



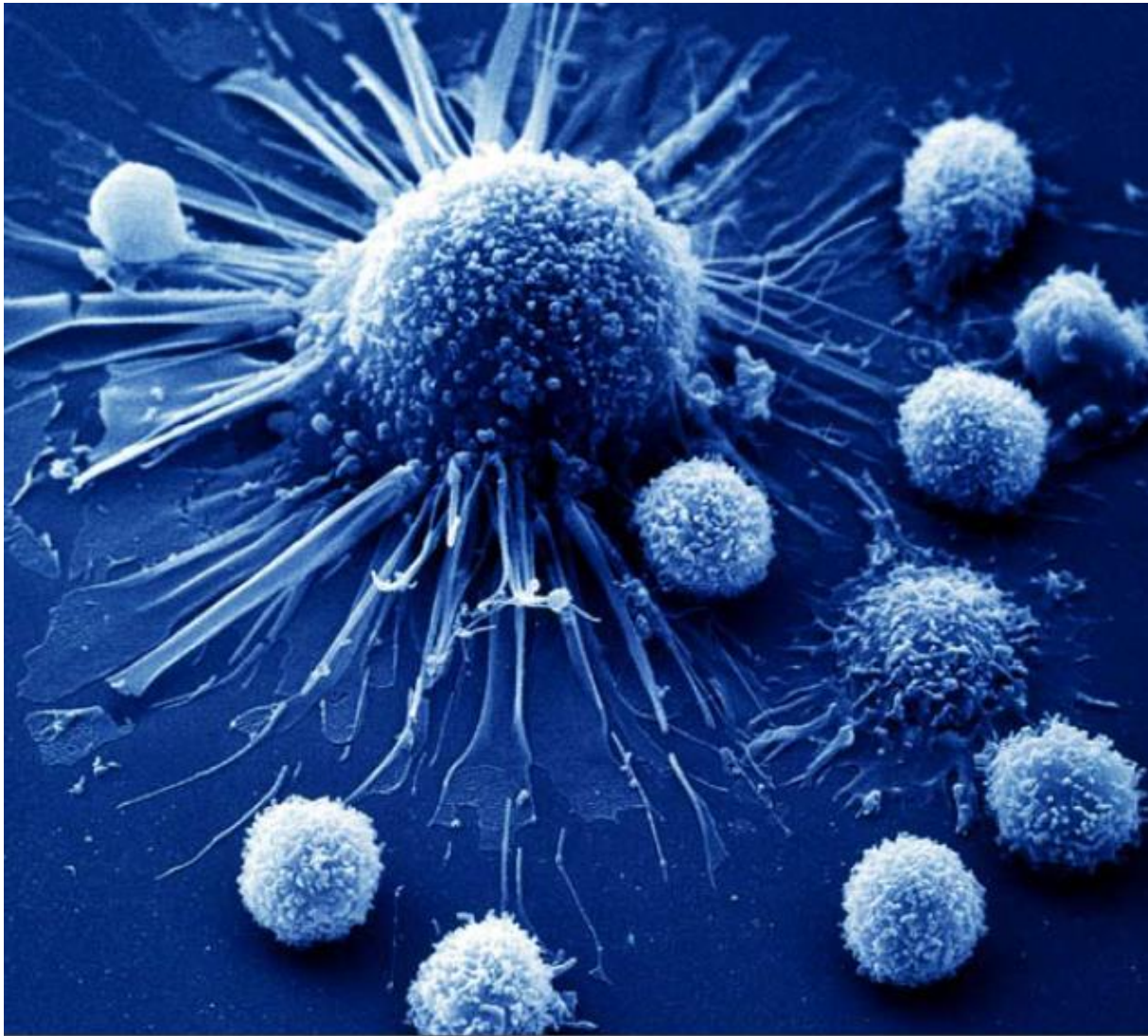
Karolinska
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Karolinska Comprehensive Cancer Center

Information about allogeneic stem cell transplantation

Karolinska University Hospital, Huddinge
CAST



Prepared by

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Photograph: Tore Dahlström

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A brochure for patients due to undergo an allogeneic stem cell transplant at Karolinska University Hospital

This brochure is aimed at patients due to undergo an allogeneic stem cell transplant, that is to say transplantation of blood stem cells from a healthy donor. It is intended to provide information and recommendations for patients and their friends and relatives before, during and after a stem cell transplant. It contains answers to frequently asked questions, but also contact details to get in touch with us if you do not find the answer you are looking for in the brochure.

Allogeneic stem cell transplantation is a treatment option for many diseases and for patients of all ages up to about 80, based on an individual medical assessment. Every disease has a specific treatment strategy. This brochure tries to cover all treatment strategies. You and your friends and relatives will be invited to a discussion in which we will talk about what your particular treatment strategy will look like.

The purpose of an allogeneic stem cell transplant is to replace your old immune system with a healthy new one from a donor. The new stem cells produce healthy blood cells, and a new immune system is created. The new immune system regards your disease as something alien, preventing your disease from returning.

Contact details

	Internal address	Telephone numbers
Coordinator for Adults	M72-74	+46 (0)8-123 825 16 +46 (0)73-668 17 04
CAST Ward	M72-M74, Medicingatan level 7	+46 (0)8-123 803 87
CAST Outpatient Unit	M44	+46 (0)8-123 875 99

Coordinator for Children	K88	+46 (0)8-123 826 23
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Children with haematological diseases, immunodeficiency and stem cell transplantation	K86-88	+46 (0)8-123 803 78 +46 (0)8-123 814 77
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Counsellor		+46 (0)8-123 870 81
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Barncancerfonden (Swedish Childhood Cancer Fund, children and young adults)
<https://www.barncancerfonden.se/for-drabbade/>

Blodcancerföreningen (Children Cancer Foundation of Sweden, patient contact)
+46 (0)722-685225

Ahead of allogeneic stem cell transplantation

When the doctor treating you starts to suspect that your disease will need to be treated with an allogeneic stem cell transplant, your case will be discussed at a multidisciplinary conference involving the doctor treating you and us as the transplantation team.

Searching for a donor

To be able to have a transplant, you will need a donor. A suitable donor will be identified either within the family or from one of the donor registries. 'Tissue typing' is first performed, a blood test that tells us what your tissue type (HLA type) is. The test is used to enable us to find a donor with a tissue type similar to yours. In the vast majority of cases the search begins among full siblings, to see whether any of them may be suitable for you. Both you and your sibling will need to take a blood test, and your sibling will be given their own contact person. This test will show whether you and your siblings have inherited the same HLA type from your parents. There is a 25% chance that you have inherited the same HLA type and are therefore fully HLA-matched.

If it turns out that your sibling is not suitable to be a donor, a search for an unrelated donor will begin in the donor registries that exist throughout the world. In most cases one or more suitable donors will be found and investigated further. Other factors are also considered in donor selection, such as the sexes, ages and blood groups of the potential donors and whether you or your donor have previously had various infections.

There are cases where the HLA type is uncommon, making it difficult to find a suitable donor. Depending on your age and diagnosis, it may be appropriate to do what is known as a haplotransplant. In this kind of transplant, the donor is a half-match, and is said to be haploidentical. This may be your parent, your child or, in some cases, your sibling.

For our youngest children an umbilical cord blood cell transplant may be relevant when no other suitable donor can be found. This involves cells being taken from the placenta, at the time of delivery of a sibling or from a cord blood bank.

Information meeting

Allogeneic stem cell transplantation is an advanced and complex form of treatment. We will therefore invite you and your friends and relatives to an information meeting with a doctor and coordinator for the purpose of describing what a stem cell transplant would involve specifically for you. The discussion will be lengthy and detailed, so we strongly recommend that one or more friends and relatives attend it.

We will tell you about the benefits and risks of the treatment so that you can participate in the decision on transplantation. Before this discussion takes place, you will need to have a lung function test (spirometry) and an ultrasound scan of your heart as a basis for risk assessment. If the assessment of risk identifies a significant risk, your treatment strategy may need to be adjusted. A form of treatment other than transplantation may be more appropriate in some cases.

If you come from a county other than Stockholm, you will have to speak to a counsellor at the time of the information meeting to find out where you and your friend or relative might stay after the transplant procedure. You will normally stay in Stockholm for 3 months after the procedure.

Ordering a donor

When a donor has been identified and the planning for the transplant begins, the coordinator will contact you. Stem cells from the donor will be ordered around 4–6 weeks before the planned procedure. All planning is preliminary. If circumstances change for you as the patient, the transplant procedure may need to be postponed or cancelled. Final donor approval will come just a few days before the treatment is planned to start.

An intensive period of tests and examinations will now begin while your donor is investigated before donating stem cells to you.

Tests, examinations and preparations for transplantation

The purpose of the tests and examinations prior to transplantation is to rule out the possibility of you having an ongoing infection and to assess your disease status. You will need to have:

- An ECG
- A chest X-ray
- A dental assessment
- Gynaecological examination
- Tests and examinations to evaluate symptoms, such as bone marrow testing or a PET CT scan, depending on your diagnosis.

Measures to maintain fertility

A transplant may affect your future ability to have children (your fertility). This should be discussed as early as possible after the decision is made for a transplant to take place if this has not been done earlier during your treatment. There may be steps that can be taken to assist your future fertility.

You will meet expert staff from Reproductive Medicine who will tell you about the options available to you.

Hair replacement

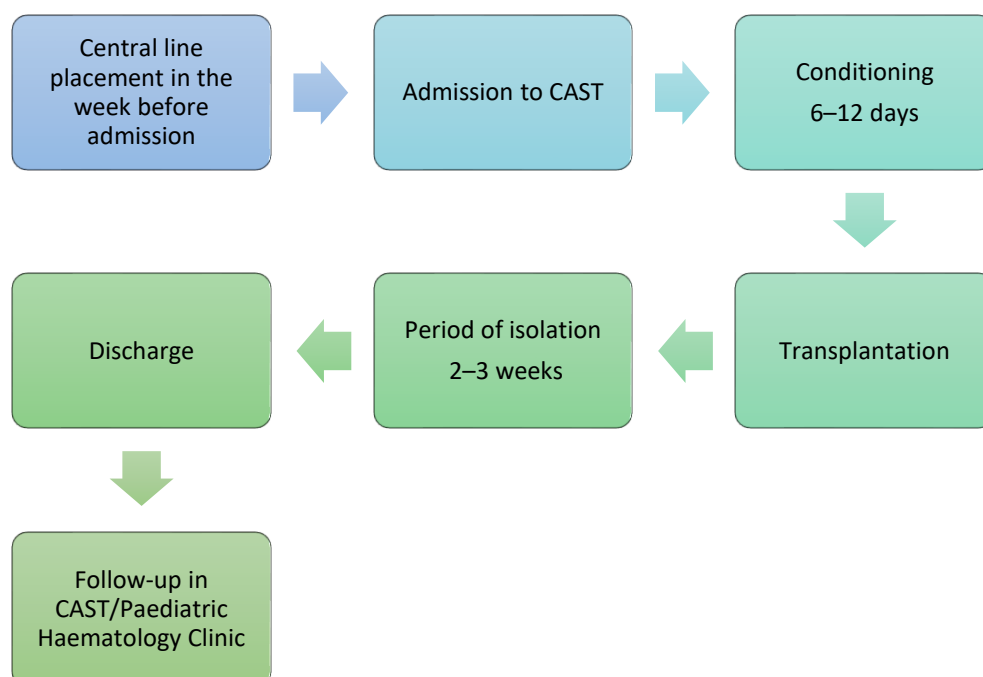
The treatment in connection with the transplant will lead to you losing hair. Your hair will usually grow back again after about 3 months. If you wish, you will be able to wear a wig, which you can try out for yourself. You should try out wigs early on, ideally at the time when the decision to have a transplant is taken. You will be given a prescription and contact details for the wig makers you can contact.

If you need to renew your prescription along the way, contact the CAST Outpatient Unit on +46 (0)8-123 97599.

Central line placement

If you do not already have a central line (central venous catheter, CVC), with more than one 'lumen' (channel), you will have one surgically inserted. The central line is a tube usually consisting of two lumens that enters a blood vessel on the neck. A small tunnel is made beneath the skin below the clavicle and is taken out through the skin. This is done on the surgical ward under local or general anaesthetic. You will need a central line because we will have to be able to give you fluid and medications and take blood without having to jab you every time. If you have a central line with just one lumen, it will need to be replaced.

You are now ready to start your transplantation phase.



Time for transplantation

A few days before being admitted, you will meet one of our nurses for a brief discussion, and we will also swab your nose to rule out the possibility of you having a viral infection.

Friends and relatives and visiting

If you have a friend or relative who is able to stay with you in your room during your period of care, this is likely to prove a source of great support for you. We do not have any particular visiting hours, and it is you as the patient who decides if and when you want to have visitors, preferably no more than a few people at a time. Visitors must not show any signs of infection, for example signs of a cold, fever or diarrhoea.

What do I need to bring with me to the ward?

When planning what to pack for your stay with us, you should remember to bring:

- Indoor shoes for you and your friend or relative
- Personal hygiene items such as shower cream, shampoo/conditioner, skin cream. Bear in mind that these products need to be unopened. You will get a toothbrush and toothpaste from us.
- You may wear your own clothes, but there are no washing facilities on the ward. Clothes are available to borrow for you and your friend or relative, as you will need to change them daily during your period of care.
- Please bring something to keep you entertained, such as books to read, handicrafts, a laptop, a tablet or a mobile phone. Wifi is available in the hospital.
- Cap or sunbonnet for sunny days when you take a walk.

If you wish to bring something edible with you, check with your coordinator or the staff on the ward.

There is fruit on the ward, and it will be handled by the staff as it needs to be peeled before being served to you. It's fine to bring sweets with you in sealed bags, not loose. If you wish to bring home-made food with you, it needs to be capable of being heated. A friend or relative can leave food or other items you need during your period of care with the staff on the ward without coming in. They will just need to ring the bell by the door.

If you take herbal medicines and vitamins, these should be discussed with your transplant specialist, as they may interact with the treatment you receive. Remember that you will only be allowed to take the medicines you receive from the medical staff on the ward.

Your room

You and your friend or relative will have a room of your own, equipped with a shower, toilet and exercise bike. You are welcome to make your room homely, with personal items such as photographs, a radio or something else from home. However, you must not nail or stick anything on the walls. It's fine to have cut flowers, and staff on the ward will arrange for the water to be changed every day. Soil contains bacteria and fungi, so you will not be allowed to have potted plants. Do not have too many things in your room, as it will have to be cleaned every day.



Discussion at the time of admission

At the time of admission, you will meet a doctor, nurse and nursing assistant, who will inform you about your period of care on the ward. You will run through procedures and the treatment you will receive, and you will be able to talk about what is important to you during the treatment. Blood will also be taken along with various routine cultures. We will also welcome your friends and relatives and show you and them around the ward.

We at CAST work in as person-centred a way as possible and therefore base our work on the three cornerstones of the person-centred care model. These cornerstones are:

1. The patient's narrative/the discussion
2. Partnership between the patient and caregiver
3. Joint action plan

Taking a person-based approach enables us to prepare you and your friend or relative for various stages in the process. To enable you and you and your friend or relative to cope with various situations that may arise, it is important to us that care and support are given on basis of both your needs.

The team surrounding you also includes a dentist, physiotherapist, counsellor, occupational therapist and dietician. If you are a child, you will also meet a play therapist, music therapist, the teacher from the hospital school and our clowns. We will all work with you to try to make sure you recover as quickly as possible.

Conditioning

Your stem cell transplantation journey is said to start with the intensive pre-treatment that involves reducing your own bone marrow by treatment with chemotherapy and/or radiotherapy. This pre-treatment is also known as conditioning, and is necessary to remove the diseased cells in your body and to remove your own immune system so that the new stem cells are not rejected. The diseased cells also disappear thanks to what is known as the anti-leukaemic or anti-tumour effect that arises through transplantation. The new immune system regards the diseased cells as something alien and rejects them.

There are several different types of conditioning. Don't worry if you hear one being mentioned that differs from the one you have had, or if your treatment does not entirely agree with the one described here. Conditioning is divided into intensive and reduced-intensity conditioning. Some forms of conditioning involve radiotherapy and others only involve chemotherapy. Which specific treatment you receive depends on you and your disease.

The chemotherapy may make you feel nauseous, and if it does, you will be given medication to prevent this.

If radiotherapy forms part of your conditioning, this will take place at Karolinska Hospital in Solna. The treatment will usually go on for two to four days in succession, and we will arrange transport, usually by taxi. Before having radiotherapy, you will be asked to attend the radiotherapy unit for some tests and examinations and will then have an opportunity to ask questions about the treatment. Your salivary glands may be affected, leading to a dry mouth, and your skin may also redden after radiotherapy. In the long term, total body irradiation may increase the risk of cataracts. This is a clouding of the eye's lens that usually appears between one and five years after the transplant. Cataracts can be treated surgically by replacing the lens with a synthetic one. Vision is usually normal after such a procedure.

As well as chemotherapy, antibody therapy (immunosuppressant therapy) is given in most cases to prepare your body to receive the new stem cells. It is common to develop fever with this treatment. You will be given cortisone to prevent this side effect.

The day before your transplant is due to take place, immunosuppressant therapy will first be started in the form of a drip, before changing over to tablets. You will need to take this medication for about 6 months.

You may be disturbed by staff during the pre-treatment, both day and night, as we will need to monitor how you are feeling, carry out checks, take blood or give you medication.

The conditioning will take about 6 to 12 days, and you will then be ready to receive your new stem cells.

Stem cell transplantation

Your donor will donate stem cells the day before or the same day as your transplantation. There are two ways of collecting stem cells from the donor. The most common is to force the stem cells out into the bloodstream by stimulation with a biosimilar hormone, in the form of self-administered injections for the donor. These can then be harvested from a blood vessel in the arm, and what is known as peripheral stem cell harvesting will be carried out at the blood donor centre.

The other method is to harvest the stem cells directly from the bone marrow. This means an operation for the donor in which the stem cells are aspirated using syringes in roughly the same way as for bone marrow. The donor is anaesthetised during the donation.

The stem cells will be collected in a bag and given as a drip through your central line. The quantity may vary, but the number of stem cells will be calculated according to your weight, and transplantation will be performed inside your room. The transplantation will be over after one to four hours. You may have immunological reactions primarily in the form of fever, chills and headaches, and you will therefore be monitored for the first few hours.

The new stem cells are now in place in your body and will need to be left for about 2–3 weeks to start to produce new blood cells and a new immune system.

Can I get in touch with my donor?

Yes, most donor centres have a rule that two years need to pass after the transplant before it is possible to break confidentiality between you and the donor. Both you and the donor will need to give consent.

However, you and the donor have the option to send an anonymous card or letter to one another before those years have passed. The letter is sent through the Coordinator at CAST. Contact the Coordinator for more information.

Isolation period

While you wait for the new stem cells to start to work, you will be very susceptible to infection. You will be isolated in your room to reduce the risk of infection. You will also have

to wear a mask when we as staff visit you. It will, however, be possible for you to go for a walk outside during the evening and at the weekend.

Note: We may need to alter the option of spending time outside during the COVID-19 pandemic. We will let you know what rules are applicable.

Despite preventive measures in the form of isolation and medication to prevent infection, it is still common to be affected by an infection with fever during the period of care. The infection is usually caused by the body's own bacteria, and is treated with antibiotics. Early treatment provides the best results. Your temperature will therefore be measured several times a day. Cultures will be routinely taken in the event of fever in an attempt to identify the cause. We will monitor how well you feel and initiate treatment.

The conditioning you have received means that the production of white and red blood cells and platelets stops. You may need blood and platelet transfusions in the weeks immediately following the transplant.

The conditioning also affects healthy cells in the mucous membranes and hair cells. This can lead to blisters and ulcers in the mouth and throat and diarrhoea. You may find it difficult to eat and may need painkillers. About a week after the conditioning you will lose your hair. Many patients find losing their hair unpleasant. It's a good idea to talk to the staff on the ward so that you can be given support.

It is common to feel tired and exhausted from the treatment and possible side effects or infection.

Diet

The best thing for you to do is to try to eat and drink exactly as normal. Your appetite may, however, change during your period of care. You may feel nauseous, have less appetite and find eating difficult due to pain in your oral mucosa or throat. We can help you find a diet that suits you. You can try a liquid diet or small and enriched portions of food, for example. We will monitor that you meet your daily need for calories and make up for the loss with a nutrient drink and sometimes a nutrient drip if it proves necessary.

We can also offer a nasogastric tube, which is a soft, thin tube that is passed down into your stomach from your nose. This will enable you to receive nutrients and also medication if you find it difficult to eat. There are advantages to a nasogastric tube over nutrient supply via the blood for patients with diabetes, as a more even blood sugar level is obtained when the nutrients are supplied by the natural route.

There are certain restrictions regarding food during the isolation phase. This principally applies to pathogens that must not be transferred to you, for example through uncooked vegetables, raw fish, cheeses with moulds and similar items. (See list)

There is a special kitchen on the ward for those who are not in isolation and their friends or relatives. There are facilities there for eating and cooking your own food. You will be given more detailed information when you are admitted.

What you must NOT eat or drink

- Water from water containers with a tap.
- Ice from an ice machine.
- Raw, soft-boiled eggs or fried eggs not cooked on both sides, which are not Swedish.
- Loose sweets, nuts or dried fruit.
- Fresh or fresh-frozen shellfish that has not been boiled.
- Raw fish, for example sushi.
- Dried fish/meat must not be eaten if it is not cooked.
- Cold cafeteria food and ready meals from chilled food counters.
- Dressings and sauces from street food stalls, etc.
- Buffet food.
- Cheeses with mould and unpasteurised cheeses.
- Raw meat.
- Soft ice cream and milkshakes, for example from McDonalds
- Health foods (medicines, loose teas and spices)
- Vacuum-packed cold meats close to their sell-by date.
- Smoked or cured fish
- Fermented products, for example kimchi, sauerkraut.
- Grapefruit interacts with your immunosuppressant medication.

Please note that these lists only apply during the period of care in connection with your transplant when you have no white blood cells and a severely impaired immune system.

What you MAY eat and drink

- Water must be newly drawn from the tap.
- Fruit and vegetables must be washed thoroughly and peeled. If they have grown in soil, they must be cooked; berries too must be cooked before they may be eaten.
NOTE: You must not peel anything yourself due to the risk of infection.
- Sweets and dried fruit in a sealed bag.
- Salted nuts in a sealed bag.
- Hard cheese.
- Liver pâté.
- Soft cheese in a tube.
- Swedish eggs.
- Vacuum-packed cold meats.
- Tea only from a sealed pack.
- Pasteurised juices.
- Industrially packaged honey. No honey for children below 1 year of age.
- All spices must be added before cooking/heating. Spices in disposable packs may be used after cooking.
- Newly bought packs of cinnamon, for example, may be used.
- Ice cream that is pasteurised.
- Fried or boiled mushrooms. The mushrooms must be carefully cleaned before cooking.
- Well-done hamburgers with bread but without salad and dressing. Dressing in a disposable pack may be eaten.
- Preserved/marinated shellfish. Shellfish in brine.
- Shellfish that has been boiled; you must not peel it yourself.
- Anchovies, mackerel in tomato sauce, marinated herring and fermented Baltic herring.
- Pizza without cold sauces and lettuce. No ingredients may be used as pizza toppings after cooking.

Oral care

The treatment you receive ahead of the transplant may lead to symptoms in the mucosa of the mouth appearing during the period of isolation. Symptoms do not appear immediately but usually develop the week after the transplantation itself. The first sign may be that your mucous membranes turn whitish and that a sensation of a coating or roughness develops. A sensation of dryness in the mouth and changes in the consistency of saliva are fairly common side effects. After a few days your mucosa may become red and inflamed, and ulcers will sometimes appear. You may consequently also experience a stinging sensation and pain, as well as difficulty in swallowing.

To alleviate these problems, reduce the risk of infections and keep your mouth as clean as possible, it is crucial that you follow the instructions given below.

- You must brush your teeth twice a day with an extra-soft toothbrush and toothpaste, which will be provided on the ward. You will be given a new toothbrush every day. Only the surfaces of the teeth should be brushed, and the gums should as far as possible be avoided. Floss, or interdental brushes, may be used with great caution if necessary and if you are familiar with their use.

Users of dentures should not wear their dentures other than at mealtimes.

- To prevent the development of fungal infections, the oral cavity will be treated with an antifungal in the form of tablets or a mixture, 4 times daily.
- You should use lip balm regularly so that your lips do not dry out. If your lips crack due to dryness, it will be difficult to get them to heal.
- To relieve stinging and reduce thick saliva, you should rinse your mouth with a saline solution every hour during waking hours. The solution will be provided by the staff. Some patients find it better if the solution is cooled.
- To have a chance of reducing symptoms in the mucous membranes of the mouth, you should suck crushed ice as often as possible while chemotherapy is in progress.
- Sucking ice cubes and/or placing ice wrapped in a towel or similar against the lips and cheeks reduces swelling and pain and can reduce any bleeding.
- If you have a dry mouth, rinse your mouth often, at least once an hour, with water if you have not rinsed it with saline solution. Saliva substitutes and gels to keep the mouth moist are also available if needed.
- If you start getting painful sensations from your mucous membrane, inform the staff so that the right pain relief can be initiated.

Your mouth will be examined once a day during the period of care. This check is carried out so that we can discover and treat any complications as quickly as possible after their onset.

Contact the ward staff or the dentist immediately if it becomes difficult to follow these routines, if symptoms develop in your mouth or if you have any questions.

Activity – Physiotherapy

Much of your activity will be confined to your room during your period of care. You will be given an exercise bike in your room, as well as support from a physiotherapist in finding an exercise programme that suits you. The exercise is intended to maintain your existing muscles.

You will be advised to set aside time for exercising daily. Small activities are also important, such as sitting at the table at mealtimes and sitting on the sofa rather than in bed. These changes of position help with your breathing and prevent complications.

A walk outdoors in the evening or at the weekend is beneficial to your well-being.

Counsellor support

You will be offered the support of a counsellor before, during and after transplantation. The counsellor can give you advice and support in municipal assistance, social insurance, rehabilitation and other social resources based on your situation. You will also be offered counselling to help you cope with and process this difficult situation.

Your friends or relatives can also receive counselling and advice. Children who are family members are also entitled to information and support.

The library

The library in Huddinge has novels, non-fiction books, newspapers and magazines, audio books, DAISY books, music and films. You can borrow tape players, DVD players, CD players and headphones. Contact the library to tell them what it is that you want.

You can find details at <https://www.karolinska.se>

Educational Resource Room

The hospital's special educational and cultural activities for children who are patients in the hospital are brought together in the Educational Resource Centre.

Play therapy

The play therapist will visit you in your room, and you will discuss together what material you would like to have in your particular room. Play therapy can offer many different creative materials, toys, games and so on.

We will be happy to spend a while with you in your room if you would like to create, play or do something else together.

If you feel a little worried about any of your treatment procedures, the play therapist can help you to show what happens on dolls or using other material.

Please tell your play therapist if you are anxious about treatment, and we will try to help you.

The hospital school

The hospital school serves as an extension of the ordinary home school. We are there for you if you need help with your school work during your hospital stay and if you are at primary, lower secondary or upper secondary school. The hospital teacher will contact your home school with the aim of you being able to keep up with your ordinary school instruction.

The hospital teacher will be happy to come to your room, where you can have lessons together.

Music therapy

Music therapy is offered to patients at CAST. Along with your music therapist, you can play or sing, listen or perhaps paint to music. You do not need to have any prior knowledge, and there are no requirements for performance levels. You decide for yourself what you think we should do. Mum and Dad can be there with you if you wish.

The Film Workshop

With the Film Workshop you can make your own film! You can create characters, set up a stage and decide on the plot for your film. It takes about one and a half hours to make a film.

The Film Workshop is in Huddinge one day a week and will be happy to come to your room if you wish.

VR

VR stands for Virtual Reality, and is an activity you can try out in your patient room. With the aid of the VR equipment you can get a feeling of having moved from the hospital to different places: space, the sea, nature, etc.

Our VR educationalist is in Huddinge one day a week and will be happy to come to your room if you wish.

KulturSjukhuset (the Culture Hospital)

Berättarbyrån (the Storyteller Office)

One day a week Berättarbyrån will come to see children or adolescents. The office's drawers contain boxes of fairy stories, mysteries and characters for younger children. For those who are older there are various kinds of stories that are told verbally (not read out aloud) without props. You can just let the pictures pop up in your head while you are listening, or help make up a completely new story using the storyteller cards. It often takes between 5 and 15 minutes for a story to be told.

Clowns

Either Vicke Vaktis, Trudiluttan, Benke Blues or Rutan drop in for a visit two days a week. The clowns can offer music, magic, balloon characters and mayhem, and always adapt the encounter to the situation. Sometimes it can be completely crazy, other days quite calm and tranquil. It's also fine just to receive the day's post or a riddle through the door! The clowns will only enter the room if they get permission from the patient. They introduce themselves here in a music video:



Engraftment

It can be 2–3 weeks before the transplant takes, that is to say, the new stem cells start to produce blood cells. 'Engraftment' or 'Take' is the term we usually use for this. Your white blood cells now start to increase and you can be released from your isolation. The white blood cells will now help you repair the oral mucosa if you have had symptoms during your period of care. A complication known as GVHD (graft versus host disease) can already develop at this stage; see the section below describing this reaction. Perhaps you need to recover after an infection and/or be able to provide yourself with the nutrients and fluids you need before it is time to be discharged.

Time to go home

It can feel difficult to be discharged after spending a month more or less in isolation. Many patients are afraid of encountering the world outside the hospital with the risk of infection this can pose. Bear in mind that we will never discharge you if we do not think you will cope with it. You will be given a very detailed breakdown of follow-up visits and rules to follow by a nurse and a doctor on the ward. We are always on hand if you need to ask about anything, even after going home.

We are in contact with ASIH (Advanced Medical Care at Home), which will come to your home after you have been discharged and help you with blood tests, questions about medicines and changing of your central line. ASIH works closely with us at the hospital.

If you are from a county other than Stockholm, you will be discharged to the apartment hotel or to Ronald McDonald House.

Some recommendations on discharge

Try to follow the recommendations below for 3–6 months after the transplant:

- maintain careful hand hygiene
- socialise only with people who are healthy
- do not bathe in a pool, as the water there contains a lot of bacteria. If you still have your central line in place, you must not bathe in a pool, sea, lake or bathtub owing to the risk of infection. Nor should you take a sauna.
- do not dig in soil, as soil contains fungal spores that can cause infection.
- do not have flowers with soil in your bedroom.
- do not have close contact with pets – see instructions in the section about pets.
- do not expose yourself to too much sun and use a sun protection factor – sunburn can lead to skin GVHD.
- do not carry out renovation work in the home – building dust may contain fungal or mould spores.
- wear a mask if you spend time where lots of people gather
- do not use public transport – you will be given a patient travel card/mobility service and are advised to take a taxi or travel in your own car.
- You can now return to your normal diet, there are no more restrictions.

You are advised to do so to protect yourself, as you will still be susceptible. You can start resuming your normal life gradually, depending on what you can manage. We recommend that you take daily walks outdoors after being discharged. Avoid jolts and impacts if you have a low platelet count.

Outpatient follow-up

If you are an adult, you will be followed up at the CAST Outpatient Clinic after you have gone home, and if you are a child through Paediatric Haematology. On your first visit to the clinic, you will see both a nurse and a doctor. We will run through your health rating again and update My Care Plan. To begin with, you will be monitored intensively, with visits to see a doctor and a nurse twice a week. The visits will be both in person and online by video link. To be able to take part in a video discussion, you will need a smartphone with Bank ID. You connect through the app Alltid Öppet (Always Open), instructions for which will be sent to

you in your appointment letter. We will also prepare a rehabilitation plan for you here. The visits will start to become less frequent three months after the transplant. But we will continue to monitor you for the rest of your life.

If you need to be re-admitted for any reason, it will be to the paediatric regional ward for children and adolescents or to CAST Inpatient Care if you are an adult.

Points to bear in mind before blood tests

You must not take immunosuppressant medication (such as ciclosporin or tacrolimus) on the morning before a blood test, as the measurement of blood concentration will otherwise be incorrect. Take these medicines immediately after the blood test instead. It is important never to forget to take your ordinary medication. Failing to take medication can lead to a GVHD reaction. If you have forgotten to take your medication, you should phone the outpatient clinic or the ward. Once we have found out what has happened, we can help.

When do I need to contact the hospital?

If you are affected by any of the symptoms below, you should get in touch with us at the hospital.

- fever – make sure you have a thermometer at home.
- rash
- cough or shortness of breath
- bleeding
- diarrhoea
- vomiting
- sudden headache
- newly developed or worsened pain
- ulcers in the mouth
- difficulty in eating or drinking enough

Adult

CAST Outpatient Unit +46 (0)8 123 875 99

Weekdays 08:00–14:00

CAST Inpatient Care +46 (0)8 123 803 87

Other times

Children

Haematology Clinic +46 (0)8 123 81 47

Weekdays 08:00–15:00

Regional Paediatric Ward +46 (0)8 123 803 78

Other times

GVHD

A significant complication in allogeneic stem cell transplantation is GVHD (graft versus host disease), where the white blood cells in the transplant react against their new host – your tissues. The reaction is a complication that most people have to some extent, for good and ill. A milder form can be good for those with leukaemia or other type of cancer, as it reduces the risk of relapse. A more problematic form is less common but can become serious and be difficult to treat and even prove fatal in individual cases.

Acute GVHD

An acute GVHD reaction usually occurs within three months after transplantation. Common symptoms are a rash, which can start in the palms of the hands, under the soles of the feet

or on the face. A more widespread reaction can cause rash over the whole body, liver impairment, vomiting or troublesome diarrhoea. It is very important at all times that you get in touch with the outpatient clinic or the ward if you experience any of these symptoms.

Chronic GVHD

Chronic GVHD in most cases has limited spread. The most common symptoms you may develop are colour changes/pigment changes in the skin and dryness in the mouth, eyes and genitals. You may find the latter symptoms troublesome, and they affect your quality of life to varying degrees. More severe forms may develop and produce more severe symptoms in the mucous membranes, with ulceration and also problems in muscles and the bronchi. You may also be increasingly prone to infections. This complication is most common during the first two years, and in most patients disappears within five years after SCT.

Preventive treatment is given to avoid GVHD, but if you nevertheless develop GVHD, it is primarily treated with cortisone.

Reactivation of viruses

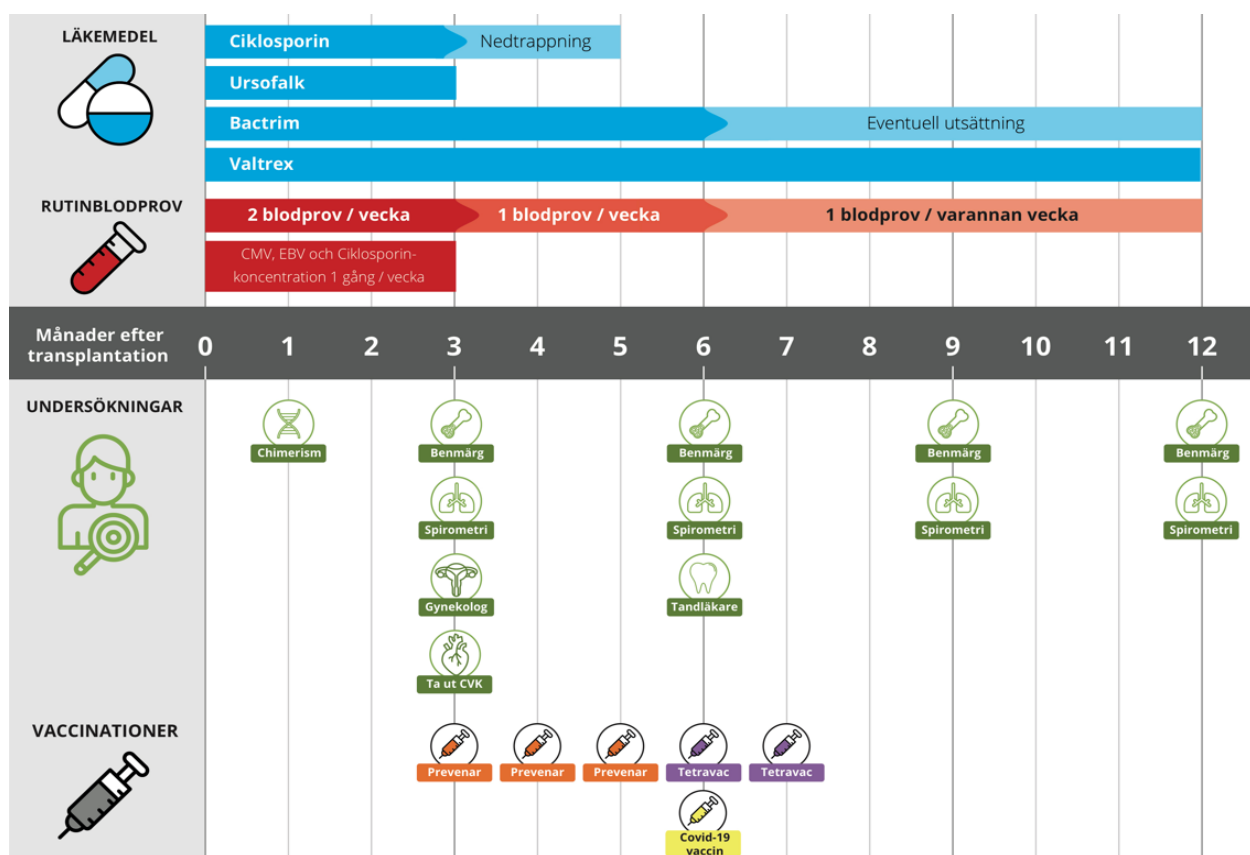
Herpesvirus is a group of viruses you may have acquired earlier in your life and that then lies dormant – latent – in your body for the rest of your life. These infections are controlled by your immune system and can be triggered if your immune system is weakened, for example in connection with a stem cell transplant.

Cytomegalovirus (CMV) is a virus that is latent and can be activated. You may also get the infection for the first time for example from your donor if they have had the infection but you have not. In these cases, you will be given preventive medication to reduce the risk of infection. CMV is usually activated between one and three months after the transplant. Among other things, CMV can give you fever and, in severe cases, pneumonia. But with early diagnosis and treatment, the virus will be discovered before you have time to develop symptoms. You will therefore be followed up with blood tests every week for at least the first three months after the transplant. If you need treatment, you will receive it in tablet form or as an intravenous drip.

Adenovirus and Epstein-Barr virus (EBV) are other viruses that can cause you infections and illness and that we will therefore look out for.

Varicella zoster virus (VZV) causes chickenpox in children and young adults and can be activated later in life and give you shingles. You will be given a preventive antiviral medicine against these infections.

Timeline for examinations, tests, medicines and vaccinations after a transplant:



LÄKEMEDEL



Ciklosporin – Immunhämmande läkemedel som skyddar mot graft versus host disease och avstötning.

Ursofalk – Läkemedel som skyddar mot graft versus host disease i levern.

Bactrim – Antibiotika som skyddar mot infektion med toxoplasma och pneumocystis.

Valtrex – Läkemedel som skyddar mot vissa virusinfektioner.

RUTINBLODPROV



CMV/EBV

Cytomegalovirus och Epstein-Barr virus kontrolleras regelbundet i blod fram tills minst 3 månader efter transplantation.

Ciklosporinkoncentration

Koncentrationen kontrolleras i regel 1 gång i veckan i ungefär en månad efter transplantation. **Vänta med att ta ciklosporin tills efter provtagning de dagar vi mäter ciklosporinkoncentration!**

UNDERSÖKNINGAR



Benmärgsprov

Prov för att utvärdera din benmärg efter transplantation, här tar vi även chimerism.

Chimerism

Prov där vi mäter hur stor andel av dina blodkroppar som har ursprung från dina gamla celler respektive donatorn.

Gynundersökning

Rutinundersökning av gynekolog efter transplantation inklusive utvärdering av eventuell graft versus host disease.

Spirometri

Utvärdering av din lungfunktion.

Tandläkare

Rutintandläkarebedömning efter transplantation, inklusive utvärdering av eventuell graft versus host disease

Borttagande av CVK

Din CVK kan tas bort när de täta blodprovstagningarna och behovet av trombocyter, blod eller intravenös medicinerings upphör, vanligtvis 3-6 månader efter transplantationen. Att ta bort CVK:n är enklare än att sätta in den, men görs i lokalbedövning då en förtjockning (kuff) sitter på katetern under huden för att hålla den på plats. Barn och ungdomar sövs.

VACCINATIONER



Prevenar

Vaccin mot pneumokocker (vanligaste bakterien vid lunginflammation)

Covid-19 vaccin

mRNA vaccin mot Sars-CoV-2 (**Covid-19**)
Antalet doser och intervall på individuell basis

Tetravac

Vaccin mot kikhosta, difteri, stelkramp och polio. Kallas även grundvaccin i öppenvården

Diet

A nutritious diet and plenty to drink are important elements in recovery after SCT. Drinking plenty reduces the risk of kidney impairment and rehydrates the mucosa of the mouth. It can be difficult to eat due to changes in taste, nausea and lack of appetite/hunger. **The most important thing is that the raw materials are fresh and that the food is thoroughly cooked to reduce the risk of stomach illness.**

You therefore need to be careful with:

- Ready-prepared products from shops or restaurants that do not have to be heated, for example sandwiches, baked goods, cold sauces, mayonnaise.
- Raw or pickled products such as fish, shellfish, meat and unpasteurised cheeses.
- Smorgasbords, buffets or salads in a restaurant.
- 'Pick-and-mix' selections in shops, such as sweets, nuts, salads and bread.
- Vacuum-packed fish (such as cured and smoked salmon) and cold meats (ham and sausage) near their sell-by date.
- Salads, including prepared salad in a bag, must be rinsed thoroughly.

Consumption of alcoholic beverages should be discussed with your doctor, as they may interact with the medicines you are taking.

You may sometimes need support from a dietician, in which case we will arrange a contact for you.

Oral health

After you are discharged, we recommend that you use an ordinary extra-soft toothbrush. Initially, however you are advised to be careful brushing your teeth so that your gums do not become sore.

In the initial period after the transplant, it is common to feel dryness in the mouth and to experience some changes in taste. To prevent tooth decay, cavities in your teeth, you should rinse your mouth with 0.02% sodium fluoride, morning and evening. You should rinse for about a minute before spitting out the solution. Fluoride solution is available over the counter at pharmacies.

Fatigue

It is common to feel both physically and mentally tired for a long time after a transplant. You may experience fatigue after chemotherapy. Your new immune system will be in the process of being built up, and that will tax your strength. Research has shown that fatigue can be counteracted by physical activity. So sleeping away the tiredness does not help. Physical activity is the best form of medication.

Physical activity

Regular physical activity does not just lead to reduced tiredness after the transplant, it also leads to better sleep, and stronger muscles and balance. It can also reduce stress, anxiety and low mood and can give you a better quality of life. Suggestions for physical activity in everyday life:

- taking the stairs instead of the lift
- walking around your home while talking on the phone
- taking a walk in the fresh air
- playing with your children
- standing up at least once an hour if you lie down or sit a lot

It is possible to make contact with a physiotherapist if necessary after you have been discharged from the ward. Ask your doctor or nurse for a referral.

We are able to offer you exercise in the physiotherapy gym twice a week if you are particularly prone to infection. There is also an option for individual appointments.

Sex and relationships

Your treatment may affect your libido and sex life. There is nothing to stop you resuming your sex life after the treatment, provided you want to, but there are a few things you need to bear in mind. Mucous membranes in general may become more brittle, and this can make penetration uncomfortable or even painful. Lubricants can be helpful for both women and men, and some people think a condom offers some protection and lubrication. If you find intercourse painful, talk to your doctor or nurse about it, as help is available. It is also important to remember that GVHD can occur on both internal and external genital organs for women (labia and vagina) and the male genital organ. Correct treatment is important if it does occur. Women may enter the menopause after a stem cell transplant (including women of a young age). Women are therefore offered a check-up by a gynaecologist a few months after the treatment, but if you experience severe problems, talk to your doctor or nurse at CAST. You may sometimes lack energy, having no desire even if there are no physical problems. This is also important to talk about, both with your partner, if you have one, and with healthcare professionals. Remember to use a condom if you do not have a steady partner, to avoid sexually transmitted diseases.

If you are a woman, you will also see a gynaecologist for a check-up before and after the transplant.

Hormonal disorders

The conditioning prior to the transplant affects the functioning of various hormone-producing glands, for example the thyroid and the ovaries in the case of women. It is common for women to need to be given female sex hormones to avoid menopausal

symptoms. Thyroid hormone is sometimes also needed. These hormones can be administered as tablets or patches.

Disturbances of hormone production in children and adolescents may affect growth and puberty. All children and adolescents who have not gone through puberty are therefore checked. Any hormone treatment you receive will be adapted to you to ensure that your growth and development will be as normal as possible.

Work/school/pre-school – pre-school children in the household

When you will be able to return to work depends on how well you feel and what kind of work you do. It usually takes 6 to 12 months after SCT, usually part-time at first, depending on what type of work you do.

Children should not attend pre-school until 9 to 12 months after SCT at the earliest. A suitable time for return to school is at least 4 to 6 months after the transplant.

If, as a transplant patient, you have a child of school age in your household, it is advisable to keep the child at home from pre-school for the first two months after you have come home from hospital. This is to reduce the risk of you being affected by infections.



Pets

If you have a pet, we are happy to talk to you about how best to look after your pet when you are prone to infection. There are risks associated with pets, but there are also good solutions for how to look after your pet.

Points to bear in mind:

Dogs – Avoid your dog's saliva, being bitten and being scratched. Do not pick up your dog's excrement. Do not allow your dog to sleep in your bed.

Cats – Avoid your cat's saliva, being bitten and being scratched. You must not clean the litter tray. Do not allow your cat to sleep in your bed.

Guinea pigs, hamsters or similar pets – Avoid your pet's saliva, being bitten and being scratched. Do not clean your pet's cage. Do not allow your pet to sleep in your bed.

Reptiles – Reptiles can spread salmonella. You must not handle the reptile or its cage/aquarium. Position the cage/aquarium in a separate room.

Fish – The aquarium must not be in your bedroom. You must not clean the aquarium.

Birds – Birds can spread salmonella. You must not handle the bird or its cage. Position the cage in a separate room.

Stables and barns – You must not enter stables or barns for the first few months after a transplant. Ask your doctor when it will be appropriate for you to resume entering stables or barns.

Disease follow-up/chimerism

We will monitor your disease at regular intervals after the transplant. Depending on what disease you have, we will look at bone marrow tests, X-rays or blood tests.

Chimerism is a test in which we can see how high a percentage of the bone marrow or blood consists of the donor's cells or your own 'old' cells. The goal is for you to become 100% donor. It is not uncommon to have a mix in the initial period after a transplant. If we find that your own cells are returning or increasing in number, we can take steps quickly to enable the donor's cells to take over. These steps may consist in scaling down immunosuppressant medication or topping up the donor lymphocytes, known as DLI, with the aim of stimulating your immune system and the donor's cells.

The underlying disease may return despite all efforts. There are various treatment options, such as chemotherapy or topping up DLI. Another transplant may sometimes be appropriate.

Removal of central line

Your central line can be removed when the frequent blood tests and the need for platelets, blood or intravenous medication end, usually 3 to 6 months after the transplant. Removing the central line is simpler than inserting it, but is done under local anaesthetic as there will be a thickening (cuff) on the line beneath the skin to help keep it in place. In children and adolescents, it is done under general anaesthetic.

Vaccinations

As a result of the transplant, you will lose the vaccinations you have received earlier in your life.

You will be given vaccinations according to a special programme, beginning around 3 months after the transplant. No vaccinations will be given without consulting the doctor responsible at the CAST Outpatient Clinic.

Influenza and COVID can be prevented by vaccination, and it is therefore appropriate for your family members to be vaccinated.

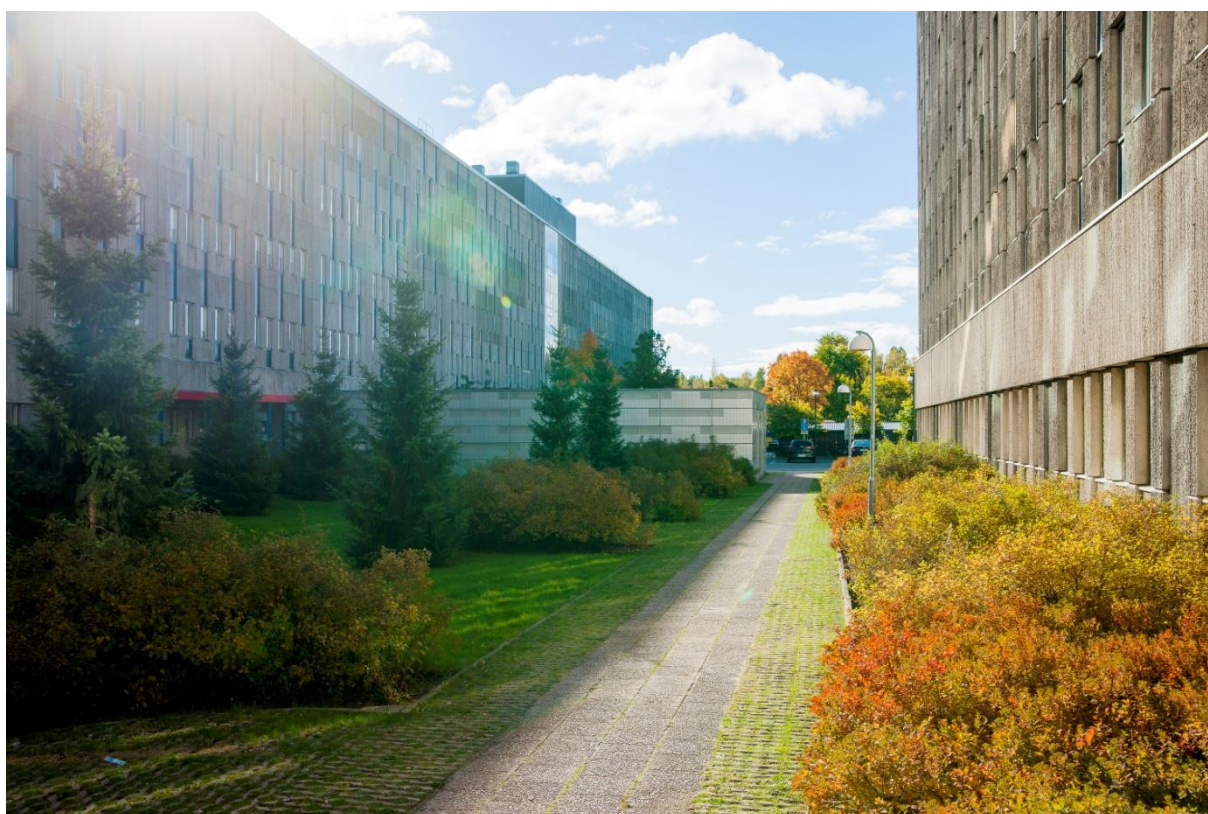
Travel

You will need to be in Stockholm County for the first three months after the transplant. Consult your doctor at the outpatient clinic about when it will be appropriate for you plan any travel.

COVID-19

COVID-19 is a respiratory infection that can have serious consequences for you as a patient. It is best if you come to us already vaccinated and if your friends and relatives are also vaccinated. If possible, we will vaccinate you again after your stem cell transplant and check your COVID-19 antibodies. Until you have built up immunity to COVID-19, you will need to be cautious, avoid large gatherings and people with disease symptoms, wear a mask and exercise good hand hygiene. You are advised not to travel during this period unless necessary. If you are diagnosed with COVID-19 after your stem cell transplant, you must contact us.

Karolinska Comprehensive Cancer Center



Photograph: Tore Dahlström

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