

CAR T-cell therapy

information for patients

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This brochure provides a first introduction to a treatment with Chimere Antigen Receptor T-cells, or CAR T-cells. You will receive general information about the principle, the purpose, the progress and the possible consequences of this treatment. As soon as you come closer to the date of your CAR T-cells treatment, you will receive more concrete information.

If you have questions after reading this brochure, please don't hesitate asking your healthcare providers. The contact details of the different departments can be found at the back of this brochure.

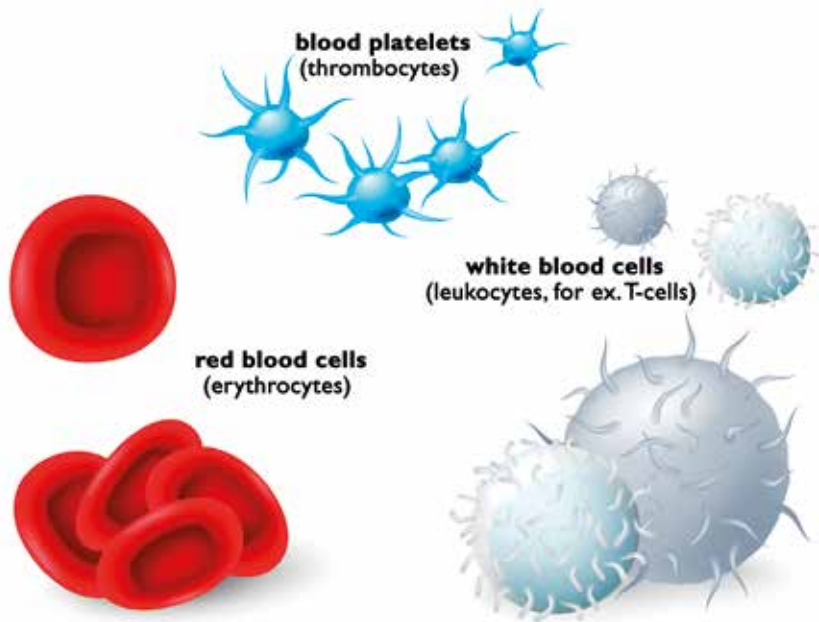
Haematology department

CONCEPTS

To understand the principle and the progress of a CAR T-cell treatment we first need to talk about blood.

Blood cells play a crucial role in our lives. Good blood production is vital in other words. There are three types of blood cells: white blood cells, red blood cells and blood platelets. Each of these three types of blood cells has its own function:

- ✓ **White blood cells** ('leukocytes') constitute the basis of our immune system or our immunity. They defend our body against infections of bacteria, viruses and other threats. There are many different types of white blood cells. They all have their own specific role in recognising and destroying germs. **The T-cell is an important type of white blood cell.** It recognises damaged cells or cancer cells by the foreign proteins on it. The T-cell binds to the foreign protein which gives it the signal to attack the damaged cell.
- ✓ **Red blood cells** ('erythrocytes') contain haemoglobin. This protein transports oxygen in the blood from the lungs to the other parts of the body.
- ✓ **Blood platelets** ('thrombocytes') are responsible for coagulation of the blood and thus stop bleeding.



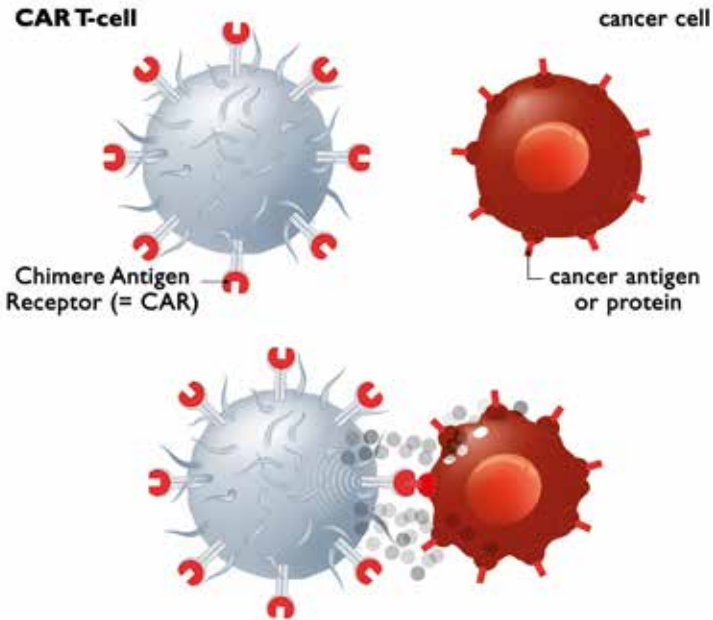
PRINCIPLE AND GOAL OF THE CAR T-CELL TREATMENT

Under normal circumstances our immune system, more specifically the **T-cells**, recognise damaged cells or cancer cells and attack them. However, some cancer cells escape detection.

Your doctor suggested immunotherapy with CAR T-cells to treat this.

This CAR T-cell therapy is a treatment with **your own modified white blood cells or T-cells**. By adding a special receptor or 'CAR' on the cell surface of the T-cells, they are able to recognise and destroy the cancer cells. Under favourable circumstances the modified T-cells remain in the body for a long time to cure the cancer and to prevent it from recurring.

Unlike other cell therapies, it is important some cancer tissue or cells are still in your body to start the CAR T-cell therapy. This tissue is needed to stimulate the CAR T-cells and to grow them.



TREATMENT PROGRESS

COLLECTING WHITE BLOOD CELLS

Because a CAR T-cell treatment requires your own white blood cells, these cells are first collected.

These white blood cells are collected on an outpatient basis in the apheresis centre with an [apheresis device](#) or 'cell separator'. This device comprises a 'centrifuge', among other things, which is able to separate the white blood cells from the rest of your blood. The white blood cells are collected in a collection bag and the rest of your blood is returned to you immediately. The collection of white blood cells can take up to six hours and may need to be repeated.

For this procedure the nurse inserts an infusion needle in both arms. It is possible you have very fine veins which means not enough blood can flow via a needle.



In that case, an anaesthetist will insert a deep venous catheter (usually in your groin). The insertion of this catheter is under local anaesthetic in the operating theatre. You will be admitted to hospital the day before the apheresis procedure. The catheter is removed immediately after the procedure so that the hospitalisation is restricted to one night.

INDIVIDUAL TREATMENT

Your collected white blood cells are then stored under controlled conditions and sent to a special laboratory for processing. By adding an extra protein, **your own T-cells are modified to CAR T-cells**. They are then cultivated until there are millions. Before these cells can be returned to UZ Leuven, they must meet all quality standards.

Following approval these cells are frozen, returned and, on receipt, checked in our own laboratory. This process takes a couple of weeks which means a bridging therapy may be required in some cases.

ADMISSION

A CAR T-cell therapy requires on average of three to four weeks in hospital.

Preparation

When the cells are ready and have arrived at UZ Leuven, the preparation can start. A couple of days before your modified T-cells or CAR T-cells are returned to you, you are admitted for a [short preparatory chemotherapy](#). This preparation is necessary to create a favourable environment for the modified T-cells to make sure they are able to multiply in your body after administering.

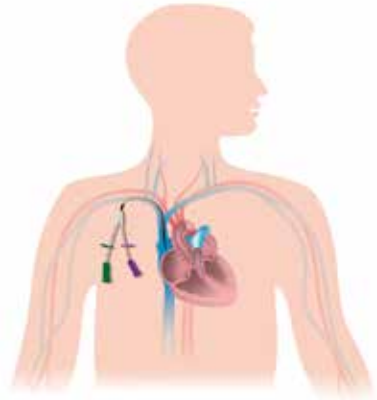
This preparation may result in a number of side effects such as nausea, fatigue and reduced appetite. The seriousness and duration of these side effects differs from person to person. Your doctor and nurse will be able to provide more information during your admission.

Dip

In the days after your chemotherapy your red blood cells, blood platelets and white blood cells will also gradually drop. This period is also referred to as 'the dip'. You may need red blood cell and blood platelet transfusions. The drop in white blood cells, including your neutrophils, make you very vulnerable to infections and may cause a fever. As soon as the values of these neutrophils have dropped under a particular level, your doctor will decide that for the time being, until your neutrophils have been sufficient restored, you may not leave your room.

Infusion of the CAR T-cells

The infusion of the CAR T-cells follows the preparation. After thawing, these cells are administered with a fast-running infusion via a 'deep vein catheter' or similar catheter. One or more bags are administered. Administering one bag takes approximately ten to fifteen minutes. This infusion is typically in your own room on the unit.



During the infusion of these cells you may suffer nausea, hot flushes and palpitations. They are caused by the preservatives added to the CAR T-cells. This is why your blood pressure, oxygen level and heart rhythm are monitored during administration. The doctor and nurse stay with you during the procedure. To prevent these infusion reactions, [anti-fever medication \(e.g. Dafalgan®\)](#) and [medication that suppresses allergic reactions \(e.g. Zyrtec®\)](#) are administered approximately one hour before the infusion of the cells.

The preservatives are also responsible for the specific smell and taste you perceive. To improve the bad taste, the nurse will give you a throat lozenge during the administration of the CAR T-cells. You can also take some mints you like as an alternative. Your body odour will also be slightly different for a few days.

Specific side effects

The CAR T-cells go to work after the infusion. Any remaining cancer tissue will stimulate the CAR T-cells, allowing them to multiply and destroy the cancer cells. This process may cause a number of **specific side effects**.

Cytokine release syndrome

The cytokine release syndrome is an extensive inflammatory response in the body. This possible response often occurs in the first week after the administration of the CAR T-cells and usually peaks between one to two weeks after administration.

The symptoms may resemble a mild flu (feverish, shivery, nauseous), but in severe cases can also affect the organs. The nurses and doctors will regularly check your blood values, temperature, blood pressure, oxygen level, breathing frequency and how much you urinate. They will also regularly ask whether you have other symptoms such as muscle aches, rashes or headaches.

Neurotoxicity

The administration of CAR T-cells may also cause unwanted effects in the brains. This possible response usually occurs in the first two weeks after the administration of the CAR T-cells. Symptoms such as headaches, feeling edgy, trembling hands, drowsiness, balance disorders, difficulties understanding words, writing and speaking are also possible. The nurse will regularly ask you a series of questions and have you carry out assignments to pick up on this in good time. These symptoms can be frightening, both for you and your family. In case of worry you can always talk to the nurse or doctor about this.

Organ toxicity

The treatment can release substances at a rapid rate, which can affect organs such as the liver and kidneys. Your doctor and nurse will therefore keep a close eye on you by regularly checking your parameters, the amount you urinate and your blood values and asking you about any inconveniences.

If you are not feeling well or if you or your family notice anything abnormal, it is important to inform the nurse as soon as possible. The sooner we can treat you, the better.

In some cases you will need temporary intensive care and monitoring in another unit.

RECOVERY PERIOD

By the time you get home, you won't have fully recovered. Your body may still feel the effects of the chemotherapy and treatment. In the first weeks you may still feel weak and tired and you may still suffer the specific side effects. **You or your family should report any abnormal behaviour as soon as possible. You will be given a questionnaire, which a family member or relative must fill in with you from time to time. You are not allowed to drive for eight weeks.** Some patients are able to resume their familiar activities more quickly than others. Your healthcare providers can advise you on how to deal with this tiredness and other inconveniences. UZ Leuven also offers a revalidation programme, i.e. KanActief (www.uzleuven.be/kanactief).

In addition, the Leuven Cancer Institute organises information and meeting moments for people with cancer and their relatives around numerous themes. You are most welcome to attend. Check out www.uzleuven.be/lki/infosessies or ask your healthcare providers for more information.

The first weeks to months after your discharge, your doctor and nurses will monitor you regularly. For this monitoring you must come to the outpatients' clinic at the Gasthuisberg campus. If you have any new complaints contact your attending doctor as soon as possible.

PSYCHOLOGICAL STRAIN

In addition to the physical strain, this intensive treatment is also a psychological strain for you and the people around you.

A CAR T-cell treatment offers hope for a future, but the physical strain can make the road to that future hard. You will face all kinds of medical procedures, physical discomforts and limitations. Both the waiting period for the infusion, the infusion itself, and the recovery period afterwards will raise new questions and concerns. Obviously this has an impact on your emotional wellbeing.

This is also a difficult period for your family, friends and acquaintances. Because they experience the situation from their own perspective, it is not always easy to understand each other. That is why it is important to talk about any concerns or negative feelings, both with those around you and with your healthcare providers.

A psychosocial team with social workers, psychologists, a psychomotor therapist and a pastor are on hand to accompany you and your loved ones during this period, together with your doctor and nurse.

RISKS AND CHANCES OF SUCCESS

There is always a risk that the cells will not be released immediately or that there will be an additional delay. This means the infusion date can still be postponed at any moment.

The chances of side effects after a CAR T-cell treatment are real. In some cases the therapy may also have insufficient effect or may not prevent the recurrence of the disease. Based on blood samples and examinations you will be monitored in the outpatients' clinic. It is important you always talk to your doctor if you have questions and concerns. Information you hear elsewhere or find on the Internet is also best discussed with your doctor. You may find specific risk percentages in other sources of information. We want to point out to you that the figures in the different sources vary strongly and are very general.

You may find the burden and risks of the treatment too heavy and doubt whether you want to undergo this treatment. Discuss these worries with your doctor. You always have the right to refuse treatment.

If this is your decision, your doctor will respect this decision and the team will continue to surround you with the best possible care.

COST PRICE

The cost price of CAR T-cell treatment is very high, but the costs are largely reimbursed by the health insurance or through a pharmaceutical company (usually a study). If you have any questions or concerns about this, please discuss them with your attending doctor and social worker.

HEALTHCARE PROVIDERS

A fixed medical staff with supervisors is responsible for the whole haematology department. During your treatment you will meet one or several supervisors.

UZ Leuven is also a doctor training hospital. These assistants are specialising under the direction of the permanent medical staff. All units of the haematology department work with assistants. The assistant and supervisor are jointly responsible for your medical treatment.

Each unit has its own group of nursing staff and is under the direction of a head nurse. The nursing staff is responsible for a number of assigned patients and their treatment.

There are also social workers, psychologists, psychomotor therapists and a pastor. They can help you if you are facing practical and emotional difficulties during your treatment. The department also has a dietician and a physiotherapist.

UNITS

The haematology department of UZ Leuven consists of different units. The units have their own organisation, but they are closely connected and supplement each other.

There are two nursing units. Both units have isolation measures during the most infection sensitive period of your treatment. Your doctor will decide which unit you go to.

Most of the monitoring of your treatment is in the outpatients' clinic. Before your treatment you may also already receive ambulatory care. The outpatients' clinic also has an apheresis centre, where your white blood cells are collected.

And there is also a consultation unit. The doctors of the haematology department are available from Monday to Friday at this unit. They will monitor your progress if you no longer have to go to the outpatients' clinic.

CONTACT DETAILS

You can contact the nursing units at the following phone numbers:

Nursing unit (E 630): tel. 016 34 63 00

Nursing unit (E 467): tel. 016 34 46 70

Outpatients' clinic oncology: tel. 016 34 76 58

Apheresis centre: tel. 016 34 83 38

Consultation oncology: tel. 016 34 66 60

WEBSITES

www.nih.gov/health-information (in English)

www.bmtinfonet.org (in English)

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Design and Production

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