MACMILLAN
CANCER SUPPORT

UNDERSTANDING STEM CELL TRANSPLANTS USING DONOR CELLS (ALLOGENEIC)

‘I am now five years in remission. I do struggle with some chest problems, fatigue and anxiety. But I was able to go back to work, and counselling has been very helpful.’

Alan, who had a stem cell transplant using donor cells

About this booklet

This booklet is about having a transplant using early cells (stem cells) from someone else (a donor). This is called a donor stem cell transplant, or allogeneic transplant.

The booklet explains how you have a donor stem cell transplant. It has information about how doctors match you with a donor, how the transplant is given, and the possible side effects. It also has information about recovery and coping after the transplant. We hope it helps you deal with some of the questions or feelings you may have.

This booklet is mainly for adults and teenagers. If you have a child who is having a donor stem cell transplant, this booklet may help you understand the different stages of treatment. But specialist children's units may have a different approach from adult units. The Children's Cancer and Leukaemia Group (CCLG) has information specific to children (see page 121).

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 120 to 127, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see page 128).

Quotes

In this booklet, we have included quotes from people who have had a donor stem cell transplant, which you may find helpful. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us, including Alan who is on our front cover. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

CLOSED

WHAT IS A DONOR STEM CELL TRANSPLANT?

The bone marrow and stem cells

To understand a stem cell transplant, it helps to know about the bone marrow and stem cells.

Bone marrow is part of our immune system, which protects us from infection and disease. It is found inside our bones, mainly in the hip bone (pelvis) and the breast bone. The bone marrow is where stem cells are made.

Stem cells are blood cells at the earliest stage of development. All our blood cells develop from stem cells in the bone marrow. Stem cells stay inside the bone marrow. When the blood cells are fully developed, they go into the bloodstream.

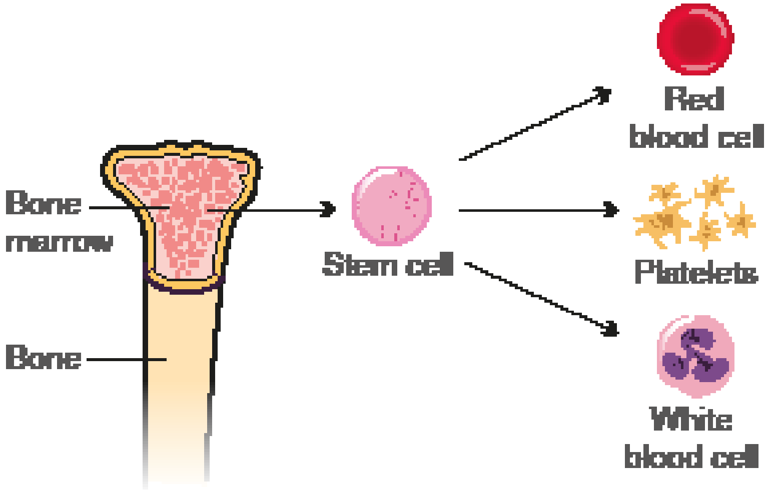
Blood cells do not live long. The bone marrow normally makes millions of new blood cells every day to replace blood cells as they are needed.

The three main types of blood cell are:

- red blood cells – these contain haemoglobin (Hb), which carries oxygen from the lungs to all the cells in our body
- platelets – these help the blood to clot and prevent bleeding and bruising
- white blood cells – these fight and prevent infection.

There are two main types of white blood cell. These are called neutrophils and lymphocytes. Neutrophils are the most common. You will hear your doctor or nurse talk about your neutrophil count during your treatment.

Bone marrow and blood cells



Your blood count

Doctors measure the number of different blood cells with a blood test. They call this either a full blood count (FBC) or a blood count. Your blood count will be checked often during and after treatment. This is because the treatment will affect the levels of your blood cells.

The figures that show your blood cell levels look complicated when they are written down. But most people with cancer soon learn what they mean. For example, you may hear doctors or nurses saying things like 'your haemoglobin is 135' or 'your neutrophils are 4'.

The figures below show the levels of different blood cells usually found in a healthy person.

Type of blood cell	Levels
Red blood cells (Hb)	130 to 180g/l (men) 115 to165g/l (women)
Platelets	150 to 400 x 10^9/l
White blood cells (WBC)	4.0 to 11.0 x 10^9/l
Neutrophils	2.0 to 7.5 x 10^9/l
Lymphocytes	1.5 to 4.5 x 10^9/l

These figures can be different from hospital to hospital. There may also be slight differences between people from different ethnic groups. Ask your doctor or nurse to explain more about your blood results if you are not sure.

About this treatment

How it works

A donor stem cell transplant replaces bone marrow that is no longer working properly with healthy stem cells from your donor. It is also known as an allogeneic stem cell transplant.

The donor stem cells make new red blood cells, white blood cells and platelets. This gives you a new, healthy bone marrow. The transplant also gives you your donor's immune system (white blood cells). This helps your body to get rid of any remaining cancer cells.

A donor stem cell transplant may be used to treat leukaemia, lymphoma and myeloma. It may also be used to treat some other blood conditions.

Your donor

Your donor may be a family member or an unrelated donor. Some people may be given stem cells from an umbilical cord (see page 27).

Where you will have it

Donor stem cell transplants are only done in hospitals with specialised transplant units. Some people may need to travel quite far to their nearest unit. You will usually need to stay in hospital for several weeks.

Some units offer what is called ambulatory care. This is where you go to the hospital during the day. If you are well and live nearby you can go home at night. If you live further away, the hospital can arrange somewhere to stay nearby. You may need to have someone staying with you. If you become unwell you will then be admitted to the hospital. You can talk to your doctor or nurse about whether ambulatory care is possible for you.

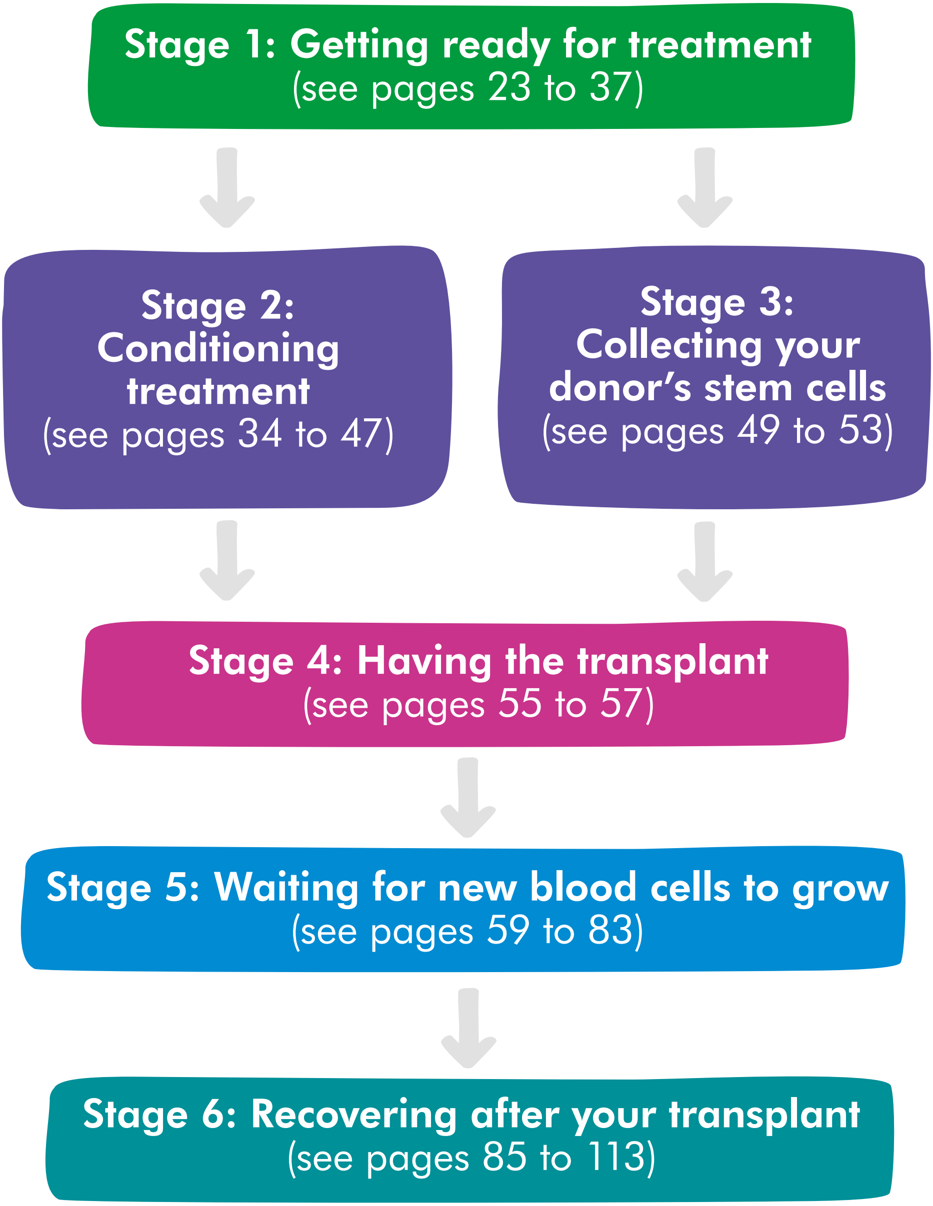
You may need to stay close to the hospital for some time after leaving the hospital. You might want to have family, a friend or a partner staying nearby during this time. Your specialist nurse can give you advice about getting financial help and making arrangements.

Having the treatment

A donor stem cell transplant is a complex treatment, but it can be divided into 6 stages. On the next three pages we give a brief explanation of what is involved at each stage.

After this, there is a chapter about each stage. You can use the diagram on the next page to find the chapter you need.

The stages of a donor stem cell transplant



Stage 1: Getting ready for treatment
(see pages 23 to 37)

Stage 2: Conditioning treatment
(see pages 34 to 47)

Stage 3: Collecting your donor's stem cells
(see pages 49 to 53)

Stage 4: Having the transplant
(see pages 55 to 57)

Stage 5: Waiting for new blood cells to grow
(see pages 59 to 83)

Stage 6: Recovering after your transplant
(see pages 85 to 113)

Stage 1 – Getting ready for treatment

Your cancer doctor, nurse or transplant co-ordinator explains why you are being offered this treatment. They explain the benefits and risks of having a transplant. If you decide to go ahead, your doctors start looking for a suitable donor. You have tests to check your general health, and are given advice on preparing for the treatment. Possible donors are asked to give a blood sample to check that their cells match yours.

Stage 2 – Conditioning treatment

You have chemotherapy drugs, sometimes with radiotherapy and antibody therapy. This destroys your immune system and prepares your body to accept the donor cells.

Stage 3 – Collecting your donor’s stem cells

While you are having the conditioning treatment, your donor’s stem cells are collected from their blood or bone marrow.

Stage 4 – Having the transplant

After the conditioning treatment has finished, you are given the donor’s stem cells through a drip (infusion). You start taking immunosuppressant drugs. These help reduce the risk of a reaction between your own cells and the new stem cells.

Stage 5 – Waiting for your new blood cells to grow

The donor's stem cells find their way to your bone marrow and start to grow and make healthy new blood cells. Doctors call this engraftment. You usually need lots of medical and nursing support while the stem cells engraft.

Stage 6 – Recovering after your transplant

When your blood cells have recovered, and you are well enough, you can go home. Your doctor or nurse will tell you what you should do to reduce the risk of getting an infection. You will have regular appointments at the day unit or outpatient clinic to check your recovery. It may take months to recover from a transplant.

Making your decision

You need to think about the benefits and risks of this treatment before you decide. It may increase the chance of being cured or going into remission more than any other treatment. But you will need to consider this against the risks.

There have been lots of developments in the care of people having a transplant. But some people will still have serious side effects or complications that may be life threatening.

Your specialist will talk to you about these. Although this can be upsetting, it is important that they tell you about all the possible risks.

You will need some time to think things over before you make your decision. You may want to talk to your family, friends and partner, if you have one. Most transplant units have a nurse specialist, transplant co-ordinator, social worker or counsellor who you can talk to.

It can help to have someone with you when you talk to the hospital team. They can support you and help you understand the information you have been given.

It is important to have all the information you need first. Make sure you ask your specialist doctor and nurse all your questions. They will usually give you written information.

Our booklet **Making treatment decisions** has information that might help you decide (see page 116).

Risks of a donor stem cell transplant

A donor stem cell transplant is a very specialised treatment. It can have many side effects and sometimes serious complications. Your doctor will consider your general health before advising you to have a transplant.

There are likely to be times when you feel very unwell. It can take many months, and sometimes up to a couple of years, to fully recover. Some people may not get back to the same level of health they had before their transplant.

The main risks include:

- serious infections when your blood count is very low (see pages 72 to 73)
- graft-versus-host disease (GvHD) when the donor's cells may attack some of your body's tissues and organs (see pages 75 to 79)
- the donor stem cells not producing new blood cells (graft failure) – see page 74.

Your doctor can tell you more about what these side effects may mean for you.

Fertility

Having a donor stem cell transplant usually affects whether you can get pregnant or make someone pregnant. This is a side effect of high doses of chemotherapy and sometimes radiotherapy. But it will depend on the treatment you have. Your cancer doctor or transplant nurse will explain the risks in your situation. If you have had chemotherapy before, your fertility may already be affected.

If you have periods, they may stop. This can be temporary or permanent. If they do come back, you are likely to have an early menopause.

If you are worried about your fertility, it is very important to talk to your specialist doctor or nurse. They can refer you to a fertility specialist to discuss possible options to preserve your fertility.

We have more information about cancer treatment and fertility for women and men in our booklets **Cancer treatment and fertility – information for men** and **Cancer treatment and fertility – information for women** (see page 116).

Questions you might like to ask

- What are the possible benefits of a donor stem cell transplant for me?
- What are the risks of the treatment?
- Are there long-term side effects?
- Will I be able to have children after treatment?
- What may happen if I decide not to have the transplant?
- Are there other treatments I could have instead?
- How long will it take afterwards before I am able to do everyday things?
- Do I need the transplant now or could I have it later if the cancer comes back?
- What happens if the cancer comes back after my transplant?

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Consent

If you decide to have the transplant, you will need to give permission (consent). Your doctor will ask you to sign a form saying that you give consent for the hospital staff to give you the treatment. No medical treatment can be given without your consent. You will also have to give consent for your information to be shared between members of the healthcare teams.

Research trials

Trials and studies are the only reliable way to find out whether a different type of treatment is better than what is already available.

Taking part

Many studies involve hospitals across the UK and other countries. You may be asked if you would like to take part in one. You will be carefully monitored during and after the study. If you decide not to take part, your decision will be respected and you do not have to give a reason. There will be no change in the way the hospital staff treat you, and you will be offered the standard treatment for your situation. We have more information on research trials in our booklet **Understanding cancer research trials (clinical trials)** (see page 116).


UNDER

STAGE 1: GETTING READY FOR TREATMENT

Finding a donor

The first step in finding a donor is for you to have a blood test. This is to find out your tissue type. Your tissue type is made up of different proteins on the surface of your cells. These are called human leukocyte antigen (HLA) markers. Your immune system uses your HLA markers to recognise your own normal body cells.

Doctors use your HLA markers to match you with a donor. They compare your tissue type with close relatives, or with volunteer unrelated donors on a registry. Doctors look for the best matched donor available for you. Having the best possible match means less risk of:

- your body rejecting the new stem cells (graft rejection)
- the new immune cells reacting against your other body cells (graft versus host disease – GvHD).

The best match is usually a fully matched brother or sister (sibling).

Your donor does not need to have the same blood group as you. After the transplant, your blood group changes to their blood group.

If you don’t have a fully matched sibling, your doctors will look for alternative donors. This could be:

- someone in your family
- a relative whose tissue is a half match (haploidentical) to yours
- someone on a donor registry.

Another option could be using a cord blood transplant.

Stem cells from a matched related donor

Brothers or sisters each have a 1 in 4 (25%) chance of being a match. Our tissue types are a combination of both our parents' genes. Not every combination is the same.

A different team from the one looking after you will contact your family to ask if they are willing to be tested. Your siblings can be tested even if they live abroad.

Stem cells from a volunteer donor

If you do not have a close match in your family your doctors will look for a volunteer donor who is not related to you. There are donor registries in the UK, such as Anthony Nolan which have lists of possible volunteer unrelated donors (see page 120).

If there is not a suitable UK donor for you, there are registries in other countries that your doctor can search. It usually takes longer to prepare a donor that does not live in UK. Occasionally no suitable donor can be found.

Half-matched donors (haploidentical)

Your specialist may advise using stem cells from a close relative whose tissue type is at least a 50% match to yours. This would happen if there is no matched donor (either family or unrelated) available. A close relative is a brother, sister, child, parent or half-sibling. Almost everyone will have at least one possible donor. This is called a haploidentical transplant.

As your donor is related, the transplant can usually be done quickly. But it is not suitable for everyone.

Because it is only a 50% match, there is more risk of complications in the first few months. These may include GvHD (see pages 75 to 79), slow recovery of the immune system and occasionally graft rejection (see page 74). But doctors are finding different ways to manage these problems. For example, they can give chemotherapy again after the stem cell transplant. This helps to reduce the risk of GvHD by killing off the donor cells that can cause GvHD.

Stem cells from cord blood

Another source of stem cells is blood from an umbilical cord. This is the cord that connects a baby to its mother during pregnancy. Cord blood can be donated after birth and frozen. It is stored in a cord blood bank and used for people needing transplants. There is no risk to the mother or baby and all cord blood is tested to make sure it is safe to use.

It may be possible to use cord blood for people who do not have a suitable donor.

With cord blood, you do not need as close a match as with an adult donor. You can also get it quickly.

A person's weight can be a factor when doctors are deciding whether a cord blood transplant is suitable. People who weigh more need more stem cells for a transplant to be successful. It may not always be possible to get enough stem cells from cord blood.

Sometimes doctors can use blood from two different cords in one transplant so enough stem cells can be given. This may be possible if both cords are a close match to each other, and a close match to you. This is called a double cord blood transplant.

Likelihood of finding a match

Most people who are white Europeans find a match.

But people from black, Asian and minority ethnic groups, without a related donor, often have difficulty finding a good match from volunteer registries. Most people registered as donors are white and tissue types rarely match across different ethnic groups. If you are mixed race, it can be more difficult.

Organisations and charities are working to increase the number of registered donors from all these groups. The numbers of volunteers have increased over the past few years. Cord blood banks have also increased the chances of finding a suitable donor.

Getting ready

Having a donor stem cell transplant is physically and emotionally demanding. Your transplant team need to make sure you are physically well enough to cope with it. They will ask you questions about your health and lifestyle and do tests to check your general health. They will give you advice on how to prepare yourself. You may see other health professionals before you go into hospital. This could include a dietitian or a physiotherapist.

If you lost weight with previous treatment, ask for advice on gaining weight. You may also have lost some fitness. Even taking regular short walks will help you to feel stronger. All this can help you with your recovery.

Being able to talk about your feelings and getting support from your family, friends, partner or transplant team is very important. It is not unusual to have complex feelings to cope with. You may see a counsellor or psychologist who can help you to cope with these feelings before your transplant. They can also support you during your stay in hospital.

When you go home you will be at risk of infection. If you live with other people, there may be things they can do to help protect you. For example, this could mean making sure they have the flu vaccination when it is available. They could also make sure any children living with you are up to date with any vaccinations.

If you work, you will not be able to go back straight away after your treatment. Being unable to work may affect your finances. You may find our booklet **Help with the cost of cancer in England, Scotland, Wales and Northern Ireland** helpful (see page 116). It may also be helpful to talk to one of Macmillan's benefit advisers or financial guides about help with money. Call 0808 808 00 00 to speak to an adviser.

> 'I was off work for 12 months first time around. After six months my pay and sick pay benefits came to a halt, so Macmillan's help to get me all my entitlements was amazing.'
>
> **Alan**

Some people find it helps to talk to someone who has already had a transplant. Your specialist or the support organisations listed on pages 120 to 127 might be able to put you in contact with someone.

You may find this video, made by Hammersmith Hospital team, helpful. In it, people share their experiences of having a donor stem cell transplant. Visit **vimeo.com/260247645**

You can also use Macmillan's Online Community to meet people who are going through similar experiences to you. Visit **macmillan.org.uk/community**

Tests

You need different tests before treatment starts. Your doctor or specialist nurse will talk to you about the tests you need.

Blood tests

You may have blood tests to check:

- your general health, such as how well your kidneys and liver are working
- whether you have any infections or viruses (including hepatitis and HIV)
- if you are cytomegalovirus (CMV) positive or negative (see page 72).

Other tests

You may also have the following tests:

- chest x-ray to check your lungs and heart
- breathing tests to check how well your lungs work
- kidney tests to see how well your kidneys are working
- heart tests such as an ECG (electrocardiogram) or ECHO (echocardiogram) to check your heart is healthy
- a bone marrow biopsy to check if there are any cancer cells in the bone marrow
- a pregnancy test.

Some of the tests will depend on the type of cancer you have.

Stopping smoking

If you smoke, your transplant team will advise you to stop. This is because smoking increases the risk of complications and long-term side effects. Stopping smoking can help your recovery.

Stopping smoking is also the most important thing you can do for your general health. Smoking increases the risk of developing heart and lung conditions, as well as smoking-related cancers.

Stopping smoking is not easy, especially when you are stressed. But there are organisations and groups that can help you. Your GP can give advice and prescribe nicotine replacement therapies, such as nicotine patches, gums and inhalers. Your hospital may have a Stop Smoking team. Your nurse or transplant co-ordinator can tell you more.

Dental care

You will be asked to visit a dentist for a check-up, and to have any dental work you need before treatment starts. Making sure your teeth or dentures are in good condition reduces the risk of problems with your mouth during treatment.

Fertility

Your specialist will be able to tell you how the treatment is likely to affect your fertility. It is important to talk to your cancer specialist about this before treatment starts. There may be ways of preserving your fertility, so that you may be able to have children in the future. If you have a partner, you may want them with you when you talk to your specialist. You can discuss any fears or worries together.

If you decide to see a fertility specialist, you will do this before you start your treatment. They will talk about the ways you may be able to preserve your fertility. This can include storing sperm, eggs or embryos before your treatment starts.

Fertility is an important part of many people's lives. Not being able to have children can seem especially hard when you already have to cope with cancer. Some people may find it helpful to talk about their feelings with a trained counsellor. If you need more specialised help, your doctor or specialist nurse can arrange this.

We have more information about cancer treatment and fertility for women and men in our booklets **Cancer treatment and fertility – information for women** and **Cancer treatment and fertility – information for men** (see page 116).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Central line

You will need to have different drugs given into your vein (intravenously). You will also need to have blood samples taken every day. To make this easier and avoid lots of injections you may have a central line. This is a thin, hollow tube that a doctor or nurse puts into a vein in your chest. It can be used to:

- collect blood samples
- give you chemotherapy and other drugs, such as antibiotics
- give you the stem cells
- give you fluids
- give you blood and platelet transfusions.

There are different types of central line available, including Hickman® lines and Groshong® lines. The doctor or nurse uses a local anaesthetic to numb the area. They make a small cut in the skin near your collarbone. They gently thread the line into a large vein just above your heart. You have a stitch to hold the line in place. This is usually taken out after three weeks when the line is secure.

You will be able to see a thin flexible tube coming out from your chest. It may divide into two or three tubes, so you can have different treatments at the same time.

PICC line

Instead of a central line, your doctors may arrange for you to have a PICC (peripherally inserted central catheter) line. This is a long, thin, flexible tube which is put into a vein in your arm, near the bend of the elbow. It is threaded through the vein until the end of it lies in a large vein near the heart.

Your nurse will explain how to care for your central line or your PICC line.

Visiting the unit

Before your treatment, you can usually visit the unit. It is a good idea to take a relative or friend with you. During the visit, you may meet members of the team who will be looking after you. They will tell you what to expect and advise you on how to prepare for your treatment. The team may include:

- a haematologist – a doctor who diagnoses and treats blood disorders and cancers
- an oncologist – a doctor who treats cancer with radiotherapy, chemotherapy and other anti-cancer drugs
- a transplant co-ordinator – a nurse who helps plan your transplant and supports you before, during and after
- a clinical nurse specialist – a nurse who gives information and support about your cancer type or treatment
- nursing staff who may give you some of the treatment (such as chemotherapy) and carry out day-to-day care
- other healthcare staff, such as social workers, dietitians, pharmacists, psychologists, counsellors, occupational therapists and physiotherapists.

The nurses may show you around the unit and the type of room you will be in during your stay. This may not always be possible. They can tell you what things you might want to bring with you for your stay in the unit (see page 46).

Teenagers and young adults

Some hospitals have teenage and young adult cancer units (sometimes called TYA units). You will be with other people your own age and cared for by people who are used to working with teenagers and young adults.

There may be internet access, a computer, games consoles, DVDs and music to help you feel more at home. Sometimes education specialists come to support you with your studies while you are having treatment.

There is a group on our Online Community for people aged 16 to 24, where you can talk to others who have had a similar experience (see page 116). You can also get support from organisations such as the Teenage Cancer Trust and CLIC Sargent (see page 126).

Getting organised

When your treatment is planned, you can start to make practical arrangements. Ask your family, friends or partner for help.

For example, you might have to:

- let your work or college know
- organise childcare
- arrange for bills to be paid
- ask someone to look after any pets
- make sure your home is going to be secure.

STAGE 2: CONDITIONING TREATMENT

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Having conditioning treatment

Before the transplant, you have conditioning treatment. This is to get you ready for your donor's cells. It usually involves having different chemotherapy drugs. Some people also have radiotherapy to the whole body, called total body irradiation (TBI) – see page 43. You may also have antibody therapy (see page 45).

Your conditioning treatment usually takes around 1 to 2 weeks. Your doctor will talk to you about the type of conditioning treatment that is best for you.

Conditioning treatment is given to:

- get your body ready to accept the donor stem cells
- weaken your immune system to reduce the risk of it attacking the donor stem cells
- remove any remaining cancer cells from your body.

During conditioning treatment, your doctors may talk about days as numbers. The day of your transplant (stem cell infusion) is Day 0. The days before transplant are counted as Day –8, Day –7, and so on. The days after transplant are counted as Day +1, Day +2, and so on.

You usually finish conditioning treatment 24 to 48 hours before the transplant (Day –2 or Day –1).

You may have your conditioning as an inpatient in hospital. Some hospitals may give some of the conditioning treatment while you are still at home or staying in accommodation nearby. You come into hospital during the day for the treatment and then, if you are well, go home at night. Your doctor or nurse will explain where you will have your treatment.

Types of conditioning

There are different types of conditioning treatment. Your conditioning treatment depends on:

- the type of cancer you have
- your age
- your general health
- what type of donor you have and if cord blood is being used
- what chemotherapy or radiotherapy you have had in the past.

Full-intensity conditioning (myeloablative)

You have high-doses of chemotherapy, sometimes with total body irradiation. This is done to destroy your bone marrow and immune system.

Reduced-intensity conditioning (RIC)

This uses fewer or lower doses of chemotherapy or radiotherapy than full-intensity conditioning. It weakens your immune system enough to allow the donor stem cells to grow in your bone marrow. But there is less risk of complications.

The donor stem cells gradually replace your immune system and attack any remaining cancer cells in your body.

Having chemotherapy

The nurses give you chemotherapy drugs through your central or PICC line with plenty of fluids (see page 36). You usually have treatment over several days. Your nurse will explain about the possible side effects and give you drugs to help control them. They will also give you drugs to help prevent infections and reduce the risk of developing graft-versus-host disease (GvHD) – see pages 75 to 79.

Total body irradiation (TBI)

Radiotherapy uses high-energy rays to destroy cancer cells. TBI treats your whole body with radiotherapy. Some people have it as part of their conditioning treatment.

You may have TBI twice a day for 6 to 8 sessions. If you are having reduced-intensity conditioning, you may have 1 or 2 low doses. Sometimes no TBI is needed.

You will have a planning session in the radiotherapy department a few days before you have TBI. The doctor, nurse or radiographer (person who gives the treatment) will explain more about the treatment and its side effects.

Before each session, the radiographer positions you carefully and makes sure you are comfortable. Radiotherapy is not painful, but you need to keep still during the treatment. You have radiotherapy to both sides of your body. So you need to change position a few times during the session. The radiographer will explain this to you.

Each session lasts about 40 minutes. But the radiotherapy itself only takes about 10 to 20 minutes. You can bring some music to listen to during your treatment.

Side effects

Possible side effects of TBI include:

- skin changes
- tiredness
- feeling sick
- diarrhoea
- loss of appetite
- dry mouth
- sore mouth.

These can happen a few days later. The radiographers will explain how to manage the side effects and how to care for your skin There is more information about the side effects of radiotherapy in our booklet **Understanding radiotherapy** (see page 116).

Antibody therapy

You may also be given antibody therapy to help damage (suppress) your immune system. This allows the donor cells to grow and make new blood cells. The drug also reduces the risk of graft-versus-host disease (GvHD) – see pages 75 to 79.

The most common antibody drugs used for conditioning are:

- Alemtuzumab (a targeted therapy drug)
- ATG (antithyroglobulin)

You have the antibody drug as a drip. Some people may have an allergic reaction to it. This is more common after the first dose. The reactions are not usually severe. Your nurse will give you drugs to reduce the risk of a serious reaction and will monitor you closely.

Common symptoms include:

- an itchy rash
- a fever and sometimes shivering (rigors)
- feeling short of breath.

Going into hospital

If you are having your conditioning treatment in hospital, you will go in 1 to 2 weeks before the transplant. Or you may go in during, or after, the conditioning treatment. You may be in a room of your own, but it depends on the unit you are in.

What to take

The nurses will suggest what to take to keep you busy and make you more comfortable. Most hospitals have TVs, but you may also want to take:

- a tablet or laptop
- books, magazines or games
- personal things, like photos.

Take some comfortable, loose-fitting clothes. Soft, cotton materials are best. Tops with buttons make it easier when you are being examined. An eye mask and ear plugs may help you sleep better.

Ask the nurses for advice about the toiletries you should bring.

Visitors

Visitors, especially close family, friends or a partner are important. They give you support and help you stay in touch with life outside hospital. Some units have rooms for family members to stay overnight if they have far to travel.

Most units are flexible about visiting, but different hospitals have different rules. You may be restricted to a certain number of visitors each day. This is to help protect you from infection. Any visitor who has, or thinks they have, an infection should not visit you. The nurses will explain more about this to you.

Questions you might want to ask

- How many visitors can I have and how long can they stay?
- Is there anyone who should not visit, such as young children?
- What precautions will visitors have to take when they come to see me?
- Can I bring my mobile phone? Is there a phone I can use, and will I need a phone card?
- Can I bring a laptop or tablet, and will I have access to the internet?
- Do I need to follow a special diet? Are there any foods that I should avoid?

STAGE 3: COLLECTING YOUR DONOR'S STEM CELLS

How your donor will prepare

Donors are given counselling before they agree to donate stem cells. Once they understand what is involved, they are asked to sign a consent form. They can still change their mind after this.

Information about the donor is confidential and cannot be shared without their permission. This is the same for related donors and unrelated donors. They are looked after by a different team to you.

The donor has tests to make sure they are fit to donate and that it is safe for them. These include:

- blood tests
- a chest x-ray
- checking their weight
- an electrocardiogram (ECG) to check the heart.

They will also have blood tests to check:

- their general health
- for infections including HIV, hepatitis and cytomegalovirus (CMV).

Collecting the stem cells

Your donor's stem cells can be collected from their blood or, less commonly, from their bone marrow.

Taking stem cells from the blood

The donor needs to have drugs to encourage their stem cells to move from the bone marrow into the blood. They have a small daily injection of a drug called a growth factor (G-CSF) under the skin. This is given for a few days leading up to the collection. It increases the number of stem cells in the bone marrow to make them move out into the blood. This is called mobilising the stem cells. There is more information about G-CSF on our website (see page 116).

The nurses can show the donor how to give the injection themselves. Or they can have it at their GP practice or the hospital. The donor's blood is checked after about 5 days of injections.

The collection

The stem cells are collected 1 or 2 days before the transplant. It takes 3 to 4 hours, usually as a day patient.

The nurse or doctor puts a cannula into a vein in each arm. The donor's blood is removed through one arm and passed through a machine called a cell separator. This separates the stem cells and collects them. The remaining blood is then returned to the donor through the tube in their other arm. If there are not enough stem cells after one collection, the donor may have to come back the next day.

Taking stem cells from the bone marrow

Sometimes stem cells are taken from the donor's bone marrow. This is usually from the back of the hip bones (pelvis). It is done under a general anaesthetic and usually means staying overnight in hospital.

Occasionally your donor may have their cells collected before you start your treatment. This may happen if your donor is away when your transplant is booked. In this case the cells are frozen until the day of transplant. They are defrosted when you need them.

STAGE 4: HAVING THE TRANSPLANT

Having the stem cells

You have your transplant of donor stem cells 1 or 2 days after conditioning treatment has finished. The transplant day is known as Day 0.

Your nurse gives you the stem cells as a drip (infusion) through your central or PICC line (see pages 35 to 36). It is like having a blood transfusion.

Some people have mild side effects while the stem cells are being given, such as feeling sick or breathless. Your nurse will give you drugs through your central line before the stem cell infusion. This is to reduce the risk of an allergic reaction. They monitor you carefully during and after the stem cell infusion.

If the stem cells were frozen, you and your visitors might notice a strong smell like sweetcorn. This can last for a few days after the infusion. It is from the preservative used to protect the stem cells during freezing.

For some people, having the stem cells may be an emotional experience. But it may also seem like any other day in hospital. There is no right or wrong way or to feel about it.

Immunosuppressant drugs

Your doctors will give you drugs to suppress your immune system and the new immune system from your donor. These are called immunosuppressant drugs. They help to prevent graft-versus-host disease GvHD – see pages 75 to 79. This is when your cells and the new stem cells react against each other.

Different drugs can be used. You will have either ciclosporin or tacrolimus. They are often given with other drugs such as methotrexate or mycophenolate. You usually start taking them in the days before your transplant.

If you are having a haploidentical transplant, you usually have chemotherapy a few days after the transplant (see page 26). This is a type of chemotherapy called cyclophosphamide. You will start your immunosuppressant drugs after this.

You usually take your immunosuppressant drugs for a few months. It is very important to take them.

Immunosuppressant drugs have side effects. Your doctor or nurse will tell you about these.

STAGE 5: WAITING FOR YOUR NEW BLOOD CELLS TO GROW

Waiting for the stem cells to grow

The stem cells travel through your blood to your bone marrow. They then begin to make new blood cells. This is called engraftment.

It can take from 10 days to 3 weeks before some of the new blood cells are released into the blood. If you had a cord blood transplant, it can take longer. This means you will have low numbers of red blood cells, white blood cells and platelets in your blood for some time. This can cause side effects, including:

- infection – because of low white blood cells
- bleeding – because of low platelets
- anaemia – low red blood cells.

You will have blood samples taken every day to check your blood count. You may need transfusions of blood or platelets to help. You may also need antibiotics. Your transplant team will care for you and monitor you very closely for complications.

You may be given a drug called G-CSF as an injection. It helps your bone marrow to make new blood cells. This reduces the length of time you are at risk of side effects. There is more information about G-CSF on our website (see page 116).

Your daily routine

Although you may expect your days to be very quiet, they may be quite busy. A lot of your time will be taken up with daily routines and checks by the doctors and nurses. This will include:

- taking blood samples from and giving medicines into your line
- changing your drip (infusion) of fluids when needed
- taking your temperature, pulse and blood pressure
- examining your tummy and mouth and checking your weight
- measuring the fluid you take in and the fluid you pass out (fluid balance)
- checking your central line or PICC line.

You may also regularly see the dietitian, physiotherapist and other members of the team looking after you.

Once the number of blood cells (your blood count) begins to rise, your medical and nursing team will start to plan for you to go home.

How you can help yourself

Being involved in your care can help you feel more in control. Depending on how you feel, you could:

- Have a shower each day and change your clothes.
- Eat regular meals and snacks, even if you do not have much appetite. Your family may be allowed to bring in food you like. But there will be some rules to help reduce your risk of infection (see page 65). The nurses will tell you more about this.
- Sit up in the chair for periods of time.
- Do any exercises you have been shown and walk around your room. When you are feeling better and your blood counts are higher, you might be able to take short walks around the unit. Some units have exercise bikes you can use.
- Measure how much you are drinking and record it for your fluid balance.
- Ask for updates on your blood counts and keep a record.

Understanding your illness and treatment can make it easier to cope. If there is anything you do not understand about your treatment or its side effects, it is important to ask.

The side effects of treatment

The side effects will depend on several things, including the type of conditioning treatment you had and your general health. People having a reduced-intensity transplant may have less severe side effects. Your hospital team will give you more information about what to expect.

Many side effects are caused by having low numbers of blood cells. When your blood count goes up, the side effects will start to improve. You will be at less risk of infection, your appetite will improve and you will start to feel better.

You will have medicines to prevent or reduce side effects. Always tell your doctor or nurse about any side effects you have. They may be able to change the medicines to ones which will work better for you.

We have more information about the side effects mentioned here, and about blood and platelet transfusions in our booklet **Side effects of cancer treatment** (see page 116).

Risk of infection

The number of white blood cells (your neutrophils) will be very low for some time. This is called being neutropenic. Neutrophils are very important in fighting infection.

During this time, you are at risk of infection, even from the normal bacteria that live on your skin and in your digestive system. These bacteria are usually useful to our bodies. But they can cause infections when your immune system is not working well.

You will be given drugs to prevent and treat infections. Your nurses and doctors will take your temperature regularly and check for signs of infection. They will also ask you to tell them if you have symptoms that could be a sign of infection. These include:

- feeling cold and shivery
- having a sore throat
- having a cough or runny nose
- pain when passing urine (peeing)
- having diarrhoea.

The hospital staff will try to protect you from possible infections. But most people need antibiotics at some point while their immune system is recovering.

Hygiene

When your blood counts are very low, you will usually stay in a single room to protect you from infection. This is sometimes called protective isolation. The room will have its own toilet and shower. Sometimes the room may have a special air conditioning system to keep the air in your room very clean.

Your room, toilet and shower are cleaned every day. Your bed sheets will also be changed every day.

It is important to keep your skin clean. Your nurses will give you advice about showering and washing your hands. They can help you with this if you are tired. They will also show you how to look after your mouth.

Being careful with food

When your blood counts are low there will be rules about what you can eat. This is to help you avoid food that may contain bacteria. Each hospital has its own guidelines. Your nurse or dietitian can explain them to you.

The rules may include:

- Avoid soft cheeses, pate and unpasteurised foods.
- Do not eat lightly cooked or uncooked eggs.
- Wash fruit and vegetables.
- Hot meals should be freshly prepared and well cooked (not reheated).
- Avoid probiotic or bio yogurts and drinks.
- Avoid takeaway foods.

Visitors

Hospitals may have different rules about visitors. You may be restricted to only a few visitors each day. The ward nurses will tell your visitors how to help protect you from infections. For example, this could mean washing their hands before going into your room and wearing a plastic apron. People who feel unwell or have an infection should not visit you.

Anaemia

The number of red blood cells in your blood will be low at times. This is called anaemia. It can make you feel tired and short of breath. You may need blood transfusions until your body starts to make enough red blood cells again.

Bruising and bleeding

The treatment reduces the number of platelets in your blood. You are likely to need transfusions of platelets to reduce the risk of bleeding or bruising.

Your doctors and nurses will examine you regularly for bruises or little red spots on the skin.

Tell a doctor or nurse straight away if you have:

- any bruising you cannot explain
- a nosebleed
- bleeding gums
- blood in your stools (poo) or urine (pee).

Irradiated blood

For a few months after your transplant, any blood or platelet transfusions you are given are first treated with radiation (irradiated). This is to prevent problems caused by white blood cells called lymphocytes, in the donated blood. Irradiated blood is not radioactive and will not harm you or anyone you come into contact with.

Some people may need all blood or platelet transfusions to be irradiated for the rest of their lives. Your doctor will talk to you about this. You will be given a medical alert card to carry in case you need blood in an emergency or at another hospital.

Tiredness

You will probably feel extremely tired and spend a lot of time sleeping. Sometimes you may feel too tired to concentrate on reading or even watching television.

At times, you may not feel able to have visitors, or see them for too long. Let them know how you are feeling so they do not disturb you if you want to rest.

Exercise

Even though you are tired, it is a good idea to try to do some gentle exercise, such as stretching. A physiotherapist will show you how. This helps reduce the chances of getting a blood clot, and it keeps your muscles working and toned.

Some transplant units may have an exercise bike that you can use when you are feeling better and your blood counts have improved.

Feeling sick

The nurses will give you anti-sickness drugs (anti-emetics) regularly. If you still feel sick, tell your nurse or doctor. They can change the anti-sickness drug to one that works better for you.

Sore mouth

The chemotherapy can cause a sore mouth and throat. You may also get painful mouth ulcers. The nurses will show you how to look after your mouth and teeth to reduce the risk of side effects. They will check your mouth regularly. If your mouth is sore, your doctor will prescribe painkillers. They may give you gels that can help.

Keeping your mouth clean is very important to prevent infections. Gently clean your teeth or dentures in the morning, at night and after meals. Use a soft toothbrush. The nurses may give you mouthwashes to use, or ask you to rinse your mouth regularly. Follow any advice you are given and drink plenty of fluids.

Diarrhoea

If you have diarrhoea caused by chemotherapy, your doctor can prescribe drugs to control it. Let them know if it is severe or if it does not get better. Make sure you drink at least 2 litres (3½ pints) of fluids every day if you have diarrhoea. If you are not able to drink very much because of a sore mouth, you may have fluids through a drip (infusion).

Eating problems

The treatment causes different side effects that can make eating difficult. These may include a sore mouth, feeling sick, loss of appetite or taste changes.

The nurses will give you advice, and you may also talk to a dietitian. It is important you do not lose too much weight. They will encourage you to try to eat small meals and snacks. You may need nutritional drinks until you can eat properly again.

You may need extra support to get the nutrition you need. Sometimes people need to have liquid food through a thin, soft tube that goes down the nose into the stomach. This tube is called a feeding tube. Some people may be given specially prepared nutrition into a vein through their central line or PICC line. As you start to eat again, the amount of liquid food you have is gradually reduced.

Hair loss

This is a common side effect of chemotherapy. You usually lose all the hair on your head. Your eyelashes, eyebrows and other body hair may also thin or fall out. It is almost always temporary and your hair will grow back after chemotherapy ends. Your nurse can give you advice about coping with hair loss. After treatment, it is important to cover your head to protect your scalp when you are out in the sun until your hair has grown back.

Bladder irritation

Some chemotherapy drugs may irritate your bladder and cause discomfort when you pass urine. You may be given fluids through a drip (infusion) and some drugs to help prevent bladder irritation. Drink at least 2 litres (3½ pints) of fluids each day. It is also important to empty your bladder regularly and try to pass urine as soon as you feel the need to.

Tell your doctor or nurse straight away if:

- you feel any discomfort or stinging
- you notice any blood when you are passing urine.

Effects on the lungs

Treatment can sometimes cause changes to the lungs. This is more likely if you already have lung problems. Always tell your doctor if you notice:

- wheezing
- a cough
- you are feeling breathless.

You should also tell them if any of these problems get worse. They can arrange tests to check your lungs.

Virus infections

Because your immune system is not working well, you are more at risk from infections caused by viruses. Some viral infections you have had before may become active again. Your doctors will check for certain viruses that may cause more serious problems.

Cytomegalovirus (CMV)

CMV is a common virus. Most people will have been infected with it by the time they are an adult. It rarely causes symptoms, so you will not usually know you have had it. It stays in your body and your immune system keeps it under control. This means it is not active and does not cause problems. But if your immune system is weakened, the CMV virus may become active again and cause problems.

Before your transplant, you and your donor are checked for CMV. If you are CMV negative, doctors try to match you with a donor who is the same.

After your transplant, you will have regular blood tests to check for CMV. People who have not had CMV may get it after a transplant. But this is very rare.

Doctors monitor CMV levels carefully to pick up changes early. If levels start to rise quickly after your transplant or become too high, you may need treatment. This is usually with tablets or sometimes drugs through a drip. You may need to be admitted to hospital for treatment.

Epstein-Barr Virus (EBV)

Most people have EBV at some time during their lives. It is also known as the glandular fever virus. After a transplant it can become active again. In rare cases, EBV infection may lead to developing another cancer after transplant. Because of this, you will have regular blood tests to check for EBV. Your doctor can then start treatment if you need it. Your doctor will tell you more about this.

Graft-versus-host disease (GvHD)

Cells from the donor sometimes react against your own cells. This is called graft-versus-host disease (see pages 75 to 79).

Less common problems

Graft failure

Sometimes the donor stem cells do not grow and make enough new blood cells. This is known as graft failure.

If there are not enough new, healthy blood cells, side effects such as infections, bruising, bleeding and anaemia can cause serious problems. G-CSF may be used to try to help the bone marrow to recover. And your dose of immunosuppressive drugs may be changed.

Total graft failure is very serious but rare. The only way to treat it is by having another donor stem cell transplant. Your doctor will talk to you about the best way to do this.

Veno-occlusive disease (VOD)

In some people, blood vessels in the liver may become swollen and blocked soon after transplant. This is known as veno-occlusive disease (VOD) or sinusoidal obstruction syndrome (SOS). It can cause pain or swelling in your tummy or right side, or jaundice (yellowing of the skin or eyes). Some people notice weight gain or swollen ankles and legs because of a build-up of fluid.

If this happens, you need treatment immediately as it can be life-threatening. You will have treatment until your liver recovers. You will need to stay in hospital for this treatment.

Graft-versus-host disease (GvHD)

After a donor stem cell transplant, cells from the donor called T-lymphocytes, or T-cells sometimes react against your own cells. This is called graft-versus-host disease (GvHD).

GvHD does not mean the transplant has failed. It can sometimes be helpful. The donor cells may also attack any remaining cancer cells.

There are two forms of GvHD:

- Acute GvHD usually develops within the first 100 days (about three months) after transplant. But it may also happen after this time.
- Chronic GvHD can start on its own a few months after transplant. Or it can sometimes progress from the acute type.

> 'A little bit of GvHD can be a good thing for controlling and fighting your disease.'
>
> **Kirsty, Online Community member**

People who have unrelated or mismatched donors are more likely to develop GvHD. It most often happens after immunosuppressant drugs are stopped (see page 57). GvHD can also happen after a donor lymphocyte infusion.

The effects of GvHD are usually mild. But in some people they can be severe and even life-threatening. GvHD mainly affects the skin, mouth, stomach, bowel and liver.

Acute graft-versus-host disease

Acute GvHD is most likely to happen in the first three months after transplant. But it may develop much later than this. The risk is increased when the donor is not related or is not a close match.

Prevention

Your doctors will give you immunosuppressant drugs to reduce your risk of acute GvHD after your transplant. These help stop your donor's T-cells attacking your body tissues.

Having antibody therapy as part of your conditioning treatment can also help reduce the risk of GvHD (see page 45).

If the risk of severe GvHD is very high, the donor's T-cells can be removed from the stem cell collection in the laboratory. This could be when stem cells from a mismatched unrelated donor or haploidentical donor are used.

Symptoms

The symptoms depend on which part or parts of your body are affected. GvHD often causes an itchy skin rash. If your bowel, stomach or liver are affected, you may have sickness and diarrhoea. If the liver is involved, sometimes the whites of your eyes become yellow (jaundiced).

Treatment

Acute GvHD is graded by how severe it is. Grade 1 is mild. Grade 4 is very severe.

If it is mild, you may be treated at home with steroid cream for your skin.

If it is grade 2 or above, you will usually need treatment with steroids. You may need to be admitted to hospital so that doctors can monitor and treat your symptoms.

If your symptoms do not get better with steroids your doctor will talk to you about other treatments that may help.

Chronic graft-versus-host disease

This may happen more than three months after transplant. It can develop from acute GvHD, or happen on its own. Your transplant team will explain what to look out for.

Any symptoms will depend on which parts of the body are affected. They may include:

- skin changes, including dryness, flaking, discolouration, thickening and ulcers
- hair that grows slowly and is brittle or patchy
- a dry and swollen mouth and mouth ulcers
- dry, gritty eyes
- diarrhoea, stomach cramps, sickness and loss of appetite
- feeling short of breath or wheezy.

You might also have more generalised symptoms. These may include repeated infections, muscle weakness and joint pain.

Chronic GvHD is usually treated with steroids and other treatments that help control the immune system. You will also be given treatment and support to manage any symptoms you have.

Light treatment

Extracorporeal photopheresis (ECP) is when your blood cells are treated outside your body with special light treatment. Doctors are not sure exactly how it works to treat GvHD. But they know that it changes the immune system without weakening it.

ECP is used more for chronic GvHD. It improves most people's symptoms. Your doctor or nurse will give you more information about the treatment. It is only available in some specialist centres.

Your central line is connected by tubes to a cell separator machine. Blood leaving your body passes through the machine. It is treated with ultraviolet (UV) light and drugs that work when exposed to light. The treated blood is then returned to you by another tube that also connects to your central line. This continues until all your blood has been treated.

If your central line has already been taken out, your doctor will use a cannula. This is a short, thin tube put into a vein in your arm.

You normally have ECP for 2 days in a row every 2 to 4 weeks.

Your feelings during treatment

Having a stem cell transplant is probably one of the most stressful things you will ever face. It is emotionally hard, as well as physically demanding.

There may be times when you are anxious, frightened or depressed. You may ask yourself questions like:

- ‘Is the treatment working?’
- ‘Will my blood counts ever go up?’
- ‘How am I going to cope with the side effects?’

> ‘When I officially passed my 100 days marker after the transplant it was my first milestone and gave me hope.’
>
> **Alan**

Talking to family and friends about how you are feeling often helps. The nurses and doctors can also give you advice and support. They may be able to put you in contact with someone else who has had a stem cell transplant. Many people find this very useful. You can also use Macmillan's Online Community to meet people who are going through similar experiences to you (see page 118).

If you are finding it difficult to cope, tell your nurse or doctor. You may find it helpful to talk to someone such as a counsellor. The hospital staff can arrange this for you.

If you are a relative, friend or partner

Family, friends and partners play an important role in recovery. Having support from regular visitors can be a big help to people in hospital. They may already feel isolated, especially if they are in a room on their own.

Most hospitals are flexible about visiting, but there may be some restrictions. Talk to the nurse looking after your relative, friend or partner before going into their room. They will explain the precautions you need to take to help protect them from infection. It is important to follow these instructions.

Here are some tips:

- Do not visit if you feel unwell, even if it is a cold or cough.
- Check with the hospital staff before bringing children. Not all units allow them to visit.
- Do not bring children if they are unwell, have been near other children with an infection, or have had recent vaccinations.
- Wash your hands before entering the room.
- Do not sit on the bed.
- Ask the nurse first before you bring in any food or flowers.

You can kiss or hug your friend, relative or partner, or hold their hand and give comfort by just sitting with them. There will be times when they will not feel or look well. Sometimes they may not feel like seeing anyone because they are too tired.

It helps if one person can co-ordinate people's visits to spread them out. Having too many visitors or long visits can be difficult to cope with for the person having the treatment. Do not take it personally if you are asked to miss a visit. You could phone or send a card, text or email instead.

STAGE 6: RECOVERING AFTER YOUR TRANSPLANT

Preparing to go home

When your blood counts have reached a safe level, your transplant team will talk to you about going home. Before you go home, you will need to:

- have recovered enough from all your side effects
- be eating and drinking well
- be walking about by yourself
- be able to take your tablets so you do not need drugs through your line.

You may feel impatient to go home but anxious about leaving the support of the hospital. If you live on your own, you need to arrange for a relative, friend or partner to stay with you. Or the hospital staff can arrange support from carers when you go home.

It can take time to adjust after spending so long in hospital. As you recover, you will find that things gradually shift away from the treatment and back to day-to-day living.

The first few months out of hospital

For the first few months, you will have a clinic appointment every week. To begin with, it may sometimes be twice a week. There you will see your specialist doctor and have blood tests.

You may still need blood or platelet transfusions. You are still at risk of infection, because your immune system is weak. You usually need to take drugs, such as antibiotics, anti-viral and anti-fungal drugs. These reduce your risk of infection. You will also continue taking the drugs to reduce the risk of GvHD. Always take your medicines as they have been explained to you.

You will need to take some precautions and be careful with hygiene. Your transplant team will explain this to you and tell you how to recognise the signs of infection.

> ‘I keep a pocket size bottle of anti-bacterial hand gel in my bag for when I am out. I use it before and after I’ve touched anything I’m wary of. ’
>
> **Tessa, Online Community**

When to contact the hospital

Always carry the 24-hour hospital phone number you have been given. If you are worried about anything, call the number at any time of day or night. The doctors and nurses on the transplant unit always prefer you speak to them rather than risk being unwell at home.

Contact your hospital straight away on the number you have been given if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have any signs of an infection – such as feeling shivery or short of breath, having a sore throat or cough, having diarrhoea or needing to pass urine often
- you have any symptoms of GvHD (see pages 75 to 79)
- you cannot take your tablets
- you have a rash on your skin, or any signs of bleeding
- you have been in contact with someone who has an infectious disease, for example chickenpox or measles.

If you feel unwell and are unable to contact the hospital, ask someone to take you to the nearest hospital accident and emergency (A&E) straight away. You may need to be admitted to hospital. It is quite common for this to happen once or twice. Although this can be worrying for you, it is not a major setback.

Monitoring for problems

After your transplant, your haematologist or specialist nurse will continue to monitor you for any problems.

Graft-versus-host disease (GvHD)

You will continue taking drugs to reduce the risk of GvHD (see pages 75 to 79). Always follow the advice your transplant team give you. Your doctor and nurse will continue to monitor you for signs of GvHD. They will tell you what to look out for. Let them know straight away if you get any symptoms, such as diarrhoea or a rash.

Viral infections

They will continue to monitor you for signs of reactivation of viruses. These include cytomegalovirus (CMV) and the Epstein-Barr virus (EBV) – see pages 72 and 73.

Checking the treatment has worked

They will also be checking that there are no signs of the cancer returning. This may be with scans or a bone marrow biopsy. How they check will depend on the type of cancer you have.

Blood counts

They will also check how well the new immune system is working. They will check the numbers of your donor's cells in your blood.

Chimerism is a word doctors use to describe how well your donor's cells have engrafted. After transplant, the aim is for full donor chimerism. This is when all your blood and bone marrow are from your donor. Sometimes chimerism is given as a percentage. It should be as near to 100% as possible.

Mixed chimerism means some of your own cells are still there. This is more likely if you had reduced-intensity conditioning. Because you had lower doses of chemotherapy, some of your own blood cells survive.

Sometimes mixed chimerism gradually improves on its own. If it does not get better, doctors can treat it by changing the dose of your immunosuppressant drugs (see page 57). Or they may treat it by giving you white blood cells (lymphocytes) from your donor (see below). The donor white blood cells destroy any of your remaining cells. The aim is to increase the chimerism level to full donor chimerism.

Donor lymphocyte infusions (DLI)

People with mixed chimerism may need an infusion (drip) of white blood cells from their original donor. This is called a donor lymphocyte infusion.

The lymphocytes are given as a drip into your line. If these cells were not saved when your donor had their first collection, they can donate more cells. They will not need injections of growth factors for this. The lymphocytes are collected in the same way as the stem cells were.

The main risk of a donor lymphocyte infusion is that you might develop graft-versus-host disease (GvHD). Your doctor will talk to you about any risks.

Eating and drinking

While your immune system is recovering, you need to avoid certain foods to reduce your risk of infection. You can still eat a healthy, balanced diet which will help your body to recover. If you are having difficulties eating, ask your nurse or dietitian for advice.

We have included some advice here on eating and drinking. Your dietitian or transplant nurse will give you more specific advice.

Some foods you may be asked to avoid are:

- raw or lightly cooked eggs
- shellfish
- all types of pate
- soft cheeses, cheeses made with unpasteurised milk (such as parmesan and feta), mould-ripened cheese (like brie) and blue cheeses (like stilton)
- probiotic or bio foods, drinks or supplements
- cooked sliced meats
- smoked fish
- reheated rice
- fresh nuts and nuts in shells
- cream cakes
- takeaway food
- pre-wrapped sandwiches.

Some general advice on eating and drinking is:

- completely defrost frozen foods before cooking
- wash fruit and vegetables, and wash salads thoroughly
- use food before its ‘use by’ date
- keep raw and cooked foods apart
- thoroughly cook all foods, especially those containing pork because of HEV (hepatitis E virus)
- cook all meats until juices run clear.

Check with your doctor before drinking alcohol. It slows down the recovery of the bone marrow and increases the risk of bleeding. It can also interact with some of the drugs you are taking.

Managing tiredness

Feeling you have little or no energy (fatigue) is very common after this treatment. It can take many months to get your energy back. For some people, it can take much longer. Recovery is a gradual process, so don’t expect too much of yourself.

Save your energy for the things you enjoy doing, or things that have to be done. Accept offers of help from family and friends. Gentle exercise, such as short walks, can help increase your energy levels. We have lots of useful information about fatigue in our booklet **Coping with fatigue** (see page 116).

Becoming more physically active

Regular, gentle walks help to keep your muscles toned. While your blood count is still recovering, certain types of exercise are not suitable. You can ask your specialist about this. After your blood counts have recovered, you can start doing more types. Regular exercise can help with your recovery and future health. But it is a good idea to increase the amount gradually.

Socialising

It is important to spend time with family, friends or a partner. You should also do things you enjoy. But try to avoid crowded places until your immune system has recovered. This includes shops, cinemas and public transport at busy times. Once you are on a low dose of immunosuppressant, or no longer need to take them, you should be able to have a full social life again.

You should still avoid contact with children who have infectious illnesses such as chickenpox or measles. Also avoid people with sickness and diarrhoea. If you are worried you have been in contact with someone with an infectious illness, contact your transplant team.

Driving

If you feel very tired, you may find it hard to concentrate. This can make you less alert and can slow down your reaction time.

It is best to avoid driving if you feel like this. Ask someone else to drive you instead. You can ask your transplant team if there is help with transport for hospital appointments.

Some drugs cause side effects that may make it unsafe for you to drive. Speak to your doctor about any concerns you have.

Your sex life

Your treatment does not stop you being able to have sex. Before going home, check with your doctor if there is any reason you cannot go back to your usual sex life. You may need to be more careful if your levels of neutrophils or platelets are low. It can take time for things to get back to how they were before.

It is normal to have a low sex drive after treatment. This may be due to low hormone levels after treatment. It may also be because you are too tired or feel anxious. This should improve as you recover. Women may be coping with effects of the menopause, such as vaginal dryness. Men may have problems getting an erection. Your doctor or nurse can tell you ways to help manage these problems.

Some people may get genital graft-versus-host disease (GvHD). It can cause narrowing and inflammation of the vagina, or redness (rash) on the penis.

If you have a partner, talk to them about how you feel. There are different ways of showing your love and affection if you don’t feel like having sex. You can wait until you both feel ready.

Some people have concerns about their body image because of changes such as hair loss or weight loss.

Let your doctor or nurse know if you are having problems with your sex life. There may be things that can help.

If you feel uncomfortable talking to your doctor or nurse, you may want to call us on **0808 808 00 00** (8am to 8pm, 7 days a week). We also have information about sexual wellbeing and body image that you might find helpful (see page 116).

Contraception

You may have been told that having a donor stem cell transplant means you can no longer get pregnant or make someone pregnant. But you should still use contraception while you are recovering from the treatment to avoid a pregnancy. Cancer treatments may harm a developing baby. And in the first few months, you will be taking medicines that could affect a developing baby.

Hormone replacement therapy

Women may have an early menopause because of their treatment. As well as periods stopping, other symptoms include:

- hot flushes and sweats
- vaginal dryness
- mood and concentration changes
- not feeling like sex (low sex drive).

Most of these symptoms can be helped by hormone replacement therapy (HRT). You can talk to your specialist doctor or nurse about this.

The first year out of hospital

By the end of the first year, your immune system should usually be starting to work well. Your bone marrow should be making healthy blood cells. For some people, this may take longer so you should continue to be careful. You will still have regular follow-up appointments with your specialist doctor and nurse.

You may still get infections, such as shingles and chest infections. Some people may need to go into hospital to have them treated. Some people will still need blood transfusions.

Your weight and strength will gradually recover. When you feel well enough, you may start thinking about getting back to work or education. Talk to your doctor about this first. Try not to overdo things.

It is common to find this a challenging time. You may be starting to return to things you did before. But you may still feel anxious about your health. Talk to your doctor and nurse about any concerns you have.

Returning to work or education

Talk to your manager, guidance staff or teachers about the best way to do this. You will need to plan a gradual (phased) return. Employers can usually support you by allowing flexible working. This may include a phased return, working part-time or working from home. They may also be able to change certain parts of your job to make things easier for you.

Think about whether you want them to tell other people about your treatment before you return. We have more information in our booklet **Work and cancer** (see page 116).

Vaccinations

After a donor stem cell transplant, you lose your immunity to illnesses that you were vaccinated against as a child. You need to have these vaccinations again. You will also need vaccinations against common infections such as flu. Your specialist doctor will talk to you about this and advise you when to have these.

There are some types of vaccines (live vaccines) you need to avoid until your immune system is fully working. Try to avoid contact with young children for a few days if they have had the flu vaccine as a spray through the nose. If your child has had the rotavirus vaccine that is given by mouth, do not change or handle any dirty nappies.

Your haematology doctor will tell you which vaccinations are safe and which ones you should avoid.

Holidays and travel

As your immune system recovers and the time between hospital visits get longer, you might think about going on holiday. Talk to your haematology doctor before booking a holiday. They usually advise you not to travel abroad in the few months after treatment. It may depend on:

- how well your immune system is working
- if you are still on high doses of immunosuppressants.

Ask your doctor about any vaccinations you may need. When you travel, it is helpful to take a letter from your doctor explaining your medical history. You should also take the contact telephone numbers for your hospital.

It can be difficult to get travel insurance if you have cancer, or if you have had cancer before. We have a booklet called **Travel and cancer** that has helpful, practical tips about travelling (see page 116).

Sun protection

After your transplant, it is important to protect your skin from the sun. Being exposed to sunshine can trigger graft-versus-host reactions. You also have more risk of developing skin cancer.

Use a suncream with a high sun protection factor (SPF 30 or higher). Avoid strong sunlight and cover up with clothing and a hat in the sun. It is important to continue protecting your skin for the rest of your life.

If you notice any changes to your skin let your doctor know.

Late effects

Some treatment side effects may become permanent and others may develop years after treatment has finished. These are called late effects. They may be due to the treatment you had, or because your immune system does not work as well as before.

Your transplant team will guide you and your GP about monitoring for late effects. Always tell your doctor about any problems you have. There are things you can do that may help reduce the risk of late effects, or help manage them.

When you have appointments, you will have blood tests to check:

- your different hormone levels are normal
- your iron levels are normal
- your kidneys and liver are working well
- you do not have high cholesterol levels (fats or lipids)
- your blood sugar levels are normal.

They will also check your blood pressure regularly.

Eye changes

Your eyes may become dry and irritated. Using eye drops regularly will help.

If you had total body irradiation (TBI), you also have more chance of developing a cataract. This is a cloudy patch in the lens of your eye. It can make your vision blurred or dim. Cataracts can be treated with a small operation.

Have your eyes checked regularly and tell your doctor if you have any problems with your sight.

Underactive thyroid

Your thyroid gland, which makes the hormone thyroxine, may not work as well. You will have blood tests to check this. It can be treated with thyroxine tablets.

Bone thinning

The drugs and treatments you have had can increase your risk of bone thinning (osteoporosis). Women who have an early menopause are more at risk. Taking HRT can help to protect your bones.

You can also ask your doctor if you should take vitamin supplements to help protect your bones.

Tell your doctor if you get any problems with your bones. Eating a healthy diet and doing regular weight-bearing exercise, such as walking, will help look after your bones.

Effects on the heart

The treatment may affect the way your heart works. You may have tests to see how your heart is working.

If you have pain or tightness in your chest, feel breathless, or notice changes to your heartbeat, tell a doctor straight away. These symptoms can be caused by other conditions, but it is important to get them checked by a doctor.

Effects on the lungs

Always tell your doctor if you develop wheezing or a cough, or if you feel breathless. You should also let them know if any breathing problems you have already have get worse. If needed, they can arrange some tests to check your lungs.

Effects on the kidneys

The treatment can affect your kidneys. You will have regular blood tests to check your kidneys are working well. It is important to drink at least 2 litres (3½ pints) of fluids each day to help protect your kidneys. If you notice any changes with passing urine, such as passing more or less than usual, let you doctor know.

Tiredness (fatigue)

Many people continue to feel very tired (fatigue) for months, and sometimes years after treatment with a donor stem cell transplant. This can be hard to cope with, but there are ways to help you manage fatigue. It can take time to recover, but going for gentle walks will help improve your energy levels. There is more information in our booklet **Coping with fatigue** (see page 116).

Risk of another cancer

After high-dose treatment you have more risk of developing a second cancer. The most common type is skin cancer. So protecting yourself from the sun is very important.

Your transplant team or your GP will monitor you closely long-term. This means that any problems with your health can be found and treated early.

What you can do

You can help to reduce your risk of another cancer and look after your bones and heart by:

- not smoking
- eating healthily and keeping within recommended alcohol guidelines
- doing regular exercise
- protecting yourself from the sun
- taking part in national screening programmes to diagnose early cancers
- seeing your dentist regularly
- going to your GP straight away if you have possible cancer symptoms such as a lump or any unusual bleeding.

Your follow-up

You will need to have regular check-ups to make sure that you stay well and that there is no sign of the cancer returning. They will also be checking for any signs of chronic GvHD.

Usually your doctor will check you over and arrange some blood tests and possibly scans.

These check-ups can be worrying, as you will probably be anxious about whether the treatment has worked. It often helps to take a relative or friend with you for support. The check-ups are a good chance to talk to your doctor about any worries or problems you have. You can also call the transplant team or your nurse if you have any concerns once you are home.

Many people go on to make a full recovery with few health problems after a transplant. You will have the support of your transplant team or haematology team during your recovery.

> ‘Four months after the transplant I had my first proper scan to see if I was clear together with a bone marrow biopsy. I got all the results a week later. I was very nervous to say the least and just kept my fingers crossed that I was clear!’
>
> Alan

Getting support

After treatment, you will need a lot of support. It is important to talk to family, friends and your partner, if you have one, about how you are feeling. Some people also find support groups and other organisations helpful (see pages 120 to 127).

Support groups

These groups offer a chance to talk to other people who have been through the same experience as you. Joining a group can be helpful if you live alone. It can also help if you don't feel able to talk to people you know about your feelings. Not everyone finds talking in a group easy, so it might not be right for you. Try visiting one to see what it is like before you decide.

> 'Counselling has been a life-saver to me to be able to tell someone how you feel each week and off-load. It's so therapeutic being able to reflect and to know that you are not alone is so important.'
>
> **Alan**

Online support

Many people get support on the internet. There are online support groups, social media sites, forums, and blogs for people affected by cancer. You can use these to share your experiences, ask questions, get advice from others and give advice based on your experiences.

Call **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** to find out about groups near you.

Visit **macmillan.org.uk/community** to join our Online Community. You can talk to people on the forums, blog your journey, make friends and join support groups.

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

On the next page are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, getting dressed or having a bath. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

> ‘The Macmillan Information Centre at the hospital was lovely; a place to chill away from the craziness of tests. The staff were really friendly and supportive and gave me lots of good advice about financial matters.’
>
> **Alan**

Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer’s Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

> 'Macmillan helped me a lot with claiming benefits. They got all the forms and helped me fill them in. They negotiated a two month mortgage 'holiday'with my mortgage lender. Macmillan told me I could have a grant too.'
>
> **Alan**

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support. If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a pay-out from an insurance scheme that you already have.

Our Online Community forum Travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00** You can also get information about benefits and other types of financial help from Citizens Advice (see page 125).

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

Stem cell transplant support

ACLT

Tel 0203 757 7700
Email info@aclt.org
www.aclt.org

Raises awareness among black people of the importance of registering as a potential bone marrow, blood and organ donor. Provides support and advice to patients and their families.

Anthony Nolan

Tel 0303 303 0303
www.anthonynolan.org

Runs the UK's largest register of fully tissue-typed volunteer donors. Accepts new blood stem cell and bone marrow donors.

Bloodwise

Helpline 0808 2080 888 (Mon, Tue, Thu, Fri 10am to 4pm, Weds 10am to 1pm)
Email support@bloodwise.org.uk
www.bloodwise.org.uk

Supports research into the causes, treatment and cure of blood cancers. Provides information and support about the diseases and their treatments.

British Bone Marrow Donor Registry

Tel 0300 123 23 23
www.nhsbt.nhs.uk/british-bone-marrow-registry

A national register of donors. Also provides information about transplants and donating blood and stem cells.

Children's Cancer and Leukaemia Group (CCLG)

Tel 0333 050 7654
Email info@cclg.org.uk
www.cclg.org.uk
Co-ordinates research and care for children with cancer and their families. Provides information and support for patients and families.

Leukaemia CARE

Tel 0808 8010 444
www.leukaemiacare.org.uk
Provides care and support to people affected by leukaemia and other blood cancers. Offers financial help, friendship and support, and local support groups.

Lymphoma Action

Tel 0808 808 5555
(Mon to Fri, 10am to 3pm)
Email information@lymphoma-action.org.uk
www.lymphoma-action.org.uk
Provides support and information to anyone affected by lymphoma.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline 0808 800 4040
(Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and their friends.

Penny Brohn UK

Helpline 0303 3000 118
(Mon to Fri, 9.30am to 5pm)
Email helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK’s biggest health information website.
Has service information for England.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm,
Sat and Sun, 9am to 5pm)
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health and illness related websites

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncras.nhs.uk
Tel (Ireland) 021 4318 014
www.ncri.ie

Scottish Cancer Registry

Tel 013 1275 7050
Email nss.csd@nhs.net
www.isdscotland.org/health-topics/cancer/scottish-cancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 029 2037 3500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300
(Mon to Fri, 9am to 5pm)
Email bacp@bacp.co.uk
www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Financial support or legal advice and information

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Northern Ireland

Helpline 0800 028 1881
www.citizensadvice.co.uk

GOV.UK

www.gov.uk

Has information about social security benefits and public services in England, Scotland and Wales.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline 0800 022 4250 (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

StepChange Debt Charity

Tel 080 0138 1111
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline 0800 023 6868
Email contact@unbiased.co.uk
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

Support for young people

CLIC Sargent

Tel 0300 330 0803
www.clicsargent.org.uk
Provides clinical, practical, financial and emotional support to children with cancer in the UK.

Teenage Cancer Trust

Tel 0207 612 0370 (Mon to Fri, 9am to 5.30pm)
Email hello@teenagecancertrust.org
www.teenagecancertrust.org
A UK-wide charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer, their friends and families.

Youth Access

Tel 020 8772 9900 (Mon to Fri, 9.30am to 1pm, then 2pm to 5.30pm)
Email admin@youthaccess.org.uk
www.youthaccess.org.uk
A UK-wide organisation providing counselling and information for young people. Find your local service by visiting **youthaccess.org.uk/find-your-local-service**

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) 0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

YOUR NOTES AND QUESTIONS

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Anne Parker, Consultant Haematologist.

With thanks to: Dr Jenny Bird, Consultant Haematologist; Dr Adrian Bloor, Consultant Haematologist; Helen Hunter, Bone Marrow Transplant Co-ordinator; Dr Nick Morley, Consultant Haematologist; Jane Nunnick, Senior Haematology Research Nurse; Dr Jiri Pavlu, Consultant Haematologist; Lara Rowley, Bone Marrow Transplant Nurse Practitioner; and Nicola Shepherd, Haematology Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Carreras, Dufour, Mohty and Kröger. The European Society for Blood and Bone Marrow Transplantation: Hematopoietic stem cell transplantation and cellular therapies. Springer, Switzerland. 2019.
FACT-JACIE International Standards for Hematopoietic Cellular Therapy – product collection, processing and administration. 7th edition. 2018.
Anthony Nolan. Operations and patient services user guide. Available from www.anthonynolan.org. Accessed January 2019.

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS YOU CAN HELP SOMEONE WITH CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

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Mr/Mrs/Miss/Other

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Surname

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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

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Visa / MasterCard / CAF Charity Card / Switch / Maestro

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Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about having a donor stem cell transplant. It is for anyone who is going to have this treatment. There is also information for carers, family members and friends.

The booklet explains what a donor stem cell transplant is, the different stages of treatment, and the possible side effects. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**.

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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5th edition. MAC11690_E05.
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