

Waiting for a new kidney

P a t i e n t i n f o r m a t i o n

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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.

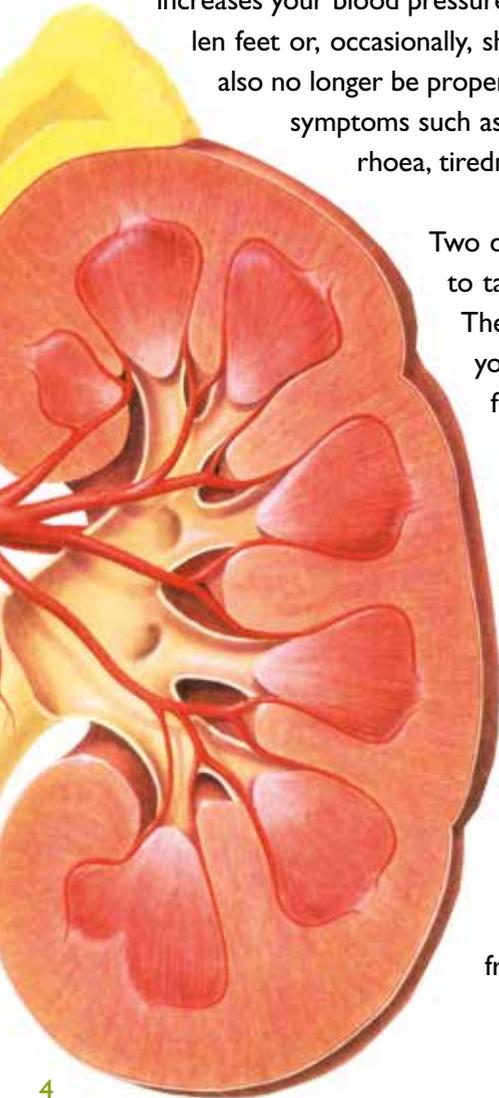
This brochure has been drawn up in consultation with the Leuven Cooperative Group for Kidney Transplants

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 be able to perform these tasks properly, resulting in excess fluid in your body, which in turn increases your blood pressure. As a result, you may suffer from swollen feet or, occasionally, shortness of breath. Waste products will also no longer be properly removed from your body, resulting in symptoms such as vomiting, nausea, lack of appetite, diarrhoea, tiredness and even coma.

Two different types of treatment are available to take over some of your kidney functions. The first of these is haemodialysis, in which your blood is cleaned artificially by an artificial kidney. The second treatment type is peritoneal dialysis via an abdominal catheter.

The only procedure that can replace both of the above treatments is restoring kidney function by transplanting a healthy kidney from a living or deceased donor. A transplant can result in near-complete recovery from the consequences of kidney disease. One important factor to note is that you will need to take medication for the rest of your life to prevent your body from rejecting the transplanted kidney.

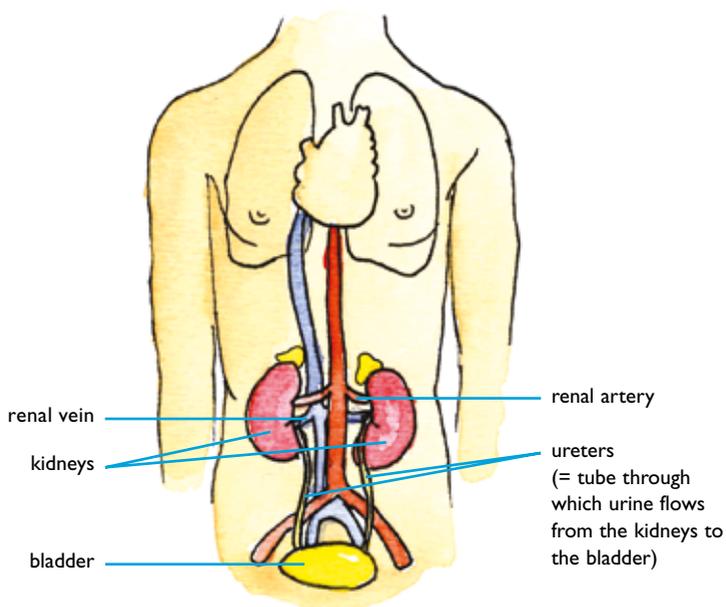


These days, the risks involved in a transplant are limited and the long-term outcomes are very satisfactory. In University Hospitals Leuven patients, around two-thirds of transplanted kidneys continue to function after ten years. If a transplant kidney stops functioning properly, the patient may become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

A kidney transplant is a major 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. Depending on the condition of your own kidneys, you will need to continue or start haemodialysis or peritoneal dialysis to replace some of the functions performed by healthy kidneys. You should be aware that dialysis involves a greater risk of death, especially in patients with diabetes and elderly patients. Later on in this brochure, we will compare these risks with the risks involved in a transplant.

Most people who have undergone a kidney transplant find that their quality of life has improved afterwards. In addition, several of 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 transplant surgeons, the nephrologists, 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:

- X blood tests, including extensive tissue typing
- X heart function tests
(echocardiogram, electrocardiogram, cardiac stress tests and coronarography, if necessary)
- X X-rays of the heart, lungs and main blood vessels
- X lung function test
- X oesophagus, stomach and large intestine test
- X dental and gum check (a dental check must be performed every six months after the transplant)
- X bladder and urinary tract tests
- X gynaecological or prostate tests
- X eye tests by an ophthalmologist
- X skin tests by a dermatologist

Sometimes, these tests can only be performed once dialysis treatment has started. 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

BLOOD GROUP

When transplanting a kidney from a deceased donor, there has to be a match between the blood group and tissue type (see below) of the donor and 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 |

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.

However, it is impossible to find a donor with an exact tissue type match for every recipient.

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:

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

As such, antibodies may be formed following contact between the patient's own body and foreign tissue types.

If a kidney transplant candidate has developed HLA antibodies, it may be more difficult to find a suitable kidney donor. A blood test is used to determine whether or not HLA antibodies are present.

KIDNEY TRANSPLANT PROGRAMME AT UNIVERSITY HOSPITALS LEUVEN

There are two potential scenarios: a kidney transplanted from a deceased donor and 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

Every patient placed on a waiting list for an organ transplant 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 collection of all patients waiting for a kidney and/or pancreas transplant. This list **does not work on a first come, first served basis**.

When a donor organ becomes available, a computer will create a priority list on the basis of points allocated for various factors, such as waiting time and a good tissue type match. The patient that has been waiting the longest and has the best tissue type match with the available donor kidney will move to the top of this list, and will in principle become eligible for a transplant using the available 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 chance of a transplant prior to starting dialysis is rather small.

However, when a kidney becomes available with a complete tissue type match (a 'full-house match'), this kidney will be allocated to the patient with the complete tissue type match, regardless of their waiting time or whether or not they have started dialysis.

There is no way 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 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.

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.

- X 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.

- X 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.

- X 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.

X 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.

X When you come to the hospital, don't forget to bring:

- your identity card, blood group card;
- nightwear, dressing gown, underwear, slippers;
- toiletries: a soft toothbrush, toothpaste, a comb or brush, a new bar of soap, shampoo;
- for men: your shaving kit;
- all medication you take, including medicated plasters, creams, homeopathic products, your CPAP device etc.

X 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, not via the accident and emergency entrance.

Please call at reception in the entrance lobby and ask for directions to the abdominal transplant surgery department, nursing unit 662 (tel. +32 16 34 66 20). Follow the beige arrow towards the lift, and use the lift to go to Level 6. 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 foreign organ will leave you more susceptible to infection. Many of the infections seen in transplant patients are caused by pathogens already present in the body prior to surgery. Some infections are passed on by hand contact. 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.

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 or the cross-matching test produces an unfavourable result, for example. 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.

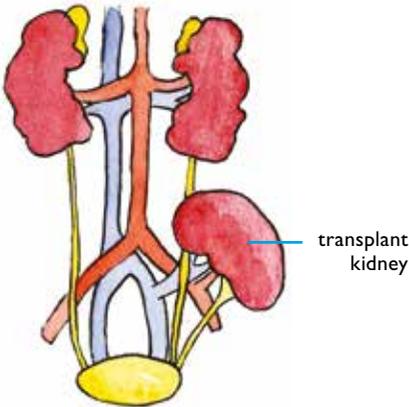
In most cases, only one patient will be called up when a donor kidney becomes available. However, in some cases, a second patient may be called up, mainly when there is a chance that the first patient cannot receive the transplant because the risk of the organ being rejected is too high. If you are that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

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 dials 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. The donor kidney will be placed in your lower abdomen and connected

to the blood vessels running down to your leg. 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.

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 donor kidney will not be implanted where your own kidneys are located, but in your lower abdomen instead. To do so, a curved incision will be made on the left or right of your lower abdomen.

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 unit 662. 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 three days, on the condition you are able to drink enough independently.

LIVING DONOR

In addition to a transplant from a deceased donor, a kidney transplant from a living donor is also an option. A living donor is a genuine alternative that often leads to better results. For live donation, the donor and recipient must be related (brother, sister, father, mother, partner). A blood relation is not required.

Candidate living donors who are not related but do have a long-term relationship with the candidate recipient (a friendship, for example) may also be eligible following the positive advice of the University Hospitals Leuven Medical Ethics Committee. Of course, the blood group of the donor must match that of the recipient, even though exceptions to this rule are possible these days. For more information, please consult your physician. 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 |

A kidney transplant from a living donor offers several benefits to the recipient:

- X No waiting time.
- X Option to receive transplant before dialysis is required.
- X Optimal kidney quality: the time the kidney spends in storage will be very brief and thanks to a range of pre-surgery tests, we can be certain of the quality of the donor kidney.
- X The average results after a transplant from a living donor are better than those after a transplant from a deceased donor.

For more detailed information and/or to request the 'Candidate living kidney donor' brochure, feel free to contact the clinical coordinator on the 'Living donor' programme at University Hospitals Leuven via telephone number tel. +32 16 34 45 98, email nele.grossen@uzleuven.be.

More information and a downloadable brochure are available on www.uzleuven.be/txsurgery.

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 and temperature 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 your creatinine levels, among other things. 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 12 or 14 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

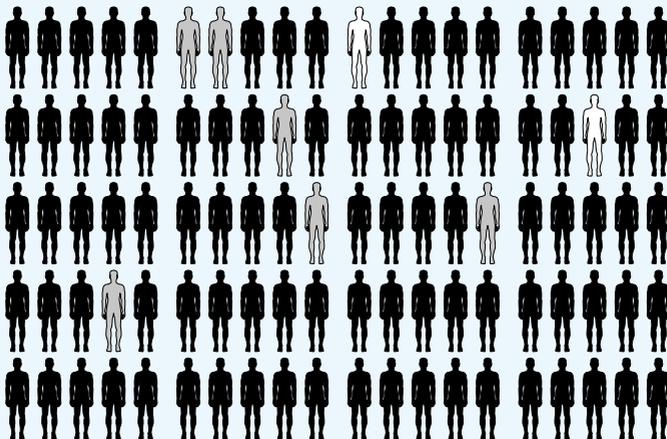
A kidney transplant usually involves few surgical or technical problems, meaning complications are rare—but the chance does exist. Below, we will run through the potential complications in detail. After surgery, it may take a few days for your new kidney to start functioning properly. This is not unusual and is often due to the storage time of the donor kidney prior to the transplant. In anticipation of a full recovery of the kidney, dialysis may be required in some cases. Dialysis will take place in your room.

In some patients, a temporary rejection of the donor kidney may occur. This often starts between five to seven 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.

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. 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.

Acute rejection

The risk of acute rejection of the kidney is around 20 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.

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. This may cause some forms of cancer that rarely occur in people who have not received a transplant (such as lymphoma). Other forms of cancer may spread more quickly. Any early-stage cancers will be ruled out by the tests prior to your transplant. After your transplant, increased vigilance will be required. To that end, regular follow-up tests will be performed, such as regular check-ups with a dermatologist, gynaecological check-up, colposcopy test, etc., to detect any problems in good time.

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. In 2015, the average age was 54, but 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 know 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, so dialysis may be needed once again soon after surgery.

Double transplants

In some cases, 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:

X 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.

X 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.

Technical tests

Sometimes, several technical tests need to be performed as a check-up, including an X-ray of the lungs, and echography or a renal scan of the transplanted kidney.

VISITATION

As mentioned earlier, 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.

X 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.

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

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

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

X 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.

No medical information will be disclosed over the telephone.

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 sup-

plementary 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:

- X Living with artificial kidney treatment is difficult. What will my life be like after a kidney transplant?
- X What will happen once I return home? Will I be able to resume my usual household role or will changes need to be made?
- X 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.

The social worker on the kidney transplant ward is Julie Willems. You can contact her on +32 16 34 86 20 or via email to julie.1.willems@uzleuven.be.

ACCOMMODATION FOR RELATIVES



University Hospitals Leuven has set up an accommodation facility to offer relatives and friends the opportunity to stay overnight, close to patients. The facility consists of single, twin and triple rooms.

A team of volunteers is responsible for the daily management of the facility, which allows us to keep the price very reasonable. Only one room can be reserved per patient. Reservations can be made by calling +32 16 33 70 04 or via the nurses or social worker on the kidney transplant ward.

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.

LIVING WITH A NEW KIDNEY

There are certain health and behaviour 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 and ensuring you get plenty of exercise.

After your kidney transplant, we will also provide information on how to recognise the early stages of rejection, 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.

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.

Do not hesitate to ask for help: courses to help you quit smoking are available both at Gasthuisberg Campus and at a location near you (your local hospital or health insurance fund). The nurse, social worker and psychologist will be happy to provide more information.

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. In the long term, a slight increase in the risk of some types of cancer may occur.



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 Tagamet[®], Zantac[®] or Pantomed[®].

Medrol[®], which contains cortisone, may produce some swelling of your face 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 days. In the event of poor dental hygiene, the use of Neoral[®] may cause unpleasant swelling of the gums.

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. You also run a higher risk of vascular disorders. However, this risk can be reduced by not smoking and by adopting a reduced salt and reduced fat diet.

The number of pills you will need to take depends on your body weight and 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. Your medication will be reduced gradually over time. After a few months, you will only need to take half a dozen pills in the morning and at night. Your medication and its side effects will be discussed extensively during your stay at the hospital to receive your transplant.

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.

DIET

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.

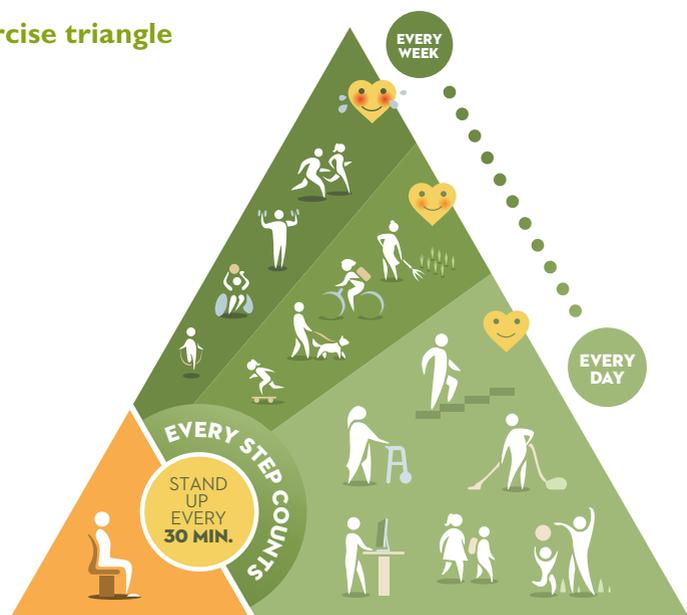
You will of course receive more extensive and personalised advice from your dietician at the nursing unit following your transplant.

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.

Exercise triangle



gezondleven.be

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PHYSICAL ACTIVITY TRIANGLE **GEZOND LEVEN**

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, 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 out-patient service.

Routine biopsies of your transplant kidney are the only way to detect 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.

USEFUL TELEPHONE NUMBERS, EMAIL ADDRESSES 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. Ben Sprangers

dr. Katrien De Vusser

dr. Amaryllis Van Craenenbroeck

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

prof. dr. Mauricio Sainz Barriga

- **Nursing unit 662 – abdominal transplant surgery and nephrology department**

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**

Julie Willems

tel. +32 16 34 86 20

julie.1.willems@uzleuven.be

- **Transplant consultant nurse**

Katleen De Bondt

katleen.debondt@uzleuven.be

tel. +32 16 34 13 80 or via unit 662 on tel. +32 16 34 03 25

- **Transplant coordinators**

Dirk Claes, Bruno Desschans, Nele Grossen,

Karen Denaux, Delphine Kumps

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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.

Make sure you watch our video about kidney transplants via: www.uzleuven.be/nl/het-traject-van-een-niertransplantatie.



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.

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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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