MACMILLAN
CANCER SUPPORT

UNDERSTANDING STEM CELL TRANSPLANTS USING YOUR OWN CELLS (AUTOLOGOUS)

> I've always believed knowledge is power, so my husband and I read up all we could and asked lots of questions about the procedure in the clinic.

Lesley, who had a stem cell transplant using her own cells

About this booklet

This booklet is about having a stem cell transplant using your own cells (autologous stem cell transplant). It is for anyone having this treatment. There is also information for carers, family members and friends.

The booklet explains how you have a stem cell transplant using your own cells. It explains the different treatment stages, and the possible side effects. It also covers 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 an autologous 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 98).

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 3 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 98 to 104, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had an autologous 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 Lesley 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

WHAT IS HIGH-DOSE TREATMENT WITH STEM CELL SUPPORT?

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.

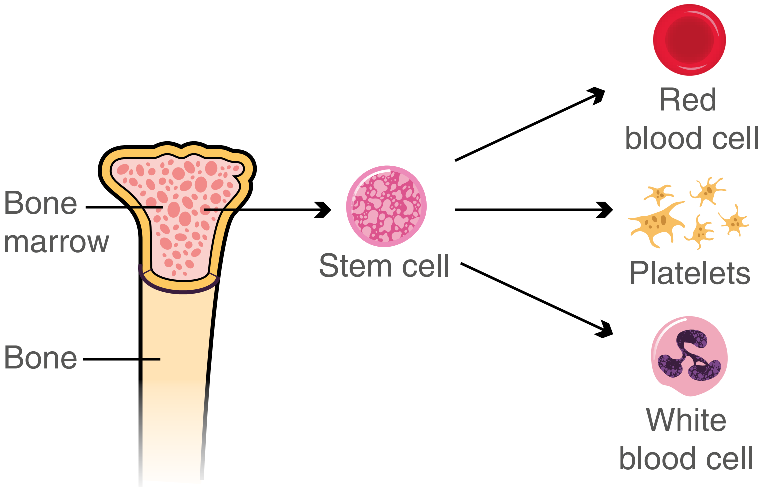
Blood cells do not live long. The bone marrow normally makes millions of new blood cells every day to replace blood cells as they are needed.

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 to 165g/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

An autologous stem cell transplant allows you to have much higher doses of chemotherapy than usual to treat the cancer.

You usually have standard-dose treatment first to get rid of as many cancer cells as possible. After this, you have high-dose treatment to destroy any remaining cancer cells. But high-dose treatment destroys the stem cells in your bone marrow as well as the cancer cells.

Because of this, some of your stem cells are taken and stored before you have high-dose treatment. After the treatment, they are given back to you through a drip (infusion). Your stem cells make their way to your bone marrow and start making new blood cells. Without this it could take many weeks or months for your blood count to recover.

An autologous stem cell transplant increases the chances of curing certain cancers, such as lymphoma. Or it can help keep certain cancers, like myeloma, in remission for as long as possible. Remission is when there are no signs of the cancer.

This treatment may be used when:

- there is a higher risk of the cancer coming back without it
- the cancer has come back after other treatment
- the cancer has not responded completely to treatment.

It is an intensive treatment. But it is less complicated than using stem cells from a donor. There are fewer problems and recovery is faster.

Where you will have it

You will be treated in a cancer unit that specialises in this treatment. Some people may need to travel quite far to their nearest unit. You will usually need to stay in hospital for a few 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 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

Your cancer doctor, nurse or transplant co-ordinator will explain why you are being offered this treatment. They will tell you about the possible benefits and risks.

An autologous stem cell transplant is a complex treatment, but it can be divided into 6 stages.

On the next two 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.

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The stages of an autologous stem cell transplant

Stage 1: Getting ready for treatment
(see pages 21 to 31)

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Stage 2: Collecting the stem cells
(see pages 33 to 37)

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Stage 3: High-dose treatment
(see pages 39 to 45)

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Stage 4: Having the stem cells
(see pages 47 to 49)

↓

Stage 5: Waiting for new blood cells to grow
(see pages 51 to 67)

↓

Stage 6: Recovering after your transplant
(see pages 69 to 91)

Stage 1: Getting ready for treatment

Your cancer doctor or nurse explains the benefits and risks of having this treatment. If you decide to go ahead, you have standard chemotherapy to get rid of as many cancer cells as possible. When you have finished this, you have tests to check your general health. This may include tests on your heart, lungs and kidneys.

Stage 2: Collecting the stem cells

This is known as the harvest. Your stem cells are usually collected at least 2 weeks before you have high-dose treatment. They are frozen and stored until they are needed.

Stage 3: High-dose treatment

You are given high-dose treatment to destroy as many cancer-dose chemotherapy on its own or with radiotherapy. This destroys most, or all, of the cancer cells. But it also affects healthy blood cells in your bone marrow. This stage is also called conditioning treatment. It can take from one day to one week.

Stage 4: Having the stem cells

After your high-dose treatment, you are given your own stem cells back through a drip (infusion).

Stage 5: Waiting for new blood cells to grow

It is usually between 10 and 12 days before the stem cells start to make new blood cells. Sometimes it may take longer. Doctors call this engraftment. You will need lots of medical and nursing support until your blood count returns to a safe level.

Stage 6: Recovering after your treatment

When your blood count has recovered, and you are well enough, you can go home. Your doctor or nurse will tell you how to reduce your risk of infection and improve your fitness. It may take months to recover from this treatment.

Making your decision

You need to think about the benefits and risks of this treatment carefully before you decide. It is important to discuss any questions you have with your cancer doctor. You may want to talk about it with family and close friends. Most units also have a nurse specialist, a transplant co-ordinator, a social worker or a counsellor who you can talk to.

Some people find it helps to talk to someone who has already had this treatment. Talk to the staff at the hospital where you are having your treatment. You can also use Macmillan's online community to meet people who are going through similar experiences to you.

We have more information in our booklet **Making treatment decisions** (see page 94).

> 'The discomfort at the time was made bearable by the knowledge that I knew it wouldn't last, and by putting total faith in the professionalism of those in charge of looking after me.'
>
> **Lesley**

Risks of an autologous stem cell transplant

An autologous stem cell transplant is a specialised treatment. The main risk is serious infections. These are most likely to happen when your blood counts are low.

You usually stay in hospital, or near the hospital if you are having ambulatory care, for 2 to 4 weeks. But some people stay longer. There may be times when you feel very unwell.

Your doctor will consider your general health before advising you whether to have this treatment. This is because your general health can affect your recovery.

Fertility

An autologous stem cell transplant can affect 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 also 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 in our leaflets **Cancer treatment and fertility – information for women** and **Cancer treatment and fertility – information for men** (see page 94).

Questions you might like to ask your doctor

- What are the possible benefits of an autologous 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 happens if the cancer comes back after treatment?
- What will happen if I decide not to have this treatment?
- Are there any other treatments I could have instead?
- How long will it take afterwards before I am able to do everyday things?

> ‘I was very lucky as my Macmillan Haematology Specialist Nurse was on the end of the phone/text whenever I needed help or to ask a question.’
>
> **Mike**

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.

STAGE 1: GETTING READY FOR TREATMENT

Getting ready

Having an autologous stem cell transplant is physically demanding. Your transplant team need to make sure that you are 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 best 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.

A stem cell transplant may be emotionally difficult for some people. You may have complex feelings about it. Having support from family, friends and your healthcare team is helpful. There may be a counsellor who can help you cope with these feelings before your treatment. 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. We have more information in our booklet **Help with the cost of cancer** (see page 94). It may 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.

Some people find it helps to talk to someone who has already had a stem cell transplant. Your specialist or the support organisations listed on pages 98 to 104 might be able to put you in contact with someone.

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).

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. The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

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 in our leaflets **Cancer treatment and fertility – information for women** and **Cancer treatment and fertility – information for men** (see page 94).

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.

> ‘PICC lines are amazing – no more needles and the whole process of bloods/treatments is super easy.’
>
> **Greg**

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.

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 (**community.macmillan.org.uk**) for people aged 16 to 24, where you can talk to others who have had a similar experience. You can also get support from organisations such as the Teenage Cancer Trust and CLIC Sargent (see pages 98 to 104).

Getting organised

When your treatment is planned, you can start to make practical arrangements. Ask your family, friends or partner, if you have one, 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.

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.

STAGE 2: COLLECTING THE STEM CELLS

Collecting stem cells from the blood

Your stem cells are usually collected from the blood. This usually happens at least 2 weeks before the high-dose treatment, when the cancer is in remission.

Stem cells usually live in the bone marrow and produce all our blood cells. The first part of collecting stem cells from the blood is making them move from the bone marrow into the blood. This is called mobilising the stem cells.

Mobilising the stem cells

To get the stem cells to travel from the bone marrow to the blood, you may have chemotherapy. This is followed by daily injections of a drug called a growth factor (G-CSF). Or you may only have the G-CSF injections.

G-CSF stimulates the bone marrow. It increases the number of stem cells and white blood cells in the blood. You have it as an injection under the skin (subcutaneously).

We have more information about G-CSF on our website **macmillan.org.uk**

You can have the injections at home. Your nurse can show you, a relative or a friend how to give them. Or your practice nurse or community (district) nurse can give them to you. Some side effects of the injections include:

- flu-like symptoms
- bone pain
- redness where the injection was given.

Your doctor or nurse will explain how many days you have the injections for. They will also explain the side effects and what type of painkiller will help.

They will test your blood regularly to check the level of stem cells. Once there are enough stem cells in the blood, they will be collected.

In a small number of people, not enough stem cells move into the blood for collection. If this happens, you may have a drug called plerixafor (Mozobil®). This helps to increase the number of stem cells released into the blood. The nurses at the hospital will give it to you as an injection under the skin.

Collecting the stem cells

You usually have stem cells collected as a day patient. It takes 3 to 5 hours. You will be sitting or lying down, so wear some loose, comfortable clothing. You may want to take some books, magazines or music to help pass the time.

The nurse will make sure you are comfortable on a chair or bed. They will put a tube (cannula) into a vein in each arm.

Each cannula is connected by tubing to a machine called a cell separator. Blood goes from one of your arms through the tubing into the cell separator. As the blood travels through the cell separator, it is spun to separate out the stem cells. These are collected in a bag. The rest of your blood is given back through the cannula in your other arm. If you have a central line or a PICC line, the nurses may use this instead. Less commonly, your doctor or nurse may suggest putting a thin tube (line) into a vein at the top of your leg. This happens if they cannot use the veins in your arms. Your healthcare team can tell you more about this.

You will not usually feel anything while you are having your stem cells collected. But sometimes people feel dizzy or light-headed.

A drug called citrate is used to stop the blood from clotting as it passes through the separator machine. A small amount of this drug gets into your blood. It can reduce the level of calcium. This can cause:

- muscle cramps
- tingling
- numbness or a cold feeling in your lips, fingers or toes.

This is common, but is usually mild. The nurse may give you a calcium tablet to chew or calcium as a drip to treat or prevent low calcium.

Sometimes not enough stem cells are collected on the first day. If this happens, you may need to have them collected again the following day.

After the collection

Counting and storing stem cells

The collected stem cells are counted to make sure there are enough. Some people need to come back over 2, or sometimes 3 days to collect enough stem cells. The stem cells are frozen and stored until you need them.

Sometimes not enough stem cells are collected over this period. There are different things your doctor can do to try to get more stem cells. They can arrange another stem cell transplant when they may give you:

- more chemotherapy with G-CSF, and sometimes with a drug called plerixafor
- G-CSF either on its own, or along with plerixafor.

Irradiated blood

For at least 2 weeks before stem cells are collected, any blood or platelet transfusions you have will be treated with radiation (irradiated) – see page 59. This is to prevent any problems caused by white blood cells in the donated blood.


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STAGE 3: HIGH-DOSE TREATMENT

Going into hospital

You usually stay in hospital to have the treatment. The treatment may only last a day or a few days, but you are usually in hospital for a few weeks. This is because you need to wait for your blood count to recover. This can take 2 to 3 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 be admitted to the hospital. You can talk to your doctor or nurse about whether ambulatory care is possible for you.

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, pictures and a clean blanket or pillow.

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 and your partner, if you have one, 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. 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?

Having high-dose treatment

High-dose treatment (also called conditioning treatment), is given to destroy as many cancer cells as possible. You will have high doses of chemotherapy. Rarely people also have radiotherapy to the whole body. This is called total body irradiation (TBI).

Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. You may have had chemotherapy as part of your original treatment. If you did, you will have an idea of what to expect.

The nurses will give you chemotherapy drugs into a vein through your central line or PICC line, along with plenty of fluids. Some people may have some of their chemotherapy as tablets. You usually have a combination of chemotherapy drugs. Your nurse will explain about the possible side effects and give you drugs to help control them.

The treatment is given over one day or a few days. This depends on the type of cancer you have. We have more information about chemotherapy and its side effects in our booklet **Side effects of cancer treatment** (see page 94).

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 high-dose treatment. You usually have it a few days after you start chemotherapy.

You may have TBI twice a day for 6 to 8 sessions. This is usually over 3 to 4 days.

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. This means you need to change position a few times during the session. The radiographer will explain this to you.

Each session lasts about 40 minutes. 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 after the treatment. The radiographers will explain how to manage the side effects and how to care for your skin. We have more general information about radiotherapy in our booklet **Understanding radiotherapy** (see page 94).


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STAGE 4: HAVING THE STEM CELLS

Having your stem cells

Your stem cells will be given back to you 1 or 2 days after the high-dose treatment has finished. The day you are given your stem cells is known as Day 0.

Your nurse gives you the stem cells as a drip (infusion) through your central line or PICC line. 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.

You and your visitors might notice a strong smell like sweetcorn. This can last for a few days after the infusion. This is from the preservative that is used to protect the stem cells during storage.

> **‘I was transfixed by the absolute wonder of watching my own stem cells being fed back through my Hickman Line, and the satisfaction that I was, essentially, healing myself.’**
>
> **Lesley**

STAGE 5: WAITING FOR NEW BLOOD CELLS TO GROW

Waiting for your blood count to recover

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

It usually takes 10 to 12 days before some of the new blood cells are released into the bloodstream. For some people it may take longer. This means you will have low numbers of red blood cells, white blood cells and platelets for some time. This can cause some of the main side effects. During this time, you are at high risk of infection and other problems, such as bleeding and 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.

You may be given a drug called G-CSF as an injection. It helps your bone marrow make new blood cells. This reduces the length of time you are at risk of side effects.

Daily routine

If you are in hospital, you may expect to have a lot of quiet time. But your day can be quite busy. A lot of your time will be taken up with daily routines and checks by the doctors and nurses. This may 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 may be some rules to help reduce your risk of infection. 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.

> ‘Being in control of my diet as an inpatient had the knock-on effect that I was in control of “some part” of the whole proceedings. I also kept a daily diary of food intake. It was very empowering.’
>
> **Lesley**

The side effects of an autologous stem cell transplant

The side effects will depend on the type of high-dose treatment you had. Your hospital team will give you more information about what to expect.

Most 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 on our website **macmillan.org.uk**

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. Infections can start 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.

Your nurses will give you drugs to prevent and treat infections. They will take your temperature regularly and check for signs of infection. They will also ask you to tell them if you have any 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 infection. But most people need antibiotics at some point while their immune system is recovering.

Hygiene

When you are in hospital 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 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 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 treatment, 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 any 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 to help. 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.

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. Rarely, 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.

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).

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.

Starting to recover

When your blood count has reached a safe level and you are improving, you can go home. You will need some support at home from a relative, friend or partner. The hospital can also arrange some help for you. You will have a 24-hour telephone contact number in case you have any worries. You will need to go back to the hospital regularly as an outpatient for check-ups.

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?'.

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.

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.

'The mental battle is really tough. I felt like the world had stopped but nobody seemed to have noticed. The only thing I can describe the process as is as a slog. Sometimes all you can do is focus on the next day, hour, even minute in front of you. The thing that kept me going was remembering that what you are going through is temporary. It's just something you've got to plough through to get to where you want to be.'

Greg

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.

We have more information in our booklet **Life after cancer treatment** (see page 94).

The first few months out of hospital

After you go home, you will need to go back to your local hospital outpatient clinic for checks. To begin with you may have 1 or 2 appointments close together. After that, you will have them less often.

Your immunity will be low for a few months. This is even after your bone marrow has recovered and your neutrophils are back to a normal level.

You may have to take regular antibiotics and anti-viral drugs to reduce the risk of infection.

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.

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 been in contact with someone who has an infectious disease, for example chickenpox or measles
- you cannot take your tablets.

It is important to follow any specific advice your cancer treatment team gives you.

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.

Eating and drinking

Your doctor or nurse can give you information about your diet for when you are home. Follow the advice that they give you.

While your immune system is recovering, try to eat a healthy and balanced diet. Try to avoid possible risks of infection from food. Your doctor or nurse may give you a list of foods to avoid, which might include:

- unpasteurised milk, and soft and blue cheeses
- raw or lightly cooked eggs
- meat, fish, shellfish or poultry which has not been thoroughly cooked
- pate
- takeaway food
- food that is not completely fresh.

Some hospitals may give different advice. Some general advice on eating and drinking is:

- completely defrost frozen foods before cooking
- wash vegetables, salads and fruit thoroughly before eating them
- do not eat food after its ‘use by’ date
- take care to keep raw and cooked foods apart.

Once your immune system is back to normal, you can eat whatever you like. Your dietitian or nurse will give you advice.

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.

> ‘I was referred to a dietitian and she was great. We went through the strategies we should look at to keep my food intake at a good level during the time I just did not want to eat and to help put some weight back on.’
>
> **Mike**

Managing tiredness

Feeling you have little or no energy (fatigue) is very common after high-dose treatment. It is usually worse in the 2 to 4 weeks after treatment and then starts to improve. After the first month you can start trying to do a bit more each week. Recovery from treatment is usually gradual and will take time.

Save your energy for the things you enjoy doing, or things that need to be done. Accept offers of help from family and friends. Gentle exercise, such as short walks, can help increase your energy levels.

Most people find that after 3 months their energy levels are close to what they used to be. But for some people the tiredness can last longer. We have lots of useful information in our booklet **Coping with fatigue (tiredness)** – see page 94.

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 and your partner, if you have one. You should also do things you enjoy. Try to avoid crowded places until your immune system has recovered. This includes shops, cinemas and public transport at busy times. After 3 to 6 months, 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 or 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 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. It can take time for things to go back to how they were before.

It is normal to have a low sex drive after treatment. This may 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.

If you have a partner, talk to them about how you feel. There are other ways of showing your love and affection for someone 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.

Contraception

Chemotherapy may affect whether you can get pregnant or make someone pregnant (fertility). If you have periods they may stop during treatment, but you might still be able to get pregnant. Cancer treatments may harm a developing baby. It is important to use contraception to prevent a pregnancy during cancer treatment and for a time after it.

Your doctor or nurse will tell you how long you need to use contraception for.

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 (a 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.

Going back to work, school or college

When your blood counts have recovered, you can ask your doctor about going back to work, school or college. You should do this gradually, by going part-time to begin with. It is a good idea to talk to your employer, teacher or tutor about the best way of returning. Think about whether you want them to tell other people about your treatment before you return. We have more information about work and cancer issues on our website **macmillan.org.uk/work**

Vaccinations

After high-dose treatment, you may lose your immunity to illnesses you were vaccinated against as a child. You may need to have some of these vaccinations again.

You will also need vaccinations to protect you against common infections such as flu. Your haematology doctor may also recommend that the people you live with have some vaccinations, for example, the flu vaccine. They will give you advice about when you should have your vaccinations.

You need to avoid some types of vaccines (live vaccines) until your immune system is back to normal. Try to avoid contact with young children who 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 for a few months after treatment.

After this, your immune system should be working well so you should be able to travel abroad. 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 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 more information in our booklet **Travel and cancer** (see page 94).

Sun protection

After treatment, your skin will be more sensitive to the sun and may burn more easily. To avoid this:

- use a suncream with a sun protection factor (SPF) of at least 30
- cover up with clothing and a hat.

Remember you can burn even through clothing if you are out in hot sun for a long time.

Some chemotherapy drugs and radiotherapy can increase the risk of some skin cancers. So it is important to continue protecting your skin for the rest of your life.

Late effects

Some people may have late effects from chemotherapy. These are side effects you still have 6 months after chemotherapy, or side effects that begin years later. Late effects are not common, and any risk is outweighed by the benefits of chemotherapy.

Your cancer doctor or specialist nurse can explain any possible late effects of your chemotherapy treatment. Different drugs cause different late effects. Some drugs may cause:

- an early menopause (see page 79)
- not being able to get pregnant or make someone pregnant (infertility) – see page 26.

Effects on the heart or lungs

Some chemotherapy drugs can increase the risk of heart or lung problems later in life. Your doctor can give you more information about this. There are things you can do to help improve your general health.

We have helpful tips on looking after your heart and how late effects can be monitored and managed.

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 will tell you what signs to look out for.

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.

> ‘Through all the trials and tribulations of managing daily a happy balance of plenty of rest with gentle exercise, I have learned to be in the moment, and not have too many things on my to-do list at one time.’
>
> **Lesley**

Your follow-up

You will have follow-up appointments to make sure you stay well. The appointments will also check that there is no evidence of the cancer returning. Your doctor or nurse will tell you how often you will have them. Usually you will have a medical examination, 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, friend or partner, if you have one, with you for support. The check-ups are a good chance to talk to your doctor or nurse about any worries or problems you have.

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.

> ‘We continued to be focused on the positive outcome, having been warned of the hard work required by us both to go through – virtually-calling Northampton General Hospital our “second home” for a year.’
>
> **Lesley**

Getting support

After treatment, you will need a lot of support. It is important to talk to family, friends or a partner about how you are feeling. Some people also find support groups and other organisations helpful (see pages 98 to 104).

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.

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.

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.

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.

> ‘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**

Here 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, having a bath or getting dressed. 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.

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.

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.

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

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.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 94).

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 102).

Our booklet **Help with the cost of cancer** has more information (see page 94).

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

Bloodwise

Helpline 0808 2080 888
(Mon, Tue, Thu and Fri 10am to 4pm, and Wed 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.

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.

Myeloma UK

Tel 0800 980 3332
Email
myelomauk@myeloma.org.uk
www.myeloma.org.uk
Provides information and support to people affected by myeloma. Helps improve treatments through research, education and awareness.

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, and 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

Northern Ireland Cancer Registry

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

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

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

Northern Ireland

Helpline 0800 028 1881
www.citizensadvice.co.uk

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Wales

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

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,
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.

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, Dunfour, 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.

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

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REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet is about having a stem cell transplant using your own cells. 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 an autologous 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.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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