Sahlgrenska University Hospital
Haematology and Coagulation Section

PATIENT INFORMATION

Autologous stem cell collection and stem cell transplantation

VÄSTRA GÖTALANDSREGIONEN
SAHLGRENSKA UNIVERSITETSSJUKHUSET

Introduction

This brochure has been written to provide you and your relatives with information and guidance before you undergo *stem cell collection* followed by *autologous stem cell transplantation,* and is a supplement to the verbal information that you will receive from your regular doctor.

The decision that you should undergo autologous stem cell transplantation as part of the treatment for your disease has been made following consultation between your regular doctor and the transplantation specialists. It is vital that you are aware of the reasons behind this decision and the benefits – but also the risks – of a transplant. If you have any further questions leading up to the transplant, they can be answered in the first instance by your doctor or by our transplantation coordinators. Questions regarding stem cell collection can be answered by the Apheresis Clinic. Support is also available from a counsellor and through *Blodcancerföreningen*, the Leukaemia Society, in western Sweden. Our staff are trained and highly knowledgeable. Feel free to ask questions at any time.

What is autologous stem cell transplantation?

Autologous stem cell transplantation is part of the treatment for certain diseases that are sensitive to chemotherapy and the whole procedure is described in this brochure.

The procedure involves
1) collecting and freezing blood-forming stem cells, what is known as *stem cell collection*
2) the patient undergoing very powerful chemotherapy
3) giving back, *transplanting*, the stem cells to the patient to avoid permanent damage to the bone marrow.

Stem cell collection

The stem cells are normally collected from the blood through *stem cell apheresis*, a form of centrifugation where different blood cells can be separated. Sometimes the collection of stem cells in the blood is unsuccessful. In that case, it could be necessary to collect stem cells using what is known as *bone marrow harvesting*.

Frozen cells may not be used for anyone else, or for any purpose other than transplantation. Frozen cells that are not used are discarded when they are no longer needed.

Stem cell apheresis

Apheresis involves collecting stem cells from your blood at our Apheresis Clinic. With the aid of the growth factor G-CSF, stem cells are released from the bone marrow into the bloodstream 10-14 days after chemotherapy. The actual collection takes place using a special apheresis machine.

Before stem cell collection, various blood tests are carried out, including tests for blood-borne infections such as HIV, hepatitis and syphilis.

Arranging and performing stem cell apheresis

- You will undergo chemotherapy at your local clinic 10-14 days before the scheduled apheresis.
- A few days later, G-CSF will be injected each day into your thigh or stomach until the apheresis has been completed. You can choose to inject yourself or you can receive help from a relative or a member of the healthcare staff. The G-CSF must be stored in a refrigerator.
- G-CSF stimulates the production of blood cells and increases the number of stem cells in your blood.
- When there are enough stem cells in your blood, they are collected using the apheresis machine.

Discomfort and side effects

Side effects of G-CSF, such as muscle pain and bone pain, headaches or tiredness, could occur for a few days. In that case, contact your doctor for possible pain relief. If you have a fever, or if you do not feel well in some other way, you must always contact your regular doctor.

Blood vessels

To ensure there is a sufficiently good flow of blood into the machine, and to be able to perform the apheresis, a *peripheral venous catheter* is often inserted into a blood vessel in the crook of your arm. If this is not considered possible, a *central venous catheter* is inserted under local anaesthetic the week before apheresis. This is done at the surgery department. The nurse at the Apheresis Clinic or at your local clinic will decide which of the two procedures will be selected.

When is it time for apheresis?

Your blood count is checked according to a special schedule. All the test results are sent to the Apheresis Clinic and based on these results an assessment is made about when the stem cells will be collected.

What does apheresis involve?

Apheresis takes 3-5 hours and can be repeated several days in succession. Your blood is passed continuously into what is known as an apheresis machine, which uses centrifugation technology to collect the stem cells while the other components in your blood (red blood cells for example) are returned to you.

The actual apheresis procedure is not painful although you may feel a tingling sensation in your lips. The reason for this is temporary blood calcium deficiency, which can be corrected quickly by taking a calcium supplement.

At the Apheresis Clinic, the apheresis procedure, including tests, takes 5-6 hours each day plus travelling time. It is recommended that you bring something with you to eat. During apheresis, you can watch television if you wish.

If a peripheral venous catheter is used, it is removed at the end of each day you undergo apheresis. If a central venous catheter has been inserted, it is removed once a sufficient number of cells have been collected.

Bone marrow harvesting

In those cases where stem cell apheresis does not produce satisfactory results or cannot be carried out, *bone marrow harvesting* may be necessary. This involves blood-forming stem cells being collected from the bone marrow under general anaesthetic. First you will have general anaesthetic. Lying on your stomach on the operating table, two doctors will then *aspirate* (extract) bone marrow from the back of your pelvis (which is where bone marrow samples are usually taken). The cells are then collected, processed, calculated and frozen. Following collection, the patient is woken up and most patients are discharged the next day. You may have some pain in your pelvis for 24 hours or so after the procedure.

Stem cell transplantation

Preparations before transplantation

A number of examinations and blood tests are required in preparation for stem cell transplantation. This normally includes an ultrasound examination of your heart, an x-ray of your lungs and sinuses, and a whole series of blood tests, including tests for blood-borne infections such as HIV, hepatitis and syphilis. These take place either at your local hospital or at Sahlgrenska. A hospital dentist will also contact you to examine your teeth. You will always be allowed to see the results from the tests and examinations.

Admission to a department

You will be admitted to a department at Sahlgrenska University Hospital or at your local hospital shortly before the chemotherapy. In some cases, you can undergo both the chemotherapy and transplant as an outpatient, either completely or partly. If so, you will be admitted to the department later. In the case of stem cell collection, you will have a chance to talk to your doctor about the routines that could apply specifically to you. You retain contact with your regular doctor while you are undergoing treatment although the department doctor is responsible for your day-to-day care and information.

In order to put you on a drip, administer medication and take blood samples without resorting to an injection, you will have a *central venous catheter* inserted. This catheter is inserted into a large blood vessel close to your collarbone. This is done under local anaesthetic at the surgery department or radiology department.

Chemotherapy

Chemotherapy takes place either at an inpatient department or an outpatient department.

The purpose of chemotherapy is to kill cancer cells. Unfortunately, the treatment also affects healthy cells in your body, which could result in tiredness, loss of appetite and nausea. If you are receiving chemotherapy as an outpatient, you will be required to register your fluid and food intake at home.

All the blood cells – red (Hb), white (LPK) and thrombocytes (TPK) – fall significantly in number within a week of competing chemotherapy. You will probably need transfusions of both red blood cells and thrombocytes although white blood cell transfusion is not possible. A low number of white blood cells means that you run the risk of fever and infection, see below. Normally, the new white blood cells begin to increase in number 9-12 days after the transplant and any fever usually disappears at that point.

The transplant

The transplant means that after chemotherapy you receive back your own stem cells at the department or clinic at Sahlgrenska University Hospital. The cells are first thawed and then returned to you via your central venous catheter. The time it takes for you to receive back the cells can vary, but normally it is 10-45 minutes. It is a procedure that seldom causes any noticeable discomfort. The freezing agent that was used to protect the cells when they were frozen in conjunction with the transplantation may be noticeable in the form of an odour and a bad taste in your mouth although this will disappear after about 24 hours.

Department routines

Throughout your treatment, you will have regular check-ups and blood tests. The healthcare staff and doctors will monitor bowel function and they will keep a check on the central venous catheter, the mucous membrane in your mouth, your anus and your skin. The dietician, doctor and healthcare staff will keep a check on your food intake.

An important part of your recovery is that you try to spend as much time out of bed as possible during the day. Among other things, it will reduce the risk of pneumonia. It will also help you maintain your muscle strength. The physiotherapist will go through various deep breathing techniques with you as well as adapted physical training exercises.

Complications during treatment

Chemotherapy damages cells, which divide more often. These include cells in the mucous membrane and the hair follicles.

Gastrointestinal tract (digestive tract). Following chemotherapy, when your blood count is low, you will experience pain in your mouth, throat and stomach. It could be difficult to eat and it may be necessary for you to be put on a drip. Nausea and diarrhoea could occur, but these conditions can be treated and usually disappear once the new stem cells start working. However, loss of appetite and a change in taste sensitivity could persist for a long time.

Hair. Another side effect of chemotherapy is that you lose your hair within about two weeks. It will grow back again after about three months. In the interim, you can wear a wig which you can choose in advance of the transplant.

Infections. Fever is common during treatment and could be due to a number of things. Most infections derive from the body’s own bacteria, which could penetrate through the mucous membrane in your mouth and intestines after being damaged by the chemotherapy, or they could enter via your central venous catheter. You will be given medication to protect against infection. If a fever or other signs of infection arise, cultures are taken and your lungs will be x-rayed frequently. You will be put on antibiotics as quickly as possible.

Other complications. Despite the very powerful treatment, it is rare that it causes permanent damage to kidneys, liver, heart or lungs. The risk of suffering life-threatening complications as a result of the treatment and autologous transplantation is very small.

Life at home following autologous stem cell transplantation

General

You will receive an appointment for a follow-up with your regular doctor. He or she is the person you should contact in the first instance if you have any questions or problems. If you have specific questions, particularly during the initial period after you have been discharged, you are welcome to get in touch with the department or our outpatient clinic.

Get back to normal life as soon as you have the strength. Walks and exercise are good for you.

The length of time you are on sick leave depends on how you feel and what kind of job you have. Most people only go back to work part-time to begin with.

Infections

Your resistance to infection is lower following the transplant. For six months after the transplant you should avoid:

- anyone who has a cold and children with chicken pox or any other infectious disease
- going close to building sites or doing any renovation work at home. Dust from cement and plasterboard contains fungal spores
- close contact with rotting grass and leaves

Even if you have been vaccinated previously, your resistance to polio, tetanus and diphtheria is considerably lower following the transplant. You must be very cautious.

Polio: The polio virus is spread through contaminated water, which should be avoided. Consult your doctor before travelling abroad.

Tetanus: Tetanus bacteria from soil and other contaminated sources enter the body through a sore or a crack in the skin. Avoid digging in soil using your bare hands.

Diphtheria: A serious throat infection that is rare in Sweden. Consult your doctor before travelling abroad.

You will be vaccinated against these diseases according to a special schedule some time after the transplant.

Food and drink

Before you are discharged, you will receive brief instructions and advice about food and drink on your return home. Extra advice is available from the dietician.

Briefly, it can be said that certain foods could contain bacteria, mould or fungal spores and they should therefore be avoided during the initial period after transplantation. This includes unpasteurised dessert cheeses and dairy products. Otherwise, you can eat all types of food, including unpeeled fruit and raw vegetables. It is important that your energy and fluid levels are maintained.

Sex life

You can resume sexual activity as soon as you feel the desire. It is recommended that women make an appointment with their gynaecologist as they could have problems with dry mucous membrane after the transplant. Due to the risk of infection, it is recommended that a condom be used.

Other things to bear in mind

- Wash your hands after you have been in contact with pets and do not allow pets in your bedroom
- Be careful when sunbathing for the first year after the transplant and use a sunscreen with a high sun protection factor
- Do not take a bath – either in hot or cold water – as long as you have a central venous catheter inserted
- Expect to be on sick leave for 3-6 months and that to begin with you will only return to work part-time

Acute contact with the hospital after discharge

If, during the initial period after the transplant, you have any of the following symptoms, you must contact your doctor or your department immediately.

- Signs of infection, such as a temperature above 38.5°C, shivering, a bad cough, generally feeling under the weather, or difficulty breathing
- Bleeding

Side effects

Hormone imbalance. Chemotherapy affects the functioning of different hormone-producing glands, such as the thyroid gland, as well as the man’s testicles and the woman’s ovaries. The thyroid hormone could need to be replaced by taking tablets (Levaxin). It is relatively common that women require oestrogen treatment because their periods have stopped. A man’s testosterone production could be affected and treatment may be necessary.

Sterility

High doses of chemotherapy and radiation reduce the potential for having children. This means that there is a significant risk of permanent sterility following autologous stem cell transplantation. You ought to discuss this with your doctor. For men, it could be a question of freezing sperm before the transplant. If you are a woman, egg cells could in certain cases be frozen for use later.

Relapse of the underlying disease

Sometimes it happens that the underlying disease reoccurs, despite all the efforts that have been made. Another form of chemotherapy could then be necessary. Your underlying disease and your other conditions are the deciding factors when choosing treatment.

Informed consent

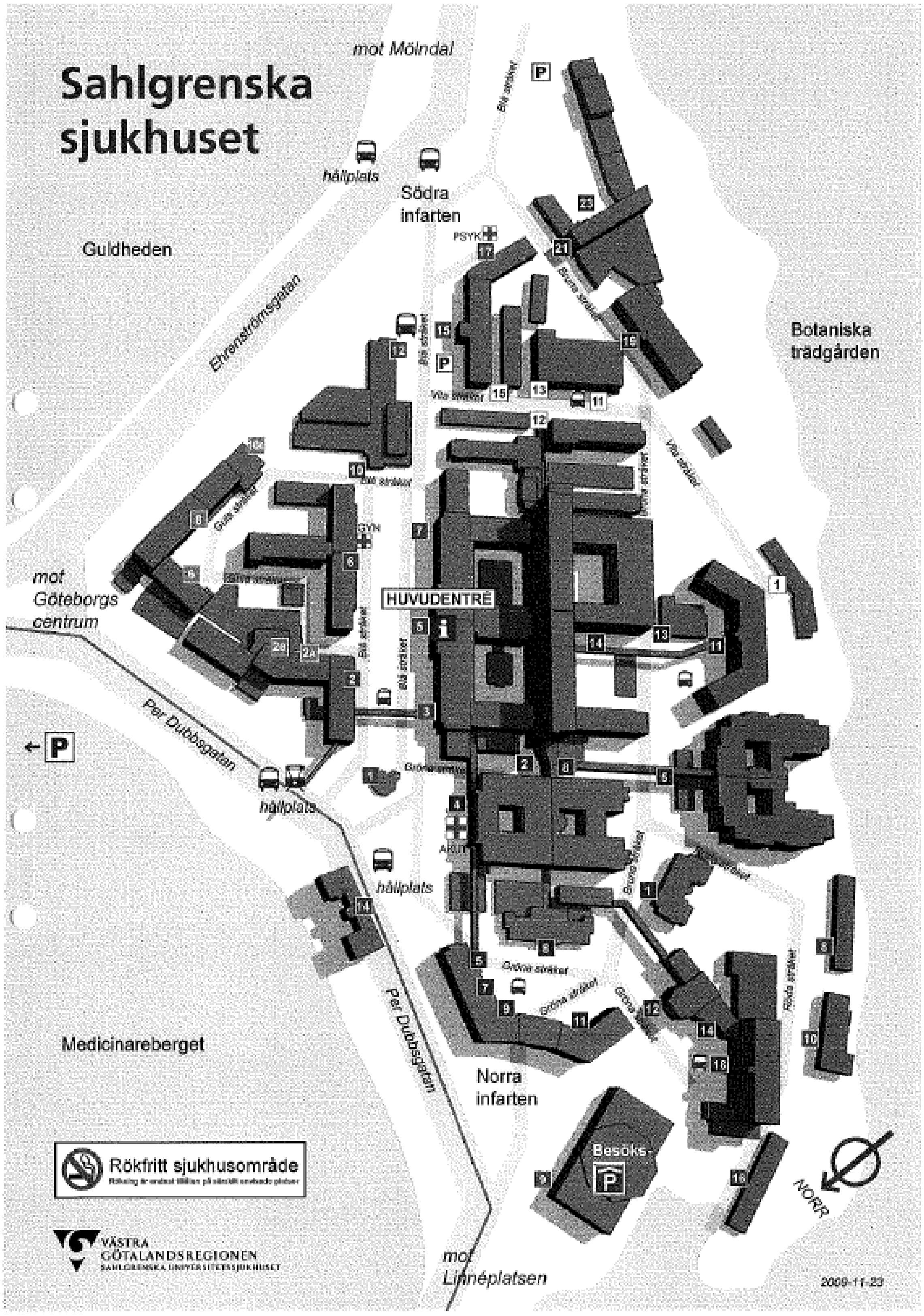
Your approval is required

It is vital that each patient who is due to undergo autologous stem cell transplantation is well informed about the various stages in the procedure and about the benefits and risks of a stem cell transplant. According to the regulations, this information must be provided both verbally and in writing. As a patient, you can with your signature confirm that you have been given sufficient information and that you have received answers to your questions. Your written consent is also needed for the routines associated with collection and transplantation.

Your consent is required for registration of patients in our own registers and in international registers. We have our own registers to facilitate planning, follow-up, evaluation and improvement of the care we provide. Details will also be reported to Swedish and international registers, including EBMT, a central European register belonging to the European Society for Blood and Marrow Transplantation, and CIBMTR, the Centre for International Blood and Marrow Transplant Research.

Contact

Transplantation Coordinator	031-342 37 67
Apheresis Clinic Haematology Clinic, SU Bruna stråket 5, 5th floor 413 46 Göteborg	031-342 73 70
Department 141	031-342 11 41


Sahlgrenska sjukhuset
mot Mölndal
hållplats
Södra infarten
Guldheden
Ehrenströmsgatan
PSYK
Blå stråket
Bruna stråket
Botaniska trädgården
Vita stråket
Gula stråket
GYN
HUVUDENTRÉ
mot Göteborgs centrum
Per Dubbsgatan
P
hållplats
Gröna stråket
AKUT
hållplats
Röda stråket
Medicinareberget
Norra infarten
Besöks-
P
NORR
Rökfritt sjukhusområde
VÄSTRA GÖTALANDSREGIONEN
SAHLGRENSKA UNIVERSITETSSJUKHUSET
mot Linnéplatsen
2009-11-23

Informed consent before autologous stem cell collection and stem cell transplantation

If we are to carry out the planned autologous stem cell transplantation, it is necessary that you confirm with your signature that you approve the information you have been given and that you accept the routines and procedures described in this information brochure and which have been explained to you verbally. Collectively, this is known as *informed consent*, which you can of course revoke later without having to give a reason.

1. I have read the written information and received verbal information about stem cell collection and stem cell transplantation
2. I have received information about the tests and examinations in conjunction with stem cell collection and stem cell transplantation and the benefits and possible risks.
3. I have been told that I will be notified about the test and examination results if I wish.
4. I consent to stem cell collection and treatment in conjunction with collection.
5. I consent to the planned autologous stem cell transplantation.
6. I have received information stating that the frozen cells will not be used for any other purpose and they will be discarded when it is considered that they are no longer needed.
7. I consent to information regarding my stem cell collection and transplantation being entered into my medical records and reported to local, national and international registers.
8. I consent to information about my examination and the results of my tests being sent by fax.

I have read this information and I consent to the above.

Date

Name

Name in block letters

Civic registration number

Verbal information provided by:

This form must be handed in to the Apheresis Clinic at the Haematology Section at Sahlgrenska University Hospital and it will be scanned into the patient's medical records.