

Information regarding transplantation with donor stem cells.

Pre-transplant examinations

- Anyone who is scheduled for allogeneic stem cell transplantation has to undergo check ups to determine the functioning of the body's vital organs, which is the heart, kidneys and lungs.
An evaluation of any previous treatment is made.
Verification of past viral infections is reviewed.
- It is important that any dental treatment is completed at least two weeks before admission, so that you do not have any remaining infection in dental mucosa or jawbone.
- To prepare yourself mentally and to solve any practical problems in your home situation for the duration of your treatment you will be offered to talk to a counsellor. You are also welcome to contact our counsellor before you come here, please refer to the last page.
- The waiting time can feel long and uncertain. Take the opportunity to build up your well-being.



At the prospect of admission

- Please feel free to bring any books, records or needlework you would like to have. You can bring a laptop if you have one (broadband in your room). Laptop computer and VCR / DVD player can also be borrowed. We anticipate that you will be in hospital 6-8 weeks plus possibly some time in the patient hotel.
- If you would like to, you may have a relative or friend staying with you in your room. Anyone who is staying in your room should be free from infection, take care of themselves and follow our procedures for hygiene, etc. Above all they should be a support for you. The person who is staying with you during the hospital stay will be served breakfast and snacks. These meals can be taken in the family room in the ward. The family room also has a microwave oven, refrigerator and freezer.
- Please bring indoor shoes and socks but also outdoor wear appropriate for taking walks. Exercise has many positive effects; you should try to maintain your condition even while you are in hospital. Please talk to our physical therapist if you have questions about training! You may want to get in contact with them before you go in for your treatment, please refer to the last page.
- A washer and a dryer are available in the ward.

General information about the Haematology ward

- This department specializes in the care and treatment of patients with haematological disorders (blood diseases) and transplantations with blood stem cells.
- Many of our patients are highly susceptible to infections due to illness and/or treatment. Specific hygiene rules are applicable for staff, patients and visitors.
- Nutrition and food handling has a central place in the health care of our department.

Treatment before transplantation

1. Admission to the Haematology ward, G41, occurs 2-3 days before the start of conditioning treatment. During these days, your test results will be evaluated. The doctor does a final check to see that the results from your pre-transplant examinations were acceptable, and that all necessary tests were carried out. For most patients a bone marrow examination is required.

2. During the transplant period, you will need a central venous catheter (central line) with three lumens (openings) for us to take blood samples and administer intravenous medication by. If you already have a central line with fewer than three lumens you will need an additional catheter with 1-2 lumens. Insertion of the central line is performed by an anaesthesiologist under local anaesthesia in the surgery department.
3. Hydration therapy will be started the night or day before you start chemotherapy. This will be accomplished either by you drinking extra or by an intravenous drip. Before treatment starts, you will receive medication against nausea and possibly other drugs to prevent potential treatment side effects. You will have a room in the isolation¹ part of the ward from when your treatment starts.
4. Conditioning: In some cases, an antibody therapy (immunosuppressive therapy) is given in addition to the tumor/bone marrow treatment (chemotherapy) as a preparation for reception of donor cells (the stem cell transplant).
5. During conditioning, you may be disturbed by staff both during the day and during the night. Some treatments require that we measure both the liquid you drink and volume of your urine production. Daily inspections of your weight will be done and during certain periods several times per day. Blood sampling can be needed at any time of the day or night.
6. The day before transplantation immunosuppressive therapy is started, usually a medicine called cyclosporine². To start with, it will be administered intravenously, later on as tablets.

7. Transplantation

The same day as the last antibody treatment, or a night or two after completion of chemotherapy, the donor stem cell transplantation will be performed. The donor is usually harvested for stem cells the same day or the day before and the cells are usually fresh. In some cases they have been frozen and are thawed at the time of the transplant.



The transplant is given as an injection into your blood stream through your central venous catheter. The volume can vary, but the number of stem cells is calculated according to your weight. The transplantation is performed in your room. You are monitored over the next few hours with regard to immunological reactions. Similar reactions can also occur when transfusions of blood components are performed.

Effects and side effects of conditioning

The chemo treatment that you receive before transplantation (conditioning) may give several side effects along with the desired effects on your disease. When your conditioning commences, your own bone marrow production and maturing process of blood cells ceases. Other fast-growing cells that are damaged in the process are mucosa (membranes) in the mouth and digestive tract. After about two weeks you can lose your hair and nail formation may also be affected.

Blood samples are taken daily to monitor the levels of white blood cells, haemoglobin and platelets.

- The white blood cells disappear gradually from the blood stream, being at the lowest after about a week. To reduce the risk of severe infections, you will receive preventive drugs

¹ Isolation means that the door to your room will be closed. Anyone who enters your room must wash their hands and use hand disinfectant and otherwise follow our procedures for hygiene. For more detailed information, see the binder in your room.

² Cyclosporine is available both as an infusion, and as capsules. The medicine is given to all patients who have undergone transplantation due to the risk of rejection. In the case of transplantation of stem cells, it aims to mitigate the transplanted cells' immune response against the host. The level of cyclosporine in the blood is measured regularly.

against viral, fungal and bacterial infections. In the case of fever and signs of infection you will be given intravenous antibiotics.

- Platelets (thrombocytes), which help to stop bleeding, may need to be replaced with platelets from healthy donors. You may need transfusions even after you leave the hospital, for a shorter or longer period of time.
- The red blood cells, that provide the body with oxygen, may also need to be replaced. The haemoglobin value, but also your "feel good value" determines the frequency of blood transfusions required. In case of bleeding or haemolysis (breakage of red blood cells) you may require more frequent transfusions. The number can vary from a few weekly transfusions to several per day. You may also need a few transfusions after you leave the hospital.
- Sores in the mucous membranes can occur which often leads to pain. You may need morphine based pain relief a shorter or longer period of time and during this period it can be difficult to eat normal food. Instead, we give you nutrition drips. When you are able to eat it will be possible for you to choose what to eat, to a certain extent. Departmental staff and our dietician will do everything they can to help you.
- Damaged intestinal mucosa can lead to diarrhoea and pain.
- Nausea is a common side effect and the duration of nausea can range from a few days to several weeks.

Effects and side effects of the transplantation

When stem cells harvested from peripheral blood are used in transplants it takes about 10-20 days before the new production of white blood cells and platelets can be seen in the bloodstream. With stem cells harvested from the bone marrow it will take about a week longer.

- Typically, the number of white blood cells increases first. Then the production of thrombocytes will appear.
- The red blood cells determine your blood type. If the donor has a different blood group you will switch over to the donor's blood type. It may take 3-4 months before all of your red blood cells are donor type.
- In connection with the production of blood cells the membranes of your mouth and digestive tract will begin to heal.
- GvHD is an abbreviation for "graft versus host disease" and means your new cells fight against your body. Your new bone marrow not only produces blood cells but is the foundation for an entirely new immune system. This immune system will take shorter or longer time to adapt to every cell in your body.

Your new immune system may cause more or less severe inflammation in your body tissues. For example, inflammation of the skin that gives redness, warmth and soreness. If the intestines are affected, you may get diarrhoea. Liver values can rise which may make your skin become yellow and so on. Your doctor will treat all these reactions with immunosuppressive therapy in order to reduce them to an acceptable level until the reaction stops.

Discharge

When you no longer need intravenous antibiotic treatment, nutrition or daily transfusions of blood components the time to leave the department has come. Daily contact with physicians and / or nurse is required during the first period of time after discharge. If you live in the vicinity of Umeå you can stay at home, otherwise we will put you up at the patient hotel.

Blood sampling is done daily or several times a week the first weeks after leaving the hospital. You may get your blood samples taken at the Haematology/Lymphoma service or at your local hospital/health care centre. Your test results will be checked and if any measures need to be

taken that will be planned by doctors at the clinic and you will be contacted as soon as the doctor has determined the treatment needed. Signs of GvHD and any infections should be observed.

The most important check ups are:

- Complete blood count to see if you need blood or platelet transfusions.
- The level of immunosuppressants in your blood is followed and the dose of the drug is prescribed. This blood sample should be taken before taking the drug, i.e. 12 hours after the last dose.
- Renal and liver function is checked regularly.
- Tests for early detection of activation of the cytomegalo virus (CMV) and Epstein-Barr virus (EBV) are done regularly.

More in-depth check ups are performed 3, 6, 9 and 12 months after the transplantation. These are generally done at the Haematology/Lymphoma service in Umeå. After that, you will be going to annual check ups.

At home

Even if your blood counts are good your immune system is still weakened. This is particularly true in the first three months after transplantation, or as long as you are taking immunosuppressive drugs. The new blood stem cells are building a new immune system and it may take a year or longer before the immune system recovers. You will also be re-vaccinated against childhood illnesses as well as polio and tetanus.

 It is important that you always contact the hospital or the Haematology/Lymphoma service in case you develop infection symptoms.

Symptoms of infection can be:

- Fever
- Coughing
- Swelling / redness / blistering
- General feeling of discomfort

It is relatively common for transplant patients to contract shingles. On suspicion of shingles, medication should be administered immediately. This also applies if you are exposed to chickenpox.

General advice for avoiding infections:

- Damage to the skin or mucous membrane can be the gateway for bacteria.
- The lungs are at risk of airborne infections such as fungal spores and viruses. You should avoid large crowds indoors. Avoid dusty and dirty environments such as barns, woodsheds and garden work. Avoid smoking.
- The hot water temperature at your house must be raised to 60 °C at regular intervals. Preferably, the water in the pipes should always be above 50 °C. This is to prevent growth of Legionella bacteria in the water vapour you inhale whilst taking a shower.
- Always observe good hand hygiene
- The foods you eat should be recently prepared and handled in a hygienic manner

 Your new immune system can cause GvHD. It is important that you contact us immediately if you experience any signs of acute GvHD.

Symptoms of acute GvHD can be:

- Rash, redness, itching
- Nausea, vomiting
- Abdominal pain
- Diarrhoea

GvHD may also be more chronic in its nature with symptoms like dry skin, dry mouth and dry eyes. Be especially observant if you have any problems with dry mucous membranes in the genitals as this need to be treated to prevent adhesions. If you experience any problems please talk to the doctors in the Haematology/Lymphoma service.

- ❖ It is normal to experience physical and mental fatigue for a long time after the transplant. However, it is important for your rehabilitation and welfare that you exercise to the extent you can handle. Start slowly, but increase the dose as you get stronger.
- ❖ The time you need to be on sick leave after the transplant is individual, but count on at least 6 months.
- ❖ Your hormone production may be affected after the transplant. Both men and women can become sterile. Women may need hormone treatment to alleviate menopausal symptoms. Sometimes substitution of thyroid hormones is also needed.
- ❖ Sexual relationships can be resumed when you want to and feel strong enough. Many patients experience difficulties when they try to take up their sex life, do not hesitate to consult your doctor and/or counsellor.
- ❖ Be cautious about sunbathing since the skin can be extra sensitive and sunburn can cause GvHD.
- ❖ Many patients look forward to going to a restaurant or travelling abroad, please consult with your doctor at your three-month check up about what applies to your situation.

If you have pets:

- ❖ Wash your hands after contact.
- ❖ Wash yourself if you get licked.
- ❖ Ask someone else to clean the litter box/cage.
- ❖ Vacuum your home frequently.



Despite all the restrictions which confine your lifestyle, try to live as normally as possible.

Telephone numbers where you can reach us:

 Haematology/Lymphoma Service (daytime)	090-785 3927
 Haematology ward, G41 (weekends, evenings and nights)	090-785 1413
 Dietician	090-7852646
 Physiotherapist:	090-7852625
 Counsellor:	090-7852624
 Questions about transplantation: Transplant coordinator	090-7852621

E-mail (non-emergency cases)

 Dietician:	Stina.Selberg@vll.se
 Physiotherapist:	Taru.Tervo@vll.se
 Counsellor:	Mirjam.Bergknut@vll.se

Finding information on the web

-  <http://www.blodcancerforbundet.se/>
-  www.tobiasregistret.se
-  www.ebmt.org
- 