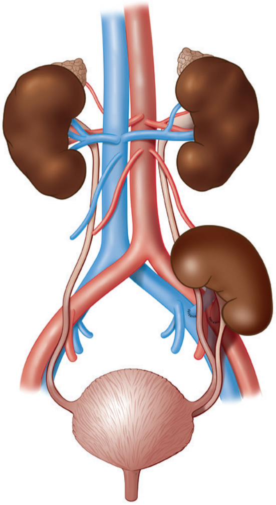


Waiting for a new kidney

Patient information

Introduction

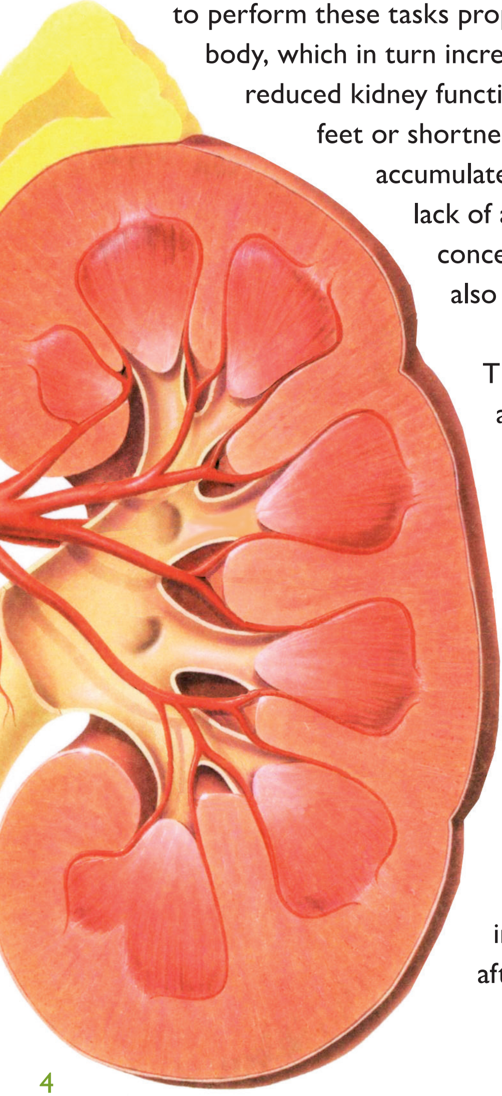
Your kidney specialist has told you that a transplant is one of the treatment options for your kidney condition. Understandably, you and your relatives will have a range of questions as a result.

This brochure contains practical information about the preparation for surgery, the surgery itself, your stay at the hospital, the costs and what to expect of life with a new kidney.

If you have any questions, please do not hesitate to raise them with your physician, nurse, social worker or transplant coordinator.

WHY DO YOU NEED A KIDNEY TRANSPLANT?

Regulating your body's water and salt balance and removing waste products are the main functions of your kidneys. When your kidneys no longer work as normal, they will no longer to be able to perform these tasks properly, resulting in excess fluid in your body, which in turn increases your blood pressure. With reduced kidney function, you may experience swollen feet or shortness of breath. As waste products accumulate, side effects such as vomiting, nausea, lack of appetite, itching, fatigue, difficulty concentrating and sometimes coma may also occur.



There are different types of treatment available to take over some of your kidney functions:

- Haemodialysis: here the blood is artificially purified by an artificial kidney.
- Peritoneal dialysis or abdominal irrigation: in this, blood is purified through the peritoneum.
- Kidney transplant: this involves implanting a kidney from a living or deceased donor, partially restoring kidney function. However, it is important to take lifelong medication after a transplant to prevent rejection.

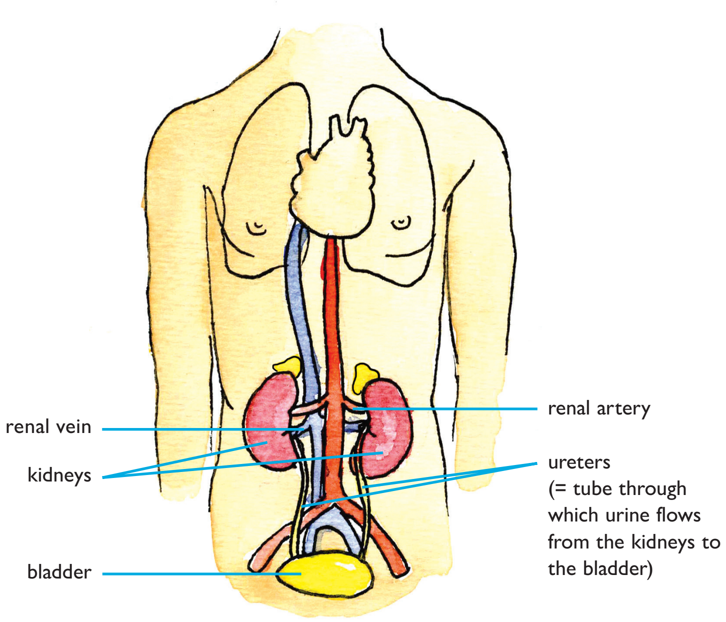
These days, the risks involved in a transplant are relatively limited and the long-term outcomes are very satisfactory. In University Hospitals Leuven patients, around two-thirds of transplanted kidneys continue to function after ten years. If a transplant kidney stops functioning properly, the patient may become eligible for another transplant or may restart dialysis.

A kidney transplant is a surgical procedure that involves certain risks, but it does give you the option to stop dialysis or avoid having to start dialysis.

It is important to understand that you do not need to undergo a kidney transplant if you would prefer not to. It is possible to survive without a kidney transplant. Dialysis will then be started and cannot be stopped. You should be aware that dialysis involves a greater risk of death, for example due to cardiovascular disease. Later on in this brochure, we will compare these risks with the risks involved in a transplant.

The timing of a kidney transplant depends on a number of factors. In particular, whether or not there is a living donor plays an important role. If there is a living donor candidate, the transplant can be planned as soon as the kidney function is greatly reduced. That way, there is no need to start dialysis. If there is no living donor available, it is often not possible to be transplanted before dialysis has to be started and it may be a longer wait for a deceased donor kidney.

Most people who have undergone a kidney transplant find that their quality of life has improved afterwards. In addition, the disadvantages, inconveniences and complications of dialysis can often be avoided.



PREPARATORY TESTS

Your eligibility for a kidney transplant depends on several factors, which are assessed during pre-transplant tests. The purpose of these tests is to detect (and treat, if possible) any problems prior to your transplant.

These tests can usually be performed at your own dialysis centre. The results will be discussed with the nephrologists, the transplant surgeons, the transplant coordinators, the transplant consultant nurse and the social worker during a consultation at University Hospitals Leuven. Some patients may need to be admitted to the hospital to perform these tests.

PRE-TRANSPLANT TESTS

The main tests are:

- ✔ blood tests, including extensive tissue typing and tissue antibody retrieval
- ✔ heart function tests (echocardiogram, electrocardiogram, cardiac stress tests and coronarography, if necessary)
- ✔ X-rays of the heart, lungs and a scan of the main blood vessels
- ✔ lung function test
- ✔ examination of the oesophagus/stomach (gastroscopy) and colon (coloscopy)
- ✔ dental and gum check
- ✔ abdominal ultrasound, with examination of the bladder and urinary tract
- ✔ gynaecological or prostate tests
- ✔ eye tests by an ophthalmologist
- ✔ skin tests by a dermatologist

Additional tests are sometimes required based on your personal medical history.

Some patients are also advised to lose weight prior to transplantation. The target weight is a BMI less than 30, i.e. your body weight (in kilograms) divided by the square of your height (in metres) is a number less than 30. You may need guidance from the obesity clinic for this.

It is important that you stop smoking at least 6 months before transplantation. For this, you can apply to the hospital's smoking cessation counselling service.

As your medical condition is always evolving, some of these tests will need to be repeated on a regular basis.

If you plan to travel to a destination for which vaccination against yellow fever is required, it is best to have this vaccine prior to your transplant (the vaccine will remain effective for ten years).

KIDNEY TRANSPLANTS AT UNIVERSITY HOSPITALS LEUVEN

As follows, you will find more information on two aspects that are important for a successful kidney transplant: blood group and tissue characteristics of yourself and the donor.

BLOOD GROUP

When transplanting a kidney from a deceased donor, the donor's blood group must be compatible with that of the recipient.
A blood group test provides us with certainty in this regard.

The rhesus factor (+ or -) is immaterial.

Donor blood group	Recipient blood group
O	O - A - B - AB
A	A - AB
B	B - AB
AB	AB

For transplantation with a kidney from a living donor, this compatibility between blood groups is no longer necessary. When someone applies to donate a kidney, that person can register at the transplant centre and is checked there to see if any blood group incompatibility is a problem. Usually, this is not the case.

TISSUE TYPING OR HLA

Tissue typing involves proteins known as Human Leucocyte Antigens (HLA) that occur on nearly all cells in our body. These proteins are unique in every human being. Tissue typing plays an important role in organ transplants, as the human body has a natural defence system that reacts to foreign invaders.

The better the tissue type match between the donor and the recipient, the lower the risk the organ will be rejected. This is taken into account when allocating kidneys from deceased donors (see below).

With living donor candidates, however, the ‘tissue match’ plays little role, because the medication taken against rejection is usually potent enough to prevent rejection, even if there is a weaker match between the tissue characteristics of recipient and donor. So living donation is certainly possible even between unrelated individuals.

Some people can develop HLA antibodies, which is a specific reaction by the body against foreign tissue types.

The development of HLA antibodies can be triggered by contact of the body with foreign tissue characteristics:

- blood transfusion;
- pregnancy;
- a previous transplant.

If a patient who is a candidate for a kidney transplant has developed HLA antibodies, it may be more difficult to find a suitable deceased donor kidney. Even in living donation, the presence of such antibodies may make transplantation impossible.

Whether HLA antibodies are present is determined by a blood draw. That test is part of the pre-transplant examinations mentioned earlier.

KIDNEY TRANSPLANT PROGRAMME AT UNIVERSITY HOSPITALS LEUVEN

There are two potential scenarios:

- a kidney transplanted from a deceased donor

or

- a kidney transplanted from a living donor.

An overview of the process the recipient goes through is provided below, both for a kidney from a deceased donor and a kidney from a living donor.

We will also take a brief look at the process a living donor goes through.

WAITING LIST

Any patient with an approved pre-transplant report and who agrees to transplant with a kidney from a deceased donor, will also be added to the Eurotransplant waiting list. Eurotransplant is an international organisation that includes every transplant centre in eight countries, being Belgium, the Netherlands, Luxembourg, Germany, Austria, Slovenia, Croatia and Hungary. All patient details (name, address, telephone numbers, blood group, tissue type, dialysis start date etc.) are gathered in the central Eurotransplant database. As such, the waiting list is a register of all patients waiting for a deceased donor transplant.

On Eurotransplant's waiting list, there is no order, but a points system is used. When a donor organ becomes available, the central computer will make a list with an order based on this point system. This point system takes several factors into account, such as the waiting time in dialysis and the tissue match. Whoever has been waiting the longest and has a reasonable tissue match with the available donor kidney will be at the top of this list and will then be called up for transplantation with this kidney.

The waiting time is calculated from the 'dialysis start date'. Patients who have not yet started dialysis can be added to the waiting list but will not score any points on the 'waiting time' criterion. As such, the chances of transplantation before a patient has started dialysis are rather small, but not non-existent. We therefore aim to put patients on the waiting list as much as possible before starting dialysis treatment. However, this is not always possible.

It is not easy to predict how long you will have to wait for a suitable transplant organ. Some patients may receive a transplant after a few months on the waiting list, but the majority face a longer wait: between two and five years.

A number of factors influence the waiting time:

- Blood group: patients with blood group O will mostly wait the longest.
- For patients who have developed HLA antibodies, it may be more difficult to find a suitable kidney, which will drive up their waiting time.

The various transplant centres have no way of influencing Eurotransplant's scoring and allocation system.

CALL FOR TRANSPLANT

When a kidney has become available for you, Eurotransplant will notify the transplant coordinator at University Hospitals Leuven. The transplant coordinator will then discuss the available organ with the surgeon and nephrologist at University Hospitals Leuven. Your attending nephrologist will also be notified.

The transplant coordinator will then contact you and ask you to come to University Hospitals Leuven's Gasthuisberg campus.

- ✓ As soon as your attending doctors have confirmed you are on the waiting list, you must be available at all times (day and night)!

  This means you must have a mobile phone, and that your mobile phone number – as well as your landline number and the (mobile) numbers of relatives, friends, neighbours, etc. – must be passed to the nephrology office at University Hospitals Leuven (tel. +32 16 34 45 97 or +32 16 34 45 80). Please make sure that your mobile phone battery is always charged and that you always have your phone with you. It is absolutely essential that you are available at all times. You must notify us of any changes of address and/or telephone number straightaway.

- ✓ If you are planning a holiday abroad, you must notify the nephrology office in advance of the period you will be away (tel. +32 16 34 45 97). You will be marked as 'inactive' on the waiting list for this period, meaning you will not be called up for a transplant. This will not affect your waiting time.

- ✓ When you receive a call, you should come to the Gasthuisberg campus at the agreed time. We expect you to arrive no later than three hours after the call (taking into account traffic and weather circumstances, of course).

  Please let the transplant coordinator know if you are not at home when you receive the call, so we can take this into account when agreeing a time for you to arrive at the hospital.

- ✓ It is best to think ahead about the transport alternatives available to you in the event of a call:
  - your own car, a relative's/friend's/neighbour's car, etc.;
  - a taxi service via your health insurance fund;
  - an ambulance via your health insurance fund.

  Make sure you discuss these options with the social worker at your dialysis centre.

- ✓ When you come to the hospital, don't forget to bring:
  - your identity card;
  - card of your hospitalisation insurance
  - nightwear, dressing gown, underwear, slippers;
  - toiletries: a soft toothbrush, toothpaste, a comb or brush, soap, shampoo;
  - optionally: your shaving kit;
  - a recent list of all the medication you take, including medicated plasters, creams, your CPAP device etc.

- ✓ Please do not consume any food or drink from the moment you receive your call.

If you are not at home when you receive a call, you can ask a relative to bring these items at a later stage. This will save you having to return home first to pick them up.

You should enter the hospital via the main entrance, at night and on weekends you go through the emergency department. Please call at reception in the entrance lobby and ask for directions to hospitalisation 13 (abdominal transplant surgery, tel. +32 16 34 66 20). To do so, follow 'Gele straat' (Yellow street), 'poort 4' (gate 4) and then go to floor 6, sequence a. You do not need to register at reception.

ADMISSION TO THE TRANSPLANT DEPARTMENT

You will be admitted to a single room, which will not be charged as a private or semi-private room. Staying in a single room is necessary to protect you against infection after your transplant, because the medication you will need to take to suppress your body's defence mechanism against the new organ will leave you more susceptible to infection. To protect you against these infections, we will take a number of other precautions in addition to admitting you to a single room:

- ✓ Once you are no longer on any intravenous drips or drains, you may only leave your room after at least a week has passed, with the agreement of your attending doctor.
- ✓ You may only leave the ward itself for tests, and not to visit the restaurant, for example.

At the time of admission, a physician will review your medical record and run through your medical history with you. He or she will examine you and ask you a few questions about your current health. A blood sample will be taken for additional tests, and your lungs and abdomen will be X-rayed. You will be prepared for the transplant and placed on dialysis for a few hours if necessary.

When the operating room and surgical team are ready to perform the transplant, you will be taken to the operating room. In some cases, barely any time will elapse between your arrival at the hospital and your transplant, but in other cases, you may need to wait several hours before surgery.

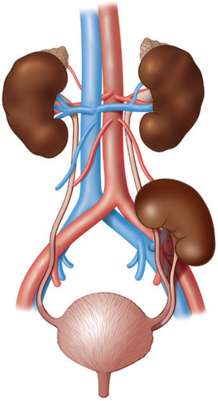
Sometimes, the tests will show we cannot proceed with your kidney transplant, because the quality of the donor kidney is inadequate, the cross-matching test procedures an unfavourable result or because you have an infection. In this case, you will need to return home, which we appreciate will be hard to take. As such, it is important for you to understand that a transplant may be cancelled if the physicians believe transplanting the kidney in question may have a detrimental effect on you. Feel free to ask the transplant team for more information, so you understand why this decision was made. You will of course remain on the waiting list after any cancelled surgery, in anticipation of a more suitable opportunity.

In most cases, only one patient will be called up when a donor kidney becomes available. However, in some cases, a second patient may be called up, mainly when there is a chance that the first patient cannot receive the transplant because the risk of the organ being rejected is too high. If you are that second patient and there is a significant chance the first patient will be unable to receive the transplant, this will be discussed when you are called up.

SURGERY

Your kidney transplant will be performed by an experienced and trained surgical team under the leadership of the abdominal transplant surgery staff member.

We cannot guarantee that a certain surgeon will perform your procedure, but the person performing the transplant will have the necessary experience.



The procedure

Kidney transplant surgery is performed under general anaesthetic. You will have the opportunity to discuss the potential side effects and risks of general anaesthetic in detail with an anaesthetist.

During the general anaesthetic, we will insert multiple intravenous dips into the blood vessels in your arm and neck to supply fluids and medicines, to take blood, and to monitor you during and after your transplant. We will also insert a stomach tube through your nose; this can be removed later that day or the day after. A urinary catheter to drain urine will be inserted during surgery; this will usually remain in place for five days (sometimes up to ten days).

The first thing the surgery team will do is prepare the donor kidney for transplantation. It will then be transplanted into your body.

A donor kidney is not implanted where your own kidneys are, but in the lower abdomen, linked to the blood vessels entering the leg. To do this, a curved incision is made on the left or right side of the lower abdomen.

The donor kidney's ureter will be attached to your bladder. To ensure this connection heals properly, a small plastic tube called a stent will be placed in the kidney's ureter. This stent will be removed from the bladder under local anaesthetic a few weeks after the transplant. The stent is just a few millimetres wide. Two further tubes (drains) will be left in the wound to drain the blood and fluid surrounding the kidney. These drains can only be removed once the volume of discharge from the wound has reduced to a minimum, usually after a few days.

Your own (unhealthy) kidneys are not usually removed and simply remain in situ.

To facilitate the transplant in male patients, it is sometimes necessary to cut the sperm duct running through the surgical field. Cutting one of your two sperm ducts can reduce your fertility but has no effect on your sexual experience.

The procedure will last two to three hours.

Recovery

During surgery, your breathing will be taken over by a machine. To facilitate this, a tube will be inserted into your trachea through your mouth during the anaesthesia. This tube will be removed as soon as the procedure has finished. You may experience some throat ache, a prickly cough or feel a little hoarse after surgery as a result. These symptoms will disappear after a few days.

As you will not produce any tear fluid yourself during the surgery, a cream will be applied to protect your eyes from drying out. This may cause hazy vision when you recover from the anaesthetic. The nurse will be on hand to help you remove this cream.

After the procedure, you will be transferred to the recovery unit, where specialist nurses under the leadership of an anaesthetist will take care of you until your general anaesthetic has worn off and you are sufficiently conscious and stable to be returned to the hospitalisation unit. This will usually take a few hours.

In some cases, you will need to spend a few days in the intensive care unit, usually because your medical condition prior to the transplant put you at higher risk. However, this may also be the result of complications during the procedure. If your medical team anticipates that admission to intensive care will be required, they will tell you in advance.

- ✔ **Going home:** you will need to stay in hospital for around two weeks after a kidney transplant. The exact duration of your stay is dependent on the progress of your general condition and the functioning of the donor kidney. In some cases, you will need to stay in hospital for longer. The physicians will keep you informed of your progress.

- ✔ **Check-up consultations and medication:** you must take your medicines as prescribed and you will be asked to attend regular check-ups. More information can be found in the ‘Living with a new kidney’ brochure.

The urinary catheter may give you a ‘phantom’ urge to urinate after surgery.
The urinary catheter will be removed no earlier than five days after the transplant, and then only when the surgeon feels it is safe to do so. The intravenous drips inserted during the anaesthetic will be removed after two or five days, on the condition you are able to eat and drink enough independently.

LIVING DONOR

Besides a kidney transplant using a kidney from a deceased person, there is also the option of receiving a kidney from a living donor.

Living donation is a fully-fledged alternative with even better short- and long-term results than transplantation with a kidney from a deceased donor.

Living donors can be related to the recipient (sibling, parent, partner), although blood relationship is not necessary. As explained earlier in this brochure, a tissue agreement is usually not necessary. People who are not familially related, but who have a lasting bond (e.g. close friends), may also be eligible for living donation.

Until a few years ago, blood group compatibility was a prerequisite for kidney transplantation. This is no longer the case. If the blood group is not compatible (see below), living donation is still possible in most cases. This can be done by performing additional treatment on the recipient, starting from one month before the planned transplant with the living donor kidney.

Donor blood group	Recipient blood group
O	O - A - B - AB
A	A - AB
B	B - AB
AB	AB

A kidney transplant from a living donor offers several benefits to the recipient. That this operation can be planned ensures that :

- ✓ the transplant often can be planned before dialysis needs to be started.
- ✓ the waiting time and the duration of the dialysis treatment can be reduced for patients who still need dialysis first.
- ✓ the kidney is of optimal quality : the storage time is very short and, thanks to the various preoperative examinations, we have certainty about the health of the donor and the donor kidney.

The average results after living donation are better than after transplantation with a kidney from a deceased donor, both in the short and long term.

For more detailed information, feel free to contact the clinical coordinators (Nele Grossen and Delphine Kumps) of the 'Living donation' programme ('Levende donatie' in Dutch) at UZ Leuven. You can reach them on +32 16 34 45 98 or +32 16 34 09 26, or via levendedonatie@uzleuven.be.

AFTER SURGERY

Immediately after surgery

You will feel tired and sleepy. To ensure you recover as quickly as possible, it is best to sleep as much as possible. All tubes, drains and drips will be carefully monitored by the nurse. If necessary, you can ask for pain relief. You should limit the number of visitors you receive in the first few days after your transplant.
You are not allowed to drink immediately after your transplant as your intestinal function will not yet have recovered. If you have dry lips and a dry mouth, you can rinse your mouth and wet your lips.
Your pulse, blood pressure, temperature and oxygen saturation will be checked regularly, as will the drainage of urine and wound discharge. Sometimes, it is necessary to administer extra oxygen after surgery.

Further process on the ward

Every morning, a blood sample will be taken to determine the kidney function. For this, we measure the creatinine levels. Creatinine is a waste product from muscle tissue, which is filtered out by your kidneys. As such, it is a good indicator of the functioning of your transplant kidney.

During the morning care routine, plenty of attention will be paid to your bodily, oral and dental hygiene. On the first day, you will be washed in bed. As soon as you feel strong enough to do so, you will be allowed to wash yourself. As with all surgery, it is recommended to get up as soon as possible, usually from the second day after the transplant. You will need to stay in bed for the first 24 hours. To prevent the formation of blood clots, we recommend that you get sufficient exercise.

The surgical wound will be covered as much as possible to prevent infection. Your wound will be monitored by the surgical team and cared for by the nurse. If your wound heals without any complications, the stitches will be removed after 21 days. Often, the wound will be sutured subcutaneously, meaning the stitches do not need to be removed.

All of your urine will be collected every day for testing. These tests will remain necessary, even when the urinary catheter is removed. If you accidentally urinate in the toilet and any urine is lost, please notify the nurse immediately. Urine samples will be requested for bacteriological testing three times a week. As long as your urethral catheter remains in place, these samples will be taken by the nurse via the catheter. Once the catheter has been removed, we will ask you to urinate into a container to allow us to take a sample.

As soon as your intestinal function is restored, you may start eating and drinking on the second day after your surgery, subject to your physician's advice. Medication will be administered orally from day one.

The composition of your diet will be discussed with the dietician. To start with, you will be served easy-to-digest foods such as custard, yoghurt, buttermilk, fish or chicken. Over the following days, your diet will be expanded and the menu will be tailored to your personal requirements, within the possibilities offered by the kitchen and taking into account any dietary prescriptions such as reduced salt and/or reduced sugar.

Potential problems

A kidney transplant usually poses few surgical-technical problems, so complications are infrequent. However, the possibility does exist. We explain in detail on the following pages which possible complications can occur.

Initial failure of transplant kidney to work

Normally, a transplant kidney starts working immediately, as early as during surgery. Sometimes it can take up to several days after surgery for the new kidney to start functioning properly. This is not unusual and is often explained by factors including the storage time of the donor kidney before transplantation and the health of the donor kidney itself, which cannot always be properly assessed in deceased donors. While waiting for the transplant kidney to fully recover, dialysis is sometimes necessary. Dialysis is done in the room. It can range from one session of dialysis to several weeks.

Rejection

In some patients, a temporary rejection of the donor kidney may occur. This often starts between some days after the transplant. In this case, a kidney biopsy will be required. Using a fine needle and under local anaesthetic, a small piece of tissue will be taken from the transplant kidney. This tissue sample will then be examined microscopically. Bed rest is mandatory after the biopsy until after the check-up echography and until the physician has advised otherwise. The results of this test will be available the day after the biopsy at the earliest. In most cases, a temporary rejection of the kidney can be treated with medication, without any lasting damage. During treatment for rejection, you will only be allowed to leave your room for tests.

Loss of transplant effect

A donor kidney will often not last a lifetime, and your transplant kidney might lose its functionality over time. When this happens, you will need to start dialysis once again. If you are fit and healthy enough, you may be eligible for another kidney transplant.

It is impossible to predict how long your donor kidney will keep functioning. Much depends on the health of the donor kidney itself, which cannot always be properly assessed prior to surgery in the case of a deceased donor kidney. One thing we can do is tell you the general outcomes achieved by University Hospitals Leuven:

- One year after a kidney transplant, around 92 out of every 100 kidneys will still function as normal. To clarify, we've included a diagram below that shows 100 people. Ninety-two of these figures are coloured black to represent those people whose kidney still works as intended one year after the transplant. The remaining eight figures represent patients whose kidney will fail during the first year. After ten years, around 70 in 100 transplanted kidneys will still work.

- There is also a small risk of death (two percent) during the first year after the transplant. This is represented by the two white figures in the image below. If we believe your risk of death will increase after your transplant, we will tell you so. It should be remembered that dialysis also involves a risk of death, especially in patients with diabetes and elderly patients. For example, if you are aged between 18 and 34, you have a 2 percent chance of death as a dialysis patient. If you are aged between 65 and 74, this figure rises to 15 percent.

Other complications:

Thrombosis

There is a small risk (2 to 4 percent) of a clot forming in one of the blood vessels of the transplanted kidney. This will cause the donor kidney to fail, so we will need to remove the clot in a further surgical procedure.

Follow-up surgery

There is a small chance (5 percent) that you will need a second surgical procedure shortly after the transplant to stop any bleeding, remove any blood clots, resolve any leakage problems near the connection to the bladder or treat a wound problem.

Wound detachment

It occasionally happens that the surgical scar does not close smoothly and the wound heals with difficulty. In some patients, it is necessary to surgically repair the wound. This mainly occurs in obese or obese people. To avoid this, it is important to consider how obesity or obesity can be addressed prior to transplantation.

Acute rejection

The risk of acute rejection of the kidney is around 10 percent. If rejection occurs, you will receive stronger medication to counter the problem. This is usually sufficient to get the rejection reaction under control. In rare cases (1 to 2 percent), the transplanted kidney may be lost as a result of acute rejection.

Delayed kidney functionality

Around 20 percent of transplanted kidneys will not work immediately after the transplant. In this case, you will need dialysis until the kidney starts to function. If you had peritoneal dialysis prior to the transplant, you will be switched to haemodialysis and a temporary dialysis catheter will be entered into one of your blood vessels.

In most cases, the kidney will start to function during the first two weeks after the transplant, but it can take longer – sometimes up to three months. In rare cases (1 percent), the transplanted kidney will never start working and you will remain on dialysis. In this event, you may be eligible for another transplant.

Diabetes

The anti-rejection medication causes a greatly increased risk of higher blood sugar levels and may also lead to diabetes. This risk is especially high in obese people and those who require additional rejection medication. This complication can also be avoided by addressing obesity prior to transplantation. Sometimes diabetes is treatable with medication, but it happens that patients develop diabetes after transplantation that needs to be treated with a daily administration of insulin.

Hypertension

Most patients have hypertension after transplantation. This is closely monitored during admission and afterwards at consultations. You may need to take one or more blood pressure-lowering drugs for this. A low-salt diet also usually has to be followed.

Lymphocele

In around 15 in every 100 patients, fluid will start to collect around the kidney during the first three months after the transplant. In some cases, this collection of fluid may exert pressure on the kidney and block the flow of urine towards the bladder. If this happens, the fluid will need to be drained and further surgery may be required.

Cancer

After the transplant, you will need to take medication that suppresses your immune system. As a result, you may have an increased risk of developing some cancers, for example skin cancer or lymphoma. Any early-stage cancers will be ruled out by the tests prior to your transplant. After transplantation, increased vigilance will be necessary, as some cancers may grow faster and cause problems due to the intake of this medication. You will be extra monitored for this to initiate timely treatment if necessary.

Infections

Due to the suppression of your immune system, the risk of infection markedly increases after a transplant. Sometimes, the viruses, bacteria or fungi causing these infections will be difficult to treat, and therefore involve a risk of death. If you experience any symptoms of infection, you must contact a physician as soon as possible, so that suitable measures can be taken. You and your physician should also discuss the option of vaccinations to prevent infection where possible.

Other complications

As with all other surgery, there is a risk of complications such as wound infections, blood clots in your legs or lungs, or fluid leakage from the drains or the wound. These complications can often be resolved through medication or further wound care. There is also a small chance of a cardiac arrest as a result of the surgery. To help reduce the risk of this, various tests will be performed on your heart to ensure it is strong enough to make it through the surgery.

Recurring kidney disease

Some kidney diseases can reoccur in the transplant kidney. If you are at risk of your disease recurring, your renal specialist will discuss this with you before adding you to the waiting list for a kidney transplant.

Other complications not described here may also occur. Your physician or nurse will be able to provide more information on these.

What are the risks associated with the donor kidney?

This section is about the donor kidney and provides more detail on some of the risks involved in transplanting a kidney. There may be other risks associated with the donor kidney that are not described here.

The kidney you will receive is not new, even though it may feel like that to you. Most organs are donated by people who have recently passed away. It is unusual for a young person to become a kidney donor or for the donor to die in an accident. Most organ donors died from a medical condition such as a stroke or cardiac arrest. The average age of Eurotransplant organ donors is increasing, including in Belgium. Some donors may be as old as 80. More than 20% (1 in 5) of kidney donors is over 65 years of age.

In general, kidneys donated by older people will not function as well or as long as those donated by young people.

If, prior to surgery, the medical team feels that the transplant kidney is not of sufficient quality to function without dialysis, the transplant will be cancelled.

As it is not always possible to know the entire medical history of deceased donors, it is not always possible to estimate correctly the quality of the donor kidney beforehand. As such, it is possible that it only becomes apparent after transplant surgery that the donor kidney had serious limitations beforehand. In most cases, these quality problems cannot be improved, resulting in graft kidney working only moderately or not at all. As a result, dialysis may again become necessary sooner than hoped.

Double transplants

Very rarely the transplant team will decide to transplant two kidneys from the same donor into your body to increase the treatment's chance of success. We will do so when we believe that one kidney from the donor might not perform adequately in your case, but both kidneys together will. If you are being offered a double transplant, we will of course let you know.
In rare cases, we may receive donor kidneys from very young patients (below 5 years of age). In these cases, it is better to transplant both kidneys into a younger recipient. In the long term, these kidneys will perform very well and they will also grow with the recipient, but because they are so small, the risk of developing a clot in the blood vessels (thrombosis) is higher than what was discussed above.

Conditions that may be passed on by the donor

Some donors have medical problems that we were not aware of at the time the donor passed away, and that may be passed on to you. We will do everything we can to check for the presence of life-threatening infections in organ donors, but some donors may carry a viral infection that we are not aware of or that we believe will only pose a minor risk to you (cytomegalovirus, for example, which can be treated after the transplant). The risk of contracting a life-threatening infection from your donor is very small (less than 1%).

In some cases, we are aware that the donor used intravenous drugs, while others may be at higher risk of hepatitis or HIV/AIDS due to their lifestyle. All organ donors are thoroughly checked for these viruses, but there is a small chance (around 1-2%) that an infection in a high-risk donor is missed and that this infection may be passed on to the recipient. If an infection is passed on to you in this way, you will need to take antiviral medication.

Around 1 in 2,000 donors have a cancer that we are not aware of and that may be passed on together with the organ. Such a complication will often result in death. Regrettably, there is no way to predict which donors are carrying a hidden cancer.

Around 2 in every 100 donors died from brain cancer. This type of cancer rarely spreads outside of the brain, and as such, it is normal for transplant teams to accept organs from these types of donors. If your organ donor suffered from brain cancer, there is a small chance (around 2%) this cancer will be passed on to you. The chance the cancer will not be passed on is 98%.

Some donors were treated for cancer in the past and were considered cured. We will do everything we can to find out the details of the cancer and the treatment before deciding whether organs from these donors are safe to transplant.

Donation after brain death or circulatory arrest

The death of an organ donor can be confirmed in two ways:

✔ **Brain death:** in the event of brain death, the brain functions – including those of the brain stem – have irreversibly ceased. Brain death can be confirmed with certainty using specific tests. Brain-dead donors are unable to breathe independently and will be on a respiratory machine, but their heart continues to beat and their organs continue to receive blood and oxygen.

✔ **Circulatory arrest:** some donors have contracted irreversible brain damage, but are not brain-dead. Still, their brain damage is so severe that recovery is impossible, and the attending medical team – in consultation with the patient's loved ones – will decide to withdraw life-sustaining treatment. The result will be an irreversible circulatory arrest once cardiac function has ceased.

Out of all kidney transplants performed in Belgium, around 1 in 4 (25%) kidneys originate from a donor who died as a result of circulatory arrest. This percentage is gradually rising.

After transplant surgery, a number of kidneys will not function immediately. These kidneys will need a few days or weeks to regain their functionality. This delayed functionality occurs more often in kidneys donated following circulatory arrest (40%) than in kidneys donated after brain death (20%). The long-term outcomes for kidneys donated after circulatory arrest those donated after brain death are similar.

We only transplant donor kidneys that we believe will provide long-lasting kidney functionality and that pose an acceptable risk.

VISITATION

In the first days after transplantation, you will be staying in a single room. Visitors are allowed in your room, but they need to follow a number of rules to reduce your risk of infection.

✓ You are only allowed up to three visitors in your room at any time. Before entering the room, your visitors need to wash their hands and take off their coats.
Tip: arrange your visits in advance, and plan who should come at which time. This way, you can avoid any visitors having to wait outside.

✓ People carrying an infection (cold, flu etc.) will not be allowed to enter.

✓ Children are allowed in, as long as they are not ill.

✓ Plants and flowers are not permitted due to the increased risk of fungal infection.

✓ Visiting hours are 14:00-20:00 every day. These hours are adhered to as strictly as possible.
Any exceptions can be discussed with the nurse at any time. It is in your own best interest to limit visitors during the period immediately after your surgery to your closest relatives only. That way, you can make sure you get enough rest.

Your physician or nurse will be happy to help with any questions your relatives may have. They are welcome to make an appointment to speak to the nurse or physician on the ward.

Medical information will never be disclosed over the telephone.

LIVING WITH A NEW KIDNEY

There are certain guidelines you should follow, both before and after your transplant. The main ones are quitting smoking, correctly taking your medication, correctly following your prescribed diet, ensuring you get plenty of exercise and a lifelong smoking stop.

After your kidney transplant, we will also provide information on what will happen during your follow-up consultations and tests and which activities you can resume at which point. Several of these aspects are discussed below.

More information can be found in the 'Living with a new kidney' brochure. Ask about it or view the brochure online: www.uzleuven.be/en/brochure/700605.

MEDICATION

You will be placed on permanent medication to suppress your body's rejection mechanism against the foreign organ. Examples of such medication include Medrol®, Cellcept®, Prograft®, Advagraf®, Certican® and Neoral®. They must be taken at exactly the right times to prevent fluctuations in your blood level. It should be pointed out that this medication also reduces your defences against pathogens, meaning you will be more susceptible to infection. This susceptibility to infection is at its highest shortly after the transplant or after treatment for rejection, as the dose of the prescribed medicine is highest at these times.

You will mainly be susceptible to viral infections. To protect you against these during the first few months after your transplant, you will be given extra medication. This medication will have certain side effects. The probability of experiencing these side effects varies from person to person and depends strongly on the dose you receive. You must never reduce your dose on your own initiative.

Given the fact that some medicines may have a detrimental effect on the wall of your oesophagus, stomach and small intestine, you will also receive medication to protect these areas. Examples of such medication include Pantomed® or Omperazole®.

Medrol®, which contains cortisone, may produce some swelling of your face and can trigger diabetes in the early stages of its use. This usually disappears when the dose is reduced. Acne may develop in some patients.

The use of Sandimmun Neoral® (Cyclosporine) or Prograft® (FK-506) may result in headaches and tremors for the first few weeks to months.

Prograft® (FK-506) and Advagraf® may disrupt your blood sugar balance (diabetes) and the main side effect of Cellept® (Mofetil) is gastrointestinal discomfort.

In the long term, your skin will become more sensitive to sunlight and you will burn more quickly. In addition, annual consultation with the dermatologist is recommended.

In the long term, a slightly increased risk of some cancers is possible (especially lymphomas). There is also a greatly increased risk of skin cancers. Partly for this reason, annual follow-up with the dermatologist after transplantation is necessary, to identify incipient skin problems early and treat them promptly.

The number of pills you will need to take depends on your blood level. During the first few weeks after your transplant, it is possible you will need to take a dozen pills in the morning and at night. Over several months, the number of medications will be gradually reduced, but you will have to keep taking the anti-rejection medication. Any medication you take for any other medical problems, hypertension and possibly diabetes will of course also remain necessary.

Your medication schedule and side-effects will be discussed in detail with you during your admission to the post-transplant ward and at consultations afterwards.

In female patients, fertility levels return to normal shortly after the transplant. Regardless, pregnancy is not recommended during the first two years after a transplant. This is because Cellcept® should not be used during pregnancy. As such, it is best to discuss the use of contraceptives with your attending doctor prior to your discharge from hospital. In case of any pregnancy desire, it is very important to discuss this with your doctor before stopping contraception.

In men, fertility may be reduced after transplantation.

QUITTING SMOKING

When you agree to a kidney transplant, you must quit smoking prior to surgery and refrain from smoking after surgery. You must have quit smoking for a period of at least six months before you are activated on the waiting list for a kidney transplant.

Smoking puts you at higher risk of infection – mainly post-surgery lung infection, but other infections too. The medication you need to take after surgery to prevent rejection puts you at higher risk of developing certain types of cancer. This risk is much higher in transplant patients who have not quit smoking or who resume smoking. Transplant patients who smoke run a much higher risk of developing throat, lung and other cancers.

Vaping (without nicotine) is also not recommended, as it can cause a toxic effect and irritation at the level of the lungs. E-cigarette smoking or vaping, can only be allowed for a short period and as a temporary smoking cessation aid.

Speak to your doctor or nurse if you want counselling to quit smoking. They can inform you about possible aids, refer you to a tobaccoologist or health insurance fund and/or make an appointment at the smoking cessation consultation in the hospital.

Taking illegal drugs is against the law and associated with serious medical risks, not just for transplant patients but for everyone.

FOOD

A healthy eating pattern – with particular attention to your salt, fat and sugar intake – is essential after your transplant.

Reducing the amount of salt you consume remains advisable and is often necessary if you tend to suffer from high blood pressure and/or fluid retention.

To control your weight and to prevent increased cholesterol after your transplant, special attention should be paid to fats. It is not just the amount fat you consume that matters; the type of fat is important too.

Sugars are permitted, except if you are diabetic, if you have gained a significant amount of weight or in the event of an abnormal sugar test after your transplant.

When your kidneys are working well, you no longer need to restrict the amount of potassium and/or phosphorus you consume or watch the amount of liquids you take in, so your diet will generally become healthier.

You will of course receive more extensive and personalised advice from your dietician at the nursing unit following your transplant.

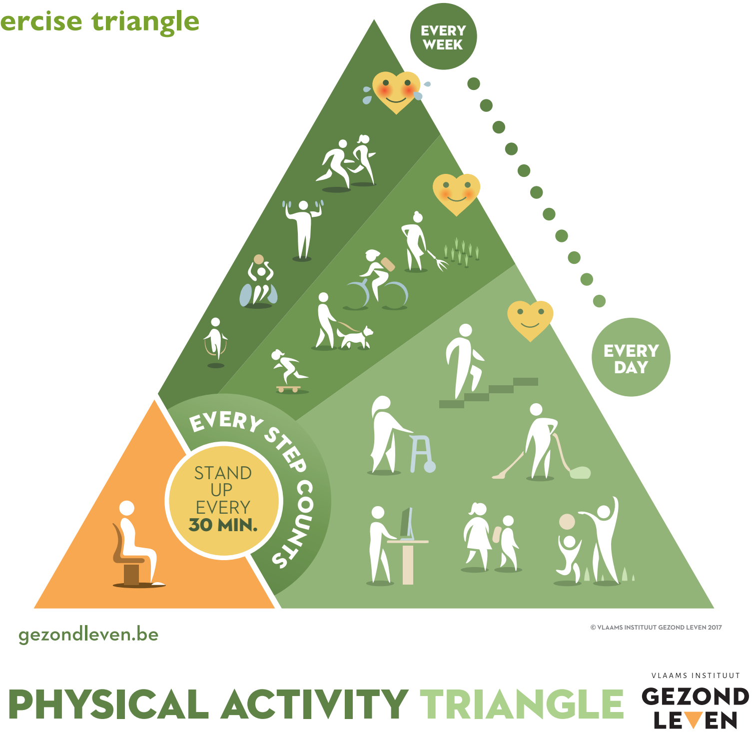
EXERCISE

Combined with a balanced diet, physical exercise is essential to staying in good shape. Studies have shown that physical exercise offers many health benefits, such as a lower risk of developing cardiovascular disorders, obesity, diabetes and high blood pressure.

Physical exercise also has a positive effect on your mood. These benefits also matter in relation to a kidney transplant.

To maintain a healthy exercise balance, you should switch between sitting down, standing up and moving around. The exercise triangle shows the best way to do so. More detailed information on exercise after transplantation can be found in the brochure ‘Living with a new kidney’.

Exercise triangle



Get into the habit of alternating between sitting, standing and moving every day. Try to do light-intensity movement for most of the day, e.g. housework or a walk. In addition, try to do some moderate-intensity exercise every day: take the stairs or the (electric) bicycle, for example. If you can, you can also plan some high-intensity exercise every week, e.g. a sports session. You can also exercise and strengthen your muscles on a weekly basis.

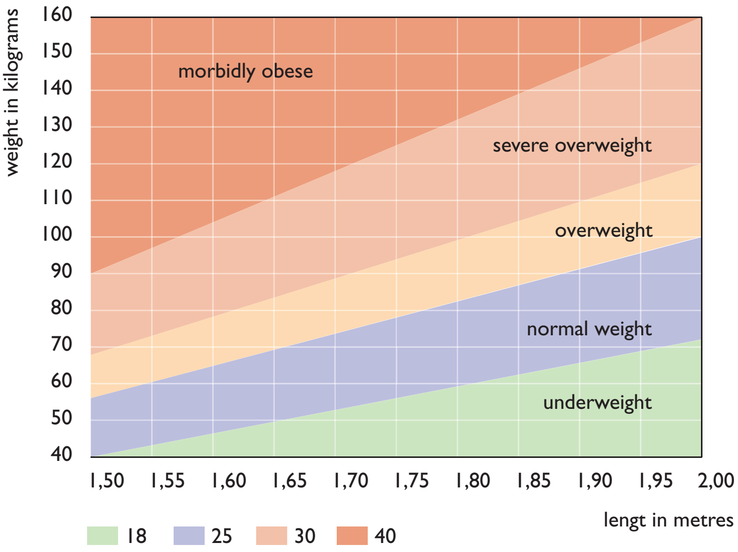
Tips

- ✓ If you are not used to exercising a lot, build up very gradually increase your amount of physical activity.
- ✓ Choose activities that fit into your daily activities such as walking, cycling, brisk walking, swimming or taking the stairs instead of the lift.
- ✓ Choose an activity you enjoy doing.
- ✓ Limit long periods of inactivity such as watching TV.
- ✓ For short distances, choose to cycle or walk.
- ✓ Increase your motivation by, for example, keeping a diary keeping a diary, finding company to exercise together, using a pedometer or activity tracker ...
- ✓ Don't get discouraged if moving one day is less successful one day. Resume the next day with good courage.
- ✓ There are many local initiatives that can help you to start moving and stick with it.

HEALTHY BODY WEIGHT

Being overweight increases the risk of diabetes, cardiovascular disease, high blood pressure and high cholesterol. All of which negatively affect your kidney function. A healthy weight can save your remaining kidney function.

To calculate whether you have a healthy body weight, you can use the following chart:



The combination of what you eat and how much you exercise affects your weight. To lose weight, you need to consume more energy than you take in. Common weight-loss tips may conflict with dietary guidelines for people with kidney disease. You can always contact the ward dietician for personal advice.

DRIVING

In principle, you will not be allowed to drive for the first month following your transplant. Your renal specialist will decide when you are allowed to resume driving. You will receive a blank ‘fitness to drive’ certificate that will only be completed by the physician once he or she deems you are fit to resume driving. This certificate should be submitted to your municipal administration to request a special driving licence. The social worker will be happy to provide more detail.

Make sure you notify your car insurance provider that you have undergone a major surgical procedure and provide them with a copy of your ‘fitness to drive’ certificate. Doing so will not increase your premiums and your insurance will continue to pay out in the event of an accident.

For more information, visit www.vias.be and www.wegcode.be

MEDICAL FOLLOW-UP

Regular check-ups remain absolutely essential after a successful kidney transplant. For the first three months, your consultations will be held at University Hospitals Leuven. To begin with, you will need to attend check-ups three times a week, reducing to once a week depending on your results.

It is important to remember you are not allowed to use public transport or drive during the first month after your surgery. Please make sure you arrange your own transport. Your health insurance fund or the social worker at your dialysis centre will be happy to help with any questions.

To detect any signs of infection or rejection, it is important to monitor certain aspects at home on a daily basis, including your temperature, blood pressure, weight and urine flow.

Following the first few months of check-ups at University Hospitals Leuven, you will be monitored further by your usual dialysis centre. To ensure this follow-up runs as smoothly as possible, the physicians involved use a shared electronic record.
As part of the further monitoring of your kidney function, a routine biopsy of your transplant kidney will be performed at regular times. The first one of these will take place three months after your transplant, with further biopsies following after one and two years. These biopsies will be performed at University Hospitals Leuven as an outpatient service.

Regular biopsies of your transplant kidney are the only way to detect rejection or damage to your kidney in good time. If necessary, your medication will be amended according to the biopsy results. Through these follow-up procedures, we hope to contribute to the long-term functioning of your transplant kidney.

FINANCIAL ASPECTS

After your transplant, you will receive two types of invoice: your hospitalisation invoice and the invoice for your follow-up consultations. Both of these invoices will be posted to you.

HOSPITALISATION INVOICE

This invoice is split into two parts. The largest share of the price will be settled via your health insurance provider (third-party payment system). The hospital will only charge you your personal contribution (including clinical biology fees, physician's fees etc.) and any supplementary fees (including telephone charges, accommodation for relatives etc.). These costs will be around 700 euros depending on the amount of time spent at the hospital and the amount of medication and tests received.

CONSULTATION INVOICES

These invoices are referred to as 'outpatient invoices'. The difference with the hospitalisation invoice is that you will be charged full price. You can receive partial reimbursement for these invoices by submitting the 'white form' to your health insurance fund. As you will need to attend frequent consultations in the early stages after your transplant, the hospital may draw up a single invoice for multiple consultations.

If you have hospital insurance, please contact your insurance provider. Depending on the type of contract you have taken out, you may be eligible for additional reimbursement.

The social worker will be happy to provide extra information during your stay at the hospital.

PATIENT SUPPORT

The things you are going through as a result of your condition and this surgery are bound to leave you with a host of thoughts and questions, such as:

- Living with a dialysis treatment is difficult. What will my life be like after a kidney transplant?
- What will happen once I return home? Will I be able to resume my usual household role or will changes need to be made?
- What will happen to my working life? Will my employer have me back after my recovery, will I be able to do the same job, and if not, will I be able to find a new job?

These are just some of the questions you may have. To discuss your concerns and for information and support regarding social security, home assistance, reimbursement of transport costs, accommodation for your relatives during your admission, buying a mobile phone, etc., you and your relatives are free to contact the social worker on the ward at any time. She will visit you during your stay in the hospital, and she will also contact your relatives. You can also ask to see her at any time via the nurse.

Feel free to contact us – even before your admission – so we can explore possible solutions to your problems together. You can contact the social worker on +32 16 34 86 20.

EXPERIENCE EXPERTS

Besides the various healthcare providers, there are also experts by experience within our service ready to support you through the kidney transplantation process. These are fellow sufferers who can mean something to you from their own experiences. Do not hesitate to discuss your questions or concerns with them.

The experts by experience are regularly present in the kidney centre. They are also willing to lend a listening ear by telephone and provide practical information about the various treatments.

Would you like to call on an expert by experience? Then give the predialysis team a call:

- tel: +32 16 34 16 84
- e-mail: predialyse@uzleuven.be

DON'T FORGET!

- Ensure you have a contact option (mobile phone) available. You must remain available day and night.
- Work out a scenario for travelling to Leuven when you receive the call for transplant surgery.
- Ask your health insurance fund about the options for reimbursement of transport costs for consultations at University Hospitals Leuven after your transplant.

USEFUL CONTACT DETAILS AND WEBSITE

- **Nephrology**
  prof. dr. Dirk Kuypers (Head of Department)
  prof. dr. Bert Bammens
  prof. dr. Kathleen Claes
  prof. dr. Pieter Evenepoel
  prof. dr. Bjorn Meijers
  prof. dr. Maarten Naesens
  prof. dr.Katrien De Vusser
  prof. dr.Amaryllis Van Craenenbroeck
  dr. Papay Jallah
  office tel.: +32 16 34 45 80

- **Abdominal transplant surgery**
  prof. dr. Jacques Pirenne (Head of Department)
  prof. dr. Diethard Monbaliu
  prof. dr. Ina Jochmans
  dr. Mauricio Sainz Barriga

- **Hospitalisatie 13 (nursing unit)**
  Carine Breunig (head nurse)
  tel. +32 16 34 03 25
  carine.breunig@uzleuven.be

- **Nephrology office:**
  providing telephone numbers and holiday plans
  tel. +32 16 34 45 97 or tel. +32 16 34 45 80, during office hours between 08:30 and 17:00.

- **Social worker**
  tel. +32 16 34 86 20

- **Pretransplant consultant nurse**
  Katleen De Bondt
  katleen.debondt@uzleuven.be
  tel. +32 16 34 13 80
  or via hospitalisatie 13 (+32 16 34 03 25)

- **Post-transplant consultant nurse**
  Eva Vanhoutte
  eva.vanhoutte@uzleuven.be
  tel. +32 16 34 45 93

- **Transplant coordinators**
  Dirk Claes, Bruno Desschans, Nele Grossen,
  Karen Denaux, Delphine Kumps

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bruno.desschans@uzleuven.be	tel. +32 016 34 46 07
nele.grossen@uzleuven.be	tel. +32 016 34 45 98
karen.denaux@uzleuven.be	tel. +32 016 34 45 96
delphine.kumps@uzleuven.be	tel. +32 016 34 09 26

or via the abdominal transplant surgery office on tel. +32 16 34 87 27

Brochures and additional information can be found on the websites of the nephrology, abdominal transplant surgery and transplant coordination departments:
www.uzleuven.be/nefrologie,
www.uzleuven.be/txsurgery, www.overlevendoorgeven.be or via transplantatiecoordinatie@uzleuven.be.

Design and implementation
This text was written by the nephrology and abdominal transplant surgery departments at University Hospitals Leuven in cooperation with the communications department.

You can also find this brochure at www.uzleuven.be/en/brochure/700544.

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

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