

A practical guide to
tests and treatments

UNDERSTANDING HIGH-DOSE TREATMENT WITH STEM CELL SUPPORT

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About this booklet

This booklet is about having high-dose treatment with chemotherapy – and sometimes radiotherapy – and using your own stem cells (early blood cells) to replace blood cells.

In this booklet, we call this high-dose treatment with stem cell support. You may also hear people call it an autologous stem cell transplant, an autograft or a bone marrow transplant.



Some transplants use stem cells from someone else (a donor). This is called a donor stem cell transplant, or an allogeneic transplant. We have a separate booklet about this type of transplant.

High-dose treatment with stem cell support can be used to treat different cancers, including lymphoma, leukaemia, myeloma and teratoma. It can also be used as a treatment for some non-cancerous conditions.

Both adults and children can have high-dose treatment with stem cell support. This booklet is for adults who are having treatment.

If you're a parent whose child is going to have high-dose treatment with stem cell support, the Children's Cancer and Leukaemia Group (see page 91) has a booklet called *A parent's guide to children's cancers*.

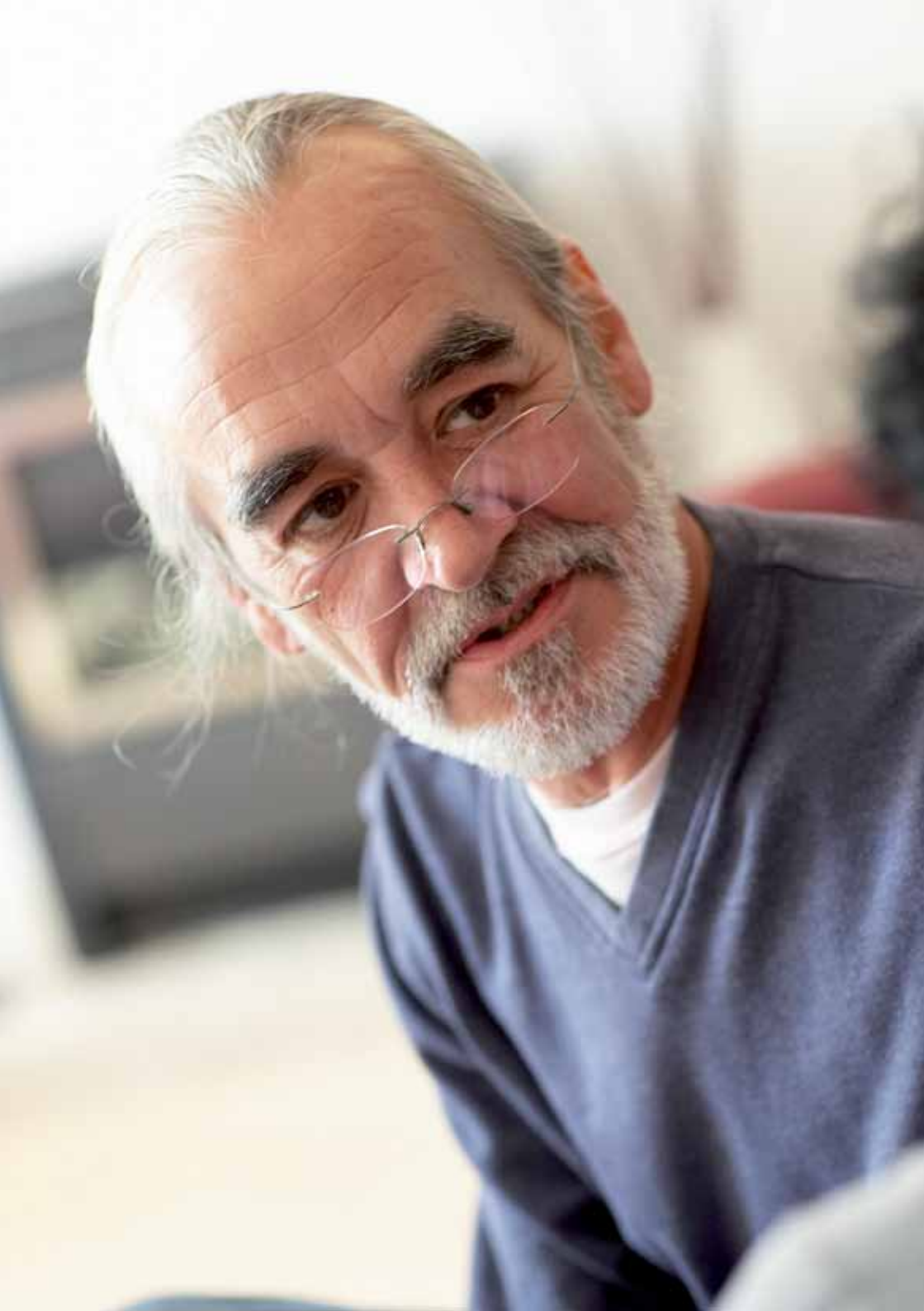
In this booklet, we've included comments from people who've had stem cell transplants. Some are members of our online community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)) and others have shared their stories on [healthtalkonline.org](https://www.healthtalkonline.org)

We can't advise you about the best treatment for you. This information can only come from your own doctor, who knows your full medical history.

Turn to pages 86–99 for some useful addresses and websites. You can write down any notes or questions for your doctor or nurse on pages 100–101.

You may also want to discuss this information with our cancer support specialists on freephone **0808 808 00 00** (Mon–Fri, 9am–8pm). If you're hard of hearing, you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. You can also visit [macmillan.org.uk](https://www.macmillan.org.uk)

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.



WHAT IS HIGH-DOSE TREATMENT WITH STEM CELL SUPPORT?

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The bone marrow and stem cells

To understand high-dose treatment with stem cell support, it helps to know about stem cells and the bone marrow.

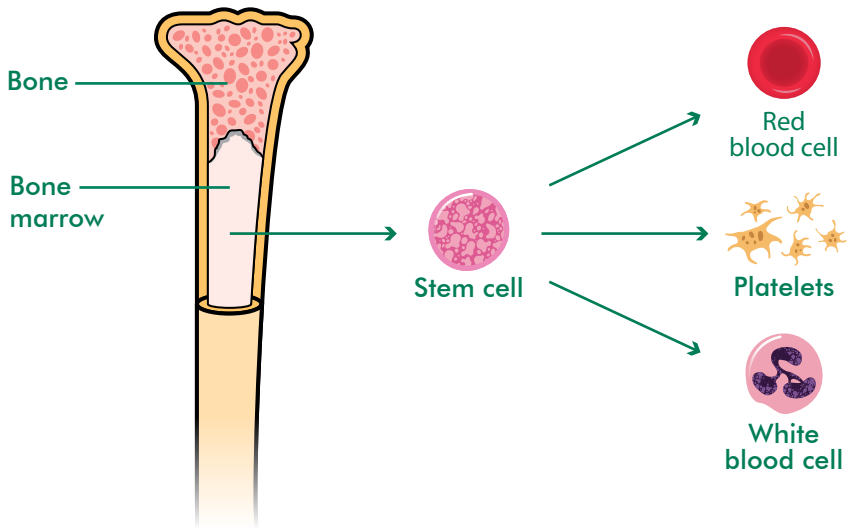
Stem cells are blood cells at their earliest stage of development. All blood cells develop from stem cells. The full name for stem cells in the blood and bone marrow is haematopoietic stem cells, but in this booklet we call them stem cells.

Bone marrow is a spongy material inside the bones – particularly the bones of the pelvis. The bone marrow is where stem cells are made.

Most of the time, almost all of your stem cells are in the bone marrow. There are usually only a very small number in the blood. Stem cells stay in the bone marrow while they develop into blood cells. Then, once they are fully mature, the blood cells are released into the bloodstream.

The three main types of blood cells are:

- **Red blood cells** – These contain haemoglobin (Hb), which carries oxygen to all cells in the body.
- **White blood cells** – These fight infection. There are several types of white blood cell. The two most important are neutrophils and lymphocytes.
- **Platelets** – These help blood to clot and prevent bleeding.



The bone marrow, a stem cell and blood cells

The levels of blood cells in your blood are measured in a blood test called a full blood count (FBC). It's often just called a '**blood count**'.

The figures below are a guide to the levels usually found in a healthy person.

Type of blood cell	Levels found in a healthy person
Red blood cells (Hb)	130–180g/l (men)
	115–165g/l (women)
Platelets	150–400 x 10 ⁹ /l
White blood cells (WBC)	4.0–11.0 x 10 ⁹ /l
Neutrophils	2.0–7.5 x 10 ⁹ /l
Lymphocytes	1.5–4.5 x 10 ⁹ /l

These figures can vary from hospital to hospital. Your doctor or nurse can tell you what levels they use. They can also vary slightly between people from different ethnic groups.

The figures might look complicated when they're written down, but in practice they're used in a straightforward way. For example, you'll hear doctors or nurses saying things like 'your haemoglobin is 140' or 'your neutrophils are 4'.

Most people with cancer or leukaemia soon get used to these figures and what they mean. But you can always ask your medical team to explain if you're not sure.



CLAUDE

About the treatment

High-dose treatment with stem cell support allows you to have much higher doses of chemotherapy than usual to treat the cancer or leukaemia. It's usually given after you have had standard dose treatment to get rid of as many cancer cells as possible. High-dose treatment is then given to try to destroy any remaining cancer cells.

High-dose treatments with stem cell support are given in hospitals with large cancer units that specialise in giving this treatment. You will usually need to stay in hospital for a few weeks.

High-dose treatment with stem cell support can be used to increase the chances of curing certain types of cancer or leukaemia. It can also be used to help keep cancer in remission for as long as possible. Remission means there are no signs of the cancer.

This treatment may be used when:

- there is a high risk of the cancer returning
- the cancer has come back after treatment
- the cancer hasn't responded completely to treatment.

High-dose treatment will destroy the stem cells in your bone marrow (see pages 6–7) as well as the cancer cells. Because of this, some of your stem cells are taken and stored (see pages 31–36) before you have high-dose treatment.

After high-dose treatment, the stored stem cells are given back to you through a drip (infusion). The cells go to your bone marrow and start to make blood cells again. Without stem cells, it could take weeks or even months for your blood count (see page 8) to get back to normal.

Although it's an intensive procedure, high-dose treatment with stem cell support is less complicated than treatments that use stem cells from a donor (called allogeneic transplants). There are fewer problems and recovery is faster.

Having the treatment

Your cancer doctor, nurse or transplant coordinator will explain why you are being advised to have a stem cell transplant. They will also tell you about the possible benefits and risks.

i On the next two pages is a brief explanation of what's involved in high-dose treatment with stem cell support. The treatment can be broken down into stages. In this booklet, there is a chapter for each stage. You can use the diagram on the next page to quickly find the chapter you need. The chapters also match the colours in the diagram.

The stages of high-dose treatment with stem cell support

Stage 1 – Preparing for treatment
(See pages 21–29)



Stage 2 – Collecting the stem cells
(See pages 31–36)



Stage 3 – High-dose treatment
(See pages 39–45)



**Stage 4 – Having the stem cells
(transplant)** (See pages 47–49)



**Stage 5 – Waiting for your blood count to
recover (engraftment)** (See pages 51–67)



Stage 6 – Recovery after a transplant
(See pages 69–83)

Stage 1 – Preparing for treatment

High-dose treatment with stem cell support is usually given after several courses of chemotherapy. This is to get rid of most or all of the cancer cells. It gives the treatment the best chance of working. Once you have finished this chemotherapy, you will have tests to check your general health and your heart, lungs and kidneys.

Stage 2 – Collecting the stem cells

This is known as the harvest. Your stem cells are usually collected a few days or weeks before you have high-dose treatment. They are frozen and stored until they're needed.

Stage 3 – High-dose treatment

High-dose treatment is given to get rid of any cancer cells left in your body. You may have high-dose chemotherapy on its own or with radiotherapy. This will destroy most or all of the blood cells in your bone marrow. This stage is also called conditioning treatment. It can take from one day to up to a week.

Stage 4 – Having the stem cells (transplant)

After your high-dose treatment, your own stem cells are given back to you through a drip (infusion). This is a bit like having a blood transfusion

Stage 5 – Waiting for your blood count to recover (engraftment)

It is usually two weeks before the stem cells start to make new blood cells. You'll need lots of medical and nursing support until your blood count returns to a safe level. You'll probably be looked after in a room of your own to protect you from infection.

Stage 6 – Recovery after a transplant

You will be able to go home once your blood count has recovered and you are feeling well enough. You'll be given advice about any precautions you need to take in the first few months, for example in your diet or lifestyle.

Risks of high-dose treatment

High-dose treatment with stem cell support is a complex and specialised treatment. The main risks are serious infections and bleeding, which are most likely to happen when your blood counts are low (see pages 55–57).

You will usually stay in hospital for 3–4 weeks, but for some people it may be longer. There are likely to be times when you feel very unwell.

Your doctor will take into account your age and general health before advising you whether to have this treatment. Guidelines recommend an upper age limit of 70 because the risks of severe side effects are higher after that age. It may also take longer to recover. But the age limit can be flexible depending on your general health, the risk of side effects and the risk of the cancer coming back.

Fertility

Unfortunately, high-dose treatment usually causes infertility (being unable to have children). Occasionally, after high-dose chemotherapy without radiotherapy, some people may still be able to have children. In this situation, fertility does not usually return until a few years after treatment.

It's important to talk to your specialist doctor or nurse if you are worried about your fertility. They can tell you about any options for preserving your fertility before treatment starts. There's more information about this on pages 28–29.

Making your decision

You'll need to think about the benefits and risks of this treatment carefully when deciding whether to have it. It's important to discuss any questions you have with your cancer doctor. You'll probably need some time to talk about it with family and close friends. Most units also have a nurse specialist, a transplant coordinator, a social worker or a counsellor who you can talk to.

Some people find it helps to talk to someone who's already had this treatment. Your specialist or the support organisations listed on pages 91–92 might be able to arrange this. You can also use Macmillan's online community to meet people who are going through similar experiences to you – visit **macmillan.org.uk/community**

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. You might decide to do this if you're concerned about the treatment that has been recommended for you. If you want a second opinion, you can ask your specialist to refer you for one. You can have a second opinion through the NHS so you don't have to pay, or you can choose to have one privately. You'll need to go to a different hospital for a second opinion. You may have to travel some distance as only specialist units carry out transplants.

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. This can help make sure your concerns are covered during the discussion.

Giving your consent

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment. You can use pages 100–101 to do this.

People sometimes feel that hospital staff are too busy to answer their questions, but it's important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Questions you might like to ask your doctor

- What are the possible benefits of high-dose treatment with stem cell support for me?
- What are the risks?
- Are there long-term side effects?
- Will I be able to have children after treatment?
- What happens if my cancer comes back after my high-dose treatment?
- What will happen if I don't have this treatment?

You can use pages 100–101 to write down any questions you have and the answers you get.

Research – clinical trials

Research trials are carried out to try to find new and better ways of carrying out stem cell treatments. Trials that are carried out on patients are known as clinical trials. Trials are the only reliable way to find out if a different type of treatment is better than what's already available.

Taking part in a trial

You may be invited to take part in a clinical trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.




We have a booklet called *Understanding cancer research trials (clinical trials)*, which describes research trials in more detail.

Emotional effects

Having high-dose treatment with stem cell support can be emotionally demanding and you may have many strong feelings. There may be times when you find this difficult to cope with. It might help to talk to a family member or friend. Some people find it useful to talk to someone outside their family, such as a GP or counsellor. We have more information about coping with emotions on pages 64–65.





'It is a very scary prospect, so there is absolutely no shame in admitting any nervousness.'

Ian

STAGE I: PREPARING FOR TREATMENT

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Getting ready for treatment

Having high-dose treatment with stem cell support is very physically demanding. It's important to make sure that you're fit enough to have the treatment. The doctors need to know whether you have any medical conditions that could cause complications afterwards, so they will ask you some questions about your health before treatment begins.

If you smoke, you'll be advised to stop, as it increases your risk of complications and long-term side effects. Your GP can give you advice on stopping smoking. You might also find it helpful to read our booklet, *Giving up smoking*.



Tests

You'll have a number of tests before the treatment. Your doctor or specialist nurse will explain what they are and why they are needed. They may include:

- blood tests to check your general health and whether you have any infections (including hepatitis B and C, and HIV)
- a chest x-ray to check your lungs and heart
- tests to check how well your lungs work
- tests to check how well your kidneys work
- tests to check that your heart is healthy, such as an ECG (electrocardiogram), an echocardiogram or a MUGA (multiple gated acquisition) scan
- a dental check to make sure you don't have any problems that might cause an infection
- a computerised tomography (CT) scan
- a bone marrow biopsy or lumbar puncture to check whether there is any disease in the bone marrow or spinal fluid.

The tests you have will depend on the type of cancer or leukaemia you have and the stage of your disease.



Our booklet about your type of cancer or leukaemia will have more information on some of the tests mentioned here.



Central line

While you're in hospital, you will have regular medicine into your veins (intravenously) and will have several blood tests. To make this easier, a soft, plastic tube (central line) can be put into a vein in your chest. Your doctor will arrange for you to have a central line before your treatment starts. The person in the photograph opposite has one.

Central lines can be used to:

- give drugs and fluids
- give the stem cells
- collect blood samples.

The type of central line most commonly used for high-dose treatment is called a skin-tunnelled central venous catheter. Different brands are available, including Hickman[®] or Groshong[®], and you may hear them being called these names.

The central line is inserted under a general or local anaesthetic. Usually, a small cut (incision) is made in the skin of your chest, and the tube is put under the skin and into a large vein. The other end of the tube stays outside your body and has a screw cap at the end. Drips or syringes can be attached to it.

The area may feel sore for a couple of days, but it should then be painless. The line can stay in for several months. The nurses will show you how to look after it to help prevent infections.

Other types of central line include:

- **A PICC (peripherally inserted central catheter) line** – This is a thin, flexible tube that is put into a vein in the bend or upper part of the arm. It is threaded through the vein until the end of it lies in a vein near the heart. The other end of the tube stays outside your body and has a screw cap at the end. Drips or syringes can be attached to it.
- **An implantable port** – This is a thin, soft, plastic tube that is put into a vein in the chest and has an opening (port) just under the skin on your chest.



Our website has two animations that explain PICC lines and central lines. Visit macmillan.org.uk/havingaPICCline and macmillan.org.uk/havingacentralline. We can also send you some more information about them.

Visiting the unit

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

- one or more haematologists who specialise in diagnosing and treating blood disorders and blood cancers
- an oncologist (cancer specialist) who specialises in treating your type of cancer and giving radiotherapy
- a transplant coordinator (specially trained nurse) who gives information and support during the treatment and may also arrange some of the tests you need before and after treatment
- nurses who specialise in the type of cancer you have and give information and support
- nursing staff who may give you some of the treatment (such as chemotherapy) and carry out day-to-day care

The team may also include other healthcare staff, such as social workers, dietitians, pharmacists, psychologists, counsellors and physiotherapists.

The nurses may show you around the unit and the type of room you will be in during your stay, although 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 pages 42–43). Once you understand what the treatment involves, you can take time to think about it and start to make practical arrangements.

Fertility

In most cases, high-dose treatment stops women's periods and stops men from producing sperm. Your specialist will be able to tell you how the treatment is likely to affect your fertility. It's 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 to be with you when you talk to your specialist, so you can discuss any fears or worries together.

Men

You can usually store sperm before your treatment starts. It can be used later with fertility treatment, when you're ready to have a family. Storing sperm for use in the future is also important for teenage boys.

Women

It may be possible to store fertilised eggs (embryos), which can be used in the future when you're ready to try to get pregnant. If you don't have a partner, it may be possible to store unfertilised eggs. Another way of preserving women's fertility is to remove and freeze tissue from an ovary that contains eggs. This is a new and experimental technique and may not be available everywhere.

For some people, high-dose treatment needs to start as soon as possible. Storing eggs or embryos can take a few weeks, so there's not always enough time to store either of these.

Contraception

Although your fertility may be affected, it's still important to use effective contraception after chemotherapy to avoid pregnancy, as the drugs might harm a developing baby. Your doctor or nurse will advise you to use reliable contraception for a few months afterwards.

Support

Fertility is a very 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 can arrange this for you.



We have booklets about cancer treatment and fertility, including one for young people.

ON ARRIVAL TO THE CLINIC
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MEMBER OF STAFF

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STAGE 2: COLLECTING THE STEM CELLS

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Collecting stem cells from the blood

Stem cells are usually collected from the blood. Occasionally, they may be collected from the bone marrow (see page 35).

You will usually have your stem cells collected a few days or weeks before the high-dose treatment. You can normally have them collected as a day patient. It takes 3–4 hours. You will be sitting or lying down, so it can help to wear loose, comfortable clothing. You may want to take some books, magazines or music to help pass the time.

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

You may be given chemotherapy followed by daily injections of a drug called a **growth factor** (G-CSF). Or, you may have only G-CSF injections.

Growth factors are natural substances. They stimulate the bone marrow and increase the number of stem cells and white blood cells in the blood. The growth factor is given as an injection under the skin (subcutaneously). People with lymphoma and myeloma may also be given a drug called plerixafor (Mozobil®) to help increase the number of stem cells. It's given with the G-CSF as an injection under the skin.

You or a relative can be taught to give these injections, or you can go to your GP, district nurse or the hospital to have them.

'They give you all the injections that you need, to show you how to do them. Then you come home and you inject yourself in the stomach each day for several days. It makes all of your stem cells really produce, really active so you can get a good harvest of your own stem cells.'

Pedro

Your blood will be tested regularly to check the level of stem cells. Once there are enough stem cells in the blood, they will be collected (see next page). In a small number of people, not enough stem cells move into their blood for collection.



We can send you more information about the growth factor G-CSF.

Collecting the stem cells

A nurse will make sure you are comfortable on a chair or bed. They will put a short, thin tube (cannula) into a vein in each arm. Sometimes a vein at the top of your leg is used. If you have a central line or implantable port (see pages 25–26), this will be used instead.

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's spun to separate out the stem cells, which are collected in a bag. The rest of your blood and blood cells are then returned to you through the cannula in your other arm.

You won't usually feel anything while you are having your stem cells collected, but occasionally people feel dizzy or light-headed. Some people may experience muscle cramps or a tingling, numb or cold feeling in their lips, fingers or toes. This is caused by a drug called citrate, which is added to prevent the blood from clotting while it's out of the body. You may be given a calcium tablet to chew, which can treat or prevent this side effect.

You may feel very tired afterwards, so it's a good idea to arrange for a family member or friend to take you home.

'When you read the documents and the descriptions of some side effects and possible this, possible that, it all looks very scary. But in fact, the reality was I was sitting there having my lunch and watching videos, one of which was 'Dumb and Dumber', and everyone in the whole room was having a laugh.'

Marcus

Collecting stem cells from the bone marrow

Although it's more common to collect stem cells from the blood, sometimes they are collected from the bone marrow. These are usually collected a few days or weeks before you have the transplant. You will have a general anaesthetic or an anaesthetic given into the spine, so you won't feel any pain. Usually, bone marrow is taken from the back of the hip bones (pelvis).

Rarely, bone marrow is taken from the breastbone (sternum) or the front of the pelvis. If this needs to be done, the doctor will explain more about it to you.

The doctor inserts a needle through the skin and into the bone. Bone marrow is then drawn into a syringe and placed in a sterile container. The doctor may do this a number of times during the collection, taking bone marrow from more than one area of the pelvis.

For an adult, about one litre of bone marrow is removed – only about 10–15% of the body's total. This leaves plenty for your body's needs. The body quickly replaces the bone marrow that's been removed.

You may have to stay in hospital overnight after the collection. It's common to feel sore for a few days, but regular painkillers can help. You'll be given a supply to take home if you need it. There may also be some bruising from where the bone marrow was taken, which may last for a few weeks.

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 two or three days to collect enough stem cells. Collected stem cells are frozen and stored in the laboratory until you need them.

Sometimes, not enough stem cells are collected over this period. If this happens, doctors can arrange for you to try again using another course of chemotherapy and G-CSF, or G-CSF on its own (see pages 32–33).

Irradiated blood

For at least two weeks before stem cells are collected, any blood or platelet transfusions you have will be treated with radiation (irradiated). This is to prevent any problems caused by white blood cells in the donated blood. Any transfusions you need in the future will also need to be irradiated. There is more information about this on page 57.





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What is involved?

High-dose treatment, also called conditioning treatment, is given to destroy as many cancer cells as possible that remain in your body. The treatment involves high doses of chemotherapy. Some people also have radiotherapy to the whole body. This is called total body irradiation, or TBI (see opposite page).

Going into hospital

You usually stay in hospital to have the treatment. Although it may only last one or a few days, from this point you will probably be in hospital for a few weeks. This is because after the treatment you need to wait for your blood count to recover (see pages 52–53). This can take 2–3 weeks. In some hospitals, you have high-dose treatment as a day patient and stay in accommodation nearby, which the hospital arranges for you. When your blood counts become low, you will be admitted to the hospital.

Chemotherapy

Chemotherapy is the use of anti-cancer drugs to destroy cancer cells. You'll probably already have had some chemotherapy as part of your original treatment, so you may have some idea of what to expect.

The chemotherapy is given through your central line, PICC line or implantable port (see pages 25–26), along with plenty of fluids. The treatment is usually given over several days and often involves a combination of chemotherapy drugs. There is information about the side effects of chemotherapy on pages 54–60.



Our booklet *Understanding chemotherapy* has more information. Or visit macmillan.org.uk/chemotherapy

Radiotherapy

Radiotherapy uses high-energy rays, similar to x-rays, to destroy cancer cells. Depending on your type of cancer, you may be given **total body irradiation (TBI)** as part of the high-dose treatment.

If you're going to have radiotherapy as well as chemotherapy, you'll usually go to the radiotherapy department for a planning session. This will be a few days before the treatment begins. The doctor will explain what will happen during your course of radiotherapy, and you can ask any questions you have.

Total body irradiation may be given twice a day over 3–4 days, so you'll have 6–8 sessions. Each session lasts about 40 minutes. You can bring music to listen to during your treatment.

Before each session, the radiographer will position you and make sure that you're comfortable. You'll have to change position a few times during the session. The radiographer will explain this to you.

During the treatment, you'll be left alone in the room, but you'll be able to talk to the radiographer. They will be watching from the next room. Radiotherapy isn't painful, but you do have to keep still while your treatment is being given.

Common side effects of radiotherapy are tiredness, feeling sick (nausea), diarrhoea and a sore mouth. We explain more about these on pages 58–60.



Our booklet *Understanding radiotherapy* explains the treatment and its side effects. You can also visit macmillan.org.uk/radiotherapy to watch a video about radiotherapy and see how treatment is given.

Going into hospital

What to take with you

The nurses will give you ideas about what to bring with you to help pass the time and make you more comfortable. This can vary between units. It's a good idea to take some books, magazines, music or audiobooks. You may also be able to bring films or computer games. Many hospitals have radios, TVs and DVD players. The nurses will tell you what's provided.

As you will be staying in your room for a few weeks, you may want to bring items from home to make you feel more comfortable. You might like to have personal things with you such as photographs, pictures or possibly a special blanket or pillow that has been cleaned.

You will also need to bring comfortable, loose-fitting clothes. Soft, cotton materials are best, and tops with buttons will make it easier when you're being examined. Ask the nurses for advice on the kind of toiletries you should bring with you.

'It might be worth getting into a good box set series as they pass the time well, but you don't have to concentrate for too long at a time if you don't want to.'

Sarge

Teenagers and young adults

Some hospitals have specially designed teenage and young adult cancer units (sometimes called TYA units). There may be computer games, DVDs and music to help you feel more at home. You may have access to a computer so that you can do some of your school or college work if you feel well enough. There may also be education specialists who can stay in touch with your school or college and support your learning needs while you're having treatment.



Visitors

Visitors, especially close family and friends, are important. They give you support and help you keep in touch with life outside hospital. Some units have rooms where family members can stay overnight. This is useful if your relatives have to travel to hospital.

Most hospitals are flexible about visiting, but different hospitals have different rules. You may be restricted to a certain number of visitors each day to help protect you from infection (see pages 55–56). The nurses will explain more about this to you.

‘When I was prone to infection, I didn’t have as many visitors, because it was just the fewer people I saw, the less chance of catching a bug. But that was fine. It was actually quite good to see my daughter just occasionally, because my wife would bring her at times when I was particularly low, and my little girl would come through the door with a beaming smile.’

Joshua

Questions you might want to ask

- How many visitors can I have and how long can they stay?
- Is there anyone who shouldn't visit, such as 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 coins or a phone card?
- Can I bring a laptop or mobile computer (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?

You can use pages 100–101 to write down your questions and the answers you get.



STAGE 4: HAVING THE STEM CELLS (TRANSPLANT)

Having the stem cells

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Having the stem cells

Your stem cells will be given back to you by infusion (drip) through your central line, PICC line or implantable port. This will be 1–2 days after the high-dose treatment has finished. This is similar to having a blood transfusion.

You'll be closely monitored during the infusion. Some people have mild side effects during the infusion, such as breathlessness or feeling sick (nausea). Rarely, a severe allergic reaction can happen. You will be given medicine before the infusion to help prevent or reduce any reaction.

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



STAGE 5: WAITING FOR YOUR BLOOD COUNT TO RECOVER (ENGRAFTMENT)

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Waiting for your blood count to recover

Once you've had the infusion, the stem cells travel to your bone marrow. They then begin to make blood cells. This is called **engraftment**. It can be two or more weeks before some of the new blood cells are released into the bloodstream. During this time, you are at high risk of infection and other problems such as bleeding and anaemia. There is information about these side effects and others you may have on pages 54–60.

You will have low numbers of red blood cells, white blood cells and platelets in your blood for some time. This can cause some of the main side effects. You'll have blood samples taken every day to check your blood count.

You may be given growth factors by injection (see page 32). This is to stimulate your bone marrow to produce new white blood cells more quickly. Using growth factors can reduce the length of time you're at risk of some of the side effects.

You'll usually stay in a single room to help protect you from infection. You may think that you'll have a lot of time on your hands, but a daily routine of care and checks will keep you quite busy.

A daily routine of care may include having:

- blood taken from your central line (see pages 25–26)
- medicines given into your central line
- your drip (intravenous infusion) changed when needed
- your temperature, pulse and blood pressure taken
- your tummy and mouth examined
- your central line checked.

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

'I'd get up, wash and make calls/FaceTime® with my daughter before the docs came around at 11ish. By the time they'd finished my partner would be in until late afternoon just before tea was served. Sometimes I'd get a bit bored in the evening, but by the time 10pm came around I was desperate to get some sleep.'

Sarge

The side effects of high-dose treatment

The side effects you have will depend on the type of high-dose treatment you had. Most side effects are worst when your blood count is at its lowest – usually at the end of the first week and throughout the second week after high-dose treatment. When your blood count goes up, the side effects will start to improve. You'll be at less risk of infection, your appetite will improve and you'll start to feel better.

You will be given 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 you're already taking to more effective ones. Your hospital team will give you more information about what to expect.



We can send you more information about all of the side effects mentioned here, and about blood and platelet transfusions – call 0808 808 00 00.

Risk of infection

A neutrophil is a type of white blood cell. It is very important for fighting infection. The number of neutrophils in your blood will be very low after high-dose treatment. This increases your risk of infection.

You'll be at risk of infections from the bacteria that live on your skin and in your digestive system. These bacteria are normally useful to our bodies, but when the immune system isn't working as well as usual, they may cause infections. A lot of your care will involve preventing and treating infection.

You'll be given medicines to prevent and treat infections. Nurses and doctors will monitor you closely for signs of infection. They'll 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 pain when passing urine.

The hospital staff will take precautions to protect you from possible infections, but most people develop a high temperature and need antibiotics at some point while their immune system recovers.

Keeping clean

The hospital staff will try to make sure you aren't exposed to any infections. Your room will be cleaned daily and your sheets changed. In most hospitals, you'll have your own toilet and shower.

It's also important to make sure your skin is kept clean. The nurses will give you advice about showering and washing your hands. They can help you if you're tired. They'll also show you how to look after your mouth and keep it clean (see page 58).

Being careful with food

While you're in hospital, there will be rules about preparing food and what you can eat. This is to help you avoid foods that contain harmful bacteria. Each hospital will have its own guidelines. The nurses and doctors will give you advice. Some general precautions are:

- Avoid soft cheeses, pâté and unpasteurised foods.
- Don't eat lightly cooked or uncooked eggs.
- Fruit and vegetables (if allowed) need to be thoroughly washed and peeled.
- Hot meals should be freshly prepared and thoroughly cooked (not reheated).
- Avoid takeaway foods.

Visitors

Hospital rules about visitors vary. You may be restricted to only a few visitors each day. People who are unwell because of an infection, such as a cold or tummy bug, will be told not to visit. The nurses will explain whether your visitors need to take any precautions.

Anaemia

High-dose treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If there are low levels of red blood cells, you may be tired and breathless. Tell your doctor or nurse if you feel like this. You may need regular blood transfusions until your body starts to make enough red blood cells again.

Irradiated blood

If you have a blood transfusion, the blood may be treated with radiation (irradiated) before being given to you. This is to prevent any problems caused by white blood cells called lymphocytes, which may be in the donated blood. Irradiated blood isn't radioactive and won't harm you or anyone you come into contact with.

You will continue to have irradiated blood, when you need a transfusion, for up to six months after treatment has finished. Some people may need to have irradiated blood for the rest of their life. Your doctor can talk to you about this. You will be given a medical alert card to carry in case you need blood in an emergency.

Bruising and bleeding

High-dose treatment reduces the number of platelets in your blood. Platelets are cells that help the blood to clot. You're likely to need transfusions of platelets (which may also be irradiated) to reduce the risk of bleeding or bruising. Doctors and nurses will examine you regularly for little red spots on the skin. If you have any bruising you can't explain, a nosebleed, bleeding gums or blood in your stools (bowel motions) or urine, tell a doctor or nurse straight away.

Feeling sick (nausea) and being sick (vomiting)

High-dose treatment can make you feel sick or sometimes be sick. Your doctor will prescribe anti-sickness (anti-emetic) drugs to prevent or reduce this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can try. Anti-sickness medicines can be given as tablets, by injection into your line or port, or under the skin (subcutaneously).

Sore mouth

The treatment can cause painful throat and mouth ulcers. While your white blood cell count is low, you're also at risk of mouth infections. Keeping your mouth clean is important to prevent infections that can spread to other parts of your body.

The nurses will advise you how to look after your mouth and teeth. Use a soft toothbrush when cleaning your teeth to protect your gums. You'll be given mouthwashes to use regularly to try to prevent infections. If your mouth is sore, talk to your doctor or nurse. They can give you some painkillers.

Eating problems

During treatment, it's important you don't lose too much weight. You'll be encouraged to try to eat small meals and snacks even if you don't have much appetite or if food tastes different. The nurses will give you advice, and you may also talk to a dietitian to make sure you're eating as well as possible.

If you have a sore mouth, eating may be difficult. You may need to have nutritional drinks until you can eat properly again. Occasionally, people need to have liquid food through a thin, soft tube that goes down the nose into the stomach (a feeding tube).

Some people may have another type of liquid food that's given through their central line. As you start to eat again, the amount of liquid food you're given is gradually reduced.



There is more information in our booklet *Eating problems and cancer*. There's also lots of information online at macmillan.org.uk/eatingwell

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 doesn't get better. Make sure you drink at least two litres (three and a half 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 be given fluids through a drip (infusion).

Hair loss

This is a common side effect of high-dose 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.



Our booklet *Coping with hair loss* has useful information and tips on using hats, scarves and wigs. There's also a video of someone sharing their experience of hair loss at macmillan.org.uk/hairloss

Tiredness (fatigue)

You'll probably feel extremely tired and spend a lot of time sleeping. Sometimes, you may feel too tired to concentrate enough to read or even watch television. At times, you may not feel up to seeing many visitors or seeing them for too long. Let them know how you're feeling so they don't disturb you if you want to rest.

Exercise

Even though you're tired, it's a good idea to try 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're feeling better and your blood counts have improved.



Our booklet *Coping with fatigue* has useful information on ways of managing fatigue. There's also a video of someone sharing their experience of fatigue at macmillan.org.uk/fatigue

Starting to recover

When your blood count has reached a safe level, you'll be able to go home, as long as a relative or friend stays with you. You'll be given a 24-hour telephone contact number in case you have any worries. You'll need to go back to the hospital regularly as an outpatient for check-ups.



Less common problems

Graft failure

Sometimes the infusion of stem cells doesn't work and the bone marrow doesn't produce enough new blood cells. This is known as graft failure and can lead to repeated infections, bruising, bleeding and anaemia. In this situation, growth factors (see page 32) may be used to try to stimulate the bone marrow to recover.

Total graft failure is rare, and the only way to treat this is with a second infusion of stem cells.

Second cancer

High-dose treatment can increase the risk of developing some types of cancer or leukaemia later in life. This is rare, and your doctors will weight up this small increase in risk alongside the benefit of treating your cancer.

How you can help yourself


Being involved in your care can help you feel more in control. When you feel well enough, you could:

- Ask for regular updates on your progress and write them down in a notebook or journal.
- Get up every day, have a shower and change your clothes.
- Ask if you can do things like measure how much fluid you're drinking and record it.
- Try to eat regularly, even if you don't have much appetite. Your family can usually bring in foods you like, but make sure it's been prepared following the advice you've been given.
- Keep doing the exercises you've been shown, and walk around your room. When you're 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.

Understanding your illness and its treatment means you'll be better prepared to cope with your situation. If there's anything you don't understand about your treatment, its side effects and the possible outcome, it's important to ask. It's also important to tell the doctors and nurses if you have new symptoms or side effects.

Your feelings during treatment

Having high-dose treatment with stem cell support is probably one of the most stressful situations you'll ever face. As well as being physically demanding, it's a very emotional time too. It's normal to find your emotions difficult to cope with at times.

At times you may feel anxious, frightened or depressed. You may ask yourself questions like, 'Is the treatment working?', 'Will my blood counts ever go up?' or 'How am I going to cope with the side effects?'.


Talking to family and friends about how you're feeling often helps. The nurses and doctors can also give you advice and support. Some hospitals can put you in contact with someone else who has had high-dose treatment. 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 – visit [**macmillan.org.uk/community**](https://www.macmillan.org.uk/community)

'I was watching a lot of TV and getting quite depressed. My son told me I had to engage my brain – with reading, or games, or meditation – it was good advice and I felt better.'

Jackie

If you're struggling to cope with low moods, let your nurse or doctor know. You may find it helpful to talk to someone such as a counsellor or social worker. The hospital staff can arrange this for you.



You may want to read our booklets *How are you feeling? The emotional effects of cancer* and *Talking about your cancer*.

As you get closer to leaving hospital, you may find yourself becoming impatient and longing to get home. Or, you may feel anxious about going home and leaving the support of the hospital. It can be hard to adjust to life at home after spending so much time in hospital. There will still be some restrictions on your life, but as you recover, the focus will gradually shift away from the treatment you've had and back to day-to-day living.

If you're a relative or friend

Family and friends play an important role in helping people get through the treatment. Visitors can be a real help to people in hospital, especially if they are in a room on their own.

Most hospitals are flexible about visiting, but there may be some restrictions. When you arrive, speak to the nurse looking after your relative or friend before going into their room. You'll have to take certain precautions to protect your relative or friend from infection. If you're unsure about anything, ask the doctors or nurses. Here are some general tips:

- Don't visit if you feel unwell, even if it is just a cold or cough.
- Don't bring children who are unwell, or who have been near other children with an infection. Don't bring children who have had recent vaccinations. Most units allow children to visit, but it is best to check with the hospital staff.
- Always follow hospital instructions – for example, washing your hands and putting on an apron before going into the room.
- Ask the nursing staff for advice before bringing in food. Some gifts such as flowers may not be allowed because of the risk of infection.

You can still kiss and hug your relative or friend, and hold their hand, but it's important to follow the precautions.

Be prepared that there will be times when they won't look or feel well. It's often enough just to sit with them. Sometimes, they may not feel like seeing anyone because they're too tired.

It can help if one person coordinates visiting so that it's spread out. It can be difficult to cope with too many visitors or with long visits. Don't be upset or take it personally if you're asked to miss a visit. You could phone or send a card, text or email instead.

If you're worried about anything, you can always talk to the doctors and nurses on the unit or ward.



You may find our booklet *Lost for words – how to talk to someone with cancer* helpful.

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STAGE 6: RECOVERY AFTER A TRANSPLANT

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The first few months out of hospital

When your blood counts have reached a safe level, you will be able to go home. But you will need to go back to the hospital outpatient clinic for regular checks. Even after your bone marrow has recovered and your neutrophils are back to a normal level, your immunity will be low for a few months.

Occasionally, you may still need blood or platelet transfusions. These can usually be given as a day patient. You may have to take regular doses of antibiotics and anti-viral drugs to reduce the risk of infection.



Hospital contact

You should always carry a 24-hour telephone number for the hospital with you. If you're worried, you can ring at any time of day or night to speak to someone who knows about your treatment. The doctors and nurses would prefer you phoned and spoke to them rather than risk being unwell at home.

It's very important to take great care of your health during this time. Your doctors and nurses will give you advice about the type of precautions you'll need to take once you are home.

Contact your hospital immediately if:

- your temperature goes over 37.5°C (99.5°F) or over 38°C (100.4°F), depending on the advice given by your transplant team
- 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 a lot.

If you become unwell, you'll need to go back into hospital. It's quite common for this to happen once or twice after high-dose treatment. This is not a major setback, although it can be very worrying.



If you feel unwell and are unable to contact the hospital, ask someone to take you to the nearest hospital immediately.

Eating and drinking

Your doctor or nurse can give you information about your diet once you are home. While your immune system is recovering, try to eat a healthy, balanced diet and avoid possible risks of infection from food.

It's best to avoid:

- reheated food
- raw or lightly cooked eggs
- shellfish
- all types of pâté
- soft cheeses
- takeaway food
- pre-wrapped sandwiches
- cooked sliced meats
- smoked fish
- cream cakes
- food that's not completely fresh.

Make sure that frozen foods are completely defrosted before you cook them. Wash salads and fruit thoroughly before eating them. You may be told to peel fruit. Don't 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. Heavy drinking will slow down the recovery of the bone marrow. If your platelet count is low, drinking will increase the risk of bleeding. Alcohol can also interfere with some of the drugs you may be prescribed.



We can send you a booklet about healthy eating.

Coping with tiredness

Feeling that you have no energy at all (fatigue) is common after high-dose treatment. Getting your energy levels back to normal can take months. Don't expect too much of yourself, and remember that it's a gradual process. Pace yourself and save your energy for the things that you want to do or need to do. Accept offers of help from family and friends. Gentle exercise, such as short walks, can help increase your energy levels.



There's lots of useful information in our booklet *Coping with fatigue*.

Exercise

Regular, gentle walking is good exercise to keep your muscles toned. Ask your specialist which type of exercise is suitable for you while your blood count is still recovering. After this, you can start doing whatever exercise you like, although it's wise to increase the amount gradually. Regular exercise can help with your recovery and benefit your future health.



We can send you information about physical activity and cancer treatment.

Socialising

When possible, you should avoid crowded places until your immune system has recovered. This includes cinemas, pubs, shopping centres and public transport at busy times. You should be able to have a full social life again 3–6 months after your treatment. You should avoid contact with children who have an infectious disease such as chickenpox or measles. If you're worried that you've come into contact with someone with an infectious disease, contact your transplant team.

Having sex

High-dose treatment won't affect your ability to have sex. But it's not unusual to find that your sex drive is reduced for some months after treatment. This may be because you feel anxious or depressed. You may have body changes such as hair loss or weight loss that can affect your confidence. Tiredness is also a common problem.

Some people may worry that sex will never be an important part of their life again. Cuddles, kisses and massages are affectionate and sensual ways of showing how much you care for someone, even if you don't feel like having sex. You can wait until you feel ready.

Let your doctor or nurse know if you're having problems with your sex life. There may be things they can do to help. If you feel uncomfortable talking to your doctor or nurse, you can call us on **0808 808 00 00**.

Some people may find it helpful to talk to a sex therapist. You can contact a therapist through the College of Sexual and Relationship Therapists (see page 96).



Our *Sexuality and cancer* booklets discuss possible problems following treatment and have tips on ways of coping. There's a booklet for men and one for women.

Contraception

Although your fertility may be affected, it's still important to use effective contraception after treatment to avoid pregnancy. Doctors and nurses usually advise you to avoid getting pregnant or fathering a child soon after treatment. This is because in the first few months, you will be taking medicines that could affect a developing baby. Your doctor or nurse will tell you how long you need to use effective contraception for.

Hormone replacement therapy (HRT)

Women whose treatment has caused an early menopause may have symptoms such as hot flushes, dry skin, dryness of the vagina and a low sex drive. Hormone replacement therapy can relieve many of these symptoms. If your doctor hasn't already talked to you about HRT, you could ask about it to see if it would be suitable for you.

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's 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. Check that you feel comfortable with the way they plan to do this.



Our booklet *Work and cancer* has more information about employment rights and financial issues. There's also information about education and going back after a transplant on our website for teenagers and young people – macmillan.org.uk/youngpeople

Vaccinations

After a donor stem cell transplant, you may lose your immunity to any illnesses you were vaccinated against as a child. You may need to have these vaccinations again. You will also need some other vaccinations to protect you against common infections such as flu. Your haematology doctor will discuss your immunity with you and give you advice about when you should have your vaccinations.

There are some types of vaccines (live vaccines) that you'll need to avoid until your immune system has recovered. Your haematology doctor will tell you which vaccinations are safe for you to have and which you should avoid.

Holidays and travel

As your blood counts improve and the gaps between hospital visits get longer, you might start thinking about going on holiday. You'll usually be advised not to travel abroad in the first year after treatment, unless there is a nearby cancer treatment centre.

After the first year, your immune system should be working well and you should be able to travel abroad. Talk about your holiday plans with your doctor or nurse. For some countries, you need to have certain vaccinations. But there are some vaccinations you should avoid after high-dose treatment. Your doctors may also suggest medical centres you could contact if you have any problems while you're away. They may send information about your recent treatment to the centre if it will help. It's helpful to carry a letter from your doctor that explains the treatment you've had and gives a contact telephone number.

For several months after treatment, you'll be more sensitive to the sun and your skin may burn more easily. Use a suncream with a sun protection factor (SPF) of at least 30, and cover up with clothing and a hat. It's important to remember you can burn even through clothing if you are out in hot sun for a long time.



People who've had cancer often find it difficult to get travel insurance. Our booklet *Getting travel insurance* lists companies that may provide policies for people with cancer. We also have a booklet called *Travel and cancer* that has helpful, practical tips about travelling.



**'I'm glad the
transplant is done.
I am now moving
forward with my life
with the knowledge
that because of the
transplant, there is
less chance of
a relapse.'**

Paul

Your feelings after treatment

You may experience a range of emotions once treatment is over. Many people feel they still need a lot of support. There is no right or wrong way to feel and you'll cope with things in your own way. Talking to family and friends about how you feel can help. Or, you may prefer to talk to someone outside your immediate family and friends, such as your GP or a counsellor (see page 80). There are also other ways to get support, such as through support groups and online communities.

Support groups

These groups offer a chance to talk to other people in similar situations to you, who are facing the same challenges. Joining a group can be helpful if you live alone or don't feel able to talk to those around you 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's like before you decide whether to join.

Online support

Many people get support through the internet. There are online support groups, social networking sites, forums, chat rooms 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, where you can talk to people in chat rooms, blog your journey, make friends and join support groups.

Who can help?

Many people are available to help you and your family while you are in hospital and when you go home.

In the hospital, you can speak to the **doctors, specialist nurses and transplant coordinator**. The **hospital social worker** can also help in many ways. They may be able to arrange childcare during and after treatment. They can also tell you about social services you may be entitled to, for example home help or help with hospital fares.

If you saw a **dietitian** or **physiotherapist** in hospital, they will arrange follow-up for after you leave. You may see them at home or at your clinic appointments.

District nurses work closely with GPs and, if needed, they can make regular visits to you and your family at home.

Some people need more than advice and support. You may feel depressed, helpless or anxious. There is specialist help available to help you with these emotions. You may find it easier to talk to someone who is not directly involved in your illness. Some hospitals have their own emotional support services with specially trained staff. Nurses may be trained in counselling and they can also give advice about practical problems. When you go home, you can ask your specialist or GP to refer you to a psychologist or counsellor who specialises in the emotional impact of cancer. Some people find comfort in religion at this time and wish to talk to a spiritual or religious adviser.



Our cancer support specialists on 0808 808 00 00 can tell you about services in your area.

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called **Universal Credit** has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called **Disability Living Allowance (DLA)** in England, Scotland and Wales.

Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for **Carer's Credit**. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see pages 97–98). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 97–98.



Our booklet *Help with the cost of cancer* has more information. Our booklets *Insurance* and *Getting travel insurance* may also be helpful. You might find our video at [macmillan.org.uk/gettingfinancialhelp](https://www.macmillan.org.uk/gettingfinancialhelp) useful.



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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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

There you'll also find videos featuring real-life 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
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you'd 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**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](https://www.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](https://www.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](https://www.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](https://www.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 advice

Our financial guidance team can give you advice 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**

Other useful organisations

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

African Caribbean Leukaemia Trust

Southbridge House,
Southbridge Place,
Croydon CR0 4HA
Tel 020 8240 4480

www.aclt.org

Raises awareness among black, mixed race and ethnic minority groups of the importance of registering as a potential bone marrow, blood and organ donor.

CLIC Sargent

Horatio House,
77–85 Fulham Palace Road,
London W6 8JC

Tel 0800 197 0068

Email

helpline@clicsargent.org.uk

www.clicsargent.org.uk

Provides support to children with cancer and to their families and carers.

Children's Cancer and Leukaemia Group (CCLG)

University of Leicester,
3rd Floor, Hearts of Oak House,
9 Princess Road West,
Leicester LE1 6TH

Tel 0116 249 4460

Email info@cclg.org.uk

www.cclg.org.uk

Coordinates research and care for children with cancer and their families. Has specialist centres in the UK and Ireland for treating childhood cancers.

Leukaemia and Lymphoma Research

39–40 Eagle Street,
London WC1R 4TH

Tel 020 7405 0101

Email info@

beatingbloodcancers.org.uk

www.leukaemia

lymphomaresearch.org.uk

Researches blood cancers

such as leukaemia,

lymphoma and myeloma.

Provides information on the diseases and their treatments.

Has a free, helpful booklet called *Bone marrow and stem cell transplantation (BMT) – for children and adults*,

which explains stem cell transplants, where stem cells come from, types of transplant, and what's involved. To order, call **020 7405 0101**.

Leukaemia CARE

1 Birch Court, Blackpole East,
Worcester WR3 8SG

Tel 08088 010 444

Email

care@leukaemicare.org.uk

www.leukaemicare.org.uk

Provides care and support to those affected by leukaemia, lymphoma and allied blood disorders. Offers a 24-hour helpline, holiday programme and financial assistance, and regional support groups throughout the UK.

Lymphoma Association

PO Box 386, Aylesbury,
Buckinghamshire HP20 2GA

Tel 0808 808 5555

(Mon–Thu, 9am–6pm,
Fri, 9am–5pm)

Email information@

lymphomas.org.uk

www.lymphomas.org.uk

Provides emotional support and information to anyone affected by lymphatic cancer. Also has a free booklet called *Allogeneic stem cell transplants*, which explains donor stem cell transplants and what to expect before, during and after treatment. To order, call **01296 619 400**.

National Blood Service (England and North Wales)

Colindale Avenue,
London NW9 5BG

Tel 0300 123 23 23

www.blood.co.uk

Delivers blood, blood components, blood products and tissues anywhere in England and North Wales. Provides specialist medical advice and support to hospitals, and educates and trains transfusion specialists.

Northern Ireland Blood Transfusion Service

Lisburn Road,
Belfast BT9 7TS

Tel 028 9032 1414

Email

inet@nibts.hscni.net

www.nibts.org

Supplies all hospitals and clinical units in the Northern Ireland with blood, blood products and other related services. Manages the collection, testing and distribution of blood donations.

Scottish National Blood Transfusion Service

21 Ellen's Glen Road,
Edinburgh EH17 7QT

Tel 0845 90 90 99

www.scotblood.co.uk

Provides transfusion medicine in Scotland and supplies blood, tissues, products and services. Researches new products, technologies and services to improve the care for Scotland's NHS transfusion patients.

Welsh Blood Service

Ely Valley Road,
Talbot Green,
Pontyclun,
CF72 9WB

Tel 0800 25 22 26

Email

donor.care@wales.nhs.uk

www.welsh-blood.org.uk

Collects, tests and distributes blood donations and products in south, west and part of mid Wales. Also supports stem cell transplant services and operates a national panel of unrelated potential blood stem cell donors, the Welsh Bone Marrow Donor Registry.

Cancer information and support

Cancer Black Care

79 Acton Lane,

London NW10 8UT

Tel 020 8961 4151

(Mon–Fri, 9.30am–4.30pm)

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers information and support to people with cancer from ethnic communities, and their friends, carers and families.

Cancer Focus

Northern Ireland

40–44 Eglantine Avenue,

Belfast BT9 6DX

Tel 0800 783 3339

(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK

www.cancerhelp.org.uk

Has patient information on all types of cancer and has a clinical trials database.

Cancer Support Scotland

Calman Cancer Support

Centre, 75 Shelley Road,

Glasgow G12 0ZE

Tel 0800 652 4531

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.

Maggie's Centres

The Gatehouse,

10 Dumbarton Road,

Glasgow G11 6PA

Tel 0300 123 1801

Email enquiries@

maggiescentres.org

www.maggiescentres.org

Offer access to information, benefits advice and emotional or psychological support. You don't have to make an appointment or be referred and everything is free.

Penny Brohn Cancer Care

Chapel Pill Lane,
Pill, Bristol BS20 0HH

Tel 0845 123 2310

(Mon–Fri, 9.30am–5pm)

Email

helpline@pennybrohn.org

**www.pennybrohn
cancercare.org**

Offers a combination of physical, emotional and spiritual support, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.

Teenage Cancer Trust

3rd floor, 93 Newman Street,
London W1T 3EZ

Tel 020 7612 0370

www.teenagecancertrust.org

Runs a support network for young people with cancer and their families and friends. Raises funds to build teenage cancer units in hospitals.

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD

Tel 0808 808 1010

(Mon–Sun, 8am–8pm)

www.tenovus.org.uk

Aims to help everyone get equal access to cancer treatment and support. Provides mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

General health information

Health and Social Care in Northern Ireland www.hscni.net

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

Healthtalkonline www.healthtalkonline.org www.youthhealthtalk.org (site for young people)

Has information about cancer, and videos and audio clips of people's experiences.

NHS Choices www.nhs.uk

The UK's biggest health information website. Also has service information for England.

NHS Direct Wales www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

NHS Inform www.nhsinform.co.uk

NHS health information site for Scotland.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

BACP House,
15 St John's Business Park,
Lutterworth LE17 4HB
Tel 01455 883 300

Email bacp@bacp.co.uk
www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

College of Sexual and Relationship Therapists (COSRT)

PO Box 13686,
London SW20 9HZ
Tel 020 8543 2707

Email info@cosrt.org.uk
www.cosrt.org.uk

Previously called the British Association for Sexual and Relationship Therapy. Provides information and support on sexual problems. Lists of therapists are on the website.

Youth Access

1–2 Taylors Yard,
67 Alderbrook Road,
London SW12 8AD
Tel 020 8772 9900
(Mon–Fri, 9.30am–1pm
and 2–5.30pm)

Email

admin@youthaccess.org.uk
www.youthaccess.org.uk

National membership organisation for young people's information, advice, counselling and support services (YIACS). The largest provider of advice and counselling services in the UK.

Relate

Premier House,
Carolina Court,
Lakeside,
Doncaster DN4 5RA
Tel 0300 100 1234

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through their website.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Tel 0800 220 674
(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

Textphone 0800 243 787
**www.nidirect.gov.uk/
money-tax-and-benefits**

Provides information and advice about disability benefits and carers' benefits.

Citizens Advice

Provides advice on financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at **adviceguide.org.uk**

**Department for Work
and Pensions (DWP)
Disability Benefits Helpline**

08457 123 456

Textphone 0845 722 4433

**Personal Independence
Payment Helpline**

0845 850 3322

Textphone 0845 601 6677

Carer's Allowance Unit

0845 608 4321

Textphone 0845 604 5312

**[www.gov.uk/browse/
benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in
England, Scotland and Wales.

You can apply for benefits
and find information online
or through its helplines.

GOV.UK

www.gov.uk

Has comprehensive information
about social security benefits
and public services.

**National Debtline
(England, Wales
and Scotland)**

Tricorn House,
51–53 Hagley Road,
Edgbaston,
Birmingham B16 8TP

Tel 0808 808 4000

(Mon–Fri, 9am–9pm,
Sat, 9.30am–1pm)

www.nationaldebtline.co.uk

A national helpline for
people with debt problems.
The service is free, confidential
and independent.

**Personal Finance Society –
'Find an Adviser' service**

www.findanadviser.org

Use the website to find qualified
financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk

www.unbiased.co.uk

On the website you can
search for qualified advisers
who specialise in giving
financial advice, mortgage,
accounting or legal advice.

Support for carers

Carers Direct

PO Box 4338,
Manchester M61 0BY
Tel 0808 802 0202
(Mon–Fri, 8am–9pm,
Sat–Sun, 11am–4pm)

www.nhs.uk/carersdirect

Offers comprehensive information to anyone who carers for someone, including information about financial help and employment.

Carers UK

Tel (all UK)

0808 808 7777
(Mon–Fri, 10am–4pm)

Email (all UK)

advice@carersuk.org
www.carersuk.org

(England)

20 Great Dover Street,
London SE1 4LX

(Wales)

River House,
Ynys Bridge Court,
Cardiff CF15 9SS

(Scotland)

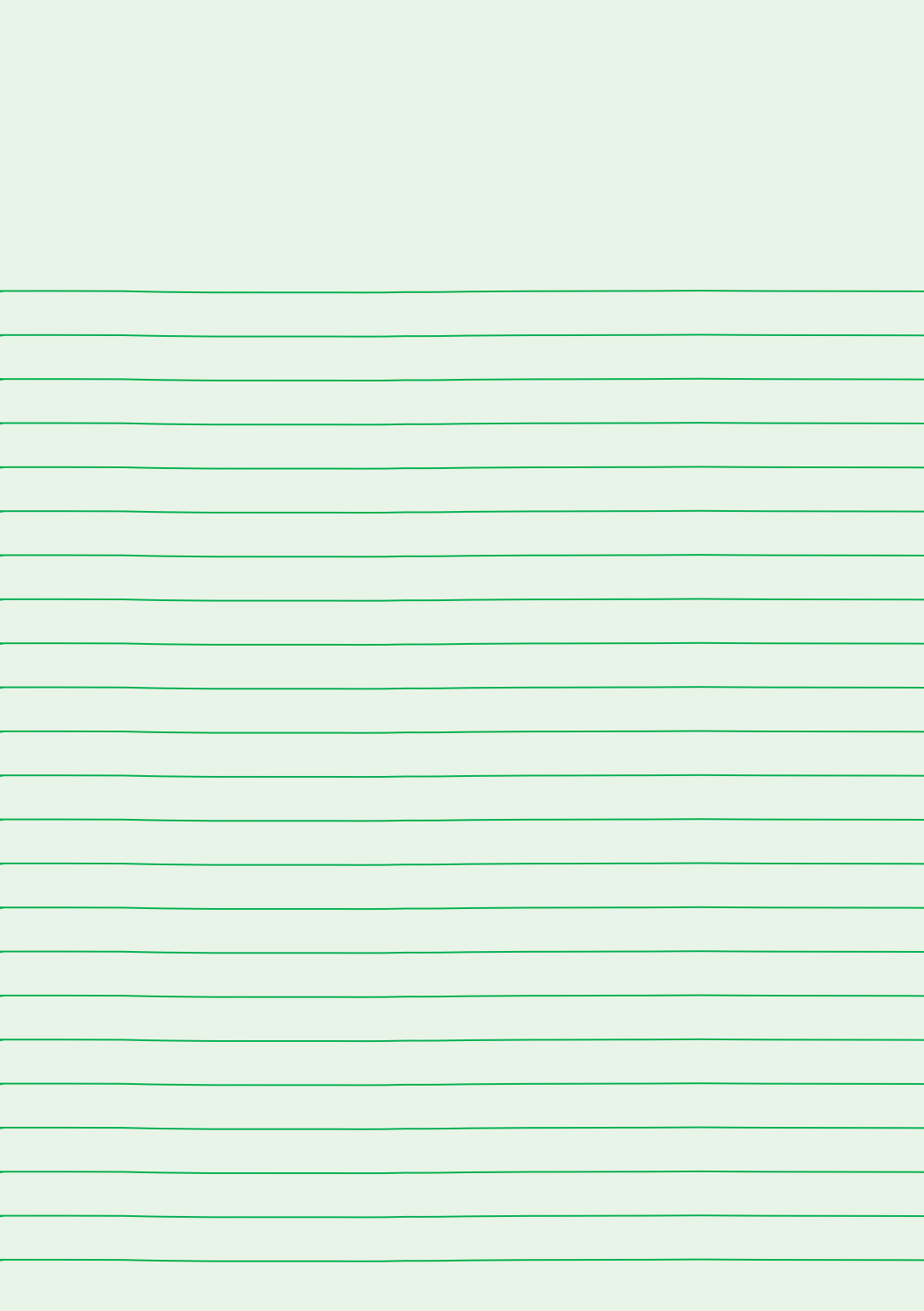
The Cottage,
21 Pearce Street,
Glasgow G51 3UT

(Northern Ireland)

58 Howard Street,
Belfast BT1 6JP



You can search for more organisations on our website at macmillan.org.uk/organisations, or call us on 0808 808 00 00.



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 photographs 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 one of our Senior Medical Editors, Dr Anne Parker, Consultant Haematologist, and by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Dr Charles Crawley, Consultant Haematologist; Dr Peter Johnson, Consultant Haematologist; Julie Suhr, Macmillan Haematology Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

Sources

We've listed a sample of the sources used in this publication below. If you'd like further information, please contact us at bookletfeedback@macmillan.org.uk

Greer, et al (eds). *Wintrobe's clinical haematology*. 12th edition. Lippincott Williams and Wilkins. 2008.

Munker R, et al. *The BMT data book: including cellular therapy*. Cambridge University Press. 2013.

National Institute for Health and Care Excellence (NICE). *Improving outcomes in haematological cancers – The manual*. October 2003.

Use of plerixafor for stem cell mobilisation – Guideline. The Leeds Teaching Hospitals NHS Trust. 2012.

Treleaven J, et al. Guidelines on the use of irradiated blood components prepared by the British Committee for Standards in Haematology blood transfusion task force. *British Journal of Haematology*. 152: 35–51. 2011.

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.



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

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Signature _____

Date / / _____

Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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.



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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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CANCER SUPPORT**