



understanding stem cell and bone marrow transplants

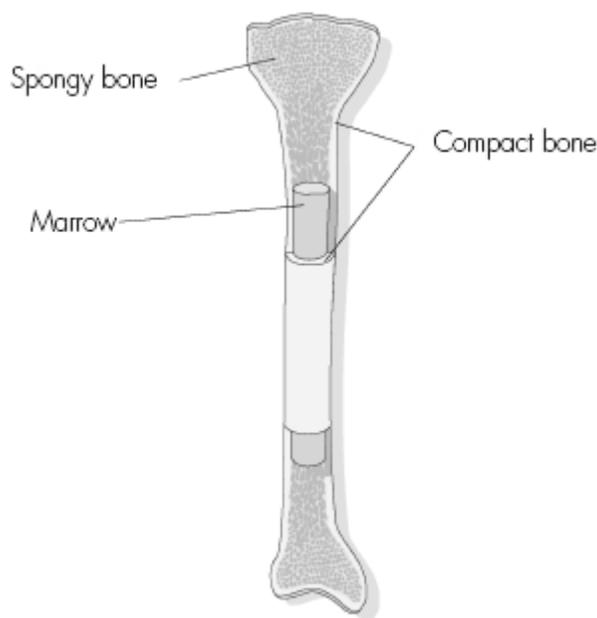
From the JASCAP booklet series

14 January 2009

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Bone marrow and stem cells

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Bone and bone marrow

Like a factory, bone marrow produces the cells which develop into the three different types of blood cells:

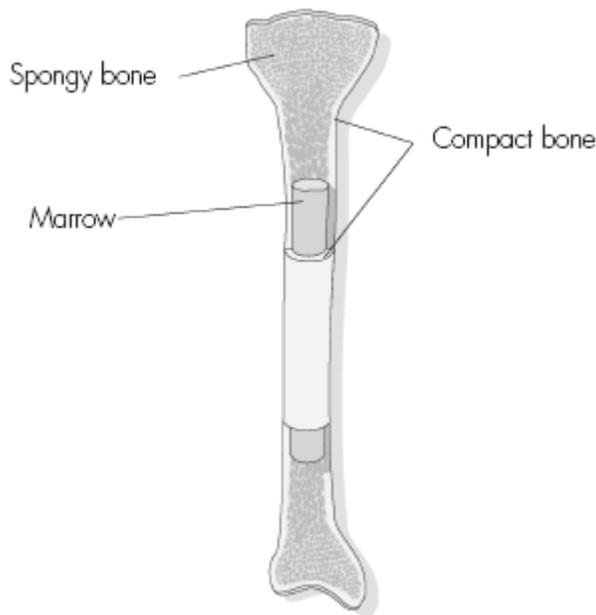
- red blood cells**, which carry oxygen to all cells in the body
- white blood cells**, which are essential for fighting infection
- platelets**, which help the blood to clot and prevent bleeding.

Normally, most of the stem cells in the body are in the bone marrow and there are only very small numbers in the bloodstream. However, it is possible to stimulate the stem cells to move into the bloodstream, by using low doses of certain chemotherapy drugs or injections of growth factors. Stem cells can be collected from the bloodstream or from the bone marrow.

A transplant using stem cells collected from the bone marrow is sometimes called a bone marrow transplant, when in fact it is really a transplant of stem cells.

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Steps in a transplant

There are four main steps in the process of both **high-dose treatment with stem cell support** and **allogeneic transplants**. These are described briefly below and explained further throughout this booklet.

- Step one
- Step two
- Step three
- Step four
- Giving your consent

Step one

The first step is to reduce the leukaemia or cancer to as low a level as possible, using chemotherapy and/or radiotherapy. Ideally you should have no detectable cancer (this is known as being in remission) at the time of your high-dose treatment. This gives the best possible chance for the treatment to work. However, it may also be done if there is only a small amount of cancer still present.

Step two

The second step is the collection of the stem cells from you or your donor. This is known as the **harvest**.

Step three

The third step is the high-dose treatment. The aim is to remove any remaining cancer cells from your body. You may be treated with chemotherapy alone. Sometimes radiotherapy is given as well. This intensive treatment will completely destroy all your normal bone marrow. This step is sometimes called the **conditioning regimen** and usually lasts only a few days. It can make you feel very ill and sick. You will be given anti-sickness (anti-emetic) drugs, which may also make you feel sleepy. These drugs are very effective, and can usually control feelings of sickness (nausea) and vomiting.

Step four

The fourth step is to give the stem cells to you through a drip. This is a bit like having a blood transfusion. It will be 2–4 weeks before the cells find their way through the bloodstream into the bone marrow and start to make new blood cells for you. You will need to be in hospital until the number of blood cells in your blood stream has gone back to a safe level.

While your level of healthy blood cells is low, you will need to have antibiotics. This is because you will have very little resistance to infection. You may be given injections of growth factors (G-CSF) to help your bone marrow to make new blood cells more quickly. You will also need to have blood and platelet transfusions. You may be looked after in a room on your own to protect you from infection. During this time you will need constant medical and nursing support.

Giving your consent

Before you have any treatment your doctor will explain the aims of the treatment to you. You will usually be asked to sign a form saying that you give your 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 have been given full information about:

the type and extent of the treatment you are to have
 the advantages and disadvantages of the treatment
 any other possible treatments that may be available
 any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Some cancer treatments are complex, so it is not unusual for people to need repeated explanations.

It is often a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go for your appointment.

Patients often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you, and the staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment, if you feel that you can't make a decision when it is first explained to you. You are also free to choose not to have the treatment, and the staff can explain what may happen if you do not have it.

It is important to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You do not have to give a reason for not wanting to have treatment, but it can be helpful to let the staff know your concerns so that they can give you the best advice.

High-dose treatment with stem cell support

High-dose treatment with stem cell support can be used to treat a number of different cancers, including some types of lymphoma and leukaemia, myeloma and testicular cancer.

The high-dose treatment will destroy the cells in your bone marrow. Your own stem cells can be used to help 'rescue' you from this intensive treatment. Some of your own stem cells are taken and stored before you have high-dose treatment. After the high-dose treatment, your stem cells are given back to you through a drip into a vein (like a blood transfusion).

The treatment
 Risks of high-dose treatment
 Fertility
 Some questions you might like to ask your doctor

The treatment

High doses of chemotherapy, and sometimes radiotherapy, are given to improve the chances of curing your cancer or prolonging a remission. It may be given when the cancer, leukaemia or lymphoma has not completely gone away after standard treatment. It can also be used when there is known to be a higher risk of the cancer returning or when the cancer comes back after initial treatment.

For high-dose treatment with stem cell support to be successful, it is important that there is no sign of any cancer cells in the bone marrow. So this treatment is usually given if the cancer has not spread to the bone marrow or has been cleared out of the bone marrow by previous chemotherapy treatment. Sometimes the collection of cells (harvest) is put through a type of cleaning process (purging) to try to remove any cancer cells that may still be present. Purging the cells in this way is still being tested to see if it is safe and effective, and so is not often used as a treatment in the UK.

Although high-dose treatment with stem cell support is a serious procedure it is less complicated than using stem cells from a donor. There are fewer complications and recovery is usually faster. It is carried out in hospitals that have large cancer units.

Risks of high-dose treatment

The main problems occur during the time when your bone marrow is recovering. This is when you could have possible life-threatening infections and bleeding. Your doctor will take into account your age and your general health when considering high-dose treatment for you. The upper age limit is usually 65–70. This is because the intensity of treatment increases the risks of severe side effects or of dying from the treatment after that age. High-dose treatment can sometimes be given to people over 65–70, depending on their general health and the risk of the cancer coming back.

This treatment is both physically and emotionally demanding. You may need to stay in hospital for up to four weeks or longer, and there will be times when you feel very unwell.

You need to weigh up the benefits and risks of this treatment, including the possible side effects (especially serious infection or bleeding). It is important to discuss this in detail with your doctor and your family and/or the transplant counsellor at the hospital.

Fertility

One issue that your doctor should discuss with you, if it is relevant for you, is fertility. Unfortunately, infertility is usually a side effect of this treatment, for both men and women. See *Life after high-dose treatment* for more information.

Some questions you might like to ask your doctor

If I do have high-dose treatment with stem cell support...

- What are the benefits for me?
- What are the risks?
- What are the long-term side effects?
- How will it affect the way I live?
- Will I be able to have children after treatment?
- How long will it be before I can start to live my normal life again?
- What happens if my cancer comes back after high-dose treatment?

If I don't have high-dose treatment with stem cell support...

- What other treatments are there for me?
- What will happen with my cancer?
- Will I be able to go on living my normal life?

You do not need to feel that you have to rush into making a decision about whether to have high-dose treatment. Most doctors understand that you may want time to think about their recommendations and to discuss them with your family or other people close to you. Most hospitals have staff you can talk things over with, such as a nurse specialist, a transplant coordinator, a social worker and a counsellor.

Stem cells from a donor

In this type of transplant, stem cells are donated by another person (a donor). Doctors call this an **allogeneic transplant** or an **allograft**. It is sometimes used as part of the treatment for cancers that are in the bone marrow, such as leukaemia and myeloma. It can also be used to treat some rare non-cancerous diseases of the bone marrow or the immune system.

- The treatment
- Why donor stem cell transplants are used
- Risks of a donor transplant
- Fertility
- Some questions you may like to ask your doctor

The treatment

Treatment with high-dose chemotherapy is given to destroy the cancer cells in your bone marrow. This also destroys your healthy stem cells. After the treatment, stem cells donated by someone else (a donor) are given to you by drip. The stem cells go into the bone marrow and start to produce blood cells. This helps you to recover from the high-dose treatment.

The most suitable donor is usually a brother or sister whose bone marrow is a close match to your own.

Occasionally it is possible to use stem cells from a person who is not related to you, if tests have shown that their white blood cells are a good match with yours. This is known as a matched unrelated donor (MUD) transplant.

The stem cells from a donor will contain immune cells. These immune cells can sometimes attack some of the cells of the person who has received the transplant (the recipient). This can cause a reaction in the body known as graft-versus-host disease (GvHD). As well as attacking healthy cells, the immune cells from the donor may also attack any cancer cells that are left. This is known as graft-versus-disease (GvD).

An allogeneic transplant is a very serious and complicated procedure. This intensive treatment is carried out in specialised transplant units in larger university hospitals.

Why donor stem cell transplants are used

Donor stem cell transplants may be used to treat some types of leukaemia, lymphoma and myeloma. These allogeneic stem cell transplants are used to improve the chances of curing the disease or prolonging a remission. A transplant may be carried out in the early stage of treatment when the disease is in remission. A transplant may also be done if the illness comes back after treatment. There are different types of leukaemia and lymphoma and a donor transplant is not a suitable treatment for everyone. Whether there is a suitable donor is one of the important factors for doctors to consider.

Other factors your doctor will take into account when considering whether to recommend a transplant for you are your age and general health. There are no lower age limits, but guidelines recommend that for donor transplants the upper age limit is 45–50. This is because the risk of severe graft-versus-host disease is much higher after that age. However, sometimes a donor transplant may be given to people older than 45–50. This depends on your general health and the risk of recurrence of the disease.

A donor stem cell transplant procedure is extremely demanding, both physically and emotionally. You may need to stay in hospital for 4–6 weeks or longer. For most of that time you will usually be in a room of your own, and you will probably feel very ill.

Risks of a donor transplant

An allogeneic stem cell transplant is a complicated and specialised treatment. It has many side effects and possible complications.

The main risk comes during the time after the high-dose treatment when your bone marrow is recovering. At that time, you are at risk of possible life-threatening infections and bleeding. There is also the risk of graft-versus-host disease, in which the donor's marrow or stem cells react against your own tissue. Very occasionally, the donated marrow or stem cells do not start to produce new blood cells (this is called graft failure). If this happens it may be necessary for you to have more stem cells donated by the same donor.

Your age and general state of health are key factors to take into account. A transplant takes a long time and may make you very ill. If you are at the upper age limit and your general health is not good, you are more likely to have complications.

You need to weigh up the benefits and risks of this treatment very carefully. The treatment may give a greater chance of curing the cancer than any other type of treatment. However, this has to be weighed against the possible side effects and the fact that some people die during the procedure. You will want to discuss this in detail with your doctor and your family. Most hospitals that carry out blood stem cell transplants have a transplant counsellor you can talk to about any fears or worries.

Fertility

One issue that your doctor should discuss with you, if it is relevant for you, is fertility. Unfortunately, infertility is usually a side effect of the intensive treatment, for both men and women. There is a higher risk of infertility with an allogeneic (from a donor) transplant than with high-dose treatment with stem cell support. See the booklet on life after high-dose treatment for more information.

Some questions you may like to ask your doctor

If I do have a transplant from a donor...

- What are the benefits for me?
- What are the risks?
- What are the long-term side effects?
- How will it affect the way I live?
- Will I be able to have children after treatment?
- How long will it be before I can start to live my normal life again?
- What happens if my cancer comes back after my transplant?

If I don't have a transplant from a donor...

- What other treatments are there for me?
- What will happen with my cancer?
- Will I be able to go on with my normal life?

You do not need to feel that you have to rush into making a decision about whether to have a donor transplant. Most doctors understand that you may want time to think about their recommendations, and to discuss them with your family or other people close to you. Most hospitals have staff you can talk it over with, such as a nurse specialist, a transplant coordinator, a social worker and a counsellor.

Finding the donor for an allogeneic transplant

Finding a match
 Related donor
 Unrelated donor

Finding a match

To reduce the risk of your body rejecting the donated stem cells (graft rejection), the donor's tissue type has to be closely matched to yours. The matching process involves a blood test, and is done by looking for specific proteins known as **markers** on the surface of the cells. The markers are called human leukocyte antigens (HLAs). Once the HLA type of your bone marrow has been found, other people can be tested to see whether their bone marrow and stem cells are the same type as yours. The closeness of a match needed for a good result depends on which particular tissue markers are the same as yours. For some markers, doctors may decide to accept small differences, to improve the chances of finding an acceptable donor. In this situation, the transplant is known as a **mismatched transplant**.

Donors need to be in good health. They will be given a thorough medical check-up to make sure that there will be no risk to their own health from the procedure. The donor will have to go to the hospital for a couple of outpatient visits for these checks. They then have either their bone marrow or stem cells collected at the hospital.

Related donor

Usually brothers and sisters (your siblings) are tested first, as they are likely to have the best match. Because of the way that your siblings inherit the 'HLA markers' from your parents, some will be more likely to be a good match, others will be less likely. If one of your siblings is completely matched to you, they are known as an **HLA identical donor**. The match is unlikely to be perfect unless you have an identical twin. A transplant using bone marrow or stem cells from an identical twin is called a **syngeneic transplant**. Parents, half-brothers and half-sisters will not usually be a good match, although they may be tested if you have no other siblings, or if your doctors have not been able to find a complete match for you.

Unrelated donor

If you have no suitable relatives it may be possible to find a matched unrelated donor (known as MUD). Remember, however, that it may be very difficult and time-consuming to find a good match. Overall, only about 1 in 10 searches will find a closely matched, unrelated donor.

People from ethnic groups often have difficulty finding a good match from the volunteer registries. This is because most people (in the UK) who register as potential bone marrow donors are from the white population, and tissue types rarely match across different ethnic groups.

Graft-versus-host disease

If you have had stem cells from a donor, even a brother or sister, there is a possibility that the new cells (the graft) will react against your tissues (the host). This reaction is called graft versus host disease (GvHD). This happens when the donor's immune system attacks the patient's body. You will be prescribed medicines to prevent GvHD happening, so it is usually mild. However, in some people it

can become very severe and even life-threatening. It mainly affects the skin, the gut (stomach and bowel) and the liver. The reaction can occur up to six months after your transplant.

Occasionally the donor's bone marrow may be treated (purged) with antibodies to remove a type of white blood cell (T-lymphocyte) which is thought to cause the GvHD. Removing the T-lymphocytes is most often done if a severe graft versus host reaction is possible – for example, if bone marrow from an unrelated donor is used.

If GvHD occurs, it does not mean that the transplant has failed. It may even be helpful, as some of the cells involved in the reaction may also attack any cancer cells in the body that have survived the high-dose treatment.

Stem cell and bone marrow transplants in children

The procedures for high-dose treatment with stem cell support and allogeneic transplants in children are similar to those for adults described in this booklet.

Donors who are children will always have stem cells collected from their bone marrow. Older children (usually over 10) now sometimes have stem cells collected from their blood.

When planning the transplant, doctors will consider very carefully the effects of the intensive preparatory treatment, so that long-term effects – for example, on the child's growth, development and future fertility – are kept to a minimum.

You may find that the approach to treatment used by specialist children's units is different from that used in adult units (and described here); for example, your child may not be in a room on their own for very long, if at all.

When your child is back at school and mixing with other children, they will need to take care to avoid infections, including common childhood diseases such as chickenpox and measles. Your child's doctors will discuss with you when your child should have immunisations.

Many organisations can support and advise the parents of children who have cancer.

Research trials for stem cell and bone marrow transplants

Many people have now had transplants. Everyone who has these treatments helps doctors and researchers to understand more about the process.

However, until it is a completely safe procedure, and works well for all the diseases it is used to treat, more research is needed to improve the techniques.

Research is going on around the world to try to decide on:

- the best forms of preparatory treatment
- ways of preventing graft-versus-host disease
- and techniques for speeding up bone marrow recovery time.

Several international organisations monitor statistics for transplant operations, and their outcomes, from many countries. They provide researchers with all the available data so that they can compare treatment methods and procedures.

Many of these intensive treatments are done as part of cancer research trials (clinical trials). If you are invited to take part in a trial, it is important to remember that whatever treatment you are offered will have been carefully researched in preliminary studies before it is fully tested in a clinical trial. It will also have been approved by an ethics committee.

Your doctor must have your informed consent before entering you for a trial. Informed consent means that you know what the trial is about; you understand why it is being conducted and why you have been invited to take part; and the treatment has been discussed with you.

Even after agreeing to take part in a trial, you can still leave the trial at any stage if you change your mind.

If you choose not to take part in a trial, this will not affect your doctor's attitude towards you. If you do take part, you will be helping to advance medical science and improve prospects for patients in the future.

Preparing for your transplant or high-dose treatment with stem cell support

Having high-dose treatment with stem cell support or a transplant is very demanding, physically and emotionally. Your family and friends may also find this a very stressful time. It may be helpful to talk about your fears and concerns. Some people are able to discuss things with the people closest to them, and find that this brings them even closer together. Other people prefer to talk to someone outside their immediate circle, such as their GP, a specialist nurse, a counsellor or a social worker.

It is important that you understand why you are having the treatment and what the actual processes will be. Then, you can make practical arrangements and also prepare yourself mentally. Before you go into hospital, it is a good idea to have a discussion with the doctors and nurses who will be looking after you. They can explain what is likely to happen, so that you know what to expect. It is helpful to take your partner, a close relative or a friend with you. They will then be informed and can explain visiting arrangements and precautions to your other visitors. They can also warn them that you will not be well for some time.

Hospitals vary in the way they look after people. However, you will usually be in a room on your own for a while, perhaps even several weeks. The isolation and visiting restrictions may make you feel very lonely, frightened and depressed at a time when you might want people around you. If you feel like this it is helpful to let the staff looking after you know.

You may think that you will have a lot of time on your hands. However, you may not feel well enough to do very much, at least at the beginning of your treatment. A lot of your day will be taken up with medical and nursing procedures including:

- regularly taking medicines
- having your temperature and blood pressure checked
- frequent visits and examinations by the doctors and nurses looking after you.

But, it is a good idea to take in some books, pens and paper, a radio or personal stereo or other pastimes. Then you will have them for the times when you do feel ready for a little activity. Many hospitals have radios, TV and DVD players so you can also listen to or watch your favourite programmes or DVDs.

Some question you might like to ask

- Who can visit me?
- What are the visiting hours?

How long can my visitors stay?
 Will my treatment make me feel too ill to see people?
 What precautions will my visitors need to take when they come to see me?
 What do you suggest I should bring into hospital with me to make my stay more comfortable?
 Is there a television in the room?
 Is there a telephone link in the room? Will I need coins or a phone card to use it? Can I bring in a mobile phone?
 Can I bring in a laptop computer? Will I be able to access the internet?
 Can I bring in my own nightclothes? Will I have to ask a relative to wash them for me?
 What will I be able to eat?
 Are there any foods that I should avoid?
 What can my visitors bring when they come to visit me? What about flowers and favourite foods?

Try to visit the unit or ward more than once before you go in to the hospital for your treatment, and write a list of further questions before your second visit. Many people find it very helpful to discuss the procedure with someone who has already had the same treatment. Your doctor or the support organisations should be able to put you in contact with someone.

Being fully informed and prepared will help to make the treatment easier for you and your family.

Collecting stem cells

Taking stem cells from the blood
 Collecting a donor's stem cells

Taking stem cells from the blood

First the stem cells are made to move from the bone marrow into the blood. To do this you will usually be given some chemotherapy, followed by a course of daily injections of a growth factor (G-CSF). The growth factor is given as an injection under the skin. Sometimes stem cells can be made to spill over into the blood using growth factors alone. You or a relative can be taught to give these injections, or you can go to your GP or the hospital to have them. Your blood will be tested regularly, and when there are enough stem cells in the blood, they will be collected.

Collecting the stem cells takes 3–4 hours. You will be asked to lie down on a couch and a drip will be put into the vein of each arm. Blood will be taken from one arm, through the drip, into a machine called a cell separator. The separator spins the blood to separate out the stem cells. These are collected, and the remaining blood is given back to you through the drip in your other arm. Sometimes a tube may be put into a vein at the top of your leg (instead of your arm) to collect the stem cells. If you already have a central line, or a PICC line, going into the main vein in your chest this can be used. The stem cells are then frozen until you have had the high-dose treatment.

Collecting a donor's stem cells

Your donor will have their stem cells taken directly from the bloodstream in the same way except they are not given chemotherapy drugs. They will be given a short course of injections of a growth factor (G-CSF). This encourages the production of stem cells so that they spill over from the bone marrow into the blood. The stem cells are then collected from the blood, usually in one session, which takes 3–4 hours. Occasionally, if not enough stem cells are collected, the donor may have to come in for another collection. This can all be done as a day patient.

Taking stem cells from the bone marrow

Although it is much more common for the stem cells to be collected from your, or your donor's, blood, in some situations the stem cells may be collected from the bone marrow.

How is it done?

About a week or two before the bone marrow is taken, you (or a donor) may have 1–2 pints of blood taken. This will be given back to you after the bone marrow is collected.

The collection of bone marrow is done under a general anaesthetic or an anaesthetic given into the spinal cord, so you will feel nothing. Some marrow is taken from inside the bones at the back and front of the pelvis (the hip bones). Rarely, marrow is taken from the breastbone (sternum). It is not usually possible to collect bone marrow from areas that have previously been treated with radiotherapy.

The doctor inserts a special needle through the skin and into the bone. The marrow is then sucked out into a syringe and put in a sterile container with various liquids. These liquids keep the cells healthy during processing and storage. The bone marrow is taken from a number of different areas in the pelvis. This is done through several small punctures, which quickly heal. You are likely to have some bruising for a few weeks afterwards.

For an adult, approximately one litre of bone marrow will be removed in this way - about 10–15% of the body's total. This leaves plenty for your or your donor's needs, and very quickly the body will replace the bone marrow that is removed.

You will have to stay in hospital overnight to recover from the general anaesthetic. You will feel very sore for a few days afterwards and will need to take painkillers. You will be given a further supply of painkillers to take home if you need them.

The high-dose treatment

High-dose treatment (sometimes called the conditioning regimen) is given to destroy any remaining cancer cells in your body.

How it is given
Chemotherapy
Radiotherapy

How it is given

When you are having your own stem cells, the treatment may be given at any time from one day to a few weeks after the stem cells or marrow have been collected.

When you are having an allogeneic transplant you will usually be given your donor's stem cells within a day of finishing your treatment. The donor will have their stem cells collected within 24 hours of you finishing your high-dose treatment.

While you are in hospital, you will need to have regular doses of medicines and many blood tests, over several weeks. To make this easier, and to prevent you from having frequent injections, a plastic tube (called a central line) can be put into a vein in your chest. The tube is put in under a general or local anaesthetic. Usually a small cut (incision) will be made in the skin over your chest, and a narrow flexible plastic tube will be placed under your skin and into a large vein in your neck. The other end of the tube stays outside your body and has a screw cap at the end. The tube can be used to:

give drugs and fluids

give the stem cells or bone marrow
collect blood samples.

After the line has been put in, the area may feel sore for a couple of days, but it should then be painless. The line can stay in for months and the nurses will show you how to look after it to help prevent blockages or infections.

Instead of a central line, a PICC line (peripherally inserted central venous catheter) or an implantable port may be used. A PICC line is a long, thin tube put into a vein in the crook of your arm. The doctor or chemotherapy nurse will explain the procedure to you. You will be given a local anaesthetic before the line is put in. An implantable port 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 or arm.

The high-dose treatment usually lasts a few days (this varies from one hospital to another) and consists of high doses of chemotherapy. The chemotherapy is sometimes followed by radiotherapy to your whole body (known as total body irradiation, or TBI).

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. You will probably already have had some chemotherapy as part of your original treatment, and so may have some idea of what to expect.

Our booklet on chemotherapy, explains the treatment and has tips on how to cope with side effects.

The high-dose chemotherapy is given through your central line, PICC line or implantable port, together with plenty of fluids. The treatment is usually given over several days.

During this time, it will probably be suggested that you do not have many visitors. The high doses of chemotherapy drugs may make you feel sick. You will be given anti-sickness medicines (anti-emetics), which will reduce or stop you feeling sick.

The chemotherapy drugs will make your hair fall out. Your hair will grow back once the treatment is finished, but it may seem hard to bear at the time. You may find it helpful to read our booklet on coping with hair loss.

Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells. You may be given radiotherapy to your whole body - known as total body irradiation (TBI) - as part of the high-dose treatment (or conditioning). Radiotherapy is used as part of the treatment for some types of cancer.

If you are to have radiotherapy as well as chemotherapy, you will probably go to the hospital for a planning session a few days before the treatment begins. The doctor will explain what will happen during your course of radiotherapy, and you can use this as a chance to ask questions.

The total body irradiation may be given twice daily over three days, in 6–8 sessions. Each session lasts about 40 minutes. The TBI can also be given in a single session over several hours.

Before each session the radiographer will position you carefully, standing, sitting or lying, and will make sure that you are comfortable. You will have to change position a few times during the session and the radiographer will explain this to you. During the treatment you will be left alone in the room, but you will be able to talk to the radiographer who will be watching you from the next room. Radiotherapy is not painful but you do have to keep still while your treatment is being given.

Many people find that they do not have many side effects from total body irradiation. This is because the treatment gives only a relatively low dose of radiation to any one part of the body. Common side effects are feeling sick (nausea), diarrhoea and a painful mouth.

If you still feel sick from the effects of the chemotherapy, you will probably be given an anti-sickness medicine before each session of radiotherapy, to make you more comfortable.

Giving back the stem cells

A day or more after the high-dose treatment has finished, your own, or the donated, stem cells will be given to you through your central line. This is similar to having a blood transfusion.

The stem cells will find their way back through the bloodstream to the bone marrow. In the bone marrow they will start to grow and develop into mature blood cells. It will be at least two or three weeks before some of the 'new' blood cells are released into the bloodstream. It may then be up to six weeks before you can leave hospital. This is because you will be very vulnerable to infection until your body is once again producing enough blood cells to protect you.

You may be given growth factors through your central line, PICC line or implantable port. These stimulate your bone marrow to start producing new white blood cells more quickly. Using growth factors can reduce the length of time you are at risk from some of the side effects.

If you are having an allogeneic transplant (from a donor) you will usually stay in a single room to help protect you from the risk of infection. This is especially important when your blood count is at its lowest, about 2–4 weeks after the high-dose treatment.

Newer treatments

Mini transplants

These are similar to allogeneic transplants (from a donor) except that standard-dose chemotherapy is given instead of high-dose. This treatment may be given to people who cannot have high-dose chemotherapy, possibly due to their age or because they are not fit enough. A course of standard-dose chemotherapy is given, usually over five days, before the patient is given the donor's stem cells or bone marrow. A drug which works on the immune system to reduce the risks of graft-versus-host disease is also given. It is hoped that this will trigger an immune reaction which will encourage the donor's cells to take over in the patient's bone marrow.

This is a new and still experimental treatment, which is being carried out in clinical trials. It is sometimes called a mini-allo or a non-myeloablative transplant.

Tandem transplants

In a tandem transplant, high-dose chemotherapy with stem cell support is followed within 3–6 months by another high-dose chemotherapy treatment with more stem cell support. It is thought that this may make the treatment more effective in controlling the illness. However, tandem transplants are still in the early stages of research.

Cord blood

It is now possible to take stem cells from the umbilical cord of a newly born baby. These stem cells may be used if the baby's cells are a match for a brother or sister who needs a transplant. A major drawback is that usually not enough stem cells are collected. This treatment is also experimental and further research is going on to look at using stem cells from cord blood.

Feelings during and after your treatment

Having a transplant or high-dose treatment with stem cell support can be a very frightening experience. Although you may sometimes feel optimistic, there may be other times when you are anxious, afraid 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?'

As the time for you to leave hospital comes closer, you may find yourself becoming impatient and longing to get home. But at the same time it can be quite hard to readjust to leading a more independent life again, after spending so much time as a patient. You may find our booklet, *Adjusting to life after cancer*, helpful.

Even when the treatment is over, you may resent the restrictions on your life. It may sometimes seem as though you will never be able to go back to your normal life again.

How you can help yourself

If you and your family understand your illness and its treatment you will be better prepared to cope with your situation. If you don't understand something about your treatment or disease, or if you want to know about side effects and possible outcomes of your treatment, it is important to ask.

If you don't understand the explanation, keep asking until you do.

Ask your doctor for regular updates on your progress and ask them to explain to you how things are going. Talking about your fears to your family and friends or to support organisations can help to relieve tension.

Your emotional well-being is as important as your physical health. Everyone needs some support during difficult times and having a transplant may be one of the most stressful situations you ever face. If you feel that low moods are getting the better of you, try to talk over your feelings with someone you feel close to, who is a good listener. You may also find it helpful to discuss your feelings with a trained counsellor, a leader or member of your religious faith, or a social worker.

You may feel comfortable talking about your concerns with your doctor or nurse. They can often help you to bring your feelings out into the open. If necessary, they can refer you to a counsellor or social worker for further help.

You could read our booklet, *Talking about your cancer*.

After treatment

- The first few months out of hospital
- Hospital contact
- The first year out of hospital
- The future

The first few months out of hospital

For the first two to three months after leaving hospital, you will have frequent blood tests to check the numbers of blood cells.

If you have had donated stem cells, you may have to take regular doses of several different drugs. Antibiotics and anti-viral drugs are given to reduce the risks of infection. Drugs which work on the immune system to reduce the risks of graft versus host disease (GvHD) are also given. The doses of all these drugs will be checked regularly. Depending on the results of your blood tests, the dose of your drugs may need to be changed.

If you have had high-dose treatment with stem cell support you may need to take antibiotics and anti-viral drugs for a time when you go home.

Occasionally you may still need to have blood or platelet transfusions. These can usually be given as a day patient.

If you become ill you will need to go back into hospital. It is quite usual to have to go back into hospital once or twice after a transplant - this is not a major setback but it can be very worrying for you.

It is essential that you take great care of your health during this time. There are a number of possible problems that might occur, because your immunity is reduced. Get in touch with your hospital immediately if you have any of the following symptoms:

- feeling ill
- a persistent temperature over 37.5°C (100.5°F) for more than two hours
- infections eg of the skin, mouth, bottom
- skin rashes
- severe diarrhoea
- breathlessness or breathing difficulties (it is particularly important to have these symptoms dealt with quickly).

Hospital contact

You should always carry a 24-hour telephone hospital contact number with you. If you are worried, you can ring the hospital at any time of the day or night to speak to someone who understands the treatment you have had. The doctors and nurses on the transplant unit or ward would rather be contacted unnecessarily than risk you becoming ill at home.

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

Many people will not have any major problems after leaving hospital. However, it is just as well to have a discussion with your doctors before you leave hospital, about what you should do if anything happens that worries you.

The first year out of hospital

By the end of the first year, your immune system will probably have returned to normal, and the bone marrow will be producing blood cells normally. Occasionally this may take a little longer. If you have had high-dose treatment and stem cell support it is unlikely that after a year you will have any of the problems described below.

You should continue to be careful and you will still have regular check-ups, which may include a bone marrow biopsy. You may get infections, such as shingles and chest infections, and if so you will need to go into hospital for treatment. Very occasionally, some people still need blood transfusions, and often your drugs will be continued to reduce the risks of infection and GvHD. You may be advised to carry a Medic alert card in case of an accident.

When you only need occasional blood tests or infusions your central line will be taken out.

You should gradually start to recover your weight and strength, and may be able to go back to work during this time. If you had high-dose treatment with stem cell support you may already have gone back to work.

It is very important to keep in close contact with your doctors and to discuss any problems or worries with them. This can be a difficult time psychologically, as you start to adjust to the outside world again, while still not being sure about your health in the longer term.

The future

You will need to have regular check-ups to make sure that you stay well and that there is no evidence that your cancer has come back. Usually these will take the form of a medical examination, a blood test and possibly x-rays. Eventually, if all stays well, these will become yearly visits. You should be able to go back to a normal way of life, without restrictions.

These check-ups can be frightening. You will probably be anxious about whether the transplant or treatment has worked. It often makes it easier if you take a relative or friend along to support you. The check-ups are a good opportunity to discuss with your doctor any worries or problems you may have.

Life after high-dose treatment

- Your diet
- Socialising
- Going back to work/ school/ college
- Exercise
- Vaccinations
- Holidays and travel
- Sex
- Fertility

Your diet

For the first few months while your immune system is returning to normal, it is important to try to eat a healthy and balanced diet and avoid possible risks of infection from food.

This means eating freshly cooked food and avoiding reheated food. It is best to avoid:

- fast food
- takeaways
- cream cakes
- any food that is not completely fresh.

Make sure that frozen foods are completely defrosted before cooking, and wash salads and fruit thoroughly before eating. Avoid soft cheeses, live yoghurt and dishes containing uncooked or lightly cooked eggs.

Once your blood count is back to normal, you can usually eat what you like. Your doctor or nurse will give you advice about this.

It is fine to drink a small amount of alcohol, but heavy drinking will slow down the recovery of the bone marrow, and increase the risks of bleeding (especially if your platelet count is low). Alcohol can also interfere with some of the drugs that you may be prescribed.

Socialising

To reduce the risk of infection, it is best to avoid crowded places such as cinemas, pubs, and public transport, until your white blood cells are well within the normal range. Your doctor can tell you what your blood count is.

By 3–6 months after your treatment you should be able to take up a full social life again. However, avoid contact with children who have an infectious disease such as chickenpox or measles.

Going back to work/ school/ college

When your blood count has gone back towards normal, you could discuss with your doctor whether it would be advisable to go back to work, school or college. Ideally, take it gradually, by going only part-time to begin with. It is a good idea to discuss this with your employer, teacher or tutor. They can help you to work out a satisfactory way of going back to your work or education in stages. You might also want to discuss whether you would like them to talk to your colleagues or fellow students about your illness and treatment before you return. If so, check whether you feel comfortable about the way they plan to do this.

Exercise

Regular gentle walking is good exercise to keep your muscles reasonably toned until your platelet count has gone back to normal. After this, you can start doing whatever exercise you like, although it is wise to gradually build up the amount of exercise that you take.

Vaccinations

After an allogeneic (donor) transplant you will lose your immunity to any illnesses you were vaccinated against as a child. After about a year, your doctor will discuss your immunity and when would be the best time to revaccinate you against diseases such as measles, mumps and polio.

If you have had high-dose treatment with stem cell support, your immunity will recover within a few months and you will not need to have your vaccinations again.

Holidays and travel

For the first 3–6 months after the transplant or high-dose treatment, you will still have to go back to the hospital regularly and may need blood transfusions.

As your blood counts improve, and the gap between hospital visits gets longer, you can discuss your holiday plans with your doctors. If you have had high-dose treatment with stem cell support there should be few restrictions on travel once your blood count has recovered. Ask your doctor for advice on travel and discuss any vaccinations needed.

After a transplant you will normally be advised not to travel abroad in the first year unless there is a nearby cancer treatment centre. Your doctors can arrange to send details of your recent treatment.

It is important to avoid sunburn in the first two years after your treatment, as it can trigger graft-versus-host reactions. Always wear a long-sleeved shirt, a hat and a high-factor suncream (SPF30 or higher) when you are exposed to the sun.

After the first year, when your immune system should be working well, you should be able to travel freely. However, certain types of vaccination should be avoided. Again, discuss your plans with your transplant doctors. They may be able to suggest medical centres that could cope with complications, if they arise.

It is usually helpful to carry with you a short letter from your doctor, outlining the treatment you have had and giving a contact telephone number.

Sex

Your physical ability to have sex will not be affected by your treatment, and there is no medical reason why you cannot go back to your normal sex life when you leave hospital. You may find, however, that your sex drive is reduced for some months. This may be a result of the treatment itself, or perhaps because anxiety about the future makes it hard for you to feel enthusiastic about sex. Sometimes changes in your appearance, such as weight loss or hair loss due to the treatment, can make you feel uneasy about your body.

Women whose treatment has caused an early menopause may get menopausal symptoms such as hot flushes, dry skin, dryness of the vagina, and a low sex drive. Most women can be helped by hormone replacement therapy (HRT) which can quickly help to relieve many of these effects. If your doctor has not already talked to you about HRT, it might be worthwhile asking them about it, to see whether it would be suitable for you.

You need not feel embarrassed about asking for professional advice if you are having sexual problems. Your doctor or social worker may be able to help you directly, or can refer you for specialist counselling if you think that would be helpful.

See our booklet on Sexuality and cancer for more information.

Fertility

In most cases, the high-dose treatment will make women's periods stop, and will stop men producing sperm. Fertility is a very important part of many people's lives, and not being able to have children can seem especially hard when you are also having to cope with cancer. Many people are devastated when they discover that the treatment they need will mean they cannot have children.

Loss of fertility can take a long time to come to terms with. Allow yourself time to adjust to it and to express your sadness that a part of your life and a function of your body have been lost. When you feel ready, talking with your partner, family or a close friend may help you to cope.

Some people find it helpful to talk through their feelings with a trained counsellor.

Men

It may be possible for men to store sperm before they have the treatment, so that it can be used later if they want to have a family. The hospital may charge a fee to store sperm. You will need to discuss this at the hospital where you have your treatment. Parents of teenage boys should also be aware of this so that, where possible, sperm can be stored for later years.

Women

It may be possible to store fertilised eggs (embryos), with the chance of re-implanting them into the womb later. It may also be possible to store unfertilised eggs, although the success rate when using these is much lower than using embryos. To do either of these, the cancer needs to be at a stage where the treatment can be delayed for several weeks while the eggs are collected and fertilised.

It may be possible for women to have a piece of tissue from their ovaries removed before they have the treatment. It is not yet possible to achieve a pregnancy from this type of sample, but the ovarian tissue can be stored, in the hope that it will be possible to use it in the future. Only a few hospitals in the UK are able to store samples in this way. This research is still at an early, experimental stage and is not widely available. Your doctor or specialist nurse can discuss this with you.

See our booklet on Fertility and cancer for more information.

If you are a friend or relative

Visitors are very important to people in hospital, especially if they have to be nursed on their own. Most hospitals allow relatively free visiting. When you arrive it is best to let the nurse in charge of the ward know that you want to visit your relative or friend, before you go in to see them.

You will have to take certain precautions to make sure you do not take in any infection. If you are unsure about anything, ask the nurses or doctors.

You should not visit if you are at all unwell, even with a minor cold or infection.

Many hospitals allow children to visit - but, not if they are unwell or have been in contact with other children with an infectious disease such as chickenpox. It is best to check with the hospital staff.

Follow any hospital instructions (eg to wash and dry your hands thoroughly or to put on protective clothing) before going into the patient's room.

Ask the nursing staff about bringing in food, flowers, etc.

Even with the protective measures, you can still kiss, hug or hold your friend or relative's hand and give comfort and support by being there. If you cannot visit, a telephone call or card to the patient will help them to feel less isolated.

Be prepared for the fact that your friend or relative will not look or feel well, and may not have enough energy for many visitors or for a long visit. It may be helpful if one person coordinates visiting, so that the patient is not overwhelmed.

It is often enough just to sit with your relative or friend. You don't have to worry about keeping them entertained. Often, patients may not feel like seeing anyone, and this is quite normal. Don't be upset or take it personally if you are asked to miss a visit.

Our booklet Talking to someone with cancer looks at some of the difficulties people may have when talking about cancer, and suggests ways of overcoming them.

If you are worried about anything, please talk to the doctors and nurses on the unit or ward. They rely on the patient's family and friends to play an important part in helping the patient through this difficult procedure.