



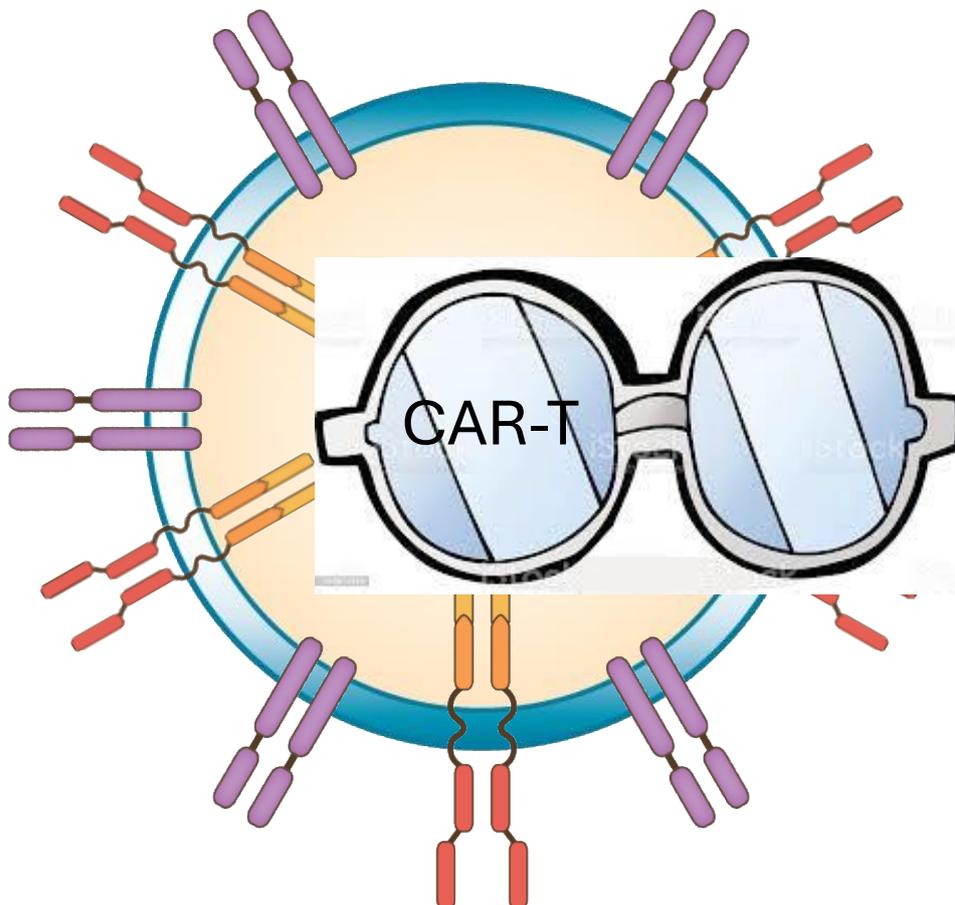
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Karolinska Comprehensive Cancer Center

Information about

Chimeric Antigen Receptor (CAR-) T cell therapy at ME CAST



Image, modified from other illustrations, Professor Stephan Mielke: 'CAR-T cells: glasses for immune cells'

For patients due to undergo CAR-T cell therapy at ME CAST

*This brochure is aimed at patients due to undergo CAR-T cell therapy at the **Medical Unit Cell Therapy and Allogeneic Stem Cell Transplantation (ME CAST)**. CAST is part of **Karolinska Comprehensive Cancer Center and Karolinska ATMP Center** and is certified according to **JACIE**, an international quality organisation.*

The brochure is intended to provide information and recommendations for you and your family and friends before, during and after CAR-T cell therapy. It contains answers to frequently asked questions, but also contact details so that you can get in touch with us if you do not find the answer you are looking for in the brochure.

CAR-T cell therapy is a type of therapy for many diseases and for patients of different ages, based on an individual medical assessment. Each disease has a specific kind of CAR-T cell product. This brochure describes in general terms how CAR-T cell therapy works. You and your family and friends will be invited to an information session in which we will talk about what your particular CAR-T therapy will look like.

The aim of CAR-T cell therapy is to use your own white blood cells to create a genetically modified cell, a medication that searches for the cancer cell and kills it. It could be said that your white blood cells are given 'glasses' to detect the cancer cell.

The CAST Team



Contact details for ME CAST

	Internal address	Telephone number
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
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Coordinator for Children	K88	+46 (0)8-123 826 23
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

Before CAR-T cell therapy

When the doctor treating you starts to suspect that your disease will need to be treated with CAR-T cells, your case will be discussed at a national conference and if recommended at a multidisciplinary conference at Karolinska involving the doctors treating you and us as the cell therapy team.

Consent

When a recommendation is made to offer you CAR-T cell therapy, you will meet the doctor responsible for you to sign consent forms regarding the disclosure of your personal data under GDPR. This is to enable us to start the process of producing CAR-T cells for you.

You will need to have blood tests to check for viruses and how your immune system is working.

Information session

CAR-T cell therapy is an advanced and complex form of treatment. We therefore invite you and your family to an information session with the doctor and coordinator to describe what CAR-T cell therapy would mean in your particular case. The session contains a lot of detail, so it is strongly recommended that one or more family members or friends are present.

We will tell you about the possible benefits and risks of the therapy so that you can be involved in the decision on the therapy.

If you come from another county, contact will be made with our counsellor prior to the therapy for information about accommodation in Stockholm for you and your family after the therapy. You will normally stay in Stockholm for one month after the cell therapy.

Assessment of blood vessels

In connection with the information session, we will visit the Apheresis Clinic where the actual harvesting of your cells takes place. Here you will meet a nurse who will describe the harvesting process and look at your blood vessels.

Harvesting of cells

Your white blood cells (lymphocytes) are harvested using a process called leukapheresis. It works in much the same way as when blood donors give blood. The blood is withdrawn through a cannula in the crook of your arm and passes through a cell centrifuge that collects the white blood cells while the other cells are returned to the body through a cannula in the other arm. If you have poor blood vessels, you may need to have a haemodialysis catheter inserted. This remains in place until harvesting has been completed.

Harvesting takes about 4 hours and you can then go home.

Treatment while awaiting CAR-T cells ('bridging')

While waiting for the CAR-T cells to be produced, you will receive the appropriate treatment for your disease. Your haematologist/oncologist will arrange this. Production time is usually about 4 weeks before the CAR-T cells arrive at the hospital and we can start planning your therapy.

Tests, examinations and preparations prior to CAR-T therapy

The purpose of the pre-therapy tests and examinations is to evaluate disease status. We sometimes need to examine your heart and lungs. You will need to have:

- Disease-evaluating tests and examinations such as bone marrow examination, cerebrospinal fluid testing, brain MRI or PET-CT, depending on your diagnosis.

If your disease-evaluating tests show that you have responded well to your treatment, we will plan your CAR-T cell therapy immediately. If it turns out that you have not responded to your treatment, you may need further treatment. The CAR-T cells are stored at the hospital until you have responded to your treatment.

Time for CAR-T therapy

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

Family and friends and visiting

If you have a family member or friend 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 decide if and when you wish to have visitors, preferably no more than a couple of people at a time. Visitors must not show any signs of infection, for example signs of a cold, fever or diarrhoea. Sometimes the visitor may

need to take a COVID test before visiting. Ask your nurse what will be needed in your particular case.

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 family member or friend
- 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 family member or friend, 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, craft activities, a laptop, a tablet or a mobile phone. Wifi is available in the hospital.

If you wish to bring something to eat, please speak to the coordinator or 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 given 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 heatable. A family member or friend can bring you food or anything else you need while you are in hospital.

If you take herbal medicines and vitamins, these should be discussed with your doctor, as they may interact with the therapy 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 family member or friend will be given a room of your own, equipped with a shower, toilet, television 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. They will run through procedures and the treatment you will receive with you, 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 family and friends and show you 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 care provider
3. Joint action plan

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

Pre-treatment (lymphodepletion therapy)

Before you receive your CAR-T cells, we need to prepare your body with a pre-treatment consisting of chemotherapy (cytotoxic drugs). The exact treatment you receive depends on your disease.

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

You may be offered the option to receive your pre-treatment at CAST outpatients or as an inpatient. If you receive the pre-treatment in the outpatient clinic, you will come in for treatment in the morning and will then go home. You will then be admitted to inpatient care the day before you are due to receive your cells.

The pre-treatment lasts for about 3 days and you will then be ready to receive your CAR-T cells.

CAR-T cell delivery

The CAR-T cells come collected together in a small bag or syringe. Staff from the stem cell laboratory will come to your room to thaw your cells before you can receive them. Some products come to you thawed in a syringe. The cells are given as a drip or injection through your subcutaneous venous port or central venous catheter. There will be a lot of staff in the room during cell delivery to check that you remain well. The actual cell delivery takes just a few minutes. 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.

You will need to stay on the ward for at least two weeks after cell delivery. This is because there may be side effects as the cells start to work and fight your cancer cells. You may be offered home care during these weeks.

Side effects

Cytokine release syndrome (CRS)

When the CAR-T cells attack your cancer cells and kill them, it releases a lot of substances called cytokines into your body. This may cause you to experience high fever and malaise in the form of joint pain and headache. You will receive treatment for your fever.

The symptoms can sometimes get worse, and you may need to be cared for in the intensive care unit.

Neurotoxicity (ICANS)

The therapy can also affect the brain and you may experience sudden mental impairment. It can cause a number of neurological symptoms such as speech difficulties, lowering of consciousness, impaired memory, seizures and even coma. Sometimes we need assistance from the intensive care unit if the effect is significant. There is treatment for this condition, and it is usually temporary. In order to detect symptoms of neurotoxicity early, you will have to undergo a series of tests every day. For example, you will be asked to write a sentence every morning and count.

CRS and ICANS usually occur in the first two weeks after you receive your CAR-T cells, in which case you will be treated in hospital or at home. There is a small risk of this occurring in the first few weeks after discharge, so it is important that a family member or friend is at home with you during these weeks. If you do not have a family member or friend, the

Advanced Healthcare in the Home (ASIH) service will attend and we will be in closer contact with you.

Activity

Much of your activity will be confined to your room during your hospitalisation. You will be provided with 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

You will be supported by a counsellor before, during and after treatment. The counsellor can give you advice and support regarding assistance available from the local authority, social insurance provisions, rehabilitation and other social resources based on your circumstances. You will also be offered counselling to help you cope with and process a difficult situation.

Your family members 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 you would like.

You can find contact 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 Room.

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 own room. Play therapy can offer many different creative materials, toys, games etc.

We are happy to spend some time with you in your room if you would like to play, create, take part in games or do something else together.

If you feel a little worried about any of your treatment procedures, the play therapist can help you by demonstrating what will happen on dolls or using other material.

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

The hospital school

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

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 or Dad can join 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 visits 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 sensation of having moved from the hospital to various places, such as space, the sea, nature, etc.

Our VR educationalist visits 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 older patients there are various kinds of stories that are told verbally (not read out) 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 will 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 it's quite quiet and calm. 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:



Discharge and follow-up

Two weeks after the CAR-T therapy, it's time for you to go home or to your hotel if you're not from Stockholm. If you live in Stockholm, the Advanced Healthcare at Home service will be involved and will visit you to carry out tests. You will also need to come to CAST Outpatients for medical appointments. We recommend that a family member stays at home with you for the first few weeks after discharge.

You will be given instructions on what you need to look out for, and you will need to monitor your temperature for your first few weeks at home. You will be given contact details so that you know who to get in touch with if you have questions or feel unwell.

If you do not live in Stockholm, you will stay in the hotel until one month after the CAR-T cell infusion, about two weeks after discharge.

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.
- chills
- behavioural changes
- cough or shortness of breath
- bleeding
- diarrhoea
- vomiting
- sudden headache
- newly developed or worsening pain
- mouth ulcers
- 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

Bone marrow impairment

The therapy may affect your bone marrow function, and you may therefore have a low blood count and be susceptible to infection after the therapy. This effect can last for a long time, up to a few years.

B-cell deficiency

As CAR-T cells affect your B-cells, which are your body's defence against viruses and bacteria, you will need immunoglobulins to boost your immune system. For more information, please contact our Outpatient Service.

Disease follow-up

We also monitor your disease with bone marrow examination or PET scans.

Fertility

As the CAR-T cell is a genetically modified product, there may be a risk in having children. You therefore need to use effective contraception such as condoms. If you are planning a pregnancy, it is important that you contact CAST Outpatients for a discussion with our doctors.

Tiredness/fatigue

It is common to feel both physically and mentally tired for a long time after the therapy. You may experience tiredness of the brain (fatigue) after chemotherapy and cell therapy, and this saps your strength. Research has shown that fatigue can be counteracted by physical activity. Sleeping away the tiredness does not help. Physical activity is the best medicine.

Your own notes & questions

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