



Waiting for a new heart

Information for patients and their families

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Your cardiologist has informed you that a heart transplant is a possible way forward to treat your heart disease. To investigate whether this would indeed offer a solution in your particular case you will be admitted to the Universitair Ziekenhuis Leuven (UZ Leuven – Leuven University Hospital), Campus Gasthuisberg. This brochure provides you and your family with additional information on the pre-transplant screening and examination process, the waiting time for a heart transplant, the immediate preparations for the operation, the progress of the operation and your stay in hospital following the operation. It also summarises the process of living with a new heart.

After the transplant you will receive a second brochure entitled 'Living with a new heart' which looks in more detail at the process of living with a new heart.

Not all information is relevant to everyone. The contents page of this brochure will consequently help you quickly find information relevant to you.

This information is in no way intended to replace personal contact with members of the heart transplant team. Should you have further queries, please do not hesitate to contact members of the heart transplant team, who will happily provide further explanation.

The heart transplant team and members of the
E 435 cardiology/heart transplant and
E 437 cardiac surgery units.

WHY A HEART TRANSPLANT?

A heart transplant is considered for patients with advanced (end stage) heart failure, who would have a low life expectancy without a transplant. With end stage heart failure the heart function is seriously underperforming and medication, heart surgery and other treatments no longer offer a solution.

For further information on heart failure please refer to the 'Living with heart failure' information brochure, which can be obtained from one of the E 435 or E 437 team members.

During a heart transplant the diseased heart is replaced by a healthy donor heart. The term 'donor' is derived from Latin and refers to the person donating the heart. A donor heart originates from a healthy person with serious and irreversible brain damage, which has resulted in brain death (e.g. as a result of an accident or cerebral haemorrhage).

HISTORY OF HEART TRANSPLANTS

The very first heart transplant was carried out on Louis Washkansky in 1967 in the Groote Schuur Hospital in Cape Town, South Africa. The operation was performed by Dr. Christiaan Barnard. Washkansky died from a lung infection 18 days after the operation. The infection was caused by the fact that immunosuppressants had seriously weakened Washkansky's immune system. Immunosuppressants are

drugs that prevent the recipient's immune system from rejecting the donor organ, which is foreign to the body. They act by suppressing the immune system.

One month later the same team carried out a second heart transplant on a 50 year old dentist, Philip Blaiberg. Blaiberg lived for 19 months after the operation but eventually died as a result of chronic rejection of the donor heart.

Fortunately nowadays the prognosis following a transplant is much better. The medical establishment developed a much better understanding of the rejection mechanism resulting in greatly improved immunosuppressant medication. The discovery of cyclosporin in 1972 was highly significant. When it was marketed in the early eighties the chances of survival for transplant patients improved considerably and transplants really became established.

In UZ Leuven the first heart transplant took place in 1987. Since then approximately 20 to 25 heart transplants are carried out each year, which means that UZ Leuven is one of the larger European transplant centres.

There are seven heart transplant centres in Belgium:

- X Universitaire Ziekenhuizen Leuven (UZ Leuven), Leuven
- X Universitaire Ziekenhuizen Antwerpen (UZA), Antwerp
- X Universitaire Ziekenhuizen Gent (UZ Gent), Ghent
- X Onze-Lieve-Vrouweziekenhuis Aalst (OLV Aalst), Aalst
- X Hôpital Erasme Brussel (ULB), Brussels
- X Cliniques Universitaires Saint-Luc (UCL), Brussels
- X Centre Hospitalier Universitaire (CHU), Liège

SCREENING FOR A HEART TRANSPLANT

Before being placed on the waiting list for a donor heart you will have to undergo extensive screening. This pre-transplant screening process consists of various medical examinations, consultations with different specialists and meetings with the heart transplant team. You will be **admitted to hospital** for the screening to ensure that a large number of examinations can be carried out in the shortest possible timeframe. Where possible the necessary examinations will be planned to allow you to go home within about ten days. Another advantage of hospital admittance is that you will get to know the department and staff much better.

OBJECTIVE OF PRE-TRANSPLANT SCREENING

Screening is used to:

- ✓ check the seriousness of your heart failure and thus make a prognosis as accurately as possible
- ✓ rule out other treatment options
- ✓ verify that in your specific situation a heart transplant would definitely offer a solution, by excluding contraindications (see below)
- ✓ trace and where possible treat problems prior to the transplant (e.g. treatment of infection or a stomach ulcer)

PRE-TRANSPLANT EXAMINATIONS

Heart transplant screening in UZ Leuven usually includes the following examinations:

Blood samples

- Blood group verification

There are several blood groups (A, B, AB and O). The donor and recipient blood groups don't necessarily have to be identical, but they have to be **compatible**. When a transplant is performed between a donor and recipient with incompatible blood groups there is a serious risk of rejection following the transplant.

Blood group	A	B	AB	O
Can receive from	A and O	B and O	A, B, AB and O	O
Can donate to	A and AB	B and AB	AB	A, B, AB and O

A donor with blood group O is referred to as a universal donor. He/she can donate an organ to a patient with blood group A, B, AB or O. If a patient with blood group O requires an organ he/she can only receive an organ from a donor with blood group O.

A donor with blood group AB is referred to as a universal recipient. He/she can only donate an organ to a patient with blood group AB. When a patient with blood group AB requires an organ he/she can receive from donors with blood groups A, B, AB and O.

A donor with blood group A can donate an organ to a recipient with blood group A or AB. If he/she requires an organ they can receive from a donor with blood group A or O.

A donor with blood group B can donate an organ to a recipient with blood group B or AB. If he/she requires an organ they can receive from a donor with blood group B or O.

- **Extensive HLA tissue typing**

'Human Leucocyte Antigens' (HLA) or tissue proteins are proteins that are present in most of our body cells. Each individual has a unique combination of tissue proteins. As a result the natural immune system can differentiate between the body's own and foreign substances. Viruses and bacteria are part of the latter group, i.e. foreign invaders. A transplanted organ may also be considered a foreign body and consequently rejected. **The higher the level of tissue type compatibility between donor and recipient, the lower the risk of rejection.**

Some people have already developed antibodies to specific tissue proteins before the transplant. These antibodies are created following contact with foreign substances, for example, following a blood transfusion, pregnancy or an earlier transplant. If a patient has already developed antibodies it may be more difficult to find a suitable donor heart.

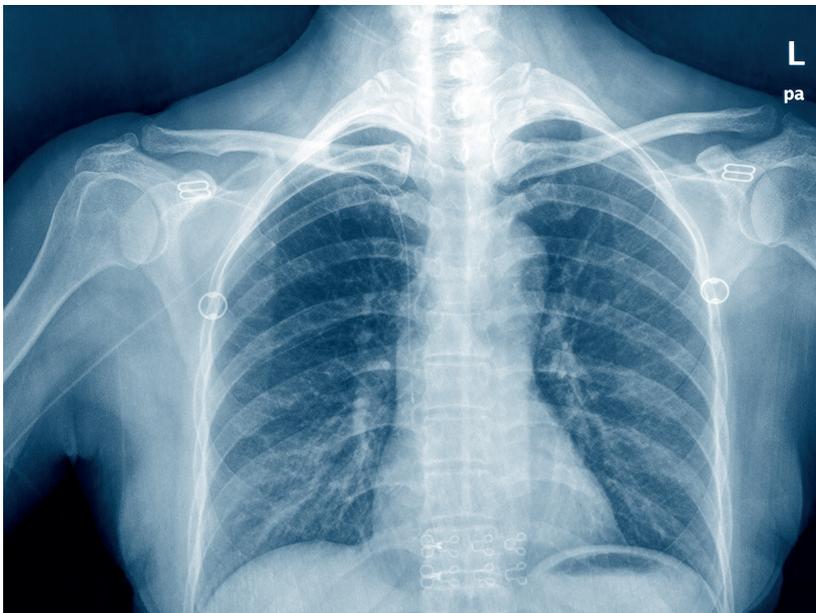
- **Evaluation of infection risk following a transplant**

Using a blood sample as well as a culture developed from phlegm, faeces or urine, the presence of bacteria and viruses is investigated (cytomegalovirus, Epstein-Barr virus, HIV, hepatitis A, B and C). This makes it possible to trace and if necessary treat certain

chronic infections in good time. After all, patients will be given immunosuppressant drugs following the transplant making them more prone to infection.

Chest and blood vessel X-ray

- This involves radiography during which images are produced of the chest cavity, heart, lungs and main blood vessels using X-rays. The examination consists of several X-rays during which you will have to stand, sit or lie down in different positions. It is important to remember that you must not move at all during the X-ray. The radiology nurse or technician will provide appropriate instructions.
- You will be allowed to eat and drink prior to the examination.
- On average the examination will take five to ten minutes.
- Radiography is usually pain free. If you feel discomfort when taking up the various positions please tell the nurse or technician.



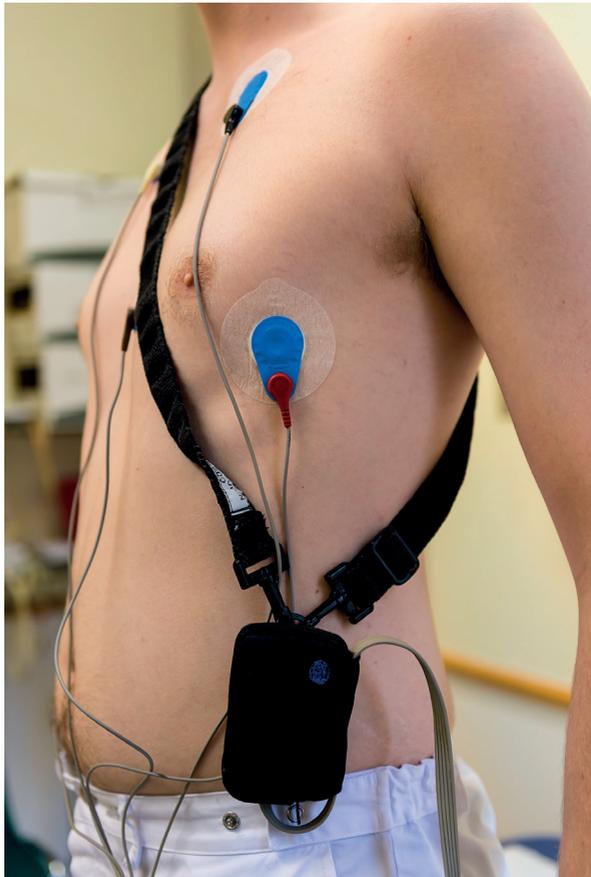


Elektrocardiogram (ECG)

- Any muscle activity, including contraction of the heart muscle, is associated with electrical activity. An electrocardiogram or ECG measures this electrical activity. Electricity is conducted by the body and skin and can, therefore, be measured on the surface of the body.
- Prior to the test six electrodes will be attached to your chest and four to your arms and legs. Electrical heart activity can be measured by comparing the signals of two electrodes. The electrical activity is recorded by a specific apparatus.
- In a healthy person the heart function, i.e. the contraction and release of the heart muscle, is based on a specific pattern. Doctors can detect disruptions in this pattern from an ECG. An ECG also provides information on blood flow, oxygen release and potential damage to the heart, as well as the heart rhythm and frequency.
- You will be allowed to eat and drink as usual prior to the examination.
- On average the examination will take five minutes.
- An ECG is pain free.

Holter monitoring

- Some types of cardiac arrhythmia occur infrequently. This type of arrhythmia can be detected using Holter monitoring or registration. Five electrodes are attached to the chest to register the heart function for 24 hours or longer. The device is carried in a small pouch throughout this period.
- You will be allowed to eat and drink prior to the examination.
- Holter attachment takes on average 15 minutes.
- It is pain free.



24 hour blood pressure measurement

- 24 hour blood pressure measurement is used to gain a better insight into your blood pressure profile. A recorder registers your blood pressure at programmable intervals for a period of 24 hours.
- You will be allowed to eat and drink prior to the examination.
- Attaching the blood pressure meter takes on average 10 minutes.
- It is pain free.

Transthoracic echocardiogram (TTE)

- This test measures, amongst others, the heart function using ultrasound (i.e. inaudible) waves. An echocardiogram provides dif-



ferent information from, and supplements, an electrocardiogram or ECG.

- A small probe (a kind of microphone) is attached to the chest above the heart using gel. You will be asked to strip to the waist and lie on your left hand side. Images of the heart are created because sound waves are reflected by the different parts of the heart. This will give your physician detailed information on the structure and functioning of the heart muscle, heart valves and major blood vessels around the heart.
- You will be allowed to eat and drink prior to the examination.
- On average the examination will take 20 minutes.
- An echocardiogram is pain free.

Left cardiac catheterisation and coronarography

- This is an X-ray examination during which the coronary arteries (which provide the heart with oxygen) are made visible using a contrast fluid. The aim of coronarography is to check whether the coronary arteries have narrowed (atherosclerosis) or are blocked. Atherosclerosis or blockages may prevent oxygen rich blood from flowing to the heart. The heart muscle's pumping action and functioning of the mitral and aorta valves are also made visible during this examination.
- You will be allowed to eat and drink as usual prior to the examination. Your groin or wrist will be shaved in preparation for the examination. You will also be fitted with a drip (or intravenous access) in your arm. You will only be allowed to wear a hospital gown during the examination. All jewellery, piercings and watches



must be removed. To ensure that you are comfortable during and after the examination it is advisable to visit the toilet on the nursing ward before leaving as it will no longer be possible during the examination.

- The examination is conducted via an artery in the groin or wrist. Following the administration of a local anaesthetic a sheath will be inserted in the artery to facilitate access to the blood vessel. Using a catheter (long thin tube), which is inserted up to the start of the coronary arteries, the physician will inject a contrast fluid into the coronary arteries. This will make them visible and narrowing or blockages will be highlighted.
- A coronarography on average takes 45 minutes.
- If you feel pain or discomfort during the procedure you must inform the physician or nurse.
- After a coronarography in the groin you will have to stay in bed for six hours and will not be allowed to move your legs.

Right heart catheterisation – pressure measurement

- This examination measures the pressure in the right side of the heart and pulmonary artery, which usually also includes a cardiac output measurement (i.e. the number of litres of blood your heart circulates per minute).
- With a right heart catheterisation the catheter is not inserted via an artery but via a vein in the neck or groin. Following the administration of a local anaesthetic a sheath will be inserted in the vein to facilitate access to the blood vessel. A flexible tube or catheter is inserted via the sheath through the vein up to the pulmonary artery. Blood pressure is registered via the catheter.
- You will be allowed to eat and drink prior to the examination.
- On average the examination will take 30 to 45 minutes.
- If you feel pain or discomfort during the examination you must inform the physician or nurse.

Pulmonary function test

- This test checks the functioning of the lungs. A pulmonary function test may consist of several examinations, one of which is a spirometry test. A spirometer measures the maximum volume of air inspired or expired by the lungs. This provides information on lung volumes. The measurement also checks how much air you can expire in one second, which provides information on potential narrowing of the airways.

- The examination is carried out whilst you are in a sitting position. You will be provided with a mouthpiece connected to the apparatus that takes the measurement. The person conducting the pulmonary function test will explain what you should do.
- You will be allowed to eat and drink prior to the examination.
- A pulmonary function test is pain free.



Abdominal ultrasound

- An ultrasound test provides images obtained via sound waves (not X-rays). The test is carried out to highlight the blood vessels and organs in the abdomen (liver, spleen, gallbladder, pancreas, kidneys, bladder, womb and ovaries) and to rule out, for example, gallstones or kidney stones.

- To do the test the radiologist will apply gel to your abdomen and move a small device across it. He will check the monitor to see whether there are any abnormalities.
- You must **not eat or drink** from 4 hours prior to the test to ensure that the gallbladder is clearly visible.
- The examination will take approximately 10 to 20 minutes.
- An abdomen ultrasound test is pain free.

Consultation with dentist to check teeth and gums for infection and/or poor dentures.

Consultation with ENT physician to rule out chronic infections in the ears, nose and/or throat and other problems in that area.

Eye examination, to establish (amongst other things) whether blood pressure has been raised for a long time.

For women a **gynaecological examination** and **mammography** will also be scheduled.

Important to remember

- ✗ The physician in charge of your treatment may decide that some tests are not necessary or that other tests not included in the list should be carried out. Amendments to this list of examinations on the basis of your specific case are the rule rather than the exception.
- ✗ You should also remember that one day may be busy involving a programme with many tests and another day quiet with far fewer examinations.
- ✗ Some tests may be repeated because your medical condition changes (e.g. after having been on the waiting list for six months).

HEART TRANSPLANT CONTRAINDICATIONS

A heart transplant still requires major surgery. It is important, therefore, that all other organs (e.g. kidneys and lungs) are functioning properly. Except for your heart, you should actually be in a healthy condition. It is also important that you should be motivated about the surgery and have no problems with taking medication at regular intervals. There may consequently be both medical and psychosocial reasons why a heart transplant is not the right solution for you. These are referred to as contraindications.

Potential contraindications include:

- ✓ pulmonary hypertension
- ✓ malignant disorders (cancer) or recent treatment thereof
- ✓ irreversible poor functioning of the liver, kidneys or lungs
- ✓ active infection
- ✓ too old
- ✓ advanced diabetes
- ✓ serious coronary artery problems
- ✓ obesity
- ✓ poor overall health
- ✓ casual approach to the use of medication
- ✓ active addiction, e.g. to smoking or alcohol.

If you smoke you are expected to stop smoking permanently. You will have to have refrained from smoking for at least six months before you are admitted to the waiting list. Some people can stop smoking without assistance, others require support from a smoking cessation specialist. You can talk to, and ask for support from, the psychologist/smoking cessation specialist during the screening period. They can also be contacted after your admission (see Useful telephone numbers and websites).

PEOPLE YOU WILL ENCOUNTER DURING THE SCREENING PROCESS

Cardiologists

A cardiologist is a heart specialist who studies the history of your heart disease and possible other disorders, adapts your medication and decides which examinations are required during the screening process.

Nursing staff



Day to day activities will be coordinated by the nursing staff during your stay in hospital. They will inform you about various examinations and together with the logistics team will ensure that you attend them on time. You can also contact them at any time with queries about life after a heart transplant. If you have questions about the heart

pump you have been fitted with you can contact the nurse specialised in heart pumps at any time.

Dietician

The dietician will evaluate your dietary requirements and discuss your eating habits. If necessary you will be given dietary advice.

X Patients without a heart pump

A low salt diet is recommended in the event of serious heart failure.

The dietician may give you a number of tips on how to limit your salt intake. For example, you can prepare hot meals without adding salt and choose low salt sandwich fillers. For further information please refer to the “*Living with heart failure*” information brochure, which can be obtained from one of the E 435 or E 437 team members.

X Patients with a heart pump

If you have been fitted with a heart pump a healthy diet is imperative. Sometimes a Low Saturated Fat diet may be temporarily suspended to strengthen your system. After the transplant it is again important to eat a minimum amount of saturated fat. The dietician will provide further information in this respect after the transplant.

Physiotherapist

The physiotherapist will explain the correct breathing technique to use also after the transplant. Initially breathing exercises will be required to train your chest and abdominal muscles to breathe better and more deeply. You will also learn to cough more effectively and less painfully to release phlegm from the lungs after the operation. If your condition allows it light exercise can maintain or improve your basic condition and muscle tone. This can be continued at home, if necessary together with a physiotherapist. This improved physical condition will also help you relax whilst you are on the waiting list. Sometimes specific relaxation exercises may be recommended.

Social worker

A heart transplant also puts great social pressure on the patient and those around him/her. That's why the social worker will arrange a meeting to discuss your family situation, your perception of the disease, your social interaction and whether or not you are insured. This will create an overview of you as a person, your perception of a heart transplant, your home situation and the social network you can rely on. After all, it is important that you have sufficient people around you who can provide support.

Psychologist

Most patients consider a heart transplant a second chance, an opportunity they want to seize with both hands, although they may be anxious or insecure about the waiting time, the operation, practical matters etc. All this can be discussed during the pre-transplant meeting with the psychologist

During this meeting the psychologist will assess whether you will adapt easily and will comfortably meet the requirements associated with life after a transplant. For example, you will have to take medication daily at regular intervals following the transplant. In the event of problems you will have to react appropriately and contact the transplant centre. You will also have to visit the hospital regularly for check-ups. It is important that you should familiarise yourself with these matters beforehand.

The psychologist has to verify whether you'll be able to adapt to the new circumstances before and after the transplant. We try to gain an insight into the way in which you managed earlier problems or diseases and gauge the balance between burden and ability to cope

in day to day situations. We look at your character (are you able to ask for help or do you prefer to solve things on your own) and your social functioning (your steadiness in your working life and equilibrium in your relationships with others).

Other aspects we look at include your perception of the disease and possible pre-history of psychological problems (anxiety, depression, sleeping problems, worrying, etc.).

If necessary psychological support may be suggested either from the departmental psychologist or from an external therapist of your choice.

Psychosocial problems are rarely of such significance or unsolvable to the extent that they would prevent a heart transplant from being a solution for your heart disease.

Pastor

Confrontation with a possible transplant has consequences in different areas such as relationships, emotional wellbeing, everyday life, exercise and social functioning. There may also be various questions relating to faith and spirituality. Waiting, unanswered questions about the future for yourself and your next of kin, loneliness, silence,... but also: looking forward, intense awareness of day to day events, immense expectations, strong faith in recovery. These experiences are not always easy to share with those close to you. The pastor, who is accessible day and night, can provide a listening ear for you and your next of kin.

DECISION TO GO AHEAD WITH THE TRANSPLANT

Once the screening process has been completed, the cardiologist and other members of the transplant team will know whether a transplant is/is not the right solution for you.

If disorders or abnormalities have been revealed that make the risks associated with a transplant unacceptably high or clearly reduce the chances of a successful transplant, we will have to favour a different approach. This may consist of an adjustment to your medication or the insertion of a three chamber pacemaker. If you have been fitted with a heart pump you will obviously retain it.

The screening results and further practical planning are discussed in detail during a final meeting at the end of your hospital admission or during a subsequent consultation. Because a lot of highly significant information is provided during this meeting it is recommended that a member of your family or a friend should attend.

TIME SPENT ON THE WAITING LIST

REGISTRATION AT EUROTRANSPLANT



If you and the transplant team agree that a heart transplant is the best way forward for you, the transplant team cardiologist will register you with Eurotransplant. Eurotransplant is an international organisation appointed by the Belgian government that helps convey suitable organs to the right people. Transplant centres in eight countries (Bel-

gium, the Netherlands, Luxembourg, Germany, Slovenia, Croatia and Hungary) are members of the organisation.

WAITING TIME

Once you are on the Eurotransplant waiting list you will face a difficult period of just waiting because for various reasons it is impossible to predict how long this will be. It is usually several months. When a donor heart becomes available Eurotransplant is notified and allocates the donor heart to a specific patient on the waiting list.

Factors affecting this decision include:

- ✓ the donor heart must have a compatible blood group
- ✓ the donor heart must be of a suitable size for the patient in question (not too small, not too large)
- ✓ it can be more difficult to find a suitable heart for patients who have developed antibodies, also referred to as 'immunised patients'
- ✓ if a donor heart is suitable for several patients on the waiting list, it is allocated to the patient who has been on the list the longest
- ✓ medical urgency: if your general condition is deteriorating significantly you may, in very exceptional cases, be put on an emergency waiting list, the so-called High Urgency list. Any patient allocated an HU code will be subject to an

audit, i.e. three Eurotransplant physicians will have to approve the transplant indication and agree to give priority over the waiting list.

ACCESSIBILITY

Once you are on the waiting list you and/or your family must be accessible at all times. It is impossible to predict when the call will come from the hospital telling you that a new heart is available and you are expected at the hospital. The transplant has to be completed quickly because the time between the donor heart being removed and transplanted has to be minimal. The social worker will, therefore, discuss practical arrangements such as transport to the hospital, contacts and telephone numbers with you. It is recommended that you use a mobile phone to increase your freedom of movement.

Make alternative transport arrangements now to rely on in the event of a call:

- own car, car of family member, friend, neighbour, etc.
- taxi service arranged by the health insurance fund
- ambulance via the health insurance fund.

Discuss this with the social worker.

If the telephone numbers you have provided us with change, please inform the heart transplant secretariat immediately (see Useful telephone numbers and websites section).

PRE-TRANSPLANT MONITORING

During the waiting time you will be expected, whenever possible, to regularly visit the hospital to enable us to monitor your heart and general health as they have to remain in the best possible condition in anticipation of the operation. Every two months you will have a consultation with the cardiologists involved in the heart transplant programme. At least every six months (if the waiting time exceeds six months) you will be re-admitted for a reassessment of your heart failure.

If your heart has weakened significantly a heart pump may be fitted in anticipation of a heart transplant. The pump helps the weakened heart to circulate blood around the body to ensure that all organs receive sufficient oxygenated blood. In such cases the blood flows from the heart, through the pump, and via the aorta to the body. Depending upon the type of pump, it may be fitted in the chest cavity or outside the body. A heart pump is used to support the heart and help it cope in anticipation of the transplant.

PSYCHOSOCIAL ASPECTS

As a rule waiting for a donor heart is a difficult period. The registration with Eurotransplant is not just the conclusion of a long period of tension and insecurity, but also the start of a new but again stressful period of potential tension and insecurity. Your family and others around you will be focused on the imminent transplant. Any phone call can result in you being operated on in Leuven just a few hours later. And new anxieties will surface if the phone call doesn't come and your physical condition deteriorates. Questions such as "Will a donor heart be found for me in time?" or "Am I actually on the

waiting list?” or “They haven’t forgotten me in Leuven have they?” or even “Has the phone broken down?” will be at the forefront for many patients. Endless waiting and insecurity can be difficult to cope with during this stage.

During the time spent on the waiting list you can also contact the UZ Leuven heart transplant team (cardiologists, nursing staff, psychologist, social worker) should you have any queries or problems. They will help you bridge the waiting time as best as possible. Being able to talk about anxieties often alleviates them. Waiting for a transplant can also generate psychological stress for the family and those close to you. They sometimes feel isolated because all the attention and care is lavished on the patient and not everyone is able to cope with this. They can also contact the heart transplant team to discuss any problems.

Meeting others in the same situation can also help reduce anxiety. If you would like to talk to someone who has already undergone a transplant the psychologist or social worker will be able to arrange this for you.

HEART TRANSPLANT CALL

HOW DOES THE CALL-UP PROCESS WORK?

When a heart has been found for you Eurotransplant will notify the transplant coordinator at UZ Leuven. The latter will discuss the organ offer with the surgeon and cardiologist. If they accept the offer the cardiologist will call you and ask you to come to the UZ Leuven Gasthuisberg campus (unless you have already been admitted to hospital). In that case come to the hospital as quickly as possible, but don't rush.

Once you have received the phone call you must not eat or drink anything.



Enter the hospital via the emergency department (as requested in the telephone call). Tell the staff that you have been called in for a heart transplant. The radiology section at A&E will initially produce an X-ray of the heart and lungs (chest and blood vessel X-ray). You will then be taken to E 435, the heart transplant unit (purple arrow, third floor), to be prepared for the operation.

WHAT SHOULD YOU BRING TO THE HOSPITAL?

- X identity card
- X where applicable blood group card
- X if you have been fitted with a heart pump, remember to bring the batteries and controller.

Because you don't know beforehand when you will be called up for the transplant, it is advisable to keep everything with you at all times ready to bring to the hospital when called.

You don't need to bring personal effects. You will be provided with hospital gowns before and for a few days after the operation. When you leave the intensive care unit and return to the E 435 cardiology/heart transplant unit a few days after the operation, your family will be able to bring clothing and toiletries for you. (also refer to Stay at E 435 cardiology and heart transplant unit).

PREPARING FOR THE OPERATION

A nurse will welcome you to the E 435 cardiology/heart transplant unit and prepare you for the operation. If you are on another ward at the time of the call the nurse on the other ward will prepare you in consultation with the nursing staff on E 435.

The preparations will have to be done quickly because a donor heart can only survive four hours without blood supply. Some patients are phased by this rapid approach so be prepared for it.

HOW DOES THE PREPARATION PROCESS WORK?

- ✓ You will be given a wrist band with your name and date of birth.
You must wear this at all times in the hospital for identification purposes.
- ✓ A nurse will measure your blood pressure, heart rhythm, temperature and weight.
- ✓ A nurse will also take a blood sample and ask you to urinate in a small jar so that your urine can be checked for infection.
- ✓ A nurse will produce an electrocardiogram (ECG) on the ward.
- ✓ You will be given an enema, whereby liquid will be injected into the intestine via the anus to empty your bowels.

This is necessary because the general anaesthetic during an operation stops the bowel working. If the bowel is full before the operation and doesn't work for a couple of days, faecal matter will be retained and harden. An enema before the operation avoids subsequent painful and difficult to manage constipation.

- ✓ Your skin will be treated to limit the risk of infection and allow the wound to heal better after the operation. Your arms, chest and upper legs will be shaved with an electric trimmer. You will also be asked to shower with disinfectant soap. The nurse will provide this and explain how to use it.
- ✓ Disinfectant ointment will be inserted in the nose and you will have to rinse your mouth with a liquid disinfectant, which you will have to swallow. Just before leaving for the operating theatre you will be asked to drink this disinfectant for a second time.
- ✓ You will be asked to put on a hospital gown.
- ✓ The cardiologist will now check your physical condition in great detail.

Once the preparations are complete you can wait with your family until it is time to proceed to the operating room.



Remember: having inspected the donor heart the surgeon may still reject it because it is not of a desirable quality (despite preliminary tests). This will mean that the operation cannot take place and you will have to go home again, which will obviously be a major disappointment for you having waiting anxiously for the transplant. You and your family will probably need time to come to terms with this. It is important, therefore, to always take into account that the operation can still be cancelled – even at the last minute!

TO THE OPERATING THEATRE

Your family will be able to accompany you as far as the surgical wing from where you are escorted to the operating theatre by the nursing staff. Your family can then wait there or return to E 435. They'll be able to wait for news in the day room on the ward or go back home if they prefer to do so. Once the operation is finished your family will be informed about its progress and immediate further plans (admission to the intensive care unit, visiting arrangements, etc.)

THE OPERATION

In the operating theatre you will meet the anaesthetist who will administer the general anaesthetic. Then your breathing will be regulated by a machine. To facilitate this a tube is inserted via the mouth into the trachea during anaesthesia. Once the drips and the gastric tube have been inserted the operation can commence.

During the operation the blood is circulated through the body via a heart/lung machine. Your own heart will be removed in its entirety and replaced by a donor heart. The heart surgeon will connect the new heart to the major arteries and then disconnect the heart/lung machine to restore circulation. On average the operation takes 4 to 6 hours. Obviously the time may vary on an individual basis dependent upon the patient's condition and seriousness of the heart disease.

If you were previously fitted with a pacemaker, defibrillator or heart pump, they will be removed during the operation.

After the operation a few tubes/drains will remain in place to discharge wound secretions, gastric secretions and urine and to administer liquids and medication. They will gradually be removed during the following few days.



YOUR STAY IN THE INTENSIVE CARE UNIT

Also refer to Intensive care information brochure

Following the operation you will initially be taken to an intensive care unit where specialised doctors and nurses will monitor you day and night.

They will use monitoring equipment that emits an alarm signal with the slightest change in your condition. That is why you will be connected to various apparatus that monitor significant functions such as blood pressure and heartbeat.



APPARATUS, HOSES AND TUBES

X Breathing

- After surgery rest is very important to allow your body and particularly your heart to heal as best as possible. That is why your breathing will temporarily be taken over by a ventilator. To this end the anaesthetist will insert a ventilator tube into the trachea via the mouth, whilst you are under general anaesthetic in the operating theatre.
- The tube will be attached to your cheek and linked to the ventilator. You will not be able to speak, eat or drink whilst the tube is inserted. Every now and then saliva will have to be

sucked from your trachea as well. This is slightly irritating and may make you cough. Some patients are kept in a deep sleep during this stage of the treatment.

- The length of this ventilator treatment depends upon your general physical condition before the operation and your body's reaction to the operation. It varies from a few hours to several days.
 - You will be allowed to breathe independently again as soon as you are able to. It is important to breathe deeply and steadily. Once breathing independently via the breathing tube has stabilised the tube will be removed and you'll be able to talk again. You may be slightly hoarse at first.
 - Once the breathing tube has been removed you will be given oxygen via a mask or nasal cannula. Breathing exercises and initial movements in bed will then start under the supervision of a physiotherapist.
- X A plastic tube will also be inserted into a jugular vein during the operation, via which you will receive liquid food and drink during the initial period after the operation. Any necessary medication will also be administered this way, i.e. anti-rejection, cardiac support and urination medication, painkillers, antibiotics, vitamins, etc.
- X One to three hollow plastic tubes will also emanate from between the ribs (chest drains) as there is always some loss of blood and wound secretion afterwards from the site of the heart operation. This needs to be discharged to prevent it from accumulating

in the chest cavity. Wound secretion will cease a few days after the operation and the tubes will then be removed.

- X A urinary catheter will also be inserted in your bladder during the operation to monitor the amount of urination, which provides information on kidney function.

ROOM

We cannot tell you beforehand which room you'll be in. It may be a single room or a room shared with another patient. In any case all visitors will have to observe a strict procedure (wear a gown, mask and gloves) to minimise contact with infectious agents.

VISITOR INFORMATION

Visiting times

Visiting will be limited because of the nature of the special care administered within intensive care and to ensure that you get enough rest.

Next of kin will be allowed to visit three times a day for 15 minutes with a maximum of 3 family members at any one time. Normally children below 12 will not be allowed to visit.

Daily visiting times are as follows:

14.00 to 14.15 hrs
19.00 to 19.15 hrs
20.30 to 20.45 hrs

Notwithstanding the limited visiting times, the number provided by the nursing staff can be called day and night for information.

Accessibility

To proceed to the intensive care unit visitors should follow the pink arrow in the hospital's reception hall (first floor) and report to reception at the entrance to the intensive care unit.

YOUR STAY AT E 435 CARDIOLOGY/ HEART UNIT

From the intensive care unit you will transfer to E 435, the heart transplant unit, for further recovery. Here the monitoring procedure will be less intensive. Contact with nursing staff will be less frequent. You should not worry unduly as you will still be frequently checked and your heart rhythm will continue to be monitored via a central monitor in the nursing station to which you are connected (telemetry). If necessary you can call the nurses via the bell system at any time.

In most cases patients have recovered sufficiently to go home three weeks after the operation.

NURSING IN AN ISOLATION ROOM

You will be taking immunosuppressant medication to prevent rejection of the donor heart, which will make you more **susceptible to infection**. This risk of infection is highest at the beginning, which is why you will initially be in an isolation room on E 435 to provide additional protection. This room will be the same as any other room but all visitors will have to comply with specific **isolation measures**:

- hands must be disinfected using hand alcohol;
- everyone must wear a mask, a green gown and gloves;
- items brought into the room must be disinfected before entering;
- the door to the room must be kept closed as much as possible;
- windows will remain closed; air cooling will be used during the summer.



Because of the risk of infection nursing staff will provide you with a new digital thermometer to measure your temperature during your stay in hospital. It will be for your own personal use, will be included on the hospital invoice and you'll be able to take it home with you.

Throughout the remainder of your hospital stay physical activities will gradually be taken up again under the supervision of a physiotherapist. A psychologist will be available upon request to help you cope with the changes. The social worker can provide support concerning social benefits, home help, transport costs etc.

VISITOR INFORMATION

Also refer to E 435 Cardiology and heart transplant information brochure

Visiting times

Daily visiting times are from 14.00 to 20.00 hrs.

Your family will also be able to call you direct. The nursing staff will provide your room telephone number.



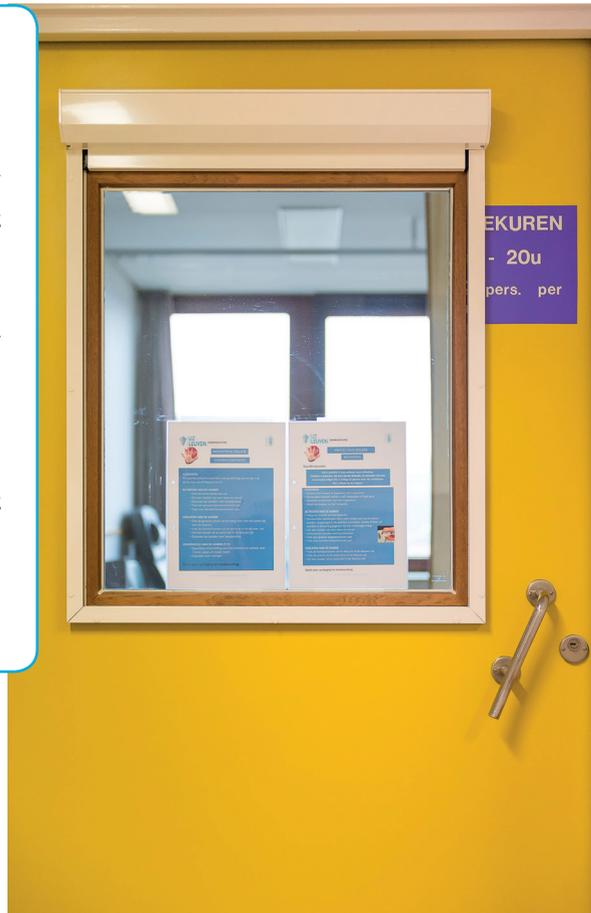
Accessibility

To proceed 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.

Isolation rules

Visitors will be escorted to the room by a nurse. They will also have to comply with isolation measures before entering the room (see page 39). Isolation instructions will be displayed on the door to the room. Nursing staff will assist your family during the first visit.

- Maximum two visitors in the room at any time.
- Visitors who have a cold or another infection must not enter the room.
- Children under 12 can only enter after approval from the ward physician.
- Flowers and plants cannot be taken into the room. Please tell your family and friends beforehand.



To be provided by the family

- ✓ linen (sleepwear, dressing gown and underwear): preferably to be washed at minimum 60°C. Once ironed the linen must be individually wrapped in sealed plastic bags. Ask your family to regularly take home dirty washing.
- ✓ slippers (new or washed), spectacles, and for men: an electric razor (no razor blades).
- ✓ tube of toothpaste, brush or comb, shower gel and shampoo.
- ✓ the hospital will provide towels and facecloths, they needn't be brought in.
- ✓ the room is equipped with radio, TV, telephone and internet connections, but you can arrange for your laptop and mobile phone to be brought in. However, they must be disinfected first.

Ask the nursing staff 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.
- ✓ flowers and plants cannot be taken into the room. Please tell your family and friends beforehand.
- ✓ consult the nursing staff about any other matter (prior disinfection may be required).

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

The social worker can arrange a visit to the transplant department beforehand upon request.

LIFE FOLLOWING A HEART TRANSPLANT

The following are brief details about life after a heart transplant. Further information will be provided after the transplant in the 'Living with a new heart' brochure.

LIFELONG PUNCTUAL TAKING OF MEDICATION

You will have to take medication for the rest of your life to prevent your body from rejecting the donor heart. This medication is referred to as **immunosuppressants**. Examples include Prograf[®], Advagraf[®], Neoral[®], Cellcept[®], Certican[®] or Medrol[®]. It has to be taken **punctually at set times**. However, this **immunosuppressive medication** will also lower your resistance to infectious agents, making you more susceptible to infection. This susceptibility to infection is at its highest soon after the transplant or after rejection treatment because the dose of prescribed medication is at its highest then.

Immunosuppressants can have side effects. Sensitivity to side effects varies (some people are not affected at all, others are) and the amount of medication can also play a part. Immunosuppressants can affect, for example, your blood pressure, cholesterol, blood sugar

and kidney function, which is why you may also be given various other drugs. After the transplant you will have to take several medications every day, often several times a day. Usually the medication schedule is gradually reduced during the initial months (fewer types and smaller quantities).

LIFELONG MONITORING

In addition to taking medication you will have to be monitored for the rest of your life to optimise your prognosis after the transplant. You will have to visit the hospital regularly particularly during the first 12 months after the operation. These are ambulant check-ups, i.e. you will not have to be admitted to hospital but will be able to go home the same day after the check-up examinations. After the first year you will have to attend every 3 months and have a blood sample taken every month (your GP can also do this). Once a year you will be admitted for 2 or 3 days for an annual check-up, involving a number of more in-depth examinations to confirm and maintain the successful functioning of the donor heart.

GOOD PHYSICAL HYGIENE

Good personal hygiene is crucial to prevent infection, which is why it is important to regularly take a shower and wash your hands, particularly after visiting the toilet and before eating. Oral hygiene is equally important. Clean your teeth every day and visit the dentist twice a year. Tattoos and piercings are not advisable because of the risk of infection.

GOOD SKINCARE

Suppressing the immune system long term with medication has an impact on your skin. The main side effect is an increased risk of skin cancer. It is essential, therefore, that you protect the skin when exposed to sunlight and avoid using sun beds. You can arrange annual visits to your GP or checks will be made during your annual check-up. Skin problems detected early can usually be treated effectively without too much discomfort.

HEALTHY DIET

During the first 6 months after the transplant you must comply with several hygiene, storage and preparation instructions. Foods must be stored and prepared to minimise infectious micro organisms (e.g. bacteria and fungi) in them. Foods containing pathogenic agents should also be avoided because of the risk of food poisoning. High risk foods include, for example, untreated nuts, raw meat, raw fish, raw poultry and raw eggs, preparations containing raw eggs, blue cheeses and unpasteurised cheeses (check the packaging). Your dietician will provide appropriate advice after the transplant. After 6 months it is important to maintain a healthy diet. The risk of being overweight, raised cholesterol, high blood pressure, osteoporosis and diabetes is slightly higher in people taking immunosuppressants. Try to keep your weight down with a healthy diet and sufficient exercise. Avoid eating too much fat or salt and maintain a low cholesterol diet. Eat plenty of fresh fruit and vegetables each day and include a wide range of starch and fibre. Also avoid foods with too much added sugar. Drink 1.5 litres of water each day and moderate your intake of alcohol and sugary drinks.

PHYSICAL EXERCISE AND SPORTS

Exercise is important to maintain your physical condition and reduce the risk of heart and cardiovascular disease. It will also prevent bone, muscle and tendon related complications as a result of taking various types of medication. Regular exercise also has a positive impact on cholesterol values, weight and stress.

During the initial weeks after your discharge from hospital a home physiotherapist can help you continue your exercise regimen. Avoid lifting heavy weights for the first 6 weeks after the operation in order not to inhibit the healing of the wound and sternum. Outdoor cycling is also not recommended during the initial 8 weeks because of the risk of impact and falling. You can take a walk, cycle on a home trainer and carry out domestic tasks.

Once your body has repaired itself you will be able to participate in various activities and specific sports again. However, not all sports (e.g. weight lifting, combat and contact sports) and certain other activities (e.g. chopping wood) are equally 'heart friendly' in terms of risks, nature of the effort and muscle and joint load bearing capacity.

DRIVING

You will be able to drive again two months after the operation. If you are recovering according to plan your physician will provide a fitness certificate upon request.

RETURN TO WORK

Consult the transplant physician to discuss your return to work. Providing there are no medical objections you will be able to return to work, although sometimes the nature of the work will have to be adapted.

TRAVEL

It is not advisable to travel abroad during the first 12 months after the operation. The risk of problems (rejection, infection, etc.) is highest during the initial months, but even after that you will need regular check-ups. If you would like to plan a trip later on consult your transplant physician before making a decision about your travel destination, as some (exotic) destinations require special preventive measures (vaccinations), or in the worst cases should not be visited at all.

NON SMOKING

Smoking damages health and is bad for the heart, blood vessels and lungs. Being a transplant patient and taking immunosuppressants you are even more prone to heart and cardiovascular disorders and infections. Transplant patients are consequently expected not to smoke at all. If you feel you need support to stop smoking permanently you can contact the psychologist/smoking cessation specialist of the transplant unit at any time.

PETS

It is advisable to remove pets (cats, dogs, birds, hamsters, etc.) from your home during the first 12 months after the transplant because they often carry viruses. Definitely avoid getting a new pet. If you already have pets it is recommended that you get someone else to look after them. If no one is available to do this you must, as a minimum, wear gloves and maintain good hand hygiene.

SEXUAL ACTIVITY

Sexual activity after surgery is related to what the transplant has repaired. Physical causes of sexual problems before the transplant may have improved or disappeared altogether because you have regained your biological equilibrium and normal physical condition. Nevertheless, a return to a satisfactory sex life is not easy. Sexual problems following a transplant are usually of a psychological nature. Do not hesitate to contact the physician or psychologist at the transplant unit.

PREGNANCY

In principle women can become pregnant again after a heart transplant. However, pregnancy within the first two years of a transplant is definitely not recommended, due to, amongst other things, the fact that some essential medication may increase the risk of congenital abnormalities in the unborn child. Reliable contraception is consequently a must. For men taking immunosuppressants the risk of congenital abnormalities in their offspring is minimal. Also remember that survival following a heart transplant is uncertain with all the associated consequences for the child when growing up.

If you and your partner would like children discuss the issue with the transplant physician, who may be able to provide advice on the possibility and desirability of medication changes taking into account your individual medical history. If necessary, he may also refer you to a gynaecologist for intensive support.

Participation in a clinical study

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 cardiologist may propose participation in a clinical study. You are at liberty to decide whether or not to participate taking into account all the useful and relevant information about the clinical study provided by the cardiologist and study nurse. By participating you will help promote medical progress (for further information request the Participation in a clinical study information brochure).

FREQUENTLY ASKED QUESTIONS

WHAT IS EUROTRANSPLANT?

Eurotransplant is a non-profit organisation, based in Leiden (the Netherlands), which coordinates the allocation of donor organs to patients on the organ transplant waiting lists in a number of European countries. The Belgian government has decreed that all Belgian transplant centres must cooperate with Eurotransplant.

A central computer database in Leiden comprises a number of data on each candidate: blood group, HLA typing, antibodies, weight, height, age, waiting time duration, etc. When a donor organ becomes available the computer selects a patient on the basis of this objective data. Medical urgency and proportional distribution in accordance with the number of donors per country play a significant role in this process. Eurotransplant notifies the transplant centre where a patient is registered.

HOW DOES THE TRANSPLANT PROCEDURE WORK?

Once your cardiologist has accepted the donor offer and you have been asked to come to the hospital two surgical teams are activated: the operating team, which carries out the transplant, and the retrieval team, which collects the organ from the donor hospital. The organ may become available in a Belgian hospital, or in any other country such as Austria or Slovenia, in which case it will be transported by plane or helicopter.

Once the heart has been removed the clock starts ticking as the donor heart will only survive for 4 hours without blood supply. The operating team will prepare you for surgery in anticipation of the actual transplant. The retrieval team and transplant coordinator remain in constant touch to ensure that the operating team can start on time. The diseased organ will only be removed when the donor organ has safely reached the hospital.

DOES THE TRANSPLANT PATIENT FIND OUT THE IDENTITY OF THE DONOR?

The transplant patient will not receive any information about the donor's identity. This is a legal requirement. The donor's next of kin are not told who received the donor organ either. If they ask for information, they will be told how the transplant went and how the patient is progressing. Contacts run via the transplant coordinator. Where applicable, an anonymous letter of thanks from the transplant patient to the donor's next of kin will be transmitted via the same procedure. The letter will be read by a transplant coordinator before being forwarded to the next of kin.

WHAT HAPPENS TO MY HEART?

The diseased heart is sent to the anatomic pathology lab for analysis.

CAN I ACQUIRE CHARACTER TRAITS FROM THE DONOR?

The heart is often linked to traits such as character, soul and intelligence. When a heart is transplanted into another body it is sometimes wrongly assumed that these characteristics are also transplanted. An individual's character doesn't change following a donor heart transplant. However, the waiting time, the operation and subsequent recovery can lead to a change in your attitude to life and that of the people close to you.

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 nursing staff:

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Heart transplant specialist nurse:

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Heart pump specialist nurse:

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Day ward nursing staff:

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Study nursing staff:

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Social worker:

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Psychologist/smoking cessation specialist:

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Physiotherapists:

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Dieticians:

.....

Pastor:

.....

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 general

UZ Leuven campus Gasthuisberg

Herestraat 49

3000 Leuven

UZ Leuven switchboard: 016 33 22 11

www.uzleuven.be

Intensive care

Secretariat	016 34 50 68
Nursing desk E 513 ITE (A)	016 34 40 60 or 016 34 40 62
Nursing desk E 514 ITE (B)	016 34 40 70 or 016 34 40 72
Nursing desk E 509 ITE (C)	016 34 87 70

E 435 cardiology and heart transplant unit

→ In the event of queries or problems

Nursing desk E 435	016 34 43 50
Medical staff E 435	016 34 43 55
Heart transplant specialist nurse	016 34 11 06
Heart transplant day ward E 439	016 34 43 56 or 016 34 25 38
Social worker E 435	016 34 86 20
Psychologist/smoking cessation specialist E 435	016 34 19 89
Physiotherapist E 435	016 34 14 33
Pastor	016 34 86 20 or 016 34 67 61

→ To arrange or change appointments

Heart transplant secretariat 016 34 42 63 of 016 34 42 68

E437 cardiac surgery

Nursing desk E 437	016 34 43 70
Medical staff E 437	016 34 08 45
Heart pump specialist nurse	016 34 27 98

Interessante websites

Patiëntenvereniging HaTrActief (Patient Organisation)	www.hatractief.be
Eurotransplant	www.eurotransplant.org

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Design and implementation

This brochure was written by the cardiology/heart transplant, cardiac surgery and communications departments in conjunction with the patient organisation HaTrActief and patients on the waiting list for a heart transplant.

This brochure can also be accessed at www.uzleuven.be/brochure/700611.

Comments or suggestions concerning the brochure can be forwarded via communicatie@uzleuven.be.

Patients can also manage their appointments, invoices and personal data online via **mynexuz**. Visit www.mynexuz.be for further information.

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