



Information for a possible stem cell donor

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Introduction

Soon one of your family members will undergo a stem cell transplantation. For this treatment, a stem cell donor is required who is related to him/her.

This folder gives further information about choosing a suitable stem cell donor, the tests that will be performed on the donor, and the procedure involved in collecting the stem cells from the donor's bone marrow or from the blood. The specific subject of this folder is stem cell *donation*; there is another folder that gives further information about stem cell *transplantation*. This folder is intended to supplement the information that was given to you orally.

Why have a stem cell transplantation?

Your family member has a form of cancer for which there is a greater chance of recovery if several chemotherapy treatments are followed by stem cell transplantation.

Preceding the stem cell transplantation, chemotherapy is given, possibly in combination with total body radiotherapy. This treatment will damage the patient's bone marrow as well as his/her immune system. Through the use of healthy donor stem cells, we can ensure that the patient's blood and immune system will recover. In addition, the donor immune cells can eliminate the patient's remaining diseased cells. This is called an *allogeneic* stem cell transplantation, i.e. when stem cells from a healthy donor are used.

Choice of donor

To be eligible as a stem cell donor, the donor's HLA typing must be suitable. When choosing a donor, the first step is to determine the tissue type of the patient's nearest relatives (brothers, sisters and parents), in order to determine the hereditary characteristics present on their cells. This is called HLA typing (HLA is short for Human Leukocyte Antigen). For HLA typing, a few tubes of blood are drawn from the family members. This is usually done some weeks or months before it is decided whether a stem cell transplant is the best possible treatment for the patient.

The formation of blood cells (haemopoiesis)

Every day, many billions of blood cells are created in a healthy person, to keep the number of blood cells at the right level. The red blood cells (erythrocytes) are needed to transport oxygen throughout the body. The white blood cells (leukocytes) ensure resistance to infection. The blood platelets (thrombocytes) play an important role in blood clotting. In addition to blood cells and blood platelets, the blood consists of plasma.

six hours. In almost all cases, two days is enough to harvest sufficient stem cells. Depending on the type of transplantation, a third or fourth day is sometimes required. As soon as sufficient stem cells have been collected, you can stop administering the growth factor. After stem cell aphaeresis is finished, you can go home; so you will not have to stay in hospital. You may feel tired after stem cell aphaeresis, so we advise you not to drive home by yourself.

In some cases the veins in your arms may not be suitable for inserting an infusion needle. In this case a needle is inserted into a bigger vein: a vein in your groin. Through this groin line blood will be drawn by means of a machine, and the processed blood will be returned to your body. If stem cells have to be collected for several days in this case, you do have to stay in hospital so that the infusion needle can be left in the groin.

Side effects of the growth factor

Because the growth factor stimulates the creation of stem cells from the bone marrow, a slight pressure on the periosteum (the fibrous membrane covering the surface of bones) may result, which may lead to aching bones. This can be effectively treated with a painkiller (e.g. 500 to 1,000 milligrams of Paracetamol, no more than 3 to 4 pills a day). The bone ache will go away as soon as the treatment with the growth factor ends. During the days when you are given the growth factor, you can also feel as if you are getting the flu. In a small percentage of cases, the growth factor can cause an enlarged spleen, allergic reaction or thrombosis.

Side effects of stem cell aphaeresis

For stem cell aphaeresis it is usually necessary that an IV-drip is inserted in both your arms, through which your blood is drawn and the processed blood is returned. In view of the great speed at which the blood is drawn, a fairly thick infusion needle is required, which is usually inserted in the fold of the elbow. The insertion of an infusion needle can be painful. In addition you will have little mobility in your arms during the stem cell aphaeresis process. During aphaeresis, a fluid is added drop by drop to the blood that was drawn, which will keep your blood from coagulating inside the machine. This anticoagulant solution will then also enter your body, where it binds the calcium. In some cases, this can cause tingling in your lips or fingertip. If this happens, it is often easy to do something about this to minimize these complaints. It is important, therefore, to let us know as soon as possible if you have any complaints. Stem cell

aphaeresis lasts several hours, and can be an uncomfortable and boring procedure. We advise, therefore, to bring something to keep you occupied (such as music). Finally, you should know that stem cell aphaeresis 'harvests' only a very small percentage of the total quantity of stem cells that you possess; so you do not have to be afraid that the procedure will cause any lasting harm.

Stem cells from the bone marrow: bone marrow collection

Because bone marrow collection is done under general anaesthesia, you will be examined by the anaesthesiologist, who will discuss a few points with you that are relevant to the anaesthesia. Preceding the collection in the operating room, an IV-drip is inserted through which the anaesthesia is administered. During bone marrow collection, you will lie on your stomach. Next, the bone marrow (mixed with blood) is suctioned out on both sides of the pelvis by two doctors, by means of bone marrow needles. No more than a few percent of the entire quantity of bone marrow is harvested. In due time, this will be replenished by the bone marrow itself. The bone marrow collection takes about two hours. In the afternoon your own red blood cells that were drawn together with the bone marrow stem cells, will be returned to your body.

After you have been examined by the haematologist on duty, you will be able to go home by the end of the day. In view of the anaesthesia we advise you not to drive home alone.

Side effects of bone marrow collection

In the week following the collection of your bone marrow, you may feel more tired than usual. It is important, therefore, that you take time to recover. The place where the bone marrow was taken, is often bruised and painful. This feeling may last for a couple of days, and is often easily treated with a painkiller (e.g., 500 to 1,000 milligrams of Paracetamol). The anaesthesia can cause a (slight) feeling of sickness. Also, you may develop low blood pressure in the first hours after collection. If this is the case, additional fluid is administered through an IV-drip.

What happens after the stem cells have been collected?

Stem cell transplantation

After the stem cells have been collected, they are

counted in the laboratory and processed if necessary. Depending on the type of transplantation, the stem cells are administered to your family member through an IV-drip either immediately (that same day and/or the next day), or they are frozen, and unfrozen and returned a few weeks later: the actual transplantation. Via the bloodstream the stem cells make their way to the bone marrow, where they can then nestle and ensure the production of healthy blood and a healthy immune system. In consultation with your family member, you can be present for the transplantation if you like.

Donor lymphocytes infusion

After the stem cell transplantation, you can be approached again, this time for the donation of white blood cells. This can happen if the malignancy has come back, or if in the end not all of the patient's blood cells prove to originate from the donor. If such a situation occurs, this is discussed with you, and you will be asked to donate white blood cells. At the dialysis ward, the white blood cells (leukocytes) are collected by means of leukapheresis. This time you do not have to administer growth factor; after all, no stem cells will need to be mobilized from the bone marrow into the blood, because this concerns the harvesting of white blood cells that circulate in the blood under normal conditions. Whether or not this situation will occur again depends on the type of transplantation.

Who is suitable as a stem cell donor?

HLA-typing

When choosing a donor, the first step is to determine the hereditary characteristics on the cells (not the same as blood type), the so-called HLA typing, because to be eligible as a stem cell donor the donor's HLA typing needs to be suitable. In addition, the donor must be in a good physical condition, to be able to cope with the procedure. Also, the donor should not have any blood-transmissible diseases which could be harmful to the recipient, and his/her blood formation has to be normal.

Donor testing

Once we know whether you have an HLA typing that is suitable for your family member, you will be asked by one of the stem cell transplantation coordinators whether you want to be a stem cell donor. If you agree to donate your stem cells, a follow-up appointment is made for you for further blood tests and a general physical examination.

You can donate stem cells only if you are in good health and do not run any unnecessary risks by the collection of stem cells. If you are prepared to donate stem cells, the stem cell transplantation coordinator will invite you

to meet with an independent doctor (not your family member's attending physician). During this meeting you are informed in more detail about the stem cell transplantation and stem cell donation procedures. This is followed by a physical examination in order to check whether your health permits you to donate stem cells. On this occasion your blood will also be taken for additional testing. Among other things, your blood will be tested for the presence of blood-transmissible virus infections such as Hepatitis B and C (jaundice) and HIV (the condition that causes AIDS).

After giving you extensive information, the doctor will ask you whether you agree to donate stem cells on behalf of your family member. Your permission is then recorded in writing. Naturally, you are free to refuse, or withdraw your permission in the interim.

After testing, you will meet with the stem cell transplantation coordinator, who will give you additional information, both orally and in writing, about matters such as the donation procedure. In addition, the stem cell transplantation coordinator can answer any questions you may have.

To most people, giving stem cells to help a member of your family is the obvious thing to do. However, we can imagine a situation where this is less obvious; for instance, if your relationship is not all that good. If you have any doubts, do not keep them to yourself, but talk about how you feel with a person you trust, with the doctor, the stem cell transplantation coordinator or your GP.

Final check-up

About six weeks after stem cell collection, you will be invited to meet the doctor. He/she will discuss with you the entire donation procedure, answer any questions, and will ask you if you have any physical problems.

Mental stress

The request to be a donor may well cause some emotional stress on your part, and this should not be minimized. While it is true that your relative will receive the best therapy available by means of this treatment, this does not mean a 100% guarantee that the disease will go away and stay away. It is also possible that the white blood cells from the donor graft (the T-lymphocytes) will cause a severe immunologic reaction against the patient: the so-called 'graft-versus-host disease'. The course of this disease may be moderate to severe; the outcome can sometimes even be fatal to your relative. These are things about which

you as donor can do nothing. In case of some diseases, such as chronic myeloid leukaemia and possibly other types of leukaemia as well, the graft-versus-host disease also has a useful aspect: the white blood cells from the graft taken from the donor will also fight any malignant cells that may have remained.

Maybe you feel that by donating stem cells you are “really” doing something for your sick family member. But later on you may start feeling insecure or even guilty if, for instance, the graft is rejected. These and other complications are matters that cannot possibly be helped by you as a donor.

Donors are sometimes afraid to get sick or get a cold. Sometimes, the people around you pay extra attention as well. Of course you do have a certain responsibility, but you can live, work and enjoy your hobbies just as you normally would. You can eat and drink normally. Just try to avoid unnecessary risks, and protect yourself a bit better from infectious diseases. If you should fall sick before the donation, do get in touch with your stem cell transplantation coordinator as soon as possible.

Practical matters

The medical costs that are incurred on behalf of you as donor are basically reimbursed by the patient’s health insurance. So you will not get any invoices. If this should nevertheless happen, we advise you to contact the stem cell transplantation coordinator. It is also possible that the health insurance company does not want to reimburse the G-CSF growth factor. If this is the case, do not ask your own pharmacy to deliver the G-CSF, but get in touch with the stem cell transplantation coordinator.

Any travelling expenses made by you as donor can be reimbursed by the health insurance company. This depends on the conditions of your family member’s insurance; he/she will have to get in touch with his/her health insurer him/herself. If you do not have overnight accommodation near the hospital, please contact the stem cell transplantation coordinator to find an alternative.

Not every donor wants to discuss stem cell transplantation with his/her employer. Of course this is up to you, but it is our experience that most employers do show understanding. Often they are prepared to grant you special leave, so that you do not have to call in sick or take days off. The same applies to donors who are in school. If the employers or school directors have any questions that you cannot answer, they can get in touch with the attending physician of your relative.

Naturally, confidential information such as the results of tests that were done on you or information regarding the patient will never be communicated to them.

If you need to cancel a vacation because of the transplantation, you will only get your money back if you have taken out cancellation insurance.

In conclusion

People who were HLA-typed on behalf of a family member and were not chosen as donor, can register through the Europdonor Foundation (Stichting Europdonor) as a non-related bone marrow donor. For information about this, check the Europdonor Foundation website www.europdonor.nl. This is the foundation that manages the Dutch bone marrow donor bank.

If you have any further questions after reading this information or if anything is unclear, you can contact the attending physician at any time (phone +31 43 387-7025) or one of the stem cell transplantation coordinators (phone +31 43 387-5009), even if some time has already passed since the transplantation. Or you can contact the Bone Marrow Transplantations Contact Group (Contactgroep Beenmergtransplantaties – BMT). This contact group gives support to patients, family members and donors. Folders about this are available at the polyclinic or the nursing department.

This brochure contains information about stem cell donation; it is currently being printed. Further information about stem cell transplantation can be found in the brochure ‘Bone Marrow and Stem Cell Transplantation’. the polyclinic and at the nursing department. Information can also be found on our Further information on HLA typing is found in the brochure ‘HLA typing’. This brochure is available through your stem cell transplantation coordinator (phone +31 43 387-5009).

Glossary

Allogeneic: Originating from a genetically different individual.

Bone marrow: The ‘blood factory’: the bone marrow contains the stem cells that engender the creation of blood cells. The bone marrow is a soft mass located on the inside of the bones.

Bone marrow puncture: A needle is used to suck the bone marrow cells from a bone (usually the hipbone).

Blood (cells): Blood consists of blood fluid (plasma) and blood cells. The red blood cells (erythrocytes) ensure the transport of oxygen throughout the body, while the white blood cells (leukocytes) constitute the immune system that protects the body from infection. The blood platelets (thrombocytes) are needed to ensure that the blood coagulates.

Chemotherapy: The treatment of cancer with cell growth inhibitors. These medicines are used to combat uninhibited cell growth (i.e., cancer).

CMV: Cytomegalovirus: a virus infection which many people may have had without being aware of this, and which may flare up again in case of reduced immunity.

G-CSF: A growth factor that ensures that stem cells are transported from the bone marrow into the blood.

Graft-versus-Host disease: A side effect that can occur after stem cell transplantation: the donor stem cells view the patient's body as 'foreign' and attack.

Haematologist: Internist specializing in the treatment of people with diseases of the blood, bone marrow and lymph nodes.

HLA: Human Leukocyte (white blood cells) Antigen (markers).

HLA typing: Tissue typing. Comparable to blood type, but not the same. The HLA type can be identical while the blood type is different, or vice versa. There are a great many different HLA types. Allogeneic stem cell transplantation is possible only if a donor is found with a (virtually) identical HLA type.

Stem cells: Progenitor cells that mature into blood cells.

Stem cell aphaeresis: A method of harvesting stem cells from the blood.

Stem cell transplantation: The administration of stem cells after (high doses of) chemotherapy.

Important addresses and telephone numbers

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A5 Nursing Department +31 43 387-6510
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Secretarial Office: +31 43 387-7025
Stem Cell Transplantation
Coordinators: +31 43 387-5009
Bone Marrow Transplantations
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