Other useful contacts

Acas

[acas.org.uk](https://www.acas.org.uk)

0300 123 1100

Impartial advice on workplace rights, rules and best practice for employers and employees. They also offer training and help to resolve disputes.

Carers UK

[carersuk.org](https://www.carersuk.org)

0808 808 7777

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

Citizens Advice

[citizensadvice.org.uk](https://www.citizensadvice.org.uk)

03444 111 444

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

Do-it

[do-it.org](https://www.do-it.org)

The UK's national volunteering database.

Equality Advisory & Support Service (EASS)

[equalityadvisoryservice.com](https://www.equalityadvisoryservice.com)

0808 800 0082

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

Equality and Human Rights Commission

equalityhumanrights.com

0808 800 0082

Advice and guidance for employers and employees about equality and employment rights.

GOV.UK

gov.uk

Government information on benefits and disability for the UK.

Labour Relations Agency (LRA)

lra.org.uk

03300 555 300

Provides information for employees and employers on information matters in Northern Ireland.

Macmillan Cancer Support

macmillan.org.uk

0808 808 00 00

Physical, emotional and financial support for people with cancer, and their family and friends. Provides a Work Support Service via their helpline.

Maggie's

maggies.org

0300 123 1801

Provides cancer support and information in centres across the UK and online.

MoneyHelper

moneyhelper.org.uk

0800 138 7777

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

National Careers Service

nationalcareers.service.gov.uk

0800 100 900

Provides information, advice and guidance to help you make decisions on learning, training and work.

OpenLearn

open.edu/openlearn

Free online courses from the Open University.

Scope

scope.org.uk

Provide practical information and emotional support for people with disabilities, including about work and equality law.

Turn2us

turn2us.org.uk

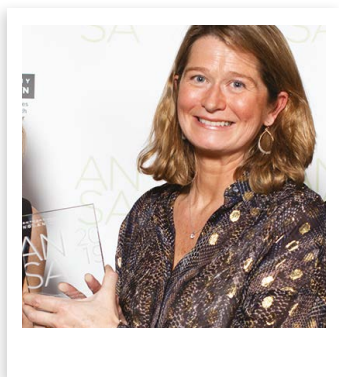
Helps people in financial hardship gain access to welfare benefits, charitable grants and support services.

Working To Wellbeing

working2wellbeing.com

0330 0552903

Helps people return to work following transplant or other medical treatment, and provides information and training for employers.



A transplant is hard emotionally and physically. If we can survive one and still come out positive and ready to meet the working world again, we can only be an asset to any organisation.

Joanna, who had a stem cell transplant to treat AML



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0303 303 0303

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