

Myeloma Infoguide Series



Contents

2	Introduction
4	What are the current treatments for myeloma?
5	What are stem cells?
6	What is high-dose therapy and stem cell transplantation and why is it needed?
8	What is the difference between a stem cell transplant and a bone marrow transplant?
9	What are the advantages and disadvantages of high-dose therapy and stem cell transplantation?
11	High-dose therapy and stem cell transplantation – the process
25	Supportive care and follow-up when you return home
33	Further treatment and measuring response to treatment
37	Allogeneic transplantation
41	The future
42	Questions for your doctor / medical team
43	Medical terms explained
46	Treatment guidelines
47	References
48	Appendices
51	Further information and useful organisations
54	With Myeloma UK you can...
55	We need your help
56	Other information available from Myeloma UK

Disclaimer

The information in this Infoguide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your individual situation.

Introduction

This Infoguide is written for patients with myeloma, their families and friends. The information given in this Infoguide focuses mainly on high-dose therapy and stem cell transplantation. This is a treatment option for many people who have myeloma and is carried out in specialist centres for hundreds of patients each year in the UK.

This Infoguide contains information covering what high-dose therapy and stem cell transplant is, why it is needed, potential advantages and disadvantages, what to expect when going through a transplant and some do's and don'ts when you return home after a transplant. It also provides information on less common types of transplants carried out for myeloma patients. A table at the end of this Infoguide summarises some of the advantages and disadvantages of the types of transplants discussed.

Some of the more technical or unusual words appear in bold the first time they are used and are explained in the Medical terms explained section at the back of the Infoguide.

Aims of this Infoguide

- To help you understand more about high-dose therapy and stem cell transplantation
- To provide answers to the questions you may have
- To help you make informed treatment decisions
- To help you understand more about other types of transplantation used in myeloma treatment

Myeloma UK provides a range of specific Infoguides and Infosheets which cover all aspects of the treatment and management of myeloma. You will find a list of these at the back of this Infoguide.

If you would like a more general overview of what myeloma is, how it is diagnosed, the most commonly used treatments and many of the things you may have to cope with in living with myeloma, please see *Myeloma – Your Essential Guide* and *Living with Myeloma – Your Essential Guide*. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332**. This information is also available 24 / 7 on our website at www.myeloma.org.uk

If you would like to talk to someone about any aspect of myeloma, its treatment and management, call the **Myeloma Infoline on 0800 980 3332**. Your call will be answered by Myeloma Information Nurse Specialists who are supported by medical and scientific advisors. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK. From outside the UK, call +44 131 557 3332 (charged at normal rate).

What are the current treatments for myeloma?

Myeloma is currently considered to be an incurable cancer but treatments are available to halt the progress of the disease, treat the symptoms and improve the quality of life of patients.

The mainstay of treatment for myeloma includes **chemotherapy** alone or followed by high-dose chemotherapy and **autologous stem cell transplantation** (using your own cells). In addition there are a range of treatments that are effective in controlling the symptoms of the disease including **bisphosphonates**, **erythropoietin**, antibiotics and pain medication.

High-dose therapy with **allogeneic stem cell transplantation** using a sibling (brother or sister) donor or, rarely, using a volunteer unrelated donor, is a treatment that aims to provide longer remissions by using the donor's immune system to attack myeloma. Whilst not common, this option offers the possibility of long-term disease free survival. Allogeneic transplantation, including the newer 'mini' **allogeneic transplant** is discussed in more detail on page 37.

There is also an increasing number of new drugs being developed for the treatment of myeloma. Over the last few years **thalidomide** has emerged as an important treatment option.

So far thalidomide has been used mainly to treat relapsed or refractory disease, but emerging results from clinical studies show that it may be just as effective at other stages of the disease.

Other new drugs being studied include **VELCADE® (bortezomib)**, **REVLIMID® (lenalidomide)** and **Arsenic Trioxide**. These treatments are all being tested in clinical studies throughout the UK and the world.

For more information on the treatment of myeloma, please see Myeloma UK's booklet *Myeloma – Your Essential Guide*. Myeloma UK also has a range of Infoguides on specific treatments, such as thalidomide, Velcade and Revlimid. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332**.

What are stem cells?

There are various types of stem cells, but when talking about transplantation in myeloma, we are talking about blood stem cells. These are truly extraordinary cells and their role as a type of 'mother cell' is vital in the process of stem cell transplantation.

Blood-forming stem cells exist in the bone marrow and have the capacity to divide and develop into the three main types of cells found in the blood: red cells, white cells and platelets. Each of these cells performs essential functions in the body:

- Red blood cells carry oxygen from the lungs to the entire body
- White blood cells combat bacteria and viruses to fight infections
- Platelets form clots and help control bleeding from injuries

It is the unique capacity that stem cells have to divide into blood cells, along with their ability to be collected from a person safely, that makes high-dose therapy and stem cell transplantation a possible treatment option for people with myeloma.

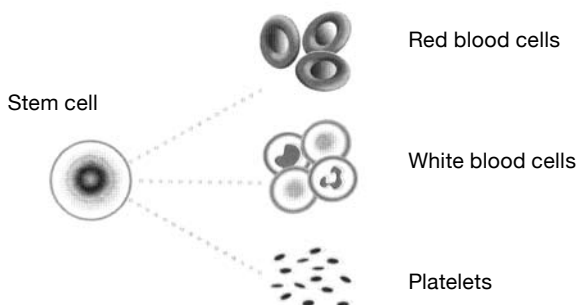


Figure 1 - Stem cell division

What is high-dose therapy and stem cell transplantation and why is it needed?

Standard chemotherapy, given alone or in combination, is an effective way of treating myeloma. In the majority of cases chemotherapy is easy to administer and can often be taken at home.

However, a major draw back of chemotherapy is the inability to give high doses safely. This is because chemotherapy, particularly in higher doses, kills healthy, good cells as well as myeloma cells.

This can result in blood production being severely affected and blood cells may fall to dangerously low levels, causing a number of potentially serious problems such as **neutropenia** and **thrombocytopenia**.

In addition, over time, myeloma cells can become resistant to the drugs used, even in lower doses. Therefore responses are often quite gradual, residual disease is common and durable, deep remissions are harder to achieve.

An autologous stem cell transplant uses healthy stem cells, previously collected from the patient, to offer a way round this problem. It provides a means of giving higher doses of chemotherapy, to consolidate previous chemotherapy treatment, without causing permanent damage to blood cell production.

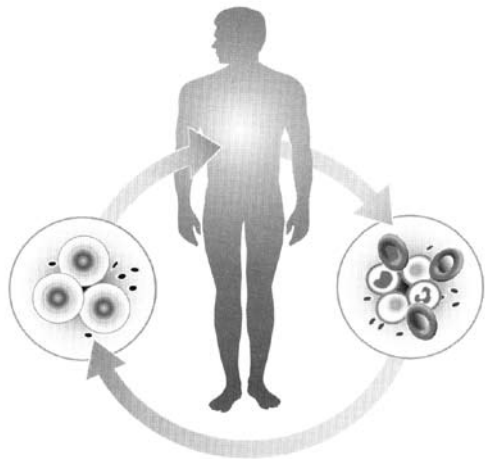


Figure 2 - Autologous transplantation

Giving back previously collected healthy stem cells after high-dose chemotherapy effectively 'rescues' the patient's bone marrow. It means that healthy blood cell production can continue until the bone marrow, damaged by the high doses of chemotherapy, recovers and produces new blood cells.

High-dose therapy and stem cell transplantation therefore has the ability to destroy in a safe way more myeloma cells than would be possible with lower doses of chemotherapy, improve the duration of remission and provide a better quality of life.

It is worth noting however, that myeloma is a very individual disease. Each patient's disease has its own distinct characteristics, which may affect the outcome of high-dose therapy and stem cell transplantation and not all patients achieve the desired response.

For a small group of younger patients, autologous stem cell transplantation may also to be used before an allogeneic transplant. Allogeneic transplantation is discussed further on page 37.

What is the difference between a stem cell transplant and a bone marrow transplant?

In the past, stem cells were obtained by collecting them directly from the bone marrow. This involved an aspiration of bone marrow from the bone, usually the pelvis. Hence, the procedure was known as a 'bone marrow transplant'.

More recently, certain **growth factors**, such as G-CSF (granulocyte colony stimulating factor) have been developed, which stimulate stem cells to multiply and move from the bone marrow into the peripheral blood stream.

These 'mobilised' stem cells can then be collected from the peripheral blood using a special machine. This can usually be done without a stay in hospital and, other than the insertion of lines (drips), should not cause any discomfort.

Collecting stem cells in this way is easier and a more reliable number of cells are provided. In addition, stem cells from the peripheral blood are slightly more mature than those in the bone marrow and therefore develop and grow more quickly, which often means a shorter period of **immunosuppression**.

Collecting stem cells from the peripheral blood rather than the bone marrow has now become the standard method of obtaining stem cells and almost all transplants will use stem cells collected in this way.

What are the advantages and disadvantages of high-dose therapy and stem cell transplantation?

Understanding the potential advantages and disadvantages of any treatment is an important step in the decision-making process.

The advantages include the following:

- The relative safety of the procedure means that high-dose therapy and stem cell transplantation can be considered an option for older patients, often up to the age of 70 years, as long as they are fit enough.
- There is a potential improvement in general quality of life as less residual disease can mean fewer future complications, such as bone disease.
- There is strong evidence from clinical studies that the use of high-dose therapy and stem cell transplantation as consolidation treatment after initial induction treatment improves duration, depth and quality of response and improves overall survival compared with conventional chemotherapy alone.
- As the patient serves as their own donor, there is no need to find a suitable match and therefore no risk of incompatibility.

Nonetheless, high-dose therapy and stem cell transplantation does not benefit all patients and there are some potential disadvantages.

The disadvantages of high-dose therapy and stem cell transplantation include:

- High-dose chemotherapy is more toxic than standard doses of chemotherapy and therefore there is a risk of more side-effects.
One important issue that may be discussed before you start the high-dose chemotherapy is the effect of this on fertility. You should discuss with your doctor the potential strategies to preserve fertility such as sperm banking.
- The success of this or any other treatment cannot be guaranteed, as not all patients will achieve the desired response. (see Table 1a and 1b – Measuring response to treatment on pages 33 and 34).
- High-dose therapy and stem cell transplantation is unable to cure myeloma; most people will have recurrence of their disease over time.
- It is possible that the re-infused stem cells may be contaminated with myeloma cells, although there is no definitive evidence from clinical studies to indicate that this causes relapse.

Current methods of purging stem cells, which aim to reduce contamination of the healthy stem cell collection with myeloma cells, have not shown any additional benefits and are therefore not usually performed.

High-dose therapy and stem cell transplantation – the process

The whole process, from the initial discussion with your doctor to recovery after the transplant, can take several months and can be daunting if approached as a whole. It is often easier to prepare for and face each stage separately.

Due to the nature of this treatment option, only hospitals with appropriate accreditation and medical and nursing experience perform high-dose therapy and stem cell transplantation.

If your hospital does not have accreditation, you will be referred to the nearest hospital that does. Here, your care will be transferred to the specialist transplant team, but your own doctor will still be keeping a close eye on how things are going.

When the transplant process is over, and you return home, you will be referred back to your local haematologist or receive 'shared care', which means visiting both hospitals for a period until you are discharged completely from the care of the specialist transplant team.

If your local hospital is one that performs transplants, then you will not need to be referred to another hospital, but you will be under the direct care of the specialist transplant team during the transplant process.

What follows is a brief overview of the various stages involved in the transplant process.

Considering the options and making a decision

The process begins with looking at the options and making a decision to have the treatment. The option of high-dose therapy and stem cell transplantation may sometimes be broached by your doctor quite soon after diagnosis, whilst you are still learning about your disease. For others, it may be discussed a little later, when initial chemotherapy treatment is underway.

When considering the option of a high-dose therapy and stem cell transplantation, it is important to understand what this treatment involves, and receive the information that you need in order to make an informed decision. An informed decision is a vital part of giving your consent (permission) for the hospital staff to perform the treatment.

Before making any decision, information should be provided on the treatment, its potential advantages, disadvantages, risks and side-effects, and all possible alternatives and options that may be available. Every person is different and has their own priorities, concerns and lifestyle – all of which can play a significant part in the decision-making process.

After discussion with your own doctor you may be referred for a consultation with a specialist at an accredited transplant centre. This appointment is a further chance to discuss this treatment option and ask questions, so that you are able to make an informed decision.

At this point, you may also need to have some tests performed to check your suitability for a transplant.

These will include tests of your heart, kidneys and lungs. It may also be possible to meet the nursing staff and look around the transplant ward, which can help relieve some of the anxieties you may face about having the transplant.

For some, the decision to have high-dose therapy and stem cell transplantation is not an easy one and you may feel you need time to make a decision. This is normally possible and you should use this time to find out as much as you can, seek more than one opinion and speak to other patients who have had this type of treatment. You must be sure that this is the right treatment for you before giving your consent.

This type of treatment is not for everybody. Those who are reluctant to proceed, even if they are a suitable candidate, should discuss all other options with their doctor.

If you decide that this treatment is not for you, it may still be worthwhile collecting and storing stem cells if you can, as it may be possible to use them at a later stage in the disease.

In those patients who, for whatever reason, are not able to have this procedure, the best and most appropriate other treatment options will be discussed with you by your doctor.

Although there is no rigid age cut off for this procedure, it is not generally recommended in patients over the age of 70. This is primarily because the possible benefits are often outweighed by the potential risks to older, less fit patients. There are, however, excellent treatments that are recommended for this group of patients in which the benefits do out-weigh the risks and very good responses are often achieved.

Induction chemotherapy

Induction chemotherapy is the initial chemotherapy you are given for myeloma, which aims to reduce the amount of myeloma in the body and help to relieve any symptoms.

There are a number of induction regimens to choose from, all of which have more or less been shown to be comparably effective. Individual disease factors, as well as doctor / patient preference will determine which regimen is the most appropriate to use.

See Appendix one on page 48 for common chemotherapy combinations used in myeloma. Courses of chemotherapy usually last for several months and are given in cycles. The number of cycles given will depend on individual patient factors and how the myeloma responds, so it is difficult to know exactly how long this induction treatment will go on for, but it is often about four to six months.

Chemotherapy can cause side-effects such as sickness, fatigue, hair loss, sore mouth and an increased risk of infection. These side-effects can vary greatly between individuals and are almost always short-term.

A **HICKMAN® catheter** or **GROSHONG® catheter** may be required for some of the regimens. A **HICKMAN® catheter** is a hollow tube that is inserted into a large vein in the neck and tunnelled under the skin.

- 1) Central line is inserted into a vein here
- 2) The line is tunnelled beneath the skin
- 3) The tube comes out here

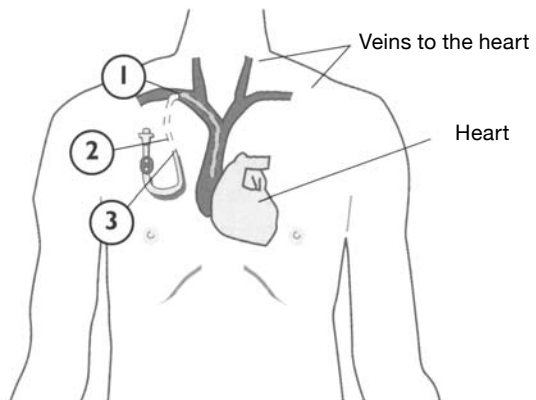


Figure 3 - **HICKMAN® catheter**

HICKMAN® catheters are normally kept in for several months and are necessary to administer chemotherapy and the other medications you will need. They can remain in place until after the treatment is finished, if no problems occur, such as infection.

For more information please see Myeloma UK's Infosheet *Chemotherapy*.
To order your free copy, contact the **Myeloma Infoline on 0800 980 3332**.

Once induction chemotherapy treatment is completed, the next stage in the process is obtaining the stem cells.

Mobilisation of stem cells

Stem cells that are collected from peripheral blood are referred to as peripheral blood stem cells or 'PBSC'. As explained earlier, it is necessary to move the stem cells into the blood stream in order to be able to collect them.

This is achieved by giving a special type of drug called a 'growth factor'. Growth factors increase the number of stem cells in the bone marrow, causing them to 'spill over' into the blood, where they can be collected more easily.

This growth factor is called G-CSF (granulocyte-colony stimulating factor) and is given as an injection under the skin for several days prior to collection of the stem cells. The injections are given in the outpatient clinic or at home either once or twice daily, depending on the dose prescribed.

Although it is possible to mobilise stem cells using G-CSF alone, a cycle of chemotherapy is often given before the G-CSF injections.

Chemotherapy temporarily reduces the number of stem cells in the bone marrow. When the bone marrow recovers, it goes into stem cell production 'over-drive' and with added G-CSF at this point it is usually much easier to collect the desired number of stem cells.

The type of chemotherapy most often used is cyclophosphamide and usually requires a one or two night stay in hospital. For some, the side-effects, such as nausea, may be more apparent than those experienced with the induction chemotherapy, but they usually resolve quite quickly.

G-CSF is given consecutively over about five to seven days when used alone, or about ten days when used after chemotherapy.

You may be encouraged to give your own injections of G-CSF and the nurses at the hospital will teach you, or a family member, how to do this. If this is not possible for any reason, community nurses can come to your home to give the injection. It is important to have the injection around the same time each day and to store it as directed.

G-CSF injections can cause side-effects for some people. The most common side-effect is a flu-like feeling (fever, aches and joint pain). This symptom is temporary and should disappear when the injections stop. It may be necessary to take simple painkillers to relieve the joint pain. Some people prefer to have the injections in the evenings so that they can sleep off any aches.

For more information please see Myeloma UK's Infosheet *Growth Factors*. To order your free copy, contact the **Myeloma Infoline on 0800 980 3332**.

Collection and storage of stem cells

If you are referred to another centre for your transplant, the induction chemotherapy and G-CSF are usually given at your local hospital, whilst the collection of the cells takes place at the specialist transplant centre.

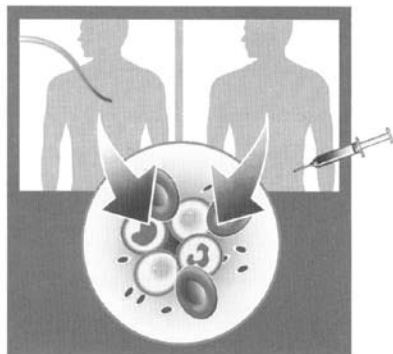


Figure 4 - Collection

Collecting stem cells from the peripheral blood can be done in the day care area of the outpatient department, so an overnight stay in hospital is not normally needed. No anaesthetic is involved, so any risks related to general anaesthesia are avoided.

To make sure that there are enough stem cells in the blood for collection to take place, a blood test may be taken. This blood test is called a CD34 blood test and is performed towards the end of the course of G-CSF. CD34 is the technical name given to surface markers on the stem cell.

If the cell count is high enough, collection will take place using a special machine known as a cell separator or **apheresis** machine. Apheresis is the process of collecting the cells using this machine.

Collecting the stem cells usually takes about three to four hours. You will be asked to lie down on a bed, or sit in a chair and a line will be connected into a vein in each arm.

Blood is taken from one arm and goes through the line, into the apheresis machine. The blood is spun in the machine, which separates out various cell components.

Stem cells are drawn-off and the remaining blood returned to you through the drip into your other arm. If you have a HICKMAN® or GROSHONG® catheter already in place, this may be used.

Sometimes enough cells will be collected in just one session. Commonly, two or three sessions over consecutive days may be needed to achieve the number of cells required.

During the stem cell collection process, the most common side-effect is a cramp-like or tingling sensation in the hands, feet or around the mouth.

This happens because your blood is mixed with an anti-coagulant drug that stops the blood from clotting in the machine and this can cause a drop in your body's calcium levels. This is usually easily corrected by drinking some milk. You will feel tired after the collection and will probably need to rest that evening.

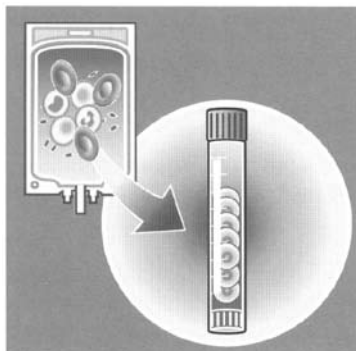


Figure 5 - Apheresis-collection

For some people a sufficient number of cells cannot be achieved by collecting the stem cells from the peripheral blood. If this is the case then stem cells may be collected from the bone marrow.

Collecting stems cells from bone marrow does not require treatment with growth factors or chemotherapy beforehand. It usually involves a two-night stay in hospital and the collection takes place in theatre, under general anaesthetic.

Using a needle and syringe, the haematologist will take bone marrow from several different areas of the hipbone (pelvis). There may be some soreness and bruising in the hip area for a few days.

After collection, from either the blood or the bone marrow, the stem cells are carefully labelled and taken to the processing laboratory in the hospital. The stem cells are then frozen and placed in special bags before being stored in liquid nitrogen.

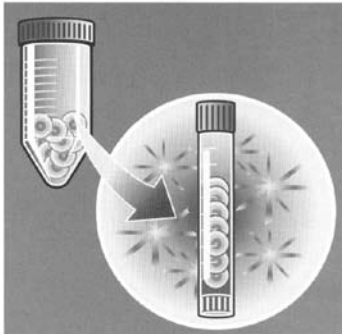


Figure 6 - Cryopreservation

A chemical called **DMSO** is mixed with the stem cells before freezing. DMSO prevents the water in the cells from forming ice crystals that would permanently damage the cells during the freezing process.

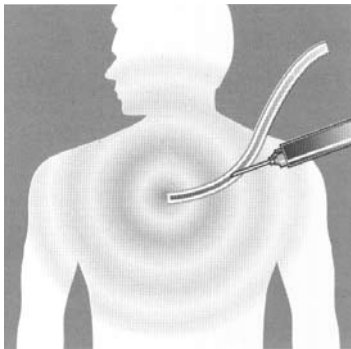
Stem cells can be stored for many years and therefore patients do not have to have the transplant immediately, although most probably would.

It is usually possible to collect the desired number and quality of stem cells from patients either from the peripheral blood or from the bone marrow itself. If, for whatever reason, this is not possible, your doctor will discuss the options that are available to you. It is almost always the aim to collect enough stem cells for two transplants, even though most patients only receive one.

Receiving the high-dose chemotherapy

After the stem cells have been frozen and stored, the next step is to come into the hospital to receive the high-dose chemotherapy followed by the transplant of stem cells. Although it can vary from patient to patient, you will be in hospital for approximately three to four weeks.

The high-dose chemotherapy is often referred to as 'conditioning' therapy and is given through the vein, usually via a HICKMAN® catheter.



If you do not have a HICKMAN® catheter already in place, you may have one put in either just before or as soon as you are admitted to hospital for the transplant.

The high dose of chemotherapy used is called melphalan, which is an effective drug in treating myeloma.

Figure 7 - High-dose chemotherapy

Before starting this high-dose chemotherapy, large amounts of fluid will be given to you through a drip, which aims to prevent any dehydration and kidney damage caused by the toxicity of the chemotherapy. If your kidney function is poor, the dose of chemotherapy may be adjusted.

You are likely to experience nausea and occasionally vomiting, as a side-effect of the high-dose chemotherapy. The severity of this can be greatly reduced with the use of appropriate anti-sickness drugs. It is important to let the nurses know if you are feeling sick so that they can give anti-sickness drugs as soon as possible.

Having your stem cells returned - the transplant

Within a day or so of completing the high-dose chemotherapy, the frozen bags of stem cells are brought to the ward, thawed in a warm water bath and given back as an intravenous drip or injection. This process, which takes on average about one hour, is relatively straightforward.

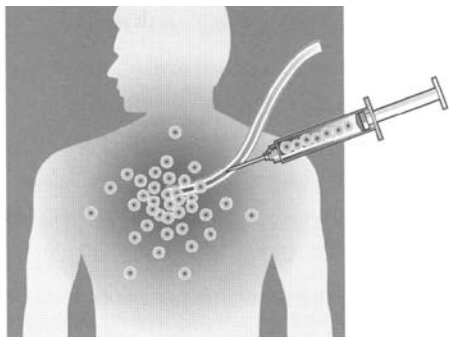


Figure 8 - Re-infusion

The most common temporary side-effects are caused by the DMSO and may include nausea and vomiting, abdominal cramping, feeling chilled and experiencing an unusual odour and taste of garlic or sweetcorn. In rare cases, the infusion may cause low blood pressure, a fast heart rate and shortness of breath. Medications are given before the infusion process to prevent or lessen some of the expected effects of DMSO infusion.

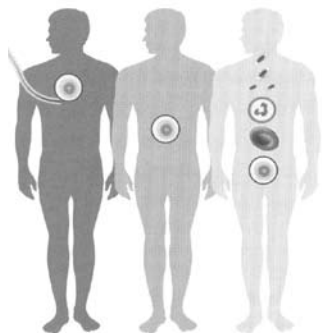


Figure 9 - Engraftment

Engraftment

Once the stem cells are put back into the blood stream, they travel to the bone marrow, where they settle and develop into new blood cells - a vital process known as **engraftment**.

The engraftment process signals the beginning of the period of immunosuppression and the need to stay in a clean environment such as a single room, or special bay for an average of 10 to 14 days. This is often referred to as the period of isolation.

During this time your body will go through the extraordinary and key process of making new blood cells from the transplanted stem cells.

Supportive care whilst in isolation

The period of time waiting for the new cells to grow can be daunting and difficult to face; it is probably the toughest period of the transplant process for the patient.

Until the new blood cells are produced and show up in your blood stream, you will be at risk from infections, **anaemia** and bleeding. Therefore, special precautions and supportive measures are necessary during this time.

Protection against infection

Until your white cell count rises, you will be vulnerable to infection. Several precautions are taken to help reduce this risk and you will be observed and monitored very closely during this time by the doctors and nurses to check for signs of infection.

Often these infections originate from your own body, not from your environment or another individual. They are termed 'opportunistic' infections and occur because your immune system is weakened.

You will be asked to bath or shower daily, wear clean clothes and use fresh towels and bedding each day.

Fresh fruits, vegetables and flowers may not be allowed in your room, as they can carry bacteria and fungi. Some hospitals recommend that you follow a special diet, which avoids foods that may cause stomach infections.

This diet is known as a 'clean diet' and should be discussed with you before admission so that you know which foods to avoid. Most hospitals will have a booklet or fact sheet on clean diets.

Your mouth will be more prone to infections after your transplant, so you should clean your teeth after meals and use any mouthwashes as directed by the nurses.

Antibiotics and drugs to help prevent bacterial, fungal and viral infections are prescribed, usually as tablets, so there can be a number of pills to take. If an infection does occur, you will need intravenous antibiotics. Occasionally infections can be very serious, sometimes life-threatening.

Visitors are usually allowed to come and see you when in isolation unless they have an infection themselves. Visitors will be asked to wash their hands and wear protective aprons when they come in.

Protection against bleeding and anaemia

Low levels of red blood cells cause anaemia and you may be at risk of bleeding because of low levels of platelets. Blood transfusions will help reduce the side-effects of anaemia and platelet transfusions will help reduce the risk of bleeding.

You will find that your mouth feels dry and your gums may bleed easily if your platelet count is low, so be gentle and use a soft toothbrush when you are brushing your teeth.

Before you receive blood or platelets they are treated to destroy any white cells in the blood products that can cause a type of reaction associated with blood transfusion after a stem cell transplant. This treatment is called 'irradiation' and it is important that you receive only 'irradiated blood products' following your transplant.

General measures and emotional support

You may experience some later side-effects of the chemotherapy, such as a sore mouth and diarrhoea. A sore mouth is often referred to as **mucositis**. This can vary from mild soreness of the mouth and taste changes, to being more painful, perhaps causing difficulty in eating and drinking.

Mucositis can be treated with pain medications and is a temporary problem, usually resolving within a few days. There are also medications available to treat and control diarrhoea, should this be a problem.

You will find that you lose your hair, which has sometimes only just started to grow back after previous treatment. This happens about two to three weeks after the chemotherapy has been given, but will start to grow back again in two to three months.

Many patients choose to have a wig fitted before they return home. There are a number of specialist suppliers and their details are available from your nurse.

In order to pass the time whilst you are in this isolation period you will usually have a phone and a TV in your room and will be allowed to bring in books, tapes, CDs - things to help keep you occupied. It may even be possible to use your computer and perhaps keep in touch with people by email, although this may not be possible in all centres.

It is common to feel a lack of concentration during this time, so it is a good idea to bring things in to do that are relaxing and that you can pick up and put down easily.

Exercise bikes may be available in some hospitals and using a bike or doing regular gentle exercises can help reduce the loss of muscle tone that can occur during this period of reduced activity.

Rarely, stem cells do not engraft well and this is apparent in prolonged low blood counts. In the event of this happening, treatment can be carried out with injections of growth factors (G-CSF) and in some cases a 'top-up' of stem cells may be given if they are available. There are a number of reasons for this including certain viral infections and side-effects of drugs used to treat some infections.

When your blood counts are high enough, you are free from signs of infection and generally well enough, you should be allowed to return home. Once at home, the recovery period can often last for months and can vary greatly, depending on the individual.

Supportive care and follow-up when you return home

The recovery time at home can be a challenging one. Attempts to get back to normal life have to be balanced against some possible physical and emotional difficulties that commonly occur during this time.

People often have a mixture of emotions when they leave hospital after a transplant. The excitement of going home and relief that the actual transplant is over, may be mixed with anxiety about coping at home and wondering how successful the treatment has been. This is a very normal reaction for which there is no miracle cure.

You may feel vulnerable and nervous about managing without the presence of nurses and doctors at hand. Make sure you have the correct telephone numbers of the hospital so you know whom to call if you are worried about anything.

Before you are discharged make sure you know which symptoms you need to look out for and report and are clear about any precautions you need to take to reduce the risks of infection.

The following pages provide a few guidelines and pointers to help you manage this recovery period when at home.

Treatment follow-up and appointments

For the first few weeks, it is important that any problems are picked up early and therefore you will need to attend the hospital for follow-up appointments. These appointments, in the outpatient's department, are often about once a week to begin with.

If you live a long way from hospital, or have difficulty travelling to your appointments, talk to the staff in the outpatients department as it may be possible to get hospital transport or help towards travel costs.

At these appointments your continuing recovery will be monitored and you will have your blood tested to check that your blood counts are getting back to normal.

Sometimes your blood counts recover more slowly and blood or platelet transfusions may be needed, which are usually given as a day patient. The doctors and nurses will offer advice about any aspect of your condition, so remember to report any new problems or raise any worries you have.

Tablets to help prevent bacterial, viral and fungal infection may be continued after high-dose therapy and stem cell transplantation for a period of time, usually about three months.

Other drugs that may be needed are anti-sickness drugs, supplements of electrolytes, such as potassium and magnesium and drugs that protect the stomach from ulcers.

Bisphosphonate therapy, to strengthen and protect the bones, is normally stopped during the transplant process. It usually continues to be given afterwards, either by tablet or intravenously, unless there is a specific reason for not receiving it.

Some months after a stem cell transplant, certain vaccinations to protect against infections may be necessary.

If needed, for at least one year after high-dose therapy and stem cell transplantation, you should receive only irradiated blood products, as described earlier.

The hospital may give you a card to carry in case of an accident, to help ensure only irradiated blood products are used. Some patients wear Medic Alert bracelets, particularly if they also have drug allergies, such as with penicillin.

When doctors are satisfied that your condition is stable and depending on local arrangements for sharing your care, you will go back to your local haematologist for routine appointments and monitoring.

Reducing the risk of infection at home

As already mentioned, it can take many months after the high-dose therapy and stem cell transplantation for your blood counts and therefore your immune system and energy levels to recover fully.

Because of this, you may need to take precautions at home and when you are out and about in the community for the initial period in order to reduce the risk of infection and to build up your strength.

Here are a number of do's and don'ts to help you recover at home:

Food and diet - Doctors or nurses will advise you regarding food restrictions and will tell you when to return to normal eating as your blood counts increase. Good common sense is essential with regard to what you should and should not eat.

Always remember to wash your hands before eating and keep your kitchen clean. Food should be cooked properly and eaten by the 'best before' or 'sell by' dates. You should buy from reputable stores and avoid foods that may have been left out for some time.

Personal hygiene - You should continue to have a daily bath or shower, wash your hands before eating, preparing food and after going to the toilet. You should use a clean towel every day and allow your towel to dry before you use it again.

If you have a HICKMAN® catheter in place, make sure you know how to care for it and what you should do if you suspect problems.

It is important to continue to keep your mouth clean and use any mouthwashes that are prescribed. You may find that it takes a few weeks before your sense of taste returns to normal. Inform your dentist that you have had a transplant before having any dental treatment.

Shingles - Some people may get shingles in the weeks following a transplant. Shingles is an infection that can begin as a painful sensation and rash, often on the chest or back. It can be treated with anti-viral drugs which should be started as soon as possible after shingles is diagnosed.

Pain and fatigue from shingles can sometimes go on for a few weeks or more, which can be difficult to cope with after going through so much treatment. Remember that it is a common set back which many patients face.

Out and about and socialising - When you first go home, it is often advised that you avoid crowded public areas, in which you are in a confined space with others (such as buses, trains, pubs and cinemas), to limit your chance of catching infections.

Visiting family and friends can be a good way to start getting out and about, so long as they are free from colds or flu.

Dust from building work, renovation or decoration may carry a fungus called 'aspergillus'. It is wise to suspend any work on your house until your doctor's approval.

Pets and gardening - Pets should never be allowed on the table or in areas where food is prepared. Do not handle cat litter trays or dog faeces, as they can be a source of infection. When gardening, wear gloves as soil can harbour organisms that could be harmful.

Coping with fatigue

It is normal to feel some degree of fatigue after having high-dose therapy and stem cell transplantation and this may continue for some time. People often worry that there is something wrong and are reassured to find that their fatigue is a normal and expected side-effect.

Fatigue can also be related to myeloma itself and prolonged fatigue can sometimes be because of this rather than the high-dose therapy and stem cell transplantation.

Talk to your doctor or nurse about the fatigue you are experiencing as there may be ways of improving energy levels through treatments or advice on lifestyle such as diet and exercise.

There is no time limit on fatigue and each individual is different and recovers in his / her own time, so try not to compare yourself with other patients you see in the clinic.

Work, driving and holidays

You may be uncertain about when you should return to work. It may be possible to go back to work sooner if you have a sitting or desk job, or if you are able to start back on a part-time basis. Again, talk to your doctor or nurse about when it is advisable to return to work, or if you have concerns about any risks there may be within your work or workplace.

It is usually safe to start driving as soon as you feel well enough, but again do check with your doctor.

It is not advisable to plan a holiday outside the UK for six months after high-dose therapy and stem cell transplantation. You should always inform your doctor about any travel plans prior to booking a trip and discuss issues such as safety to fly and vaccinations.

When you are on holiday, it is important to use adequate skin protection and avoid sunburn as your skin may be much more sensitive after **chemotherapy** treatment.

Your emotions and relationships

Treatment with high-dose therapy and stem cell transplantation from start to finish can put an enormous physical, emotional and financial strain on the whole family. It is not uncommon to feel low and depressed and for there to be an impact on family life.

There are however a number of things that can be done to help you and your family through this difficult and challenging time.

Seek practical and financial help if you feel you need it. You may be able to talk to your family about your problems but you may also find it useful to see people outside your immediate family, such as friends, health care professionals and support organisations. Details of support organisations that can provide information and advice are listed at the end of this Infoguide.

A patient support group is another way of sharing your experiences and gaining advice and support by listening to the experiences of others. Complementary therapies such as relaxation, visualisation and art therapy may be helpful.

For details of your nearest myeloma support group, contact the **Myeloma Infoline on 0800 980 3332**.

Physical relationships are often affected by having a diagnosis of myeloma and resultant treatment. It is usually safe for you to have sexual intercourse, unless your doctor advises against it. However, if your white cell count is low, it is advisable to use a condom to reduce the risk of infection.

Women may experience vaginal dryness if their hormone levels are affected by the high-dose chemotherapy. Lubricating creams may help and hormone replacement therapy may be appropriate for some women.

It is common to feel a loss of sex drive for some months after high-dose therapy and stem cell transplantation, perhaps due to the treatment, but also because of the emotional effects and the changes in body image which can occur.

Try to discuss these problems with your partner to avoid feelings of hurt or frustration. Specialist help is available, so do talk to your doctor or nurse if you need advice on sexual problems.

Adjusting to life after having high-dose therapy and stem cell transplantation is not always easy. There is often a balance to be struck between coping with the effects of the treatment whilst trying to return to doing some of the things you have been unable to do for a while.

It is important to regain some 'normality' in your life. However it may be necessary to modify the type or amount of work you do. It may be an opportunity to make some beneficial changes to your life and for some it can be a positive turning point.

If you would more information about many of the things you may have to cope with in living with myeloma, please see *Living with Myeloma – Your Essential Guide*. Myeloma UK also has a range of Infoguides on specific issues such as mouthcare, nutrition and diet, fatigue, travelling and travel insurance. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332**.

Further treatment and measuring response to treatment

In order to consider whether further treatment after high-dose therapy and stem cell transplantation is required, it is important to find out what the response has been.

A number of specific tests including regular blood and urine tests, bone marrow biopsies and occasional X-rays or scans are used to measure response to treatment.

Response to high-dose therapy and stem cell transplantation is often categorised using the response criteria shown in the tables below.

Table 1 - Measuring response to treatment

Table 1a European Group for Blood and Marrow Transplantation (EBMT) response categories 2001

Treatment outcome	Definition
Complete remission response (CR)	No detectable paraprotein in the blood and normal percentage of plasma cells in the bone marrow or absence of myeloma cells in the bone marrow
Very good partial response (VGPR)	Greater than 90% decrease in paraprotein since start of treatment
Partial response (PR)	Greater than 50% decrease in paraprotein
Minimal response	More than 25% but less than 50% decrease in paraprotein
Stable disease (SD)	<25% decrease in paraprotein but not increasing
Progressive disease (PD)	Greater than 25% increase in paraprotein or detection of new bone abnormalities

Table 1b International Myeloma Working Group (IMWG) uniform response criteria 2006

Treatment outcome	Definition
Stringent complete response (SCR)	CR as defined below plus normal free light chain ratio, absence of clonal cells in bone marrow
Complete response (CR)	≤ 5% plasma cells in bone marrow, no detectable paraprotein
Very good partial response (VGPR)	90% or greater reduction in blood and urine paraprotein
Partial response (PR)	≥ 50% reduction of paraprotein in blood and 24 hr urinary paraprotein by ≥ 90%
Stable disease (SD)	Not meeting criteria for CR, VGPR, PR or progressive disease

If further treatment is recommended or required after the initial transplant, it falls into two main categories:

- Treatment which aims to prolong response
- Treatment for myeloma that has returned (relapsed) more quickly than had been expected

Treatment to prolong response

Maintenance treatment aims to prolong the period of response, whether in remission or plateau after high-dose therapy and stem cell transplantation. Interferon and steroids, such as dexamethasone, can be used as maintenance treatments.

Unfortunately not every patient will benefit from these treatments and any benefits will have to be balanced against any side-effects that may occur and side-effects can be significant with both steroids and interferon.

More recently thalidomide has been used as maintenance treatment and early results are very encouraging. Other new treatments such as Velcade and some types of vaccines are being considered as potential maintenance treatments in ongoing clinical studies.

Tandem stem cell transplantation means that a patient has two planned stem cell transplants, usually within six months of each other. Stem cells will be collected for both transplants and approximately half will be used for the first transplant while the other half will remain frozen until required for the second one.

Emerging evidence from clinical studies suggests that it is possible that tandem transplants may, in some patients, improve response rates and offer increased survival. However, this evidence is very limited and therefore the potential benefits are still not known for certain.

Such benefits need to be weighed up against the potential risks involved and the effect on quality of life that having two transplants within a few months may have.

Further clinical studies are ongoing and results from these will help doctors understand the true potential of the tandem transplant option.

Allogeneic transplantation – for a small group of patients an allogeneic transplant, usually a ‘mini’, may be offered. This is a transplant from another person, normally a brother or sister.

These mini-transplants are often given after initial treatment with high-dose therapy and autologous stem cell transplantation to try to achieve a greater anti-myeloma effect. Allogeneic transplantation will be described in more detail on page 37.

Treatment for myeloma that has relapsed

Despite the excellent potential response to high-dose therapy and stem cell transplantation, it is not considered a curative treatment and relapse almost always occurs. This is understandably a difficult and traumatic time for patients, especially when relapse occurs sooner than was hoped for.

The time of relapse will differ from patient to patient and many factors will determine when relapse might occur. The amount of time in remission or plateau before relapse and previous sensitivity to drugs and regimes, are factors which are taken into account when deciding on further treatment options.

There are a number of effective treatments that may be offered if myeloma has relapsed. These include:

Standard chemotherapy

It is possible to receive more chemotherapy, alone or in combination. It can be given as an injection or in tablet form and may be the same as the first chemotherapy used or a different type, depending on the original degree of response and timing of the relapse.

A second transplant

Having a second transplant at the time of relapse is different to a tandem transplant, where two transplants are planned at the outset. A second transplant may be offered if relapse occurs and often enough stem cells will be stored for use in this event.

A course of chemotherapy is given before the second transplant is performed, in order to reduce any residual myeloma. The option of a second transplant will depend on the timing of the relapse, age, previous treatment given and general fitness to undergo the procedure. Again, decisions for the patient will depend on the potential benefits versus the risks and the impact it may have on their quality of life.

Other treatment options

Steroids, often high-dose dexamethasone, may be given alone or with chemotherapy. Newer treatments, such as thalidomide may be offered and again this can be given alone or with steroids and chemotherapy.

Other new treatments and / or clinical studies may be available. These include Velcade, Revlimid and Arsenic Trioxide. It is important to understand that not every new treatment being studied may be suitable, so discussion with your doctor is very important in order to find out what treatment options are available for you.

As has been shown already, high-dose therapy and stem cell transplantation using the patients own cells is not considered curative and the myeloma almost always comes back.

Allogeneic transplantation

In order to try to lengthen remission periods and offer a chance of long-term disease free survival, allogeneic stem cell transplantation may be a potential option for a small group of younger patients.

Allogeneic transplants have important differences compared with autologous stem cell transplants, both in the potential benefits and the risks involved.

In addition, it is important to understand that not only are there significant differences between an allogeneic stem cell transplant and an autologous stem cell transplant, but there are also important differences between the different types of allogeneic transplant that are used, both in terms of the transplant process and the risks involved.

What follows is an overview of what an allogeneic transplant is and the different types that are available. A summary of the main advantages and disadvantages of each are outlined on page 49.

What is an allogeneic transplant and what are the different types available?

All types of allogeneic transplants involve taking stem cells from either the bone marrow or the blood of one person (the donor) and giving them to the patient (the recipient).

Allogeneic transplants aim to use the immune system of the donor to help fight against myeloma in the patient. The donated stem cells are transplanted into the patient where they mature into functioning cells of the immune system. They can then potentially attack any myeloma present – this effect is known as '**graft-versus-myeloma**' and is thought to be responsible for the lower rate of relapse often seen when compared with an autologous transplant.

The donated cells need to be a suitable match and the donor is usually a sibling. Allogeneic transplants are possible from an unrelated donor, but carry much higher risks as there is more incompatibility between the patient and donor. They are sometimes referred to as a volunteer unrelated donor transplant or VUD for short and are not commonly carried out for myeloma patients.

The main disadvantage of an allogeneic transplant is the risk of **graft-versus-host** disease (GVHD), which is a potentially life-threatening condition. This can happen because the donated cells not only attack the myeloma cells but can also destroy the patients own body tissue.

The reason for this is that the donated cells, although a match, may still recognise the patient's body as foreign. GVHD is a major problem and is one of the reasons why allogeneic transplants have a higher mortality rate than autologous transplants.

In order to reduce the risk of GVHD and prevent rejection of the new cells, it is necessary to receive **immunosuppressive drugs** such as cyclosporin.

As patients have a greater degree of immunosuppression when undergoing an allogeneic transplant than they have for an autologous stem cell transplant, there is a higher risk of serious infections occurring.

If a transplant is carried out using an identical twin as the donor it is called a **syngeneic stem cell transplant**. Syngeneic transplant means that the match is likely to be perfect so there is little risk of graft-versus-host disease. However this means that there is unlikely to be any graft-versus-myeloma effect either.

In order to reduce the risks associated with an allogeneic transplant, while still holding on to the benefits of giving donor cells, a newer type of transplant has been developed. This is the reduced-intensity conditioned transplant or mini-allogeneic transplant, which involves giving a lower dose of chemotherapy than would be used for a standard allogeneic transplant.

Donors (normally a sibling) usually donate their stem cells from the peripheral blood rather than the bone marrow. Additional infusions of white blood cells (lymphocytes) from the donor may also be given if needed at a later date, in order to continue the graft-versus-myeloma effect. Care must be taken however, as infusions of these white blood cells can also trigger GVHD.

The lower doses of chemotherapy used mean that mini transplants are often safer than standard allogeneic transplants and are therefore suitable for more patients. Mini-transplants are often planned after (within six months of) an autologous stem cell transplant to give greater anti-myeloma effect. This type of transplant is still being investigated in clinical studies, so there is no long-term data regarding its safety and effectiveness.

The decision to have an allogeneic transplant of any type is not easy to make, as the treatment can be lengthy and complex and the potential problems can seem daunting. However, each individual must ultimately balance the risks and side-effects against the potential benefit of increased duration of response.

Detailed discussion and consideration of all the factors involved is important. This discussion may involve the doctor, nurse, family, Myeloma UK and other patients who have been through such a transplant. A second opinion from another transplant specialist may also be helpful and can usually be arranged through your own myeloma specialist.

What will the donor go through?

If a patient has a sibling, they have a one in four chance of the sibling being a suitable match. In order to find out if a sibling is a match, the sibling has a blood test to determine their tissue type. This is then compared to the tissue type of the patient.

If the sibling is a match and agrees to donate their cells, they will need to attend the hospital to discuss stem cell donation with the transplant team. Medical examinations and tests, such as chest X-rays and tests of the heart function, will be performed in order to make sure that they are fit enough to donate their cells safely.

Sibling donors will usually give stem cells from the blood rather than from the bone marrow and will only have injections of growth factor (G-CSF) to mobilise their stem cells. After about four or five days of G-CSF injections they will have their cells collected on the apheresis machine.

The cells will be collected over one or two days, so very little time off work should be needed. If cells are collected from the bone marrow, this will involve an approximate two-night stay in hospital, as outlined on page 17 – collection and storage of stem cells.

Collection of cells from a donor usually takes place shortly before the patient comes into hospital to receive the chemotherapy for the transplant procedure.

The future

High-dose chemotherapy and stem cell transplantation is now the treatment of choice for most patients who have myeloma. Studies such as MRC Myeloma IX continue to compare the effectiveness of high-dose therapy and stem cell transplantation with conventional chemotherapy and also look at the use of maintenance treatments such as thalidomide.

It is thought that if a strong remission is achieved with high-dose therapy and stem cell transplantation, it can act as a platform upon which other anti-myeloma treatments can be continued in order to prolong the remission. Such treatments include thalidomide, which works in a different way to chemotherapy.

Research is also taking place to determine which patients respond best to high-dose therapy and stem cell transplantation. An increased understanding of how an individual patient may respond to treatment will allow doctors to prescribe a treatment plan suited to their own particular disease profile.

Mini-allogeneic transplants continue to be researched and developed and are also part of the MRC Myeloma IX study. As this study progresses, there will be more long-term data available to determine the effectiveness and safety of these types of transplants.

An important aspect of mini-allogeneic transplant research is to determine the best way to use donor lymphocytes, in order to maximise their effectiveness against the myeloma, without increasing the risk of graft-versus-host disease.

Research is continually taking place to make all types of transplant as safe and effective as possible. Many advances in supportive care are taking place, such as more effective antibiotics, anti-sickness medication, better fatigue management and multi-disciplinary support. This may not only make transplants safer, but may also improve quality of life both during and after the procedure.

For more information on clinical studies, please see Myeloma UK's Infoguide *Clinical Studies* and *MRC Myeloma IX*. To order your free copies, contact the **Myeloma Infoline on 0800 980 3332**.

Questions for your doctor / medical team

When meeting your doctor / medical team, it is often difficult to remember every question you would like to ask.

Below are some sample questions that you might want to ask in order to fully understand what high-dose therapy and stem cell transplantation means for your individual situation.

- What are the objectives of the treatment?
- What exactly does this treatment involve?
- How long will the entire treatment take (from referral to recovery)?
- What are the alternatives to this treatment?
- How ill might I feel before, during and after treatment?
- What about side-effects? What will they be? How long will they last? What is the likelihood of getting them? Are they serious? Life-threatening? What can be done to treat side-effects?
- Why are you recommending this treatment for me?
- In the event of relapse, what would the options be, recognising that these may change in the future?
- Which doctor will be responsible for my care whilst I am having the transplant? Will I see my consultant during this time?
- How can I best prepare myself for a transplant?

Medical terms explained

Allogeneic stem cell transplant: A procedure in which stem cells or bone marrow from a compatible donor (usually a sibling) are collected, stored and given to the patient after high-dose chemotherapy treatment.

Anaemia: A reduction in the number of red blood cells or the haemoglobin that they contain. This reduces the ability of the blood to supply oxygen to the body, causing fatigue and weakness.

Apheresis: A procedure in which stem cells are collected from the blood using a machine which separates them out, returning the remainder of the blood components to the donor. As stem cells are within the white blood cell components, it is also sometimes referred to as leukapheresis.

Arsenic Trioxide: A potential new treatment for myeloma that is undergoing clinical studies.

Autologous stem cell transplant: A procedure in which a patient's own stem cells are collected, stored and then given back following high-dose chemotherapy.

Bisphosphonates: A type of drug that binds to the surface of bone where it is being resorbed (or destroyed) and protects against osteoclast activity. In myeloma, bisphosphonates are used to treat bone disease and a high level of calcium in the blood (hypercalcaemia).

Chemotherapy: Treatment with potent drugs intended to kill cancer cells. Chemotherapy can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

DMSO: Dimethyl sulfoxide, a colourless chemical used in the storage of stem cells.

Engraftment: The process by which the transplanted stem cells travel to the recipient's bone marrow, where they will begin to grow and develop into new blood cells. During this time the number of red cells, white cells and platelets in the blood may be lower than normal.

Erythropoietin (EPO): A hormone produced by the kidneys that controls red cell production - a synthetic form of EPO can be used to treat anaemia.

Graft-versus-host disease: A complication of allogeneic transplants whereby the donor cells (the graft) recognises the recipient's body (the host) as foreign and mounts an attack. This can cause skin, liver and gut problems and is usually treated with steroids.

Graft-versus-myeloma: A beneficial effect of an allogeneic transplant which may result from the donor cells mounting an attack on the recipient's myeloma cells.

Growth factor: A protein that stimulates the development and growth of stem cells. Granulocyte colony stimulating factor (G-CSF) is a growth factor used to stimulate the growth of stem cells before collection

HICKMAN® catheter: A catheter (tube) that is inserted into a large vein in the neck and then tunnelled under the skin. A HICKMAN® catheter can be kept in place for several months and is necessary to be able to give the chemotherapy and other medications required when having a stem cell transplant.

Hypercalcaemia: A raised level of calcium in the blood. It can occur if the bone is broken down faster than the body can cope with. It can be controlled quite quickly once it is detected but may require treatment in hospital to do so.

Immunosuppression: Suppression of the immune system, which can mean an increased risk of infection.

Immunosuppressive drug: Medication given to suppress the patient's immune system and help prevent rejection of donor stem cells.

Mini-allogeneic transplant: Also called mini-allo or reduced intensity conditioning transplant. A type of allogeneic transplant that uses lower doses of chemotherapy than a standard allogeneic transplant and avoids some of the side-effects and risks associated with higher dose chemotherapy.

Mobilisation: The process by which the number of stem cells in the bone marrow are increased, so that the cells 'spill over' into the blood stream and can be collected and stored.

Mucositis: Inflammation of the lining of the digestive tract, often seen as soreness of the mouth.

Neutropenia: A low number of neutrophils in the blood, which are white blood cells that fight infection.

Plasma cell: Normal plasma cells are found in the bone marrow and produce antibodies to fight infection. In myeloma, the malignant plasma cells produce large amounts of a single abnormal antibody that does not fight infection.

Revlimid (also known as lenalidomide): Chemically similar to thalidomide, Revlimid is an immunomodulatory drug (IMiD) that works by affecting and modifying the immune system. The exact way in which IMiDs work is not yet fully understood but, like thalidomide, it is thought to have multiple mechanisms of action.

Standard chemotherapy: Conventional dose chemotherapy treatment, given alone or in combination with other chemotherapy drugs and / or steroids.

Syngeneic transplant: An allogeneic transplant which uses a patient's identical twin as their donor.

Thalidomide: A drug that has shown to be effective in treating myeloma. It is being used and studied at all stages of disease. This drug was originally withdrawn in the 1960s because of the birth defects it caused when taken during pregnancy. Its prescription is now subject to a strict risk management programme.

Thrombocytopenia: A low number of platelets in the blood, which can lead to bruising and abnormal bleeding.

Tandem transplant: A planned double transplant procedure. It can be two autologous stem cell transplants or an autologous followed by a mini-allogeneic transplant.

Velcade (also known as bortezomib): The first of a new type of cancer drugs called proteasome inhibitors. The proteasome is a large structure inside all cells that controls cell growth and function. It works by breaking down the many different proteins that control the cell's lifecycle. Velcade works by blocking the proteasome, which can lead to slowed cell growth or cell death.

Treatment guidelines

British Committee for Standards in Haematology (BCSH)

www.bcshguidelines.com

The BCSH provides haematologists with up-to-date advice on the diagnosis and treatment of myeloma. Its website contains a range of position papers and guidelines relevant to those affected by myeloma, including the *Guidelines on the Diagnosis and Management of Multiple Myeloma* and the *Guidelines on the use of Colony Stimulating Factors in Haematological Malignancy*.

National Institute for Health and Clinical Excellence (NICE)

www.nice.org.uk

NICE has guidelines on improving outcomes in haematological cancers and guidance for the public on haematological cancer services. Details of criteria used for accreditation of transplant centres available.

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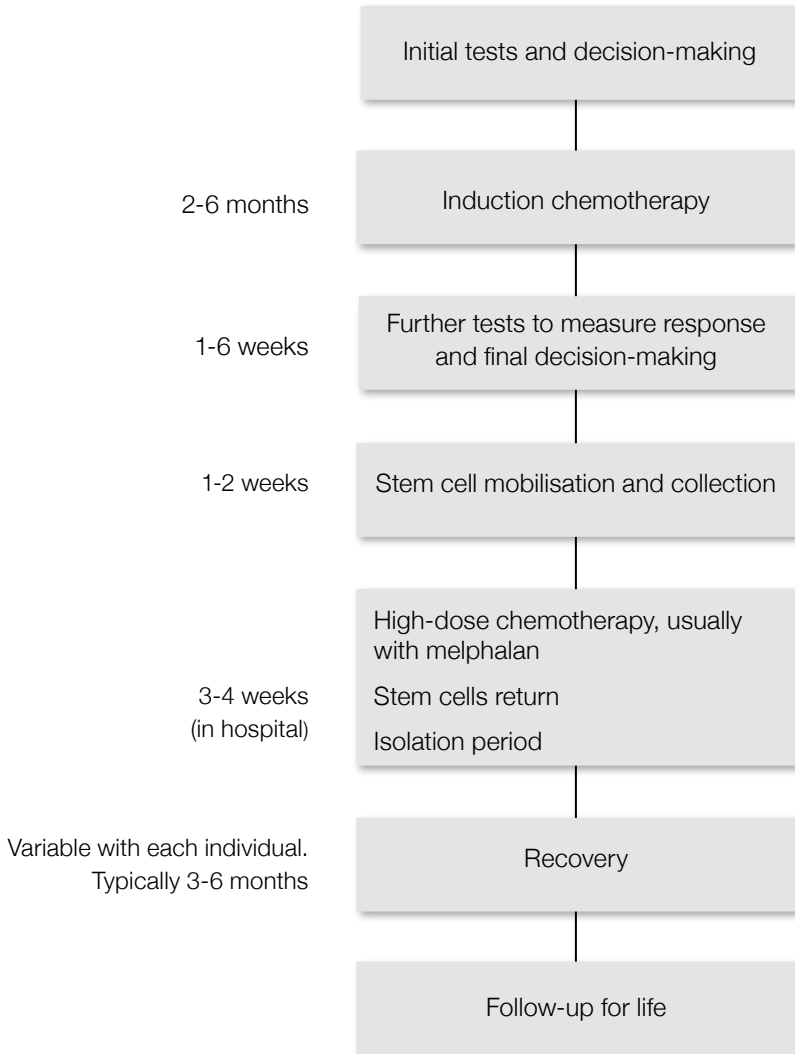
Appendix one: Common chemotherapy combinations used in myeloma

Combination	Drugs	Route
MP	Melphalan and prednisolone	Oral
C-weekly	Cyclophosphamide	Oral
ABCM	Adriamycin, BCNU, cyclophosphamide, melphalan	IV and oral
VAD	Vincristine, adriamycin, dexamethasone	IV and oral
VAMP	Vincristine, adriamycin, methylprednisolone	IV
C-VAMP	Cyclophosphamide, vincristine, adriamycin, methylprednisolone	IV
Z-Dex	Zavedos, dexamethasone	Oral
T-VAD	Thalidomide, vincristine, adriamycin, dexamethasone	IV and oral
C-VAD	Cyclophosphamide, vincristine, adriamycin, dexamethasone	IV and oral
CTD	Cyclophosphamide, thalidomide, dexamethasone	Oral

Appendix two: Advantages and disadvantages of various transplants

Transplant type	Advantages	Disadvantages
Autologous	High level of excellent remissions. At least as good as standard chemotherapy regarding overall survival and probably better in some patients. Low risk of life-threatening complications. No need for a matched donor.	Disease will usually recur. More toxic than chemotherapy alone. Risk of contaminated cells. Patients who benefit not clearly identified.
Tandem autologous	Same as for single autologous.	As yet, no clear benefit over single.
Standard allogeneic	Lower relapse rates and potential for long-term remission because of potential graft-versus-myeloma effect. Graft not contaminated with myeloma cells.	Higher mortality rates. Need for a matched donor. Risk of graft-versus-host disease, which can be life-threatening. Takes longer to recover immune function, higher risk of infection. Age limit.
Mini-allogeneic	Less toxic than standard allogeneic. Suitable for more people, as higher age cut off. Donor lymphocytes may increase graft-versus-myeloma effect.	Higher risks than with autologous transplant. Risks of GVHD. Risks are unpredictable. Still has age limit. No long-term data available.
Syngeneic	Contain no tumour cells. Less risky than other allogeneic procedures.	Twins are rare. No graft-versus-myeloma effect likely.

Appendix three: Flow chart of treatment time frame



Further information and useful organisations

Anthony Nolan Bone Marrow Trust

www.anthonynolan.org.uk

020 7284 1234 (Donor department)

The Anthony Nolan Trust provides lifesaving donors for patients in need of a bone marrow transplant. It runs one of the largest register of donors in the world. Anyone wishing to be a bone marrow donor should contact the donor department.

British Red Cross

www.redcross.org.uk

0870 170 7000

Volunteers assist with a range of local services – including care in the home, transport and medical loans – to help those with health issues lead a full and independent life.

Cancerbackup

www.cancerbackup.org.uk

0808 800 1234 (Monday-Friday, 9am-8pm)

Its helpline is staffed by trained oncology nurses who provide information and support to people affected by cancer. Cancerbackup publishes a wide range of patient information.

Citizens Advice Bureau (CAB)

www.nacab.org.uk

CAB offers free, independent and confidential advice about debt and consumer issues, benefits, housing, legal matters and employment. Check your local telephone directory or the internet to find your nearest branch.

Crossroads and Macmillan Cancer Relief

www.crossroads.org.uk

0845 450 0350 (Monday-Friday, 9am-5pm)

Crossroads, working with Macmillan Cancer Relief, employs care attendants whose role is to relieve the family carer by giving them a break from their caring responsibilities.

Institute for Complementary Medicine (ICM)

www.icmedicine.co.uk

020 7237 5165 (Monday–Friday, 10am–5pm)

ICM provides the public with information about all aspects of complementary medicine.

ICM administers the British Register of Complementary Practitioners and provide details of local registered practitioners of various complementary therapies.

Leukaemia CARE

www.leukaemiacare.org.uk

0800 169 6680 (24hrs)

Its Care Line is staffed 24 hours a day, 7 days a week by trained volunteers who offer befriending, support and information on leukaemia and other blood disorders, including myeloma. Leukaemia CARE also offers discretionary financial assistance.

Leukaemia Research

www.lrf.org.uk

020 7405 0101 (Monday-Friday, 9am-5pm)

Leukaemia Research funds research into leukaemia and related blood disorders.

It publishes patient information about myeloma and stem cell transplantation.

Macmillan Cancer Support

www.macmillan.org.uk

CancerLine 0808 808 2020 (Monday-Friday, 9am-6pm)

The CancerLine is staffed by specialist advisors who provide information, practical and emotional support to those affected by cancer. Macmillan's other services include Macmillan nurses and patient grants, as well as access to over 750 cancer self-help groups.

Medic Alert

www.medicalert.org.uk

0800 581 420 (Monday-Friday, 9am-5pm)

Medic Alert provides a life-saving identification system for individuals with hidden medical conditions.

National Blood Transfusion Service (NBS)

www.blood.co.uk

0845 7711 711 (24-hour donor helpline)

Potential donors should phone NBS or check its website for details of the nearest donor sessions.

NHS Direct / NHS24

www.nhsdirect.nhs.uk

In England, Northern Ireland and Wales call NHS Direct on 0845 46 47

In Scotland call NHS24 on 08454 24 24 24

Staffed by trained medical professionals, it provides 24-hour access to information on all aspects of health and healthcare.

Princess Royal Trust for Carers

www.carers.org

020 7480 7788 (Monday-Friday, 9am-5pm)

It provides information, advice and a range of support services for carers, including an extensive network of independently managed Carers' Centres across the UK.

Relate

www.relate.org.uk

0845 130 4016 (Monday-Friday, 9am-5pm)

Relate offers a confidential counselling service to couples or individuals experiencing difficulties in their relationship. Relate provides support face-to-face, by phone and through its website.

With Myeloma UK you can...

Call our Myeloma Infoline on 0800 980 3332

You will immediately access information and support relating to all aspects of myeloma. Your call will be answered in confidence by Myeloma Information Nurse Specialists who are supported by medical and scientific advisors. Lines are open Monday to Friday, 9am to 5pm, and are free to phone from anywhere in the UK. From outside the UK call +44 131 557 3332 (charged at normal rate).

Contact us by email

If you have a specific question about any aspect of myeloma, treatment or living with myeloma, you can also contact our Myeloma Information Nurse Specialists by email at askthenurse@myeloma.org.uk

Order our free patient information

Myeloma UK has a range of Essential Guides, Infoguides and Infosheets which give information on myeloma and related disorders, providing details of treatment options and disease management. You will find a list of the information available from us at the back of this Infoguide.

Attend our Patient and Family Myeloma Infodays

These are full-day meetings, where you can learn about the latest in the treatment and management of myeloma from a panel of experts. They are also a valuable opportunity to meet others affected by myeloma.

Subscribe to *Myeloma Matters*

The only myeloma-specific newsletter available in the UK, *Myeloma Matters* offers a fantastic range of features, articles and stories to help you keep abreast of the latest developments in treatment and research.

Visit our website - www.myeloma.org.uk

Developed to provide immediate, 24-hour access to information about myeloma and related disorders to individuals affected by the disease and to the people caring for them.

We need your help

Each year, Myeloma UK sends Infoguides and Infosheets to nearly 10,000 patients and their families, and helps thousands more through providing services such as the Myeloma Infoline and Patient and Family Myeloma Infodays.

That is why we need your help

We depend on the support and generous donations from people like you to provide these important services which are available free to myeloma patients, their families and carers.

Will you help us to help others?

- £5 will pay for an Infopack to be sent to help one more patient
- £20 will allow one of our highly trained Myeloma Information Nurse Specialists to help two callers on our Myeloma Infoline
- £50 will pay for a family of three to attend a Myeloma Infoday
- £250 will pay for 2,000 patient information Infosheets

Simply choose the amount that is right for you, or, if you prefer, choose an amount of your own. To donate you can either post your donation (by cheque or CAF), use your credit card to donate by telephone or use the Myeloma UK website www.myeloma.org.uk

We can make your money go further if you are a UK taxpayer. If you pay tax at the basic rate, we can claim money back for every pound you donate. For example, if you donate £10 then we are able to claim back £2.80, (£2.50 after April 2008) so your donation becomes £12.80 (£12.50 after April 2008). This extra comes from the taxman and doesn't cost you anything. This process is called Gift Aid.

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Other information available from Myeloma UK

Myeloma Infopack

The Myeloma Infopack contains general information about myeloma, treatment options and disease management. It also has information about Myeloma UK and the range of services available to those affected by myeloma.

Booklets

Myeloma – Your Essential Guide

Living with Myeloma - Your Essential Guide

Infoguides

Balloon Kyphoplasty

Bone Disease and Bisphosphonates

Chemotherapy

Clinical Studies

MRC Myeloma IX

Percutaneous Vertebroplasty

Revlimid

Serum Free Light Chain Assays

Thalidomide

Velcade

Infosheets

Infosheet topics include:

Diet and Nutrition; Erythropoietin; Fatigue; Growth Factors; Managing Your Finances (including Benefits); Mouthcare; Pain; Peripheral Neuropathy; Plasmapheresis; Radiotherapy; Steroids; Support Groups; The Kidney; Travel Insurance; Travelling.

Leaflets

Myeloma – An Introduction

There are a number of conditions closely associated with myeloma. Myeloma UK has information available on AL amyloidosis, Waldenström's macroglobulinaemia and MGUS.

To order these free publications please contact Myeloma UK.

Myeloma Infoline: 0800 980 3332 (freephone number) or 0131 557 3332

www.myeloma.org.uk email: myelomauk@myeloma.org.uk

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All Myeloma UK's publications are reviewed by patients and healthcare professionals prior to publication.

Myeloma Infoline 0800 980 3332

www.myeloma.org.uk



For more information or to access any of the information and support services listed, contact Myeloma UK

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