MyelomaUK

High-dose therapy and autologous stem cell transplantation

Treatments and tests Infoguide

This Infoguide has been made possible thanks to the generosity of Myeloma UK supporters.

To find out how you can support our vital work call **0131 230 0429** or email **fundraising@myeloma.org.uk**

We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you.

Call the Myeloma Infoline on

0800 980 3332

Email Ask the Nurse at

AskTheNurse@myeloma.org.uk

Visit our website at

myeloma.org.uk

Contents

You will find a definition of the terms highlighted in **bold** throughout this booklet in the 'Medical terms explained' section on page 46.

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.

This Infoguide is intended for a UK audience.
It therefore may not provide relevant or accurate information for a non-UK setting.

Myeloma – an overview

Myeloma is a type of cancer arising from plasma cells that are normally found in the bone marrow. Plasma cells are a type of white blood cell which form part of the immune system.

Normal **plasma cells** produce different types of **antibodies** to help fight infection. In myeloma, the plasma cells become cancerous (sometimes called **malignant**) and release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. It is often through the measurement of paraprotein that myeloma is diagnosed and monitored.

Myeloma affects multiple places in the body (hence why it is sometimes referred to as 'multiple myeloma') where **bone marrow** is normally active, such as the bones of the spine, pelvis, rib cage and the areas around the shoulders and hips.

Most of the complications and symptoms of myeloma are caused by a build-up of the cancerous plasma cells (often called myeloma cells) in the bone marrow and the presence of paraprotein in the body.

Common problems in myeloma include bone pain, bone fractures, fatigue, frequent or recurrent infection and kidney damage.

Myeloma is highly treatable in the majority of cases. Treatment is aimed at controlling the disease, relieving the complications and symptoms it causes, and extending and improving the **quality of life**.

Treatment for myeloma is often most effective when two or more drugs, with different but complementary mechanisms of action, are given together. Treatment is made up of cycles of drugs. Each cycle consists of drugs given in a pattern over a number of weeks. A series of treatment cycles is referred to as a course or line of treatment.

While there are many effective treatments for myeloma, unfortunately it is currently incurable. This means that even after successful treatment has

provided a period of **remission** or stable disease, the myeloma will return. This is called a **relapse**.

The causes of myeloma are not fully understood but it is believed to be caused by an interaction of both genetic and environmental factors.

Key facts

- There are approximately 5,800 people diagnosed with myeloma every year in the UK
- There are over 24,000 people living with myeloma in the UK at any one time
- Myeloma is the third most common type of blood cancer, and accounts for 2% of all new cancer cases diagnosed each year
- Although more common in older people, around a quarter of myeloma patients are diagnosed under the age of 65

What are stem cells?

There are various types of stem cell, but when talking about transplantation in myeloma, we are referring to blood stem cells (also called haematopoietic stem cells).

Blood **stem cells** exist in the bone marrow and can divide and develop into the three main types of cell found in the blood: **red blood cells, white blood cells** and **platelets** (see Figure 1). Each of these cells perform essential functions in the body:

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

It is the unique ability of blood stem cells to divide into blood cells and the fact that they can be collected safely that makes **high-dose therapy** and **autologous stem cell transplantation** (HDT-ASCT) a treatment option.

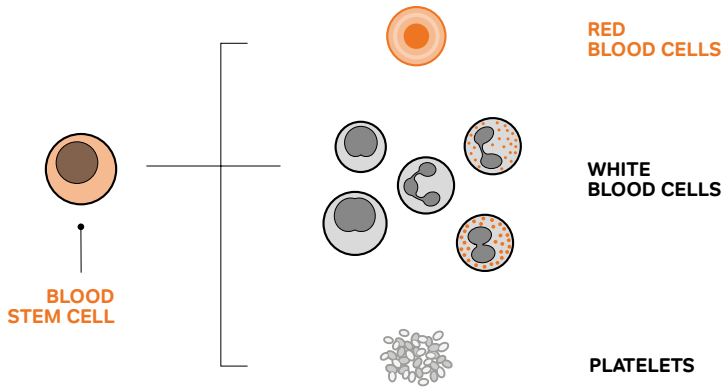

Figure 1. Blood cell development from stem cells

What is HDT-ASCT?

Initial treatment for the majority of newly diagnosed myeloma patients involves the use of combinations of different anti-myeloma treatments. These combinations, which are given in relatively low doses, provide an effective way of treating myeloma.

However, a major drawback of treatment, particularly with **chemotherapy** drugs, is the inability to give high doses safely. This is because high doses are very toxic to the blood-forming stem cells in the bone marrow and severely affect blood cell production. This results in **blood counts** falling to dangerously low levels, causing potentially life-threatening complications.

HDT-ASCT provides a solution to this problem. It involves giving high doses of chemotherapy to kill the myeloma cells and then giving stem cells to the patient to 'rescue' the bone marrow. This allows the bone marrow to recover and blood cell production to continue.

Therefore, when HDT-ASCT is used, more myeloma cells can be killed than would be possible with lower doses of chemotherapy.

This increases the likelihood of a longer remission or **plateau** and a better quality of life. However, it is worth noting that myeloma is a very individual cancer and each patient's myeloma has its own distinct characteristics, which may affect treatment outcomes.

Overview of the treatment

Each step of the treatment will be covered in more detail from page 14 onwards. The steps are:

1. **Induction treatment** – a course of anti-myeloma treatment to try and kill the bulk of the myeloma cells
2. Stem cell mobilisation – healthy stem cells are encouraged to multiply and move from the bone marrow into the blood
3. Stem cell collection – healthy stem cells are filtered from the patient's blood and stored
4. High-dose **melphalan** – a large dose of the chemotherapy drug melphalan is given with the aim of killing the remaining myeloma cells. This is sometimes called **conditioning treatment**
5. Autologous stem cell transplant – the previously collected healthy stem cells are infused back into the patient

See Figure 2 for an overview of these treatment steps.

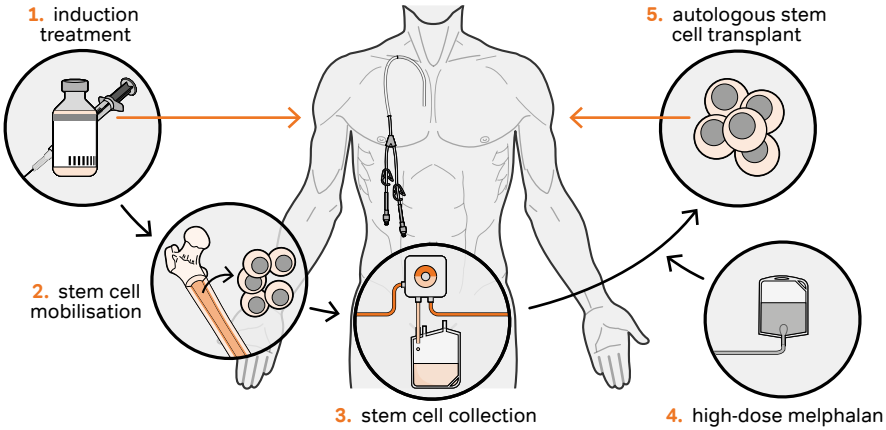

Figure 2. Overview of HDT-ASCT process

Some patients will also receive **maintenance treatment** following their HDT-SCT – read more about this on page page 30.

After several months of induction treatment, the HDT-ASCT process will take a few weeks and will be followed by some months of recovery (see Figure 3).

Types of stem cell transplantation

Autologous means 'from the same person'. If the patient's own stem cells are given back to them it is called an autologous stem cell transplant. This is by far the most common type of transplant carried out in myeloma. If the stem cells

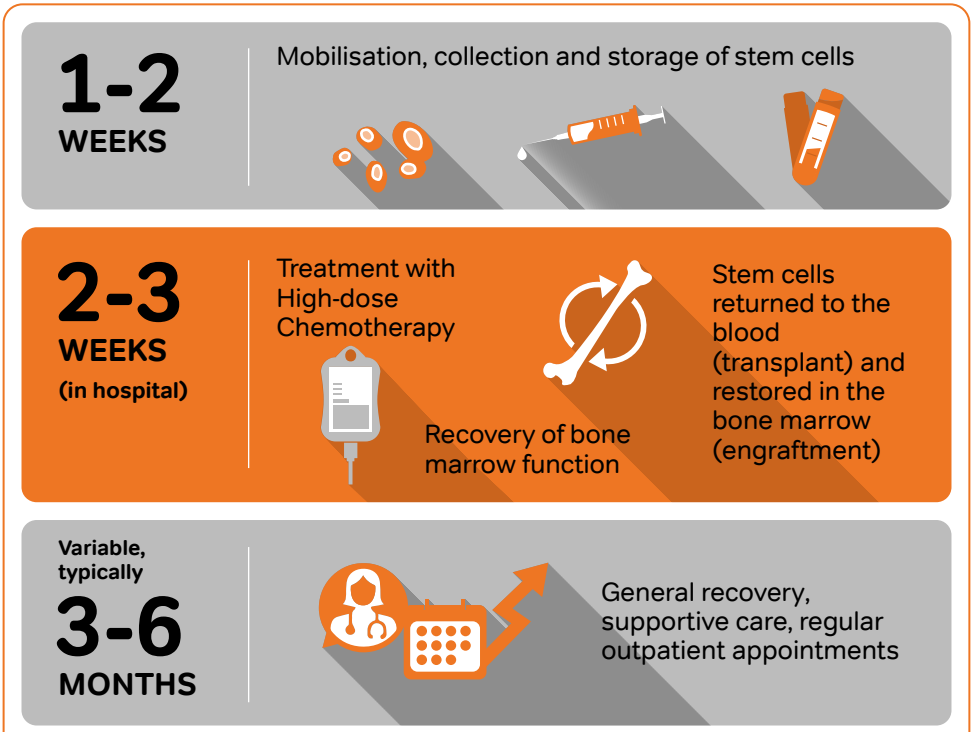

Figure 3. Timescale of HDT-ASCT process

come from a donor (**allogeneic** stem cells), the transplant is called an **allogeneic stem cell transplantation**.

For more information see the **Allogeneic stem cell transplantation Infosheet** from Myeloma UK

Who can have HDT-ASCT?

HDT-ASCT is an intensive treatment option that is not suitable for everyone. It is generally limited to younger and/or fitter patients.

There are no rigid age cut-offs but if you are over the age of 65–70 years or if your general health is not good (i.e. older and/or less fit), you would not normally be a candidate. This is mainly because the possible advantages are almost certainly outweighed by the possible disadvantages of the treatment. However, some patients aged over 70 may be able to receive HDT-ASCT if they are fit enough. Your doctor will discuss your suitability with you.

What are the possible advantages and disadvantages of HDT-ASCT?

Understanding the possible advantages and disadvantages of any treatment option is important in making decisions about the management of your myeloma.

The possible advantages of HDT-ASCT include:

- The relative safety of HDT-ASCT means that it can be considered as an option for patients who are younger and/or fit enough (see page 8)
- The potential for improvement in quality of life after the transplant as fewer residual myeloma cells may mean fewer ongoing complications, such as myeloma bone disease
- The evidence from clinical trials that the use of HDT-ASCT can improve the duration, depth and quality of response compared with currently used standard anti-myeloma treatments

However, HDT-ASCT may not benefit everyone and there are some possible disadvantages:

- High-dose therapy is more toxic than standard doses of chemotherapy and therefore there is a risk of more side effects
- There is a long recovery period following HDT-ASCT
- The success of this or any other treatment cannot be guaranteed. Not everyone will achieve the desired response, and unfortunately HDT-ASCT is not a cure for myeloma
- The effects of HDT-ASCT may affect fertility. If this is a concern for you, you should discuss this with your doctor before starting treatment as options such as sperm banking or egg storage may be considered
- As with all procedures, there is a small risk of death

Considering the options and making a decision

The whole process, from the initial discussion with your doctor to your recovery after the transplant, can take several months and may seem like a daunting prospect.

The process begins by looking at all available options and making a decision to have the transplant. If you are a suitable candidate, the option of HDT-ASCT may be raised by your doctor quite soon after your diagnosis or it may be discussed a little later when initial anti-myeloma treatment is underway.

When considering the option of HDT-ASCT it is important to understand what is involved in order to make an informed decision. An informed decision is a vital part of giving your consent (permission) to the doctors to treat you.

Before making any decision, information should be provided on the treatment, its possible advantages, disadvantages, risks and potential side effects and all other alternatives and options that are available for you. Everyone is different and you will have your own priorities, concerns and lifestyle preferences – all of which can play a significant part in the decision-making process.

For some, the decision to have HDT-ASCT is not an easy one and you should take your time and not be rushed into making 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.

If you would find it useful to speak to one of our Myeloma Information Specialists, call the **Myeloma Infoline** on **0800 980 3332** or **1800 937 773** from Ireland

HDT-ASCT is only performed in approved specialist transplant centres within larger hospitals. If there is not one at your hospital you will be referred for a consultation with a transplant expert at the nearest specialist centre. This appointment provides you with another opportunity to discuss this treatment option and ask questions.

This treatment option does not suit everyone. If you choose not to proceed for whatever reason, even if you are a suitable candidate, you can discuss all other options with your doctor.

The choice and time to have HDT-ASCT will be based on your circumstances, taking into account not only your clinical circumstances but also your lifestyle/family situation.

If you decide that this treatment is not right for you at this time, it may be an option just to collect and store your stem cells. It might then be possible for the stem cells to be used for a transplant at a later stage. You should discuss this option with your doctor as practice varies around the country and not all hospitals have the facilities to store stem cells.

Watch videos about HDT-ASCT online at **myeloma.org.uk/videos**

Pre-transplant tests and investigations

Depending on your individual medical history and any myeloma-related tests you have had recently, you may have some or all of the tests and investigations below before starting the process of HDT-ASCT.

Some of the tests and investigations listed are done to ensure that your body systems are working well enough for the transplant to proceed and may include testing your kidney, heart and lung function.

In addition, tests done at this stage provide a baseline against which post-treatment tests can be compared to determine your response to treatment.

Tests that may be done include:

- Blood tests – provide information about your myeloma as well as your general health. Tests may include: full blood count; blood group; kidney, liver and thyroid function; blood clotting; paraprotein level; iron and glucose levels
- A bone marrow test – this involves putting a needle into a bone (usually your hip bone) to get a small sample of the bone marrow. This is done under local **anaesthetic** and you may also be offered a sedative. There are two types of bone marrow test that may be carried out. A **bone marrow aspirate** is where a small amount of liquid bone marrow is removed. A **bone marrow biopsy (trephine)** is where a small core of solid bone marrow tissue is removed. Both are used to establish the presence and amount of myeloma cells in your bone marrow, and the two tests are usually done together. Bone marrow tests are particularly important for patients with **non-secretory myeloma,** a type of myeloma where neither paraprotein nor **free light chains** (part of the paraprotein) can be measured in the blood or urine
- **Serum Free Light Chain Assay (SFLCA)** – this measures the amount of free light chains in your blood and/or urine. This can be done at the same time as other routine blood tests and is particularly important for patients

with **light chain myeloma** (a type of myeloma where only light chains are produced, and not paraproteins)

- A chest X-ray is a simple way to screen the health of your lungs, heart and bones of the rib cage
- An ECG (electrocardiogram) is a simple test which records the rhythm and electrical activity of your heart. A series of electrodes (like sticky plasters) are placed on your chest, ankles and wrists. These are connected to an ECG recording machine which picks up the electrical signals that make your heart beat. The electrical signals are drawn as a graph and any problems with your heart rhythm can be picked up by a change in the shape of the graph. The test itself is not painful, but you will need to sit or lie still for 5–10 minutes which may cause discomfort if you have bone pain

For more information, see the **Tests and investigations in myeloma Infoguide** from Myeloma UK

Induction treatment

If you are going to have HDT-ASCT, the initial treatment you are given is called induction treatment. This aims to reduce the amount of myeloma in the bone marrow before the stem cells are collected.

Courses of induction treatment usually last for several months and are given in cycles. The number of cycles given will depend on various factors relating to your myeloma, the type of induction treatment you have and how well you respond to treatment. Therefore, it is difficult to know exactly how long this induction treatment will last, but it is often between four and six months.

A commonly used induction treatment in the UK is a combination of three different drugs – **bortezomib (Velcade®)**, **thalidomide** and **dexamethasone**, often referred to as VTD.

Other induction treatment combinations may be used under certain circumstances, for example, if you are unable to take thalidomide or if you are taking part in a clinical trial.

Anti-myeloma treatments can cause side effects such as sickness and diarrhoea, fatigue, sore mouth, increased risk of infection, blood clotting and **anaemia**.

These side effects can vary greatly from patient to patient, but can usually be prevented, treated or managed. You may be given additional treatments, e.g. **antibiotics** or **anticoagulants**, to help prevent or reduce the risk of getting some of these side effects.

It is important to report any side effects to your doctor or nurse as soon as possible so that they do not become serious or cause permanent damage. In many instances, side effects can be reduced simply by lowering the dose and/or changing the treatment schedule. Side effects are almost always short-term and usually resolve once treatment has finished.

You will need a good response to your induction treatment in order to progress to the stem cell collection stage of the process. This generally means a 50% or better reduction in paraprotein levels.

To determine your response to treatment and the extent of some of the side effects you may have (e.g. anaemia, blood clotting problems) you will need to undergo routine blood tests at the end of each cycle.

After 3–4 cycles of treatment more thorough investigations, such as bone marrow tests or repeat X-rays/scans, may be needed to assess how well you have responded to the induction treatment.

If after 3–4 cycles, you have not responded well enough to your induction treatment, you may be switched to an alternative induction treatment. If you fail to respond to the second induction treatment, you may not be able to continue with HDT-ASCT and your doctor will discuss other options available to you.

If you are undergoing the HDT-ASCT process as part of a clinical trial, there may be differences to what is described above e.g. in the induction treatment combination, and there may be less flexibility with changes to doses or treatment schedules.

For more information on drugs used for induction treatment, see the **Treatment Guides** from Myeloma UK

Stem cell mobilisation

In preparation for HDT-ASCT, you must first have enough stem cells collected from your blood. Normally the number of stem cells present in the blood is very low.

The aim of stem cell mobilisation is to increase the number of stem cells being produced and to stimulate their release from the bone marrow into the blood.

Stem cell mobilisation can be achieved by a number of different methods.

Mobilisation with growth factor

The most common method of stem cell mobilisation is to give a form of **growth factor** called **granulocyte-colony stimulating factor (G-CSF)**.

G-CSF is the main protein that controls the growth, division and maturation of blood stem cells in the bone marrow.

Treatment with G-CSF (e.g. Neupogen®, Ratiograstim®, lenograstim) increases the number of stem cells in the bone marrow, causing them to 'spill over' into the blood where they can be collected. It is given as an injection under the skin **(subcutaneous)** daily for 5–7 days prior to collection of stem cells.

The nurses at the hospital will teach you, or a family member, how to administer the G-CSF injections at home. 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 the G-CSF as directed.

Side effects of G-CSF

Treatment with G-CSF can cause side effects in some patients. They are usually mild and get better once the G-CSF treatment stops. Your healthcare team will give you information about possible side effects with the G-CSF type you have been given. Some of the more common possible side effects include:

- Pain in the joints or bones
- Redness of the skin around the injection site
- Headache
- Fever

- Feeling sick or not feeling like eating
- Bruising or bleeding gums

In rare cases patients can have an allergic reaction to G-CSF. Signs of a severe allergic reaction include a widespread rash, difficulty swallowing or breathing, or swelling of the lips, throat or tongue. If you experience any of these symptoms, or if you experience any problem that is concerning or doesn't improve, you should get urgent help.

Mobilisation with a chemotherapy drug and growth factor

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

Cyclophosphamide temporarily reduces the number of stem cells in the bone marrow. When the bone marrow recovers, it goes into stem cell production 'overdrive'. With the addition of G-CSF, it is usually much easier to collect the stem cells needed.

G-CSF is given consecutively over approximately 10 days when used after cyclophosphamide treatment.

Side effects of cyclophosphamide and G-CSF

The most common side effects of cyclophosphamide include loss of appetite, skin rash, sickness, nausea and general weakness.

Some patients may experience a side effect called febrile neutropenia (fever combined with reduced levels of a type of white blood cell called neutrophils).

For some, the side effects of cyclophosphamide may be more apparent than with the induction chemotherapy, but they usually resolve quickly. The side effects associated with G-CSF are described in the previous section.

Mobilisation with a combination of growth factor and plerixafor

Mobilising stem cells with G-CSF and cyclophosphamide is successful in most patients. However, in a small number of patients, not enough stem cells for a transplant are collected.

In this case, you may be given a drug called **plerixafor (Mozobil®)**. This works by disrupting the way stem cells are anchored to the bone marrow, resulting in release of stem cells into the blood.

The effect of plerixafor combined with G-CSF greatly increases the number of stem cells that can be collected from the blood.

Plerixafor may be used if:

- A previous attempt at collecting a sufficient number of stem cells has failed
- You are considered by your doctor not to have a reasonable chance of collecting sufficient stem cells based on your low blood stem cell count during the mobilisation process, or
- Your previous anti-myeloma treatments mean that you may not mobilise stem cells well (for example if you have previously received melphalan)

If you are being given plerixafor, you will first be given G-CSF injections daily for four days. After this you will be given a subcutaneous injection of plerixafor as well for several days, before the stem cells are collected.

If the number of stem cells collected at this stage is not enough, you will be able to have further attempts at collection. Before each attempt, you will receive the G-CSF and plerixafor injection as before.

Side effects of plerixafor

The most common side effects associated with plerixafor include diarrhoea, nausea, dizziness, headache, pain in your joints and irritation or redness at the injection site. These are temporary and should disappear when the injections stop.

Stem cell collection and storage

If you have been referred to a specialist transplant centre for your transplant, the induction treatment will usually be given at your local hospital but the collection of stem cells takes place at the specialist transplant centre.

Collecting stem cells from the peripheral blood can be done as an outpatient, so an overnight stay in hospital is not normally needed and no anaesthetic is involved.

To make sure that there are enough stem cells in the blood for collection to take place, a blood test is required. This is called a **CD34+ blood test** and is done towards the end of the course of G-CSF treatment.

CD34+ is the name for a protein found on stem cells. Measuring CD34+ is a useful way of 'tagging' stem cells which enables the number of stem cells in the blood to be counted.

If the cell count is high enough, collection will take place using a machine known as a cell separator or **apheresis** machine. Apheresis is the technique through which stem cells are collected from the blood.

Collecting the stem cells usually takes about three to four hours. A line will be inserted into a vein in each arm. If you have a **central line** already in place this may be used.

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 is returned to you through the line into your other arm (see Figure 4).

It is a common concern of patients that the stem cell collection might contain some myeloma cells that will then be re-infused with their stem cells following the high-dose therapy. The apheresis machine is programmed to 'skim off' stem cells, separating them out from other blood cells. Any remaining myeloma cells – a different cell type entirely from stem cells – should therefore

not be collected or re-infused. Studies have shown that, if any myeloma cells do 'contaminate' the stem cell collection, this does not appear to affect the success of the procedure.

The minimum number of stem cells needed for a successful transplant is two million stem cells per kilogram of body weight. For some patients, the aim will be to collect enough stem cells for a possible second HDT-ASCT.

Sometimes enough stem cells will be collected in just one session. Commonly, two or three sessions over consecutive days may be needed.

Unfortunately, for a very small number of patients, it is not possible to collect enough stem cells even after additional mobilisation treatments such as cyclophosphamide or plerixafor. In this situation, you would not be able to proceed safely to HDT-ASCT and other treatment options for the future would be discussed.

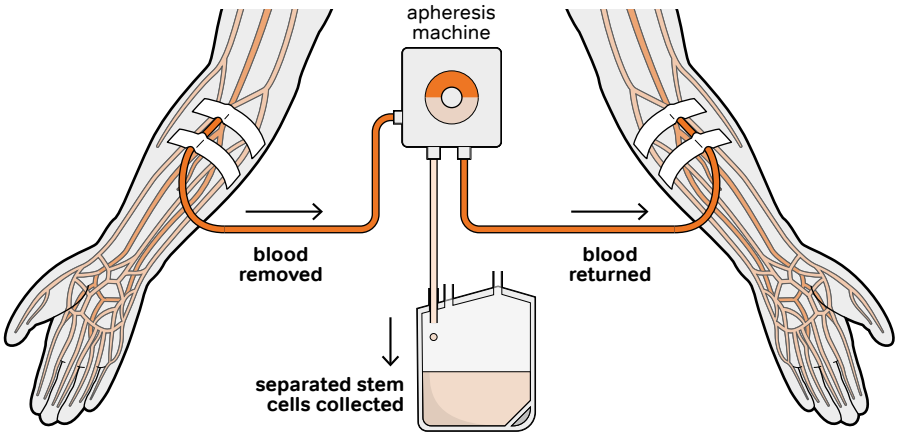

Figure 4. Apheresis process to collect stem cells

Side effects of stem cell collection

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 anticoagulant drug that stops it from clotting in the machine and, when the blood is returned to you, 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 for the remainder of the day.

Changes in the volume of blood in your body during apheresis can also cause side effects, including dizziness and heart rhythm changes. You will be carefully monitored during apheresis to minimise the risk of these side effects.

Storage of stem cells

After collection, 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 until your transplant.

A chemical called **dimethyl sulphoxide (DMSO)** is mixed with the stem cells before freezing.

DMSO prevents the water in the cells from forming ice crystals, which would permanently damage the stem cells during the freezing process.

Catheter insertion

When you are in hospital for your transplant, you will need a number of intravenous (into a vein) drugs and regular blood tests.

The easiest way to administer these is to have either a central line or a **PICC (peripherally inserted central catheter)**, which may be put in before your stem cells are collected, and will likely remain in place whilst you are recovering in hospital from the transplant. This allows all of your drugs to be given without inserting a new line into your veins each time. It also allows blood samples to be taken without the need for repeated needle insertions.

Central line

The central line is a catheter (tube), which is inserted into a large vein in your chest. The most common type of catheter used for myeloma patients is a **Hickman® catheter/ line**.

How is a central line inserted?

Your central line is usually inserted into one of your large veins through a small cut in your upper chest. Before this, you will be given an injection of local anaesthetic into the skin to numb the area around your collar bone and chest.

The central line is placed under the skin from the chest to the neck and once in the neck, is inserted into a large vein which leads to the heart (see Figure 5). The part of the central line outside your body is stitched or taped to the chest and dressed to ensure it does not come out and that it remains clean and dry. The insertion procedure usually lasts between 30–60 minutes, but occasionally may take longer.

PICC

A PICC is inserted into a vein on the inside of the elbow and slowly advanced until the end of the catheter sits in one of the large veins that feed the heart. The line is stitched in place and then a special X-ray, called fluoroscopy, is used to confirm that the PICC is correctly positioned.

Caring for your central line or PICC

If your central line or PICC is inserted whilst you are an outpatient and for any period you have it during your recovery at home, you will need to be responsible for caring for it. Your nurse will show you what to do. When you are an inpatient, your nurse will be responsible for this.

Some things to remember when you have a central line or PICC are:

- Always wash your hands thoroughly before and after touching your line or the site where the line enters your skin
- Cover your central line site while showering
- Re-dress your line site after showering, or at least twice a week if you are not showering daily
- Inspect the area of skin around the line site daily, checking for any redness, pus or bleeding
- Seek advice from your nurse if the dressing is irritating your skin
- Do not clean your line site with anything other than the solutions your nurse recommends
- Do not leave a wet dressing on your line site
- Do not swim or immerse the line in water

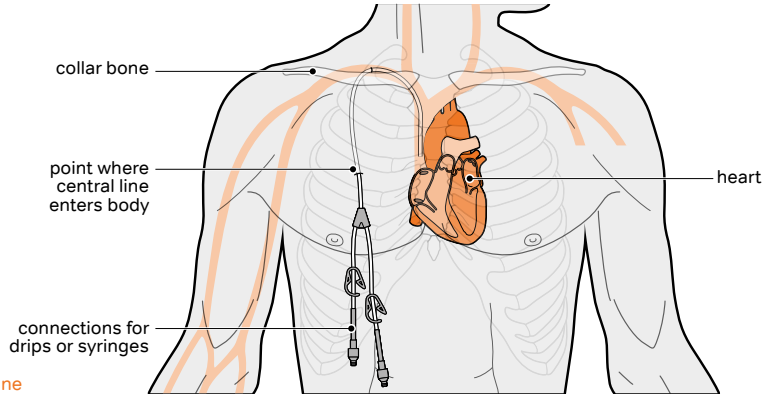

Figure 5. Central line

Hospital admission or outpatient care

Depending on a number of factors including what transplant centre you're being treated at, how far it is from your home and your general fitness, you may stay in hospital during your HDT-ASCT or be treated for some or all parts of it as an outpatient (ambulatory care).

If you are to be treated as an in-patient, you may be in hospital for approximately 2–3 weeks after receiving the high-dose therapy, although this can vary from patient to patient.

Some patients may have out-patient care for part of the HDT-SCT process. This depends on a number of factors. The patient may be able to stay at home or in accommodation near the hospital for part of the time, attending regularly as an out-patient, and then go into hospital for part of the process. Patients treated as out-patients in this way can still be admitted to hospital at any time if it is necessary, for example in the case of an infection or other side effects developing.

Receiving the high-dose therapy

In most cases, you will receive high-dose therapy followed by a stem cell transplant within 4–6 weeks of your stem cell collection.

The high-dose therapy is a chemotherapy drug called melphalan which is given intravenously, usually via a central line or PICC. This dose of melphalan aims to remove as many as possible of the residual myeloma cells you may have following induction treatment. High-dose therapy is also known as conditioning treatment.

Immediately before receiving the high-dose therapy, you will be given extra fluid through a drip, which aims to prevent any dehydration and kidney damage the melphalan can potentially cause. If your kidney function is poor, the dose of melphalan may be adjusted.

The dose of melphalan given will affect the blood cells and stem cells within your bone marrow and within a few days of receiving the melphalan, your blood counts will start to drop.

Any other treatments you are on, such as **bisphosphonate** treatment which helps protect your bones and prevent further bone damage, are normally stopped during the transplant process.

Side effects of high-dose therapy

Nausea and vomiting

When you begin your high-dose therapy you will be prescribed an **anti-emetic** (anti-sickness) drug to help prevent and minimise nausea and vomiting. This may be given orally (as a tablet) or intravenously.

Tell your nurse if your nausea/sickness is not well controlled as a different anti-emetic can be prescribed. Generally, nausea and vomiting are short-term side effects.

Sore mouth

It is quite common to have a sore mouth (also called **mucositis**) for a short time after receiving high-dose therapy.

This is because chemotherapy drugs attack fast dividing cells, such as the myeloma cells in your bone marrow but also the cells lining your

mouth and digestive system. This can lead to inflammation which can vary from mild soreness of the mouth and taste changes, to being more painful with ulcerations, perhaps causing difficulty in eating and drinking.

To help reduce the risk of mucositis, you may be given ice cubes or an ice lolly to suck when the high-dose therapy is administered. Ask your doctor or nurse if you can bring in your own if the hospital is unable to provide something.

Your nurse will show you how to care for your mouth. This may include using antibacterial and antifungal mouthwashes, brushing your teeth frequently (generally with a soft toothbrush), and inspecting your mouth for signs of infection.

If the mucositis is painful, you may need painkillers and your doctor or nurse will assess and review this on a daily basis.

Fatigue

You may feel very tired and lethargic after you have received your high-dose therapy and find you are unable to concentrate or that you are sleeping more than usual whilst you are recovering. This is quite common and it may be some time before your energy levels return to normal.

Fatigue may persist longer than the other side effects noted above and you may notice that you still feel very tired even for a few months after the HDT-ASCT.

Effects on fertility

If you or your partner is receiving melphalan, you should take contraceptive precautions. Melphalan may harm your eggs or sperm, and may also affect your ability to become pregnant or father a child. Talk to your healthcare team about how this may affect you and what your options are for storage of eggs or sperm.

Hair thinning or loss

You will probably find that you begin to lose your hair 2-3 weeks after your high-dose melphalan. However, your hair should re-grow after 3-6 months.

Altered taste and smell

The high-dose therapy can alter your sense of taste or smell. You may find you dislike the smell of some foods or that you don't have an appetite. This is quite normal and your sense of taste and smell will return to normal, although this may take some time.

For more information about melphalan see the **Melphalan Treatment Guide** from Myeloma UK

The transplant – having your stem cells returned

Within a day or so of receiving the high-dose therapy you will need to have your stem cell transplant so that your bone marrow can start to produce blood cells again.

At this point, the frozen bags of stem cells are brought to the ward, thawed in a warm water bath and returned to your blood system via an intravenous infusion. This process, which takes on average about an hour, is relatively straightforward.

The most common temporary side effects of this step are caused by the DMSO the stem cells have been stored in and may include nausea and vomiting, abdominal cramping, feeling chilled and an unusual odour/taste of garlic.

In rare cases, the infusion may cause low blood pressure, a fast heart rate and shortness of breath. Treatments are given before the infusion process to prevent or lessen some of the expected effects of DMSO infusion.

Engraftment

Once the stem cells are put back into the bloodstream, they migrate 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 bone marrow recovery period. It takes 10–14 days for adequate numbers of newly formed blood cells to be produced from the engrafted stem cells and to enter the blood and until this time you will remain severely **immunocompromised**. This means you will need to stay in a clean environment such as a single room, or specialist ward until engraftment is fully established. During this time, regular blood tests will be done to check your blood counts. Further precautions you will need to take during this time are covered in the next section.

Very 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 stem cells not engrafting well, including certain viral infections and side effects caused by drugs used to treat particular types of infection that you may have had in the past.

Maintenance and consolidation treatment

Maintenance treatment after HDT-SCT is the name for further treatment given for an extended period of time of months or years, often at a lower dose. The aim of maintenance treatment is to prolong remission, with minimum side effects.

Lenalidomide maintenance treatment has recently been approved in the UK for newly diagnosed myeloma patients following HDT-SCT.

The evidence for use of lenalidomide maintenance included a major UK clinical trial called Myeloma XI. In this trial, lenalidomide maintenance after HDT-SCT increased the time before the patients' myeloma returned, and also increased their overall length of life. The benefits were seen in patients with all types of myeloma in the trial, including high-risk myeloma.

The dose of lenalidomide given for maintenance is normally 10 mg per day. Lenalidomide will be continued until relapse, unless stopped sooner due to side effects.

For more information see the **Lenalidomide (Revlimid®) maintenance Treatment Guide** from Myeloma UK

Consolidation treatment after HDT-ASCT is an anti-myeloma treatment given at a standard dose over a short period of a few weeks after the ASCT. The aim is to deepen and prolong the response.

The benefits of consolidation treatment are still under investigation, and it is not yet part of standard treatment after HDT-ASCT. It is generally given in a clinical trial setting. Clinical trials have investigated bortezomib in combination with various other drugs for consolidation treatment.

Supportive care during recovery

The period of time waiting for the stem cells to engraft and start producing new blood cells is, for many patients, the toughest part of the transplant process.

Until the new blood cells are produced and show up in your bloodstream, you will be at risk from infection, anaemia and bleeding. Special precautions and supportive measures are necessary during this time. The most common precautions are described below.

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 to check for signs of infection.

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

Some centres may ask you to follow a special diet which avoids foods that may cause a stomach bug. This diet is sometimes called a '**clean diet**' and, if this is the policy at your transplant centre, it will be discussed with you before the HDT-ASCT process begins so that you know what to expect. Some centres no longer insist on clean diets, but you will be given advice on the importance of general hygiene during food preparation.

Your mouth will be more prone to infection after your transplant, so you should clean your teeth with a soft toothbrush after meals and use any mouthwashes as directed by your nurse.

Antibiotics and other drugs to help prevent fungal and viral infections are prescribed, usually as tablets, so there can be a number of pills to take. It is quite common to develop an infection at some point when your white cell count is low and a raised temperature is a typical sign that you have an infection. If an infection does occur, you will need intravenous antibiotics as an in-patient in hospital. Occasionally an infection can be very serious, sometimes life-threatening.

There will be restrictions on visitors, and any visitors you are allowed will be asked to take precautions to prevent infections.

Sometimes infections originate from your own body, not from your environment or another individual. These 'opportunistic' infections occur at this time because your immune system is significantly weakened.

Protection against anaemia and bleeding

Similarly, until your red blood cell and platelet counts start to rise, you may be at risk of anaemia or at risk of bleeding. You will find that your mouth feels dry and your gums may bleed easily if your platelet count is low, so remember to brush your teeth gently with a soft toothbrush.

If needed, blood transfusions can help reduce the side effects of anaemia and platelet transfusions can help reduce the risk of bleeding. Blood and platelets are treated before you receive them to destroy any white blood cells that can cause a reaction associated with blood transfusions after HDT-ASCT. This treatment is called 'irradiation' and it is important that you receive only irradiated blood products following your transplant.

General measures

Because high-dose melphalan may cause hair thinning or loss, many patients choose to have their hair cut short or shaved before receiving the high-dose therapy and/or have a wig fitted. There are a number of specialist suppliers and their details will be available from your nurse.

During your recovery period in hsopital you may find that TV, music and books or DVDs can help keep you occupied.

It is common to feel a lack of concentration during this time, so it is a good idea to do things 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. You may also have the opportunity for complementary therapies that are suitable for you while in hospital, such as aromatherapy.

Continuing recovery and follow-up care

When your blood counts are high enough, you are free from signs of infection and generally feeling better, you should be able to leave hospital, or be seen less regularly as an outpatient by the transplant team.

Your blood counts may not be at normal, pre-transplant levels but they will be at a safe level to allow you to begin your next phase of recovery.

You may have a mixture of emotions when you are discharged from hospital. The excitement of going home and relief that the transplant is over may be mixed with anxiety about coping at home and wondering how successful the treatment has been. You may feel vulnerable and nervous about managing without nurses and doctors at hand.

Before you are discharged, you should make sure:

- You know the signs and symptoms of any side effects to look out for and report
- You are clear about any precautions you need to take to reduce the risk of developing an infection
- You have the correct telephone numbers of the hospital and that you know who to call if you are worried about anything

The full recovery period may last for months but can vary greatly, depending on the individual. It can be a challenging time for patients and their families. Attempts to get back to normal life have to be balanced against some possible physical and emotional difficulties that commonly occur during this time.

The following sections provide a few guidelines and pointers on what to expect and help you manage the recovery period at home.

Treatment follow-up and appointments

For the vast majority of patients, there is a gradual recovery following the return of adequate blood counts and new problems do not develop. However, for at least the first six

months following HDT-ASCT, it is important that any problems are picked up early. Therefore you will need to attend the transplant centre for regular follow-up appointments.

These appointments in the outpatient department will be about once a week to begin with. If you live a long way from the hospital, or have difficulty travelling to your appointments, talk to the staff in the outpatient department as it may be possible to get hospital transport or help towards travel costs.

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

Sometimes your blood counts recover more slowly than expected and blood or platelet transfusions may be needed. These are usually given as an outpatient.

Antibiotics and other tablets to prevent viral and fungal infection may be continued 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.

The doctors and nurses are there to help you so remember to report any new problems or raise any worries you have.

Some months after a stem cell transplant, certain vaccinations to protect against infection may be recommended. These may be vaccinations that you had before as a child. Your doctor will discuss this with you.

For more information see the **Vaccines and myeloma Infosheet** from Myeloma UK

If you have had HDT-ASCT, you should only receive 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 MedicAlert® bracelets, particularly if they also have drug allergies.

When the transplant team, which may be different from your usual myeloma team, is satisfied that you are recovering well, you will go back to your local haematologist for routine appointments and monitoring.

Bisphosphonate treatment, normally stopped during the HDT-ASCT process, is usually resumed afterwards unless there is a specific reason for not receiving it.

Reducing the risk of infection at home

As mentioned before, it can take many months after the HDT-ASCT for your blood counts, and therefore your immune system and energy levels, to improve and return to normal.

During this time, you will need to take precautions at home and when you are out and about to reduce the risk of infection.

Diet and nutrition

Your doctor or nurse will advise you regarding any food restrictions.

Good common sense is essential with regard to what you should and should not eat. For example, always remember to wash your hands before eating and keep your kitchen clean. Food should be cooked properly and eaten by the 'use 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, and 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 central line or PICC, 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.

Remember to tell your dentist that you have had HDT-ASCT before having any dental treatment so that they remain vigilant for signs of infection.

Shingles

Some patients may develop shingles in the weeks following HDT-ASCT. Shingles is a virus infection which can begin as a painful or tingling sensation in an area of skin, followed by a rash. The affected area is often the chest or round your middle, but shingles can appear anywhere on your body, including your face, eyes or genitals. The rash appears on one side of your body only.

You can only get shingles if you have had chickenpox in the past. Shingles can be treated with anti-viral drugs. Treatment should be started as soon as possible, so you should get any symptoms checked out quickly.

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.

Socialising and getting out and about

In the first few weeks following HDT-ASCT you will be advised to avoid crowded public areas where you could find yourself in a confined space with others (such as buses, trains, pubs and cinemas) to limit your risk of catching an infection.

You are also likely to have to avoid meeting family and friends in person for a time after your HDT-ASCT to reduce your risk of infection. If so, it is good to keep in touch by phone or video call, so you can feel less at a distance from them.

Dust from building work, renovation or decoration may carry a fungus called ‘aspergillus’. Therefore, it is wise to suspend or delay any work on your home until you get 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. Any cuts you get from gardening must be cleaned thoroughly and dressed if necessary, and you should be vigilant for signs of infection. If a cut does become infected, you may need antibiotic treatment.

Coping with fatigue

Fatigue is a major issue for many during the recovery period and this may continue for some time.

However, it can also be related to the myeloma itself, other treatments you are on, loss of appetite or dehydration. Therefore, prolonged fatigue can sometimes be due to other factors rather than the impact of the HDT-ASCT.

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.

For more information see the **Fatigue and myeloma Infoguide** from Myeloma UK

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 can work from home, have a sitting or desk job, or if you are able to start back on a part-time basis. 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 HDT-ASCT. 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 prolonged exposure to the sun, as your skin will be more sensitive after high-dose therapy.

Emotional effect of HDT-ASCT

Treatment with HDT-ASCT from initial induction to recovery can be a long process and will include ups and downs for patients and their families.

Each stage of HDT-ASCT can cause a variety of emotions but you may find the period of recovery afterwards brings additional or surprising challenges.

For most patients and their families there is a huge sense of relief when the treatment is over. However, adjusting to life after HDT-ASCT is not always easy and it is not unusual for patients to feel quite low as they are recovering.

The reduction in care and support from your healthcare team can be daunting and may cause a sense of abandonment. However, returning home is a positive thing and as you recover over the weeks and months following HDT-ASCT, you will adjust to seeing your healthcare team less often. They will still be available to support you so if you have any worries or concerns, you should contact them.

The side effects of HDT-ASCT, and fatigue in particular, can be very draining, last longer than expected and may make you feel unable to live life as you would like to. It can be frustrating to have months of recuperation, but you should try not to be too hard on yourself or push yourself too far while you are still recovering. Although all patients are different, it is normal for energy levels to take several months to return. As your energy levels increase and other side effects diminish, your mental and emotional wellbeing is likely to improve too.

During your recovery period, it is important to regain some 'normality' in your life, however, it may be necessary to modify the type or amount of activities you do. There is often a balance to be struck between dealing 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.

This can be a challenging time of waiting to find out whether the treatment has worked and thinking about the future. You and your family members may have feelings of

anger, resentment, depression and anxiety over the unknown future, a sense of a lack of control and knowledge that things will not be the same as before. There may also be physical and financial challenges which amplify the emotional effects of HDT-ASCT.

Sources of support

There are a number of things that can be done to help you and your family if you're facing difficulties or challenges during this time.

Seek practical and financial help if you feel you need it. You may be able to talk to your family, but it might also be useful to speak to people outside your immediate family, such as friends, healthcare professionals and support organisations.

Many patients and carers find speaking to someone who has been through a similar situation comforting and valuable for sharing tips and experiences.

Myeloma UK provide a number of ways to connect with others:

- Myeloma Support Groups provide the opportunity to meet other patients, carers and family members to share experiences and information in an informal and supportive setting

  Visit **myeloma.org.uk** to find your nearest Support Group

- The Discussion Forum on the Myeloma UK website is a place where you can connect with others affected by myeloma by posting messages, asking questions and sharing experiences

  To join the Discussion Forum go to **forum.myeloma.org.uk**

- A telephone based service which connects people with similar experiences

  Call the **Myeloma Infoline** to find out more about this service

Long-term effects of HDT-ASCT

Evidence suggests patients who have received HDT-ASCT, together with the newer anti-myeloma treatments and improved supportive treatment and care available, are living longer and have a better quality of life.

However, as patients are living longer they may be at greater risk of some of the more long-term and late effects associated with HDT-ASCT.

These may include:

- Organ damage – in particular, damage to the lungs can occur in rare cases. Always tell your doctor if you develop symptoms such as breathlessness or a persistent dry cough, or if existing breathing problems get worse
- Eye changes – your eyes may become dry and irritated, and eye drops can help with this. You may also have more chance of developing a cataract, and it is important to have your eyes checked regularly
- Infertility – see page 26 for further information
- Second cancers – all chemotherapy drugs work by damaging the **DNA** in cells and potentially can cause second or new cancers. Although very effective against myeloma cells, the high-dose melphalan used as part of the HDT-ASCT process can also damage normal cells. While most normal cells are able to repair the damage, occasionally the damage cannot be repaired causing these cells to become cancerous. In myeloma, second cancers tend to be other blood cancers such as leukaemias and lymphomas

How do I know if my treatment has worked?

The aim of all myeloma treatment is to kill the myeloma cells to control the symptoms and complications they give rise to.

To find out how a patient is responding to treatment, several tests will be carried out regularly. These tests may vary from patient to patient, but generally will include regular blood and urine testing, a bone marrow biopsy usually around three months (100 days) post-transplant and occasional X-rays or scans. In general terms, your doctor will measure your response to HDT-ASCT according to the criteria shown in Table 1.

Reponse	Criteria
Stringent Complete Response (sCR)	No detectable paraprotein, normal free light chain ratio and absence of myeloma cells in bone marrow
Complete Response (CR)	Less than 5% plasma cells in the bone marrow, no detectable paraprotein and disappearance of any plasmacytomas
Very Good Partial Response (VGPR)	Reduction in blood paraprotein of 90% or more, and urine paraprotein less than 100 mg/24h
Partial Response (PR)	Reduction in blood paraprotein of 50% or more, and reduction in 24h urinary paraprotein or light chain of 90% or more
Stable Disease (SD)	Not meeting criteria for CR, VGCR, PR or progessive disease
Progressive Disease	Increase of more than 25% in blood or urine paraprotein, or the development of new myeloma-related symptoms, or new bone lesion(s) seen on scan

Table 1. Criteria used to measure response to treatment

Other types of transplant

A single HDT-ASCT is currently the most usual type of stem cell transplant treatment for myeloma patients. However, other transplant approaches are taken sometimes.

Having a **tandem stem cell transplant** means having either a second HDT-ASCT or an allogeneic transplant shortly after your initial HDT-ASCT (usually within six months of each other).

There is some evidence from clinical trials to suggest that tandem HDT-ASCT may improve response rates in some patients, including patients with **high-risk myeloma**. An alternative strategy is to collect enough stem cells to carry out two HDT-ASCT but to delay the second HDT-ASCT until relapse. Second transplants delayed until relapse are discussed in more detail on page 44.

An allogeneic transplant is a stem cell transplant using the stem cells from a matched donor, usually a brother or sister. Allogeneic transplants aim to use the immune system of the donor to help fight the patient's myeloma. This represents the main advantage of allogeneic SCTs compared to autologous SCTs – the donated stem cells have the potential to attack myeloma cells and prevent relapse. However, the risk of this procedure is that the donor's immune cells also attack the patient's healthy cells, leading to what is called **graft-versus-host disease (GVHD)**, which can be serious and potentially life-threatening.

In recent years another transplant procedure has been used successfully in myeloma patients. This involves giving lower doses of chemotherapy in the allogeneic transplant, which is called a **mini-allogeneic transplant** or reduced intensity transplant. The lower doses of chemotherapy reduce the risks associated with 'full intensity' allogeneic transplant. A mini-allogeneic transplant would usually be done as part of a tandem transplant after an ASCT.

Mini-allogeneic transplants are not part of routine treatment in myeloma and investigations are still ongoing to determine their benefit. Most

are done at the doctor's discretion if a matched donor is available, or carried out within a clinical trial.

For more information see the **Allogeneic stem cell transplantation in myeloma Infosheet** from Myeloma UK

Treatment for myeloma that has relapsed after HDT-ASCT

Despite the potential for an excellent response, like all myeloma treatment HDT-ASCT is not a cure and relapse almost always occurs. This is understandably a difficult time both for you and your family, especially if the relapse occurs sooner than expected.

Why is HDT-ASCT not a cure for myeloma?

Relapse occurs in after HDT-ASCT because the high-dose therapy is not able to kill all of the myeloma cells in the bone marrow. It can kill most myeloma cells, but cells that are resistant to the treatment will survive. Over time, these residual cells multiply and grow to numbers large enough to cause relapse.

When your healthcare team are considering further treatment options for you, they will take into account factors such as how long you were in remission or plateau before your relapse, and how you responded to other drugs and drug combinations previously.

Treatment options at relapse after HDT-ASCT

There are a number of options available if your myeloma has relapsed at this stage. These include:

Standard treatment with anti-myeloma drugs

Most patients in the UK relapsing from HDT-ASCT will receive bortezomib, usually in combination with steroids, and/or other anti-myeloma treatments.

A second transplant

Having a second HDT-ASCT at the time of relapse is different from a tandem transplant, where two transplants are planned at the outset and occur usually within six months of each other. A second HDT-ASCT may be offered if relapse occurs and there are enough stem cells still stored that can be used.

The option of a second HDT-ASCT will depend on the timing of the relapse, your age, previous treatment and general health/fitness to be able to undergo the procedure again. Generally, a second HDT-ASCT will only be offered to patients who have been

in remission or plateau for at least 18–24 months after their first HDT-ASCT.

Before a second HDT-ASCT is performed, a course of anti-myeloma treatment (re-induction treatment) is given to reduce the amount of the myeloma. This may be the same as the first induction treatment you received, or a different combination might be given.

A UK clinical trial called Myeloma X, published in 2014 and 2019, showed that a second HDT-ASCT was more effective than standard chemotherapy in myeloma patients who had relapsed following their first HDT-ASCT.

This was the first time that researchers had looked at the role of a second HDT-ASCT in a multi-centre randomised controlled trial involving a large group of relapsed myeloma patients.

A second SCT done at relapse is sometimes called a salvage SCT.

Clinical trials

Novel drugs under investigation in clinical trials may be available for relapsed patients. It is important to understand that not every patient is suitable for every new treatment or clinical trial, but if you are interested in participating in a trial you should discuss it with your doctor.

For more information see the **Myeloma Trial Finder** on **trials.myeloma.org.uk**

Medical terms explained

Allogeneic: A word used In transplants to mean taken from a donor.

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

Ambulatory care: medical care provided on an outpatient basis

Anaemia: A decrease in the normal number of red blood cells, or the haemoglobin that they contain, causing shortness of breath, weakness and tiredness.

Anaesthetic: A type of drug used to temporarily reduce or take away sensation so that otherwise painful procedures or surgery can be performed. A general anaesthetic makes the patient unconscious and therefore unaware of what is happening. A local anaesthetic numbs the part of the body that would otherwise feel pain.

Antibiotic: A type of drug used to prevent or treat an infection caused by bacteria.

Antibodies (immunoglobulins): Also known as immunoglobulins, antibodies are proteins found in the blood which are produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign such as bacteria and viruses. They enable other cells of the immune system to destroy and remove them, thereby helping to fight infection.

Anticoagulant: A type of drug used to prevent blood clots from forming.

Anti-emetic: A type of drug used to prevent or minimise nausea and vomiting.

Apheresis: A procedure in which stem cells are collected from the blood using a machine that separates them out and returns the remainder of the blood components to the patient or donor.

Autologous: Something taken from and given back to the same person.

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.

Bisphosphonate: A type of drug that slows down or prevents bone damage.

Blood count: The number of red blood cells, white blood cells and platelets in a sample of blood.

Bone marrow: The soft, spongy tissue in the centre of bones that produces white blood cells, red blood cells and platelets.

Bone marrow aspirate: A procedure to remove a sample of fluid and cells from the bone marrow for examination and testing.

Bone marrow biopsy (trephine biopsy): A procedure to remove a small sample of bone marrow tissue (for examination under a microscope).

Bortezomib (Velcade®):
A proteasome inhibitor drug which is given as an intravenous infusion or subcutaneous injection.

CD34+ blood test: A test which measures the amount of stem cells in the blood.

Central line: A catheter (tube) which is inserted under the skin in the chest into a large vein just above the heart. It can be kept in for several months and is used to administer treatments and to take blood samples. Also known as a Hickman® line or a central venous access device

Chemotherapy: A type of drug intended to kill cancer cells. Chemotherapy drugs can be injected into a vein (intravenous or IV) or swallowed as tablets (orally).

Clean diet: A diet sometimes recommended for people who have a compromised immune system. Excludes 'higher risk' foods e.g. soft cheeses, live yogurts and pâté.

Conditioning treatment: Treatment with high-dose chemotherapy and/or radiotherapy before a stem cell transplant, to kill myeloma cells.

Consolidation treatment: Further treatment which is given over a short period of time after the main (standard dose of) treatment has finished, with the aim of deepening and prolonging the response.

Cyclophosphamide:
A chemotherapy drug which is given orally or as an intravenous infusion.

Dexamethasone: A steroid which is given orally or as an intravenous infusion.

Dimethyl sulphoxide (DMSO): A chemical used to preserve and store collected stem cells.

DNA (deoxyribonucleic acid): The material inside every cell of a living organism that carries all the instructions the organism needs for to grow, reproduce and function. DNA is organised into genes.

Engraftment: The process, following HDT-SCT, by which transplanted stem cells travel to the bone marrow, where they begin to grow and develop into new blood cells.

Free light chain: A molecule which normally makes up part of an antibody. Called 'free' light chain when it is not attached to the rest of the molecules that make up the antibody.

Graft-versus-host disease (GVHD): A complication that can occur after an allogeneic stem cell transplant in which the newly transplanted donor cells attack the patient's own tissue.

Granulocyte-colony stimulating factor (G-CSF): A growth factor which is used to stimulate the production of stem cells.

Growth factor: A protein produced by the body that stimulates the development and growth of cells. Growth factors can also be made synthetically and given as a treatment in some circumstances.

Hickman® catheter/line: The brand name for the catheter (tube) which is inserted under the skin in the chest into a large vein just above the heart. It can be kept in for several months and is used to administer treatments and to take blood samples. Also known as a central line and a central venous access device.

High-dose therapy: High-dose chemotherapy given intravenously, usually via a central line (such as a a Hickman® line or a PICC line), prior to patients receiving healthy stem cells as part of the transplantation procedure. Also known as conditioning treatment.

High-risk myeloma: A more active or more difficult to treat myeloma, often associated with certain genetic abnormalities.

Immune system: The complex group of cells, tissues and proteins (including antibodies), that protect the body against infection and disease.

Immunocompromised: The term used to describe a person whose immune system is impaired and unable to fight infection or disease as normal.

Immunoglobulins (antibodies): See antibodies (immunoglobulins).

Induction treatment: The initial standard-dose chemotherapy that patients receive before a stem cell transplant procedure. Induction treatment aims to reduce the amount of myeloma in the bone marrow before the stem cells are collected.

Intravenous: Into a vein.

Lenalidomide (Revlimid®): An immunomodulatory drug which is given orally.

Light chain myeloma: A type of myeloma where only the light chain portion of the immunoglobulin is produced.

Maintenance treatment: Further treatment which is given over an extended period of time after the main treatment has finished, often at a lower dose. The aim is to prolong remission, with minimum side effects.

Malignant: Cancerous cells which have the ability to spread.

Melphalan: A chemotherapy drug which is given orally or intravenously.

Mini-allogeneic transplant: A type of allogeneic transplant that uses lower doses of conditioning chemotherapy than normal. Also called a reduced intensity transplant.

Mucositis: Pain and inflammation of the lining of the mouth and/or gastrointestinal tract.

Non-secretory myeloma: A type of myeloma in which there is no detectable paraprotein or light chains in either the blood or urine.

Paraprotein: An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.

Peripherally Inserted Central Catheter (PICC) line: A catheter (tube) inserted into one of the large veins of the arm (or leg) and threaded into the vein until the end sits in a large vein just above the heart. It is used to administer treatments, commonly chemotherapy.

Plasma cells: Specialised white blood cells that produce antibodies (immunoglobulins) to fight infection.

Plateau: A period of time when the myeloma, and the paraprotein level, is relatively stable. Often referred to as stable disease.

Platelets: A type of blood cell involved in blood clotting.

Plerixafor (Mozobil®): A drug used to help move stem cells from the bone marrow into the blood for collection prior to transplantation.

Quality of life: A term that refers to a person's level of comfort, enjoyment, and ability to pursue daily activities. It is a measure of an overall sense of wellbeing.

Red blood cells: A type of blood cell which transports oxygen around the body.

Relapse: The point where disease returns or becomes more active after a period of remission or plateau.

Remission: The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Serum Free Light Chain Assay: A test used to detect and measure the amount of free light chains in the blood.

Side effects: The undesired effects caused by a drug or treatment, for example fatigue or nausea.

Stem cell: A type of cell from which a variety of cells develop. Haematopoietic stem cells give rise to red blood cells, white blood cells and platelets. They are harvested and collected for stem cell transplantation.

Stem cell transplant: The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Subcutaneous: Under the skin.

Tandem stem cell transplant: A planned procedure where patients receive two transplants over a short period of time, usually within six months. This can be two autologous stem cell transplants, or an autologous followed by a mini-allogeneic transplant.

Thalidomide: An immunomodulatory drug which is given orally.

White blood cells: A type of blood cell involved in the body's immune system, which help to fight infection and disease.

Useful organisations

Carers UK www.carersuk.org
0808 808 7777
Provides advice, information and support for carers.

Citizens Advice www.citizensadvice.org.uk
England: **0800 144 8848** Wales: **0800 702 2020**
Scotland: **0800 028 1456** Northern Ireland: **0800 915 4604**
Offers advice about debt and consumer issues, benefits, housing, legal matters and employment.

Macmillan Cancer Support www.macmillan.org.uk
0808 808 0000
Provides practical, medical and financial information and support to all cancer patients and their carers.

Maggie's www.maggies.org
0300 123 1801
Provides free practical, emotional and social support to people with cancer and their family and friends.

Mind www.mind.org.uk
0300 123 3393
Provides advice and support to empower anyone experiencing mental health problems.

NHS 111 Service www.nhs.uk/111
111
Call 111 when you need medical advice fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year.

Samaritans www.samaritans.org
116 123
Listening and support free, 24 hours a day, to anyone who's struggling to cope.

We're here for everything a diagnosis of myeloma brings

Call our **Myeloma Infoline** on **0800 980 3332** for practical advice, emotional support and a listening ear.

Get answers to your questions by emailing **AskTheNurse@myeloma.org.uk**

Learn about myeloma from experts and meet other patients at our **Patient and Family Myeloma Infodays**.

Order or download our **information booklets**, which cover all aspects of myeloma – call **0800 980 3332** or visit **myeloma.org.uk/publications**

Join your nearest **Myeloma Support Group** to meet up and talk to other people face to face.

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.

Watch **Myeloma TV**, videos about myeloma presented by experts, patients and family members.

Use the **Discussion Forum** for the opportunity to share experiences and advice about living with myeloma.

We need your help

Thanks to our generous supporters we are able to provide information and support to patients and their families, as well as fund vital research that will help patients live longer and with a better quality of life.

Myeloma UK receives no core government funding. We rely on fundraising activities and donations.

You can support Myeloma UK by:

- **Making a single donation or setting up a Direct Debit**
  Online at **myeloma.org.uk/donate**
  Over the phone **0131 230 0429**
  Or by posting a cheque payable to **Myeloma UK** to:
  Myeloma UK, 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG
- **Fundraising** – fundraising is a positive way of making a difference and every pound raised helps. As myeloma is a rare, relatively unknown cancer, fundraising is also a great way to raise awareness
- **Leaving a gift in your will** – legacies are an important source of income for Myeloma UK and help us to continue providing practical support and advice to myeloma patients and their families. They also help us to undertake research into the causes of myeloma and investigate new treatments

However you decide to raise funds, our Fundraising Team is here to support you. Contact us on **0131 230 0429** or email **fundraising@myeloma.org.uk**

Notes

Notes

Nobody ever forgets the moment they are diagnosed with myeloma. Myeloma UK advances the discovery of effective treatments, with the aim of finding a cure. That is what patients want, it's what they deserve and it's what we do.

Judy Dewinter – President, Myeloma UK

We appreciate your feedback. Please fill in a short online survey about our patient information at **myeloma.org.uk/pifeedback** or email any comments to **patientinfo@myeloma.org.uk**

For a list of references used to develop our resources, visit **myeloma.org.uk/references**

Treatments and tests Infoguide:
High-dose therapy and autologous stem cell transplantation

MyelomaUK

We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on
0800 980 3332

Email Ask the Nurse at
AskTheNurse@myeloma.org.uk

Visit our website at
myeloma.org.uk

Trusted Information Creator
Patient Information Forum

Myeloma UK
22 Logie Mill, Beaverbank Business Park,
Edinburgh EH7 4HG
0131 557 3332
myelomauk@myeloma.org.uk
Registered Charity No: SC026116

Published by:	Myeloma UK
Publication date:	April 2007
Last updated:	September 2021
Review date:	September 2024