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Living with a new heart

Care guide for patients and family after a heart transplant

Introduction

You recently had a heart transplant. This will not only have a significant impact on your life, but also on your family and the people close to you. You probably have many questions now: How do I start to rebuild my life? How can I prevent rejection of my new heart? How will I get things organised at home? Will I be able to return to work or go to school? When can I drive my car again? Am I still allowed to travel? This brochure tries to answer all these and other questions.

Not all the information in the brochure is relevant to everyone. The contents page will help you quickly find the information relevant to you.

This brochure is in no way intended to replace personal contact with members of the heart transplant team. Should you have further queries after reading this brochure, we will happily provide further explanation

We wish you a speedy recovery!

The heart transplant team and the staff of
the E 435 hospitalisation ward cardiology/heart transplant
and E 439 heart transplant day ward

YOUR TRANSPLANT TEAM

Lifelong monitoring by the transplant team is important. The transplant team is a multidisciplinary team (a team of specialists from different disciplines) in which each member will make their own specific contribution to support you and those around you through the transplant process, and this for medical, psychosocial and practical matters.

The team consists of the following members:

YOU AND THE PEOPLE AROUND YOU

You and the people around you (family, friends) are the most important members of the team!
It's important you play an active role and are involved in the whole transplant process and have a good understanding of what a transplant entails.
Support of your friends and family is important in this process.
The other team members will support you and the people around you.

CARDIOLOGISTS/ TRANSPLANT PHYSICIANS

A cardiologist is a medical heart specialist.
After the transplant, the cardiologist specialised in heart transplants is responsible for your medical follow-up (including your medication, medical problems or questions related to the heart transplant, check-ups).

NURSING STAFF

The nursing staff of the hospitalisation ward coordinate your daily routine and look after you during your hospital stay. During your hospital stay they will provide extensive information about you medication and lifestyle aspects after a heart transplant (for example physical hygiene, recognising symptoms of a possible rejection, travelling, sun protection).

After your hospital stay the day ward nurses will provide further support. The head nurse and the heart transplant specialist nurse are also always available to listen to your questions and needs.

PHYSIOTHERAPIST

During your hospital stay your physical activities are gradually resumed under the supervision of a physiotherapist. When you're home again, it's also important to further improve your exercise capacity and muscle strength.
The physiotherapist will discuss your continued rehabilitation after your discharge and refer you to a rehabilitation centre. More information on exercise and rehabilitation is available on page 53.

DIETICIAN

The dietician informs you about the dietary guidelines after the transplant. The first 6 months after your transplant, foods containing pathogenic agents should be avoided. You must also respect hygiene, storage and preparation guidelines. After 6 months the main thing is to maintain a healthy diet. The dietician will guide you. More information on dietary guidelines is available on page 57.

SOCIAL WORKER

The social worker provides help and advice during your hospital stay to make your discharge from hospital as smooth as possible. If you want, the social worker can help you find home help services for possible care (e.g. wound care) or household help (e.g. cleaning help). When you're at home, you can talk to the transplant team's social worker for questions about your school or work situation, financial difficulties, social services, insurance, legal matters, contacts with fellow-sufferers and so on. This is possible by phone or during your outpatient check-up at the heart transplant day ward.

PSYCHOLOGIST

A heart transplant is a significant event, both for you and for your immediate family members. A psychologist can provide support to help you process this and discuss your experience: how do you feel after the transplant? How have your partner, friends and family reacted? Are you managing to respect the rules and recommendations?

After your hospital stay you'll be discharged and you can go home. You might feel anxious leaving the hospital or you have mixed feelings. Preparing the discharge and organising your return home is often stressful for family members.
After a further recovery at home, an adjustment period starts. If you or your family have questions during this stage, the psychologist of the heart transplant team is also on hand to help you.

PASTOR

Having a heart transplant can spark certain emotions and questions relating to faith and spirituality. The pastor can provide a listening ear for you and your next of kin if you want. The pastoral services can also contact people of other faiths or denominations.

HEART TRANSPLANT SECRETARIAT

The administrative employees of the heart transplant team take care of your appointments and hospital stays. If you contact them by phone, they can forward you to the right care provider.

STAY AT THE E 435 CARDIOLOGY/ HEART TRANSPLANT WARD

After the transplant, you go to the intensive care unit. When you've recovered sufficiently, you go to E 435, the cardiology and heart transplant hospitalisation ward. Generally, you stay here for 3 weeks. You need this period to recover and to learn how to properly look after your body and new heart. In case of complications you may have to stay longer.

During your stay at E 435, you'll be dealing with new impressions and facing many questions. We've listed a few things so you can read everything again in the comfort of your home.

NURSING IN AN ISOLATION ROOM

The use of immunosuppressant medication will make you more prone to infection. This risk of infection is highest immediately after the transplant. To provide additional protection you'll be in a separate 'protective isolation room'. This room looks the same as any other room but all visitors will have to comply with specific precautionary measures:

- ✔ Wash your hands with soap and water and disinfect them with hand sanitiser.
- ✔ Everyone wears a mask, apron and gloves.
- ✔ All materials are disinfected before they enter the room
- ✔ The door and windows remains closed; air conditioning will be used during the summer to keep the room comfortable.

There's an isolation card on the door with all the instructions for visitors and care providers.

ELECTROCARDIOGRAPHY

The follow-up at the heart transplant unit is not as intensive as at the intensive care unit. The nurses are no longer constantly present in your room.

You needn't worry, we continue to carry out checks and your heart rhythm is monitored by telemetry. Telemetry means 'remote measurement' and involves measuring your heart rhythm with a device you carry with you. Five electrodes are stuck to your chest and connected to the device via cables.

The device records the heart's electrical impulses, converts them into a signal and transmits the data to a monitor in the nursing station where the nurses are able to monitor your heart rhythm.

DAILY SCHEDULE

The exact daily schedule depends on the tests or your treatment.

A normal daily schedule at the heart transplant unit looks like this:

- 7.00 – 7.15: Start of the morning shift with nurse's briefing
  As the hospital provides 24-hour care, nurses work in 3 shifts a day. Per shift, a nurse is assigned to you. Points of attention regarding your care and treatment are passed on to the nurse taking over the shift. To ensure the efficiency of the briefing, you're asked not to call the nurses at these times unnecessarily.

- 7.15 – 9.00: Morning round by the head nurse
    - Parameter checks (blood pressure, pulse, temperature, pain, oxygen concentration, breathing, and if necessary blood sugar)
    - Measuring your weight (in the morning after urinating) and urine flow (the total quantity you urinated over the past 24 hours)
    - Possibly a blood test
    - Preparing and taking medication (attention: don't take any medication if your blood hasn't been tested yet)
    - Intravenous administration (administration via a vein) of medication if necessary

- ± 8.00: Breakfast

  Unless fasting is necessary for a test.

- ± 9.00: Consultation moment between nurse and ward physician

- 9.00 – 11.00:
    - Body care
    - Oral hygiene (brush teeth, mouthwash with Perio-aid® and Nilstat®)
    - Wound care
    - Make bed:
    - Any examinations:
        - → On day 7, day 14 and day 21 after the transplant, a biopsy of the heart is taken (see page 32 for more information). An ultrasound of the heart, an electrocardiogram and an RX-thorax (X-ray of your chest) are always made after the biopsy.
        - → In the week before your discharge from hospital, a 24-hour Holter monitoring, a 24-hour blood pressure measurement and photographs of the spinal column are scheduled.

- 11.30: Lunch

  Unless fasting is necessary for a test with subsequent oral hygiene (brushing teeth, mouthwash with Perio-aid® and Nilstat®).

- 13.55 – 14.15: Start of the evening shift with nurse's briefing

- 14.15 – 16.30: Afternoon round by the head nurse
    - Parameter checks
    - Preparing and taking medication if necessary
    - Any other tests

- ± 17.00: Dinner with subsequent oral hygiene (brushing teeth, mouthwash with Perio-aid® and Nilstat®)

- 19.00/21.45: Evening round by the head nurse
  - Parameter checks
  - Preparing and taking medication
  - Administration of the necessary care (for example wound care)

- 21.45 – 22: Start of the night shift with nurse's briefing

- 22.00 – 7.00: Sleep!
  - The night nurse regularly checks on you to make sure everything is OK and will administer any care to you if necessary (e.g. parameter check, administration of intravenous medication).
  - Don't forget oral hygiene before sleeping (brushing teeth, mouthwash with Perio-aid® and Nilstat®).

During the day, the nurses make time to give you information about tests that are still scheduled and about your life after the heart transplant.

The physicians visit at least once a day (more frequently if necessary) for your medical follow-up.

The physiotherapist visits every day to guide you in your resumption of physical activities.

The dietician visits at least once during your stay to provide nutritional advice.

A psychologist will be available upon request to help you process what happened to you.

The social worker can provide support concerning social benefits, home help, transport costs, etc.

The pastoral worker can also be a listening ear.

INFORMATION FOR VISITORS

See also information brochure ‘E 435 cardiology and heart transplant’ (www.uzleuven.be/brochure/700306).

Visiting times

In non-pandemic conditions, visits are possible every day from 14.00 to 20.00.
Please check www.uzleuven.be in case of changes in visiting hours.

Your family can also call on a direct line.
A nurse will give you the phone number of your room. Ask your family to bring your mobile.

Accessibility

To go to E 435, visitors should follow the purple arrow from the reception hall to the third floor. Your family can report to the nursing station, where a nurse will provide further instructions.

Changing procedure and other isolation rules

Visitors must carefully follow the instructions below to protect against infections:

- ✓ Maximum 3 visitors in the room at any one time.
- ✓ Visitors who have a cold or other infection must not enter the room.
- ✓ Children below the age of 12 can only enter subject to approval from the ward physician.
- ✓ Flowers and plants cannot be taken into the room.
- ✓ Follow the instructions on the door of the room (the nurse will always help your family with this):

- Before entering the room:
  - → hang your coat on the coat rack and put your handbag in the space or locker provided (you need a 1 or 2 euro coin to close the locker)
  - → put a face mask over your nose and mouth
  - → disinfect your hands with hand sanitiser
  - → put on a disposable apron
  - → put on disposable gloves
  - → consult the nurse if you want to bring something into the room (it may need to be disinfected first)
  - → the door to the room must be kept closed as much as possible

- On leaving the room:
  - → throw gloves, apron and mask in the blue bag in the corridor
  - → disinfect your hands with hand sanitiser

To be provided by the family

✔ Linen (sleepwear, dressing gown and underwear): preferably washed as hot as possible (according to the requirements of the clothing) and iron if possible. Ask your family to bring the washed and ironed clothing in a clean bag. Ask your family to regularly take home dirty washing.

✔ Slippers and closed shoes (new or washed)

✔ Spectacles if necessary

✔ Tube of toothpaste, comb or brush, shower gel and shampoo and, for men, an electric razor (no razor blades)

✔ The hospital provides towels and facecloths, they needn't be brought in.

✔ The room is equipped with radio, TV, telephone and an internet connection, but you can arrange for your laptop and mobile phone to be brought in. However, they must be disinfected first.
Ask the nurse for your personal code to use the telephone and internet, and the direct line in your room where your family can reach you.

✔ New books, newspapers and magazines can be taken into the room.

✔ Consult the nurse about any other matters (prior disinfection may be required).

These measures only apply during your stay in hospital immediately after the operation, not during any subsequent admission.

DISCHARGE FROM HOSPITAL

The physician in charge of the treatment will let you know on time when you're allowed to go home.

Before you go home, you need to be able to:

☐ recognise your medication

☐ know why and how you take the medication

☐ take your medication correctly according to the prescription, based on your medication scheme

☐ recognise signs of rejection and infection and know when to contact the heart transplant centre

☐ respect the follow-up appointments

Find out for yourself whether you need extra help at home. In the first weeks after your hospital stay, you may not have enough energy or strength to do household chores. Find out in advance whether you know people who can help you with this. If this is not possible, home care can be called in. The social worker can help you with this.

On the day of discharge, the physician will give you a discharge letter intended for your GP. The physician will also give you prescriptions for medication and physiotherapy and an appointment for a first check-up at the heart transplant day ward (E 439).

The head nurse will provide further information and specific notifications and instructions. The nurse will give you medication for 2 days. Make sure you go to the pharmacy as soon as possible with the medication prescriptions you received from the physician.

When the physician and the nurse have given you everything, you may leave the unit. Let the head nurse know that you're leaving.

MEDICATION

You'll have to take medication for the rest of your life after your heart transplant. Your treatment may differ from that of other patients, as the physician looks for the most suitable combination of drugs in your specific situation. Here is information on the most commonly used medication after a heart transplant:

MEDICATION TO PREVENT REJECTION OF THE TRANSPLANTED HEART (= IMMUNOSUPPRESSANTS)

Every human body has an immune system. The purpose of the immune system is to protect us from foreign invaders, such as bacteria and viruses. It detects these foreign invaders and renders them harmless. A donor heart is also considered as something that doesn't belong in your body. This means your immune system needs to be supressed after a transplant, otherwise the body would reject the foreign donor heart. Suppression of the immune system has to be lifelong after a heart transplant. The medication used for this has to be taken strictly and at set times.
This medication is referred to as immunosuppressant medication or immunosuppressants in short.

The most commonly used immunosuppressants are discussed below. They don't all have to be taken. The physician decides which medication is the most suitable for every patient. This means not every heart transplant patient takes the same combination and quantity of medication. After a heart transplant usually a combination is prescribed of Prograft® (tacrolimus), Cellcept® (mycophenolate mofetil) and Medrol® (methylprednisolone). Over the course of the first year, the dose of Medrol® is usually decreased and, if possible, completely stopped from 6 months onwards. After the first year, there's often a switch from Prograft® to Advagraf®. Unlike Prograft® which is taken twice a day, taking Advagraf® once a day is sufficient.

Points of attention for all immunosuppressants:

✔ Find out from the transplant physician which dose you need to take. The physician will take regular blood tests and do other examinations to determine the right dose.
Never adjust your dose on your own initiative! Consult the transplant physician if you're not sure of the correct dose.

✔ Take your medication every day at the same time!

→ The medication can be taken before or after meals, but do not alternate.
The absorption in the blood of certain immunosuppressants (e.g. Cellcept®) is affected by food.
You need to decide whether you take the medication with or without food, and then you take them the same way every day.
In this way we can be sure that the same amount of medication is absorbed into the body every day.

✔ Don't push the capsule out of the blister strip until you take the medication.

✔ Swallow the capsule/tablet whole with enough water (do NOT open the capsule; do not chew or split the tablet).

✔ NEVER take the immunosuppressants with grapefruit (juice). This may affect how the medication works.

✔ Store at room temperature, away from light and moisture.

✔ Do not use the medication after the expiry date. This can be found on the packaging after 'EXP' where a month and a year are specified. The last day of that month is the expiry date.

✔ All the immunosuppressants below are fully reimbursed by the health insurance and are available from pharmacies on prescription, with the exception of Medrol®. Only the 32 mg tablets are fully reimbursed. The other doses are partially reimbursed.

Prograft®

Substance name:
tacrolimus

Available forms:
0.5 mg, 1 mg, 5 mg

Ingestion: Take Prograft® twice a day and 12 hours apart (for example at 8.00 and at 20.00).

Possible side effects: trembling hands, headache, high blood pressure, increased blood sugar level, diarrhoea, nausea

Advagraf®

Substance name: tacrolimus in prolonged release dosage

Available forms:
0.5 mg, 1 mg, 3 mg, 5 mg

Ingestion: Take Advagraf® once a day.
Advagraf® is released slowly by the capsule. This means 1 dose of Advagraf® a day is sufficient. This is unlike Prograft® capsules, which have to be taken twice a day. Please note: Advagraf® and Prograft® are not mutually interchangeable!

Possible side effects: trembling hands, headache, high blood pressure, increased blood sugar level, diarrhoea, nausea

Neoral-Sandimmun®

Substance name: ciclosporin

Available forms:
10 mg, 25 mg, 50 mg,
100 mg

Ingestion: Take Neoral-Sandimmun® twice a day and 12 hours apart (for example at 8.00 and at 20.00).

Possible side effects: high blood pressure, headache, trembling hands, increased hair growth on face and body, thickening of the gums

CellCept®

Substance name: mycophenolate mofetil

Available forms: 250 mg, 500 mg

Ingestion: Take CellCept® 2 (12 hours apart) to 3 times (6 hours apart) a day (for example at 8.00 and 20.00 in case you take it twice or at 8.00, 14.00 and 20.00 in case you take it 3 times).

Possible side effects: nausea and vomiting, diarrhoea or constipation, reduced number of white blood cells in the blood

Myfortic®

Substance name: mycophenolate sodium, the active component is mycophenolic acid

Available forms:
180 mg, 360 mg

Ingestion: Take Myfortic® twice a day and 12 hours apart (for example at 8.00 and at 20.00).

Possible side effects: vomiting, diarrhoea, reduced number of white blood cells in the blood

Medrol®

Substance name: methylprednisolone

Available forms:
4 mg, 16 mg, 32 mg
(please note: regardless of the dose, the tablets look almost identical)

Ingestion: Take Medrol® once a day

Possible side effects: increased appetite, bloated face, brittle and fragile skin, slow wound healing, osteoporosis, muscle loss, increased blood sugar levels

Certican®

Substance name:
everolimus

Available forms: 0.25 mg, 0.5 mg, 0.75 mg

Ingestion: Take Certican® twice a day and 12 hours apart (for example at 8.00 and at 20.00).

Possible side effects: nausea and vomiting, abdominal pain, diarrhoea, wound healing problems, inflammation of the mouth, pneumonia and, in men, a reduced sperm production is possible, reducing the ability to conceive children (usually reversible)

Imuran®

Substance name:
azathioprine

Available forms:
25 mg, 50 mg

Ingestion: Take Imuran® once a day.

Possible side effects: nausea and vomiting, reduction of the number of white blood cells

(Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.)

! What you need to know about taking immunosuppressants.

Importance of lifelong correct and punctual taking of medication

The body does not regard a transplanted heart as its own over time. In other words, you'll have to take anti-rejection medication for the rest of your life. It's also important never to forget this medication and to take it correctly every day at the same time. Taking the medication at a different time or skipping it is best avoided.
Because you don't immediately feel anything if you haven't taken your medication once, transplant patients sometimes think they don't need the medication anymore or that the time they take it is not important.

Unfortunately, this is not the case. Studies show that taking medication incorrectly seriously affects the chances of survival of your transplanted heart.

Therapy non-compliance can lead to:
- complications that may threaten your life or the future of your transplanted organ
- rejection or loss of your transplanted organ

Taking medication correctly and punctually at all times is not easy. If you struggle with this, ask the heart transplant team for help. They can work with you to find solutions.

Regular blood samples to monitor medication levels

Balanced medication in the body is important. Too few immunosuppressants in the body means the immune system is not suppressed enough which increases the risk of rejection of the transplanted heart. Too many immunosuppressants in the body means the immune system is suppressed too strongly which increases the risk of infections.

To check whether there is enough medication in your body, blood is taken before you take the medication. This is referred to as a ‘trough level’. Because the amount of the drug has reached its lowest level.

When taking Prograft® or Advagraf® → tacrolimus level
When taking Cellcept® → mycophenolate mofetil level
When taking Neoral® → ciclosporin level
When taking Certican® → everolimus level

Based on the blood results, the physician will determine the dose you should take.
A punctual and correct intake of your medication helps to keep the medication levels in the blood stable.

Adjustments to the immunosuppressant medication

Adjustments to immunosuppressants can only be made by the transplant physician. Stopping or changing the immunosuppressant medication can be dangerous and result in a rejection of the transplanted heart. Never adjust your medication of your own accord or ask a physician who is not a transplant specialist to adjust it!

Also make sure you always get the same medication when you go the pharmacist with your prescription. If the medication looks different from what you're used to or if the dosage instructions have changed, contact the transplant physician as soon as possible to make sure you have the right medication.

Interaction with other drugs

Some drugs enhance each other's effects and others work against each other. This can lead to an increased risk of rejection of the transplanted heart or an increased risk of side effects.

Please watch out with the following medication:

- Anti-inflammatories, the so-called non-steroidal anti-inflammatory medication: (NSAIDs): for example ibuprofen (Brufen®, Ibuprofen®, Nurofen®), Diclofenac®, Voltaren®, Spidifen® and Feldene®. The combination of these painkillers together with immunosuppressants can cause kidney damage. In case of pain, use other drugs such as Paracetamol (Dafalgan®, Perdolan®). If they don't work, contact the transplant physician.
  Local anti-inflammatory therapy, such as the use of ointments, creams and gel (for example Flexium®, Fastum®) is permitted.
- Antifungals and antibiotics: for example ketoconazole, fluconazole (Diflucan®), itraconazol, voriconazol, clotrimazol, erytromycine, claritromycine, josamycine and rifampicin.
- Herbal medication: for example St John's wort (Hypericum perforatum) or other herbal products.
  For a full list of medication that interacts with other medication, consult the package leaflet of your immunosuppressant medication.

Always notify the transplant physician if you're taking, have recently taken or intend to take any of this medication or these products in the future. If taking any of this medication is medically necessary, it may be necessary to temporarily interrupt the immunosuppressants or increase or decrease the dose.

And if your GP wants to put you on new medication, it's best to discuss this with the transplant physician first, as certain medication cannot be combined with immunosuppressants.

Interactions with foods

Interactions with foods are also possible. Examples include grapefruit (juice), and some other citrus fruit such as lime, pomelo and bitter orange. Substances in this fruit slow down or block the breakdown of medication. This increases the amount of medication absorbed by the body. Operation and side effects increase in this way. The effect of medication you take together with a glass of grapefruit can be 5 to 10 times stronger than the same medication with a glass of water.

Prograft® (tacrolimus), Neoral® (ciclosporin), Certican® (everolimus), cholesterol-lowering drugs (for example pravastatine, simvastatin), Plavix® (clopidogrel), some antibiotics and Motilium® (domperidon) are known examples of medication where grapefruit and other bitter citrus fruit can affect the operation.
To be on the safe side, it's recommended not to eat or drink grapefruit, lime, bitter orange and other citrus fruit when taking medication. Eating oranges and tangerines is okay.

For a complete list of foods that cause interactions with certain medication, always consult the package leaflet, or discuss the interactions with your physician or pharmacist.

Time of taking

The hospital uses fixed times to take any medication (usually 8.00, 12.00 and 20.00).
Once you're at home, these times may not be convenient for you. Discuss with the transplant physician or nurse which times are convenient.
The most important thing is that you always take the medication at the same time. For example, when taking Prograft® it's important the 2 doses are always taken 12 hours apart. Advagraf® needs to be taken once a day, this means the time between 2 doses is 24 hours.

For example:
10.00: Prograft® 3 mg; **20.00:** Prograft® 3 mg → WRONG
10.00: Prograft® 3 mg; **22.00:** Prograft® 3 mg → CORRECT

What if the hour changes (summer or winter time) or you go on holiday?

An hour's difference, such as winter or summer time, is not a problem. You don't have to take into account the clock changing and you can just stick to your own fixed time when you take your medication.

If there's more than an hour's time difference (for example when you go on holiday), you should contact the transplant physician or nurse for advice.

What if you've **forgotten** to take the anti-rejection medication?

To prevent rejection, it's important you don't skip a dose of the immunosuppressants. If you have forgotten to take a dose (or several doses), proceed as follows:

- If you take this medication once a day (for example Advagraf®):
  → Take the forgotten dose as soon as possible on the same day. Don't take a double dose the following morning.

- If you take the medication twice a day (for example Prograft®, Neoral®, Cellcept®, Myfortic®, Certican®):
  → Take the forgotten dose as soon as possible. If it's more than 4 hours after the normal time, skip the forgotten dose. Then continue as before and follow your normal schedule. Don't take a double dose to compensate for a dose you forgot!

When in doubt, contact a transplant nurse (see useful telephone numbers page 83).

Certain medication (other than immunosuppressants) should also be taken punctually, such as epilepsy and Parkinson's medication. Discuss this with the physician in charge of your treatment. For most other medication the rule is that when you've forgotten to take it, you should take it as soon as you remember. And then go back to your normal schedule. But always consult the package leaflet or contact your physician as well.

The above advice should not give the impression that forgetting anti-rejection medication is not that important. It's better to find out why you forgot to take the medication and how to prevent it from happening again in the future.

The following tips can help you not to forget to take the medication:

- Set your mobile's alarm to the times you normally take your medication.
- Put your medication box in a visible place that you pass regularly, such as on the kitchen table or on the sideboard in the living room.
- Link the times when you take your medication to a daily activity, e.g. brushing your teeth.
- Prepare your medication for the next day in the evening.

What if you vomit after taking anti-rejection medication

Medication takes about an hour to be absorbed by the body. If you vomit after taking the medication, follow the guidelines below:

- If you vomit immediately after taking the medication and you can see remnants of the medication in the vomit, take the medication again immediately.

- If you vomit within an hour, take half the dose again. Remember: tablets should not be broken. Only take half the dose if possible. For example:
  You normally take 2 mg Prograft® → if you vomit 1 hour after taking Prograft®, take 1 tablet of 1 mg Prograft®. If you take 0.5 mg of Prograft®, it's not possible to take half a dose. Prograft® is available in 0.5 mg, 1 mg and 5 mg (see infra).

- If you vomit more than an hour after taking the medication, you don't have to do anything.

If you have to vomit several times, contact the heart transplant team. They will look for a possible cause of the vomiting and medication can be prescribed to reduce nausea and vomiting.
If this proves insufficient and the vomiting persists, admission to hospital may be required.

What if you have diarrhoea?

Diarrhoea can have several causes. If you have diarrhoea for 1 day, there's no need to be worried. This discomfort may be caused by irritated intestines due to certain foods (fatty, spicy, etc.). If you have diarrhoea 2 days in a row, contact your GP, transplant physician or nurse. The blood levels of the immunosuppressants may be disrupted and an additional blood test required.
If your blood levels are disrupted, this may cause side effects (increased risk of rejection, damage to the kidneys, liver, etc.).
Make sure you keep drinking to avoid dehydration!

What about the anti-rejection medication if you have to fast for a test?

If you have to fast for a particular test, contact the transplant physician or nurse to find out which medication you should (not) take. The rule is that anti-rejection medication (Prograft®, Neoral®, Cellcept®, Myfortic®, etc.) and cortisone (Medrol®) should always be taken at their fixed time. If you have to fast, try taking the immunosuppressants with as little water as possible. The other medication can be taken when the test is over.

What if you feel ill because of the medication or there are side effects?

Never stop taking your medication of your own accord or change the prescribed dose.
If symptoms persist or get worse, consult your transplant physician.

What with alternative medication, homeopathy and plant extracts?

Any medication, including supposedly harmless plant extracts and over-the-counter products should be discussed with the transplant physician first.
Even 'harmless' products can enhance or weaken the effect of your medication. Some homeopathic products can also strengthen the immune system (e.g. Echinacea), which may increase the risk of rejection. The long-term effects are often unknown and difficult to study, as these products are not subject to the same (strict) legislation that conventional medication falls under before they are sold. Be aware of the possible consequences and always contact the heart transplant team before taking these drugs.

What if you've (almost) gone through your supply of medication?

Contact your GP immediately for new prescriptions. In exceptional cases, you can ask the transplant physician for additional prescriptions. Only if you can no longer get this medication from the pharmacist on time and you don't have any medication anymore, you can exceptionally get it at E 435.

Avoid running out of medication as it may take 1 to 2 working days for your pharmacy to get the new medication. Always check your supply of medication before coming to the day ward and request the necessary prescriptions.

What if you fast during Ramadan?

You can take the medication between sunset and sunrise. If these times don't correspond with the times you normally take your medication, contact the transplant physician or nurse for advice and discuss it with your imam. Never stop taking your medication.

OTHER MEDICATION

Immunosuppressants can affect your blood pressure, cholesterol, blood sugar, kidney function, etc. It's likely you'll need to take other medication.
In particular, medication to prevent infections, cholesterol and blood pressure lowering medication, stomach protectors and medication to prevent bone loss are often part of the treatment.

Medication to prevent infections

Some brand names: Bactrim®/Eusaprim forte®, Zitromax®/Azithromycine®

Bactrim® or EUSAPRIM forte®

Substance name:
co-trimoxazol

Form: 160 mg/800 mg

Aim: prevention of pneumonia caused by the Pneumocystis jiroveci bacterium (formerly called Pneumocystis carinii) and prevention of toxoplasmosis

Ingestion: Take Bactrim® or EUSAPRIM forte® (depending on the prescription) twice a day for 7 consecutive days a month, up to 6 months after the transplant. Always try to take the medication in the same week of the month.

Possible side effects: stomach and intestinal complaints (nausea, vomiting, diarrhoea)

Valcyte® or Valaciclovir Sandoz®

Substance name:
valganciclovir

Form: 450 mg

Aim: prevention of cytomegalovirus (CMV) infections

Ingestion: once a day up to 200 days (approximately 6 months) after the transplant

After you've stopped taking this medication the chances of a CMV infection are still very real. Usually it occurs between 4 to 8 weeks after you've stopped taking Valcyte®.

During this period pay extra attention to possible signs of infection such as fever, vomiting, nausea, diarrhoea, muscular pain, unusual fatigue, etc. If you suffer these symptoms, contact the heart transplant centre.
Please note: Swallow the whole tablet (do not chew or split the tablet!).

Possible side effects: drop in red and white blood cells

Perio-aid® mouthwash

Active ingredients: Perio-Aid 0.12% Chlorhexidine Mouthwash+ 0.05% Cetylpyridinium Chloride

Form: bottle 500 ml

Aim: Some areas of the mouth are difficult to reach with a toothbrush. Rinsing with mouthwash ensures that any residue left behind is rinsed away. Perio-aid® also has a bactericidal effect. It prevents infections, irritations and caries.

Ingestion: Rinse your mouth 4 times a day for 30 seconds with 15 ml of mouthwash and spit it out. Do not swallow Perio-aid®. Do not rinse with water after using mouthwash.

Please note! Perio-aid® is incompatible with anionic ingredients commonly found in toothpastes. This is why it’s better to brush your teeth before using Perio-aid® mouthwash. Use Perio-aid® up to 3 months after the transplant.

Possible side effects: There may be changes in taste and a tingling sensation on the tongue, especially in the beginning. Tooth discolouration or discolouration of the tissue in the mouth may occur after prolonged use, in combination with coffee, tea or red wine. These side effects will disappear when you stop treatment or can be easily removed by the dentist or dental hygienist. Very rarely, swelling of the salivary glands under the ear has been reported but in all cases these disappeared again after stopping treatment.

Nilstat®

Substance name:
nystatin

Form:
30 ml bottle with yellow liquid with drop counter. The suspension contains 100,000 IE nystatin/ml.

Aim: prevent fungal infections in mouth and oesophagus

Ingestion:
- Shake the bottle before use.
- Put 5 ml of liquid into mouth and rinse as long as possible before swallowing.
- Use Nilstat® 4 times a day after rinsing with Perio-aid® (see infra).
- Use Nilstat® up to 3 months after the transplant.

Possible side effects: Stomach and intestinal complaints have been reported.

Daktarin®

Substance name:
miconazole

Available forms:
Spray powder 100 g

Aim: against fungal skin infections

Ingestion:
- Apply the spray twice a day under your armpits, in your groin and between your toes.
- The spray should only be applied during your hospital stay.

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

High cholesterol medication

Despite taking high cholesterol medication a healthy and balanced diet remains important.

Some brand names with their active substance: Prareduct® and Pravasine® (pravastatin sodium), Crestor® (rosuvastatin), Lipitor® (atorvastatin), Zocor® (simvastatin)

Ingestion:

- Take this medication once a day, preferably in the evening.
- Swallow the whole tablet with enough water (do not chew or split the tablet!).

Possible side effects: muscle and/or joint pain

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

High blood pressure medication

Some brand names with their active substance: Amlor® (amlodipine), Coversyl® (perindopril), Moxon® (moxonidine)

Ingestion:

- Take the medication with enough water.
- Only split the tablets if a break line is provided on the tablet, never break capsules.

Possible side effects: headache, dizziness, fluid retention of ankles (only with Amlor®, contact your GP or cardiologist in case of serious fluid retention)

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

Medication to protect the stomach

Some of the medication you have to take may irritate the stomach and, in a worst case scenario, could lead to a stomach ulcer. That's why medication to protect the stomach is sometimes (temporarily) prescribed.

Pantomed® or Pantozol®

Substance name: pantoprazol

Ingestion:
- Take Pantomed® or Pantozol® 1 hour before a meal.
- Swallow the whole tablet with enough water (do not chew or split the tablet!).

Possible side effects: headache, dizziness, diarrhoea, constipation, nauseousness, vomiting, dry mouth

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

Medication against osteoporosis

The purpose of this medication is to prevent (worsening of) osteoporosis. This medication is available without a medical prescription from pharmacists.

Cacit Vitamin D3® or Steovit®

Substance name: a combination of calcium (carbonate) and colecalciferol (vitamin D)

Ingestion:
- Preferably take this medication in the evening.
- The chewable tablets need to be chewed or sucked.
- The film-coated tablets can be swallowed or chewed.
- Dissolve the effervescent tablets or granules in a glass of water and drink as soon as the bubbles have gone.

Possible side effects: increased calcium content in urine and blood

Alendronate® of Fosamax®

Substance name: alendronic acid (sodium acid)

Ingestion:

- Preferably take this medication in the morning before you eat, drink or take any other medication.
- Don't lie down for the first 30 minutes after taking it. If you lie down after this half hour, make sure you've eaten something first.
- Swallow the tablet whole with a large glass of tap water (not mineral water and not less than 200 ml, do not chew or split the tablet!).

Possible side effects: bone, muscle and/or joint pain that can sometimes be severe, heartburn, difficulty swallowing, abdominal pain, headache

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

Diuretics

Diuretics help rid your body of salt and water (water pills).
They reduce the excess fluid in the body and protect the body from fluid retention. You may only take them in joint consultation with the transplant physician after the transplant.

Burinex®

Substance name: bumetanide

Beschikbare vormen:
1 mg, 5 mg

Ingestion: Take Burinex® early in the morning or early in the afternoon.

Possible side effects: potassium deficiency, dry mouth, dizziness and muscle cramps (particularly in the legs). Note: in case of muscle cramps, extra magnesium supplements may be taken (these are available without prescription from your pharmacist).

Available with medical prescription from the pharmacist

Consult the package leaflet or contact your pharmacist or physician in charge of your treatment for more information and advice.

POSSIBLE COMPLICATIONS

Everyone's recovery and health after the transplant is different. Some people have problems with rejection or other complications, others have few problems.

REJECTION

Our body has an immune system that detects and attacks foreign bodies, such as bacteria and viruses.
A donor heart is also considered as something that doesn't belong in the body. Despite the medication you receive after the transplant to prevent rejection, there's a risk of your body rejecting the transplanted heart.
Rejection can be acute (fast and intense) and chronic (slow and gradual).

Acute rejection

In case of an acute rejection, the complaints manifest themselves in a short space of time, i.e. days. The risk of acute rejection is highest during the first year after the transplant. Late (> 1 year) acute rejection reactions are rare and usually result from therapy non-compliance. Acute rejection is usually treatable (see infra 'How to treat rejection', page 33).

Chronic rejection

Chronic rejection usually occurs months to years after the transplant. It's impossible to predict in advance if and when chronic rejection will occur.
Chronic rejection is a gradual process whereby the heart function gradually deteriorates. It's characterised by a thickening of the inner wall of the entire vascular system of the transplanted heart. It's also referred to as 'transplant vasculopathy' and differs from 'classic' atherosclerosis. The immune system plays a key role in the development of transplant vasculopathy. Chronic rejection, unlike acute rejection, can still not be treated well (see infra 'How to treat rejection', page 34). It's an irreversible process and eventually leads to failure of the donor heart.

How can you recognise rejection?

Rejection is not always noticeable right away. Usually, you feel weaker after a while. This is because the organ is affected by the rejection and will not function as well. Rejection is in fact an inflammatory response, with all the known characteristics, such as a rapid onset of fatigue and sluggishness. Only an examination of the tissue can give absolute certainty.

Alarm bells that may indicate rejection are:

- abnormal tiredness
- abnormal shortness of breath, inability to lie flat
- unexplained and rapid weight gain (2 kg in 48 hours)
- fluid retention (e.g. swollen legs or ankles)
- low blood pressure
- dizziness, palpitations
- reduced appetite, nausea
- feeling unwell, flu-like feeling

If you have these systems, contact your GP or the heart transplant team (see useful phone numbers page 83).

How can you detect rejection

Because a rejection causes few symptoms initially and because the risk of rejection is highest the first year after the transplant, cardiac biopsies are routinely taken in the first year. Early detection of a rejection allows us to treat the rejection before significant tissue damage occurs.

Cardiac biopsy

- Aim: By examining a small amount of myocardial tissue, the pathologist-anatomist (= physician who examines tissues and cells), using a microscope, can check for signs of rejection in the transplanted heart.

- Preparation: You don’t need to fast for the examination, unless the physician also takes blood during the examination.

- Description: A tube (the sheath) is inserted through a large vein on the right side of your neck. Along this tube, 4 small pieces of heart tissue (the size of a pinhead) are taken from the inner wall of the right ventricle using forceps (biotome).

- Follow-up: A pressure bandage is applied at the insertion opening for a few minutes after the procedure and then covered with a plaster.
- Duration: The examination takes approximately 30 minutes.
- Results: The result of the tissue examination is usually known the next day.
- Frequency: Cardiac biopsies are performed at regular intervals. During the first year after the transplant, 11 biopsies are performed: in week 1, 2, 3, 5, 7, 9, 14, 17, 21, 25 and 40 after the transplant. 2 or 3 biopsies are performed during your hospital stay straight after the transplant, the other biopsies are at the heart transplant day ward.

  A biopsy is performed at the end of the second or the third year after your transplant or when the physician deems it necessary.

How is rejection treated?

Rejection does not imply that your new heart will stop functioning. Rejection is usually easy to treat, especially if detected early. This is why regular monitoring after discharge from hospital is so important. If the biopsy result shows rejection, the physician will initiate treatment.

In case of acute rejection, treatment consists of a temporary increase of the immunosuppressant medication. In case of a serious acute rejection, you're admitted to the heart transplant unit for administration of high doses of corticosteroids. Usually, this suffices to bring the rejection under control again.

Unlike acute rejection, chronic rejection is not easily treatable. Sometimes, the treatment works and the heart function is partially restored. Often, the chronic rejection process cannot be controlled, and classic heart failure medication has to be restarted to stabilise the effects of chronic rejection for as long as possible.

How can you prevent rejection?

Rejection is inherent to transplants and unfortunately cannot always be avoided. However, you can significantly reduce the risk of rejection by always taking the prescribed anti-rejection medication punctually and by adopting a number of habits that will help you detect rejection or other problems on time (see chapter ‘Self-care and lifestyle aspects after the transplant’, page 45).

INFECTIONS

Infections often occur after a transplant. This is because the medication you take to reduce the risk of rejection also weakens your immune system. This makes you more prone to infections. Susceptibility to infections is highest shortly after the transplant or after rejection treatment, because the doses of immunosuppressant medication are highest at this time.

Infections can be caused by bacteria, viruses and fungi. It may be a new infection (from outside or via the donor organ) or a reactivation of a dormant infection already present before the transplant.

In the first weeks after the transplant, classic post-operative surgical infections are most common. This mainly concerns bacterial or fungal infections of the surgical wounds, catheters, lungs and urinary tract. In the months after the transplant viral infections become important, such as, for example, the cytomegalovirus (CMV) and the Epstein-Barr virus (EBV). In the longer term, we see the infections that also occur in the general population (flu, upper respiratory tract infections, pneumonia, urinary tract infections, etc.).

How can you recognise an infection?

You may have caught an infection in case of:

- an increase of the body temperature (≥ 37.5°C) or fever (≥ 38°C)

- respiratory complaints:
  - → nasal congestion and headache (sinusitis)
  - → sore throat
  - → coughing, phlegm (change of colour and quantity)
  - → shortness of breath

- abdominal complaints:
  - → diarrhoea, vomiting
  - → abdominal pain
  - → pain or burning sensation while urinating

- skin complaints:
  - → rashes, inflamed wound
  - → ulcers, blisters, painfully swollen glands in armpit, groin or elsewhere

- general complaints:
  - → fatigue
  - → muscle pain
  - → headache
  - → poor appetite
  - → join pains

It is important to know that the inflammatory response in people who take immunosuppressants may be reduced. This means there may be fewer signs of infection (for example fever) and it can be more difficult to diagnose.

Avoiding infections

To prevent certain infections, the physician will prescribe preventative medication in the first half year after the transplant (see also ‘Medication to prevent infections’, page 14).

Measures you can take yourself to prevent infections include:

✔ Maintain good personal hygiene.

✔ Wash your hands thoroughly (particularly before eating, after sneezing or coughing, after every visit to the toilet).

✔ Maintain good oral and dental hygiene: brush your teeth in the morning, evening and after every meal. The first 3 months after the transplant you must also use Perio-aid® and Nilstat® mouthwash.

✔ Avoid contact with people who have a cold, flu or other infection (e.g. cold sores).

✔ Avoid contact with children suffering from childhood diseases.

✔ Avoid contact with people who have recently been vaccinated with live vaccines such as measles, rubella and chicken pox. The following vaccines are not a problem: flu vaccine, tetanus and whooping cough. In case of doubt consult the physician.

✔ For the first 6 months after the transplant, avoid places where many people gather, e.g. a busy cinema, restaurant, public transport, supermarkets during the rush hour, festivals, etc.

✔ Except in the first year after the transplant, an annual flu vaccine is recommended (not during rejection treatment or illness).

✔ A pneumococcal vaccine is best done before the transplant. After the transplant a five-yearly booster is recommended.

✔ A coronavirus vaccine is best administered before the transplant.

✔ The first 6 months after your transplant, foods containing pathogenic agents should be avoided. (see chapter ‘Diet’, page 57).

✔ Be hygienic when cooking.

✔ Wear gloves if you work in the garden.

✔ Don’t get any pets during the first year after the transplant. If you do have pets keep them outside as much as possible and avoid contact during the first year. Let others look after them. If no-one is available to do this you must, at least, wear gloves in case of contact with faeces (for example when cleaning the litter tray, bird cage or the stables) and observe good hand hygiene.

- ✓ Tell the dentist you've had a heart transplant. They must consult with the heart transplant team to discuss which procedures require antibiotics in advance (endocarditis prophylaxis).
- ✓ Do not smoke and avoid other smokers (passive smoking).
- ✓ Do not have any piercings or tattoos.

The measures you can take yourself to reduce the risk of infections are explained in more detail under 'Self-care after the transplant', from page 45.

SIDE EFFECTS OF ANTI-REJECTION MEDICATION

High blood pressure (hypertension)

See also 'Self-care after the transplant – Monitoring – Measure your blood pressure', page 46.

When do we talk of high blood pressure?

Blood pressure refers to the pressure that blood exerts on the arterial walls while circulating in the body. Blood pressure is usually expressed in mmHg (millimetre mercury pressure). Blood pressure is represented by 2 values: on the one hand, the maximum pressure the blood exerts on the arterial walls when blood is pumped out of the left ventricle as it contracts (systolic pressure). And on the other hand, the minimum pressure when the left ventricle is at rest (diastolic pressure).

- Consultation
  The blood pressure is normal if the systolic pressure is lower than 140 mmHg (14 cmHg) and the diastolic pressure is lower than 90 mmHg (9 cmHg). A high blood pressure is from 140/90 mmHg.

- Measuring at home
  When you're taking your blood pressure at home, 135/85 mmHg is used as the target value.

! Note! For people with diabetes, severe kidney disease or high cardiovascular risk, the target value is lower.

High blood pressure after a transplant

Many patients have high blood pressure after the transplant. This increases the risk of a stroke and a heart attack. It is therefore important to treat high blood pressure. Treatment consists of a low-salt diet, weight control, adequate exercise.
If the blood pressure remains high, blood pressure-lowering medication is started.
The physician or nurse may ask you to monitor your blood pressure at home.

Osteoporosis

What is osteoporosis?

Osteoporosis is a condition that develops when bone mineral density decreases. As a result, the bone tissue becomes progressively brittle. This can cause some bones to break faster (especially wrist and hip) and collapse (vertebrae).

Osteoporosis and transplants

Osteoporosis is common after a heart transplant. Often there is already osteoporosis before the heart transplant. Especially when a long period of illness with bedridden and reduced appetite preceded the transplant. Osteoporosis after a transplant is mainly due to the use of cortisones (Medrol®) to prevent rejection of the donor heart.

How can you find out whether you have osteoporosis?

A bone density measurement or bone densitometry (abbreviated BMC: bone mineral content) measures the amount of minerals (calcium and phosphorus) in the bone and allows the bone mass to be assessed.
The measurement uses a narrow beam of weak X-rays focused on a particular part of the skeleton (at the hip or spine). The result of the bone densitometry indicates the risk of bone fracture. The more negative the bone densitometry value, the higher the risk of fracture.

How can you prevent the development of osteoporosis?

The following measures help you to protect your bones from further weakening:

- sufficient exercise
- especially exercises whereby you carry your own weight, such as walking, climbing stairs
- sufficient calcium intake (dairy products in particular are rich in calcium)
- avoiding overweight

Sometimes calcium and/or vitamin D supplements are prescribed. They slow down osteoporosis and stimulate bone formation.

Diabetes (diabetes)

What is diabetes?

In people with diabetes, the pancreas produces insufficient insulin, or your body doesn't respond to the insulin that is produced. This means sugar from food cannot be sufficiently absorbed into the various cells to serve as an energy source there. This causes an increase in blood sugar levels.

Diabetes after transplant

Due to the combination of certain medications (e.g. high doses of cortisone/Medrol® and Prograft®/Advagraf®), transplants may develop diabetes in the first months after the transplant. This is often only a temporary side effect. Sometimes it's necessary to temporarily follow a diet low in sugar. Long-term intake of cortisone (Medrol®) can trigger diabetes in some people. The risk of diabetes is higher in people who are overweight.

How can you find out whether you have diabetes?

The blood sugar level is tested after every blood test (if you fasted). If this value is repeatedly higher, you may have diabetes. In this case, further examination will confirm the diagnosis and you'll be referred to a diabetes specialist (endocrinologist).

How can you prevent diabetes?

There are 2 types of diabetes: type 1 and type 2. Type 2 diabetes is also known as adult-onset diabetes. While type 1 diabetes seems mainly congenital, type 2 diabetes is a condition that develops later. You cannot change a genetic disposition to diabetes, but type 2 diabetes is preventable in almost 90% of cases. The main risk factors for developing type 2 diabetes are: diet and exercise.

Some tips that may help:

- avoiding overweight
- eating regularly
- watching what you eat
- exercising sufficiently

If you're diagnosed with diabetes after the transplant, you'll receive more information about this condition and how it is treated by the dietician and the diabetes specialist (endocrinologist).

Renal insufficiency

What is renal insufficiency

The kidneys filter your blood 24/7. They remove excess fluid and waste products from our body in the form of urine. When the functioning of the kidneys decreases, there's an accumulation of waste products. This is known as renal insufficiency. The reduction in kidney function often develops over a period of months or years.

Renal insufficiency and transplant

Anti-rejection medication such as Prograft® and Neoral® can be harmful for the kidneys. In the long term this can result in kidney failure. This is why the kidney function is monitored regularly after a transplant.

Symptoms of renal insufficiency

Important symptoms that may indicate a deterioration of the kidney function are:

- Accumulation of waste products
  This can cause fatigue, a feeling of sickness, itching and cramps. Forgetfulness, insomnia, nausea and decreased appetite are also common. Susceptibility to infections is increased.

- Problems with fluid balance
  Both fluid retention and dehydration are possible. People with fluid retention often have swollen ankles and a bloated face. Dehydration can be recognised by sunken eyes, a dry mouth and dry mucous membranes.

- Hormonal disorders
  Reduced kidney function causes the kidney to produce extra hormones which increases blood pressure. The production of other hormones decreases and anaemia and fatigue may occur. Another consequence is osteoporosis.

Increased cholesterol level

What is cholesterol?

Cholesterol is an essential building block for our body to function properly. Our body produces cholesterol itself (2/3, mainly in the liver), but cholesterol also enters our body through our diet (1/3). It serves as a raw material in the construction of cell walls and for the production of a number of hormones and vitamins. We cannot live without cholesterol but too much cholesterol is harmful.

Consequences of too much cholesterol

High levels of cholesterol in the blood increase the risk of cardiovascular disease. HDL cholesterol, the ‘good cholesterol’, cleans the blood vessels. LDL cholesterol, the ‘bad cholesterol’, causes blood vessels to clog up and increases the risk of heart attacks or strokes.

Increased cholesterol level and transplants

Abnormalities in the cholesterol level have several causes. They may be hereditary but usually are caused by an unhealthy diet or are related to a disease (diabetes, renal insufficiency and so on). Anti-rejection medicines may also cause an increase of the cholesterol level.

How can you prevent a high cholesterol level?

You can do a number of things yourself:

- Don’t eat too many snacks such as chocolate, cakes, biscuits and crisps: they are high in saturated fats.
- Choose lean meat and dairy products.
- Don’t use too much salt.
- Restrict alcohol.
- Avoid overweight.

An increased cholesterol level does not in itself cause any symptoms.
Regular check-ups are recommended. Your cholesterol level will be tested several times a year. Even if the cholesterol level in your blood is good, the physician will often prescribe cholesterol-lowering medication. Studies have shown that cholesterol-reducing medication may reduce the risk of transplant vasculopathy (see ‘Chronic rejection’, page 31).

TRANSPLANT-RELATED CANCERS

Skin cancer

Long-term suppression of your immune system increases the sensitivity for skin cancer, and particularly for a certain form of skin cancer: squamous cell carcinoma (SCC).

Squamous cell carcinoma is a malignant tumour of the keratinocytes (the cells of the epidermis that are essential for skin repair). These tumours can develop on the skin and on the mucous membranes. They are relatively harmless and usually easy to treat in people with normal immunity. These tumours occur mainly in older people on areas of the skin exposed to the sun: face, backs of your hands, bald scalp, lower lip, etc.

How can you prevent skin cancer?

To prevent skin cancer, always protect your skin from the sun. Wear protective clothing and a hat, regularly use sun cream with a high protection factor (+50), avoid the hottest hours of the sun (12-16 hours) and don't use sunbeds.

More information in connection with skin cancer, how you can limit the risk and how you can recognise (the precursors of) this skin cancer is available on page 52.

How can you detect skin cancer prematurely?

Almost all skin cancers can be treated well if detected at an early stage. Heart transplant patients should examine their skin every month. Look for small changes or blemishes that grow and itch, new warts or blemishes. As you have a higher risk of skin cancer, an annual check-up with the skin specialist (dermatologist) is recommended.

Post-transplant lymphoproliferative disorder (PTLD)

Post-transplant lymphoproliferative disorder (PTLD) is a special form of lymphoma that only occurs in people who had a transplant.

Most post-transplant lymphoproliferative disorders are caused by an infection with the Epstein-Barr virus (EBV). About 70% of the adult western population is a carrier of this virus without being affected by it. The disease caused by this herpes virus is known to most people by the name ‘glandular fever’. Like all herpes viruses, EBV remains in the body for life and can be (re)activated in people with a reduced resistance. And this is exactly the case after a transplant. The activated virus causes the blood cells to multiply out of control which can degenerate into a (malignant) lymphoma.

An early diagnosis is important for a cure. This is why the physician will regularly check the amount of DNA of the EBV in your blood.

The simplest treatment of a PTLD consists of lowering the anti-rejection medication to allow your immune system to deal with the post-transplant lymphoproliferative disorder.
When this is impossible or the lymphoma doesn’t respond to a dose reduction, chemotherapy is started. Rituximab® is often used, which specifically targets the white blood cells involved. The medication is administered by IV for a number of weeks and usually has few side effects, unlike chemotherapy, which is also used against tumours and has many side effects. This medication has ensured that this formerly deadly form of cancer can now be cured.

DENERVATED HEART

During the transplant, the nerves of the heart, which regulate heart rhythm and frequency, among other things, are cut. A transplanted heart therefore has no connection to the nervous system. It is ‘denervated’. After the transplant, these connections are usually not re-established. The commands from your brain are no longer transmitted directly to your heart via the nervous system, but via hormones in the blood circulation.

What is the effect of denervation?

- Your heart will respond differently to exercise than before the transplant. A normal heart is notified via the nervous system that the body is exerting itself. This causes it to beat faster almost immediately. A transplanted heart doesn't receive that 'fast' signal and your heart rhythm takes longer to speed up.

- You gradually have to increase your exercise level because your heart doesn't adapt immediately. Conversely, after exercise, it may take longer for your heart rate to slow down again. Generally speaking, people with a transplanted heart have a faster heart rhythm at rest than people without a transplant (a heart rhythm up to 110 beats per minute).

- Usually, no pain signals come from the heart. For example, someone with a transplanted heart usually does not suffer from heart cramp (or angina pectoris): chest pain due to a lack of oxygen.

SELF CARE AND LIFESTYLE ASPECTS AFTER THE TRANSPLANT

You can also make an important contribution to the care of your transplanted heart. Careful use of your medication is of course part of this (see the chapter on “Medication”, page 14). But the following measures can also help you maintain a healthy lifestyle.

SELF-MONITORING

By adopting some habits at home, you can detect rejection, infection or other problems. Be sure to do the following for at least the first year after the transplant or longer at the physician’s request.

These habits are:

Weigh yourself

When? Weigh yourself every day at the same time, preferably in the morning before breakfast.
How? Always in the same conditions (e.g. wearing your nightwear, without shoes or dressing gown, after urinating).

If you gain more than 2 kg in 48 hours, notify the heart transplant team.

Measure your temperature

It’s important that you regularly and correctly take your temperature. Do this once or twice a day for the first few months after the transplant and afterwards if you feel unwell or feverish. Always take your temperature at the same time (e.g. morning and evening). Put the thermometer under your armpit and leave it there until you hear the sound signal.

	Values	What must you do?
Normal temperature	between 36°C and +37°C	You don't need to do anything.
Increase in/subfebrile temperature	between 37°C and +38°C	Check the temperature again after 1 hour. If the temperature remains at more than 37.0°C or continues to rise, contact your GP or the heart transplant team.
Fever	38°C or higher	Contact the GP or the heart transplant team.

Note: Taking Medrol® can mask a rise in temperature. This means you may be ill but not have a fever.

Measure your blood pressure

Earlier in this brochure we explained that high blood pressure can be a consequence of anti-rejection medication (see chapter ‘Complications or side effects of anti-rejection medication’, page 16). In this chapter, we explain why measuring your blood pressure is important and how to measure it correctly.

Why should I measure my blood pressure?

Measuring blood pressure at home pays off:

✓ When a healthcare provider takes your blood pressure, it’s often higher than at home because the presence of a healthcare provider may trigger a (subconscious) tension that raises your blood pressure. This is referred to as ‘white coat syndrome’ or ‘white coat hypertension’. Conversely, it’s also possible for your blood pressure to seem fine when measured by the healthcare provider, but still be high elsewhere (e.g. at home or at work). This is referred to as masked hypertension.

✓ You’re more involved if you do the measurement yourself. If you take high blood pressure medication, you can also check how well you respond to them.

✓ Self-measurement helps the physician decide whether treatment should be started or adjusted. After all, multiple measurements give a better idea of the average value of your blood pressure.

Which blood pressure monitor should I choose?

Several models are available. Only use a digital blood pressure monitor that measures your blood pressure using an inflatable cuff around the upper arm. The cuff should be the right size or adjustable. Wrist or finger blood pressure monitors are not recommended due to many inaccuracies during measurements. The blood pressure monitor should be well maintained and checked regularly (at least every 2 years).
Preferably buy a blood pressure monitor ‘with a memory’ which allows you to retrieve blood pressure readings. If you have a blood pressure monitor ‘without a memory’, write down the readings.

There is a big choice in blood pressure monitors. The following websites provide an overview of all reliable, electronic blood pressure monitors:

- www.stridebp.org/bp-monitors
- http://bihsoc.org/bp-monitors

How do I measure my blood pressure correctly?

- First read the manual for a correct use of your blood pressure monitor.
- Measure your blood pressure in the morning and evening, before eating and before taking medication.
- Rest for 5 minutes before measuring.
- Don’t smoke or drink caffeine 30 minutes before the measurement.
- Sit down, with both feet flat on the floor, your back and arm supported and raise your arm to heart level (e.g. on a table or armrest).
- Measure on an exposed upper arm: roll up the sleeves of thinner clothing, a cardigan or jumper should be taken off.
- The cuff should be 1 to 2 centimetres away from your elbow crease and you should be able to put your finger under the cuff.
- Avoid talking and moving during the entire measuring process (inflation and deflation).
- Measure your blood pressure on both arms the first time. If you repeatedly notice a big (e.g. 20 mmHg) difference in blood pressure between your left arm and your right arm, always measure on the arm with the highest blood pressure afterwards. Carry out several measurements. Self-measurement may cause stress and thus affect your blood pressure. If you’ve carried out successive measurements at the same time, it’s therefore advisable to exclude the first measurement if it’s clearly higher than subsequent measurements.

- After every measurement write down your systolic pressure (highest number) and your diastolic pressure (lowest number).
- We recommend that you first use the bought blood pressure monitor with an experienced healthcare provider (physician, nurse, pharmacist, etc.). A check of the measurement technique by the healthcare provider after a certain period of time (e.g. 1 or 3 months) is also useful.
- How often you should measure your blood pressure depends on the measured blood pressure. Discuss the desired frequency with your physician.

Do not adjust your blood pressure-lowering treatment of your own accord! Always discuss the results of blood pressure measurements with your physician first.

How can you prevent or treat high blood pressure?

High blood pressure can primarily be avoided by a healthy diet (e.g. limiting salt and fat intake, eating enough fruit and vegetables, etc.), exercising regularly, not being overweight, not drinking too much alcohol, not smoking and avoiding stress. If these lifestyle adjustments are not enough, treatment with medication may be prescribed.

Recognising other problems

Diarrhoea

If you have diarrhoea (= thin, watery and frequent stool) that persists more than 2 days, you should contact the heart transplant team. Diarrhoea can have several causes. For example, it may indicate an infection, but it may also be a side effect of medication (e.g. Cellcept®).

It’s also best to check the concentrations of the anti-rejection medication in the blood by taking a blood sample. Diarrhoea may cause elevated concentrations.

Never take anti-diarrhoea medication (e.g. loperamide-based medication such as Imodium®) of your own accord. They combat the symptoms but not the cause of the diarrhoea. However, you should drink enough to prevent dehydration and have good hand and toilet hygiene.

Vomiting

If you vomit multiple times, contact the heart transplant team, especially if this prevents you from taking your medication.

You have to follow certain steps if you've vomited less than 1 hour after taking medication, see the section on 'Medication' (page 23).

Vomiting also increases the risk of dehydration. Try drinking small sips of water regularly. Even if you vomit again afterwards, more water remains inside your body than comes out.

Wounds

Often, not all surgical wounds are completely healed when you're allowed to go home. If the wounds need care on a daily, two-daily or three-daily basis, you may require home nursing care. Discuss this with the physician or nurse. On your discharge from hospital, the physician will give you a prescription with the necessary wound care instructions. Give that prescription to the home visit nurse.

Bear in mind that wounds may heal slower due to the immunosuppressant medication you're taking. Keep a close eye on the wound. Pain, redness, swelling and warmth indicate an inflammation. In this case, notify your physician.

Other

Contact your GP or heart transplant team if you notice anything else such as red and painful gums, changed vaginal discharge, white coating on the tongue, feet or hands, etc.

GOOD PERSONAL HYGIENE

To avoid infections, good personal hygiene is important.

Hand hygiene

- ✓ Wash your hands before and after every meal and after contact with bodily fluids, for example after going to the toilet or blowing your nose.
- ✓ Use running water and liquid soap. Liquid soap is more hygienic than hand soap.
- ✓ Rub your hands thoroughly for at least 15 seconds to reach all parts of the hands (palms, fingertips, between your fingers and balls of your thumbs).
- ✓ Rinse all soap residue under running water.
- ✓ Keep your nails short and clean.
- ✓ Avoid contact between your hands and mouth as much as possible. This avoids any transfer of bacteria from your hands.

Oral and dental hygiene

Good oral hygiene is also important to avoid gum infections and other oral diseases:

- ✓ Brush your teeth in the morning and evening and after every meal.
- ✓ If you have removable dentures, take them out so that you can brush them completely.
- ✓ Use a soft toothbrush to prevent gum bleeding. Electric toothbrushes are strongly recommended.
- ✓ Brush for at least 2 minutes.
- ✓ Replace the toothbrush or electric toothbrush head at least every 3 months.

- ✓ Floss every day.

- ✓ The first 3 months after the transplant also rinse your mouth with Perio-aid® and Nilstat® (see chapter 'Other medication', page 25).

- ✓ Dry lips or a dry mouth increase the risk of infections. In this case use Vaseline or a hydrating cream for dry lips and rinse your mouth regularly.
  Mouth piercings are not recommended.

- ✓ After the transplant, you should wait 6 months before visiting your dentist for a check-up (unless you have toothache). You should then have your teeth checked every 6 months. Always tell the dentist you're a transplant patient and which medication you use. You may need to take antibiotics to prevent infections in case of a dental procedure. Contact the heart transplant team for this.

- ✓ Contact the heart transplant team if you have the following complaints: red, swollen and painful gums, mouth ulcers or a white coating in your mouth you can't rinse away (probably a fungal infection).

General personal hygiene, facial and hair care

- ✓ Wash every day.

- ✓ Pay extra attention to body surfaces that may contain germs such as skin folds, armpits, genitals, feet and nails.

- ✓ Dry skin folds thoroughly.

- ✓ Avoid physical contact with people who have an infection.

- ✓ The first 6 months after the transplant avoid spaces where may people gather (for example cinema, restaurant, public transport, aircraft, school, department stores during peak hours, festivals, etc.).

- ✓ Piercings and tattoos are not recommended.

- ✓ Avoid saunas, hot jacuzzis and swimming in tropical swimming pools.

- ✓ If you have a wound, clean it with water and disinfect it in case of an infection. Check that the wound is healing properly. Pain, redness, swelling and heat may indicate an infected wound. Contact the physician in this case.

SKIN PROTECTION

The immunosuppressant medication means you're more likely to have skin problems (e.g. dry brittle skin, acne, warts, excessive hair growth, brittle hair). Skin cancer is also more common in transplant patients.

Below is some advice for dealing with skin problems and preventing skin cancer:

✓ Rub moisturising cream on dry skin.

✓ If you have brittle skin, always be careful when removing adhesive bandages and plasters.

✓ Excessive hair growth can be removed with electric hair removal equipment, depilation cream (follow the guidelines on the packaging as these creams can sometimes cause skin irritation), or bleach with hydrogen peroxide. An increase in body hair may impact your mood. Discuss this with your heart transplant team.

✓ Check your skin regularly for developing and/or changing blemishes or warts. Ask your partner or a relative to check your back or the backs of your legs. Consult a dermatologist if a blemish or warts appears or changes.

✓ Book an annual appointment with a dermatologist in any case. They will check your skin thoroughly for any skin lesions.

✓ Limit exposure to sunlight and ultraviolet light (UV light):

- Wear a T-shirt and a wide-brimmed hat.
- Use sunscreen with a high protection factor (+50) and apply to areas exposed to the sun 30 minutes before sun exposure and repeat every 2 hours during exposure.
- Choose a sunscreen that also protects against UV-A-rays. Remember that these creams do let UV radiation through. In other words they don't form an impenetrable layer which means you can't sunbathe endlessly.
- Reapply every time after swimming.
- Take a siesta. UV radiation is the strongest between 12.00 and 16.00 (summer time). Schedule outdoor activities in the morning before noon or in the afternoon after 16.00.
- Remember there is more UV radiation high in the mountains than at sea level. Bear in mind that you'll burn more easily on the water or in the snow because some of the UV radiation is reflected. In other words, good skin protection is extra important in the mountains, on the water and in the snow.
- Avoid using a sunbed.

REHABILITATION, EXERCISE AND SPORT

Rehabilitation in the hospital

During your hospital stay, physical activities are gradually resumed under the supervision of a physiotherapist. The main aim of the exercises is to help you resume normal day-to-day activities. Exercises are started when you're still in intensive care and initially extended in the room. Depending on the results of the cardiac biopsies, exercise outside the room may be intensified.
These exercises include breathing exercises (deep breathing + coughing with fixation), mobilisations, cycling on an exercise bike, walks in the corridor and climbing stairs.

The first 6 weeks after surgery avoid lifting heavy weights to allow the breastbone and the wound to heal. Pulling yourself up in bed with one arm on the support above your head is not recommended either.

Before you leave hospital, your muscle strength and exercise capacity will be tested through some muscle strength tests and a six-minute walking test.

Costs

The treatment in hospital falls under cardiac rehabilitation. The necessary arrangements will be made for this during your hospital stay.

Rehabilitation and training after discharge from hospital

Home physiotherapist

To ensure an optimum recovery, physiotherapy needs to be continued at home. This is with a home physiotherapist at first.

You're responsible for starting up these treatments with a physiotherapist of your choice. Preferably, the sessions start 2 to 3 days after your discharge from hospital. When you're discharged from hospital you'll be given a notice of discharge and a prescription of the physician with the necessary information for your home physiotherapist This prescription entitles you to 18 physiotherapy sessions. Because you were in intensive care, the home physiotherapist can request an F-pathology which is good for 60 extra sessions.

Cardiac rehabilitation

To regain your full strength and fitness, you should also start outpatient multidisciplinary cardiac rehabilitation 6 weeks after surgery at the earliest.
Depending on your own needs and in consultation with your physiotherapist, this treatment can be started later.

Extensive physical exercises are performed during these sessions to regain your fitness. An individual exercise schedule is drawn up based on a maximal fitness test (bicycle test). The rehabilitation also shows you what your body's possibilities and limits are. You'll be exercising safely and responsibly and regain confidence in your body.

To start up this rehabilitation you need contact a centre of your choice. You'll receive a list with the different cardiac rehabilitation centres from the heart transplant team's physiotherapist.
This information is also on the website (only in Dutch or French) of the RIZIV (National Institute of Health and Disability Insurance) (www.riziv.fgov.be): click *Thema's*, and then *Verzorging: kosten en terugbetaling, Ziekten* and finally *Hartziekten.*
For this cardiac rehabilitation, you're entitled to a maximum of 90 sessions in a recognised cardiac rehabilitation centre within the 10-month period after the transplant. These sessions are also covered by the convention arrangements, which were already requested during your stay in hospital after the transplant.

Costs

The home physiotherapy and cardiac rehabilitation rates after the transplant may vary depending on the accreditation of the physiotherapist or the centre of your choice. The convention arrangements mean the sessions in the hospital and the sessions in a certified rehabilitation centre fall under increased reimbursement by the health insurance. Please contact the rehabilitation centre or the physiotherapist of your choice for more information.

Exercising and sports in the long term (the rest of your life)

It's important to keep exercising after your rehabilitation. Exercise is good for everyone, also and particularly for people who've had a heart transplant. It helps prevent new heart problems and is good for your mental well-being. Advice on the recommended amount and intensity of exercise can be found at www.gezondleven.be/files/beweging/aanbevelingen-bsg-volwassenen-en-jeugd.pdf (website of the Vlaams Instituut Gezond Bewegen) (in Dutch).

It recommends at least 150 minutes a week of moderate intensive activity, preferably spread over several days.

Some people with a transplanted heart are able to do intensive sports. Others only just manage to sustain some physical exercise. The most important thing is to keep moving to the best of your ability.

every step counts, every day

Exercise and sports is something you can do alone, but also within a 'heart'-specific sports club such as Harpa, Transplantoux, etc. Please ask the day ward nurse and/or the physiotherapist of the heart transplantation team for more information

Take into account the following:

- Do not cycle outside for the first 6 weeks because of the danger of bumps and falls and their adverse effect on the wound and breastbone. Cycling indoors on an exercise bike is allowed.
- It's best not to swim in a public swimming pool until 6 months after the transplant because of the risk of infection. Hot jacuzzis, tropical swimming pools and saunas should be avoided for life. Hygiene is important in showers and swimming pools.
- Also avoid heavy lifting with chronic use of corticoid therapy (Medrol®) because of the increased risk of spinal collapse. Normally, this does not pose a problem as corticoid therapy is scaled down during the first year after transplant.
- Contact sports such as boxing, judo, karate or rugby are best avoided. Discuss the possibilities with your transplant physician.
- After a heart transplant the heart rate at rest is higher and after exercise your transplanted heart reacts slower because there is no longer a connection to the nervous system (see also 'Denervated heart', page 43). Make sure you warm up sufficiently and build up exercise levels gradually. Immediately after exercising it will also take longer for your heart rate to go down again (importance of cooling down). You'll learn to deal with this during the outpatient multidisciplinary cardiac rehabilitation.
- Don't exercise if you don't feel well or if you have a fever. Wait a few days until you've recovered and then resume your training slowly.
- If you want to take part in competitions, consult your physician. Expert guidance is necessary.

Costs

Exercise and sports needn't be expensive. Cycling, walking, jogging, etc. don't cost anything! A number of health insurance companies and health insurance funds also reimburse full or partial medical fitness. Ask your insurance company and health insurance fund about this.

NUTRITION

The first 6 months

The treatment has suppressed your immune system and made you more susceptible to infections. Infections can also be transmitted by what you eat. During your hospital admission, safe food is ensured by following the hygiene measures laid down by law. To protect yourself at home, you and your housemates can follow some basic food safety rules during the first 6 months.

Buying food

- Buy products with the longest possible expiration date.
- Don’t buy damaged cans or packaging.
- Buy fruit without bruises.
- Buy chilled and frozen products at the end of your supermarket visit. Keep them refrigerated during transport, use an insulating bag. When you get home, immediately put them in the fridge or freezer.
- Individual or small packaging is preferable.

Preparing a meal

- Always wash your hands before preparing, serving and eating meals.
- Don’t allow pets in the kitchen.
- Preferably use a pedal bin for kitchen waste.
- Don’t keep vegetable, fruit and garden waste in the kitchen.
- Change kitchen towels, dishcloths and scouring pads daily.
- Use clean and dry crockery, cutlery and kitchen utensils. Always keep the kitchen sink clean and dry.
- Don’t use wooden chopping board or spoons. An undamaged chopping board (plastic, bamboo or glass) is preferable.
- Use gloves if you have wounds, cuts or an infection on the skin of your hands.
- Kitchen utensils that have been in contact with raw meat, chicken, fish and eggs should not be reused for prepared food. After use, wash in soapy water and rinse under hot water or use the dishwasher.

- A dishwasher is a safe way to clean kitchen equipment. If you wash by hand, it is important to use plenty of hot water and detergent. If necessary, change the dishwashing water in between.
- Wash vegetables carefully under cold running water, especially if they're eaten raw. This also applies to prepackaged vegetables (e.g. mixed lettuce).
- Wash fruit carefully under running water, always cut it in half and check for mould and blemishes.
- Do not let dishes cool on the counter, at room temperature. Place in the refrigerator or freezer as soon as possible. If the dish is still too hot, cooling can be accelerated by placing in cold water for a while.
- Defrost frozen products just before cooking in the microwave or on a tray at the bottom of the fridge. Definitely don't defrost on the worktop. Collect any thawing water and pour it away as it contains bacteria.
- Treat frozen products like fresh products and make sure they are heated sufficiently. Even if you reheat meals or products, they should be heated to the core.

Storage of food

- Do not eat products with expired expiration dates.
- Based on taste and smell, you can't always tell whether food is still okay. When in doubt, throw it away.
- The temperature of the refrigerator should be 4°C or lower. The freezer temperature should be -18°C or lower. Check the temperature of the refrigerator and freezer regularly.
- Eat the meal as soon as possible after preparing. Place in refrigerator as soon as possible if you want to keep the meal longer.
- Use storage boxes with lids or cover food with cling film.
- Store opened packs of savoury prepackaged sandwich fillings in the refrigerator for up to three days.
- Ready meals that you want to eat later should be kept in the fridge for 1 day at most. If you want to keep a meal longer than 1 day, freeze it.
- Don't refreeze thawed products.
- Don't drink from a bottle, use a clean glass.

Food sharing

- Do not eat together from the same bag of chips or other snacks.
- Do not use large cookie boxes that have cookies loose in them.
- Avoid passing around boxes of chocolates.
- Be careful with meals that stay on the table for long periods of time such as barbecue, or food that stays out of the refrigerator for long periods of time such as cold sauces.

High-risk food

Some foods contain a large amount of germs (fungi, bacteria) and thus pose a higher risk during the first few months after a transplant. Many of these foods can be made safer by heating through or cooking. Below is a list of food that is best avoided the first six months.

Meat and eggs

- Raw meat: filet american, carpaccio, steak tartare
- Insufficiently cooked meat: extra rare, rare, medium rare meat, roast beef
- Sliced meat that was insufficiently heated during the production process: salami, dry sausage, chorizo, smoked meat, Parma ham, Coburger ham, Serrano ham, filet de Saxe, filet d'Anvers, paté, liver sausage, bacon, raw bacon
- Food in which pork, wild boar or venison liver and/or blood has been processed, regardless of whether it was heated: paté, black pudding, etc.
- Sliced meat from the fresh food section, caterer or butcher
- Half-cooked eggs: fried egg, soft-boiled egg, poached egg
- Artisanal egg preparations: fresh mayonnaise, fresh chocolate mousse, fresh tiramisu
- Partly cooked eggs: pastry cream, artisanal ice cream, hollandaise sauce, béarnaise sauce

Fish, crustaceans and shellfish

- Raw fish: sushi, tartare, sashimi, ceviche, raw herrings
- Smoked fish: smoked salmon, smoked eel, smoked halibut, etc.
- Raw crustaceans and shellfish: oysters, raw scallops

Dairy products and cheeses

- Yoghurt with probiotics: Activia®, Yakult® and Actimel®
- Cheese based on raw milk: certain types of grated cheese, certain types of Parmesan, cheeses with specification 'au lait cru'
- Blue cheese or cheeses with a mould rind: Gorgonzola, Roquefort, Brie, Camembert, etc.

Vegetables, fruit, nuts, seeds and kernels

- Ready-made vegetable salads: coleslaw, potato salad
- Sprouts and shoots (raw): alfalfa, leek shoots, clover, radish shoots, soybean shoots
- Raw mushrooms
- Unpasteurised vegetable juice
- Grapefruit, blood orange, pomelo, sweetie, minneola and star fruit (due to the interaction with medication)

- Fresh fruit salads or pre-cut ready-made fruit
- Fresh fruit juice that isn't drunk immediately, unpasteurised smoothies
- Nuts, freshly picked: chestnuts, walnuts, hazelnuts, beech nuts
- Nuts and peanuts in the shell: shelled walnuts, unshelled peanuts
- Seeds and kernels with peel: unshelled sunflower seeds

Drinks

- Unbottled spring water, well water
- Soft drinks with grapefruit, blood orange and/or pomelo or extracts of this fruit, for example Schweppes® agrum, Tönissteiner lemon, etc.

Snacks, biscuits and sweets

- Easy scoop ice cream, soft ice cream, ice cream in big tubs, artisanal ice cream
- Pick and mix sweets
- Loosely sold snacks: olives, sun-dried tomatoes, tapenades, capers, etc.
- Artisanal products: honey from a beekeeper, artisanal market stalls, farm shops, etc.

Ready-made meals, restaurants, take-away meals

- Ready-made take-away meals: Chinese, Indian, pizza, shawarma, Thai, chips from the chip shop, hot dogs, hamburgers, etc.
- Buffet
- Prepared sandwiches
- Take-away rotisserie chicken, spare ribs, etc.

After the first 6 months

The hygienic food measures apply particularly for the first six months after the transplant. Subsequently, barring a few exceptions, these measures don't have to be strictly respected. This is because the first months after the transplant the medication doses are highest. As this medication needs to be taken for life, you need to remain cautious.

In case of rejection, the medication will be increased. In this period the hygienic restrictions need to be strictly respected again.

To prevent a Hepatitis E virus infection, the following foods are banned for life:

- raw or insufficiently cooked crustaceans and shellfish
- raw or insufficiently cooked pork
- raw or insufficiently cooked wild boar or venison
- raw or insufficiently cooked pork liver
- products in which raw pork liver has been processed (e.g. specific types of French dried sausage)

Interaction with the medication

Grapefruit and blood orange are banned for life as these types of fruits can raise medication levels in the blood. Keep in mind that not only this fruit is banned, but also any derivatives such as the juice or concentrates of the fruit. The following lesser-known fruits are also banned: pomelo, minneola, sweetie and star fruit (carambola). Also avoid St John's wort.

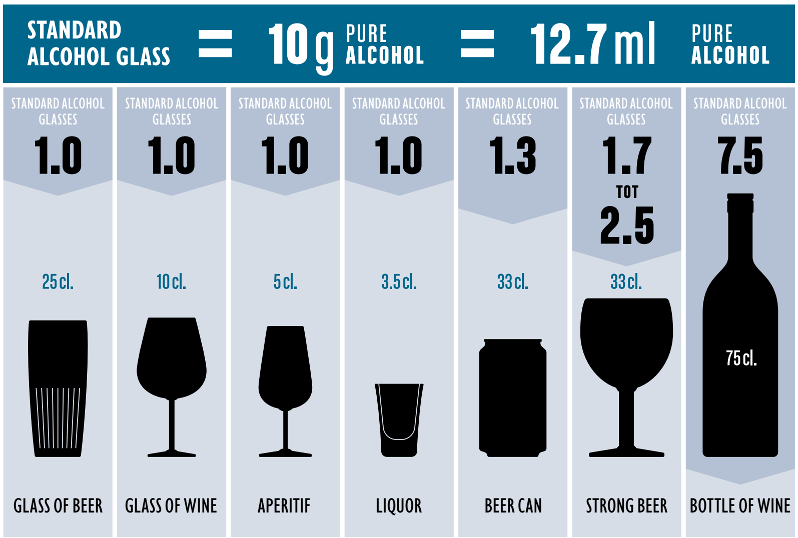
Other citrus fruits and fruits do not affect the medication.

The dietician will come to see you before you go home. They will give you comprehensive personal advice tailored to your needs.

ALCOHOL CONSUMPTION

Alcohol is a harmful substance that can cause many problems in terms of health and safety. The World Health Organisation has linked alcohol consumption to more than 200 diseases and injuries. The carcinogenic effect of alcohol is increasingly clear. If you don't want to run any risk, it's best not to drink alcohol. If you do drink alcohol, drink in moderation and spread your consumption over several days in the week and don't drink for a couple of days.

Specifically, the maximum recommended amount of alcohol for adult men and women over 18 is 10 standard glasses per week.



© VAD

Tips for people who want to drink alcohol

- ✔ Decide on your maximum intake in advance and stick to it.
- ✔ Drink slowly (at least half an hour per glass), eat while drinking and alternate with non-alcoholic beverages.
- ✔ If you're thirsty, drink water: alcohol will make you thirstier.
- ✔ Limit the total amount you drink in one go.
- ✔ Spread alcohol consumption over several days in the week.
- ✔ Insert at least 2 alcohol-free days a week to avoid addiction.
- ✔ If you're in doubt about your alcohol consumption, write down what you drank and when for a few weeks.
- ✔ For the first 6 months after the transplant, it's best not to drink high-fermentation beers, organic cider, eggnog (contains raw eggs) and home-made fruit wines.

More information is available on the website of the VAD, Flemish Expertise Centre for Alcohol and other Drugs: www.vad.be/themas/alcohol

SMOKING AND ILLEGAL DRUGS

Everyone knows that smoking is unhealthy. It increases the risk of cardiovascular diseases, respiratory diseases and cancers. Thousands of people die every year in Belgium as a result of their tobacco use.

In people who've had a transplant, the harmful effects of smoking can be even greater. The anti-rejection medication you have to take for life already increases the risk of all kinds of conditions including cardiovascular diseases, infections and cancers. Smoking can further increase the risk of these conditions.

Studies have indeed shown that the risk of cardiovascular disease, cancers and even death is almost twice as high for people who smoke after a transplant compared to non-smokers. Smokers also have shorter lives.

You were asked to stop smoking before the transplant. Are you finding it hard time not to smoke after the transplant? If so, please discuss this with someone from the heart transplant team. Various aids exist that increase the success rate of not smoking. These include smoking cessation medication, nicotine substitutes and support of a registered tobaccologist.

Staying in a smoky environment also has negative effects after the transplant. We therefore advise you to ask your immediate environment (partner, family, visitors) not to smoke or to smoke outside.

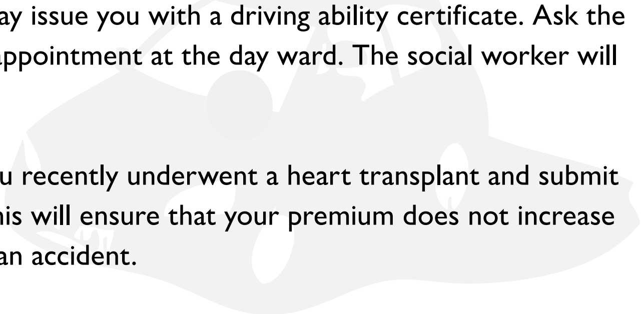
More information:
www.tabakstop.be
www.vlaanderenstoptmetroken.be
www.vrgt.be
www.erkendetabakologen.be

Drugs are prohibited by law and carry serious medical risks. We therefore strongly advise against taking drugs after a transplant.

DRIVING

By law, driving a car is allowed from 6 weeks after the transplant at the earliest. If your recovery is satisfactory, your physician may issue you with a driving ability certificate. Ask the physician for this certificate during your appointment at the day ward. The social worker will provide further information on this.

Inform your car insurance broker that you recently underwent a heart transplant and submit a copy of the driving ability certificate. This will ensure that your premium does not increase and that you are covered in the event of an accident.



Please note that in the first few weeks you'll need to provide transport for your check-ups in the day ward. If you can't rely on family or friends for this, transport can be arranged to take you to and from the hospital. The social worker will provide you with extra information on this.

Remember that wearing a seat belt is a legal requirement, especially after heart surgery.

For more information please contact the Centre for Driving Ability and Vehicle Adjustment (CARA).

RETURNING TO WORK OR SCHOOL

The aim has always been for you to go back to work and school after a transplant. It's the best way to reintegrate into society.

Allow for a recovery period of about 6 months. Discuss with your transplant physician, the medical consultant of your health insurance and your employer when and how you can resume work. Patients frequently return to work part-time to start with and then go back to full-time after a number of months.

Unfortunately, not everyone is fit enough to return to work. This may be due to the actual working conditions or to the extent to which you have recuperated after the transplant. Sometimes the nature of the work will have to be adapted. Retraining may offer a solution.

The social worker may be able to help you look for new employment and put you in touch with various organisations such as the VDAB Werkwinkel (a group of organisations that help people find suitable employment), expert career planning and guidance.

Students should consult their physician about when to return to school.

TRAVEL

The first year

The first year after the heart transplant it's better to plan holidays in Belgium and the immediate surroundings. The risk of rejection and infections is still quite high and you need regular check-ups.

After the first year

The first year after the heart transplant, you can plan a trip abroad without any problem. However, discuss your travel destination with the transplant physician first. Some (exotic) destinations require special precautions (e.g. vaccinations, see next chapter). Some trips to tropical or remote holiday resorts are not recommended due to poor hygiene measures, increased risk of infections, or limited medical care. In other words, make an appointment with the transplant physician in good time prior to departure. The physician can decide whether an additional appointment at the 'Travel Advice and Vaccinations' consultation is necessary.

I'm going on a trip and I'm taking with me …

✓ Enough medication:

  - Bring more than necessary in case you have to stay longer unexpectedly.
  - When travelling by air, always take your medication in your hand luggage. Suitcases can get lost and not arrive at your destination or be delayed.
  - Keep your medication with you, shelter it from sun and heat.

✓ An English document with your transplant details, an overview of your medication and the contact details of the transplant centre. This document may avoid problems at the border or airport and is useful if you need medical treatment.
The day ward nurse can help you prepare this document.

✓ Details of the closest hospital or transplant centre to your holiday destination.

✓ Sun protection (see chapter 'Skin protection', page 52).

VACCINATIONS

It's important to protect yourself as much as possible against all kinds of infections after the transplant. Vaccinations are an important part of this. Ideally, they're given before the transplant because you won't be taking immunosuppressant medication yet. Always consult your transplant physician in advance to see which vaccinations are necessary and permitted and which aren't.

Which vaccinations should you NOT have?

You must not be given vaccines made from live attenuated viruses. Examples include vaccines against chicken pox, measles, rubella, mumps and yellow fever. If you're taking anti-rejection medication, these vaccines may cause the disease they're supposed to prevent.

Which vaccinations can you have?

Non-live (inactivated) vaccines, vaccines that use an attenuated and harmless vector (e.g. AstraZeneca's corona vaccine) and mRNA vaccines (e.g. Pfizer's corona vaccine) can be used without risk. Therefore, get your flu jab every year.
You also need a vaccine against pneumococcal disease every 5 years. Pneumococci are responsible for a certain type of (bacterial) pneumonia that can have serious consequences. Just keep in mind that the immunosuppressant medication you take may cause the protection provided by the vaccine to be weaker.

Check with your health insurance company regarding possible reimbursements for vaccines.

SEXUAL ACTIVITY

Nothing is preventing a healthy sexual relationship as soon as you feel able to do so. Any physical causes of sexual problems that were present before the transplant may even have improved after the transplant as you are normally in better shape again.

However, returning to a satisfying sexual life is not easy.

Many transplant patients worry about the effort involved in sex. Can my heart handle this strain? During sex, the heart rate increases and blood pressure rises. However, if you measure the pulse and blood pressure during ordinary daily activities, the cardiac strain is found to be the same.

Sexual activity can be compared to normal activity and is therefore not dangerous. For most people the energy needed for this activity can be compared to going up 2 flights of stairs. If you can do this without pain or excessive respiratory problems, your heart has recovered sufficiently for sexual activity. Are you short of breath, in pain or are you having palpitations? It's advisable to stop and report it the physician.

Possible causes for reduced sexual activity

It is not unusual to feel less keen on sexual activity when you're physically unwell, tired and dealing with pain, fatigue, nausea and so on. Emotional problems can also get mixed up with physical complaints and have an effect on intimacy and sexual activity.

Below is a list of factors that may affect intimacy, sexuality and safe sex. This list helps you recognise these symptoms early and discuss them with your GP or someone from the transplant team.

Problems in resuming your sexual relationship may be caused by:

- processing the illness and the transplant
- side effects of certain medicines (against high blood pressure, against rejection, etc.)
- complaints from the operation wounds or scars
- reduced self-confidence due to a changed body image
- fear of physical exertion
- partner's anxiety and fear
- changed roles and relationships
- physical problems such as fatigue, pain, weakness, vaginal dryness, fungal infections, impotence and ejaculation problems
- psychological problems
- problems in the relationship
- etc.

Specific concerns for women

Female transplant patients sometimes experience vaginal dryness. This may be caused in part by a reduced immunity due to the anti-rejection medication. This may make sexual intercourse painful or cause contact bleeding. It's always a good idea to consult your GP to rule out another cause (such as an infection). To reduce vaginal dryness, several non-hormonal creams and gels are available at pharmacies and chemists that can be applied prior to intercourse. To prevent urinary tract infections, women are advised to urinate shortly after intercourse.

Specific concerns for men

Male transplant patients sometimes experience erectile dysfunction or impotence. This can partly be caused by medication such as beta blockers. This may make sexual intercourse difficult or impossible. Discuss any difficulties or insecurities with your GP or someone of the transplant team. If the problem is physical, some medicines may improve the success of sexual intercourse, give you renewed confidence and make the fear of failure disappear.

Safe sex after an organ transplant and the risk of sexually transmitted infections (STI)

The anti-rejection medication suppresses your immune system and therefore increases the risk of infection. Using condoms reduces the risk of infection with STIs, such as candida, chlamydia, gonorrhoea, herpes, genital warts, hepatitis B, hepatitis C, HIV, etc.
Your suppressed immune system means these infections may be more severe or less treatable. In case of abnormal vaginal discharge, itching or other unexplained symptoms, it's wise to contact your GP to rule out an infection or have it treated. Ask if your partner also needs treatment. In case of new sexual contacts, always use a condom to avoid the risk of a sexually transmitted disease. It is advisable to have your partner tested for sexually transmitted diseases before you stop using a condom. If you stop using a condom, good intimate hygiene of your bed partner is very important.

Even if sexuality is not an easy topic to discuss, don't hesitate to discuss it with someone from the transplant team: good information and some advice provides reassurance. Depending on your question or problem, you may also be referred to other care providers (psychologist, sexologist, etc.).

PREGNANCY AND ANTICONCEPTION

Most women can become pregnant after a transplant and men can also have children after a transplant. Keep in mind that some heart conditions are congenital and your child may have the same heart condition you suffer. The transplant physician can check whether the heart condition for which you received a transplant is congenital. If the congenital cause of your heart condition is known, measures can be taken to ensure you don't pass on the condition to your offspring.

However, women should absolutely not become pregnant in the first year after the transplant. Pregnancy is too great a burden and carries too many risks for both mother and child. Female patients of childbearing age should therefore use reliable contraception, especially in the first year after the transplant.

Do you want children after the first year? Discuss it with the transplant physician before you get pregnant. The transplant physician is able to assess whether pregnancy is possible in view of your medical history. Sometimes certain medicines have to be temporarily interrupted because they cause serious abnormalities in the unborn child. Never stop taking medication of your own accord.

Keep in mind you have an increased risk of serious health problems after a heart transplant. As a result, it's possible your partner will take on a large part of the parenting. Also keep in mind that survival after a heart transplant is limited which may have the necessary consequences for your partner and the growing child. Make a well-considered decision together before you proceed. If there are no medical objections to a possible pregnancy, the transplant physician will refer you to a gynaecologist experienced in transplant patients for further advice. The gynaecologist will also consider the risks of a pregnancy and guide you during a possible pregnancy.

Male heart transplant patients should also discuss this with the transplant physician.

PETS

It's wiser to keep pets (cats, dogs, birds, guinea pigs, etc.) out of the house for the first year after the transplant as often they carry viruses. Don't get any new pets in the first year after the transplant. If you already have pets it's recommended that you get someone else to look after them. Avoid all bodily fluids from animals and wash your hands after touching them. In any case, get others to clean the litter box, basket and aquarium. If no-one is available to do this you must, at least, wear gloves and maintain good hand hygiene.

PLANTS AND GARDENING

Keeping cut flowers or houseplants indoors is allowed, but don't overdo it. Leave watering or repotting to someone else during the first 6 months. Stagnant water is a source of bacteria and fungi, and potting soil also contains fungi. Flowers should be given clean water every day.

Gardening is allowed after 6 months, provided you wear gardening gloves. Wash your hands after coming into contact with soil. Also be careful with organic material and compost and/or compost barrels. It’s best to leave this to others.

PSYCHOLOGICAL ASPECTS

A heart transplant is a significant event, both for you and for your immediate family members. Some people find it very hard to cope emotionally.
After a transplant, you may feel joy and gratitude, but also anxiety, depression and uncertainty. Is everything going well and will it continue to go well? Do my symptoms indicate rejection? The thought of having someone else’s heart in your chest is not always easy either. It may also be difficult to redefine your life after the transplant. Your expectations may have been too high beforehand, leading to a disappointing recovery. You need to be able to cope with any setbacks. The psychologist on the heart transplant team can help you handle all this.

Also keep in mind that certain emotions or feelings, such as mood swings (sometimes being very sad, but also very happy or euphoric), irritability, anxiety, feelings of depression, and so on, can be a side effect of the medication. Let the transplant team know how you feel.

On a social level, some transplant patients struggle to cope with reactions from friends or acquaintances after a transplant. Their feelings and thoughts don’t always match yours. It’s sometimes difficult for them to understand that you may still have limitations after a transplant. Try talking to them about this. Do you find this hard or are you not sure how to deal with this? The heart transplant team can help you.

LIFELONG FOLLOW-UP AT THE TRANSPLANT CENTRE

A heart transplant signifies a fresh start for you, but also requires lifelong follow-up and guidance by the heart transplant team. Your body never stops fighting the transplanted, foreign organ. In addition, anti-rejection medication can have negative effects for your body. You're expected at the hospital regularly to check the functioning of your new heart, to detect rejection and infections early, and to stop the side effects of the medication in time. You'll also receive guidance on necessary lifestyle adjustments and your psychosocial well-being.

What does the follow-up look like?

In the first year after the transplant, your visits to the E 439 heart transplant day ward are laid down in the fixed schedule. The first 2 weeks after your discharge from hospital you have weekly check-ups. After a few weeks this will be reduced to once a fortnight, later to every 3 weeks and then every 4 to 6 weeks. After the first year, you're expected at the day ward every 3 months for the rest of your life. Monthly blood tests are necessary. This is possible at UZ Leuven's blood centre, but also at your GP's or at a local clinical laboratory. Once a year, you'll be admitted to hospital for 2 or 3 days for a more extensive annual check-up.

FOLLOW-UP VISITS AT THE HEART TRANSPLANT OUTPATIENT CLINIC (E 439)

Follow-up visits are check-ups for which you're not admitted to hospital but go home the same day. You'll be given an appointment for an initial outpatient check-up in the day ward when you leave hospital. Subsequent appointments at the day ward are notified by the secretariat of the heart transplant department by letter. These appointments can also be consulted on the website and the mynexuzhealth app. You can also access your medical record in this way. If you're not yet registered, ask the (day ward) nurse for a personal code card.

Preparing for the appointment at the day ward

- Fasting is mandatory

  You need to fast until after the blood test, this means:
  → No eating or drinking after midnight. Only water is allowed.

→ Don’t take any medication on the morning of the appointment at the day ward. You may only take the medication after the blood test. You already took the medication at home? Tell the day ward nurse.

- Don’t forget:

→ identity card (registration)
→ breakfast
→ medication for one day
→ medication scheme (most recent version)
→ list with required certificates and prescriptions

Where should you be?

On arrival in the hospital you must first register at reception. You can do this at a kiosk or with a staff member at the registration counter. You’ll need your identity card to do this. You can also register via the mynexuzhealth app on your smartphone. If you’re having a cardiac biopsy, register at the counter.

Until further notice, heart transplant day ward appointments take place at consultation E 409, oranje straat - gate 4. The secretariat will keep you up to date. After registering, follow the orange arrow to the sign that says ‘poort 4’. Turn left and report to the staff member at the desk.

What tests are performed during your appointment at the day ward?

It consists of 2 appointments:

❶ An appointment with the day ward nurse: for a talk, medication enquiry, checking blood pressure, pulse and weight, blood test and an electrocardiogram (ECG).

❷ An appointment with the consultant in training: for a talk, clinical examination and an ultrasound of the heart.

Other examinations are possible during these appointments depending on how long ago you received the transplant or if the physician deems it necessary. For example, during the first year after the transplant, you’ll have a cardiac biopsy with pressure measurement in the right ventricle at regular intervals. After the biopsy and pressure measurement, we make an RX-thorax (picture of the heart and lungs) and an ultrasound of the heart for monitoring. The physiotherapist performs a six-minute walk test and muscle strength measurements at week 7 OR 9 after the transplant. Please wear sports shoes and take into account this is a longer visit. You can also make an appointment with the psychologist, social worker, dietician or physiotherapist.

After registering, always come to see the day ward nurse first. The nurse will go over the planning for the day with you. If everything goes well, you can go home at 14.00 at the latest. The results of all examinations are reviewed by the supervisor in the evening. You can call for the results of the examinations the next working day (i.e. Monday if the day ward examination is on Friday) between 9.00 and 11.00: Tel. 016 34 43 55. The physician will then also inform you if your medication needs to change. Keep your medication scheme close at hand in other words. Indicate clearly if you haven't understood something.

Schedule:

Tests	**Weeks after the transplant**					
	Week 1, 2, 3 [a]	Week 4	Week 5	Week 7, 9 [b]	Week 11	Week 14, 17, 21, 25
Biopsy	✓		✓	✓		✓
Echocardiography	✓	✓	✓	✓	✓	✓
Electrocardiogram	✓	✓	✓	✓	✓	✓
RX thorax	✓		✓	✓		✓
Clinical tests [b]				✓		

Tests					
	Week 29	Week 34	Week 40	Week 46	> 1 year (1x/3 months)
Biopsy			✓		
Echocardiography	✓	✓	✓	✓	✓
Electrocardiogram	✓	✓	✓	✓	✓
RX thorax			✓		
Clinical tests [b]					

[a] Wa Weeks 1 and 2 always take place during your hospitalisation, in the event of a very smooth recovery, week 3 may exceptionally be at the day ward.

[b] Clinical tests take place in week 7 or week 9 in consultation with the physiotherapist. The secretariat will confirm this appointment. Please wear sports shoes to this appointment.

MONTHLY BLOOD TEST

After the first year, monthly blood tests monitor the trough level of the immunosuppressant medication, the kidney function, the cardiac enzymes and the white blood cells. For a correct trough level, the blood test should be performed in the morning just before you take the immunosuppressant medication. The blood test can be done at UZ Leuven's blood centre (orange arrow, gate 2, waiting room K), but also at your GP's or at a neighbouring hospital or clinical laboratory. Discuss this with the day ward nurse. The day ward nurse will arrange an appointment at the blood centre or provide you with the necessary documents to have the blood tests done elsewhere. If the blood test is done by the GP or at a local hospital or clinical laboratory, please have a copy of the results sent to hartfalen.htx@uzleuven.be or by fax to 016 34 42 40.

The transplant physician assesses the results and will contact you by telephone if any adjustments to the medication are needed. If no adjustments are needed, you won't hear from the physician. Is it the first time a blood test is being done elsewhere? Call the heart transplant secretariat a week later to check whether they received the results. And at your next appointment at the day ward, check whether they received the results of the blood tests.

ANNUAL CHECK-UP AT THE HEART TRANSPLANT UNIT (E 435)

Once a year, you'll be admitted to E 435 for a more extensive check-up. Preferably, this annual check-up takes place during the period in which you received the transplant. It takes 2 to 3

days. An annual check-up usually starts on a Monday, Wednesday or Friday at 7.30 or 8.00. You must first register at the registration counter in the hospital reception.

Preparing for the annual check-up

- Blood thinners
  You need to stop taking some blood thinners (Marcoumar®, Marevan®, Sintrom®, Pradaxa®, Lixiana®, Xarelto® and Eliquis® etc.) for a couple of days. Discuss this during your previous appointment at the day ward or call the ward physician: Tel. 016 34 43 55.

- Fasting
  You need to fast. This means:
  → No more eating or drinking from midnight. Only water is allowed.
  → Don't take any medication the morning you're admitted.
  → You already took the medication at home? Tell the nurse.

- What must you bring?
  → identity card (registration)
  → medication box
  → medication for at least 3 days
  → medication scheme (most recent version)
  → list with required certificates and prescriptions

Where should you be?

After registering, follow the purple arrow to the third floor and go to the E 435 cardiology and heart transplant ward (to the right when you come out of the lift). Register with the staff member at the counter.

Procedure of the annual check-up

During the annual check-up the following tests are performed, spread over 2 to 3 days:

- blood and urine tests
- RX-thorax or CT-thorax (photograph or ‘scan’ of heart and lungs)
- photograph of the vertebrae
- electrocardiogram (ECG)
- 24-hour blood pressure measurement
- 24-hour Holter monitoring
- ultrasound of the heart or magnetic resonance imaging (cardiac MR) of the heart
- pulmonary function test
- bone densitometry
- heart catheterisation. Depending on how long ago you received the transplant, this will be a right heart catheterisation, a cardiac biopsy and/or a film of the coronary arteries (the arteries that supply oxygen to the heart).

Other tests in addition to these standard tests are possible if the physician deems it necessary.

Please schedule a yearly appointment yourself with a dentist, ophthalmologist, dermatologist and gynaecologist (for women only). This may be done at UZ Leuven or elsewhere. In the latter case, please bring a report of the results with you when you come for annual check-ups.

FINANCIAL ASPECTS

HOSPITAL BILL

A hospital admission always involves costs. A few weeks after your discharge from hospital, the co-payment bill will be sent to your home. The costs charged are broken down into fixed headings (including accommodation costs, fixed costs, pharmacy, fees, other supplies, patient transport, miscellaneous costs, etc.). The hospital bill specifies the amount the hospital charges directly to your health insurance, as well as the amount you need to pay.

If you took out private insurance that pays hospitalisation expenses, you can get a partial or full refund of the amount you have to pay yourself. Some hospitalisation insurance policies apply the third-party payer principle and settle with the hospital and only provide you with the co-payment bill, in accordance with your non-reimbursable policy.

COSTS OUTPATIENT CLINIC VISITS

You will be invoiced for each appointment at the day ward after the transplant. Usually the invoices for 2 or 3 consultations will be combined. You must pay the specified amount in full to the hospital. You only need to pay the co-payment for the blood tests and consultation.

If there's a white form with this invoice, send it to your health insurance for a partial refund. Otherwise, the health insurance will already have settled the invoice with the hospital and will only charge you the co-payment.

If your hospitalisation insurance includes reimbursement of outpatient care (sometimes a period before or after hospitalisation), you can still claim part of these costs through your insurance.

BALANCE DUE INSURANCE

We're aware that before and after a transplant, patients have difficulties taking out insurance, including, therefore, balance due insurance policies when buying a home.

Try visiting as many different insurance companies as possible and compare the terms and conditions. In case of refusal, try to negotiate terms including deposit, group insurance, investment insurance, etc.

The website below shows the latest developments regarding this difficult theme:
www.vlaamspatiëntenplatform.be

CONTACTS BETWEEN PEERS TO SHARE EXPERIENCES

The transplant can have a significant impact on you and your environment. Contact with a fellow sufferer or going to activities with peers is supportive and helpful. Listening to people with recognisable problems and sympathising with them can give you courage and help build a realistic expectation pattern around transplants for both you and the people around you. The social worker or day ward nurse will gladly tell you about associations for people living with a transplant. They can put you into contact with peers if you want.

GRATITUDE FOR THE DONOR AND THEIR FAMILY

The law on organ donations and transplants is based on strict anonymity of donor and recipient. However, some people want to thank their donor's relatives after receiving a transplant. There is the possibility of sending an anonymous letter of thanks to the donor's family but this is up to you and there's no obligation to do so.

For some donor families, a letter can be comforting and help them in their grieving process. Other families may still be too upset or overwhelmed and have no desire to hear from the transplant donor or recipient. It's not possible to predict what feelings or reactions your letter might trigger.

Complete anonymity must be maintained in everything you make or write. This is a legal obligation. Make sure that everything you wrote is really intended for a donor's family and most of all respect the feelings of grief of your donor's relatives.

Give this letter to someone from the transplant team, who will pass on your letter to the transplant coordinator. The latter will contact the person who coordinated the donor procedure at the centre from which your donor came. The team member who knew the donor's family will inform them that you wrote a letter. If the family agrees, your letter will be delivered to them.

PARTICIPATION IN STUDIES

In addition to patient care and training the tasks of a university hospital also include research. If current knowledge is not sufficient to determine the optimum approach for a specific problem your treating physician may propose participation in a clinical study. You are at liberty to decide whether or not to participate based on the information about the clinical study provided by the physician and study nurse. You are under no obligation to participate. By participating you'll help promote medical progress. For more information, request the 'Participation in a clinical study information brochure' (www.uzleuven.be/brochure/700284).

SUMMARY

Everything you should know in a nutshell:

- After a heart transplant, you'll have to take medication for the rest of your life to prevent your body from rejecting the new heart.
- Always take this medication correctly and punctually. Do not skip a single dose.
- Store the medication at room temperature, away from light and moisture.
- Do not push the anti-rejection medication out of the blister strip until you're about to take it.
- Avoid eating or drinking grapefruit (juice).
- Never change or stop the anti-rejection medication of your own accord. This may lead to rejection.
- Only the transplant physician can make adjustments to anti-rejection medication.
- Never take non-prescribed medication of your own accord.
- Inform any dentist or physician who wants to start or stop medication that you're a heart transplant patient taking important medication. Even if a GP wants to start a treatment, it is advisable to discuss this treatment with the transplant physician first. Some medication should not be combined with anti-rejection medication.

- Taking anti-rejection medication puts you at greater risk of infections. Protect yourself from infections by:
    - → Good body hygiene.
    - → Washing your hands thoroughly (particularly before eating, after sneezing or coughing, after every visit to the toilet).
    - → Good oral and dental hygiene. Brush your teeth in the morning and in the evening and after every meal. The first 3 months after the transplant you must also use Perio-aid® and Nilstat® mouthwash.
    - → Avoid contact with sick people.
    - → Avoid large groups of people during the first 6 months after the transplant.
    - → Avoid foods containing pathogenic agents during the first 6 months after the transplant and handle all food under hygienic conditions.
    - → Wear gloves when gardening.
    - → Do not swim in a public swimming pool during the first 6 months after receiving a transplant. Hot jacuzzis, tropical swimming pools and saunas should be avoided for life.
    - → No piercings or tattoos.
    - → Keep pets out of the house for the first year after the transplant as they often carry viruses. If you already have pets it's recommended that you get someone else to look after them. If no-one is available to do this you must, at least, wear gloves and maintain good hand hygiene.
    - → No new pets.
- Lifting weights is prohibited until 6 weeks after surgery, as your breastbone still needs to heal.
- Driving a car is possible at the earliest 6 weeks after the transplant and only following the transplant physician's approval. Wearing a seat belt is compulsory.
- Return to work is strongly encouraged.

- A healthy lifestyle is important:
  - → Eat healthy and balanced meals (limit your salt intake and fats).
  - → Get enough exercise and don’t sit too long.
  - → Do not smoke and avoid passive smoke.
  - → Be moderate in your alcohol consumption.
  - → Always protect your skin from the sun to prevent skin cancer: wear protective clothing, regularly reapply sun cream with a high protection factor (+50), avoid the hottest hours of the sun and don’t use sunbeds.
  - → Get vaccinated if necessary (except for live vaccines, e.g. chicken pox, measles, rubella, mumps and yellow fever).
- Following all lifestyle recommendations is not easy. If you experience any difficulties in doing so, don’t hesitate to discuss this with the heart transplant team.
- Contact the heart transplant team in case of the following complaints or symptoms:
  - → Feeling unwell, flu-like feeling
  - → Abnormal fatigue
  - → Increase in body temperature or fever (from 37.5°C)
  - → Dizziness, palpitations, chest pain
  - → A weight gain of 2 kg or more over the space of 48 hours
  - → Fluid retention (for example swollen legs or ankles)
  - → Low blood pressure
  - → Airway complaints (for example coughing, shortness of breath)
  - → Stomach complaints (for example diarrhoea longer than 2 days, nausea, vomiting, reduced appetite)
  - → Pain or a burning sensation during urination, urinating a lot and small quantities, badly smelling urine
  - → Suspicious skin lesions, infected wound (a wound that is painful, red, warm or swollen)
  - → Red, swollen and painful gums, mouth ulcers or a white coating in your mouth you can’t rinse away (probably a fungal infection)
  - → For women: changed vaginal discharge

THE HEART TRANSPLANT TEAM

Obviously a heart transplant involves many more people than those listed below. Heart surgeons, anaesthetists, intensivists, nursing staff in the operating theatre and intensive care unit, transplant coordinators and many more are part of the heart transplant team and make vital contributions to the success of this undertaking.
The list below is merely for practical purposes and comprises the names of the people who will be in frequent contact with you following the transplant.

Physicians:

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Head nurse: ....

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Transplant nurses:

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Day ward nursing staff:

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Heart transplant specialist nurse:

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Social worker:

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Psychologist:

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Physiotherapist:

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Dietician:

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Pastor:

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Heart transplant secretariat:

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USEFUL TELEPHONE NUMBERS AND WEBSITES

The following is a list of useful telephone numbers and websites:

UZ LEUVEN

University Hospitals Leuven – Gasthuisberg Campus
Herestraat 49
3000 Leuven
UZ Leuven switchboard: 016 33 22 11
www.uzleuven.be

HEART TRANSPLANT TEAM UNIVERSITY HOSPITALS LEUVEN

What's wrong?	When should you call?	Which number?	Who will you be talking to?
For medical questions or questions about blood test results and examinations (between 9.00 and 11.00 from Monday to Friday)	on working days from 8.00 to 13.00	016 34 43 55	consultant in training
For care-related questions or questions about lifestyle after a transplant	On working days from 8.00 to 13.00	016 34 43 56	Day ward nurse E 439 or heart transplant specialist nurse
For urgent matters or emergency situations if the day ward is closed (24/7)	24/7	016 34 43 50	Logistics worker or nurse E 435 - hospitalisation
To make or change appointments	On working days from 8.30 to 11.00 and from 12.30 to 16.30	016 34 42 63 or 016 34 42 68 e-mail: hartfalen.htx@uzleuven.be	Heart transplant secretary

OTHER USEFUL TELEPHONE NUMBERS

Social worker	016 34 43 47 or 016 34 86 20 (working days from 8.00 to 17.00)
Dermatology	016 33 78 70 (working days from 8.00 to 17.00)
Eye illness	016 33 23 70 (working days from 8.00 to 17.00)
Dentistry	016 33 24 80 (working days from 8.30 to 17.00)
Gynaecology	016 34 47 50 (working days from 8.00 to 12.00 and from 13.00 to 17.00)

INTERESTING WEBSITES

About passing on life
www.overlevendoorgeven.be

Eurotransplant
www.eurotransplant.org

Vlaams Instituut Gezond Leven
www.gezondleven.be

Flemish expertise centre for Alcohol and other Drugs:
www.vad.be/themas/alcohol

Tabakstop
www.tabakstop.be

Tobaccologist near you
www.erkendetabakologen.be and www.vlaanderenstoptmetroken.be

NOTES

NOTES

Ontwerp en realisatie
This text was written by the cardiology/heart transplant department in cooperation with the communications department.

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Please send comments or suggestions relating to this brochure to communicatie@uzleuven.be.

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