Stem cell transplants

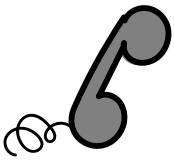
A guide for adults with leukaemia, myelodysplastic syndromes (MDS) or myeloproliferative neoplasms (MPNs)

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Our services

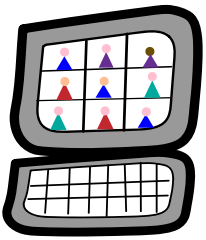


Helpline

Our helpline is available 9am to 4:30pm Monday to Friday. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9am to 5pm.

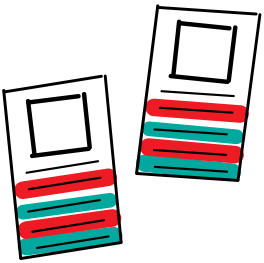
Support Groups



Our nationwide support groups are a chance to meet and talk to other people who have been affected by a leukaemia, MDS or MPN diagnosis. For more information, scan this QR code:

Buddy Support

We offer one-to-one phone support with volunteers who have had leukaemia, MDS or MPN themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemiacare.org.uk



Counselling Service

Our counselling service helps patients and their loved ones access up to six sessions of counselling. To apply, scan this QR code:

Advocacy and Welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding a leukaemia, MDS or MPN diagnosis.

These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.

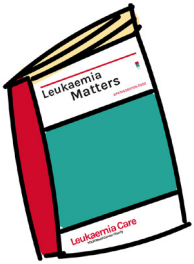
Cost of Living Fund

This fund provides grants to patients and families affected by leukaemia, MDS or MPN, to help with essential living costs. All applications must be made via the form which can be found by scanning the QR code:

Write a Will

Using our complimentary service, you can write a simple Will so you know what happens to your estate when you die. To start writing your free Will today, scan this QR code:

Patient Magazine



Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe to our magazine, scan this QR code:

In this booklet

There is a lot of information about cancer on the internet. Some of it may not be reliable or up-to-date, and much of it will not be applicable to you. Your haematology team is best placed to give you information that is specific to you because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Look for a quality mark, such as the Patient Information Forum (PIF) tick.

Introduction

There is a lot of information in this booklet. Each chapter has a summary at the beginning if you'd prefer a short overview.

This booklet is about stem cell transplants for people with leukaemia, myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs). We do not cover stem cell transplants for people with other conditions.

This booklet is only a guide of what you might experience. Your haematology team will give you a copy of your specific treatment plan.

We'd like to thank Fiona Heath, Nurse Advisor, Leukaemia Care, Dr Donal McLornan, Consultant Haematologist, University College London Hospitals, Dr Renuka Palanicawandar, Consultant Haematologist, Imperial College Healthcare NHS Trust, and Jo Preston, Haematology Clinical Nurse Specialist, Manchester Royal Infirmary for reviewing this information. We'd also like to thank our patient reviewers Charlotte, Deb, Peter, Sophie, Terence and Vaughn. We'd also like to thank everyone who shared a quotation of their experience of a stem cell transplant.

Throughout this booklet, you will see QR codes and URLs that link to webpages for further support. If you are not able to access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

About stem cell transplants

Summary

- A stem cell transplant is an intensive type of treatment that replaces damaged or destroyed blood-forming cells with healthy ones.
- There are two main types:
  - Allogeneic stem cell transplants use stem cells from a donor.
  - Autologous stem cell transplants use your own healthy stem cells.
- A stem cell transplant might be an option for some people with:
  - Acute leukaemias such as acute myeloid leukaemia, acute promyelocytic leukaemia and acute lymphoblastic leukaemia
  - Myelodysplastic syndrome
  - Myeloproliferative neoplasms such as myelofibrosis
  - Mixed myelodysplastic-myeloproliferative neoplasms
  - Other blood or immune system disorders
- Stem cell transplants are rarely used to treat people with chronic myeloid leukaemia or chronic lymphocytic leukaemia.

What is a stem cell transplant?

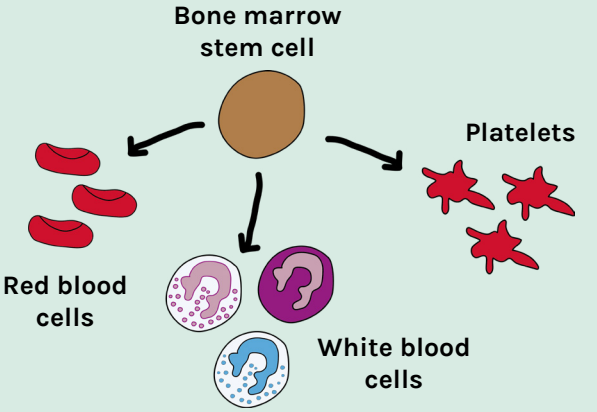
A stem cell transplant replaces damaged or destroyed blood-forming cells with healthy ones. It is a very intensive type of treatment and it is not suitable for everyone.

You might need a stem cell transplant if:

- Your own stem cells are unhealthy or not working properly
- Your own stem cells are healthy, but the treatment you need for your cancer will destroy them

More about stem cells

Stem cells are blood-forming cells that mainly live in your bone marrow. This is the spongy tissue in the middle of some of the large bones in your body. It's where your body makes blood cells.



Stem cells can grow into:

- Red blood cells, which carry oxygen around your body
- White blood cells, which fight infections
- Platelets, which help your blood clot

Most blood cells don't live for very long, so your stem cells work all the time to make more. This keeps your blood counts at a healthy level.

Types of stem cell transplant

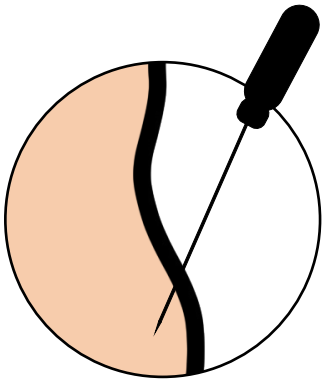
There are two main types of stem cell transplant:

- **Allogeneic stem cell transplants** use healthy stem cells from a donor to replace damaged or destroyed stem cells. The donor stem cells gradually replace your whole immune system too. Your new immune system might be able to recognise and attack any cancer cells left in your body.
- **Autologous stem cell transplants** use your own healthy stem cells. These are usually collected before you have chemotherapy or radiotherapy, or sometimes afterwards. This type of stem cell transplant does not treat your cancer directly. Instead, it allows you to have high-dose treatment that kills as many cancer cells as possible. The downside is that this also kills healthy stem cells in your bone marrow, so you can't make enough red blood cells, white blood cells or platelets while you are recovering. Having a stem cell transplant helps your bone marrow recover faster.

Almost all stem cell transplants for people with leukaemia, MDS or MPNs use stem cells from a donor.

Is a stem cell transplant the same as a bone marrow transplant?

Stem cell transplants and bone marrow transplants are almost the same. The only difference is where the healthy stem cells come from.



- When they're collected from the bloodstream, it's called a stem cell transplant. This is the most common type of transplant.
- When they're collected from the bone marrow, it's called a bone marrow transplant.

Most of the time, people say 'stem cell transplant' to mean both.

Who might have a stem cell transplant?

Stem cell transplants are not suitable for everyone. Many people with leukaemia, MDS or MPNs don't need one. Your medical team might suggest one if you are fit enough and you have:

- **Acute myeloid leukaemia (AML)** and
  - A medium or high risk of your leukaemia coming back after treatment or
  - Your leukaemia did not respond to your first treatment or
  - Your leukaemia came back after treatment
- **Acute promyelocytic leukaemia (APL)** and
  - Your leukaemia did not respond to your first treatment or
  - Your leukaemia came back after treatment
- **Acute lymphoblastic leukaemia (ALL)** and
  - A high risk of your leukaemia coming back after treatment or
  - Your leukaemia did not respond to your first treatment or
  - Your leukaemia came back after treatment
- **Myelodysplastic syndrome (MDS)** and
  - A high risk of your MDS developing into AML or
  - Previous treatments did not work
- **Myelofibrosis (MF)** and a medium or high risk of your cancer growing quickly
- A mixed **myelodysplastic-myeloproliferative neoplasm (MDS/MPN)** and a high risk of your cancer growing quickly

People with **chronic myeloid leukaemia (CML)** or chronic **lymphocytic leukaemia (CLL)** do not usually need stem cell transplants. Occasionally, your team might recommend one if other treatments have not worked or if you have a high risk of your leukaemia growing quickly.

We have information on different types of leukaemia, MDS and MPNs. Follow the link, scan the QR code or search for the name of your condition at www.leukaemiacare.org.uk

Stem cell transplants are also used to treat people with lymphoma, myeloma and other bone marrow or immune system disorders. We don't cover those in this booklet.

Anthony Nolan, the stem cell transplant charity, has information about other blood conditions that might need a stem cell transplant. They also have links to charities supporting people with different blood conditions. Scan the QR code, click the link or visit www.anthonynolan.org

Before having a stem cell transplant

Summary

- Having a stem cell transplant is a big decision. You'll have time to discuss it with people close to you and ask any questions you have.
- You'll be looked after by a team of health professionals at a specialist hospital.
- You'll have tests to check that a stem cell transplant is suitable for you and that you're fit enough to have one.
- You might need treatment to get or keep your cancer under control while you're getting ready for your stem cell transplant.
- Your transplant team will fit a central line to make it easier to give you medicines into your veins and take blood tests.
- If you're having an allogeneic stem cell transplant, your transplant team will search for a suitable donor. This might be a brother or sister, or an unrelated donor.
- Some treatments you have as part of a stem cell transplant can affect your fertility. Your team will explain this and talk to you about your options.
- Most people who have a stem cell transplant stay in hospital for several weeks. It takes many months to recover.
- You may need to arrange for people to help look after children, pets, your home or garden, and to support you as you recover.

Deciding whether to have a stem cell transplant

Having a stem cell transplant can be daunting. It involves intensive treatment that can have serious side effects. If a transplant is an option for you, your transplant team will explain the benefits and the risks of having one. They will give you the chance to ask questions so you can decide if it's the right choice for you.

"I was scared as I knew little about what this entailed, but it sounded like my only choice. It might work and it might not. So many side effects and talk of death made me realise I had a massive decision to make and I wasn't sure if I was strong enough or my body could take it. Many nights were spent crying. I decided to go ahead and try to save my life in any way I could."

Tracy, who had a stem cell transplant for AML in 2018

It's a big decision. You might want to discuss it with family or friends before you make up your mind. But the final decision is yours. Nobody else can, or should, make it for you.

Make sure you ask all the questions you have. It's a good idea to write them down beforehand so you don't forget what you wanted to ask. You could take someone with you to your appointments to help you make your decision.

"After hundreds of sleepless nights, calls to specialists, discussions and soul searching I decided to go ahead."

Kate, who had an autologous stem cell transplant for APL in 2017

Questions you could ask include:

- Where will I have the stem cell transplant?
- How long am I likely to be in hospital?
- How long do you think it will take me to recover?
- What is the outcome likely to be for me?
- What other options are there?

You may want more information to help you decide.

Anthony Nolan have online and print information about all aspects of having a stem cell transplant. Click the link, scan the QR code or search 'understanding stem cell transplants' at www.anthonynolan.org

Blood Cancer UK produce a detailed book about stem cell transplants. Click the link, scan the QR code or search 'stem cell transplant' at shop.bloodcancer.org.uk to download it or order a free copy in print.

Preparing for a stem cell transplant

If you have a stem cell transplant, you'll be referred to a hospital that has the facilities and experience to do it safely. This might not be your nearest hospital.

You'll be looked after by a whole team of health professionals – your transplant team. It could include:

- Haematologists
- Specialist nurses
- Physiotherapists
- Occupational therapists
- Dieticians
- Pharmacists
- Dentists
- Psychologists
- Counsellors

Your key contact is usually your transplant coordinator or transplant clinical nurse specialist. They will explain what you can expect before, during and after your transplant.

Anthony Nolan have more information about preparing for a stem cell transplant. Click the link, scan the QR code or search 'preparing for a stem cell transplant' at www.anthonynolan.org

Consent

Before you have your transplant, your team will ask for your written permission. This is called consent. It is to make sure:

- You understand what a stem cell transplant involves
- You know what the possible risks and benefits are
- You agree to having it

Your team should explain everything on the consent form to you. Ask them if anything is not clear. It's important you have enough information to give informed consent.

Tests and scans

Before having a stem cell transplant, you'll have tests to check it's suitable for you and that you're fit enough to have one. This might include:

- Blood tests
- A bone marrow test
- A chest X-ray
- Breathing tests
- A heart tracing and heart scan
- Dental checks
- A pregnancy test

Your team might also recommend other tests and scans. You'll probably have a meeting with the hospital psychologist too.

If you have tooth or gum disease, you'll need to have it treated before your transplant to lower your risk of a mouth infection.

Finding a donor

This section is relevant if you are having a stem cell transplant using donor cells. It does not apply to you if you're having a stem cell transplant using your own cells.

The healthy stem cells you have must be a close match to your own stem cells. This reduces the risk that your body will reject them and increases your chance of success.

> **"I had a rare tissue type, and it would be hard to find a donor, so it was amazing when a 10/10 match was found with somebody from the Czech Republic."**
>
> Georgina, who had a stem cell transplant for ALL in 2018

You and any possible donors will have blood tests to check how closely your tissue types match. You might hear your transplant team call this HLA typing.

- If you have any full brothers or sisters who are willing and fit enough to donate cells, your transplant team will test them first. Occasionally, they might test parents or children, but they are less likely to be a good match.
- If you do not have any suitable relatives, or they're not a good enough match, your team will search for a matched unrelated donor (MUD). They will do this through a register of possible donors in the UK and all over the world.

Possible donors have more tests to make sure they are a good match, and to check that they're healthy. This step can take a few weeks. It can be harder to find a donor for people from some ethnic backgrounds.

More about HLA typing

HLA stands for human leucocyte antigen. It's a marker on the surface of your cells made of proteins. It's how your immune system works out what is 'you' and what is not.

There are lots of different HLA proteins. Different people have different ones. Tissue typing tests for the most important HLA proteins. The aim is to get as close a match as possible to yours.

"My brother was my donor. He selflessly went through a heap of appointments, checks and blood tests and finally the donation. I will forever be in debt to him for saving my life."

Charlotte, who had a stem cell transplant for AML in 2022

Once a suitable match is confirmed, your team will start planning the date of your transplant.

Anthony Nolan have more information about finding a donor. Click the link, scan the QR code or search 'finding a stem cell donor' at www.anthonynolan.org

Other organisations that help find stem cell donors include:

- **NHS Stem Cell Donor Registry**
- **DKMS**
- **NMDP**

Fertility options

Your transplant team will ask you if you might want to have children in the future. This is because some treatments you have as part of a stem cell transplant can affect your fertility. Your team will tell you if this is likely to be the case. If it is, they will talk to you about your options. This could include freezing eggs, sperm or embryos, although this may not be possible for everyone. They may refer you to a fertility specialist.

> **"I asked for a chance to have my eggs frozen, should there be any left undamaged."**
>
> Kate, who had an autologous stem cell transplant for APL in 2017

The Human Fertilisation and Embryo Authority (HFEA) has more information about fertility preservation for people with cancer. Click the link, scan the QR code or search 'fertility preservation' at www.hfea.gov.uk

Cancer, Fertility and Me helps people with cancer make decisions about fertility preservation. Scan the QR code, click the link or visit cancerfertilityandme.org.uk

Treatment to get your cancer under control

You might need treatment to get or keep your leukaemia, MDS or MPN under control while you are waiting for your stem cell transplant.

This varies depending on the type of blood cancer you have and how you've responded to previous treatment. If you need it, your transplant team will explain what they recommend and what you can expect from it.

> **"After a donor was found for me, the consultants suggested that I go home for a few days before starting the treatment. I was told it would do me good to have a change of scenery and some home cooking."**
>
> Terence, who had a stem cell transplant for AML in 2017

We have information on different types of leukaemia, MDS and MPNs. Follow the link, scan the QR code or search for the name of your condition at www.leukaemiacare.org.uk

Having a central line fitted

Stem cell transplants involve a lot of treatments that have to be given through a drip. They also involve lots of blood tests. Your transplant team will fit a central line to make this easier. You have a local anaesthetic to numb the skin first so it does not hurt when the line goes in. You might have a sedative too, if you need one.

More about central lines

A central line is a long, thin plastic tube that enters the skin in your arm or your chest. It runs underneath your skin and ends in a large vein near your heart. It can be used to give treatments straight into your veins, and to take blood samples.

A central line can stay in place for weeks or months. Having one fitted means:

- You don't have to have a tube put into a vein every time you go for treatment
- You don't need to have a needle put into your arm when you have blood tests
- Your treatment goes into larger, sturdier veins that are less likely to leak or be damaged

"My line was inserted, and I was good to go. This proved a huge psychological help for me. No more jabbing needles into veins."

Lisa, who had a stem cell transplant for AML in 2016

You'll need to keep your central line clean and dry to reduce the chance of it getting infected. It needs to be flushed with a special sterile fluid once a week to stop it getting blocked. Your team will arrange for someone to do this for you.

Macmillan have more information about central lines, including how to look after them. Scan the QR code, click the link or search 'central lines' at www.macmillan.org.uk

Practical things to think about

Most people who have a stem cell transplant stay in hospital for several weeks. Some hospitals offer treatment as an outpatient, under close supervision. If the hospital is not close to your home, you may need to think about travel or accommodation for people you'd like to support you during this time.

> **"The little things meant so much—having a friend to hold my hand as they shaved my head, my coffees and cakes, friends of friends sending small gifts and messages of support from people I hadn't seen for years—it all meant so much."**
>
> Sarah H, who had a stem cell transplant for AML in 2018

After you go home, you'll have frequent hospital check-ups for at least 3 months. It can take a year or more to recover.

Depending on your circumstances, you may need to arrange for people to help:

- Look after your children
- Look after your pets
- Water your plants
- Mow your lawn
- Collect your post
- Keep an eye on your home
- Run your car for a few minutes each week
- Take you to or from appointments
- Support you at home during your recovery

If you usually work, talk to your employer about having time off. You may be entitled to benefits if you are unable to work.

Our Advocacy and Welfare Team can help you find support. Contact advocacy@leukaemiacare.org.uk or call 08088 010 444.

Maggie's also have information about taking time off work and benefits you may be able to claim. Macmillan have information about work and cancer.

Scan the QR codes, click the links or search 'work and cancer' in your preferred search engine.

Getting your hospital bag ready

Things you might want to take into hospital with you include:

- Loose, comfy clothes and nightwear that's easy to take on and off over a drip
- Toiletries, including gentle shampoo and body wash
- A soft toothbrush that you can use when your mouth is sore
- Alcohol-free mouthwash to lower your risk of mouth infections and tooth decay
- Moisturising cream, lip balm or lip salve to help with dry skin and lips
- Soft tissues and toilet paper
- Period products if you need them
- Glasses, contact lenses or hearing aids if you need them
- An eye mask and earplugs
- A phone, laptop or tablet and charger
- Things to do, including things that don't need much energy
- Some home comforts to make your room more welcoming

You won't be allowed to have flowers or plants in your room.

"My initial recovery was very slow and frustrating. No one can prepare you for the debility and weakness following a transplant, but I remember receiving invaluable tips from fellow patients who had been through the same experience."

Jude, who had a stem cell transplant for AML in 2015

Having a stem cell transplant

Summary

Stem cell transplants involve a few steps.

1. Collecting the stem cells (from you or from your donor, depending on the type of transplant you're having):
   - You or your donor have injections to boost stem cell production and encourage the cells to move into your bloodstream.
   - The stem cells are then collected. They can be used straight away or frozen to be used later.
2. Conditioning therapy:
   - This gets your body ready for the stem cells.
   - It usually involves chemotherapy, radiotherapy to your whole body, or both. Most people need to stay in hospital to have it.
3. Having the stem cells:
   - This is a quick process, similar to having a blood transfusion.
   - It can feel like an anticlimax.
4. Waiting for your bone marrow to recover:
   - It takes a few weeks for your bone marrow to start making new blood cells.
   - Your blood counts might get very low. You'll have transfusions to top up your red blood cells and platelets.
   - Your immune system will be very low. You'll probably stay in a room on your own to lower your risk of infections.

What does a stem cell transplant involve?

Stem cell transplants involve a few steps:

- Collecting the stem cells (for transplants using your own cells). It takes a few days to get your stem cells ready for collection. The collection itself takes a few hours.
- Conditioning therapy to prepare your bone marrow. This usually happens over a few days.
- Having the stem cells. This takes a few hours.
- Waiting for your bone marrow to recover. This takes several weeks.

"My Leukaemia Care Buddy, a stem cell transplant survivor herself, was an invaluable support during this period, helping me through this next stage of treatment. The mental side of leukaemia is tough, so having someone who understood exactly what I was going through was a great support."

Janine, who had a stem cell transplant for AML in 2022

To find out more about our Buddy Support Service, follow the link, scan the QR code or search 'buddy support' at www.leukaemiacare.org.uk

Collecting stem cells

This section is relevant if you're having a stem cell transplant using your own cells. It does not apply to you if you're having a stem cell transplant using donor cells. But you might be interested to know what happens for your donor.

Stem cells usually live in your bone marrow. They can be collected from there, too, but most of the time, they're collected from the bloodstream.

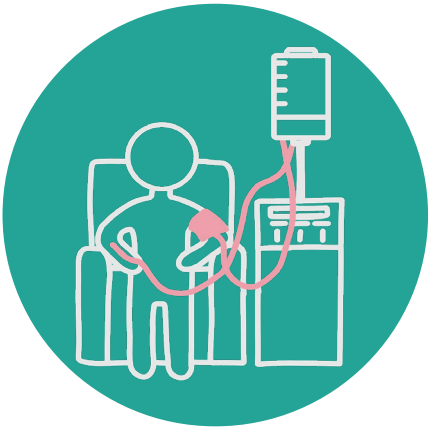
To have stem cells collected from your bloodstream:

- You have injections of medicines called growth factors every day for around 5 days. This boosts the number of stem cells you make. This also encourages the stem cells to move from your bone marrow into your bloodstream. If you're having a stem cell transplant using your own cells, you might also have chemotherapy. This is not the case when stem cells are collected from a donor.

"I had my stem cells harvested over 2 days, 6 hours spent on the machine each day, unable to move my arm or use the loo! Eventually, after a special injection to get my stem cells overproducing, enough were harvested for the transplant to take place and they were put on ice."

Kate, who had an autologous stem cell transplant for APL in 2017

- The stem cells are collected using a cell separator machine. This usually takes 4 to 6 hours.
  - The machine takes blood out of one of your arms (or from a connector on your central line).
  - The blood passes through the machine, which removes the stem cells.
  - The rest of your blood then goes back into your other arm (or into another connector on your central line).



- The stem cells can be used within 3 days, or frozen and stored to be used at a later date.
- Sometimes, there may not be enough stem cells from the first collection and you'll need to go through the process again.

Conditioning therapy

Conditioning therapy is the treatment you have to get your body ready for the stem cells. It has three main aims:

- It helps get rid of any cancer cells that are left in your body
- It makes space in your bone marrow for the new stem cells
- In the case of a donor transplant, it aims to kill immune cells that could reject the donor cells

It usually involves chemotherapy, radiotherapy to your whole body, or both. Some people might also have a targeted medicine or antibody therapy. Your transplant team will tell you what they recommend for you. This will depend on things like:

- The type of blood cancer you have
- The genetic changes in your cancer cells
- The level of cancer cells in your body
- How you've responded to treatment
- Your age and general fitness
- Any other conditions you have

"I got progressively sicker as the days went on. My hair, which was now about two inches long and had been dyed pink, started to fall out again. I thought chemo would be easier second time around but in fact it was harder. I had received more high dose chemo and began to puff up. Once again, I was on numerous tablets and IVs. Then the day of transplant came!"

Kate, who had an autologous stem cell transplant for APL in 2017

Most people need to stay in hospital to have conditioning therapy. Some hospitals might offer treatment as an outpatient, under close supervision. You usually have it over several days. You'll also have treatment to help with side effects (page 38).

More about conditioning therapy

There are two main approaches to conditioning therapy:

- **High-dose conditioning** aims to kill all the cells in your bone marrow. This is called myeloablative conditioning. It is very intensive.
- **Lower-dose conditioning** reduces the cells in your bone marrow but does not completely destroy it. This is called reduced-intensity conditioning. It aims to lower your immune system enough to accept the donor stem cells, but it does not kill all the cancer cells in your body. The idea is that your new immune system will do that instead. Your team might suggest reduced-intensity conditioning if you're not fit enough to cope with high-dose conditioning.

Macmillan have more information about particular chemotherapy combinations, including those you might have as conditioning therapy. Scan the QR code, click the link or visit www.macmillan.org.uk and either search for your treatment or choose the 'Treatment and drugs A to Z'.

Having the stem cells

You have the stem cells once you've finished your conditioning therapy. The day you have them is sometimes called day zero.

"The transplant was very calm. Two nurses had to be with me for 3 hours, watching it go in in case of reactions. It was so lovely to just sit and chat, hearing about their families and their lives."

Lisa, who had a stem cell transplant for AML in 2016

- You have paracetamol and antihistamines first to reduce the chance of having a reaction to the cells.
- A nurse checks your blood pressure, heart rate and temperature. They also put a small probe on your finger to check your oxygen levels.
- If the stem cells have been frozen, the nurse defrosts them in a water bath.
- Then you have the stem cells through your central line. You might need more than one bag of them.
    - It can take from 10 minutes to a few hours to have the stem cells. It depends on how many bags you need and whether they are fresh or frozen.
    - A nurse stays with you the whole time. They check your pulse, blood pressure and temperature every 15 minutes.
    - If the stem cells have been frozen, you might notice a strange smell and get an odd taste in your mouth when you have them. This is from the preservatives used to store the stem cells.
- After you've had the stem cells, the nurse monitors you every 30 minutes for the next few hours.

Tell your nurse if you feel unwell or if you think you might be having a reaction to the stem cells. Signs include:

- Feeling sick
- A rash or flushed skin
- Feeling short of breath
- Tightness in your chest
- Chills or shivers

"My stem cells were warmed up out of their deep freeze and fed back into me through my Hickman line. At this point my bone marrow had been obliterated by the radiotherapy and chemo and this was the starting point, the reset button so to say. An exciting time! It took 2 days in total and the stem cells had a distinctive aroma and taste of sweetcorn. I can't touch the stuff since!"

Kate, who had an autologous stem cell transplant for APL in 2017

You might feel a range of emotions when you have your stem cells. Some people say it feels like an anticlimax after all the preparation.

"I was given strong antihistamines so was very drowsy during the process and slept for a while after. The nurses did lots of checks and then simply inserted the stem cells through my PICC line, simple as that, no fireworks, no special feeling, just easy peasy."

Vaughn, who had a stem cell transplant for ALL in 2018

Waiting for your bone marrow to recover

"I'd set an alarm, have a shower and slowly get dressed. That'd take about 2 hours and then I'd always put some mascara and lippy on, ready for the day. I always wore my own clothes (albeit trackies) and loved popping down to the laundry room every few days to do my washing. It was far from a normal life, but gave me that little bit of purpose."

Lisa, who had a stem cell transplant for AML in 2016

It takes a few weeks for your new stem cells to settle in and start to work. During this time, your transplant team monitor you closely. They will give you treatments to support your recovery and help with side effects (page 38).

"One thing I have learnt during this period of recovery is that you need to be kind to yourself – in all ways! If you are feeling tired or weak, accept it and know when you need to rest. If you feel like having a big cry, then have a big cry! If you feel you need to speak to someone, reach out to people."

Sarah L, who had a stem cell transplant for AML in 2017

Low blood counts

Before your new stem cells start to work, your body will not be able to make enough blood cells. Your blood counts might get very low. You'll have frequent blood tests to check this.

- If your red blood cell count is low, you may feel tired and breathless. You might get a fast or uneven heart rate. You will have transfusions to top up your red blood cells.
- If your platelet count is low, you might bleed or bruise easily. You will have transfusions to top up your platelets.
- If your white blood cell count is low, you have a high risk of getting an infection, which could be very serious. White blood cells don't survive long outside the body, so you can't have a transfusion to top up your white blood cells. But there are things you, your transplant team and your visitors can do to keep your risk of getting an infection as low as possible.

"I was placed in isolation and rapidly went downhill. My mouth was agony with mucositis and I was being sick. I couldn't eat and ended up on a morphine driver for the pain. I felt very low and wondered if I would ever recover again. Maybe this was all too much? The wonderful staff got me through and after 2 weeks I was sent home."

Kate, who had an autologous stem cell transplant for APL in 2017

Reducing your risk of infection

- You might have antiviral, antibiotic or antifungal medicines to prevent infections.
- You'll probably stay in a room on your own. This should be cleaned, and the bedding changed, every day.
- Try to wash yourself and brush your teeth regularly, even if your mouth is sore. Use alcohol-free antibacterial mouthwash.
- Your transplant team will monitor you for signs of infection, and treat you promptly if you get one.
- They'll keep your central line clean.
- Anyone entering your room should wash their hands thoroughly.
- They might need to wear a mask, apron and gloves if your white blood cell count is very low.
- Anyone preparing food for you should follow standard food safety guidance. Your transplant team might recommend avoiding foods that may cause food poisoning while your white blood cell count is very low.
- Visitors should stay away if they are unwell.
- **Tell your transplant team straight away if you feel unwell, especially if you have chills or feel feverish.**

"Isolation is incredibly difficult when you are a sociable person and I felt that I was slipping away from who I really was. No hair, no control, no energy, no family or friends around me. I bravely stepped into the world of Instagram setting up a new account to separate the old me and the cancer me."

Charlotte, who had a stem cell transplant for AML in 2022

Coping with isolation

Being alone for a lot of the time can be difficult, especially when you're feeling unwell. Some people find these things helpful:

- If you have one, take a phone or tablet so you can speak to friends or family even if they can't visit. You could also download films, TV programmes or games.
- Take things to help pass the time, like magazines, puzzles or crafts. Include things that don't need much energy, like music, podcasts or audiobooks.
- Have cards or photos to remind you that family and friends are thinking of you.
- If your hospital allows it, take some home comforts. Some hospitals let you take your own bedding – but you must have someone who can wash it daily.
- It is common to feel anxious, scared or upset. Tell your transplant team if you are struggling. They may suggest things to help, or refer you to a counsellor.

"It was like being locked down – except worse because you were restricted to only one room and it lasted for 7 long weeks. I was in hospital for all this time as my whole immune system was totally wiped."

Beth, who had a stem cell transplant for AML in 2015

Anthony Nolan have information about coping with isolation. Scan the QR code, click the link or search 'isolation' at www.anthonynolan.org

Checking the stem cells are working

Your blood counts are a good indication of how well your new stem cells are working. As they settle into your bone marrow and start to make new blood cells, your blood counts should start to rise. This usually takes a few weeks.

> **"I was in hospital for 3 weeks, and as soon as my white blood cell count was high enough, I was allowed home. I was still neutropenic and had to be careful with what foods to avoid. Plus, a list of things to be careful with and rules to follow."**
>
> Tracy, who had a stem cell transplant for AML in 2018

Some people get a temperature, rash, diarrhoea and water retention when the stem cells settle into the bone marrow. This is called engraftment syndrome. You might need steroids to treat it.

If you've had stem cells from a donor, your transplant team also monitor how many of your blood cells are from the donor stem cells and how many are from your own. This is another sign of how well the stem cell transplant is working.

> **"I was discharged 17 days after my transplant as my blood counts were looking good and I had engrafted, meaning the transplant had seemingly worked, triggering my bone marrow to start producing new blood cells. I was sent to a flat close to the hospital and away from my children, who could potentially pass bugs to me. My parents were with me to support me as my wife had to split her time between being with me, working and looking after the children."**
>
> Vaughn, who had a stem cell transplant for ALL in 2018

Side effects and complications of a stem cell transplant

Summary

- Conditioning therapy can cause unpleasant or serious side effects. Your transplant team will monitor you for these.
- **Let your transplant team know straight away if you have any side effects so they can start treatment promptly.**
- If you have a stem cell transplant using donor cells, you might get a complication called graft versus host disease, or GvHD. It can cause many different symptoms.
    - It happens when your new immune system mistakenly attacks healthy cells. You have medicines to try to prevent it, but it can still happen.
    - Your transplant team will monitor you for signs of GvHD. If it develops, you might need steroids, medicines to lower your immune system, or other treatments.
- Rarely, donor stem cells do not start making new blood cells. If this happens, your transplant team will explain your options.
- Stem cell transplants can also lead to other health problems months or years later. Your transplant team will tell you what to look out for.

Side effects of conditioning therapy

Conditioning therapy kills cells that are dividing quickly. As well as cancer cells, it affects other fast-growing cells in your body, like:

- Blood cells (page 34)
- Cells lining your mouth and gut, bladder, airways or blood vessels
- Hair root cells

This causes side effects. Some of these can be serious. Your transplant team will monitor you closely so they can treat side effects promptly.

"I had terrible mucositis (painful inflammation and ulceration of the lining of the gut) which left me unable to speak or swallow. I lost my fingernails as well as my hair. However, as bad it was at the time, I look back now and feel so lucky. All the staff were absolutely amazing and really gave me the best possible treatment. I never doubted that I was in great hands."

Sarah H, who had a stem cell transplant for AML in 2018

Your transplant team will regularly check:

- Your pulse, blood pressure and temperature
- Your breathing rate and oxygen levels using a probe on your finger
- Your weight
- How much you are drinking (or having through a drip)
- How much you are peeing (or how much pee is in your catheter bag)
- Your skin for any rashes
- Your poo for signs of infection or diarrhoea

"The first week was tough with side effects from the chemotherapy and hair loss again! But by day eight, I turned a corner and was discharged within 2 weeks of the transplant day."

Charlotte, who had a stem cell transplant for AML in 2022

Mouth problems

It's common for the lining of your mouth and throat to get very sore and develop ulcers. This can be very painful. It can make it difficult to swallow and talk.

Your transplant team will give you mouthwashes, rinses and gels to help. You may need strong pain relief. If it's difficult to eat, you might need liquid foods for a while, sometimes through a feeding tube.

Drinking plenty, gargling with salt water and using lip balm or lip salve can help. It's also important to brush your teeth, including between your teeth, regularly if you can. This reduces the risk of a mouth infection.

"In the following weeks, I had several bad side effects from both the radiotherapy and the transplant itself. I had severe mucositis, stopping me being able to eat, so I was tube fed through my nose for several days. I was incredibly tired and had no energy or strength to do anything."

Vaughn, who had a stem cell transplant for ALL in 2018

Gut problems

Conditioning therapy can cause side effects like:

- Feeling or being sick
- Diarrhoea
- Changes in taste or appetite
- Tummy pain

Your transplant team will give you medicines to prevent and treat sickness and diarrhoea, but they can still happen. You might need a drip to replace the fluid you're losing.

Sickness and diarrhoea can be horrible, but they usually start to get better after a few weeks.

> **"I had some tricky days, but nothing they didn't immediately sort for me, and oh the love I felt for anti-sickness drugs!"**
>
> Lisa, who had a stem cell transplant for AML in 2016

You probably won't feel like eating much. You might find it easier to eat small meals or snacks throughout the day rather than a few larger meals. Your transplant team might suggest supplements to make sure you're getting the nutrients you need.

Tell your transplant team if you are feeling sick. Anti-sickness treatment works better the earlier you start it.

Hair loss

Many conditioning therapies cause hair loss. This can affect the hair on your head, face and anywhere on your body. Hair is often an important part of a person's identity, and losing it can be upsetting.

Hair loss happens gradually after conditioning therapy. Some people prefer to shave their hair or cut it short. This can give you a feeling of control, and reduce the emotional impact of it falling out.

You could also cover your hair loss, if you choose to. There are lots of options, like hats, headscarves, wraps, turbans or wigs.

Hair loss is usually temporary. It typically starts to grow back within a few weeks or months. It might be a different colour or texture when it grows back.

"I lost my hair through chemotherapy, but it really didn't bother me because I knew it would grow back, and when it did it was darker and really curly!"

Georgina, who had a stem cell transplant for ALL in 2018

Cancer Hair Care offer advice and support on all aspects of hair loss and hair care before, during and after cancer treatment. Scan the QR code, click the link or visit www.cancerhaircare.co.uk

Bladder problems

Conditioning therapy can make your bladder inflamed and irritated. You might have symptoms like:

- Peeing more often than usual during the day or at night
- Stinging or burning when you pee
- Blood in your pee
- Tummy pain

If this happens, your transplant team will give you treatment. You may need pain relief or extra fluid through a drip. If there are blood clots in your pee, they might put in a catheter to rinse out your bladder.

Liver problems

Conditioning therapy can damage the cells lining blood vessels in your liver. Your transplant team will do regular blood tests to check how well your liver is working. They'll also examine your tummy to check for swelling and monitor your weight closely.

This will help them spot liver problems early so they can treat them promptly.

Lung problems

Conditioning therapy can cause inflammation in your airways. You might get symptoms like a cough, breathlessness or rapid breathing. Your transplant team will monitor you for signs of lung problems. If you get them, you may need steroids, or oxygen through a facemask. You might have physiotherapy to improve your lung function.

Possible complications of a stem cell transplant using donor cells

This section is relevant if you are having a stem cell transplant using donor cells. It does not apply to you if you're having a stem cell transplant using your own cells.

If you have a stem cell transplant using donor cells, some other complications can happen.

Graft versus host disease

Donor stem cells give you a new immune system. The new immune cells can help recognise and attack any cancer cells left in your body. But they might also attack your healthy cells. This is called graft versus host disease, or GvHD.

You have medicines to lower your immune system to try to prevent GvHD. It can be a difficult balance. The aim is to stop the immune cells attacking your healthy cells, but keep them active against the cancer cells.

Anthony Nolan have online and printed information about graft versus host disease. Scan the QR code, click the link or search 'graft versus host' at www.anthonynolan.org

Acute GvHD

Acute GvHD happens within around 3 months of your transplant. It can cause:

- A rash, a bit like sunburn
- Tummy pain
- Feeling sick or being sick
- Diarrhoea
- Liver problems, which show up on blood tests

If it happens, you'll have steroids or other medicines to help treat it.

> **"GvHD was horrendous. It attacked my skin, gut, bowel and chest. I was put on a large dose of steroids and these eased the symptoms. Unfortunately, when the dose was gradually reduced, the symptoms returned. I felt that ill that I was convinced the transplant hadn't worked. Then one day the nurse walked in with a smile on her face and told me my blood test had shown a 'tremor'. There was an improvement in my blood counts."**
>
> Terence, who had a stem cell transplant for AML in 2017

Chronic GvHD

Chronic GvHD usually starts between 3 months and 2 years after your transplant but it can happen earlier. It can cause many different symptoms affecting your:

- Skin
- Eyes
- Mouth
- Gut
- Liver
- Other parts of your body, such as your lungs, muscles or genitals

"Although I'm suffering with chronic GvHD in the eyes, mouth, skin and gynaecological system, I'm under treatment for that and I'm doing really well. Things are different: my appearance has changed, I'm more tired these days, I'm also now post-menopause and having to take HRT."

Sarah H, who had a stem cell transplant for AML in 2018

Your transplant team will monitor you for signs of chronic GvHD. If it develops, you might need steroids, medicines to lower your immune system, or other treatments.

"I developed GvHD, showing bowel and gut problems. I was admitted and ended up being on the ward for a month. I was put on prednisone steroid tablets."

Tracy, who had a stem cell transplant for AML in 2018

Graft failure

Rarely, the donor stem cells do not settle into your bone marrow or start making new blood cells. There is a higher chance of this happening if the donor stem cells are not well matched with yours.

If this happens, you might have medicines called growth factors to encourage the stem cells to start making blood cells. If this does not work, your transplant team will talk to you about your options. They might suggest:

- A dose of white blood cells from your donor, called a donor lymphocyte infusion
- Another dose of stem cells
- A second stem cell transplant
- Medicines to control your symptoms and improve your quality of life

"I got the devastating news that the transplant had failed, I had lost the graft. My only option was to have another stem cell transplant, and urgently, otherwise the leukaemia would come back. I was so lucky that I had another unrelated donor on the register!"

Kelly, who had a stem cell transplant for ALL in 2018

Anthony Nolan have more information about graft failure. Scan the QR code, click the link or search 'graft failure' at www.anthonynolan.org

Possible long-term complications of a stem cell transplant

Having a stem cell transplant can help treat leukaemia, MDS and MPNs. But it can also lead to other health problems months or years later. You'll have follow-up appointments to check for these. They include:

- Your leukaemia, MDS or MPN coming back
- Getting a different cancer
- Hormone changes
- Early menopause
- Eye problems
- Damage to other organs in your body
- Emotional or mental health problems

Your transplant team will tell you what symptoms to look out for and what to do if you notice them.

To reduce the risk of problems, and spot them early if they do happen, it's important to:

- Attend your follow-up appointments
- Go to any screening tests you're invited to

"There have been a lot of times where I have felt frustrated with my post-transplant body. I remember hearing the phrase 'new normal' a lot when I had my transplant, and boy is this true! It basically means that you shouldn't be waiting for things to go back to 'normal' because that is probably not going to happen. But just because I have had to adapt to my 'new normal', it doesn't necessarily mean it's a bad thing – it is just an adjustment."

Sarah L, who had a stem cell transplant for AML in 2017

Anthony Nolan have more information about possible long-term effects of a stem cell transplant. Scan the QR code, click the link or search 'late effects' at www.anthonynolan.org

After a stem cell transplant

Summary

- Going home after a stem cell transplant can be worrying, but your transplant team are still there to support you.
- You'll have lots of medicines to take at home. You'll probably still need blood transfusions too.
- **Contact your transplant team straight away if you have any signs of infection.**
    - You should try to take precautions to reduce your risk of infections.
    - However careful you are, you are likely to get some infections and you may need to go back into hospital for a time for treatment.
- Try not to expect too much of yourself at first. Build up your activity levels slowly and rest when you need to.
- You'll have regular follow-up appointments and blood tests. These check how you're getting on, look for signs of any complications and check if your cancer is still under control.
- Having a stem cell transplant means you lose your protection against illnesses you were vaccinated against in the past. When your immune system has recovered, you should be invited to have all your vaccinations again.

Going home

When your white blood cell count is high enough and you're starting to feel better, your transplant team will talk to you about going home.

Going home after a stem cell transplant can be worrying. Remember that your transplant team are still there for you. They will tell you how to contact them for advice or support.

> **"I left the hospital 6 weeks later. I was scared as I felt so safe there, with a buzzer to press and a tiny room that required little energy."**
>
> Lisa, who had a stem cell transplant for AML in 2016

You'll have lots of medicines to take at home. You'll probably still need blood transfusions too, so you may keep your central line in for a while longer.

> **"I couldn't even walk up the stairs without help and a shower took all of my energy for the day. I would have to go back to bed after having a shower! Slowly but surely, I built up my strength."**
>
> Kate, who had an autologous stem cell transplant for APL in 2017

Your risk of getting an infection will still be high so it's important to keep this as low as possible by:

- Checking your temperature every day
- Showering every day if you can
- Washing your hands often
- Brushing your teeth regularly
- Keeping your home clean
- Following food safety guidelines for preparing and storing food
- Staying away from people who are unwell
- Avoiding crowded places
- Wearing gloves for gardening or cleaning up after pets (or asking someone else to do it for you)

Contact your transplant team straight away if you have any signs of infection.

However careful you are, it's likely you will get infections during your recovery. Most people need to go back into hospital for a time to have treatment for an infection. Your transplant team will tell you what signs to look out for and how to contact them.

"Forty-eight hours later I was in hospital again with suspected sepsis. This continued for some months, with me in and out of hospital for different reasons."

Terence, who had a stem cell transplant for AML in 2017

Once you're at home, you'll probably feel very tired at first. It will take time for your energy levels to improve. Try not to expect too much of yourself. Build up your activity levels slowly and rest when you need to. You're likely to have good days and bad days. It could take many months before you feel more like yourself again.

"I've been struggling with health anxiety. Thankfully, counselling is helping me cope because I know I can't keep feeling this way forever. It's been a few years, but I'm starting to make progress towards feeling better."

Gemma, who had a stem cell transplant for MDS in 2018

We're here for you if you need support. Contact us to find out how we can help you.

- Freephone Helpline **08088 010 444**
- WhatsApp **07500 068065**
- Email **support@leukaemiacare.org.uk**

Anthony Nolan also have loads of **resources to help during your recovery** including:

- A **transplant tracker app** to help you manage your recovery
- A **book on long-term recovery** to download or order in print free of charge

Scan the QR code, click the links or search 'recovering' at **www.anthonynolan.org**

If you work or study, you could start planning to go back once your white blood cell count has recovered and you're feeling well enough. It's a good idea to have a phased return, and gradually increase the hours you do.

You are legally entitled to reasonable adjustments at work, college or university to help you cope with going back. Talk to your employer or education provider about how they can support you.

"It's true that the stem cell transplant saved my life but it didn't give me my life back. It's given me a different life."

Terence, who had a stem cell transplant for AML in 2017

Anthony Nolan have online and printed information about going back to work. Scan the QR code, click the link or search 'returning to work' at www.anthonynolan.org

Follow-up appointments

You'll have regular check-ups after your stem cell transplant. These happen every week at first and gradually get less frequent.

You'll probably have follow-up appointments for the rest of your life. These might be at your local hospital or your transplant centre.

Your healthcare team will ask you about:

- Any symptoms or side effects you have
- How you're getting on with the medicines you take at home
- How you're coping emotionally
- Your energy and activity levels
- Any support you need

They will also check for any signs of complications or that your cancer might have come back.

"The battle for me has certainly been mental as well as physical. But I don't struggle too much on a daily basis."

Beth, who had a stem cell transplant for AML in 2015

You'll have blood tests to check things like:

- Your blood counts
- How well your liver, kidneys and thyroid are working
- Your antibody or immunity levels
- Your levels of vitamins and minerals
- Your levels of some hormones

You might have other tests or scans, depending on the type of blood cancer you have, your symptoms and any side effects you have.

It's important to attend your follow-up appointments so any complications can be diagnosed and treated as early as possible. If you're worried about any symptoms or side effects, contact your medical team – you don't have to wait for your next appointment.

"Even though a lot of people assume that I am through the 'worst' of it, in many ways life post-treatment is more difficult than during. I am suffering from multiple side effects (peripheral neuropathy, osteoporosis, early menopause, joint pain, extreme fatigue) and the loss of confidence that comes from losing so much of your old self."

Bansri, who had stem cell transplants for ALL in 2021 and 2023

Revaccination

Having a stem cell transplant destroys your immune system. This means you lose your protection against illnesses you were vaccinated against in the past.

When your immune system has recovered, you should be invited to have all your vaccinations again. This will usually be at your GP practice.

> **"I began to get all my new 'baby' jabs which I had been able to have after being 2 years post-transplant. These have all been fine; I have had hardly any reactions and it's been quite nice to know I am protected against these more serious illnesses. I also have my flu jab every year."**
>
> Sarah L, who had a stem cell transplant for AML in 2017

Live and non-live vaccines

Some vaccines use weakened versions of live bacteria to train your immune system to react to them. These are called live vaccines.

- Live vaccines may cause infections in people with low immune systems. You should not have live vaccines for at least 2 years after having a stem cell transplant.
- It is safe to have non-live vaccines.

Words you might hear

Acute lymphoblastic leukaemia (ALL): a fast-growing type of blood cancer that affects blood cells called lymphoblasts.

Acute myeloid leukaemia (AML): a fast-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Acute promyelocytic leukaemia (APL): a rare sub-type of acute myeloid leukaemia.

Allogeneic: using cells from a donor.

Anaemia: a low red blood cell count.

Anaesthetic: a medicine to numb part of your body (local anaesthetic) or send you to sleep (general anaesthetic) so you don't feel any pain during medical procedures.

Antibody therapy: a lab-made antibody that sticks to targets on cancer cells, so your immune system can kill the cells.

Antibody: an immune system protein that helps fight infections by sticking to targets on the surface of cells that don't belong in your body.

Autologous: using cells from your own body.

Bone marrow test: a test to take a sample of the spongy tissue from the centre of a bone, usually your hip bone.

Bone marrow: the spongy centre of some of your larger bones where blood cells are made.

Central line: a long, thin plastic tube used to give you medicines into your veins or take blood tests. It enters the skin in your arm or your chest and ends in a large vein near your heart.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Chronic lymphocytic leukaemia (CLL): a slow-growing type of blood cancer that affects blood cells called lymphocytes.

Chronic myeloid leukaemia (CML): a slow-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Chronic myelomonocytic leukaemia (CMML): a rare type of blood cancer that affects blood cells called monocytes.

Conditioning therapy: the treatment you have to get your body ready for a stem cell transplant.

Cytomegalovirus (CMV): a common virus that is usually harmless. It can reactivate or cause problems after a stem cell transplant.

Donor lymphocyte infusion: a dose of white blood cells from your stem cell donor that you have through a drip into a vein.

Embryo: an unborn baby at an early stage of development.

Engraftment syndrome: symptoms that sometimes happen when stem cells settle into the bone marrow after a stem cell transplant.

Graft failure: when the donor stem cells do not settle into your bone marrow or start making new blood cells.

Graft versus host disease (GvHD): when immune cells that grow from your donor stem cells mistakenly attack your healthy cells.

Growth factor: a type of medicine that encourages your stem cells to make blood cells.

Haematologist: a doctor who specialises in diseases of the blood.

Hickman line: a type of central line that enters the skin in your chest and goes into a large vein near your heart.

Hormone: a natural chemical that carries messages around your bloodstream to control many of your body's functions.

Human leucocyte antigen (HLA): protein markers on the surface of cells that your immune system uses to work out what is 'you' and what is not.

Immune system: the cells and systems in your body that protect you from infection.

Lymphoma: a type of cancer that affects blood cells called lymphocytes in your lymphatic system.

Matched unrelated donor (MUD): a stem cell donor who is not related to you but has a matching tissue type.

Mucositis: inflammation of the cells lining your mouth and gut.

Myelodysplastic syndromes (MDS): a type of cancer where your bone marrow produces immature, abnormal blood cells that do not work properly.

Myelodysplastic-myeloproliferative neoplasm (MDS/MPN): blood cancers that have features of both a myelodysplastic syndrome (MDS) and a myeloproliferative neoplasm (MPN).

Myelofibrosis (MF): a type of cancer where your bone marrow becomes filled with scar tissue, which stops it making enough healthy blood cells.

Myeloma: a type of cancer that develops from white blood cells in your bone marrow called plasma cells.

Myeloproliferative neoplasms (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Neutrophilia: a high level of white blood cells called neutrophils.

PICC line: a type of central line that enters the skin in your upper arm and goes into a large vein near your heart.

Platelet: a type of blood cell that helps your blood clot and stops bleeding.

Radiotherapy: treatment that uses high doses of radiation to kill cancer cells.

Stem cell transplant: treatment that replaces damaged or abnormal blood-forming cells in your bone marrow with healthy ones.

Stem cells: immature cells in your bone marrow that can develop into all the different blood cells your body needs.

Targeted treatment: medicine designed to block specific proteins on cancer cells.

Total body irradiation (TBI): radiotherapy to your whole body. You might have it as part of conditioning therapy.

Total parenteral nutrition (TPN): having food through a drip into a vein (or your central line).

Transfusion: having blood or blood cells through a drip into a vein (or your central line).

Veno-occlusive disease (VOD): blockage of the small blood vessels in your liver. It can sometimes happen after a stem cell transplant.

White blood cells: cells in your blood that help your body fight infections.

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

Helpline: 08088 010 444 (Monday to Friday, 9am to 4:30pm)

WhatsApp: 07500 068065 (Monday to Friday, 9am to 5pm)

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Anthony Nolan

Provide free information, emotional and financial support for people having a stem cell transplant.

0303 303 0303

www.anthonynolan.org

Blood Cancer UK

Provide free information and support for people affected by blood cancer.

0808 2080 888

www.bloodcancer.org.uk

Macmillan

Provide free practical, medical and financial support for people facing cancer.

0808 808 00 00

www.macmillan.org.uk

Maggie's

Offer free practical, emotional and social support to people with cancer and their loved ones.

0300 123 1801

www.maggies.org

How you can help us

If you've had a stem cell transplant, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications team at communications@leukaemiacare.org.uk.

Tell us what you think of this booklet

We aim to provide information that's reliable, up-to-date, and covers what matters to you. We want you to feel supported and able to be involved in decisions about your care. Please follow the link or scan the QR code to complete our short survey to help us improve our information and make sure it meets your needs. Or get in touch with us by email, phone or post.

You can also contact us if you'd like a list of the references we used to compile this booklet.

- Email our Information team at information@leukaemiacare.org.uk
- Call our Head Office on **01905 755 977**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG
- Leave us a review if you've ordered a booklet online

If we've helped you - here's how you can give back

Fundraising is at the core of what we do here at Leukaemia Care, and without it we wouldn't be able to provide the support we do.

Fundraising isn't all about running a marathon, and there are plenty of ways to give thanks and show your support.

You could:

- Ask your local shop or workplace to host a collection tin
- Ask your place of work about charity of the year partnerships or grants
- Take on one of our more accessible walking challenges
- Host a quiz night or get your friends together for a catch-up and a meal
- Host a bake sale at work or school, or even a coffee morning with friends
- Share information about the activities we have going on to get friends and family joining in
- Stream online from the comfort of your own home

However, if you can run a marathon or want to do a thrilling skydive, we've got you covered!

Whatever you want to do, we can support you to raise money for Leukaemia Care. Get in touch with the fundraising team by email fundraising@leukaemiacare.org.uk or calling **08088 010 444**.

You can also find out more about how to get involved by scanning the QR code.

Plenty of ways to give

There are so many ways you can give in support of those affected by a leukaemia diagnosis, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer your donation straight from your account to ours. Our bank details are:

Sort code: **20-98-61**

Account number: **80823805**

Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us to pay by debit or credit card over the phone. Simply call **01905 755977**.

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

WhatsApp: **07500 068065**

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum

Version 1
Reviewed: 12/2024
Next review: 12/2027