



**AKADEMISKA
SJUKHUSET**

Advice for the first six months after Allogenic Hematopoietic Stem Cell Transplantation (HSCT)

Self-Care for children < 18 years of age



The advice and guidelines presented in this leaflet does not cover all possible situations and may vary from patient to patient or have additional patient-specific advices from the treating doctor. Contact the hospital if you have any questions.



If you have questions, please contact:

Contact us via e-services www.1177.se

Daytime Monday - Friday:

Children's ward for Blood and Tumour diseases (BONK-mottagningen)

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HSCT nurse (daytime)

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Evenings/weekends:

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REGION UPPSALA

Advice before returning home. Applicable the first six months after Allogenic Hematopoietic Stem Cell Transplantation

After a hematopoietic stem cell transplantation (HSCT), the immune system is severely compromised, but it slowly recovers within 6 – 24 months. It may for example take longer if you are being treated for the graft versus host disease (GvHD, see below). Until the immune system has regenerated, you are more sensitive to infectious diseases.

For many it can take up to a year to return to your ordinary physical condition, for example you can feel tired for long periods. Psychologically the period after HSCT is a recovery phase, which can be slow and take a long time. Returning to everyday life may feel unfamiliar and unsafe but a good balance between a nutritious diet, rest and physical activity can help to make the process easier.

When is it time to be discharged from the ward?

When all three requirements are met the transition from hospital to home can start:

- The transplanted stem cells have started to produce blood cells and the white blood cells (neutrophil granulocytes) are stably rising or have reached an acceptable level
- You can take your medication yourself and you are eating properly or can receive nutrition with the aid of a feeding tube or gastrostomy
- You do not have an acute infection or GvHD that requires daily observation or medication

Check-ups after HSCT

- For the first three months there will be scheduled visits to the clinic 1-3 times a week for blood tests and medical examinations
- These check-ups will focus on blood counts, concentration of the immunosuppressive treatment (Sandimmun®/Prograf®), infection status, nutritional needs and signs of GvHD (there may also be additional or special checks and tests if necessary)
- Three or four times during the first year there are more extensive check-ups planned with blood tests, possible bone marrow tests and repetition of some of the examinations that were performed prior to the HSCT
- Between these scheduled extensive check-ups, examinations and tests can be planned at your local clinic



Social life

Engaging in social activities is an important part of recovery. Being together with friends and having fun is stimulating and strengthening for many. Physical activity according to your ability is no hinderance; on the contrary it can potentially increase your wellbeing and recovery, but a balance between exercise and rest is important.

- Contact with others should be planned in such a way that is minimizes the risk of infection
- You can normally go back to school about 6 months after your HSCT. Restarting school or preschool shall be planned and decided individually, considering factors such as age, current medication, how well you feel and how much energy you have. Home tuition or individual tuition in school is a lawful right and the school is obliged to organize it to accommodate your needs. Children under the age of 3 can normally start/return to preschool about a year after HSCT
- Avoid crowded spaces with a lot of people and kids such as public transport, shops, department stores, inside play areas and cinemas
- Public swimming pools and saunas should be avoided. All bathing in still or circulated water should be avoided, for example outdoor natural pools and waterways with still water and all pools/hot tubs/bubble pools, etc. with circulating water. If bathing is planned, it is important not to ingest any water
- There is no recommendation to abstain from sexual activity per se but consider possible infections from your partner. Avoid damage to mucous membranes

Hygiene

Good hand hygiene is important to prevent infections. Dry and brittle mucous membranes and damaged skin that crack and itches can occur, and both are a common way for infections to enter your body.

Your skin becoming dry and pigmented is common after chemotherapy and/or radiotherapy, and there may also be change to the nails. The skin is eventually replaced and becomes normal again, but good hygiene is still important.

- Wash your hands regularly with soap and water
- Shower daily and use moisturizer after
- Take care of your mouth and teeth. Keep your teeth clean and avoid snacking. Use a soft toothbrush and change it every month. Dry mouth is common after HSCT but increasing dryness of the mouth and soreness may also be a symptom of GvHD. Saliva replacements or a saliva-stimulating mouth spray may help

Food

A nutritious diet and plenty to drink are an important part of recovery after HSCT.

Eating may be difficult because of flavor changes, indisposition, or a lack of appetite. Switching to small meals and eating more often can improve food intake. A dietician at the hospital will be available to give advice.

Good hygiene is important when handling food, as well as ensuring that the ingredients are fresh. Meals must be planned and prepared with consideration and care because the amounts of bacteria in the food that would normally be harmless may cause infection in persons where the immune system is reduced.

- **General advice:** The food should be prepared immediately before it is planned to be eaten. It must be properly boiled or fried and eaten directly after it has been prepared
- Due to the increased risk of bacteria growth raw or marinated products, such as salmon, shellfish, sushi and meat as well as unpasteurized dairy products, should be avoided
- Avoid eating food at restaurants or fast-food establishments as it is difficult to monitor the quality and how long the food has been waiting, kept warm or reheated
- Avoid ready-to-eat products that are not to be properly heated or cooked, including sandwiches, pastries, cold sauces, products with raw egg, mayonnaise and similar
- Avoid pick-and-mix sweets/candy and ice cream served over the counter, as well as nuts, honey, and dried fruit, such as raisins
- Avoid fresh fruit that is unwashed, fresh or frozen berries that are uncooked and unpasteurized, juice or smoothies
- Avoid buffets or salads in restaurants
- Avoid vacuum-packed foods that are intended to last for a long time if they are nearing the use-by date
- Drinking water directly from the tap is perfectly fine. Water from a well must be tested before use (contact your local authority)

Pets

Our pets may carry various bacteria, parasite, and fungi, which can be transferred to people via feces or saliva.

- Do not get a new pet during the first 6-12 months
- Existing pets do not need to move out, but avoid contact with saliva and feces
- Do not sleep with a pet in the bed or let them sleep in your bed when you are not there
- Do not go into stables or cowsheds
- Remember to do careful hand hygiene after physical contact with animals

Pot plants/gardening/rebuilding work

Soil and building dust can contain fungal spores that can cause serious infections if you are immune compromised and therefore sensitive to infection. It is not recommended to do any home renovations during the first 6 months after the transplant.

- Avoid any gardening that involves direct contact with soil
- Avoid being near building renovations/rebuilding
- Do not have potted plants or fresh flowers in the bedroom
- Do not play in piles of leaves in the autumn
- Avoid natural Christmas trees (and alike) indoors
- Do not play in sandboxes

Exposure to the sun

Exposure to direct sunlight should be avoided during immunosuppressive treatment and with care after total body irradiation. Never stay in the sun without proper sun protection. Clothes and caps give good sun protection; high-factor sun protection must be used on exposed skin (lifelong recommendation). Avoid tanning beds.

Medication

Some medication continues after going home, the sort and duration of treatment varies for different patients. Questions about your medication and treatment times must always be discussed with the doctor responsible for your treatment. It is important to understand that discontinue the immunosuppressive medication can lead to activation of GvHD or rejection of the transplant. All herbal medicines, supplements and health foods must be discussed with your doctor.

Note! It is important to continue taking all your ordinary medicines.

GvHD-preventive medicines

GvHD = Graft versus Host Disease can occur early after transplantation (occurrence during the first three months is termed acute GvHD) or some time afterwards (occurrence more than three months is termed chronic GvHD). This is basically the new immune system that reacts to the patient's body and may show up as inflammation of the skin, intestines, liver, or lungs. Early symptoms may include skin rash, itching, diarrhea, rising liver values, breathlessness, or increased tiredness. To reduce the risk of GvHD, immunosuppressive treatment (Sandimmun® or Prograf®) is often given as prevention. The number of months for which this treatment is given varies according to the child's diagnosis and whether signs of GvHD is observed and/or continues to develop.

Infection-preventive medicines

Medicines to prevent infections are normally started before the HSCT and are usually continued for several months afterwards, based on local guidelines and the individual patients specific needs. One of the main reasons is to prevent *Pneumocystis Jirovecii*, a type of pneumonia caused by a fungus, as well as bacterial infections. The preventive treatment is also given to prevent reactivation of herpes infections and other dormant viral infections. Preventive medicine is also sometimes given for fungal infections.

Vaccinations

Basic vaccination protection normally disappears after HSCT.

- A re-vaccination program is started 3-6 months after HSCT. This program is similar to the normal vaccination program that is followed in child healthcare centers and schools. The doctor in charge of treatment will initiate and outline your re-vaccination program
- Pneumococcal vaccination is recommended, starting 3-6 months after HSCT.
- Annual vaccination against influenza is recommended, starting about 4-6 months after HSCT
- It is also recommended that other members of the family are vaccinated against influenza
- Chickenpox vaccination of family members is not recommended, since a vesicle can form within two months of vaccination that could infect the person who has had a transplant

Foreign travel

Travel within Europe to places with normal sanitary conditions is permitted once the immunosuppressive treatment has been ended. Be careful about food and think about hygiene. Travel to other parts of the world or during ongoing immunosuppressive treatment must always be discussed with the doctor.

Contact the hospital

The doctor should be contacted if any new symptom arises. Examples of such symptoms include fever, diarrhea, nausea, vomiting, weight loss, bleeding, coughing, breathlessness, pain, vision disturbances, darkened urine, skin rash/blisters or itching. If the patient or anyone in close contact is exposed or suspectedly exposed to chickenpox infection, contact the doctor.



1177 Vårdguiden

You will find information and services for your health on the website 1177.se. For health care advice call 1177, open 24 hours a day.



Contact Akademiska

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