

Blood stem cell and bone marrow transplants: The seven steps



Blood
cancer
UK

About this booklet

Blood Cancer UK has produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. This booklet was written by Clinical Nurse Specialist Michelle Kenyon and published with help and support from Blood Cancer UK. Thank you to Dr Kavita Raj for checking the content of this booklet.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 199.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

A list of references used in this booklet is available on request. Please email us at **information@bloodcancer.org.uk**

Michelle Kenyon would like to thank the following people for their help, advice, support and encouragement: Professor GJ Mufti, Professor A Pagliuca, Professor S Devereux, Nikki McKeag, RCN Haematology and Bone Marrow Transplant Nursing Forum, Sandra Gerscher and Dr David Grant.

Disclaimer

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this booklet is correct at the time it was printed (June 2017).

Date of next review: June 2020

Blood Cancer UK, 39–40 Eagle Street, London WC1R 4TH

020 7504 2200 **hello@bloodcancer.org.uk** **bloodcancer.org.uk**

© All rights reserved. No part of this publication can be reproduced or transmitted without permission in writing from Blood Cancer UK.
Registered charity 216032 (England & Wales) SC037529 (Scotland)

Contents

2	Introduction
4	About bone marrow, blood and blood cells
11	About stem cell and bone marrow transplants
21	Tests and investigations
31	Step one: Planning ahead
45	Step two: Preparing for your transplant
65	Step three: Conditioning therapy
77	Step four: The transplant
83	Step five: Waiting for engraftment
111	Step six: Recovery after engraftment
133	Step seven: Long-term recovery
141	Appendix A: Stem cell donation and harvesting
155	Appendix B: Early menopause
163	Appendix C: Total body irradiation (TBI)
169	Appendix D: Clinical trials
172	Appendix E: Glossary
196	Our health information
199	About us
209	My details

Introduction

This is a booklet for people who are going to have a stem cell transplant, and for people who know someone who is going to have a stem cell transplant.

Within this booklet, the transplant process is described as a series of steps. You might want to read the booklet one step at a time, or read it right the way through. You may want your family to read it too, so they can learn a little more about your transplant.

If you prefer, you can think of these as steps towards your recovery, or as stepping stones to help you keep moving and looking forward. Each step has its own important place, and prepares you for the next one.

You may have been considering or discussing a transplant with your doctor, and so you may already have some idea about what is involved. If you have just begun to think about a transplant as an option, but have not yet had the chance to ask questions, you should find these next few chapters helpful.

This booklet was written to provide information about the typical experience of someone receiving a stem cell transplant, but it's important to understand that details of procedures may vary from hospital to hospital and between people.

You should always rely on the advice of your specialist doctors and nurses, who are the only people with full information about your diagnosis and medical history. If you have any questions at all, do ask your hospital team.



When you get this booklet, you may already be well on the way to completing your first step, which is explained in **Step one: Planning ahead.**

You'll see lots of medical terms used throughout this booklet; for full definitions, please turn to **Appendix E: Glossary.**

About bone marrow, blood and blood cells

In order for you to understand the seven steps of your transplant, it might be helpful to have some background information about bone marrow, blood and blood cells.

All cells in our body start out as stem cells. The different types of blood cell in our bloodstream develop from special blood stem cells, which are produced in our bone marrow. This is a tissue found at the centre of our bones – for example, at the back of our hips (the iliac crests).

This area is very rich in bone marrow and so is used for getting bone marrow for tests or for collecting (harvesting) stem cells. Your bone marrow needs

to continually produce blood cells for you to stay healthy. This is because, like all cells, blood cells have a limited lifespan.

There are three different types of blood cell, each performing its own special function.

White blood cells

There are several different types of white blood cell, including the following.

- lymphocytes – which include T cells that control the body's ability to resist disease (immunity), kill viruses and cancer cells, and B cells, which make infection-fighting proteins (antibodies)
- neutrophils – which fight infection, kill germs (bacteria) and remove damaged tissue
- monocytes/macrophages – which work with lymphocytes to fight infection.

Red blood cells

Red blood cells contain haemoglobin, which is the red pigment used to carry oxygen to all parts of your body.

Platelets

Platelets help to prevent or stop bleeding or bruising.

Blood cell production

The type of blood condition or the treatment you have may affect your normal blood cell production, and without this, you're more likely to pick up infections, feel tired and develop bruises. Specific terms are used to describe low numbers of the three groups of cells listed on page 5. You will hear these terms mentioned often:

- neutropenia – low neutrophil count
- anaemia – low haemoglobin level
- thrombocytopenia – low platelet count.

Your healthcare team will tell you about treatments that can lessen the impact of these conditions. Red blood cell transfusions are given to reduce the symptoms of anaemia (such as tiredness, shortness of breath and pale skin) and platelet transfusions are given for thrombocytopenia (which can make you bruise and bleed more easily), for example.

So far, white blood cell transfusions are not available, since white blood cells have a very short lifespan once they leave the bone marrow.

A low white blood count can make you more prone to infections, so if you do have a low white cell count or you're neutropenic, you may be given antibiotics to prevent or treat infections. You may also be given growth factors. These are naturally occurring hormones that can increase the number

of white cells in your blood. Growth factors can either be given through a vein or as an injection under your skin. This treatment can make infections less severe or speed up your recovery time.

Your healthcare team will check the number of different types of blood cells in your bloodstream regularly by taking blood samples/tests and counting the different types of cell.

You might hear the number of cells in a blood sample called a blood level, blood count or value.


Each of your test results will come with a range of 'normal' values next to it, so your healthcare team can check to see whether your results are higher or lower than they should be. The normal blood values in healthy people are shown in the table overleaf.



Take a look at **Step five: Waiting for engraftment** for information about supportive treatments.

Blood cell or substance	Levels found in a healthy person
Haemoglobin (Hb) level (for red blood cells)	130-180 g/l (men) 115-165 g/l (women)
Platelets	150-400 x 10 ⁹ /l
White blood cells (WBC)	4.0-11.0 x 10 ⁹ /l
Neutrophils	2.0-7.5 x 10 ⁹ /l
Lymphocytes	1.5-4.5 x 10 ⁹ /l

Your blood values depend on a number of different things, including sex, age, and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. So this table should only be used as a rough guide. Your healthcare team can explain what your results mean for you.



**Stick to trustworthy
information from cancer
charities or the NHS.
Your healthcare team
will tell you the best
place to find it.**

**A stem cell transplant
allows you to have higher
doses of treatment, which
have a better chance of
killing cancer cells.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

About stem cell and bone marrow transplants

Stem cell transplant (SCT) is the term now most commonly used by healthcare professionals rather than bone marrow transplant (BMT).

In the 1970s, SCT was still an experimental treatment. There have been major developments since, and now a transplant has become the treatment of choice for a wide range of blood cancers and blood disorders, with other disorders and cancers responding well to high doses of chemotherapy and/or radiotherapy, which are treatments used to kill cancer cells.

What happens when you have a stem cell transplant?

When you have a transplant, you'll receive high doses of chemotherapy and/or radiotherapy beforehand. This strong (high-intensity) treatment is called a 'conditioning therapy'. It can destroy your cancer cells or change the way your condition behaves, but the treatment will also damage your bone marrow's ability to produce all other cells. Without a transplant of new stem cells, your bone marrow might not be able to recover. Therefore, after you have received the high-dose treatment, the stem cells are given to you to help you produce new blood cells.

The cells are given through a central venous catheter (Hickman® or PICC line). This is a tube that is inserted into one of your large blood vessels and is used to deliver your chemotherapy and other infusions. When the stem cells are given to you, it's known as a 'cell infusion'. The infused stem cells you receive find their way to your bone marrow and begin to produce new blood cells. This happens about two to three weeks after they have been infused. This process 'rescues' your bone marrow from the effects of the high-dose chemotherapy or radiotherapy.

There are two types of transplant.

- autograft/autologous – where your own bone marrow or stem cells are used
- allograft/allogeneic – where the bone marrow or stem cells from a donor are used.

The type of stem cell transplant depends upon the type of disease being treated and the quality of the person's own bone marrow or stem cells. If your own stem cells cannot be used, or it's believed that you would benefit from a transplant using donor cells, then you may be eligible for an allogeneic transplant.

There are still advances being made in stem cell transplant treatments. Since the 1970s, doctors and scientists have been developing ways of reducing the intensity and side effects of treatment, particularly with donor (allograft) transplants. This can be done by reducing the doses of chemotherapy or 'conditioning therapy' given before the stem cells are infused.



If you're supporting a loved one through a transplant, please ask their transplant centre what support is available. You may also find Anthony Nolan's information for parents, family and friends helpful. Go to **[anthonynolan.org/patients-and-families/support-parents-family-and-friends](https://www.anthonynolan.org/patients-and-families/support-parents-family-and-friends)**

Immunosuppressive drugs are used to stop your immune system fighting the donor stem cells, and instead allow them to grow. These are called reduced-intensity conditioned (RIC) transplants. They are quite commonly used.

Today, there are a number of different ways of giving stem cell transplant treatment. Your doctors will call these different types of treatment plans 'protocols' or 'conditioning regimen'. Some treatment protocols or conditioning regimen can include small doses of radiotherapy. However, higher-dose treatments, such as myeloablative conditioning (MAC), are still used for some people.

Risks of treatment

There are risks associated with both RIC and MAC regimen. This includes the risk of graft-versus-host disease (GvHD). This is a condition, explained in detail in step five, where the new stem cells can recognise the host (your body) as 'foreign' and fight against it. GvHD can be mild, moderate or severe; it can also be life-threatening.



GvHD and graft rejection are discussed in more detail in **Step five: Waiting for engraftment.**

There are also risks associated with bone marrow suppression such as anaemia, bleeding and bruising, and severe infections. However, the problems that people get during a transplant, such as mucositis (an inflammation of the digestive tract) tend to be less severe following a RIC transplant.

If you have any questions about these treatments, do discuss them with your doctor.

Donors and tissue typing

There are different types of donors. These include:

- an identical twin (syngeneic)
- a brother or sister (sibling)
- a parent, cousin or child (alternative family donor or haplo-identical donor)
- a matched unrelated donor or a volunteer unrelated donor (MUD or VUD)
- new mothers, who can donate stem cells from the umbilical cord and placenta after they have given birth.

It's important when selecting a donor that one with the closest tissue-type match is used. This will help to reduce the likelihood of complications and immune system reactions, such as graft-versus-host disease (GvHD) or rejection of the graft.

Human leukocyte antigen (HLA) typing is the testing used to determine a person's tissue type. HLAs are proteins — or markers — found on most cells in your body. Your immune system uses these markers to recognise which cells belong in your body and which do not.

Tissue typing is not related to blood group, so a donor can be a very good tissue-type match but a different blood group.

For the tissue-typing test itself, just a small (about 20ml) sample of blood is taken from one of the veins in your arm. This blood is then sent to the tissue-typing laboratory to be processed. The results are usually available about two weeks later but can be quicker.



See **Step two: Preparing for your transplant** for more information about blood tests and investigations..

Finding a donor

When a donor search is started, a patient's brothers and sisters are usually tested first to see if they might be a suitable match.

Although an identical twin is considered to be the closest match, there can still be issues with a transplant from an identical twin (syngeneic transplant). If your donor is identical to you then the new immune system won't react against you, so you won't get GvHD. However, since your immune systems are so similar, the transplant can fail for other reasons, such as relapse, which means the disease returns.

The next type of donor is a matched sibling (brother or sister). Because of the way we inherit tissue types from our parents, in most cases, a sibling can be a good match, half-matched (haploidentical) or not matched at all. There is a one in four chance of a brother or sister being a full match. A matched sibling donor will often be selected over other possible donors; however, under certain situations, transplants using half-matched siblings or parents as donors are performed.

For anyone who does not have any siblings, or none that match, a search of the bone marrow donor registries can be carried out to see if there is a volunteer unrelated donor with the same tissue type.

There are now several million volunteers around the world who are registered as potential stem cell donors. Anthony Nolan and the British Bone Marrow Registry have many donors on their lists – but, sometimes, a search of the registries in Europe and America needs to be made in order to find a suitable donor.

There are now several banks worldwide storing stem cells from the umbilical cords of newborn babies. This provides a further potential stem cell source in certain situations – in particular, where it's difficult to identify a suitable donor in an acceptable period of time.

Unfortunately, there are particular difficulties in finding donors for people from Black, Asian and minority ethnic groups. These groups tend to be under represented on the donor registries – but, through appeals and increasing public awareness, this is slowly improving. Stem cell transplant techniques are continually changing, so consider asking your doctors for more details about sources of stem cells.

All donors will need a physical checkup to make sure that they are fit and healthy. This will involve a physical examination by a doctor and some blood tests – including a blood count, blood chemistry and tests to check for viruses (virology screening)

like hepatitis and HIV. You will also have a heart trace (ECG) and a chest X-ray.

How are the cells collected?

The stem cells for the transplant are collected from the bone marrow or the blood. The process used to collect stem cells is called harvesting.

There are two different ways that the cells can be harvested: either through a peripheral blood stem cell harvest, or a bone marrow harvest.

The type of harvesting method that is selected for you will depend on a variety of things, such as the chemotherapy and treatment you've had before. For donor harvests, the type of method used depends on what is most suitable for the patient and donor.



These two methods are quite different and are explained in detail in the **Appendix A**.

**It can be helpful
to know what to
expect when you're
referred for a stem
cell transplant.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Tests and investigations

You will have an experienced team of healthcare professionals dedicated to looking after your special needs as a stem cell transplant patient, from the point you're referred to hospital, right through to leaving the hospital (discharge) and follow-up.

Routine

If you have not been admitted to hospital before, it may help to read the following paragraphs, which describe some of the events and tests that are normally (routinely) carried out.

Blood tests

Blood tests are sometimes performed as often as every day, depending on your treatment and general condition. These are important, but you may find them tiresome.

Blood can be taken from a vein (peripheral sampling) or from your central venous catheter, if you have one. Blood samples are usually taken in the morning, but sometimes, extra samples may be needed at other times of the day.

Your team carefully monitors the results of your investigations, but if you would like to keep your own record, please feel free to ask about the results.

X-rays

Chest X-rays are performed as often as weekly for people who are having, or have had, chemotherapy. This is because there are some types of lung infection that do not show any symptoms until they are severe. By performing regular X-rays, some of these infections can be found early.



See **Step two: Preparing for your transplant** for more information about central venous catheters.



Medicines, intravenous antibiotics and chemotherapy

Routine medicines are brought to you several times a day. Medicines, such as painkillers or anti-sickness drugs, are often given on an 'as needed' basis, so do ask your nurse when you feel you need them. Sometimes, you can receive your painkillers through a locked pump, called a PCA (patient controlled analgesia). This pump lets you control your pain without having to ask nurses for pain relief.

The pump is programmed to give you a set dose of medicine when you push a button. As an extra safety feature, the pump is also programmed to ignore any further pushes of the button for a set time following the previous dose. This is called a lock-out period. This means you can't give yourself more medicine than is safe.

Most antibiotics that are given through your veins (intravenous) are made up and given by the nursing staff. Every effort is taken to make sure that these are given during the hours that you are awake, but on occasions when many infusions need to be given, the nurses may need to start them early in the morning and complete them during the night. This may mean that your sleep is interrupted and you feel more tired the following day.

Many members of the nursing staff are specially trained to give chemotherapy. Everyone is given chemotherapy as part of a treatment 'protocol'. This is a plan of the treatment you're going to receive. Chemotherapy can be given in many different ways, but tablets and intravenous injections are the most common.

One of your doctors will explain your treatment protocol to you before you start, so that you know how often you're having chemotherapy, how long the course of treatment takes to complete, and in what form it will be given to you.

Observations

While you're in hospital, there are many ways of monitoring or observing your condition. The most common are described below.

Temperature

This will be checked regularly over the course of the day. There are different types of thermometer that may be used to measure your temperature in different places. A tympanic thermometer is placed in the outer ear, and can read the temperature electronically using an infrared sensor. Other thermometers may be placed in your mouth (under your tongue) or, if you have a sore mouth or feel sick (nauseous), may be placed under your arm.

Pulse

This may be checked regularly over the course of the day. You may find that your pulse rate is faster if you're anaemic or if you have a raised temperature because of an infection.

Blood pressure

This may be checked regularly over the course of the day. You may find that your blood pressure runs a little lower than normal when you have a raised temperature, or a little higher if you're anxious or in pain.

Respiration rate

Your respiration rate tells your healthcare team how quickly or slowly you're breathing. This may be checked often over the course of the day. The rate may be quick if you're anxious or in pain, or have an infection, and slow if you're asleep or drowsy.

Fluid monitoring

As a result of the types of treatment you're given, it's necessary to make sure that you're getting plenty of fluid, either by mouth or by drip. It's also necessary to make sure that you're passing enough urine. Too much fluid in your body can be a problem, while too little can lead to dehydration. High fluid intake can help to flush harmful toxins and waste products away.

To monitor your input and output, a fluid balance chart is used. This is a record of your input (drinks and intravenous infusions) and output (urine and other body fluids). The nurse may suggest that you keep your own record if you wish to; if not then your nurse will do this for you.

Pulse oximeter

This is a machine that can be used to measure the level of oxygen in your blood. Oxygen in the blood is important as it helps to provide nutrients to the cells of your body. The machine has a soft clip that is placed onto one of your fingers for a few moments, and then it takes a reading. This method

causes no discomfort. In some cases, the doctor may need to take a blood sample from one of your blood vessels (arteries) in the wrist or the groin, to get an accurate measure of the different gases that are in your blood.

Ward rounds

Ward rounds are the time that your doctor(s) visits to check your progress and review or change your treatment. You will also have the chance to ask questions about your treatment and take part in any decisions that need to be made.

Occasionally, there may be other doctors or medical students with your usual doctor(s) when they come to see you, as the round is an important chance for learning. If you would prefer the number of doctors that you see kept to a minimum, please let your nurse know in advance.

You may also be seen by other specialists if your transplant doctors have asked them to review a particular problem. An example of this could be if you develop a problem with your skin and then you may see a dermatologist (skin specialist).

Counselling and psychological support

Your hospital may have a counsellor who is able to help support you through your treatment. Evidence has shown that your mood and emotions can affect the way that you recover from treatment.

If you have experienced any psychological problems such as anxiety or depression in the past, or if you have taken medicine or received support for mental health problems, it is very important to make your team aware. Your healthcare team should support you and assess your emotional needs and the impact of your disease at diagnosis, as well as after any treatment.

It's also important that you and your family and friends have the chance to discuss and express feelings in confidence and in a way that feels comfortable. This can be done at your own pace and with a professional who is trained and experienced in listening and offering emotional and psychological support.



A counsellor can help by:

- offering counselling to you, your family members and friends, either individually or all together, and
- providing general advice and help with welfare benefits, housing issues, charity applications, referrals to other agencies and other practical problems.

If your hospital does not provide a counselling service for you, please ask your nurse or GP for contact details of a counsellor who can help.

**It's important to
understand how your
treatment may affect you
physically and emotionally.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Step one: Planning ahead

The time has now come for you to start preparing for your transplant. There are several things to consider before you begin treatment and these are covered in this first step.

Issues discussed in this step:

- Timing
- Fertility
- Early menopause
- Clean diet
- Losing your hair...
- ... and growing it back again

Timing

You may not have been given any dates yet, but you may have a general idea of when your transplant is due.

If you are planning any special events – such as a wedding or a family break, for example – it may be possible to move the date of your transplant to fit around this. It's worth bearing in mind that you can expect to be in hospital for up to six weeks. After this, you will need to go to the outpatient department up to three times a week, sometimes more, during the immediate period following your discharge from hospital.

This period can last anywhere between one to three months after the transplant and varies from person to person. For most people it can be at least six months, depending on the type of transplant you have, before your level of activity will return to normal. If you're concerned about the timing of going to hospital for your transplant, do discuss it with your transplant team.



For more information about benefits and your rights at work, visit our website: [bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well).

Below are some other things to consider:

- the type of transplant you're going to have and the kind of preparation you feel you need
- childcare while you're in hospital
- restricting your social activity during the weeks leading up to your transplant
- help at home when you're discharged
- how you will travel to the hospital for your appointments after the transplant
- learning about looking after your central venous catheter (Hickman® or PICC line), in hospital and at home
- financial support or benefits that may be available
- goals and targets you might wish to set during your recovery
- any arrangements that you may need to make during the time you are unable to work, as it's likely that you'll be unable to return to full-time employment for at least six months after your transplant. For many people, this period might be 12 months or possibly longer. This length of time will depend on the rate of your recovery.

All of these considerations are an important part of your psychological preparation for the transplant and are individual to you.

Often, there's no single, correct way of dealing with these concerns, but planning in advance will help when you come into hospital. Remember, your nurse and doctors are there to help you if you have any problems sorting things out, or would like more information or expert advice.

Fertility

While there is an extremely high chance of not being able to conceive a child (infertility) with most high-dose chemotherapy treatments, it's not completely certain that everyone will be infertile, and there have been cases of women becoming pregnant and giving birth after they or their partner have had a stem cell transplant. This is why methods to reduce the chance of pregnancy (contraception) are recommended following treatment, if you do not wish to become pregnant.

The ways of protecting fertility are changing, and your doctor should discuss current options and treatments with you before you begin any therapies that may damage your fertility. Some people's fertility may be reduced by their condition even before treatment begins. A specialist will assess your fertility and discuss the different options with you.

In general, the fertility options for men are easier, as taking semen is quicker than taking eggs from women, but you should discuss the current options with your healthcare team. By thinking about protecting your fertility at an early stage, you will have more time before your transplant to consider your options, and complete any fertility treatments.

Fertility options for men

Before starting your treatment, you may wish to consider storing some semen for use later on.

Donating semen is a simple procedure, and your doctor can give you more advice and information on semen storage, and can answer any questions you may have about your fertility.

Before donating semen, you will be asked to give your consent for a blood sample to be taken to test for viruses, such as HIV, hepatitis B and hepatitis C. This happens because your samples will be stored with others and the sperm bank needs to make sure that all of its samples are stored safely.

There are some other things you'll need to consider before you donate, too. You might find some of these difficult to think about, but it's important to be aware of all possibilities before you make your decision. Speak to your healthcare team if you have any questions or concerns.

Problems with your sperm

There is a chance that your sperm may already have been damaged by your illness, so the quality of your sperm and your sperm count will be checked when you donate. Samples are always stored if there is a small possibility that they are fertile, but there is no guarantee of their quality afterwards.

No guarantees

Every effort is made to make sure that your samples are stored to a high standard, but there is no guarantee that the samples will be usable after thawing, and your partner may not become pregnant with your samples, even if they appear acceptable after thawing. It's also possible that your semen may carry infections, such as viruses. It's extremely unlikely, but it's possible that the bank may carry infections or cross-infection could happen should one of the bottles containing semen break open.

Combining with IVF

To make the best use of your stored semen, your partner may need treatment with in vitro fertilisation (IVF). This is where the woman's eggs are removed, fertilised with the sperm and returned to the woman's womb (uterus). If you're eligible for NHS treatment, there may be a long waiting list, and private treatment can be very expensive.

Cost of storage

There may also be a cost for storing your semen, or you may be asked to pay an annual fee for keeping your semen stored. Please talk to your fertility unit about their arrangements.

Considering all the possibilities

Although it might be difficult to think about, for legal reasons, you'll need to let the unit know how you would like them to deal with your samples if you die. If you have a partner, you may want the responsibility to be passed onto them, and if so, you should name your partner when discussing this with the unit. Another difficult thing you need to think about is how you might feel about having a child born should you die.

Signing a contract

You'll be asked to read and sign a contract for semen storage. It's usually expected that you contact the unit every 12 months to confirm that you wish your semen samples to remain in storage. It's important to do this; samples can be removed as stocks at the bank are checked regularly.

Fertility options for women

There are some options available for women to protect fertility. You should consider your options carefully and seek advice from fertility experts who are there to help you make your decision.

Some of these options can be time-consuming, and the results can sometimes be disappointing. However, your healthcare team is on hand to discuss any concerns you have and support you through your chosen method of treatment. There are currently four options for you to think about.

Using your own eggs for embryo storage

Before starting your chemotherapy, you can be given treatment to trigger your ovaries to produce a number of eggs. These eggs are collected and then fertilised with your partner's or a donor's sperm. Eggs that are successfully fertilised (embryos) are then frozen and can be used at a later date when you have fully recovered from your chemotherapy.

Using donor eggs

You can wait until your treatment is over and then use donated eggs, rather than your own. These eggs can be fertilised with sperm and then placed in your womb, where the embryo can grow naturally. Egg donors – although available – are difficult to recruit, but you may have a relative who is willing to offer to be your donor. If you are not currently planning to have children, you can still consider egg donation as a future option.

Using your own eggs following egg storage

After your ovaries have been triggered, your eggs can be collected and frozen without fertilisation

Ovarian tissue storage

Some units are able to offer a fairly new treatment that involves freezing ovarian tissue. The eggs in this tissue are matured at a later date and then fertilised to form embryos.

It's important to remember that fertility treatments are being improved all the time and new techniques are being developed. Your fertility specialist will have the most up-to-date information about the best options for you.

Early menopause in women following bone marrow transplant and high-dose chemotherapy

Early (premature) menopause may not be your main concern at this stage of your preparation, but the high-dose chemotherapy and/or radiotherapy you receive before your transplant is likely to damage your ovaries. This damage often leads to premature menopause.



Early menopause is covered in depth in **Appendix B**.

Clean diet

Nutrition and diet are very important following chemotherapy and especially following a stem cell transplant. A clean diet (also known as a neutropenic diet) aims to reduce the risk of picking up infections that can be caught from the food you eat.

During the time when your blood count is low or you're immunosuppressed, you will be advised to follow guidelines for a clean diet.

Guidelines and restrictions vary from unit to unit, so you should ask your doctor or nurse to provide you with a copy of the diet you will be following.

A clean diet is generally recommended for people who have had a stem cell transplant, and the diet should be followed until the white blood cell count recovers.

A clean diet is usually also recommended for people who are on an intensive chemotherapy regimen or for those whose white blood count falls below $1 \times 10^9/l$ on a less intensive regimen.

People who have a chronically low white blood count, or have a weakened immune system and are immune-compromised or immunosuppressed (taking drugs such as ciclosporin or long-term steroids), should follow UK guidelines on food safety

and hygiene. These guidelines are more relaxed than those for a clean diet and are regularly updated by the government. They are available at food.gov.uk or from the dietitian at your transplant centre.

Losing your hair...

As a side effect of your treatment, you will probably lose your hair. It can take up to two weeks after you finish the chemotherapy before your hair starts to fall out. This can be a very sensitive time for you, and your team will do all they can to support you

When you lose your hair, it's a gradual process that happens over a number of days. Some people prefer their hair to fall out naturally, while others prefer their heads to be shaved.

During this time, your scalp may feel sore. Avoiding the shower or your hairbrush will not make your hair stay in any longer, and can sometimes make the discomfort worse.



See our **Eating well with neutropenia** booklet for more information about following a neutropenic (clean) diet. See **page 196** for how to order a copy.

There is a method of reducing hair loss by cooling the scalp that is not recommended for blood cancer patients, and should be avoided. This method has no effect on reducing hair loss following very high-dose chemotherapy and is not recommended because cancer cells can sometimes develop in the membranes surrounding and covering the brain and spinal cord (the meninges). Scalp cooling works by reducing blood flow to the scalp and so will also reduce the amount of chemotherapy delivered to this area.

Some people see losing their hair as a way of getting rid of the old cells and making way for the new.

When you have lost your hair, you should cover your head whenever you go outside, especially in extremes of temperature. In winter, your scalp is a great source of heat loss and you will probably find it uncomfortably cold. In summer, your scalp is at great risk of sunburn. Make sure you wear sunblock and cover up. While you're in hospital, do what feels comfortable. You can use hats, baseball caps, scarves, turbans and wigs to cover your head, if you wish.

If you're having your treatment on the NHS, you will be able to receive a free wig, or vouchers towards a wig. The best time to have a consultation and choose your wig is before you come into hospital,

or before you lose your hair. This way, your hair colour, texture and style can be matched as closely as possible.

If you don't get the chance to choose your wig before you lose your hair, don't worry. There are catalogues of styles for you to choose from and you can still take time to make sure you get the style that you feel is right for you. Once you have chosen your style, it will be ordered for you. You may wish to be shown how to shape and style it. You will also get some tips on how to look after it so it continues to look good. If you do not like the wig when you try it on, you can often order a different one in exchange.

... and growing it back again

The good news is that your hair does, of course, grow again. About six to ten weeks after the transplant, you may be able to see and feel the new growth of hair coming through. You might find it a slightly different colour and texture at first. The initial growth can tend to be slightly wavy, thicker and darker. This often changes as your hair grows longer.

Your healthcare team will help you prepare physically and emotionally for your transplant.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Step two: Preparing for your transplant

Usually, from the time you're referred for your transplant, you will begin the physical and psychological preparation for this treatment. There is a lot of important work to be done, and this will involve frequent visits to the hospital during the weeks leading up to your admission.

Issues discussed in this step:

- Consent
- Fertility appointment
- Dental appointment
- Pre-transplant appointment
- Pre-transplant investigations and procedures
- Bone marrow aspirate and trephine
- Blood tests

- 24-hour urine collection and EDTA clearance
- Lung function tests
- Chest X-ray
- MUGA scan or ECHO scan
- Electrocardiogram (ECG)
- Virology screening (including HIV)
- CT scan (not applicable for all people)
- PET scan (not applicable for all people)
- MRI scan (not applicable for all people)
- Central venous catheter insertion
- Care of your line

Consent

By law, your written permission (consent) must be received before any operation and also before some procedures and treatments can be carried out. Your hospital team will explain the risks, benefits and any other available options before they ask you to sign a consent form. If you're unsure about any part of the treatment plan, do not hesitate to speak with the doctor again.



Fertility is covered in more detail in
Step one: Planning ahead.

Fertility appointment

If you have not yet had the chance to discuss your fertility, and would like to discuss the options available to you, please ask your doctor to organise this for you.

Dental appointment

If you have any teeth that need attention (for example, fillings), you should have the work done before you're admitted for your transplant. If this work is not done, it's likely that these teeth could be a problematic source of infection that could be harmful to the outcome of your transplant.

Teeth that are simply irritating, under normal circumstances, can easily become infected. This can lead to nasty abscesses and can cause a lot of pain when your white cell count is low. This problem is difficult, though not impossible, to treat in immune-compromised people, and removing teeth (extraction) can be a high-risk procedure as a result of a low platelet count.

If you have difficulty making an appointment with your dentist, you should let your consultant know.

Pre-transplant appointment

Some people will have several appointments at the hospital where their transplant will take place, while others will have only one or two.

Try to take your partner or a relative with you, especially if they are going to play an important part in your care. If your brother or sister is going to be your donor, they will usually be sent their own separate clinic appointment.

During your appointment(s), the type of transplant that you will have and the treatment and tests that you will need before you have the transplant are explained and discussed. You may be given some rough dates for your transplant but these may not be confirmed until nearer the time.

You will also be told about the effects and side effects of a stem cell transplant, and you will have the chance to ask plenty of questions.

Pre-transplant investigations and procedures

There are a number of investigations and tests that are carried out before your transplant. These tests are done to make sure that you're generally fit and well. The doses of therapy that you will be given are very high and it's necessary to make sure that your body will be able to cope with the treatment. You will also have a number of blood tests.

These blood tests are explained later in this section. You may not need to have all of the investigations described over the following pages.

Sometimes, you may be able to get most or all of the tests done on one day. They may be planned at your local hospital or at the transplant centre. On occasion, your healthcare team may need to carry out further investigations and you may need to make more than one visit to the hospital to get them all completed.

Bone marrow aspirate and trephine

A bone marrow aspirate involves inserting a fine needle through your skin into the bone marrow space. This is usually done at the back of the hips (iliac crest), where there is plenty of bone marrow. A syringe is connected to the needle to suck out (aspirate) some liquid bone marrow and cells to smear onto a glass slide. This slide is stained and viewed under a microscope. Other tests can also be carried out on this sample, such as the study of molecules that carry your genetic information (DNA), or the thread-like structures made up of these molecules (chromosomes).

A bone marrow biopsy (trephine) is often carried out at the same time. This is where a small core of the bone marrow is removed, using a similar technique as an aspirate.

The complete results can take up to ten days, but some of your results will be available in two to three days. The test takes between ten and 20 minutes to complete.

A local anaesthetic is used to numb the area from where the bone marrow is taken. Some people cope with the procedure well, while others may feel more anxious. Consider speaking to your team if you're feeling anxious and would like to know if there is anything else they can offer to make you feel more comfortable. For example, you might be given 'gas and air' (Entonox®) or a light sedative (midazolam).

Blood tests

Blood tests are a regular part of diagnosis and can also be carried out to find out how your body has responded to treatment. You may have blood tests to check the following:

- blood count
- blood group
- kidney function
- liver function
- bone function
- thyroid function
- clotting
- iron (ferritin) level
- glucose
- immunoglobulins
- T cell numbers (CD4, CD8, CD16, CD56 and CD57)
- hormone screen
- beta 2 microglobulin, and
- lactate dehydrogenase (LDH).

EDTA clearance or Glomerular Filtration Rate (GFR)

This investigation tests the function of your kidneys. Unless you're told otherwise, you should eat and drink normally before the test.

For this test, you usually need to go to the Department of Nuclear Medicine at the hospital. For the test, you're given a small injection of radioactive dye into one of the veins in your arm. After this, a series of four blood samples are taken between two and four hours after the injection. A calculation can then be made from these blood tests.

The injections do not have any side effects and are not harmful to you.

It's important that you tell the technician if you've had any blood or platelet transfusions within the 24 hours before an EDTA clearance or GFR test.

Lung function tests

This procedure is done to find out how well your lungs are working. Most of the tests involve you breathing into different machines that work out how big your lungs are and how effectively they are functioning. Sometimes, a small sample of blood is taken to work out how much oxygen is in your blood. Some tests may involve walking on a treadmill, so do wear comfortable shoes.

If you normally take inhalers to help your breathing, try not to take them for four hours before the test. This is because the technicians can test how much the inhaler is helping your breathing. Of course, if you're feeling very breathless, then take your inhalers as usual. Please also take a list of any medication that you are taking.

Chest X-ray

This is a simple X-ray of your chest, which can be used to compare X-rays before and after your treatment.

MUGA scan or ECHO scan

These are scans to test the function of your heart. You will usually need to have only one of these scans.

Unless you're told otherwise, you should eat and drink normally before the test.

A MUGA scan is performed in the Department of Nuclear Medicine. The test involves two small injections in your arm.

Following the first injection of a small amount of radioactive dye, there is a wait of about half an hour before the second injection is given. This dye attaches itself to your blood, so that a series of pictures can be recorded. A heart trace (ECG) may also be recorded. The whole test takes about an

hour to complete. After this time, you'll be able to go home.

The injections do not have any side effects and are not harmful to you.

The ECHO scan or cardiac ultrasound is another type of scan that can be done to check your heart.

When the test starts, you're asked to undress to the waist, and then lie on a couch on your back. The doctor, or technician, who is doing the scan will place some gel on the area of skin around your heart. They then move a probe around the area and, using sound waves, this produces an image of your heart on a monitor. The doctor, or technician, then needs to repeat this process while you're lying on your side.

This test is not painful but you may be asked to lie quite still at times.

Electrocardiogram (ECG)

An electrocardiogram (ECG) is a trace of your heart rhythm. You will be asked to undress to the waist and then a series of electrodes, like sticky plasters, will be placed on your chest around your heart and on your wrists and ankles. A graph of your heart rhythm is produced on a piece of paper. The test takes about five to ten minutes to complete.

Infection screen

All people have a blood sample taken to screen for viruses and other infections, before the transplant.

This is done to check if you have had any infections that could flare up when you're immunosuppressed after a transplant.

If you've had or been exposed to a hepatitis virus, cytomegalovirus (CMV) or the Epstein-Barr virus (EBV), this could also reactivate after a transplant, particularly if you had a transplant from a donor, so you will be monitored and treated to make sure you avoid complications.

For this reason, everyone will be screened for viruses before a transplant or a stem cell harvest, if you have one. If there is a long time between the harvest and your transplant, the screen may be repeated.

The viruses that are routinely screened for include:

- HIV (type 1+2)
- hepatitis B+C+E
- CMV
- HTLV 1+2
- EBV.

There may be some extra tests that your transplant centre performs. The results are usually available

in a few days. These tests screen for infections, including syphilis, toxoplasma and MRSA.

You should be notified of the nature of these tests before they are performed, so that you can give your permission (usually by simply telling your healthcare team that you're happy for the tests to be done). If you would like to discuss these tests with your doctor, any questions or concerns that you may have can be answered. You may wish to speak to a health adviser about these tests before they are done.

If you would like any further information, please do not hesitate to ask your healthcare team.

CT scan

Before your transplant you may need to have a CT (computerised tomography) scan. The scanner is a complex X-ray unit that is able to produce cross-sectional images – a bit like slices of the head and body that are analysed on a computer. Your doctor may wish to scan a part of your body, such as your chest, stomach area (abdomen) or, in some cases, your sinuses.

You may be asked not to have anything to eat or drink for two to four hours before your scan.



During the scan, you'll be asked to lie on your back on the hard scanning table and you're then positioned in the scanner. The table passes through the scanner, and, for a short time, you may feel slightly enclosed. You're able to hear the noise that the scanner makes while it's in action.

For neck and chest scans, you may be asked to hold your breath on and off during the scan, and you may need to have a small injection into a vein in your arm. This is a special X-ray contrast fluid.

The injection may make you feel warm and occasionally makes people feel sick (nauseous) but this soon wears off.

Before scans of your stomach area (abdomen) and the area around your hips (pelvis), you're given a drink of a special dye (contrast fluid). This can taste a little like aniseed and it's diluted in about a pint of water. You can mix fruit drinks with the contrast fluid if you dislike the taste. The fluid is needed to produce good pictures. You will be given more cups of fluid during the hour before the scan.

For a scan of the pelvis only, you may need to have a small amount of the same fluid put into the rectum via a small tube. If you're a woman, you may be asked to insert a tampon. The scanning time for this examination is quite short but the total time involved, with the preparation, is longer.

PET scan

A PET (positron emission tomography) scan is where an injection of a very weak and harmless radioactive dye is used to highlight the area of the body being scanned. Pictures are then taken using a special camera. This takes about half an hour. PET and CT (PET-CT) scans can often be combined to give more detailed images.

MRI scan

This scan can be used as an alternative to a CT scan and uses radio waves rather than X-rays to produce pictures that can be analysed on a computer.

You're asked to remove all metallic objects, such as jewellery, money and keys. If you have a cardiac pacemaker then this type of scan may be unsuitable because of the powerful magnetic field. You will need to let the staff know if you have a pacemaker.

Each scan takes about one hour to complete and you may eat and drink normally before and after the procedure. It may be necessary for you to have a small injection of contrast fluid into a vein in your arm to help get better pictures.

You're positioned on a table that goes through the scanner. For a short time, you may feel enclosed and it can be quite noisy. It's a painless procedure with no known side effects.

Central venous catheter insertion

During your transplant you need a large number of infusions such as chemotherapy, blood and platelet transfusions, and possibly antibiotics. It's impossible to rely on your veins for this kind of intensive treatment. Before your transplant you have a special line inserted, if you don't already have one.

This is a surgical procedure that can be carried out in the operating theatre under general anaesthetic, or in a special X-ray department under local anaesthetic. Each hospital usually has its own preferred method.

Each hospital and transplant centre also has its own preferred type of central venous catheter. The most commonly used type of catheter is a 'Hickman[®]', but there are similar types, such as 'Groshong[®]' and PICC.

There are some risks associated with the procedure, including lung collapse (pneumothorax), bleeding and infection. The chance of any of these things happening is small, but your doctor will discuss these risks in more detail before you sign the consent form. If there is any part of the procedure that you do not understand, please ask your doctor.

The catheter is tunnelled so that it runs beneath the skin and the tip sits in one of the large veins that lead into your heart. It exits through the skin, usually about 5–10cm below the collar bone for a Hickman[®] or Groshong[®], and near the bend in your elbow for a PICC. The catheter has a cuff beneath the skin to stop it from falling out, but initially it's held in place with a couple of stitches. The width of the catheter is a little larger than a biro refill. The catheter is made from very flexible material that can bend without breaking.

Since the catheter is in such a big vein, the infusions that you're given are easily carried into your blood. Large volumes of fluid or even small infusions can be given effectively. The catheter can also be used for taking blood tests. This means that when you have a central venous catheter, you no longer need to have blood taken from your veins – except on rare occasions and if you have a temperature.

Care of your central venous catheter

Your catheter needs to be looked after, to prevent it from becoming infected or blocked. If the hospital is happy for it to be looked after at home, it's best that just one person (either you or your carer) looks after it, as this will help to reduce the risk of infection. Taking care of your catheter is not difficult; it simply requires a little practice.

Some hospitals prefer to look after the line for you and this will be done at your routine hospital visits.

Here are some hints and tips for a healthy catheter.

- Always keep your catheter secured with tape so that it won't easily get pulled.
- If it is being looked after at home, only use the technique that you have been shown by your healthcare team.

Should any of the following occur, you must contact the hospital immediately for advice – this applies 24 hours a day:

- if you get shivers at any point after flushing your catheter.
- if the area around your catheter begins to look red, or release pus or blood.
- if you notice that the ‘cuff’ is more exposed than usual.
- if you notice that your catheter has become split or damaged in any way.
- if you’re having difficulty withdrawing blood from your catheter using the usual technique, but you’re still able to flush it, the catheter may be blocked
- if you’re having difficulty flushing your catheter, it may be blocked.
- if you notice any swelling in your arm, neck or face.

The dos and don'ts of catheter care

There are certain dos and don'ts that are worth noting.

- Do redress your catheter after showering, unless you have a dressing specifically designed to protect your line when exposed to water.
- Do redress your catheter at least twice a week, if not showering daily.
- Do inspect the area of skin around the catheter daily, looking for any redness, pus or bleeding.
- Do flush your catheter once a week using either saline or heparinised saline as advised.
- Do change the bungs after each flushing (there is no need to do this if you're using a 'closed' system, such as the green Bionectors®).
- Do wash your hands before and after any catheter care.

- Don't clean your catheter with anything other than the recommended solutions.
- Don't leave your catheter without a dressing, unless advised to do so by your doctor.
- Don't keep using a dressing that irritates your skin. Seek advice from your doctor.
- Don't leave a wet dressing on your catheter.
- Don't flush or dress the catheter without first washing your hands. Always wash hands after any catheter care.
- Don't swim or bathe while you have the catheter.

Any questions?

If you're ever unsure about your catheter, or the way it's being looked after, either by you, the district nurses or the hospital, please ask.

**Before you receive your
transplant, your body
needs to be prepared
to make way for new cells.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Step three: Conditioning therapy

The following pages explain the treatment part of your transplant and how it may affect you. Some hospitals can offer outpatient (ambulatory) care for part or, sometimes, all of the transplant.

Outpatient care is where you visit the hospital daily for your treatment or post-treatment checks, but don't stay in the hospital at night unless you are unwell. Instead, the hospital provides accommodation for you and – if you have one – your carer, or you can go home if you live close enough to the hospital. Not everyone will be suitable for outpatient care and not all people would choose this option. Please ask your team if this is something that the hospital offers and for more information.

The following information is for people who are staying at the hospital (inpatients) and outpatients.

Issues discussed in this step:

- Things to take into hospital
- Conditioning therapy
- Mouth care
- Expected side effects
- Other considerations

Things to take into hospital

When you go into hospital for your transplant, you can take some personal belongings with you, such as photographs of your family and friends, books, needlework, an mp3 player or tablet. Most wards can provide WiFi access, although there may be a charge, so you can stay in touch with family and friends with mobile phones. Please ask your team whether mobile phones are allowed. You can often take your own pillow and single duvet, as long as someone can take the covers home and wash them regularly for you.

You might also want to bring:

- something to sleep in
- day clothes to help you feel more 'normal'

- a wash bag with toiletries (including a soft or baby toothbrush to keep your mouth clean if you develop mucositis).

You may wish to contact the transplant unit before you're admitted to see if there is a television or DVD player in the room.

If you're facing a long stay in hospital, you may find that joining a patient forum or writing a blog about your experience is helpful. There are lots of patient groups on social media that might also provide a source of support.

Please bear in mind that the rooms in transplant units are usually small, so you may need to be selective when planning what you'd like to bring with you.



The way the transplant is done is discussed in **Step four: The transplant.**

Things to expect during the recovery period are described in more detail in **Step five: Waiting for engraftment.**

Conditioning therapy

Before you can receive your transplant, your existing bone marrow and immune system needs to be treated and prepared to make way for the new cells. This is done using chemotherapy alone, or in combination with total body irradiation (TBI). TBI is radiotherapy that's often given in several doses, but sometimes just one low dose, to the whole body.

Almost everyone having a stem cell transplant will have chemotherapy. This can be given either as a tablet (orally) or through a vein (intravenously), depending on the type of treatment plan you have. The intravenous chemotherapy is given through your central venous catheter, either in a bag to be infused over an hour or a number of hours, or in a syringe, which is given by your nurse and takes several minutes.

You will usually begin your conditioning therapy the day after you go into hospital. Your healthcare team will take many things into consideration when deciding the intensity of the therapy that you'll receive, including:

- the type of blood cancer or blood condition you've been diagnosed with
- your age

- how well your condition has responded to previous treatments
- the amount and type of previous treatments you’ve received
- disease status or ‘stage’ (the presence or absence of disease)
- your general fitness level (determined by pre-transplant assessments).

The treatment takes anywhere from one to ten days, or possibly more, to complete, depending on the type of regimen and transplant you’re having.

Your transplant is usually scheduled for the day after the conditioning therapy has finished, although this may vary depending on the treatment and the type of transplant.



Not everyone has TBI, but if you would like to learn more about the treatment, please see **Appendix C**.

See **About stem cell and bone marrow transplants** near the start of this booklet for more about the different types of conditioning therapy.

After the transplant, it's necessary to wait for the cells to engraft (grow again). When engraftment occurs, it's usually the recovery of the white blood cells that happens first. When they are at a safe level, from two to four weeks following the transplant, you will be able to go home.

Mouth care

When you begin your conditioning therapy, you're given some products to use that help to prevent infections in your mouth. Most types of infections are caused by germs (bacterial) or fungi, such as mould or yeasts (fungal).

The mouth-care products may include antibacterial mouthwash, which you will be asked to rinse around your mouth and then spit out, and antifungal suspension, which you will be asked to swallow after rinsing. You'll be advised to use a combination of these products at least four times a day. If you have any difficulty with your mouth care, please let your nurse know.

Side effects

Nausea and vomiting

Sickness (vomiting) as a side effect of chemotherapy is generally less of a problem now than it used to be, because of the research that has been done into anti-sickness drugs.

When you begin your treatment, you're given an anti-sickness drug, also known as an antiemetic. This is to stop you from feeling sick (nauseous). This can be given as an injection through your central venous catheter or as a tablet. If you find that your sickness is not very well controlled, the antiemetic drug can be changed to another type. There are many different antiemetics to choose from, and one that is most suitable for you will be found.

You can also use medicines that help you relax (mild sedatives) to help control your nausea. These can be given intravenously.

Change in bowel habit

Another very common side effect of chemotherapy is a change to your normal bowel habit. Diarrhoea is a common complaint, both during and following treatment.

If you have diarrhoea, you're usually asked to provide a sample; it will be sent to the laboratory to make sure that infection is not the cause. You need to drink extra fluids or may need an intravenous infusion of fluid and, when infection has been ruled out, you might need to take a tablet to reduce the number of times you need to go to the toilet.

If you become constipated, please tell your nurse or doctor. They will be able to give you a laxative or a softener to help you go to the toilet.

Constipation can become very uncomfortable, so please tell someone if the medication isn't working.

Change in taste and smell

Chemotherapy and radiotherapy can change your taste and smell. You may find that you cannot tolerate some foods or scents at all during your treatment. Adding extra sugar to sweet foods and salt to savoury foods may help. You may even find that cold foods are more tasty than hot. Your sense of taste and smell will return to normal but this can take time.

Extreme tiredness

Conditioning therapy can often cause tiredness and lack of energy (fatigue). Don't be too worried if after a few days of treatment you find that you're sleeping more, especially during the day. Intensive treatment, together with the emotional stress of going into hospital, can be a strain on your reserves. You may also experience a lack of concentration and find that your sleep and rest patterns change altogether.

Fluid gain

During the conditioning therapy, you may find that you actually put on weight. This can often be caused by the build-up of the fluid that is given with your chemotherapy. This kind of fluid gain can be simply resolved using diuretics. Diuretics are drugs that are used to make you pass more urine. They can be given into a

vein (intravenously) through your central venous catheter, or as a tablet; they take about 30 minutes to an hour to start working. The effects usually wear off after about four to six hours.

Weight loss

It's common to lose weight when you're not eating your normal diet. Weight loss isn't usually a big problem during the days of your conditioning therapy, but you may find that your appetite decreases. It may help to adjust your usual eating habits by eating small amounts often and to add a nutrient drink to your diet at each mealtime. You can ask to see an expert in diet and nutrition (dietitian) for further advice.

There is a possibility, if you're losing a lot of weight, that you may need to receive extra nutrients through a tube. This is often done when you have lost roughly 10% of your starting weight and there is no immediate sign of your appetite improving. There are a number of different ways that food can be given. Nasogastric feeding and total parenteral nutrition (TPN) are the most common.

Nasogastric feeding is done using a very fine tube, which is passed through the nostril into the stomach. The nutrients can be given continuously or with breaks in between (intermittently). You'll be able to eat food during the break, if you wish, if you're receiving them intermittently.

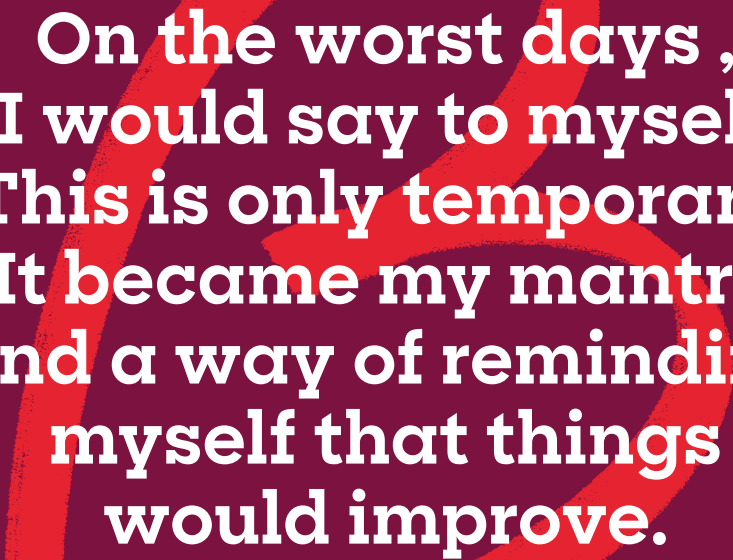
TPN is given to you via your central venous catheter. Each bag of TPN (up to 2.5 litres) is usually infused over 24 to 48 hours and contains all the nutrients and calories you need. TPN will usually help to slow down the rate of weight loss or help to maintain your weight. If you do feel like eating while you're on TPN, then go ahead.

TPN, like everything else, has some disadvantages. The nutrient-rich liquid can be a magnet for bacteria, and 2.5 litres is a large volume of fluid to be infused each day, alongside antibiotics and transfusions. As with all drugs and treatments, your healthcare team will assess whether you need additional feeding, and how you'll receive this.

Other considerations

There are some other feelings that you may experience when you come into hospital for your transplant. While you may wish to maintain your independence in hospital, it's often difficult to be totally independent when you're feeling unwell. It's common to have moments, or even days, when you don't want to do anything and would rather depend on your nurse or your carer to help you.

Try not to plan too far ahead with your visitors. While close family and partners are often more than happy to spend the afternoon watching you sleep, some friends can be more demanding. If you don't feel like having visitors, ask your nurse to let them know.



**On the worst days ,
I would say to myself
“This is only temporary.”
It became my mantra
and a way of reminding
myself that things
would improve.**

Day zero is an important milestone, but there's no right or wrong way to feel when you reach it.

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Step four: The transplant

At last the transplant preparation is complete, and you're now ready for the stem cells to be transplanted.

Issues discussed in this step:

- Your transplant
- Before the infusion
- The infusion
- After the infusion

Your transplant

The day of the transplant is often a very exciting one as it can mean a new beginning. This day is called day zero, with the days following called 'plus days'. This means the day after your transplant is day plus one; two days after is plus two, and so on.

The transplanted stem cells are infused through your central venous catheter in the same way as a blood transfusion is given to you.

You have already come a long way in your treatment and this day is an important milestone. However, the transplant itself brings you only part of the way on your journey to recovery. There is still quite a long way to go and you will continue to need help, information and support as you make your way through the remaining steps.

Before the infusion

Just before the infusion of the cells, your nurse will give you some medication through your line. The medication (an antihistamine and sometimes a small dose of steroid) is to prevent any allergic reaction during the infusion. You will start a saline drip (a solution of salt and water) at the same time. Your nurse also checks your temperature, pulse and blood pressure.

The infusion

The actual infusion of the cells can seem a little bit of an anti-climax, since it often doesn't take much longer than half an hour to complete.

However, the length of time for the infusion varies and depends on the number of bags infused. Different types of harvest can produce different volumes of fluid. If more than one harvest is needed, then there are more bags. Sometimes, there are so many bags that the cells need to be infused over two sessions, which means two days of infusion.

Fresh bone marrow cells from a donor with a different blood group to you can take as little as ten to 20 minutes to be infused, as your healthcare team will have removed the red blood cells, reducing the amount of fluid to between 80 and 100ml. Bone marrow cells that have been frozen will also have had the red cells removed, but may have been stored in more than one bag and therefore may take longer to infuse.

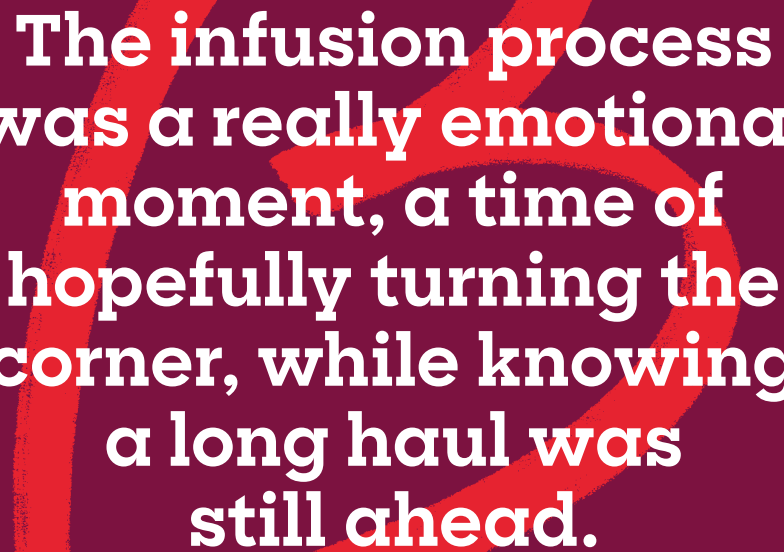
If your healthcare team does not need to remove the red blood cells, the amount of fluid that needs to be infused can be as much as 1 to 1.5 litres, and the process could take two to four hours.

Infusions of stem cells taken from the blood (peripheral stem cell infusions) also vary in duration. If the cells are collected from you, your healthcare team will probably need to infuse two to three bags – though there can be more, and occasionally these bags may need to be infused over two days. Each bag will contain between 80 and 100ml. If the cells come from a donor, there is often just one bag to infuse.

Bone marrow and stem cells that have been harvested and then stored have a preservative added to them, so that the freezing process does not damage the cells. This preservative carries a smell, often described as being ‘like boiled sweetcorn’. You may not be able to pick this smell out at all, but your relatives and visitors may well pass a comment. You release (excrete) the preservative through your skin and in your bodily fluids (in a similar way to excreting garlic) for about 24 hours after the transplant.

After the infusion

After the infusion, your nurse flushes the drip with saline and then takes it down. You have your pulse, blood pressure and temperature checked and then the transplant infusion is complete.



The infusion process was a really emotional moment, a time of hopefully turning the corner, while knowing a long haul was still ahead.

It's normal to feel anxious while you're waiting for engraftment, but knowing that you're being closely monitored can help.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Step five: Waiting for engraftment

This is the time after the transplant, where the stem cells make their way to the bone marrow. There they will start to grow and mature into normal blood cells. This is called ‘engraftment’.

Engraftment happens during the two to three weeks after the infusion, although it can sometimes take longer. Often the first sign is a rise in your white blood cell count. This rise can be unsteady, so don't worry if your count goes up and down a little during the early stages.

While waiting for your white blood cell count to improve, your healthcare team will continue to monitor you carefully.

You'll have blood and platelet transfusions as you need them, until you begin to make your own blood cells. These will help to combat side effects such as a low haemoglobin level (anaemia) and a low platelet count (thrombocytopenia) that treatment can cause.

You may find that you need blood transfusions a couple of times a week and platelet transfusions around three times a week. At times, you may need transfusions more often – for example, when you get an infection.

You may find the uncertainty of this waiting period quite unsettling and it's common to feel vulnerable at this time. You may also feel that the constant monitoring, medical procedures, infusions and treatments can intrude on your personal space. Working out a daily routine may help you to maintain some control.

Issues discussed in this step:

- Protective isolation or reverse barrier nursing
- Medication
- Infections
- CMV
- Growth factors
- Mucositis
 - Mouthcare
 - Pain

- Venous-occlusive disease (VOD)
- Kidney problems
- Graft rejection
- Graft-versus-host disease (GvHD)
- Graft-versus-leukaemia (GvL)
- Fatigue and lethargy
- Immobility
- Coping with your transplant

Protective isolation or reverse barrier nursing

During this time, your immunity against all infections is severely weakened. So if you have your transplant in the hospital, you will need to be looked after in protective isolation. Protective isolation, or reverse barrier nursing as it's sometimes called, is a way of reducing your risk of picking up infections.

Protective isolation methods do vary between transplant centres, but at most centres you're looked after in a single room with the door closed.

There are often special air-conditioning systems that make the air in your room cleaner, which reduces your risk of airborne infections. You're allowed visitors; you'll find more details about this overleaf.



When your white cell count falls, your protective isolation period begins. This is often before the day of the transplant. Activities outside the room are restricted to absolute essentials, such as X-rays or scans, which cannot be done properly in the unit. However, this does not mean that you can't move around inside your room.

It's important that you do try to get some exercise – walking to the toilet, rather than using urinals or the commode is a good way of keeping active. Your ward may have a physiotherapist who can give you exercises to do while you are in the hospital.

There are other considerations with protective isolation.

Visitors

Isolation does not mean no human contact. You should check visiting times with the nurse in charge of the unit, but on many units you're free to have visitors whenever you wish. Although some units do have a very relaxed policy, your nurses and doctors may still need to attend to you while your visitors are there. The number of visitors you have at one time should be kept to two or three. The rooms are usually quite small and seeing many people can increase the risk of infections.

Each unit has its own guidelines about children and babies visiting. If they are allowed, you should have only your own children to visit.

There are a few other things to consider if you have children. Please check the ward policy since many units have rules preventing children under 12 years old from visiting. Children and immediate family members shouldn't receive any live vaccines during this time, since these use a weakened form of the virus they vaccinate against. If you have any questions about this, you can discuss these with your GP.

Before going in for your transplant, it's worth letting your children's teachers know about your upcoming treatment so that you may be forewarned of any infections or viral outbreaks (chickenpox, measles) that your children may have been exposed to. Visits from anyone in contact with an infection are strictly out of the question until they are clear of the incubation period or they are 'infection free'.

If in doubt, please ask the nursing or medical staff.

Your visitors will be advised not to mix with other patients since this can increase your risk of catching infections. Any visitors who have been in contact with any infectious disease should not visit until they have received advice from the medical or nursing staff. If they have been in contact with, or have been suffering from, chickenpox, measles, flu, coughs or colds, or are in any doubt at all, they should contact the nursing staff before visiting.

Hand washing

The most important part of protective isolation is hand hygiene. The nurses and doctors always wash their hands with antibacterial soap (in the dispensers that are usually outside the rooms) and then rinse them with an alcoholic rub before they come into your room. Your visitors will be advised to do the same.

Clothing

Your visitors should remove their outdoor coats and put on a plastic apron and gloves before they visit you. In some situations, they may be asked to follow other instructions too, such as wearing a mask or a gown. Please check with the hospital staff if you're not sure.

Fresh flowers and plants

These are not allowed inside your room as they can carry infection. If your friends and family want to send flowers, suggest that they send flowers made of silk, paper or plastic.

Fresh fruit

Fruit is usually not allowed to be kept in your room as the skin can often carry bacteria and fungi that are dangerous when your white count and immunity are low. However, you may eat fruit that can be peeled.

Medication

There are many drugs that are used to support you through your transplant. Most of these are given to you as a tablet or capsule at first, and then can be swapped for drips and injections if you're unable to cope with (tolerate) the tablets.

Some of these are medicines to control the symptoms that you may experience, such as feeling sick and diarrhoea.

When your white blood count is low, you may need to take antibiotics to protect you from infections caused by bacteria that occur naturally in your body. This is called prophylactic antibiotic therapy. In a healthy person, these bacteria are harmless, but with a weakened immune system they can cause infections. You may also need anti-viral treatment to help prevent viral infections. These antibiotics and anti-virals are an important part of your treatment.

Despite prophylactic or preventative medication, it's likely that at some point during your transplant you will develop an infection. This is explained in more detail in the next section.

Infections

Infections are a common side effect of stem cell transplants. Your low white cell count and poorly functioning immune system mean you have a high risk of infection.

Fever is the most common sign of infection. Your temperature is checked regularly, along with your pulse and blood pressure, particularly while your white cell count remains low.

Some people can feel cold and shiver (a rigor) before the fever appears. If you experience this, you should let your nurse know straight away. Sometimes, an infection can cause your blood pressure to fall. If this happens, you will be given

extra fluid; on occasion, you may even need medication to help bring your blood pressure back up.

The medicines that are used to treat infections include antibiotics, antifungals and antivirals. Some of these drugs can cause problems with your liver or kidneys.

For this reason, these organs will be monitored very closely and your treatment can be adjusted if necessary.

When you have a fever, the doctor will examine you and will usually give intravenous antibiotics. These are antibiotics that are given to you through your central venous catheter. The doctor may also order a chest X-ray and take a blood sample from one of the veins in your arm. The nurse will take blood from each individual tube (lumen) of your central venous catheter. These blood samples, called 'cultures', are then sent to the laboratory to see if the cause of your temperature can be identified. You may also be given a dose of paracetamol, which brings your temperature down and helps you to feel a little better while waiting for the antibiotics to work.

Some other samples may also be taken to find out the cause of your infection, such as urine, stool or swabs.

It's not unusual for the laboratory to get a negative result from the cultures, despite you looking and feeling as though you have an infection. This is why a broad range of antibiotics is used to treat you for an infection. These antibiotics can work against many types of organisms and bacteria. You'll receive antibiotics until the cause of your infection is identified, or your temperature returns to normal.

If you still have a temperature after 24 to 48 hours, the tests may be repeated and the antibiotics may be changed.

Once your fever and symptoms of infection have settled, the antibiotic treatment will be stopped. It's common for people to have several fevers and 'rounds' of antibiotics during their transplant.

If you have had a donor transplant (either from a brother or sister, unrelated donor or from cord blood), or received a drug called anti-thymocyte globulin (ATG) in your conditioning therapy, once a week and sometimes more often, you may receive a viral blood screen. This is to check for any viruses in your blood that can be present without causing you any symptoms.

There are a number of viruses that can be monitored in this way. They include Epstein-Barr Virus (EBV), adenovirus and cytomegalovirus (CMV).

CMV

CMV is a very common virus. It can cause infection almost anywhere in the body, but it most commonly causes pneumonia. It's thought that more than 50% of people have been exposed to it, which means they can pass it on to others. With a normal immune system, exposure to CMV causes mild flu-like symptoms. If your immune system is poor, exposure to, or reactivation of, CMV can be serious. Good progress has been made in preventing CMV infections, especially in people who carry the virus or are at risk of reactivating the virus.

If you've had a donor transplant, you'll have regular blood samples taken – particularly during the first few months – to check for any CMV in your blood. The test that is used is extremely sensitive and can detect viral activity at very low levels. People often need treatment even though they may feel well. You will be told immediately if any viral activity is found.

Growth factors

These are drugs that can be used to speed up engraftment (cell growth). Growth factors are naturally occurring hormones that control the production and function of white blood cells.

They can increase the number of white blood cells in your blood, making infections less severe or speeding up your recovery time. Growth factors can be received through a vein (intravenously) or as an injection under the skin. The side effects are few and they do not affect your risk of relapse.

It's normal for your white blood count to fall slightly when the growth factor support is stopped. Your white count will recover again after a short while.

Mucositis (or stomatitis)

Mouth care

Almost everyone who has had a transplant will experience changes in their mouths and/or gut. This happens because the chemotherapy drugs that are used attack and damage cells that divide quickly. This includes cancer cells, but also bone marrow cells, hair cells and those cells that line the mouth and the gut. This damage usually begins a couple of days after your transplant but can start earlier. These changes to your mouth and gut are called mucositis and are caused by your conditioning therapy.

Mucositis can also be caused by treatment you may receive to suppress your immune system. The severity of your symptoms can depend on the type of conditioning therapy you receive and the type

of transplant you're having; the stronger and more intense the therapy, the greater your chance of developing mucositis.

As a rough guide, mucositis tends to be mild to moderate in people who have transplants using their own stem cells or bone marrow (autologous transplants), or where conditioning therapy is given in lower doses (reduced-intensity conditioning). It is moderate to severe in people receiving higher doses of conditioning therapy (myeloablative conditioning) before a donor (allogeneic) transplant, or those receiving TBI.

At the beginning of mucositis, you may notice that your mouth looks whiter and feels rougher than usual. Your saliva may become thicker, less manageable and more difficult to swallow. You can either spit it out into a receiver or ask one of the nurses to show you how to use the suction. When it starts to become painful to swallow your saliva or fluid, make sure you tell your doctor, as they can offer pain relief.



See **page 196** for details of how to order or download our fact sheet on mucositis: **Sore mouth or gut (mucositis)**.

As your mouth continues to change, the surface may become red and inflamed; sometimes painful ulcers can develop. The areas of your mouth that are usually affected include the insides of your cheeks, the sides and underneath of the tongue, and the back of the throat.

Your throat may also become very sore and you might find it difficult to swallow. It's often difficult to follow a mouth care routine at this time, but it's more important than ever since this is when mouth infections are most likely to occur. As well as your usual mouth care routine, there are a number of things that you can do to keep your mouth clean:

- Use a soft-bristled or baby's toothbrush for keeping your teeth clean. Although a brush is better, if the soreness is severe, try a mouth sponge instead.
- Use a mouthwash with local anaesthetic such as Difflam®.
- Suck ice cubes or ice-lollies.
- Look after your lips. They can often become sore and cracked. Try petroleum jelly or lip balm.
- Your mouth may also feel dry. Boiled sweets and tinned pineapple can help. Saliva substitutes are available and some people find them very useful in the short term.

Mucositis in your oesophagus (the canal that connects the throat to the stomach, also called the gullet), in your digestive tract and bowel can cause you discomfort, indigestion, pain and sometimes diarrhoea. Should this happen, please discuss your symptoms with your doctor so that you can receive medication.

Pain

Some people can get quite severe and painful mucositis and will need painkillers to help relieve it. Although painkillers will not make your pain go away completely, they should make you feel more comfortable. There are a number of drugs that can be used to ease the pain, such as paracetamol, special mouthwashes and morphine. There are also different ways that these drugs can be given. These include:

- by mouth (orally) – tablets or medicines dissolved in a drink (suspensions)
- on the body surface (topically) – mouthwashes, lozenges, patches
- into a vein (intravenously) – usually morphine, either given as injections into the line, or patient-controlled analgesia (PCA).

Please ask your doctor or nurse to give you more advice about these medicines.

It's important to remember that your mouth pain is temporary and it will heal once the effects of the conditioning therapy have gone and your stem cells begin to work. However, it can be some time before your mouth really feels 'normal' again.

Mouth care is essential and helps to make you feel more comfortable, reduces your risk of infection, and may help your mouth to heal more quickly.

Veno-occlusive disease (VOD)

Veno-occlusive disease is a problem with the liver. You may hear it referred to as VOD. It's a specific disease where the blood flow through the small veins of the liver is partly blocked. VOD can be life-threatening if severe. It can cause symptoms such as yellowing of the eyes and skin (jaundice), swelling of the stomach (abdomen) and a build-up of fluid.

VOD can be caused by the high doses of conditioning therapy that you have before the transplant. The stronger the chemotherapy, the higher the risk of VOD. As well as preparing the way for your transplant, chemotherapy can have a damaging effect on otherwise healthy tissues. When the liver is damaged, this can lead to VOD.



PCAs are described in more detail on **pages 23 to 24**.

VOD can happen at any time from after the start of the conditioning therapy, to the third week after your transplant; in very few cases, it can happen even later.

VOD is more common in people having myeloablative conditioned donor transplants than in those receiving reduced-intensity conditioned transplants. It's usually very mild, disappears quickly and often you may not even be aware of it.

However, VOD can be a very serious problem and your treatment is aimed at minimising its effects. Your recovery is helped by your liver's great ability to improve and restore itself from the effects of diseases like this.

Kidney problems

Your kidneys perform many important functions, such as:

- producing urine
- fluid balance
- regulating your blood pressure
- removing waste from your body
- processing drugs.

To function normally, your kidneys also rely on your other organs working normally.

Mild kidney problems are common following a stem cell transplant. Your nurse and doctor will keep a close eye on your kidney function through:

- blood tests
- checking your urine amount and quality
- daily weighing.

Such monitoring will help your doctors understand how well your kidneys are working. These problems are generally treated aggressively with fluid, or by reducing your intake of any medicines that make your kidneys work hard. Careful monitoring is important. Treatment usually resolves these problems and your kidney function will return to normal.

Graft rejection

Graft rejection can happen in donor transplants. It's when the donor cells do not engraft or grow properly, and are unable to produce enough new and healthy blood cells. If this happens, it can lead to repeated infections, bruising, bleeding and anaemia.

Graft rejection can happen while you're waiting for engraftment, or several months after your transplant – but it's not very common. If your doctors think that this is happening, they will try a number of treatments to try to reverse the process.

If these treatments do not work then you may need another stem cell transplant, either from the same or possibly a different donor.

One factor that can affect the risk of graft rejection is how closely the tissue types of the donor and yourself match. Generally speaking, the closer the tissue type match, the lower the risk of graft rejection.

Graft-versus-host disease (GvHD)

GvHD is a side effect that can happen following a donor transplant. The new stem cells (new immune system) recognise the host (your body) as 'foreign' and fight against it. The symptoms of GvHD, explained in the next section, are your body's reaction to this. GvHD can be mild, moderate or severe, and it can also be life-threatening.

There are drugs that are used to prevent GvHD and drugs used to treat it.

You'll receive prophylactic drugs to prevent GvHD as part of your conditioning therapy – this can be in the form of antibody therapy such as alemtuzumab (this depletes T-cells to stop your immune system rejecting the new stem cells), or chemotherapy, such as methotrexate.

There are many drugs that can be used to treat GvHD. Some of these include:

- ciclosporin – an immunosuppressant, which means it prevents your immune system from fighting donor cells
- steroids
- other immunosuppressive medication.

Treatment is tailored for you. These drugs can have some side effects as well as helpful effects on your body. Ciclosporin in particular is very commonly used and can cause extra hair growth (hirsutism), a build-up of fluid in your body (fluid retention), and high blood pressure. These side effects disappear once the ciclosporin has been stopped. When you're on ciclosporin, you should avoid grapefruit and grapefruit products.

GvHD can be divided into two main types: acute and chronic GvHD.

Acute GvHD

This condition usually happens within the first 100 days of your transplant, but it can happen later. It mostly affects the cells of the skin, producing a rash, but it may also attack the cells of the liver and gut. Around the time that the cells are expected to grow (engraft), your doctors will seem particularly

interested in the palms of your hands and the soles of your feet, inspecting them daily for any signs of GvHD, such as redness or itching. They will also be monitoring your gut and bowel. You'll be asked on a regular basis if you have experienced any diarrhoea, and they may ask you for a sample of your stool.

If you have diarrhoea, you may need to have a colonoscopy, which is where a specialist doctor (gastroenterologist) looks at the inside of your large intestine using a medical camera.

You may also have some biopsies taken from the inside of your bowel during the colonoscopy. These are small samples of tissue that can be analysed to see if any of the cells show GvHD or another cause for the diarrhoea. Your healthcare team should discuss these tests with you in more detail.

Your doctors will also be monitoring your liver, mostly by routine blood tests. If you have GvHD affecting your liver, you may notice a yellowing of your skin and eyes (jaundice). The doctors may wish to perform an ultrasound or CT scan of the liver.

The treatment for acute GvHD includes immunosuppressive drugs and steroids, but other treatments can also be used.

Chronic GvHD

Chronic GvHD can happen any time after your transplant and can affect you in many ways, including causing changes in your skin, liver and gut. While chronic GvHD mainly affects the skin, and can cause it to become scarred over time, it can also affect your gut and cause you to lose weight. It may also cause problems associated with malabsorption (not absorbing food properly). Chronic GvHD can also affect the cells of your eyes, mouth, liver and lungs.

If you have chronic GvHD, you'll usually be treated with immunosuppressive drugs. Sometimes it can linger and be difficult to treat. There are a number of other treatments that can be effective against this type of chronic GvHD, and after a time, your condition can improve.

Graft-versus-leukaemia (GvL)

In donor transplants the same cells that cause GvHD may also attack any remaining leukaemia cells. This is a positive and powerful effect and can be a great advantage, especially for people who have had difficulty staying cancer- or disease-free (in remission) before the transplant. This effect can also work in other diseases such as lymphoma and myeloma.

Donor lymphocyte infusions (DLIs)

Donor lymphocyte infusions (DLIs) are a top-up of immune system cells from your donor. They can be used on their own to prevent relapse (prophylactic DLIs), or with chemotherapy to treat a relapse after a stem cell transplant.

DLIs can also help to increase the GvL effect. DLIs can be carried out many times until this happens, but this treatment is sometimes unsuccessful.

Your blood and bone marrow will be tested regularly in the months after your transplant. Sometimes, these tests may show that your bone marrow contains a mixture of your own stem cells and those of your donor (mixed chimerism). This is quite common, but does not mean your cancer or blood condition has returned.

DLIs can be used to treat mixed chimerism by increasing the number of donor cells in your bone marrow, until all of your blood is made by your donor's cells, reducing your risk of relapse.

A DLI is usually given as an outpatient and is a simple procedure. If you need one, no matter what the reason, your doctor will discuss the process with you in more detail.

A known side effect of DLI is GvHD. If this happens, it may need to be treated with the drugs described on page 102.

Extreme tiredness (fatigue)

Fatigue is a very common problem during this stage. People often find it difficult to concentrate on reading a book, watching television or even holding a conversation. This is normal and it's important that you set yourself realistic goals and reasonable expectations of your abilities at this time. A balance of rest and light exercise is often helpful.

There are a number of reasons why you can feel tired. You're still having a lot of treatment, you may have a lower number of red blood cells than usual, your sleep may be disturbed, and you may still be feeling anxious about your treatment.

You may find that activities such as showering or bathing are exhausting. Try to conserve your energy by doing things for a shorter period of time, and then rest.

A good night's sleep is important to prepare yourself for the day ahead. Getting to sleep at night can be difficult while you're in hospital. You may find that earplugs and an eye-mask help to block out any sounds or overhead lighting that may stop you from getting a good night's sleep. Remember the things that you do at home that help you to go to sleep,

for example, reading, listening to the radio, hot milky drinks. Try to recreate the same atmosphere while you're in hospital.

Please talk to your nurse or doctor if you're having problems with sleeping.

Problems with your mobility

Mobility is your ability to move around freely and easily. You may experience problems associated with your mobility if you've had a long period of bed rest, and illness.

Daily light exercise helps to:

- improve fatigue
- maintain your muscle strength
- reduce muscle loss, which can happen with long periods of bed rest
- maintain your balance and co-ordination
- boost feelings of wellbeing
- improve your physical comfort
- prevent chest infections and blood clots (thrombosis), which are associated with long periods of bed rest.

You'll have some days that are better than others. Try to take advantage of these good days by getting up and moving around more.

Coping with your transplant

During this period, it's common to feel anxious and emotional. Some days you may feel very strong and ready to take on the world, while on other days you may feel weaker and unable to face the day ahead. The way of coping with these feelings is a very personal thing and you will find your own way of dealing with them.

Remember your goals and your own personal reasons for having your transplant. Focus on your future, and try to remain positive. Laughter can be very therapeutic and may give you a sense of wellbeing from the inside as well as the outside. Joining patient forums and support groups can be a great way to meet people who have been through (or are going through) a similar experience.

While it's important to remember that everyone deals with their transplant experience differently, they may be able to offer helpful tips and advice.

You may find that relaxation techniques or practising mindfulness are a useful way of overcoming anxiety.

These suggestions may also help:

- relaxation videos
- listening to music or audiobooks
- deep breathing techniques
- gentle massage
- reading
- time alone or with your partner or loved ones.

**Your healthcare team will
be there for you before,
during and after your
transplant.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Step six:

Recovery after engraftment

This step is about your continuing recovery. Even though you have engrafted, and your white cell count is recovering, you're still vulnerable to complications. In particular, people who have had a donor transplant have very immature immune systems for many months following the transplant.

Issues discussed in this step:

- Getting ready to go home
- Things to look out for
- Re-admission to hospital
- Outpatient appointments
- Drugs to take at home
- Risk of infection
- Bleeding

- Central line
- Fatigue
- Exercise
- Emotional changes
- Avoiding crowds
- Going back to work
- Appetite and diet
- Mouth care
- Skin care
- Hair regrowth
- Sexual activity
- Foreign travel

Getting ready to go home

Going home after your transplant can be a very difficult period of re-adjustment for you and your family. You have undergone an intensive and stressful procedure. Although you may feel excited on the day you go home, you may also feel a little anxious about leaving the security of the hospital.

This is perfectly normal, and if you have any questions when you get home, please phone the transplant unit. A familiar voice is often reassuring and the nurse or doctor can probably sort out any queries that you have over the phone.

During the days before you leave hospital, your nurses will help you with your plans for going home. The following section includes information that will

hopefully make this transition a little easier for you. Do not hesitate to discuss any of your worries with your doctor or nurse.

Things to look out for

You need to contact the hospital immediately if you develop any of the following symptoms.

Central line:

- shivering episode after flushing your line
- swelling, tenderness or pus around your line.

Bowels:

- diarrhoea or constipation that doesn't go away
- change in the colour or consistency of your stool
- stomach cramps.

Urine:

- change in colour
- pain or burning sensation
- red urine, clots or difficulty in passing urine.

Skin:

- appearance of a rash
- a rash that gets worse
- itching.

Temperature/shivering:

- a temperature over 38°C, with or without shivering
- shivering with or without temperature.

Pain:

- a headache that doesn't go away and doesn't respond to paracetamol
- stomach ache
- stomach cramps
- joint pain
- mouth lesions (for example, cuts, ulcers or abscess) or a sore throat.

Bleeding:

- any signs of bleeding or bruising – bleeding gums, blood in your urine or stool
- a nosebleed.

Cough or breathlessness:

- a new cough, or a cough that gets worse or doesn't go away
- shortness of breath or increasing shortness of breath
- a runny nose or sore throat, which can be an early sign of a respiratory virus (such as flu).

Feeling sick or vomiting

If this is new or is stopping you from drinking or taking your medication.

Medications

If, for whatever reason, you're unable to take your medication.

Contact with infection

If you think you might have had contact with anyone who has chickenpox, measles or shingles.

This is just a rough guide, and you may experience other symptoms that aren't included in the list above. If you do have a problem, or feel unwell, don't hesitate to call the hospital straight away. It's important and could be life-saving.

Re-admission to hospital

It's very common for people who've had a transplant to be re-admitted in the weeks or months following discharge from hospital. There are a number of reasons for this. If there's a problem, please don't delay in letting the hospital know. Try not to be too worried or disappointed if this happens to you.

Common reasons for re-admission are:

- Infections: bacterial, viral or fungal
- Feeling sick/vomiting, particularly if you're unable to drink or take your medication
- Diarrhoea, particularly if you're at risk of becoming dehydrated
- GvHD for people who have donor transplants: you may need closer monitoring and treatment.

Outpatient appointments

You need to be seen in the hospital as an outpatient quite regularly – sometimes two to three times a week – when you first go home.

Each time you go to the hospital you will have blood tests, and when the results are ready, the doctor will see you. Sometimes your doctor may arrange for you to have a chest X-ray or other tests when they see you. This is normal, and just part of the way your doctors keep an eye on your progress.

You may continue to need regular platelet or blood transfusions. These can usually be given to you at your outpatient unit.

You may also have formal clinic appointments in the outpatient clinic at the transplant centre. Here you have your progress reviewed and you'll have plenty of opportunity to ask questions.

You'll have outpatient appointments less often as your recovery continues.

Depending on your condition, you may need to have further tests following your transplant, such as scans and bone marrow tests. These tests and investigations can help your doctors to check your continuing progress and how your condition has responded to your transplant. These tests are fully explained to you as they are planned.

Don't forget that you don't need to wait until your next outpatient appointment to ask questions that might be bothering you.

Drugs to take at home

It's likely that you'll need to continue to take some of your drugs when you go home. The number and type of drugs depends on the type of transplant that you've had. The nurses will go through the drugs that you need to take and tell you how long you'll need to take them.

You're usually given a list of the drugs for your own record. It will be useful to take this list with you to your clinic appointments. At first you'll receive a supply of drugs for one to two weeks, and then you're able to get another prescription when you go to the clinic.

If you are taking ciclosporin when you go home, you need to have the ciclosporin levels in your blood checked when you go the clinic. This is done by taking a blood sample. It is very important that you do not take your ciclosporin in the morning of your appointment.



Risk of infection

Even though you're now well enough to go home, you're still at risk of infection as your white cell count is not yet normal. If you have had a donor transplant then your immune system will remain weakened (immature) for many months.

You'll need to continue with the same precautions that you began in hospital, and take some new ones, such as:

- having a daily shower
- washing your hands regularly
- taking care of your mouth regularly
- avoiding contact with people who have colds, flu or other viral infections
- avoiding contact with people who have been in contact with others, particularly children, who may have measles, chickenpox or shingles
- making sure that any pets that you have, if they can't be looked after elsewhere, are kept clean and free of fleas; and trying not to have close facial contact with them
- always washing your hands thoroughly after contact with pets
- avoiding fresh cut flowers and vases with old water in
- asking your healthcare team whether it's ok for you to do gardening and housework, and whether you should wear protective gloves.

You may begin a course of tablet antibiotics when you go home. These are to help prevent infections that can happen after your stem cell transplant. It's important that you continue to take these antibiotics until your consultant tells you to stop them.

You also need treatment to prevent you from catching a particular chest infection called pneumocystis jiroveci pneumonia (PJP).

This can be done by giving tablets or a solution (pentamidine) that you inhale through a nebuliser (a device that changes liquid into a mist that you can breathe). The nebuliser is given once a month and it takes about 30 minutes to complete each time. This treatment may continue for as long as six months, possibly longer for some people.

You should take your own temperature when you're at home, as this can tell you if you might have an infection – even if you feel well. Take your temperature at least once a day, or more often if you feel unwell.

Infections at home can get worse just as quickly as they can while you're in hospital, so if you do develop a temperature (38°C or above) you need to contact the hospital straight away. Temperatures are a common cause of re-admission to the hospital in the days and weeks after you go home. These temperatures often need urgent treatment and you

should never sit at home and wait for it to go away. If left untreated, these temperatures can develop into life-threatening infections.

Bleeding

You may still need to have platelet transfusions after you go home. You should contact the hospital straight away if you develop any new bruising, bleeding (for example, blood in your urine or stool), or if you get a nosebleed that will not stop.

Central line

If you're still needing regular transfusions (blood and platelets), you still need your line. It can be used for blood tests, as well as receiving infusions and transfusions. You'll still have these blood tests at each visit to the clinic and at other hospital visits, if needed.

The district nurse (a nurse who visits and treats you at home) can take care of your catheter for you, but you may find it much more convenient to learn to look after it yourself – or have your partner do it for you.

If you would like to learn how to look after your catheter, the staff at the transplant unit can teach you.

As soon as your blood counts are at a stable level, and your catheter is no longer needed, it's removed. This can be as early as day 100 after the transplant but is often much earlier than that. Sometimes, the line may even be removed before you are discharged from the hospital after your transplant. Having your line removed is a minor procedure and is nothing to worry about.

Fatigue

When you first go home after your transplant, no matter how keen you are, or how bored you may have been in hospital, it's common to feel tired at this stage in your recovery. This can continue for some time.

Your body has been through intensive treatment and you need time to heal and recover. If you have had total body irradiation as part of your treatment, you may feel these effects more than others who have had a transplant.

Take it easy at home: do gentle exercise and get plenty of rest. Have a sleep during the day if it helps. The important thing is not to worry. The tiredness could go on for several weeks, possibly even months in some people, but it will pass. Your nurse should be able to give you more advice about managing fatigue.

You may need to have occasional blood transfusions in the outpatient department. This is not uncommon and may help with your tiredness.

Exercise

Despite the fatigue it's important to keep active, as this can actually help to prevent some of the complications of the transplant.

At first, you probably won't feel up to much in the way of exercise. You need to start gently. Make sure you get up, shower and dress each day.

To begin with, this may feel like an incredible achievement. Soon you will be able to go for a short walk, even if it's just around the garden. The fresh air may feel wonderful and do you good after weeks in the hospital.

Gradually, you will be able to build up your physical activity, and within a couple of months you should be on your way to being back to your old self.

The journey to good health and your new normal often seems like a long one, but you have come a long way and you're almost there. It just takes time and patience.

Try to take it one day at a time. Achieving simple but realistic goals can be a huge boost to your confidence and help you to track your improvement.

Keeping a diary can help you to measure your progress over time, as you may quickly forget the improvements you have made as the weeks pass.

Emotional changes

It's also common to feel depressed or anxious at times. There are a lot of changes going on in your life at this time and you may feel that you don't need to depend on your carers as much, and you may even experience changes in your relationships with your partner and family.

You may feel the need to take back your role and some of your responsibilities in your family. This can be difficult to achieve overnight. Do make sure that the goals you set yourself aren't too hard to achieve in a short space of time. Don't be afraid to contact your healthcare team if you feel you need extra support.



My Diary provides space for you to write down your experiences and feelings. See **page 196** for how to order.

See our information about working with and after blood cancer at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

Avoiding crowds

Use your common sense to guide you in making decisions. You will need to avoid crowds, but this does not mean that you can't go out. If you want to go to public places, such as restaurants and shops, make sure that you avoid them during peak hours.

Touching people and physical contact is allowed, but you should limit this to family and others that are close to you.

Going back to work

There isn't one rule for everyone when it comes to the right time to return to work. This applies to you if you go out to work, or if you're a full-time housewife, husband, mother or father. As a rough guide, your healthcare team will advise at least four to six months off work, and many people who have had a stem cell transplant typically need to take up to 12 months off work to recover. This may be longer for people who have had GvHD or other complications.

You shouldn't consider committing yourself to the pressures of work until you feel fully able to cope. If you're able to go back part-time at first, that is best. Usually, whenever you feel ready is okay, but you should discuss it with your doctor first.

Appetite and diet

Your appetite has probably been lower while you've been in hospital. This is likely to dramatically improve as soon as you get home and away from the hospital food!

It's usually a good idea to eat small meals – little and often.

If you're having problems managing meals, consider having your food served on a small plate. A large meal often looks too difficult to manage and you can be put off as soon as you see it. It's common for partners and carers to spend a lot of time preparing your favourite meals for you. You may be quite fussy about your food. You might dream of a Sunday roast and then when it's cooked and served, you may have gone off the idea altogether. Choose food that can be prepared quickly and is tasty and easy to eat.

Go for things that you fancy. Maybe you've been craving something while you've been in hospital; now's your chance.

Even if you're not eating as much as usual, make sure that you drink plenty – aim for six to eight glasses a day.

You won't need to stick to the dietary advice quite as strictly once you go home, but do be sensible.

You should avoid eating takeaways from restaurants where the food is usually prepared in advance and then reheated. You should be eating freshly prepared food. You should also keep any alcohol to a minimum. Please ask your team for advice and guidance about food and drink during this time.

You may continue to experience taste changes for some time after your transplant. Sweet tastes often return to normal first – a good excuse to treat yourself and add extra sugar.

Your mouth may feel quite dry. Make sure you have a drink with your meals. You may find that adding gravy or a sauce makes it easier to eat your food.

You may also continue to experience some changes in your sense of smell. Cold foods tend to smell less than hot foods, so if smells make you feel sick (nauseous), try it cold.

If you're concerned about your diet and/or your weight, do ask to see an expert in diet and nutrition (dietitian).

Mouth care

You may need to continue with some mouth care once you are home. Your white cell count may still be lower than normal, so you need to protect your mouth from infections. Make sure you keep it clean, especially after eating.

You should let your doctor know if you notice any bleeding, ulcers or cold sores, or if you're having problems with your teeth. Don't visit your dentist unless you have discussed it with your doctor first.

Your mouth may also continue to be dry for some time, especially if you have had total body irradiation. Everyone finds their own way of managing this, but some suggestions include:

- increasing the amount you drink each day, especially with meals
- ice lollies
- boiled sweets
- chewing gum
- citrus fruits and tinned pineapple chunks (except grapefruit – while on ciclosporin)
- synthetic saliva sprays.

Skin care

Following your transplant, your skin may be drier or more sensitive than usual. If so, you may find it helpful to use baby oil, or another non-irritating oil or a watery (aqueous) cream such as E45.

If you develop a rash or your skin looks red, please contact the hospital straight away.

You need to be particularly careful in the sun. Sun damage can make your skin drier, increase your risk of skin cancers and, for people who've had a donor transplant, the sun can trigger GvHD. You'll be advised to avoid strong sunlight altogether for at least six months after your transplant, and then always use a sunblock.

Hair regrowth

Your hair will start to grow back, and you'll probably see a difference in a few weeks. When your hair does grow, don't be surprised if it's a different texture. People with straight hair before the transplant often develop curls during the first few months of growth. Sometimes, it's a slightly different shade than before.

These differences often disappear as your hair continues to grow. You'll be able to colour hair after it has grown back if you wish, but please speak to your healthcare team first.

Until your hair grows back, it's important to look after your scalp. Make sure it's covered when you go out in either hot or cold weather.

Sex

It's likely that your transplant will affect your sex life. At first, you may feel too tired for sex, or you may simply have a lower interest in sex at this time. This is common and it's likely that everything will return to normal in time. However, sexual dysfunction can persist in both men and women. It's quite a common problem, but it's often under-reported as people find these concerns difficult to talk about.

Sexual problems can be worrying and put an extra strain on your relationship, as well as affecting your self-confidence. It is known that when couples are sexually active during the first post-transplant year, they can have fewer sexual function problems. Help is available – please talk to your team as soon as you notice any problems with your sex life, so you can get the help and support you need.

It's often a good idea for women to use a lubricating jelly as the vagina may be drier than usual. Men should also use lubrication to prevent friction. It's recommended that you always use a reliable method of contraception, because although you may be infertile after your transplant, there are no guarantees. A barrier method of contraception such as condoms (with a spermicide) is generally suggested, as this also helps to reduce your risk of infection.

Some women may need to be referred for hormone replacement therapy (HRT), to address hormone imbalances after the transplant. Again, this will depend on the type of conditioning therapy and transplant you've had.

Foreign travel

It's not usually a good idea to plan a holiday abroad during the immediate months after your transplant, but in the longer term you may find that planning a holiday gives you something to look forward to and therefore helps your recovery. You should discuss any travel plans with your doctor. You will almost certainly need to get special travel insurance cover. Please ask your healthcare team for details.

You do not always need to be fully recovered from your treatment to be able to travel. If you do decide to travel, your healthcare team may be able to contact a local hospital to let them know that you will be in the area, so that you have a point of contact in case of an emergency.



Please see **Appendix B** for more information about early menopause.

**It's important to remember
that your recovery is an
ongoing process.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Step seven: Long-term recovery

The length of time it takes for you to fully recover from your transplant is a very individual thing and it depends on the type of transplant you've had.

Getting back to your old routine may not be exactly what you want at this stage. You may need or want to make some adjustments in your personal as well as professional life.

It's common to feel that your life has been put on hold by your ill health. Preparing to re-enter work and your family life can be difficult.

Occasionally, people feel as though they hit a wall during their recovery. Sometimes, recovery doesn't happen as quickly as you might have expected.

Some of the difficulties faced during the treatment or recovery can have a psychological impact and change the way you feel about life. Anxiety and/or depression can take hold after this treatment. Please seek help from your healthcare team if you are having such feelings.

You may be surprised to discover that your views and attitude towards many things may have changed. A few people have experienced a change of direction in their lives, more positive feelings towards others, appreciation of the simple things, and stronger relationships with their families, for example.

Many people can feel that their quality of life is better than before their illness, and are often surprised that they notice and value things in life with more enthusiasm.

Although the transplant is a serious time, most people are reassured by the results of their treatment and are very positive about their future.

Issues discussed in this step:

- Recovery of your immune system and vaccinations
- Possible late complications
- Chronic graft-versus-host disease

Recovery of your immune system and vaccinations

If you've had a transplant using your own stem cells (autologous), your immune system should recover within a few months. Some, but not all, transplant centres will arrange for you to have your childhood vaccinations if you had an autologous transplant.

If you've had a donor transplant, it can take up to a year – or even longer – for your immune system to recover. As a part of this type of transplant, your body's ability to resist the diseases that you were vaccinated against as a child (immunity) is damaged. After the first year you will see your doctor and they will decide whether you're ready to have your vaccinations. These include measles, mumps, rubella and the non-live polio vaccine.

The polio vaccine given by mouth (oral) is no longer in routine use, but if you have an infant at home, who has recently had the oral vaccine, you must avoid contact with their bodily fluids for six weeks. This is because the virus from this particular type of polio vaccine is shed in the urine and stool during this time. An alternative is to give your baby the non-live (inactivated) polio vaccine. Your GP will be able to give you advice on the vaccines available.

There is no need for isolation from family members who are having any of the other vaccines.

Possible late side effects

Infection

During the first year after a donor transplant, you may find that viruses that you or your donor have been carrying, but which have remained inactive (dormant), begin to function again (reactivate). There are a number of these, but the most common are the cytomegalovirus (CMV), Epstein-Barr virus (EBV) and adenovirus as well as the chickenpox (herpes zoster) virus.

These viruses can cause severe and, sometimes, repeated, lengthy infections. You'll have regular blood tests and examinations to look for signs of infection, and it may be necessary to be re-admitted to the hospital for treatment. However, for almost all people, the frequency and length of infections reduces with time after the transplant and as the immune system becomes stronger.

The infection that results from the chickenpox virus is called shingles. This can be painful and can cause scarring. You often need to be admitted to hospital for intravenous treatment with antiviral drugs, especially if this happens soon after your transplant or you are having lots of immunosuppressive treatment.

You may also be vulnerable to chest infections and you should report any symptoms – such as fever, cough, difficulty in breathing – to your doctor straight away.

Cataracts

Cataracts is a clouding of the lens of the eye. It causes blurring of your vision and, if left untreated, can eventually lead to blindness. However, treatment is now quite straightforward.

If you've had total body irradiation (TBI) as part of your conditioning therapy, then you are at a higher risk of developing cataracts during the first five years following your transplant. For this reason, you should have an eye examination every year.

Chronic graft-versus-host disease

Chronic graft-versus-host disease (GvHD) is a possible side-effect of a donor transplant. It can affect any part of your body, but most commonly affects the skin, and sometimes the liver and gut.

Chronic GvHD of the skin can cause it to become dry, scaly and discoloured, with patches of thicker and harder tissues underneath.

If the condition affects your eyes or mouth, they can become quite dry – and you may also suffer from mouth sores.

If you develop chronic GvHD of the gut, you may struggle to absorb nutrients and maintain your weight.

In some people, the condition can be quite extensive and, in its most severe form, can be fatal. However, it is generally easy to treat – often using immunosuppressive drugs. These will put you at greater risk of catching infections though, so you should take extra care.

Sometimes, chronic GvHD can linger and be very difficult to treat. If this happens, your healthcare team can try a number of different treatments.

Research has shown that people who develop GvHD have a lower risk of their disease returning than those who do not.



See **Step five: Waiting for engraftment** for more about this.

To find out more about long-term recovery after a donor (allogeneic) stem cell transplant, please see the booklet produced by Anthony Nolan: **The seven steps: The next steps.**

Final comment

You have now reached the end of this booklet. We hope that you have found it useful and that it makes your journey to recovery a little easier.

If you would like more information, the Health Information Team at Blood Cancer UK will be happy to help.

information@bloodcancer.org.uk

Or, for more practical or emotional support, please contact our Support Services Team:

support@bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri: 10am–4pm, Wed: 10am–1pm)

Appendix A

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Stem cell donation and harvesting

This section may be of interest to people who are donating peripheral blood stem cells or bone marrow, as well as to people with blood cancer or other conditions that can be treated with a stem cell transplant. The techniques used to collect peripheral blood stem cells or bone marrow from patients are almost the same as they are for donors, but there are some small differences.

How do we get the cells?

The cells for a transplant are collected from the blood or the bone marrow. These are called stem cells.

The process used to collect stem cells is called harvesting.

There are two ways that we can harvest the cells: either through a peripheral blood stem cell harvest, or a bone marrow harvest. These two procedures are explained in detail over the next few pages.

The type of harvesting procedure that is selected for you depends on certain factors, such as your type of disease, chemotherapy and treatment you've already had.

For donors, the two options are usually discussed at the time of the medical assessment or at the clinic appointment.

Routine virology screening

All donors and those receiving the stem cells need to have routine virus (virology) screening done before the harvest. This is done to prevent cross-infection when the cells are put into storage or infused at the time of the transplant.

The viruses routinely screened for are:

- HIV (type 1 + 2)
- Hepatitis B + C + E
- CMV
- HTLV 1 + 2
- EBV.

The results are usually available in a few days.

You may also be tested for:

- syphilis
- toxoplasma
- MRSA.

You'll be told about the nature of these tests before they are performed. If you need to discuss the test further with your consultant, please do so. You may wish to be offered counselling from a specialist health adviser before the test. If you would like more information, do not hesitate to ask. You have the right to see the results of all tests that are carried out. You or your GP will be told if any of these results are abnormal.

Peripheral blood stem cell harvesting

In healthy people, there are small numbers of stem cells circulating in the bloodstream; but not enough to collect for a harvest. It's now possible to move, or 'mobilise', stem cells from the bone marrow into the blood to provide adequate numbers for harvesting to be performed.

Mobilising your stem cells

The cells can be mobilised using growth factors, or using a combination of chemotherapy and growth factors.

Just using growth factors

This type of mobilisation is used for donors and people with blood cancer.

Growth factors are natural hormones that trigger cell production, and are given as an injection under the skin.

The growth factor used is called G-CSF, which stands for granulocyte colony stimulating factor. A number of people and donors have reported mild flu-like symptoms and moderate bone pain, often in the breastbone, hips and back, as side effects. A mild painkiller such as paracetamol should ease your discomfort. These effects disappear once the injections have stopped.

Using chemotherapy and growth factors

This type of mobilisation is only used for people receiving the stem cells.

You'll receive chemotherapy and then, as your cells recover, growth factor injections are given to mobilise the stem cells and stimulate recovery.

Separating your cells

Your stem cells are harvested by passing your blood through a machine (cell separator) You'll be connected to the cell separator by two tubes (one for the blood going out; one for the blood being returned).

You may need to be seen at the hospital before the harvest, so a nurse can assess your veins to see if they are suitable for the needles used to insert these tubes. If they are, a nurse will put a needle in one arm and another in the back of your hand. Because of this, your movements will be fairly restricted during the procedure.

If your veins are too small, you may need to have a temporary line or wide-bore catheter (a catheter with a wider diameter that allows blood to be drawn out and returned at higher speeds) inserted into one of the large veins in your groin by a doctor.

If you already have a tunnelled catheter or Hickman® line (a long, thin, flexible tube that's tunnelled under your skin and then placed into a vein), you may find that this is unsuitable for the harvest, so you may also need a temporary groin line.

Before the procedure starts, you will also need to let the doctor know that you're happy for it to take place (give your consent).

The cell separator contains a drum (centrifuge) that spins the blood at a very high speed without damaging the cells. This spinning separates the different cells in the blood into layers. The layer containing the stem cells is selected and the cells are collected in a bag.

This is a continuous process, and while blood is being spun in the centrifuge, the rest of the blood is returned to you through a return line. Any parts of the machine that come into contact with the blood are single-use only.

You can eat and drink normally while you're on the machine, so take a light snack or sandwich with you.

Each session takes about three to four hours, but you should expect to spend the whole day at the hospital or harvesting centre. You may need to arrive early for the first session to allow plenty of time for blood tests before the procedure starts. The harvest is normally completed in one or two sessions.

A third session is sometimes needed, but usually only applies to people who have already had many courses of chemotherapy.

You can bring someone with you and be driven home or accompanied on public transport. You're advised not to drive following the procedure.

Side effects

It's not unusual to experience some of the side effects listed below. If you report them immediately then they can be treated promptly and effectively, without the need to interrupt the procedure.

Although the cell separator removes and replaces only a small portion of blood at any one time (about a teacupful), changes in the amount (volume) of blood can make you feel dizzy, light-headed, cold or sick (nauseous). You should inform the nurse or doctor who is with you if you begin to feel uncomfortable.

The medicine used to prevent the blood in the machine from clotting (anticoagulant) may cause a sour taste in your mouth, tingling around your lips, cheeks or fingertips, or in other areas where you may have sensitive nerve endings. This can very easily be treated by taking a tablet called Calcichew® – which tastes like an orange lozenge – or you could have a glass of milk.

It's a good idea to have breakfast the morning of the harvest since this seems to reduce this side effect. Also, an extra glass of milk or some cheese the night before the harvest will help to give you a little extra calcium.

Once again, you should inform the nurse or doctor who is with you if you experience any of these symptoms.

You will probably feel quite tired following the procedure and will need to rest.

Bone marrow harvesting

This type of harvesting is carried out in an operating theatre under a general anaesthetic. It's considered a very safe procedure and is routinely carried out in very large numbers of volunteer donors without any significant problems.

Your bone marrow is collected from the back of your hips (iliac crests) and, on occasion, from your breastbone (sternum). A special needle is inserted through your skin into the bone and the liquid marrow is drawn off.

The harvest takes about an hour to complete and about 1 to 1.5 litres of marrow is removed. This amount of bone marrow is replaced very quickly (within about three weeks) and the procedure does not affect your blood cell production.

The bone marrow that is taken contains a number of red blood cells and they may need to be replaced with a blood transfusion of one or two units. This may be given in theatre or when you return to the ward. When you come back from the operating theatre, you'll usually have an intravenous drip of fluid to help replace the fluid that is drawn off with the bone marrow stem cells.

For some people, immediately following the harvest, the bone marrow may be 'processed' to filter out and remove the extra red blood cells, fat and other

unwanted particles. This also reduces the volume of the end product to less than 100ml. The stem cells can be used straight away, or can be frozen and stored for months or even years.

For a healthy bone marrow donor, whose normal blood level is on the low side of normal, it may be necessary to donate one or two units of blood a couple of weeks or a month before the harvest. This removes any slight risks of transfusion-related transmission of blood-borne viruses.

Admission procedure

You're usually admitted to the hospital the day before the harvest. When you arrive at the hospital, you may need to have some routine blood tests. You may also be seen by the doctor to discuss the procedure and to sign your consent form.

As part of giving consent, you'll be given information about:

- the purpose of harvesting,
- the possible benefits of the donation,
- how it will be done,
- any risks or consequences,
- any tests that may be carried out beforehand, and
- the safeguards to protect you.

The healthcare professional giving you the information will make sure that you understand it and will offer you the chance to ask questions.

As well as taking your nightwear, you may wish to take in some books or magazines.

You're not allowed anything to eat or drink from midnight the night before theatre, but you will be allowed to drink when you return.

In the morning, you will be asked to shower and put on a hospital gown. No powder, creams or make-up should be used after showering, and any nail polish should be removed. Contact lenses and any jewellery, except a wedding ring, should also be removed.

You will usually need to stay in hospital for two nights: the night before and the night after the procedure.

Side effects

There is a very small risk associated with the general anaesthetic, but if you have any concerns about this, do not hesitate to discuss them with your doctor.

It's likely that you'll feel a little sore following the procedure, but the use of mild painkillers such as paracetamol should be enough to help.

You may be slightly anaemic when you go home, and for donors a prescription of iron tablets will correct this over the following weeks.

Most people are able to go back to normal activity after a few days and will feel perfectly normal after a week or two.

Donor lymphocyte collection

In some cases, another collection is taken from the blood of the donor. This may take place around the time of the stem cell harvest or performed at a later date if needed.

The cells that are collected are called lymphocytes, and these can be used to help prevent or treat relapse of the disease.

The cells are collected in the same way as in a peripheral stem cell harvest (described in the section that starts on page 143); the big difference is that there is no need to 'mobilise' the cells or give any growth factors. The lymphocytes are readily available in the blood stream.

The process of collecting the lymphocytes is usually completed in one session of around three hours.

Storage of cells

When the cells are harvested, they can be used straight away or frozen and stored until they are needed. The latest technology and equipment is used to make sure that the cells are stored safely. Cells can be stored for many years this way, although many centres have a policy of storing cells for a set number of years.

You will be told of your hospital's policy on how long cells are stored and what is done if they are no longer to be kept. If your cells have been stored and the hospital is no longer able to keep them, you may be offered a chance to have them stored elsewhere.

When the cells are frozen, a preservative is added to them to protect them from damage during the freezing process.

Research and development continues and over the years the methods of storage and equipment may change.

Time off and return to work

Following a peripheral stem cell harvest

You should be able to work as normal on the days that you have your G-CSF injections, but you'll need to take time off work for the day(s) of the harvest.

You will be fit to return to work the day after the procedure(s). However, you may wish to take another day off too as the harvest can be tiring.

Following a bone marrow harvest

Bone marrow donors may need to take time off work before the harvest so that one or more unit(s) of blood can be pre-donated if needed.

You will need to take time off for the two days in hospital and anything up to a week after the procedure to recover.

Appendix B

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Early menopause following a stem cell transplant and high-dose chemotherapy

The menopause is when a woman stops having periods. It happens when your ovaries stop producing the hormone oestrogen and no longer release an egg each month.

This may not be your main concern at this stage of your preparation but, for women, the high-dose chemotherapy and/or radiotherapy that you receive before your transplant is likely to damage your ovaries. This can often lead to early menopause.

The menopause usually happens in your late 40s or early 50s, but early menopause as a result of treatments such as chemotherapy and radiotherapy can happen at any age.

When menopause happens because of treatments, it can come on quite suddenly. Since your ovaries cannot be protected during your treatment, this can't be prevented.

When the menopause happens, the levels of the hormones oestrogen and progesterone in the bloodstream are changed. Your body has to adapt to these changes. Often this happens with few or no problems, but sometimes the lack of progesterone and oestrogen alongside the other changes can lead to other conditions, especially if the menopause has happened at quite a young age.

The hormonal changes can affect you in different ways.

Changes in periods:

- missing your periods
- shorter times between your periods
- less frequent periods
- irregular cycle length
- lighter flow
- heavier flow.

Physical symptoms:

- hot flushes
- sweats
- dry skin
- dry hair.

Genital changes:

- vaginal dryness
- itchiness
- tenderness
- poor libido or lower interest in sex.

Other symptoms:

- headaches
- joint pain
- anxiety
- tension
- depression
- irritability.

For about 5% of women with early menopause, the ovaries become active again after a period of time and a very small number of women have become pregnant. It's for this reason that you should use some form of contraception after your transplant if you do not wish to become pregnant.

Long-term effects of early menopause

Although many of the early symptoms of menopause do lessen with time, there are other symptoms that can be more long-lasting or even permanent.

Infertility

Because you're no longer able to produce eggs once you've been through the menopause, you will no longer be fertile.

Osteoporosis

Your ovaries make the hormone oestrogen. This hormone helps to prevent osteoporosis, which is a condition where the bones become brittle and more likely to break. Osteoporosis is preventable and if it happens it can be treated effectively.

Heart disease

The risk of coronary heart disease is increased in women who are post menopause. It's thought that oestrogen helps to protect the heart. However, there are treatments available that can reduce the risk of heart disease.

Low sex drive

The start of the menopause does not mean the end of your sex life. However, many women do



The effects of high-dose chemotherapy and bone marrow transplants on fertility are explained in **Step one: Planning ahead.**

The Daisy Network is a support group for women affected by early menopause. Visit daisynetwork.org to find out more.

experience a lower sex drive during and after the menopause.

Remember, the menopause is not the only reason that you may feel less interested in sex. You have been through intensive treatment. Recovery from this treatment is at best tiring, and at worst exhausting. You may have feelings about the way you look. You may have lost weight, gained some bruises and/or lost your hair. There are many reasons why you may not feel 'sexy' after your treatment.

Don't keep your concerns to yourself as this can easily place added strain on your relationship. Try to discuss your feelings with your partner and if you feel you need extra support, please ask your healthcare team.

Treatment

The first step you should take if you begin to experience any of the symptoms associated with the menopause is to tell your consultant.

There are treatments available for your symptoms, which you may choose to take, in the form of hormone replacement therapy (HRT).

HRT contains low doses of oestrogen that help to replace your body's own oestrogen, which is lost during the menopause. The most common form of HRT is tablet, but it's available as a patch that can be worn like a sticky plaster on your skin, as a cream, and even as an implant.

HRT in tablet form is usually taken as a continuous monthly course of 28 days of oestrogen tablets combined with a ten- to 14-day course of progestogen, which produces a regular withdrawal bleed, or 'period', and helps to protect the lining of the womb.

You may be given HRT for up to two years. Some women may be given HRT on a long-term basis (for five to ten years or more), particularly if you're at risk of developing osteoporosis. You're advised not to stop any of these therapies without first consulting your doctor.

Below are some facts about HRT:

- HRT replaces the natural hormones that are lacking during the menopause.
- HRT relieves hot flushes, vaginal dryness, frequent urination and other unpleasant symptoms that can be caused by the lack of oestrogen.
- HRT helps to prevent thinning of the bones.

- HRT can help to improve your emotional state.
- HRT can be taken as tablets, creams, patches or implants.
- HRT is not a contraceptive pill. If there is any chance that you might still be ovulating and you do not want to have a baby, you should use contraception.
- HRT using combined oestrogen and progestogen is not thought to increase the risk of cancer of the lining of the womb, but some studies have shown a small increased risk of breast cancer – your doctor can tell you about the latest evidence and your level of risk.
- HRT occasionally causes breast tenderness or nausea, but this can often be cured by changing to a different tablet.
- HRT can help many women, but it's not suitable for everyone. Your doctor or clinic will be able to give you advice on what is best for you.

It's worth remembering that while HRT is used often, it's not the only treatment available for early menopause. Before you start any treatment, make sure that you ask questions about the other options.

Appendix C

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Total body irradiation (TBI)

Radiotherapy is sometimes used in stem cell transplantation. This form of radiotherapy is known as total body irradiation or TBI. The radiotherapy is given as high energy X-rays that affect your whole body; however, your normal cells are able to recover from the effects.

TBI treatment

For the actual TBI treatment, you sit in a chair, or lie on a couch, to one side of the radiotherapy machine for about eight minutes. You may have some gel packs placed around you to provide a uniform shape for the treatment. The chair is then turned around so that the other side of your body can be treated.

The treatment is not painful; in fact, you cannot see or feel it at all. You're alone in the treatment room during the treatment. The staff are at an operating console just outside the door and can see you on a TV monitor.

There is often a music player in the treatment room and a range of music you can play, but if you have strong preferences then you can take your own music with you.

You're usually treated twice a day, in the morning at around 8.30am and in the afternoon or evening usually around 4pm. There must be a minimum of six hours between treatments.

Depending on the type of transplant you're having, you may have as many as six to eight treatments over three or four days, or a single low-dose TBI treatment.

Side effects

Your doctor will explain the effects of the treatment to you. If you have any questions about the treatment or the side effects, please ask.

Short-term effects

While you're having the treatment, and after it finishes, you will be given several drugs to reduce the following side effects as far as possible.

Nausea and vomiting

Sickness (vomiting) is rarely a problem. You're given drugs to control it, which work very well. Feeling sick (nausea) can be a problem for a few people but it usually settles down after a couple of treatments. If you continue to feel sick, tell the radiographers or nurses who are caring for you, and they can try to make you feel more comfortable.

Hair loss (alopecia)

You may have already lost your hair as a result of chemotherapy. The effects are very similar following this sort of radiotherapy. The hair on your head falls out about ten to 14 days after the treatment. Other body hair may or may not fall out – everybody is different. Your hair regrows after several months.

Mucositis

Mucositis is inflammation of the inside of the mouth, tongue and throat, and is common after TBI. Good mouth care during and after treatment will help to reduce this. Once your treatment begins, changing and using a good mouthwash will help to reduce problems associated with mucositis.

Parotitis

This is inflammation of the parotid salivary glands, which are in your cheeks, just in front of the ears. The inflammation may cause some stiffness in your jaw but this usually settles after a few hours.

These glands produce most of your saliva and may stop working for a few days or weeks following the treatment. This can make eating uncomfortable. You may find that drinking more, especially with meals, or eating meals with gravy or sauces, is helpful.

Erythema

Some people, especially those with fair skin, may experience some reddening of the skin. This usually disappears within a couple of days of completing the treatment.

Diarrhoea

A few people experience a little diarrhoea during, or at the end of, their TBI. If your symptoms continue and become a problem, medication can be given to you. Please let your doctor know if you have a problem.

Cataracts

This is a clouding of the lens of the eye; it causes blurring of your vision and can eventually lead to blindness. There is a risk of developing it after you have had TBI. It tends to develop after about two years, although it can take longer. It is easily treated.

Pneumonitis

This is inflammation of the lungs, which may cause breathlessness or a dry cough.

Infertility

You may already be infertile as a result of the chemotherapy you received before this treatment. If you're not, the combination of the chemotherapy and the TBI will almost definitely make you infertile.

Long-term effects

Second cancers

In the future, partly because of the TBI you've received, there is a very slight increase in your risk of developing a second cancer. This could develop anywhere in the body, but is more common in particular organs, such as the skin. Because of this, you will be encouraged to attend lifelong follow-up checkups. Applying the right factor sun cream, not smoking and following a healthy lifestyle can all reduce your chances of developing a second cancer later in life. If you do notice any changes in your body after treatment, speak to your doctor.



Please refer to the section on fertility in **Step one: Planning ahead.**

If you'd like to find out more about long-term recovery after a stem cell transplant, please see the booklet produced by Anthony Nolan: **The seven steps: The next steps.**

Appendix D

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Clinical trials

Before starting the treatment for your transplant, you may be given information about a clinical trial or study. Perhaps you may have seen some information about trials on the internet.

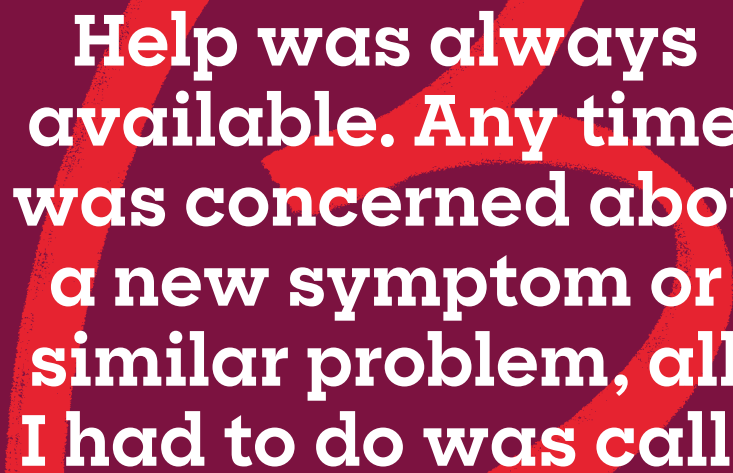
There are many types of trials. Some are run internationally (by international organisations or pharmaceutical companies); others are funded by the government (Medical Research Council trials); some by charities, such as Blood Cancer UK or Cancer Research UK; and others are performed 'in-house', for example, only at the hospital where you're having treatment.

Clinical trials sometimes test new treatments – for example, chemotherapy – but more frequently they explore new combinations of existing treatments or changes in the way they are given. This is either to make them more effective or to reduce side effects. Trials are the only reliable way to find out if a different type of chemotherapy or a stem cell transplant is better than that already available.

Clinical trials are carefully designed to lessen the risks and improve the benefits to all people who take part, regardless of which treatment they get. The trials are designed by groups of medical and other specialists.

All trials that are carried out within a hospital will have received ethical approval from the hospital's ethics committee.

You do not have to take part in clinical trials and this will not affect the care you receive. If you do take part in a clinical trial, and then wish to withdraw from that trial, the care that you receive will not be affected.



Help was always available. Any time I was concerned about a new symptom or similar problem, all I had to do was call.

Appendix E: Glossary

Some drugs used in treatment

Antibiotics

Drugs that kill or stop the growth of bacteria – for example, penicillin. These can be taken by mouth (orally) or through a vein (intravenously).

Antiemetic

A drug to prevent or ease sickness and vomiting that sometimes happens as a side effect of chemotherapy. Drugs of this type include metoclopramide (Maxalon®) and ondansetron (Zofran®). These can be taken orally or intravenously.

Antifungals

Drugs used to fight fungal infections. These can be taken orally or intravenously.

Antiviral

Drugs used to fight viral infections. These can be taken orally or intravenously.

Chemotherapy/cytotoxic drugs

Treatment using anti-cancer drugs. These may be used on their own or in combination with other drugs to kill or prevent the growth and division of

cells. Although aimed at cancer cells, chemotherapy will also affect other rapidly dividing normal cells such as those in your hair and gut, which can cause hair loss and make you feel sick (nauseous). These side effects are usually temporary and reversible. These can be taken orally or intravenously.

Ciclosporin A

A drug used to prevent and treat rejection and graft-versus-host disease in transplant patients by suppressing their normal immune system.

Diuretic

A drug to trigger your kidneys to produce urine. It may be used during chemotherapy to make sure the anti-cancer drugs are removed from the body. These can be taken by mouth (orally) or through a vein (intravenously).

Growth factors

These are proteins produced by the body to control growth, division and ageing of blood cells by the bone marrow. They are used to stimulate your body to produce white blood cells following chemotherapy or a stem cell transplant – for example, G-CSF, GM-CSF. These can be given through the skin (subcutaneously) or intravenously.

Sedative

A drug that has a calming effect.

Steroids (corticosteroids)

A group of synthetic hormones – including prednisone, prednisolone, methylprednisolone and dexamethasone – used in the treatment of some leukaemias, lymphoma and myeloma. It is also used to suppress graft rejection and graft-versus-host disease following a stem cell transplant. Side effects include an increased risk of infection, rise in blood pressure, peptic ulcers, diabetes and osteoporosis. These can be taken orally or intravenously.

General terminology

Allogeneic stem cell transplant

A transplant using stem cells collected from a healthy donor – often a brother or sister, but can also be from an unrelated registered donor. It is also called an allograft transplant.

Alopecia

The loss of hair. This is a side effect of some forms of chemotherapy or radiotherapy used to treat leukaemia and other cancers, which is usually temporary.

Anaemia

A lack of oxygen in the oxygen-carrying pigment, haemoglobin, in the blood. Anaemia causes tiredness, breathlessness and can make you look pale.

Antibodies

Naturally produced substances in your blood that destroy or neutralise certain toxins or 'foreign bodies' – for example, viruses. They are produced by the white blood cells known as lymphocytes in response to exposure to antigens.

Autologous stem cell transplant

It is also called an autograft transplant. A blood stem cell transplant using your own marrow or peripheral blood stem cells, which have been collected and stored at an early stage of the disease.

Bacteria

Microscopic organisms that cause many types of infectious disease – for example, pneumonia. People have a lower ability to fight infections following chemotherapy treatment or a stem cell transplant. This may mean that even harmless bacteria – for example, those that are normally found on the skin – may cause serious illness.

Biopsy

A small sample of fresh tissue – for example, lymph node or bone marrow – removed to be analysed in the laboratory to confirm an exact diagnosis of disease.

Blood cells

There are three main types of cells in the blood stream: the red cell, which carries oxygen; the white cell, which fights infections; and the platelets, which help prevent bleeding. The correct balance between each cell type must be maintained to keep us healthy.

Blood count

A routine test using a small blood sample to measure the number and types of cells circulating in the blood.

Bone marrow

The tissue that produces the blood cells. It's found within the hollow cavities of many of the bones of your body. Bone marrow contains the stem cells from which all blood cells are made. Examining the bone marrow can be an important part of diagnosing blood cancer and monitoring treatment.

Bone marrow aspirate

A small volume of liquid bone marrow removed under local or general anaesthetic from either your hip (pelvis) or breastbone (sternum). The cells in the sample can then be examined under the microscope to find any abnormality in the developing blood cells. A trephine biopsy, where a small 'core' of bone marrow tissue is removed under local anaesthetic, may be taken at the same time.

Bone marrow transplant (BMT)

See 'Stem cell transplant (SCT)'.

Cannula

A tube for insertion into the body, usually into a vein, by a sharp needle-type fitting, which is then withdrawn from the cannula to allow fluids to pass through the tube.

CT scan

A computed tomography (CT) scan is a sophisticated X-ray technique used to produce detailed internal images of the body, particularly the chest and abdomen. You'll lie on a couch that gradually moves through the X-ray machine, and the image is built up by a computer as a cross-section through your body.

Catheter

A hollow tube inserted into organs of your body for receiving or removing gases or liquids. For example, for the removal of urine from the bladder.

Cells

The individual units from which tissues of the body are formed.

Central nervous system (CNS)

The brain and spinal cord.

Central venous catheter

A line passed through a blood vessel into a large central vein, used for people having intensive therapy and to provide a way of taking blood samples and giving drugs without repeated needle puncture of a vein. See Hickman® line and Portacath®.

Cerebrospinal fluid (CSF)

The fluid that surrounds and protects your brain and spinal cord. Samples can be taken by lumbar puncture.

Chromosomes

Chromosomes carry the 30,000 or so genes that provide the inherited blueprint of every person. In humans there are normally 23 pairs contained in the nucleus of each cell. Alterations in the number or organisation of the chromosomes may play a key role in the development of cancer.

Contrast

A fluid that is used in certain tests to show up or highlight organs or parts of the body.

Cord blood

Blood taken from the umbilical cord of a baby at the time of birth.

Cord blood stem cells

Stem cells recovered from cord blood, which have been shown to have the ability to re-populate bone marrow and produce blood cells.

Cytogenetics

The study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow taken from those with blood cancer to detect any chromosomal abnormalities associated with the disease. These help in the diagnosis and selection of best treatment.

Cytomegalovirus (CMV)

A virus that is harmless in healthy people but may cause serious illness in severely immunosuppressed people. This is particularly dangerous following a bone marrow transplant.

Cytopenia

A reduction in the number of cells circulating in the blood.

DNA

Deoxyribonucleic acid (DNA) provides the essential building block for storing genetic material. There are four different chemical parts of DNA (bases) arranged in a coded sequence as genes that determine a person's inherited characteristics.

Donor lymphocyte infusion (DLI)

People that have had an allogeneic bone marrow transplant and relapse (the disease returns) may be given lymphocytes from the same donor. This procedure may get rid of the blood cancer cells.

Engraftment

When the donor cells start to grow and make healthy blood stem cells.

Epstein-Barr virus (EBV)

A common virus that infects B-cells.

Fungus

An infective agent such as a mould or yeast, causing particular problems in immune-suppressed people – for example, Candida.

Graft rejection

Rarely, when someone has an allogeneic stem cell transplant, the new bone marrow will fail to start producing blood cells, or may stop producing cells later on after the transplant. This is called graft rejection. It may be possible to do a second transplant using cells from the same donor or a different donor.

Graft-versus-host disease (GvHD)

A possible side effect of allogeneic stem cell transplants; where some of the donor's immune cells recognise your own cells as foreign and attack

them. It tends to occur in the skin, liver or gut, but can also affect other parts of the body. GvHD has chronic and acute forms; both are treatable with immunosuppressive drugs.

Graft-versus-leukaemia (GvL)

Describes the effect of allografted stem cells in attacking leukaemia cells. If graft-versus-host disease is present but not severe, it may be beneficial in helping to kill off leukaemia cells. If all the T-lymphocytes are removed from an allogeneic stem cell transplant it minimises the risk of graft-versus-host disease but increases the risk of relapse.

Granulocyte

A type of white blood cell. They protect the body against infection by seeking out and killing microorganisms. Neutrophils are a type of granulocyte.

Haploidentical

This means 'half-matched'. It's a term used in finding a tissue-type match for someone who needs a transplant.

Haematologist

A doctor specialising in the diagnosis and treatment of blood diseases.

Haematology

The study of blood diseases, including leukaemia, lymphoma, myeloma, myelodysplastic syndromes (MDS) and aplastic anaemia.

Haematopoiesis or haemopoiesis

A term to describe the production and ageing of blood cells from very early stem cells. This takes place in the bone marrow, which is a spongy tissue at the centre of your bones.

Haemoglobin

The iron containing pigment in red blood cells that carries oxygen around your body. Lack of haemoglobin is called anaemia. Normal values are 130g/l to 180g/l of blood in men, and 115g/l to 160g/l in women.

Haemorrhage

Bleeding to the outside of the body, through the skin or internally.

Hepatitis

When the liver is inflamed.

Hepatomegaly

When the liver is enlarged.

Hickman® line

A narrow plastic tube or catheter, which is inserted into a major blood vessel in the chest under

anaesthetic. It's used for people undergoing intensive therapy and provides a way of taking blood samples and giving drugs without repeated needle puncture of a vein.

Histology

The study of the microscopic make-up of cells and tissues.

Immune compromised/

Immunocompromised

When the body's defence system is weakened.

Immunoglobulins

Proteins in the blood plasma that function as antibodies and play an important part in controlling infections.

Immune suppression/Immunosuppression

When the body's defence system is weakened by treatment. Your doctors suppress your immune system deliberately as part of the bone marrow transplant procedure to prevent graft-versus-host disease and graft rejection.

Intensification

Increasing the amount, number, or combination of anti-cancer drugs given to you, in an attempt to kill drug-resistant or remaining blood cancer cells.

Intramuscular injection

Injection into the muscle.

Intrathecal injection

Injection of drugs into your spinal fluid to prevent or treat CNS leukaemia or lymphoma.

Intravenous infusion

Administration of antibiotics, blood products, anti-cancer drugs or nutrients into your vein over a long period of time.

Intravenous injection

The application of drugs into a vein through a syringe.

Late effects

These are the results of chemotherapy and/or radiotherapy, which may only show up after long-term monitoring over a period of years.

Leukocytes

This is a term for white blood cells.

Lumbar puncture

A procedure for removing spinal fluid from around the spinal cord using a fine needle in the lower part of the back. Samples are analysed for evidence of any CNS leukaemia. It's also used to give anti-cancer drugs to either prevent or cure CNS disease.

Lymph nodes or glands

Small structures found throughout the body – for example, the neck, groin, armpits and stomach, that contain mature and immature lymphocytes.

Lymphatic system

This system includes your spleen, lymph nodes and areas of lymphoid tissue, such as the tonsils. It's a major part of the body's immune response.

Lymphoid

This means the lymphatic system and includes lymphocytes and lymph nodes.

Magnetic resonance imaging (MRI)

A body scanning technique that uses an intense magnetic field to make images of your internal organs. Normal and cancerous tissue are different, and any malignant (cancerous) tumours can be visualised by computer processing of the signals that can be detected.

Maintenance treatment

Treatment given for a period of months or years to maintain remission and get rid of any residual blood cancer cells in the body, usually for acute lymphoblastic leukaemia.

Medical Research Council (MRC)

This is a government-funded body 'to promote the balanced development of medical and related biological research' in the UK. It organises national clinical trials for the assessment of new treatment plans for blood cancer and some related diseases.

Mucositis

Inflammation of the mouth and throat that may be caused by anti-cancer drugs.

Multi-drug resistance (MDR)

Multi-drug resistance happens when blood cancer cells eliminate anti-cancer drugs before a high enough concentration to kill the cells happens. Resistance against most drugs will make the blood cancer very difficult to treat.

Myeloablative conditioned (MAC) transplant

Where very high doses of chemotherapy, with or without radiotherapy, are used to prepare the body for a stem cell transplant.

Myeloid

This is the term for the non-lymphocyte groups of white blood cells. It includes cells from the white cell (granulocyte and monocyte), red cell and platelet families.

Neuropathy

Damage to the nerves that may happen as a complication of anti-blood cancer treatment. It usually affects the peripheral nerves (nerves to the arms and legs) and may be reversible when treatment is stopped or reduced.

Neutropenia

A condition in which the neutrophil count is reduced. It may be caused by high-dose chemotherapy and carries a higher risk of infection.

Neutrophil

The most common type of cell within the granulocyte group of white blood cells.

Oesophagus

The part of your digestive tract between your throat and stomach.

Oncologist

A specialist in the diagnosis and treatment of cancer.

Palliative care

A treatment aimed at relieving your symptoms and pain, rather than curing the disease.

Pancytopenia

A condition in which there are reduced numbers of all types of blood cells.

Paraprotein

Paraprotein is a form of antibody that is made by a clone (group) of cells of the B-cell type.

People with myeloma will have paraproteins.

Its presence in the blood can help doctors to diagnose certain conditions.

Pathologist

A doctor who specialises in the cause and diagnosis of disease and how disease affects the organs of a body.

Peripheral blood stem cell (PBSC)

There are small numbers of stem cells in the circulation. These are known as peripheral blood stem cells.

Peripheral blood stem cell transplant

The use of peripheral blood stem cells as an alternative to bone marrow transplantation. The stem cells are taken by using growth factors given to the donor to increase numbers in the circulation to a level where they can be harvested.

Petechiæ/purpura

Small red or purple pin-head spots on the skin. They are small haemorrhages (see definition on page 182) and usually the result of a shortage of platelets.

Plasma cells

Large cells that come from the lymphocytes that form antibodies. These are not normally found in circulating blood but are instead in your bone marrow and lymph nodes.

Platelets or thrombocytes

They are tiny cell-like bodies that come from a parent cell, called megakaryocytes, in the bone marrow. Platelets circulate in the blood and play an important role in preventing and controlling bleeding. Normal values of platelets are 150 to 400 x 10⁹ per litre.

Portacath®

A type of central venous line in which the whole of the line is surgically implanted within the body, unlike a Hickman® line. A membrane just below the skin gives access by a simple skin puncture to a line running straight into one of the main blood vessels. This can make it easier for your doctors to give you chemotherapy.

Prognosis

An assessment of the likely outlook of your disease. This can mean the chances of cure and complete recovery or length of survival.

Prophylaxis

A treatment given with the aim of preventing a disease occurring.

Protocol

A schedule of treatment. For example, the number, frequency and timing of a course of anti-cancer drugs.

Pruritis

Itching, sometimes severe, which may be a common symptom in lymphoma.

Radiology

The use of X-rays to diagnose a disease.

Radiotherapy

The use of X-rays and other types of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated and is therefore very good at treating disease in one place in the body, particularly in lymphoma and myeloma. Side effects vary depending on the type of treatment – this can be discussed between you and your healthcare team.

Red blood cells or erythrocytes

The cells of the blood that contain the red pigment haemoglobin and carry oxygen to all the tissues of the body.

Reduced intensity conditioned (RIC) transplant

Where the conditioning therapy used to prepare someone for a stem cell transplant is given in low

doses, so that it is tolerated by older or less-fit individuals but is still strong enough to help the donor cells engraft.

Relapse

When a disease returns. In leukaemia this may be shown by changes in your blood, bone marrow, central nervous system (CNS) or testicles, even before you may experience any symptoms.

Remission

When your blood, bone marrow and general health have returned to normal, because of the chemotherapy and/or radiotherapy.

Remission induction or induction treatment

The first course of treatment given to people on admission to hospital to remove all detectable cancer.

Septicaemia

This is a general term to describe serious bacterial infection of the bloodstream, which is often associated with high fever.

Serum

The part of your blood that remains after cells, platelets and fibrinogen (proteins that help the blood to clot) have been removed.

Specimen

A sample of tissue, blood or urine, for example, taken for examination.

Sinuses

A large channel between your brain and skull.

Spleen

The spleen acts as a filter of your blood. It can selectively remove old red blood cells and bacteria and other foreign bodies. The spleen also acts as a store for platelets. It's often enlarged in leukaemia.

Splenectomy

Surgical removal of your spleen. This is sometimes done in leukaemia or lymphoma as part of your treatment.

Splenomegaly

When your spleen is enlarged.

Staging

An assessment of the spread of disease through the body – for example, in lymphoma. It's important to stage your condition so that the best treatment is selected.

Stem cells

The earliest blood cells in the bone marrow, from which all the various types of blood cells come from.

Stem cell transplant (SCT)

The term now used instead of bone marrow transplant (BMT). SCT is a procedure used in the treatment of a range of blood disorders including leukaemia, lymphoma and sometimes myeloma.

You'll receive very high doses of chemotherapy and/or radiotherapy to treat your disease and suppress your immune system. This damages your bone marrow and makes the blood count fall.

Replacement marrow is taken from a matched donor (allogeneic bone marrow transplant), or from yourself (autologous bone marrow transplant) under a general anaesthetic and returned to you through a vein (or central venous line) in a similar way to a blood transfusion. Peripheral blood stem cells may be used instead, especially for autograft transplants.

Subcutaneous injection

An injection into tissue immediately under the skin.

Syngeneic

Means 'sharing the same genes'.

It is the term used to describe bone marrow or peripheral blood stem cell transplants between identical twins.

T lymphocyte (T cell)

A type of white blood cell that comes from the thymus (hence T cells) involved in controlling immune reactions and in fighting viral infections. Uncontrolled production (proliferation) of this type of cell can lead to T-cell leukaemia/lymphoma.

Thrombocytopenia

Shortage of platelets, which can lead to problems with bleeding.

Thrombosis

The development of a clot in a blood vessel, usually in a vein but sometimes in an artery. It's potentially life-threatening if left untreated.

Total body irradiation (TBI)

Radiotherapy often given in several doses, or a single low dose, to the whole body, before a stem cell transplant with the aim of killing any blood cancer that remains. It's used with other anti-cancer drugs, often in high doses as part of a MAC transplant regimen. Your healthcare team can discuss the procedure and its side effects with you.

Trephine biopsy

Removal of a small 'core' of bone marrow under local anaesthetic. It's used to assess the structure of your bone marrow, the number and amount of all the blood cell types. The trephine biopsy is normally done at the same time as a bone marrow aspirate.

Ultrasonography (ultrasound)

Pictures of your body's internal organs built up from the interpretation of reflected sound waves.

Virology

The study of viruses and viral diseases.

Virus

An infection, which relies on the cell it infects for its replication and survival.

White blood cells (leukocytes)

They make up several different types of cells within three main types: granulocytes (mainly consisting of neutrophils), lymphocytes and monocytes.

They are formed in the bone marrow and it's their uncontrolled production that leads to leukaemia.

Normal values are within the range
4 to 11×10^9 per litre.

X-rays

Used to diagnose conditions and stage lymphoma and myeloma. Also used to diagnose a chest infection, for example.

Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

Booklets

Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

Treatment and beyond

- Blood stem cell and bone marrow transplants: the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

My information folder

An A5 folder to keep your information in.

Fact sheets

Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

To order or download information

Visit **[bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)**

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email **support@bloodcancer.org.uk**

Or use the order form on **page 208**



**We're a
community
dedicated to
beating blood
cancer.**

About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

Because it's time to beat blood cancer.

Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: [bloodcancer.org.uk/campaigns](https://www.bloodcancer.org.uk/campaigns)

Because we'll beat it together

Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

bloodcancer.org.uk/donate

Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **bloodcancer.org.uk/fundraise**

Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities:

bloodcancer.org.uk/local-community-groups

Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **bloodcancer.org.uk/volunteer**

Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us:

bloodcancer.org.uk/corporate-partnerships

Or call us on **0808 169 5155**



**I love being part of the
Blood Cancer UK family.
Being involved has
helped me and my family
cope with my diagnosis.**

Anna, diagnosed with blood cancer aged 39



Go to **bloodcancer.org.uk/donate**, call us on **0808 169 5155** or complete and send this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George Street, Edinburgh, EH2 4JN**

Full Name

Address

Email Phone



As a supporter, you're at the heart of everything we do. We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**

I'd like to donate £10 £25 £50 Other

I enclose a cheque/CAF voucher made payable to Blood Cancer UK

OR please debit my Visa Maestro Mastercard CAF card

Cardholder's name

Card number (Maestro only)

Start date Expiry date Issue number

Make your donation worth an extra 25p for every £1 at no extra cost to you!

giftaid it

I'd like Blood Cancer UK to claim Gift Aid on this donation and any donations I make in the future or have made in the past 4 years.

*By ticking this box I confirm that I'm a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it's my responsibility to pay any difference.

*Today's date

If you stop paying tax, change your name or address, or if you have any further questions about Gift Aid, please contact our Supporter Relations Team on **0808 169 5155**.

*Information required for Gift Aid declaration to be valid.

Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

You can order more information by:

- visiting **bloodcancer.org.uk/information**
- emailing **support@bloodcancer.org.uk**
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

Please send me some information

Full Name

Address

Email

Phone

Please tell us the publications you would like us to send you, free of charge (see page X)

.....

.....

.....

.....

.....

Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**



My details

My name and hospital number

.....
.....

My NHS number

.....

My condition

.....
.....

My contacts

.....
.....

My consultant

.....

My key worker (usually CNS)

.....
.....

Haematology ward

.....
.....

Haematology clinic

.....
.....

Out of hours

.....

Other contacts

.....
.....
.....
.....
.....
.....

Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk



**Blood
cancer
UK**

Blood Cancer UK is a trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2020 SEVEN/O617.3