MyelomaUK

High-dose therapy and autologous stem cell transplant

Treatments and tests Infoguide

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Contents

2 Introduction

3 Myeloma – an overview

5 What are stem cells?

6 What is high-dose therapy and autologous stem cell transplant (HDT-SCT)?

10 What are the possible advantages and disadvantages of HDT-SCT?

11 Considering the options and making a decision

13 Pre-transplant tests and investigations

14 Induction treatment

16 Stem cell mobilisation

19 Stem cell collection and storage

22 Having a central line inserted

25 Hospital admission or outpatient care

26 Receiving the high-dose therapy

29 The transplant – having your stem cells returned

31 Maintenance and consolidation treatment

32 Supportive care during recovery

34 Continuing recovery and follow-up care at home

41 Emotional effect of HDT-SCT

43 Long-term effects of HDT-SCT

44 How do I know if my treatment has worked?

45 Other types of transplant

47 Treatment for myeloma that has relapsed after HDT-SCT

49 Hints and tips

54 Medical terms explained

62 Useful organisations

Disclaimer: The information in this Infoguide is not meant to replace the advice of your healthcare 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.

Introduction

This Infoguide is for patients with myeloma who may be undergoing a treatment called high-dose therapy and autologous stem cell transplant.

Family members and friends of myeloma patients may also find this Infoguide useful. This Infoguide covers all stages of the treatment, from making a decision and pre-treatment tests and investigations, through to long-term recovery.

The Infoguide is designed as a handbook. It has a lot of information about different aspects and stages of the treatment. You may not want to read all the information in detail at the same time. The Infoguide is divided into sections to make it easier to find the information you need.

Note: this Infoguide is about **autologous** stem cell transplant, which uses the patient's own stem cells. This is the type of transplant received by most myeloma patients. **Throughout this Infoguide, HDT-SCT refers to this type of transplant.** A few myeloma patients receive donor stem cells, and this form of transplant is called an **allogeneic stem cell transplant**.

On page 49 there are some hints and tips from patients who have undergone HDT-SCT, about how they coped with the treatment, including the hospital stay and recovery at home.

You will find a definition of the terms highlighted in **bold** throughout this booklet in the 'Medical terms explained' section on page 54.

Throughout this Infoguide, 'Healthcare team' is used to refer to your hospital team (doctors, nurses and other specialists).

We are grateful to myeloma patients and their families and friends, who have shared hints and tips from their experience, to help other patients.

Myeloma – an overview

This section explains some key facts about myeloma, including what it is, how it affects patients, and how it is treated. If you are newly diagnosed this section can be a good place to start. If you have been living with myeloma for some time, this information might be familiar, but it can still be a useful reminder before reading about specific aspects of myeloma.

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, some of the plasma cells become cancerous (sometimes called **malignant**) and usually release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. Myeloma is often diagnosed and monitored by measuring this paraprotein.

Sometimes, **myeloma cells** produce only part of the paraprotein, known as **light chains**. These also have no useful function. In other types of myeloma, the myeloma cells only produce small amounts of paraprotein or no paraprotein at all. There are other ways to diagnose and monitor these types of myeloma.

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

Most of the complications and symptoms of myeloma are caused by a buildup of the cancerous myeloma cells in the bone marrow and the presence of paraprotein or light chains in the body.

Common problems in myeloma include bone pain, bone fractures, fatigue, frequent infections and kidney damage.

Myeloma is highly treatable in most 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 treatments, with different ways of working, are given together.

Myeloma is known as a relapsing and remitting cancer: patients are treated and generally go into **remissions** when their cancer is not active and often is not being treated, followed by **relapses** when the myeloma is active and needs treatment again. Remissions can last for long periods of time, and many patients have a number of remissions and relapses during their lifetime. Although myeloma is not currently curable, the outlook for patients has improved greatly over recent years and is continuing to improve. There are many different treatments available, and others are being developed in clinical trials.

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

- On average 5,900 people are diagnosed with myeloma every year in the UK
- There are over 24,000 myeloma patients in the UK
- Myeloma is the third most common type of blood cancer, and accounts for 1 in 50 of all new cancer cases diagnosed each year
- Although more common in older people, around 1 in 4 myeloma patients are diagnosed under the age of 65

What are stem cells?

Stem cells are cells with the ability to develop into many different types of cells in the body. The stem cells used in transplants in myeloma are blood 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 transplant** (HDT-SCT) a treatment option.

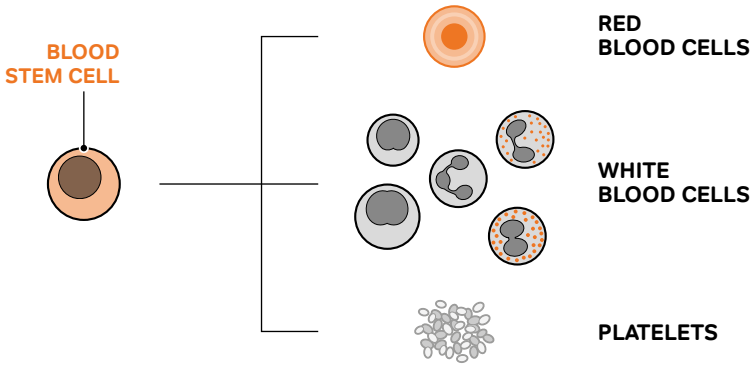

Figure 1. Blood stem cells develop into different types of blood cells.

What is high-dose therapy and autologous stem cell transplant (HDT-SCT)?

High-dose therapy and autologous stem cell transplant (HDT-SCT) is an intensive treatment which many patients receive in the early stages of their myeloma.

The treatment involves:

- Collecting and storing stem cells from your blood
- Giving you a high dose of **chemotherapy** to kill as many of your myeloma cells as possible (called high-dose therapy)
- Returning the stored stem cells to your blood (called stem cell transplant)

Autologous means the stem cells are the patient's own (not from a donor). This Infoguide is about autologous stem cell transplant. It is by far the most common type of stem cell transplant done in myeloma, and in this Infoguide it is referred to as "HDT-SCT". Transplants using stem cells from a donor are called **allogeneic** stem cell transplants. These are explained on page 'Allogeneic transplants' section on page 45.

The HDT-SCT process enables a myeloma patient to be given a high dose of chemotherapy to kill as many of the myeloma cells as possible.

High doses of chemotherapy are very damaging to the blood-forming stem cells in the bone marrow. This results in **blood counts** falling to extremely low levels, causing severe complications.

The patient's stored stem cells are used to 'rescue' their bone marrow. Once the stored stem cells are transplanted back into the patient, the bone marrow can recover and the stem cells can start making new blood cells. Without this part of the process, the high doses of chemotherapy would be too toxic to the patient.

The aim of HDT-SCT is to produce remission or **plateau** for as long as possible. However, myeloma is a very individual cancer, and each patient's myeloma is different. This may affect how well each patient responds to the treatment.

What are the steps in the HDT-SCT process?

The steps in the HDT-SCT process are listed below, and described in more detail in the following pages.

1. **Induction treatment:** a course of anti-myeloma treatment given over several months before the HDT-SCT. It is given to try and reduce the number of myeloma cells in your the bone marrow as much as possible
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 collected from the blood and stored
4. **High-dose therapy:** a large dose of the chemotherapy treatment melphalan is given with the aim of killing as many as possible of the remaining myeloma cells. It also kills healthy cells in your bone marrow and blood
5. **Autologous stem cell transplant:** the previously collected healthy stem cells are given back to you via a drip, so that they can produce new healthy blood cells

These steps are shown below in Figure 2.

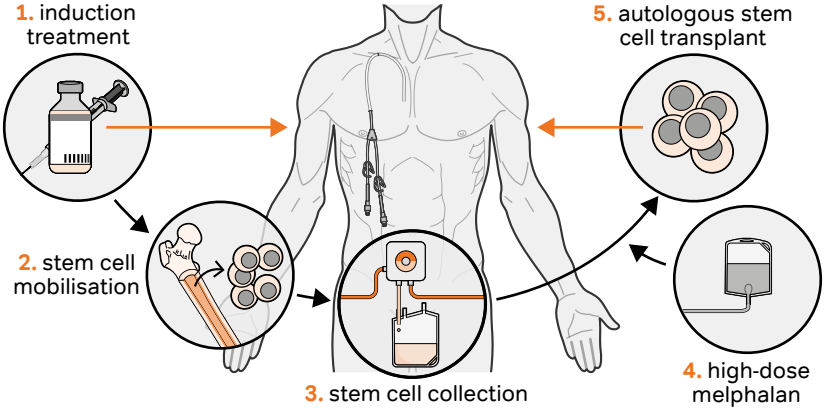

Figure 2. The steps in the HDT-SCT treatment process.

Patients usually also receive **maintenance treatment** following their HDT-SCT – read more about this on page 31.

The usual timescale of HDT-SCT is shown below in Figure 3. The timing for recovery after the stem cell transplant is different for each patient.

Who can have HDT-SCT?

HDT-SCT is an intensive treatment option that is not suitable for everyone. If you are aged over 65 to 70 years, and your general health is not good, HDT-SCT may be less suitable for you. This is because HDT-SCT is an intensive treatment and there is a risk of

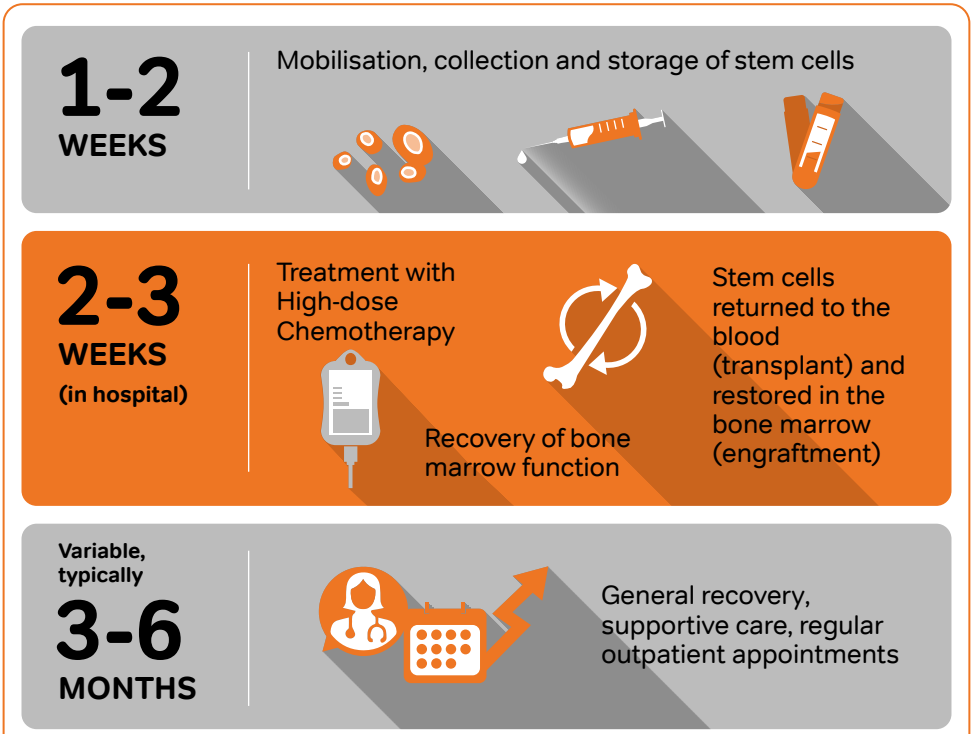

Figure 3. The usual timescale of the HDT-SCT process.

severe side effects. In older and less fit patients, the risks are likely to be greater and are more likely to outweigh the advantages.

However, there is no rigid age limit. Patients aged over 70 may be able to receive HDT-SCT if they are fit enough. In recent years, increasing numbers of older patients have successfully received HDT-SCT. Clinical studies have also provided evidence to support the use of HDT-SCT in both older patients and those with kidney disease.

Your doctor will discuss with you how suitable HDT-SCT may be in your circumstances. If it is agreed that HDT-SCT is not a good option for you, your doctor will discuss other treatments for your myeloma.

You may be given the intensive induction treatment before your healthcare team make the final decision, particularly if you are in an older age group.

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

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

HDT-SCT is an intensive treatment. For suitable patients who are fit enough, it is considered as a standard treatment, although it will not work for everyone. It has the potential to give patients a long duration of remission and good quality of life before their myeloma starts to return. There is 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.

HDT-SCT 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 severe **side effects**
- There is a long recovery period following HDT-SCT
- The success of this or any other treatment cannot be guaranteed. Not everyone will achieve the desired response, and unfortunately HDT-SCT is not a cure for myeloma
- HDT-SCT may affect fertility. If this is a concern for you, you should discuss this with your doctor before starting treatment. Options such as sperm banking or egg storage may be considered
- As with all procedures, there is a small risk of death. The risks are kept as low as possible by careful decisions about which patients are suitable for the treatment, and by close monitoring for complications, with supportive treatment for any complications that do occur

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-SCT 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. You will have several months of induction treatment before the stem cell harvest and high-dose therapy. This will give you more time to have discussions with your healthcare team and your family and friends.

Before you make a final decision to undergo HDT-SCT, you will be given information on the treatment, its possible advantages, disadvantages, risks and potential side effects, and other available treatment options. Everyone is different and you will have your own priorities, concerns and lifestyle preferences – all of which can play an important part in the decision-making process.

For some, the decision to have HDT-SCT 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. It can be useful to speak to other patients who have had this type of treatment. If possible, speak to more than one patient, as everyone's experience is different. Patients who have gone through the treatment will also be able to give you valuable tips about things that helped them during the treatment and recovery period.

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-SCT 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 the treatment is considered suitable for you, you can discuss other options with your doctor.

Storing stem cells to use in the future

If you decide that this treatment is not right for you at this time, it may be an option to collect and store your stem cells without undergoing the full HDT-SCT process. 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.

Pre-transplant tests and investigations

This section explains the tests and investigations that may be done before you start your HDT-SCT.

Some tests and investigations are done to ensure that your body systems are working well enough for the transplant to go ahead and may include testing your kidney, heart and lung function. Other tests will be done to provide a 'baseline', so that tests done after your HDT-SCT can be compared with them.

Tests that may be done include:

- **Chest X-ray:** a simple check on the health of your lungs, heart and the bones of your rib cage
- **Electrocardiogram (ECG):** a simple test of the rhythm and electrical activity of your heart. It uses electrodes (like sticky plasters) placed on your body, which pick up the electrical signals that make your heart beat
- **Serum Free Light Chain Assay (SFLCA):** this measures the amount of free light chains in your blood and urine. This is particularly important for patients with **light chain myeloma** (a type of myeloma where only light chains are produced, and not paraproteins)
- **Bone marrow aspirate or bone marrow biopsy:** this involves inserting a needle into a bone (usually your hip bone) and removing a small sample of liquid or solid bone marrow, or both. You will be given local anaesthetic on the skin before the needle is inserted, and you may be offered a sedative or gas and air (Entonox®). Bone marrow tests are particularly important for patients with non-secretory myeloma, a type of myeloma where the paraproteins or free light chains (part of the paraprotein) can not be measured in the blood or urine
- **Blood tests:** may include: full blood count; blood group; kidney, liver and thyroid function; blood clotting; paraprotein level; iron and glucose levels

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

Induction treatment

If you are going to have HDT-SCT, 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 vary, but the induction treatment will generally last 4 to 6 months.

The two most commonly used induction treatments in the UK are:

- A combination of **daratumumab (Darzalex®)**, **bortezomib (Velcade®)**, **thalidomide** and **dexamethasone**, often referred to as DVTD or dara-VTD
- The same combination but without the daratumumab, known as VTD

Some patients may receive cyclophosphamide instead of thalidomide.

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.

Side effects of induction treatment

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 treatments such as **antibiotics** or blood thinners (**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 healthcare team as soon as possible. Side effects can often be reduced simply by lowering the dose and/or changing the treatment schedule. Side effects are generally 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. You will have routine blood tests at the end of each treatment cycle. This will help your healthcare team to assess how well your myeloma is responding to the treatment, and also to monitor for some of the possible side effects.

After 3 to 4 cycles of treatment, other investigations, such as bone marrow tests, X-rays or scans, may be needed to assess how well your myeloma has responded to the induction treatment.

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

If you are undergoing the HDT-SCT process as part of a clinical trial, there may be differences to what is described above.

For more information on induction treatments, see the **Treatment Guides** from Myeloma UK

Stem cell mobilisation

In preparation for HDT-SCT, 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 several different methods.

Growth factor (G-CSF)

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. The G-CSF given in HDT-SCT is a manufactured version.

Treatment with G-CSF 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 to 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, speak to your healthcare team. 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.

Some of the more common side effects include:

- Pain in the joints or bones
- Redness of the skin around the injection site
- Headache
- Fever
- Feeling sick, loss of appetite, or diarrhoea
- Bruising or bleeding gums
- Fatigue

In rare cases patients can have more serious reactions to G-CSF, including an allergic reaction. 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 any problem that is concerning or doesn't improve, you should seek urgent medical advice.

Growth factor and plerixafor

Some patients are given a treatment called **plerixafor (Mozobil®)** in combination with G-CSF. Plerixafor works by disrupting the way stem cells are anchored to the bone marrow. This causes more stem cells to be released into the blood.

Plerixafor may be used if:

- A previous attempt to collect enough stem cells has not worked
- Your doctor thinks it is unlikely that they will collect enough stem cells without using plerixafor
- Your previous anti-myeloma treatments mean that you may not mobilise stem cells well

If you are given plerixafor, you will first be given G-CSF injections daily for 4 days. After this you will be given an 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 redness or irritation at the injection site. These are temporary and should disappear when the injections stop.

Chemotherapy and growth factor

In rare cases, a cycle of a chemotherapy treatment, usually **cyclophosphamide**, may be given before the G-CSF injections, to further increase the number of stem cells in the blood.

G-CSF is given for about 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 **neutropenic sepsis (febrile neutropenia)**. This is a serious condition where fever is combined with reduced levels of a type of white blood cell called neutrophils.

The side effects associated with G-CSF are described in the previous section.

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 ('harvesting') of stem cells will take place at the specialist transplant centre.

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

A blood test called a **CD34+ blood test** is done to ensure there are enough stem cells in the blood to be collected. This is done towards the end of the G-CSF treatment.

If there are enough stem cells, they are collected using a machine called a cell separator or **apheresis** machine. Apheresis is a procedure where your blood is passed through a machine that collects one component (in this case stem cells), and returns the rest of the blood to your body.

Collecting the stem cells usually takes about 3 to 4 hours, but is a straightforward procedure, and during the time it is being done you will be able to relax in a chair. A **line** (a thin, flexible tube) is inserted into a vein in each arm. If you have a **central line** already in place this may be used. Central lines are explained on page 22.

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).

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

It is a common concern of patients that the stem cell collection might contain some myeloma cells that will then be given back with the 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 given back. If any myeloma cells do remain in the stem cell collection, they should not affect the success of the stem cell transplant procedure.

The minimum number of stem cells needed for a successful transplant is two million stem cells per kilogram of body weight. If it is possible, enough stem cells will be collected for a possible second HDT-SCT. Only a small proportion of patients have a second HDT-SCT. There is more about second HDT-SCTs on page 47.

It may also be possible to collect and store your stem cells 'just in case', even if you have not made a final decision whether to have a stem cell transplant.

Unfortunately, for a very small number of patients, it is not possible to collect enough stem cells even after mobilisation with cyclophosphamide or plerixafor. In this situation, you would not be

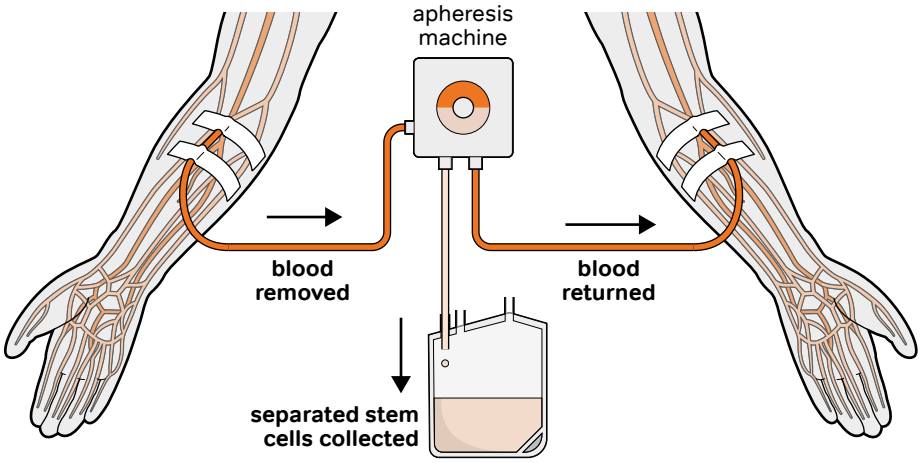

Figure 4. Apheresis being used to collect stem cells from a patient's blood.

able to proceed safely to HDT-SCT, and other treatment options would be discussed.

Side effects of stem cell collection

Stem cell collection is usually a straightforward process, though some patients may feel unwell during the process. The most common side effect is a cramp-like or tingling sensation in the hands, feet or around the mouth. This can happen when the calcium level in the blood changes during the apheresis process, and it can usually be corrected easily by drinking some milk.

You will feel tired after the stem cell 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 frozen and stored in liquid nitrogen until your transplant. A chemical is mixed with the stem cells before freezing. This is to protect them from damage when they are frozen. Stem cells can usually only be stored for 10 years at most.

Having a central line inserted

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

The easiest way to administer these is to have a central line inserted. This is a thin flexible tube (or line) inserted into a large vein. The central line 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 medicines 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.

There are different types of line that may be used (**Hickman® (tunnelled) line**, **PICC**, and **Portacath®**). There is information about these below. When the line is inserted, you will be given local anaesthetic to numb the area of skin. X-rays or scans will be used to guide the positioning of the line.

Hickman® (tunnelled) line

The Hickman® (tunnelled) line is a type of central line that is usually inserted through a small cut in your upper chest, then placed in 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 30 to 60 minutes, but occasionally may take longer.

PICC

PICC (peripherally inserted central catheter) is a type of central line that 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 then stitched in place.

Portacath® (implantable port)

A Portacath is an alternative to a Hickman line or PICC, which does not leave any tube outside your body.

A portacath consists of:

- A port (a small plastic chamber which sits underneath the skin of your chest). The port has has a rubber drum in the middle. A special needle is inserted through your skin and into the rubber drum, to give treatment or take blood samples
- A line (flexible tube). The tip of the line is placed in a large vein just above the heart, and the other end of the catheter is attached to the port

Dissolvable stitches and steri-strips will be used to close up the skin where the port and line have been inserted. The hospital team doing this will give you advice on care of the insertion sites while the skin is healing.

Problems with central lines

Although catheters can be left in place for long periods, they can sometimes cause problems. They can become blocked or an infection can occur where the line goes through your skin. Occasionally a clot can form in the line. You will be monitored for these issues.

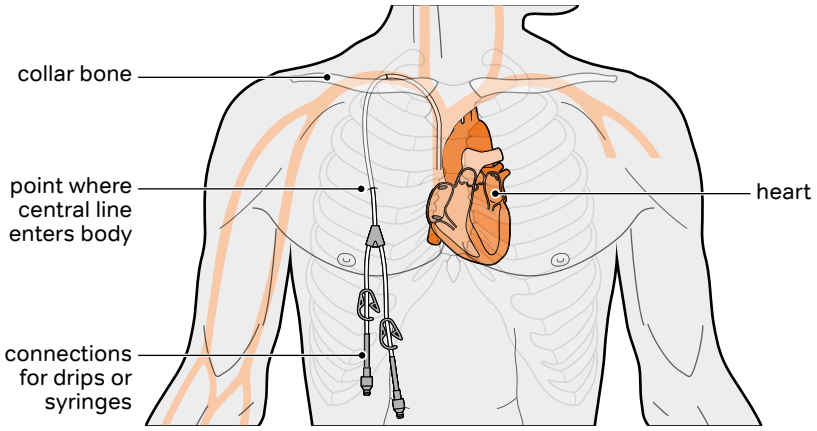

Figure 5. A Hickman® (tunnelled) line in position.

Caring for your Hickman® line or PICC

If your Hickman® line or PICC is in place while you are at home, you will 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 Hickman® 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 line site while showering
- Replace the dressing on 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

Hospital admission or outpatient care

Depending on a number of factors, you may stay in hospital during your HDT-SCT or you may be treated for some or all parts of it as an outpatient (called ambulatory care).

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

Ambulatory (outpatient) care

Some patients may have ambulatory care for part of the HDT-SCT process. This will depend on several factors:

- **Age and fitness:** You will generally need to be younger and fitter to be considered
- **Distance from the transplant centre:** You will need to live or be in accommodation close to the transplant centre, so that you can get to the hospital quickly if you develop an infection or other complications. You will need to attend the Day Unit of the transplant centre most days
- **Care at home:** You will need to have someone with you to care for you at all times. You will need to be able to take your temperature frequently, and you may need to inject treatments
- **Which transplant centre is treating you:** different centres vary in their policies.

  Even if it is arranged that you will be treated as an outpatient, you should be prepared to be re-admitted if you have complications or are very unwell. You should also be ready to say if you are finding any aspect of ambulatory care difficult.

Receiving the high-dose therapy

In most cases, you will receive your high-dose therapy within 4 to 6 weeks of your stem cell collection.

The high-dose therapy is a chemotherapy treatment called melphalan given at a high dose. The melphalan is given intravenously (into a vein), usually through a central line. The aim of the high-dose therapy is to remove as many as possible of the myeloma cells that are remaining after your 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. Within a few days of receiving it, your blood counts will start to drop.

Any other treatments you are on, such as **bisphosphonates**, are normally stopped during the transplant process.

Side effects of high dose therapy

Some of the more common side effects of high-dose therapy are listed below. These are likely to be most severe during the 2 to 3 weeks after the high-dose therapy, but some (including fatigue, loss of appetite and infection risk) are likely to continue for longer.

Risk of infection

Because high-dose melphalan damages your blood cells, including those that fight infection, you will be at increased risk of infection after the treatment. You will be monitored for signs of infection. Common signs include: high temperature (37.5°C or above); low temperature (below 36°C); feeling shivery or cold; passing urine more often or pain on passing urine; cough or cold symptoms; and rash.

You will also be monitored for a complication called neutropenic sepsis (febrile neutropenia). This a serious complication where there is a whole-body reaction to an

infection, in a patient who has low levels of neutrophils (a type of white blood cell).

Gut problems

High-dose therapy can cause gut problems, because the melphalan damages the cells lining the gut. These can include nausea (feeling sick), vomiting, diarrhoea and indigestion. You can also find your appetite is reduced. These effects are most likely to occur during the 2 to 3 weeks after the high-dose therapy, although the loss of appetite can last longer.

When you begin your high-dose therapy you will be prescribed an **anti-emetic** (anti-sickness) medicine to help prevent and minimise nausea and vomiting. Tell your nurse if your nausea and vomiting are not well controlled, as a different anti-sickness medicine can be prescribed.

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 treatments attack fast dividing cells, including the cells lining your mouth and digestive system. This makes your mouth sore, inflamed and blistered. It can make eating and drinking difficult.

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 given.

Your nurse will show you how to care for your mouth. This may include using antibacterial and antifungal mouthwashes, brushing your teeth frequently 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 and anaemia

You may feel very tired and lethargic after you have received your high-dose therapy. You may 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. One reason for the fatigue is the damage that the

high-dose melphalan causes to the production of red cells in the bone marrow. This can result in severe anaemia and cause fatigue. You may be given blood transfusions to help relieve this.

Fatigue may persist longer than some of the other side effects of the high-dose therapy. You may notice that you still feel very tired even for a few months after the HDT-SCT.

Bleeding and bruising

High-dose therapy commonly reduces the levels of platelets in the blood. This can result in increased risk of bleeding and bruising. You may be given infusions of platelets to minimise the risks of this.

Contraception and fertility

If you or your partner is receiving melphalan, you must use effective contraception during and for 6 months after the treatment, as melphalan is expected to be harmful to eggs and sperm and to a baby in pregnancy.

Melphalan may affect your fertility and ability to have a child, and may bring on an early menopause. 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 to 3 weeks after your high-dose melphalan. However, your hair should re-grow after 3 to 6 months.

'Chemo brain'

'Chemo brain' describes the mental fogginess, poor concentration and memory problems which can happen after many myeloma treatments. It is particularly common after high-dose therapy with melphalan.

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 see the **Melphalan Treatment Guide** from Myeloma UK

The transplant – having your stem cells returned

About a day after 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 chemical the stem cells have been stored in, and may include nausea and vomiting, abdominal cramping, feeling chilled and an unusual odour or 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 side effects.

Engraftment

Once the stem cells are given back, they travel from the blood to the bone marrow, where they settle and develop into new blood cells. This process is called **engraftment**.

The engraftment process is the start of the bone marrow recovery period. It takes 2 to 3 weeks for enough newly formed blood cells to be produced from the engrafted stem cells and to enter the blood.

During this time you will remain severely **immunocompromised**. This means that your immune system and your ability to fight infections are severely affected. Because of this you will need to stay in a clean environment such as a single room, or specialist ward until you have enough new blood cells. 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 explained on page 32.

Very rarely, stem cells do not engraft well and if this happens your blood counts will be low for a longer time. In this case, treatment can be carried out with injections of growth factors (G-CSF). In some cases more 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 medicines 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 (Revlimid®) has been approved in the UK for maintenance treatment after HDT-SCT, and there is strong evidence that it increases the time before myeloma returns. The dose 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-SCT is an anti-myeloma treatment given at a standard dose over a short period of a few weeks after the SCT. The aim is to deepen and prolong the response. Consolidation treatment is not part of routine treatment for patients after HDT-SCT.

Patients with **high-risk myeloma** (more active or more difficult to treat myeloma) may be given more intensive consolidation and maintenance treatment, for example, with bortezomib and lenalidomide.

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 of infection, anaemia, severe fatigue and bleeding. Special precautions and supportive measures are necessary during this time. The most common precautions are described below. On page 49, there are some hints and tips to help you cope during your hospital stay.

Protection against infection

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

You will be monitored for signs of a complication called neutropenic sepsis (febrile neutropenia). This a serious complication where there is a whole-body reaction to an infection, in a patient who has low levels of neutrophils (a type of white blood cell).

You will be asked to bathe 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 an infection (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-SCT process begins so that you know what to expect. Some centres no longer follow a formal 'clean diet', but you will be given advice on the importance of general hygiene during food preparation, and foods you should avoid.

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 treatments to help prevent fungal and viral infections will be 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 from someone else. These are called 'opportunistic' infections. They occur at this time because your immune system is very weakened.

Protection against anaemia and bleeding

Until your red blood cell and platelet counts start to rise, you will be at risk of anaemia or bleeding. Anaemia can cause severe fatigue during this time. 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. This is to destroy any white blood cells that can cause a reaction associated with blood transfusions after HDT-SCT. This treatment is called **irradiation**, and it is important that you receive only irradiated blood products following your transplant.

Continuing recovery and follow-up care at home

When your blood counts are high enough, you are free from signs of infection and you are generally feeling better, you should be able to leave hospital. If you are already an outpatient, you should be able to be seen less frequently 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.

The transition to recovering at home can be challenging. You may still be experiencing symptoms such as fatigue and weakness. You may also 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 your healthcare team nearby.

Before you are discharged, you should make sure:

- You know what signs and symptoms 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, including out-of-hours

The full recovery period may last for months but can vary greatly between patients. It can be a challenging time for patients and those close to them. Trying to get back to normal life has 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. There are also some hints and tips on coping with the recovery period at home on page 49.

Longer-lasting side effects

While you are continuing to recover at home you may still experience longer-lasting side effects of the treatment. These will vary but may include fatigue, loss of appetite, and sometimes 'chemo brain' and changes in bowel habits.

Support at home

You may want to arrange some support at home from family members or friends, in case you need it after you go home from hospital. This may help if you are experiencing ongoing symptoms, such as fatigue, dizziness and lack of appetite.

Follow-up 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 6 months following HDT-SCT, 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.

Tests and supportive treatments

At the follow-up 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 3 months.

Other treatments that may be needed are anti-sickness medicines, electrolytes (components of the

blood such as potassium and magnesium) and treatments that protect the stomach.

The healthcare team are there to help you so remember to report any new problems or raise any worries you have.

Supplements or herbal medicines that have not been prescribed by your haematologist may cause harm when taken alongside your prescribed treatment.

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.

After HDT-SCT, you will no longer be immune to diseases you were vaccinated against as a child, and you will need to be revaccinated. Each hospital has their own schedules for revaccinations after HDT-SCT, and your healthcare team will discuss this with you. Most of the vaccinations will be done at about 6 to 12 months after your HDT-SCT, while some (such as flu and COVID-19) may be done at about 3 months. Usually your GP will be given the schedule and will organise your vaccinations.

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

If you have had HDT-SCT, you should only receive irradiated blood products (see page 33). 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, or similar, particularly if they also have medicine allergies.

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

Transfer to your local healthcare team

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 healthcare team for routine appointments and monitoring.

Reducing the risk of infection at home

It can take many months after the HDT-SCT for your blood counts, and therefore your immune system and energy levels, to 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. These are described here.

Report any signs of infection

Watch out for any signs of infection, and report them to your healthcare team immediately. Common signs of infection include: high or low temperature (37.5°C or above, or below 36°C); feeling shivery or cold; passing urine more often, or pain on passing urine; cough or cold symptoms; rash.

Infection risks from food

Your healthcare team will discuss with you any precautions you should take with your diet. Commonsense measures will help you to avoid infections from your food. These include:

- Always washing your hands before eating
- Keeping your kitchen thoroughly clean and using an antibacterial surface spray
- Avoiding 'high-risk' foods such as unpasteurised milk and cheeses
- Cooking food properly
- Eating food by the 'use by' dates
- Eating food only from reputable stores and restaurants
- Avoiding foods that may have been left out for some time such as on buffets

Personal hygiene

You should continue to have a daily bath or shower, and wash your hands before eating, before 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® 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-SCT 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-SCT. 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 medicines. Treatment should be started as soon as possible.

> ⚠ **If you think you might have shingles, contact your healthcare team urgently, so that treatment can be started 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

During your recovery period at home, your risk of infections will depend on how well your white blood cell counts are increasing, and you will be advised on precautions you should take.

In the first few weeks following HDT-SCT 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).

You are also likely to have to avoid meeting family and friends in person for a time after your HDT-SCT 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 isolated from them. When you do arrange to see your family and friends, ask them to take precautions to avoid passing infections on to you (including staying away if they have symptoms, and using hand sanitisers).

Building work

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 your healthcare team advise that it is safe for you.

Pets and gardening

It's fine to have pets but you should take care of your hygiene around them, and wash your hands after petting them. 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 you are gardening, wear gloves as soil can contain 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 normal following HDT-SCT. It may be severe for a time, and may continue for some time during the recovery period. Fatigue 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-SCT.

Talk to your healthcare team about the fatigue you are experiencing. There may be ways of improving your energy levels through treatments or advice on lifestyle such as diet and exercise. Try to balance activity with rest when you have fatigue. Gentle exercise can help. Don't be afraid to ask people to help out.

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

Work, driving and holidays

The timing of returning to work will be an individual choice and will depend on the type of work you do, as well as how well you are. Returning to work may help in bringing a sense of normality. It may be possible to go back to work sooner if you can work from home, if you have a sitting or desk job, or if you are able to start back on a part-time basis. Talk to your healthcare team 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. Speak to your employer about reasonable adjustments to your duties and reduced hours, and having a phased return to your work.

It is usually safe to start driving as soon as you feel well enough, but it is a good idea to discuss this with your healthcare team.

It is not normally advisable to plan a holiday outside the UK for 6 months after HDT-SCT. 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. You may find it harder or more expensive to get travel insurance when you have a diagnosis of myeloma.

For more information see the **Travel insurance and myeloma Infosheet** from Myeloma UK.

Emotional effect of HDT-SCT

Treatment with HDT-SCT from initial induction to recovery can be a long process and will include ups and downs for patients and those close to them.

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

For most patients and those close to them, there is a huge sense of relief when the treatment is over. However, adjusting to life after HDT-SCT 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 take some adjustment. However, returning home is a positive thing and as you recover over the weeks and months following HDT-SCT, you will get used 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-SCT, and fatigue in particular, can be very draining, lasting longer than expected and making 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, you may find that you need to change the type and 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 those

close to you 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 add to the emotional effects of HDT-SCT.

Sources of support

There are a number of things that can help you and those close to you if you are 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:

- The Myeloma UK Peer Buddy service can match you up with a trained Peer Buddy for one-to-one support from someone who has experience of HDT-SCT

Visit **myeloma.org.uk/peer** to find out more about the Peer Buddy service

- 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 our Support Groups page at **myeloma.org.uk/support-groups** 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**

Long-term effects of HDT-SCT

Over recent decades, there have been dramatic increases in life expectancy and quality of life for myeloma patients. This has been related to the increasing number of effective anti-myeloma treatments, including HDT-SCT, together with improvements in supportive treatment and care.

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-SCT.

These may include:

- Organ damage – in particular, damage to the lungs can occur in rare cases. Always tell your healthcare team 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 cataracts, and it is important to have your eyes checked regularly
- Infertility – see page 28 for further information
- Second cancers – all chemotherapy treatments work by damaging the **DNA** in cells. Although very effective against myeloma cells, the high-dose melphalan used as part of the HDT-SCT 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, in order to control the symptoms and complications they cause.

To find out how your myeloma 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 3 months (100 days) after your transplant and occasional X-rays or scans. In general terms, your doctor will measure your response to HDT-SCT according to the criteria shown in Table 1.

Reponse	Summary of how the response is measured
Stringent Complete Response (sCR)	No detectable paraprotein No detectable myeloma cells in the bone marrow Normal free light chain ratio
Complete Response (CR)	No detectable paraprotein Less than 5% myeloma cells in bone marrow
Very Good Partial Response (VGPR)	More than 90% reduction in blood paraprotein Urine paraprotein less than 100 mg/24h
Partial Response (PR)	More than 50% reduction in blood paraprotein More than 90% reduction in 24h urinary paraprotein
Stable Disease (SD)	Not meeting criteria for any other response
Progressive Disease (PD)	Increase of more than 25% in blood or urine paraprotein, or development of new myeloma symptoms, or new bone damage seen on scans

Table 1. Summary of the criteria for measuring response to HDT-SCT

Other types of transplant

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

These types of transplant are described below. Your healthcare team will explain to you if one of these types of transplant is considered as a possible option for you.

Tandem transplants

Having a **tandem stem cell transplant** means having either a second HDT-SCT or an allogeneic transplant shortly after your initial HDT-SCT (usually within 6 months of each other).

It is thought that tandem HDT-SCT may benefit some patients, particularly those with high-risk myeloma.

An alternative is to collect enough stem cells to carry out two HDT-SCTs but to delay the second HDT-SCT until relapse. There is more about second transplants delayed until relapse on page 47.

Allogeneic transplants

An allogeneic stem cell transplant uses stem cells from a genetically '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.

However, the risk of this procedure is that the donor's immune cells also attack the patient's healthy cells. This can lead to what is called **graft versus host disease (GvHD)**, which can be serious and potentially life-threatening.

Allogeneic stem cell transplants are not widely used in myeloma, but may be considered in specific circumstances. They have the potential to benefit some patients, but the risks are greater than those for autologous stem cell transplants (using your own stem cells).

Mini-allogeneic transplants

Some patients may be considered for a procedure called a mini-allogeneic transplant (reduced intensity transplant). This involves giving a lower dose of chemotherapy before the donor stem cells are transplanted. The aim is to reduce the risks of GvHD compared with the risks with a 'full intensity' allogeneic transplant.

A mini-allogeneic transplant would usually be done as part of a tandem transplant after an autologous SCT (see previous page).

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

Treatment for myeloma that has relapsed after HDT-SCT

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

Why is HDT-SCT not a cure for myeloma?

Relapse occurs after HDT-SCT 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; whether your myeloma is of a higher or lower risk genetic type; and how you responded to other treatments and treatment combinations previously.

Treatment options at relapse after HDT-SCT

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

Standard treatment with anti-myeloma treatments

Most patients in the UK relapsing from HDT-SCT will receive a combination of anti-myeloma treatments. Several different combinations are available, and the choice will depend on factors including which medicines you received as induction treatment, and any complications you have had, such as peripheral neuropathy.

A second transplant

A second HDT-SCT may be offered if relapse occurs and there are enough stem cells still stored that can be

used. A second stem cell transplant done at relapse is sometimes called a **salvage stem cell transplant**.

A second HDT-SCT may be considered for you if you are fit enough, if you tolerated the first transplant well, and if you had a very good response to the first one. Some patients may decide they do not want to undergo the intensive treatment twice. In order to undergo a second HDT-SCT on the NHS, you would need to have had a long enough remission after the first transplant. Your healthcare team will be able to give you information about this.

Before a second HDT-SCT 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.

Clinical trials

New treatments 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** at **trials.myeloma.org.uk**

Hints and tips

HDT-SCT involves several weeks staying in hospital (or nearby accommodation), and a recovery period at home which may be long. These hints and tips may help you as you prepare for the treatment. They have been passed on to us by patients who have undergone HDT-SCT, and by those close to them.

Note: The hints and tips below are the personal experiences and opinions of individual patients, family members and friends, and should not replace the advice of your healthcare team. You should ask them if you have questions about your own situation. Everyone's experience of HDT-SCT is individual to them, and not all the hints and tips will be helpful to every patient.

Preparing for the treatment

- Know that no question is too silly to ask the healthcare team
- You need to be given a good understanding of the risks and benefits. These will allow you to make the best decision for you
- Because high-dose melphalan may cause hair thinning or loss, many patients choose to have their hair cut short or shaved by a hair salon before receiving the high-dose melphalan. Some may also have a wig fitted in advance. Many hospitals have a wig fitting service available, and you may be able to get a wig for free on the NHS. Your healthcare team will be able to give you details. Most suppliers will have wigs suitable for people from black and minority ethnic groups

> "A messaging group such as WhatsApp can be helpful, for the people you want to keep in the loop – to save your closest friends or partner answering the same questions multiple times!"

What to bring

- Bringing your own pillow and a colourful blanket can make your room feel more homely and comfortable
- An eye mask may help in case the hospital room is not dark enough for you to sleep easily, and a pillow spray to help combat 'hospital smells'

"Bring a photo or something that is sentimental to you to remember to keep going. Tomorrow is a new day."

- Your treatment may make your skin dry or sensitive. You might want to pack sensitive shampoo and soap, moisturisers and hand cream, even if you do not usually use these
- Bring a soft toothbrush and toothpaste, but avoid alcohol-based mouthwashes. You will be given suitable mouthwashes to use

"Bring some face flannels – very useful to cool your face on hot days"

- Bring soft toilet tissue and wet wipes, in case you are experiencing diarrhoea or sickness

Clothes

- Bring plenty of spare pyjamas, socks, a dressing gown, and slippers with non-slip soles
- Bring lots of jumpers as you may feel the cold, and also plenty of layers (T-shirts, shorts, cardigans) for times when the hospital is warm
- Ask family or friends if they can wash clothes for you and bring in clean supplies when they visit

"Clothes with loose or elasticated waistbands can be easier to wear if you have a sore stomach."

Food and drink

- If you are struggling to eat and drink (for example because of sore mouth or nausea), ask to speak to a dietitian. You may be helped by nutritional supplements, and some patients may need a feeding tube for a while
- Mints and boiled sweets (such as ginger) can help with nausea and with bad tastes in your mouth after the high-dose therapy. Cordials and fizzy water can be a change from plain water, and can help settle your stomach
- Ask if you can have food or takeaway meals delivered. Cup or packet soups may also be useful, as a change from hospital meals

“Ice lollies were an absolute godsend. They eased the soreness and got fluids into me!”

Keeping occupied and having visitors

- As well as a mobile phone, laptop or tablet, you may want to pack a pair of headphones and an extra-long cable to reach the bed. Remember your charging cables!
- During your recovery period in hospital, you may find that a mix of TV, films, magazines or music can help keep you occupied. It is common to feel a lack of concentration, so have things that are relaxing and that you can pick up and put down easily
- You may want to download some audiobooks and films in advance, and to sign up to one or two online streaming services before coming into hospital
- Visitors will be restricted, especially in the early days after your transplant, and visitors that are allowed will have to take precautions to prevent infections. You may find you don’t want visits in the very early days, as it is too tiring

“For me the thing that helped the most was having a loved one sitting close by – not speaking, just reading or knitting.”

Exercise and relaxation

- Ask your hospital if they offer complementary therapies that are suitable for you during your recovery period, such as aromatherapy
- A sleep or meditation app can be helpful
- Doing some regular gentle exercises or stretching can relax you, and help to minimise the loss of muscle tone that can occur during this period of reduced activity. Even just walking around the room can help
- Ask if an exercise bike is available in your hospital, or whether you could bring in your own or a hired exercise bike

"Try and keep routine like get up and shower, get dressed and sit in a chair and not lie in bed all day. Some days that's not possible, but even if it's an hour or two it helps."

Recovery at home

- Keep the contact details for your healthcare team handy (including out-of-hours numbers), and contact them quickly if you have any problems. In particular, contact them immediately if you have any signs of a possible infection (see page 37)
- Be as kind to yourself as you can, during your recovery period at home. It can be very frustrating when you can't do everyday tasks or they take a long time

"Try to go with what is happening, rather than battling with your expectations when progress is slower than expected. Be open to the fact that the recovery period can be very variable."

- If you're usually very independent, it can be difficult to adjust to relying on others, but ask for help, and take the help offered when you need it

"What helped? – seeing friends in short bursts. To keep infection down I tried to see them outside if the weather was good."

Recovery at home – food, exercise and rest

- Stock up on portions of bland simple-to-eat food, as your appetite may not return to normal for a while after you return home, and you are likely to lack energy for cooking meals

“ I was referred to a dietician and she recommended that I do not rely initially on full meals but snack regularly on things I might fancy. Initially these do not have to be healthy options but just ensure you eat something. ”

“ My husband had a walk out of the house every day possible, even if it was only to the end of the street and back. ”

“ Get some fresh air... I sat in the garden, even if it's only for a few minutes, it does help. If you have no access to a garden or don't feel up to it, open the window a little. ”

“ What helped? – Allowing myself to sleep and rest. You feel very weak so can't undertake normal life for a little while, so try to enjoy the quiet time. ”

Recovery at home – your emotions

- You may find your emotions are fragile when you return home – this is quite common

“ Staying positive is one of the biggest aids to recovery possible. ”

“ Being alone with cancer can be very hard. But... I did it. ”

“ Finally – You're a warrior...Go easy on yourself!! You may not have scars on the outside but ours are on the inside. Our bodies have been through something massive and so have we. ”

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 given to the patient following high-dose chemotherapy.

Ambulatory care: Medical care provided on an outpatient basis.

Anaemia: A condition in which the amount of haemoglobin in the blood or the number of red blood cells is below the normal levels, causing shortness of breath, weakness and tiredness.

Anaesthetic: A type of treatment 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 medicine used to prevent or treat an infection caused by bacteria.

Antibodies (immunoglobulins): Proteins found in the blood 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, enabling other cells of the immune system to destroy and remove them.

Anticoagulant: A type of medicine used to prevent blood clots from forming. Also known as blood thinners.

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

Apheresis: A procedure in which a person's blood is passed through a machine that collects one component (such as stem cells), and returns the rest of the blood to the person's body.

Autologous: A word used in transplants to mean 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 medicine that slows down or prevents bone damage. They are given orally or as an intravenous infusion.

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 blood cells.

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 treatment which is given as a subcutaneous injection.

CD34+ blood test: A test used to measure the number of stem cells in the blood.

Central line: A line (tube) that is inserted into a large vein just above the heart. It is used to administer treatments and to take blood samples. The type used may be a Hickman® (tunnelled) line, Portacath® or PICC. Also known as a central venous access device.

'Chemo brain': Used to describe the mental fogginess, poor concentration and memory problems which can happen after myeloma treatments. It is particularly common after high-dose therapy.

Chemotherapy: A type of treatment intended to kill cancer cells. Chemotherapy can be given orally or as an intravenous infusion.

Clean diet: A diet sometimes recommended for people who have a compromised immune system. Excludes 'higher risk' foods such as 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 treatment which is given orally or as an intravenous infusion.

Daratumumab (Darzalex®):
A monoclonal antibody treatment which is given as an intravenous infusion or subcutaneous injection.

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

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

Electrocardiogram (ECG): A test used to detect and record the electrical impulses that the heart uses to make it beat.

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 light chain (part of an antibody or immunoglobulin) that is not attached to the rest of the antibody.

Gas and air (Entonox®):
A pain-relieving gas that patients may be given during bone marrow biopsies.

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 that stimulates the production of stem cells. Synthetic (manufactured) forms of G-CSF are given to patients before stem cell collection.

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

Hickman® (tunnelled) line: A type of central line which is inserted under the skin in the chest and into a large vein just above the heart.

High-dose therapy (HDT): Treatment with high doses of chemotherapy given intravenously, usually via a central line, prior to patients receiving healthy stem cells as part of the stem cell transplant 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 treatment combination 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.

Irradiation: Process by which blood and platelets are treated before transfusion, to destroy any white blood cells. This is done to prevent the white blood cells causing a reaction in vulnerable patients (such as patients undergoing HDT-SCT).

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

Light chains: Part of an antibody (or immunoglobulin). An antibody is made up of two heavy chains and two light chains. There are two types of light chain, kappa and lambda.

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

Line: A thin flexible tube inserted into the body to administer medicines and fluids or to take blood samples.

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 treatment which is given orally or intravenously.

Mini-allogeneic transplant: A type of allogeneic stem cell 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 digestive tract.

Myeloma cells: The abnormal plasma cells that occur in myeloma.

Neutropenic sepsis (febrile neutropenia): A serious complication of chemotherapy treatment, where there is a whole-body reaction to an infection, in a patient who has low levels of neutrophils (a type of white blood cell).

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

Oral: By mouth.

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 type of central line that is 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.

Plasma cells: A type of white blood cell that produces 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 treatment used to help move stem cells from the bone marrow into the blood for collection prior to transplant.

Portacath® (implantable port): A type of central line. It consists of a small plastic chamber under the skin, attached to a flexible tube which is connected to one of the blood vessels.

Quality of life: A term that refers to a person's level of comfort, enjoyment, and ability to do 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.

Salvage stem cell transplant: A second stem cell transplant done after a patient relapses.

Sedatives: Medicines which have a calming effect to help reduce or relieve anxiety, stress or excitement, and are often used to induce sleep.

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 medicine or treatment, for example fatigue or nausea.

Stem cells: A type of cell from which a variety of cells develop. Haematopoietic (blood) stem cells make red blood cells, white blood cells and platelets. They are harvested for stem cell transplant.

Stem cell collection: Collection of stem cells from a patient's blood, using a process called apheresis.

Stem cell mobilisation: The process by which the number of stem cells in the bone marrow is increased, and they are released from the bone marrow into the blood, from where they can be collected.

Stem cell transplant (SCT): 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 6 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.

Notes

Useful organisations

Carers UK carersuk.org
0808 808 7777
Advice, information and support for carers.

Citizens Advice citizensadvice.org.uk
www.adviceni.net
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 macmillan.org.uk
0808 808 0000
Emotional, practical, physical and financial information and support to all cancer patients and their carers.

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

Mind mind.org.uk
0300 123 3393
Advice and support for anyone needing support with their mental health.

NHS 111 Service 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 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

Myeloma UK provides information and support to help you and to connect you with others with shared experiences.

Visit **myeloma.org.uk**, a one-stop-shop for information on myeloma; with videos, news and articles to help you keep up to date and live well with myeloma.

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

Get answers to your questions by emailing our Myeloma Information Specialists at **AskTheNurse@myeloma.org.uk**.

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

Learn about myeloma from experts and meet other patients at our **Infodays** and **Digital Infoday Sessions**.

Join a **Myeloma Support Group** to meet other people living with myeloma face to face or online.

Get matched up with a trained **Peer Buddy** for one-to-one support from someone with direct experience of myeloma.

Chat and share experiences with others affected by myeloma, including our peer volunteers, on the **Discussion Forum**.

We are Myeloma UK

Myeloma UK is the only UK charity focused on myeloma and its related conditions. We are here for everyone affected by myeloma. Together we make it possible to live longer and better lives with myeloma. Together, we support, so no-one faces myeloma alone.

All our charitable activity is funded by fundraising, voluntary donations, and gifts in wills. We couldn't do it without you, our supporters. Together, we are the cure.

Make a donation

You can donate online at **myeloma.org.uk/donate**, by phone, or by posting a cheque payable to **Myeloma UK**.

Fundraise

Fundraising is a positive way of making a difference. Whether taking part in or holding your own event it raises vital funds and helps raise awareness.

Leave a gift in your will

Over a third of all our charitable activities are funded by gifts in wills. That's a third of Infoline calls, a third of treatment approval panels and a third of research projects.

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

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 transplant

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

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