



Allogeneic stem cell transplant – Part I: introduction

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This brochure offers a general introduction to allogeneic stem cell transplants.

You will receive information about the principle, the purpose, the process and the possible consequences of this treatment. As we move closer to when your allogeneic stem cell treatment is about to start, you will receive more detailed information.

If you still have questions after reading this brochure, please do not hesitate to ask the medical staff looking after you.

Contact details for the various departments can be found at the back of this brochure.

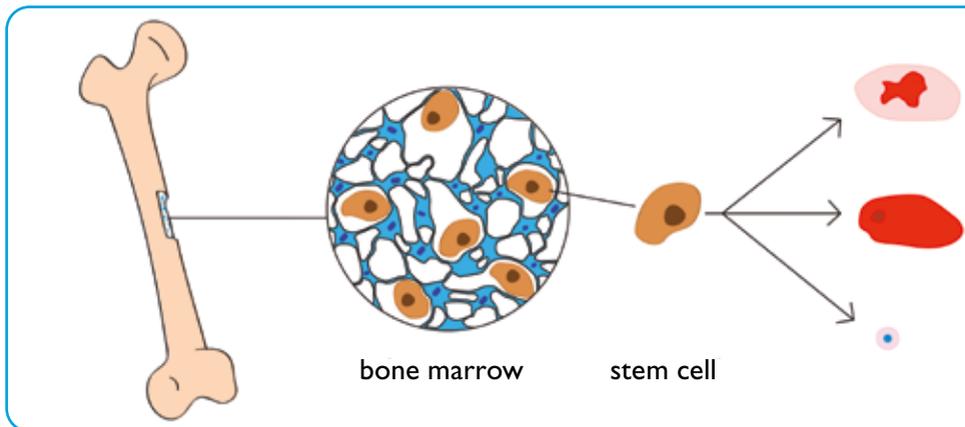
The Haematology Department

TERMINOLOGY

To understand the principle and process of a stem cell transplant, we first need to look at some of the terminology surrounding bone marrow, blood and blood formation. Below, we'll start by explaining a few of the general terms that will be used frequently in the rest of this brochure.

Bone marrow is the soft and spongy tissue in your bones. Your blood cells are formed in your bone marrow, as bone marrow contains a high volume of stem cells.

Stem cells are the parent cells of the blood cells in your blood. There are three types of blood cells: white blood cells, red blood cells and platelets. Every stem cell in your bone marrow will grow into one of these three types of blood cells, or into a new stem cell. While stem cells are mainly located in your bone marrow, some stem cells circulate in your blood stream. These stem cells are referred to as peripheral blood stem cells. Specialist methods can be used to release stem cells into the bloodstream, remove them and use them for a stem cell transplant. Additionally, alternative methods are used to retrieve stem cells directly from bone marrow.



Blood cells play a crucial role in our lives. As such, a properly functioning blood formation process is vitally important. Each of the three types of blood cells has its own function, which is explained in more detail below:

- White blood cells ('leukocytes') form the basis of our immune systems. They defend our bodies against infection by bacteria, viruses and other threats. There are different types of white blood cells, all of which play a different role in recognising, defending against and destroying pathogens. Neutrophils are one of the types of white blood cells. This group of white blood cells triggers the initial reaction of our immune systems. They make sure that infections are brought under control as quickly as possible.
- Red blood cells ('erythrocytes') contain haemoglobin. This is a protein that transports the oxygen in our blood from our lungs to other parts of our bodies.
- Platelets ('thrombocytes') cause our blood to clot to protect us when we are bleeding.

white blood cell

red blood cell

platelet

During your transplant, your blood count values will drop, and it will take some time afterwards for these values to return to normal levels. In some cases, this can take several months. As a result, your levels of all three types of blood cells will be carefully monitored during and after your stem cell transplantation.

PRINCIPLE AND PURPOSE OF THE TREATMENT

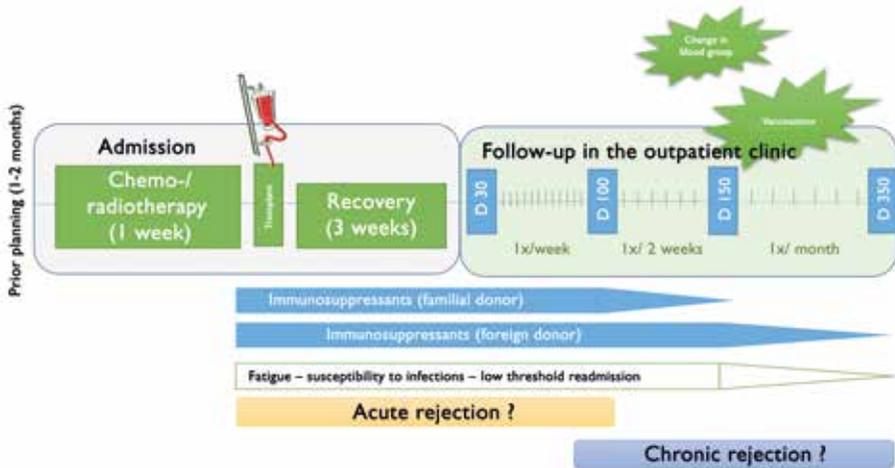
Your doctor has proposed an allogeneic stem cell transplant. The principle behind an allogeneic stem cell transplant is to replace abnormal stem cells with healthy stem cells from a donor. As such, you will need a suitable donor who is prepared to donate stem cells.

‘MYELOABLATIVE’ ALLOGENEIC STEM CELL TRANSPLANT

Prior to your allogeneic stem cell transplant, you will receive a high dose of chemotherapy and/or radiotherapy (i.e. conditioning). This treatment is necessary to kill as many of the malignant (blood) cells in your body as possible, but also to suppress the blood cells that provide your immunity to such an extent that they will not attack and reject the stem cells of your donor.

In ‘myeloablative’ conditioning, your bone marrow and blood production are suppressed so severely that they are unable to recover by themselves, meaning your blood cell formation process will be unable to get back up and running by itself or will get back up and running too slowly. The stem cells obtained from your donor resolve this life-threatening situation by helping your bone marrow and production process recover. In addition, the donor cells are able to track down and destroy any remaining malignant cells. *

* This section primarily addresses stem cell transplants in relation to malignant conditions. However, a stem cell transplant in line with these principles is also a treatment option for a number of benign conditions.



‘NON-MYELOABLATIVE’ ALLOGENEIC STEM CELL TRANSPLANT

Based on your age, your general condition, your illness or other factors, your doctor may suggest a more appropriate programme (a ‘non-myeloablative’ conditioning programme) in which the dose of chemotherapy given before the transplant is lower. Older patients may also be eligible for an allogeneic stem cell transplant as a result. However, this does not alleviate the stress of the treatment.

Due to the lower chemotherapy dosage with non-myeloablative treatment, your bone marrow is not completely destroyed. Consequently, after the donor stem cells have been transplanted, your body will contain both ‘foreign’ stem cells and your own stem cells (incl. any damaged stem cells). The donor stem cells will be able to recognise and destroy your own damaged stem cells.

THE TRANSPLANT PROCESS

LOOKING FOR A DONOR

An allogeneic stem cell transplant is only possible if a suitable donor can be found. A donor is deemed suitable if there is a sufficient match between their tissue type and yours. That's because your own cells and those of the donor will not recognise each other, and will try to reject each other as a result. To reduce the risk of rejection, your doctor will attempt to find a donor with a suitable tissue type.

Whether someone is a suitable donor has little or nothing to do with their blood group; instead, it mainly depends on the features of their white blood cells. The greater the difference in features between you and your donor, the greater the risk of rejection. However, as you and your donor are two different people, there is always a risk of rejection, even with a suitable match.

The search for a suitable donor will start as soon as you and your doctor have discussed the option of an allogeneic stem cell transplant.

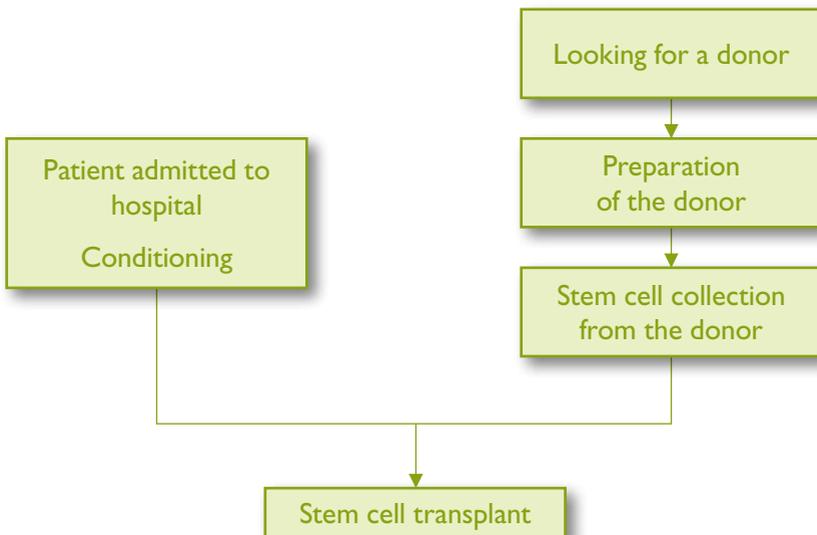
First, we will check if anyone in your family is eligible: your brother(s) or sister(s) will be the first option, and in rare cases, your parents or children may also be eligible. Blood tests are used to compare the candidates' tissue type against yours.

If no suitable donor is found among your close family members, the search will be expanded to a national and international database of non-related donors. These databases consist of people from across the world who are prepared to donate stem cells for a transplant. The identity and background of these donors is always kept confidential.

COLLECTING STEM CELLS FROM YOUR DONOR

To be able to obtain enough stem cells from the blood of your donor, the number of stem cells in his/her blood needs to be temporarily increased. In order to do so, your donor will receive subcutaneously injected growth factors a few days before his/her stem cells are collected. Once there are sufficient stem cells in his/her blood, they will be harvested by **apheresis** (see photo on p. 12). This is a technique used to remove stem cells from the bloodstream.

Apheresis is straightforward: no anaesthesia or surgical procedure is required. The stem cell laboratory will determine how many stem cells were harvested during the procedure and will process them further if necessary. After this step, your donor's stem cells will be transplanted to you as quickly as possible. For the best chance of success, it is important that the donor's preparation and the stem cell collection procedure are scheduled for the days right before your stem cell transplant.



The stem cells for an allogeneic stem cell transplant are not always collected from the donor's bloodstream. They may also be collected directly from his/her bone marrow. This procedure is referred to as a bone marrow transplant. In addition, stem cells may also be collected from umbilical cord blood. In some cases, these stem cells may also be eligible for an allogeneic stem cell transplant.



CONDITIONING

Around a week before your stem cell transplant, you will be admitted to hospital for chemotherapy and/or radiotherapy treatment. This is referred to as 'conditioning'.

As a consequence of this conditioning, you may experience side effects the same day and/or over the following days, including nausea and vomiting, reduced appetite, oral infection, fatigue, and hair loss. The exact nature of these side effects differs from person to person, and also depends on the conditioning you are given. Your doctor or nurse will tell you what the most common side effects are for your specific type of conditioning.

THE DIP

The high dose of chemotherapy and/or radiotherapy will have a destructive impact on your bone marrow. As a result, your levels of red blood cells, platelets and white blood cells will gradually, but significantly, decline in the days after your conditioning. This period is also referred to as the 'dip'. Most likely, you will require a transfusion of red blood cells and platelets. The drop in white blood cells will leave you highly vulnerable to infection and may cause a fever. As soon as your neutrophil count drops below a certain level, extra protective measures will be taken. For example, you will no longer be allowed to leave your room. From the moment your transplant starts, additional protective isolation will be set up, with extra attention given to the clothing worn by visitors and the hospital staff, for example.

Aside from chemotherapy, you will also receive other medication to suppress your immune system and to help prevent severe rejection when your donor stem cells are administered to your body.

THE TRANSPLANT



On the day of your transplant, the donor cells will be administered through a **high-speed intravenous drip** using a Hickman catheter or a central venous catheter (never via a portacath). This procedure will take around 30 to 60 minutes.

THE RECOVERY PERIOD

The side effects of your treatment certainly won't go away as soon as you have received your donor stem cells. You may still feel nauseous for some time while you are recovering, and your appetite will still be low. Your mucous membranes may still be infected, and you may feel pain in your mouth and have diarrhoea as a result. You will feel weak and tired. Your blood counts will also remain abnormal for a few days or weeks, as the stem cells will need time to embed themselves in your bone marrow and grow. As a result, you will remain highly susceptible to infection.

You will only be allowed to return home once your blood count has recovered, once you are able to eat enough and once you have adequately recovered from any complications. Usually, this will be three to four weeks after your stem cell transplant.

You will still have some way to go towards a full recovery, even when you return home. Your bone marrow will still be feeling the impact of the chemotherapy. As a result, you may still feel quite weak and tired for the first few weeks or months. In addition, your sense of smell or taste may be affected for some time, and you will remain at increased risk of infection. You will need to keep taking medication that suppresses your immune system to prevent rejection once you have returned home. Your doctor and nurses will monitor you intensively for the first few months after you have been discharged, and you will regularly need to visit the outpatient clinic as part of this.

CHANCE OF SUCCESS AND RISKS

The risk of your original illness recurring after a stem cell transplant is small, but there is a genuine risk of life-threatening complications. If you have any questions, doubts or concerns about these risks and the chance of success of your stem cell transplant, it is essential that you ask your doctor. Information you have obtained from elsewhere, such as the internet, is also best discussed with your doctor.

You may come across specific risk percentages in different sources of information. We would like to point out that the figures in different sources vary greatly and are highly general in nature. As there are a large number of individual factors at play in the chance of success and risks of your stem cell transplant, it is best to discuss these with your doctor.

POSSIBLE COMPLICATIONS

Prior to your stem cell transplant, you will receive chemotherapy and/or radiotherapy treatment as part of your conditioning. This conditioning involves a number of risks and complications in both the short and long term. These will be prevented and treated as much as possible. If you have any questions, doubts or concerns about these side effects, it is essential that you ask your doctor.

SHORT-TERM COMPLICATIONS

Infections

The chemotherapy and/or radiotherapy you receive will destroy the blood cells that control your immune system. On top of that, you will also receive medication to suppress your immune system and prevent rejection. As a result, you will be highly susceptible to infections for at least six months after your stem cell transplant.

Increased bleeding tendency

The chemotherapy and/or radiotherapy you receive will temporarily reduce your platelet count, meaning your bleeding tendency will temporarily increase. Your doctor will closely monitor the drop in your platelet count, and you will be given extra platelets as soon as necessary.

Failure to accept the stem cells

To prevent your body from failing to accept the donor stem cells, your own immune system will be suppressed using medication. It is rare for donor cells not to be accepted, but if this does occur, this complication can be life-threatening.

In this case, your doctor may consider harvesting new stem cells from your donor and transplanting these to you again.

Graft-versus-host disease

The reverse may also occur: the donor cells may reject their host, i.e. you. The donor stem cells may see your body as 'foreign' and may attack it as a result. The chance of this happening increases proportionally as the match between you and your donor gets smaller. That said, even with a perfect match, there is always a risk of rejection, as you and your donor will always remain 'foreign' to one another.

Graft-versus-host disease (GvHD) may take an acute or a chronic form. The acute form may occur from ten days after the transplant to three months after. Often, this form is temporary, and the severity of the symptoms can vary. Some patients may only experience an irritating but innocent skin reaction with redness and itchiness around the palms of their hands, soles of their feet or behind their ears. In some cases, redness may appear across the entire body. Other possible symptoms include nausea and diarrhoea. In more severe cases, rejection may cause lung and/or liver damage.

The first step in reducing the chance of rejection is to find the most suitable donor for you. In addition, you will be given medication for at least six months after your transplant to reduce the risk of graft-versus-host disease. This medication can be reduced after a while; as the donor tissue starts getting used to its host, the risk of any graft-versus-host reaction will decrease.

A mild reaction can also be beneficial. The donor cells may clear out any remaining cancer cells; in this case, the donor stem cells are reacting against your disease.

VOD

VOD stands for veno-occlusive disease of the liver. This is a rare complication, in which the small blood vessels in the liver are damaged and liver function gradually deteriorates.

The symptoms of liver VOD include abdominal pain around the liver, fluid accumulation with weight gain and jaundice. Impaired liver function prior to a stem cell transplant increases the risk of VOD.

LONG-TERM COMPLICATIONS

Chronic graft-versus-host disease

The chronic form of graft-versus-host disease usually only occurs three months after the transplant or later, and may last for years or become permanent. You may suffer from dry eyes, a dry mouth, muscle cramps and so on. The most common systems are skin changes, but other organs may also be affected.

Fatigue

Fatigue is a common side effect of stem cell treatment, and you're unlikely to stop feeling tired once your treatment is over and you return home. Many patients continue to feel tired to a greater or lesser degree for months or even years after their stem cell transplant. Some patients are able to resume their normal activities more quickly than others. The medical staff looking after you can advise you on how to deal with this fatigue.

Reduced thyroid function

If you were given total body irradiation as part of your preparation, your thyroid function may be reduced as a result. Possible symptoms include fatigue, constipation, sleepiness and weight gain. These complications can be treated fairly easily with medication.

As such, it is important that you tell your doctor about these symptoms.

Eye problems (cataracts)

If you were given total body irradiation as part of your preparation, you may develop cataracts over time. Cataracts are an eye condition in which the lens in your eye becomes cloudy, leading to blurred vision. This complication can be resolved through a minor surgical procedure.

Higher risk of (a new) cancer

A stem cell transplant is an invasive treatment that often involves a heavy dose of chemotherapy and/or radiotherapy. This treatment is necessary for your disease, but the evidence now also shows that invasive treatments of this type involve a higher risk of developing (a new) cancer in the long-term. Your doctor will take this into account and will continue to monitor you. Excessive exposure to UV radiation (through sunbeds) is best avoided in any case, and it's best to have any suspicious skin blemishes checked by a dermatologist. It is also essential that you stop smoking.

Infertility

Your preparatory chemotherapy and/or radiotherapy treatment may cause (temporary or permanent) infertility.

If you are planning to have children, it is important to discuss this with your doctor in advance. It is also a good idea to discuss how big this risk is as part of your chemotherapy treatment.

In men, high doses of chemotherapy and/or radiotherapy may reduce the volume and/or mobility of sperm cells. Erectile dysfunction may also occur. These factors may leave you temporarily or permanently infertile, so it's a good idea to have sperm frozen at the earliest possible stage of your treatment. Your doctor will refer you to a fertility doctor to help with this.

In women, stem cell treatment may cause ovarian damage, leading to irregular or missed periods. This may be temporary and doesn't necessarily lead to infertility. If your doctor believes that your treatment may leave you permanently infertile, he/she will refer you to a fertility doctor prior to the start of your chemotherapy to discuss your options.

The damage caused to the ovaries and menstruation pattern may also cause some women to experience early menopause symptoms after treatment, such as hot flashes, mood swings, vaginal dryness or itchiness and osteoporosis. Your doctor will ask you about this and refer you, if necessary.

The risk of infertility may not be a priority to you at the moment, but you may want to have a child later in life. As possible infertility can become a source of stress at that point, it is best to discuss your options with your doctor in advance.

Changed sexuality

The sexual consequences of a stem cell transplant differ from patient to patient.

Your sexual needs or libido may have changed after your treatment. Your treatment may have affected you to such an extent and take so much energy that you feel little or no need for sex or intimacy.

Physical problems may also affect your sex life. In women, the treatment may trigger early menopause symptoms. The hormonal changes that occur as part of this may leave your vaginal mucus feeling dry and delicate. Men may experience erectile dysfunction. Feel free to talk to your doctor to see what can be done about this. A specific brochure is available on sexuality after a stem cell transplant.

PSYCHOLOGICAL STRESS

Aside from physical stress, stem cell treatment also involves psychological stress for you and the people around you.

A stem cell transplant offers hope for the future, but the psychological stress involved means the road to get there can feel long and treacherous. You will be faced with all kinds of medical procedures, physical discomforts and limitations. The waiting period prior to the transplant, the transplant itself and the recovery period will all bring new questions and concerns. It goes without saying that all these aspects will impact your emotional well-being.

Your family, friends and acquaintances will also experience this as a difficult period. As they will each look at the situation from their own perspective, it is not always easy to understand each other's concerns. Consequently, it is important to talk about your concerns or negative feelings, both with the people around you and with the medical staff looking after you.

COST

The cost of a stem cell transplant is high, but most of the cost will be reimbursed by your health insurance fund. That said, you will still need to pay part of the cost yourself. It is best to discuss this with the doctor or social worker.

DECIDING AGAINST TREATMENT

Perhaps the stress and risks of this treatment seem too much for you, and you are doubting whether a stem cell transplant is right for you. Feel free to discuss these doubts with your doctor.

If you feel like you need a second opinion from another doctor at a different transplant centre in order to decide whether a stem cell transplant is right for you, feel free to discuss this openly with your doctor.

You have the right to decide against this treatment. If you decide to do so, your doctor will respect your decision and the team will continue to support you with the best possible care.

THE HAEMATOLOGY DEPARTMENT AT UZ LEUVEN

Every year, the Haematology Department at UZ Leuven performs around 120 stem cell transplants, 80 of which are allogeneic. This makes it one of the most experienced transplant centres in the country.

MEDICAL STAFF

The Haematology Department is staffed by a permanent medical team including supervisors. You will meet one or more of these supervisors during your treatment. UZ Leuven is also a teaching hospital, where residents or resident physicians specialise under the supervision of the permanent medical staff. All units at the Haematology Department have assistants. They will examine you on a daily basis and discuss the results with their supervisor.

Each unit has its own team of nurses, and each unit is managed by its own head nurse. While they are working on the unit, each nurse will be responsible for a certain number of patients allocated to him/her. The nurses contribute to the success of your treatment.

In addition to the above, social workers, psychologists, a psychomotor therapist (stress reduction and relaxation therapy) and a pastoral support worker are also available. They can help you deal with the practical and emotional difficulties you may be faced with during your treatment.

The department also has access to the services of a dietician and a physiotherapist.

UNITS

The Haematology Department at UZ Leuven consists of different units. Each of these units has its own organisation, but they are closely connected and they supplement one another.

There are two accommodation and nursing units: E 630 and E 467.

The E 467 unit only has single rooms and offers the option of isolation. Allogeneic stem cell transplants are only performed on this unit.

E 630 is a unit that has both single and double rooms and also offers the option of isolation. The preparation for your allogeneic stem cell transplantation may take place at this unit, as may any aftercare and readmissions.

E 616 is the outpatient clinic where most of your post-transplant monitoring will take place. You may also receive outpatient care at this unit prior to your treatment. The outpatient clinic also has an 'apheresis' room where your stem cells are harvested.

E 612 is our consultation unit. Once you no longer need to attend the outpatient clinic, you will be monitored there.

CONTACT DETAILS

You can contact the different nursing units using the following telephone numbers:

E 467: tel. +32 (0)16 34 46 70

E 630: tel. +32 (0)16 34 63 00

E 616: tel. +32 (0)16 34 88 66

E 612: tel. +32 (0)16 34 66 60

For more information and different brochures, visit:

www.uzleuven.be/allogene-stamceltransplantatie

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Design and Production

This text was composed by the Haematology Department in conjunction with the Communications Department.

This brochure is also available at: www.uzleuven.be/en/brochure/700074.

Any comments or suggestions related to this brochure can be shared via: communicatie@uzleuven.be.

Editor-in-chief
UZ Leuven
Herestraat 49
3000 Leuven
Telephone 016 33 22 11
www.uzleuven.be

 mynexuzhealth



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