

Information regarding transplantation with autologous stem cells

Pretransplant examination

- Anyone who is scheduled for an autologous stem cell transplantation has to undergo check ups to determine the function of the body's vital organs, that is the heart, kidneys and lungs.

An evaluation of any previous treatment is made.

Verifications of past viral infections are 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.



At the prospect of admission

- Please bring any books, records, needlework, laptop (broadband in your room). Laptop computer and VCR/DVD player can be borrowed. We anticipate that you will be in hospital four to six weeks.
- 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 in your room during the hospital stay will be served breakfast and snacks. These meals can be taken in the family room in the ward. Lunch and dinner can be ordered at current coupon rates. 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 disease) 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

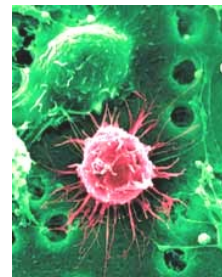
1. Admission to the Haematology ward, G41, occurs two to three days before the start of conditioning treatment. During these days, your test results will be evaluated. The doctor does a final check to see that your pretransplant examinations were acceptable and that all necessary tests were carried out. For most patients a bone marrow examination is required.
2. During the transplant period, you will need a central venous catheter (central line) with two lumens (openings) for us to take blood samples and administer intravenous medication by. 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 the time of your admittance.

4. **Conditioning:** Chemotherapy is given for one to several days depending on the disease. During the conditioning period, you may be disturbed by staff both during the day and during the night. Daily inspections of your weight will be done and during certain periods several times per day. Blood sampling can be needed at any time during the day or night.

Transplantation

One or a few days after the chemotherapy is completed with your stem cell transplant will be performed. The stem cells are stored frozen and thawed at the time of the transplant. The transplant is given as a drip or injected 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 transplant is performed in your room. You are monitored over the next few hours with respect to allergic reactions. The preservative (DMSO) that your stem cells were frozen with is eliminated through the lungs. You may notice this as a peculiar taste in the mouth and inside your room there will be a certain odour that lasts a few days.



Side effects of chemo treatment before transplant (conditioning)

With the start of conditioning 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 your 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 against viral, fungal and bacterial infections. In the case of rising fever and signs of infection you will be given an intravenous infection treatment (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 lead 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.

¹ Protective isolation means that the doors and windows to your room must be closed. Anyone who visits your room has to wash their hands and use the hand disinfectant provided and otherwise comply with the hygiene rules that exist in the ward.

Side effects of the transplant

When stem cells harvested from peripheral blood are used in transplants it takes approximately 14 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 a little longer.

- Typically, the number of white blood cells increase first, then comes the production of thrombocytes. The risk of infection is high when the level of white blood cells is low.
- The oxygen-carrying red blood cells develop at a slower pace.
- In connection with the production of blood cells the membranes of your mouth and digestive tract will begin to heal.
- Unclear infections may become noticeable when the white blood cells flow to where the viruses and bacteria are. Pus can be produced and the inflammation turns visible.

Discharge

When you no longer need intravenous antibiotic treatment, nutrition or daily transfusions of blood components the time to leave the department has come. You will be scheduled for follow up visits to the Haematology/Lymphoma practice. More in depth check ups are performed three, six, nine and 12 months after the transplantation. After that you will be going to annual check ups.

Blood tests can sometimes be needed between the scheduled visits. You may get these taken at the Haematology/Lymphoma practice or at your local hospital/medical 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.

At home

The first months after the transplant, you are more susceptible to infection and your immune system may be weakened. At the one- and two-year check ups you will be re-vaccinated against certain childhood illnesses.

- ☎ It is important that you always contact the hospital or the Haematology/Lymphoma practice in case of infection symptoms.
- ❖ 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 legionella bacteria to grow in the water vapour you inhale whilst taking a shower.
- ❖ The foods you eat should be recently prepared and handled in a hygienic manner. For example, never use the same cutting board for raw meat as for vegetables. You are welcome to contact our dietician if you have any questions about food handling, please refer to the last page.
- ❖ Always observe good hand hygiene, this is especially important if you have contact with animals.
- ❖ Avoid dusty, dirty areas.
- ❖ 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.
- ❖ Dry and delicate mucous membranes of the mouth and genital area should be moisturized to prevent damaging. If you experience any problems, please talk to the dentist or doctors at the Haematology/Lymphoma practice.
- ❖ 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 are also needed.
- ❖ 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.

- ❖ 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 with your doctor and/or counsellor.
- ❖ The time you need to be on sick leave after the transplant is individual, but count on at least three months.
- ❖ Many patients look forward to travelling abroad, please consult with your doctor at your three-month check up about what applies to your situation.
- ❖ Despite all the restrictions which confine your lifestyle, try to live as normally as possible.

Telephone numbers where you can reach us:

- ☎ Haematology/Lymphoma practice: 090-7853927
- ☎ Haematology ward, G41:
(weekends, evenings and nights) 090-7851413
- ☎ 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: Jessica.Johansson@vll.se
- ✉ Counsellor: Mirjam.Bergknut@vll.se

Finding information on the web:

UUUU <http://www.blodcancerforbundet.se/>
http://www.leukaemia.org.au/fileadmin/dl-docs/booklets/200804_autologous_transplants.pdf