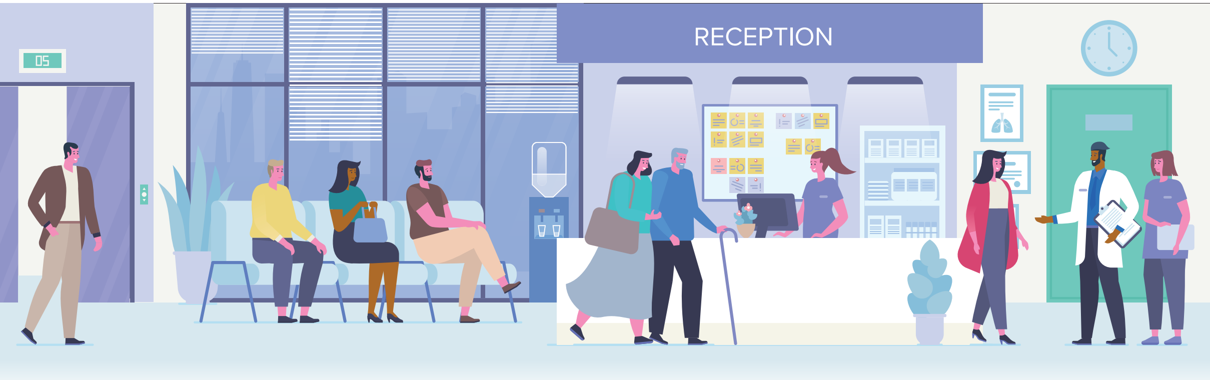
# **Preparing** for my **kidney transplant**

## Organ transplants save lives.

You have been referred for a kidney transplant because the function of your kidneys is impaired.



## INTRODUCTION

Our healthcare team has produced this pre-transplant information booklet to provide you with the best possible support and answer your many questions. Understanding what will happen before and after the transplant is extremely important. It is also essential that you ask all the questions that are troubling you throughout this process, which can be long and difficult.

Don’t be afraid to ask anything at all. Remember to write down all your questions, particularly as you read this guide, so that you don’t forget to ask them at your medical appointments, and so that you have as little to worry about as possible as you wait for your transplant. We have included pages for you to use to note down your questions at the end of this booklet.

During this period, the healthcare team at the transplant and dialysis centre is there to help and support you. Don’t hesitate to seek support from patient associations or, of course, from your family and friends.

This booklet is intended to help you throughout your care, before and after transplantation, and even in the long term. It has been designed to give you a clearer picture of the different stages of the transplant process, before, during and after the operation itself.

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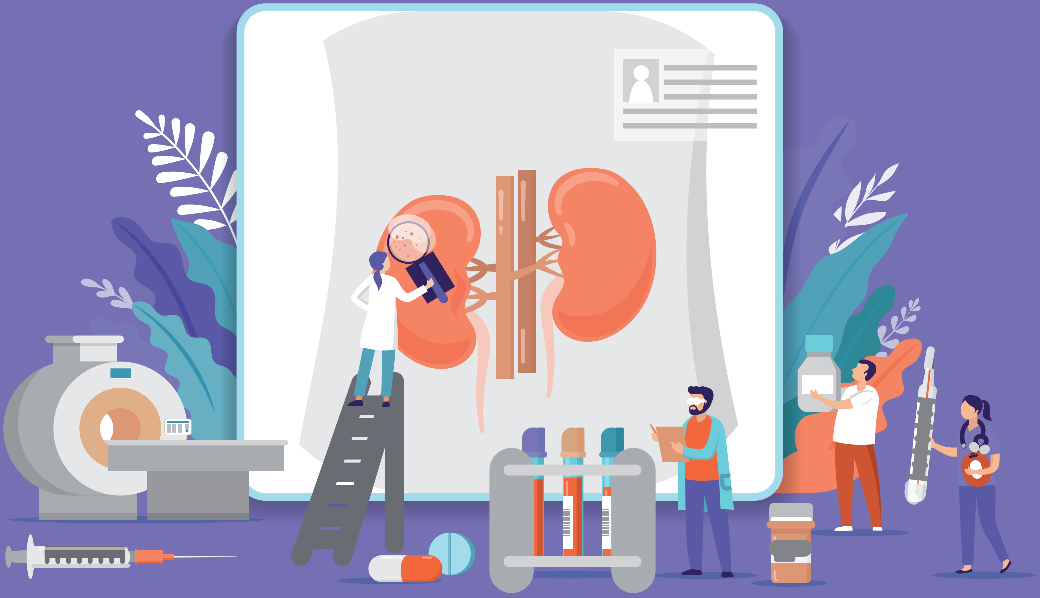


# 1 - KIDNEY FAILURE

Most people are born with two kidneys which filter the blood to eliminate waste products in the urine. They also maintain the balance of water, salt and potassium in the blood, regulate blood pressure, process vitamin D to enable calcium to be absorbed in the intestine and produce erythropoietin, which stimulates the production of red blood cells.

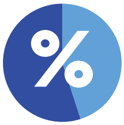
Chronic kidney disease (CKD) results in a progressive decline in glomerular filtration rate (GFR), the parameter used to assess renal function.

When the GFR falls below 15 mL/min, this is called end-stage kidney disease (ESKD). It is at this stage of the disease that a kidney transplant becomes necessary.[1]

**5 million**

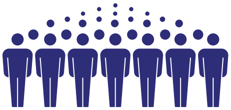
people in France suffer from chronic kidney disease

In 2022, around 93,000 people suffering from CKD received renal replacement therapy



**56 %** by dialysis

**44** are kidney transplant recipients.[1]



**22,585 patients are registered on the national transplant waiting list, including 11,666 on the active list on 1st January 2025**[1]

- In 2024, 6,034 transplants were performed
- **More than half** of these were **kidney transplants**[2]

# 2 - KIDNEY TRANSPLANTATION

Organ transplantation, one of the great medical adventures of the 20th century, is the only treatment capable of saving the life of a patient suffering from terminal failure of a vital organ such as the kidney, heart, lung or liver.[3]

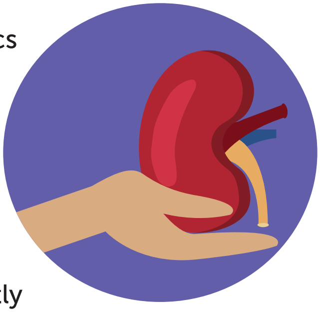
## WHAT IS A KIDNEY TRANSPLANT?

**A kidney transplant is the treatment of choice for patients with end-stage kidney disease.** It restores autonomous renal function and improves your life expectancy and quality of life, particularly compared with dialysis.[1,4,5] It is intended for patients who are already on dialysis or who have pre-terminal kidney failure but are not yet on dialysis (pre-emptive transplant).

It is the only treatment for end-stage kidney disease that allows all the kidney's functions to return to normal, and is only possible thanks to organ donation.

## TWO TYPES OF DONOR

- **The deceased donor.** The kidney is removed from a deceased patient whose brain has irreversibly ceased to function, but the vital functions of the other organs are maintained until removal. This is the most common type of donor for kidney transplants in France. Since 1 January 2017, all French citizens are automatically organ donors unless they opt out by joining the national refusal register.
- **The living donor.** Since 2011, the law on bioethics has made it possible to donate a kidney to a close relative, or even outside the family (see the following paragraph on 'Living donation').



Kidney donation is possible, even between people with different blood types. This type of transplant from living donors should be encouraged, as it significantly reduces the waiting time and increases the survival of the transplanted kidney by around seven years. The donation is freely consented to with no reward in exchange and 'no strings attached'.[1,2]

**The surgery adds the new kidney (from a deceased or living donor), in the lower abdomen on the front side of the body, without touching your own kidneys. It is described in detail in the section on surgery on page 24.**

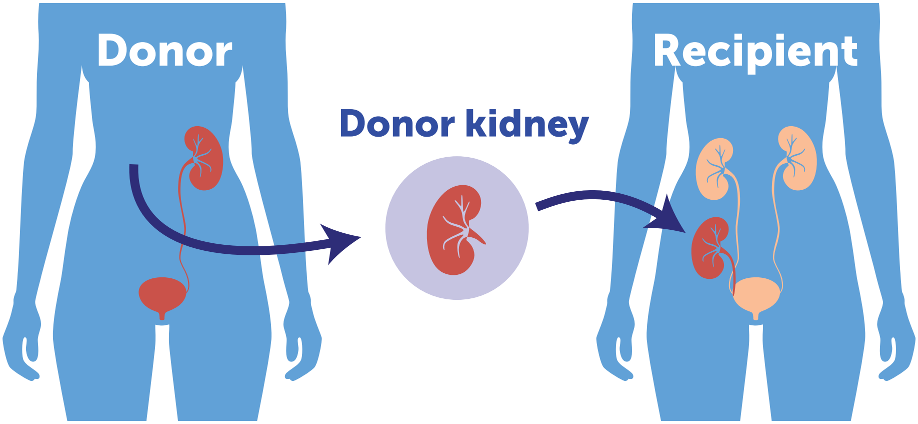
## LIVING DONATION

Transplantation from a living donor has many advantages:

- a shorter wait for a transplant, with less time spent on dialysis, or even no dialysis at all;
- better quality donor kidney and longer transplanted kidney life;
- less stress at the time of the transplant operation because everything is planned in advance and not as an emergency.

However, the conditions for living donation are highly regulated:

- only adults who are responsible for their own health can become donors;
- no one is ruled out outright as a potential candidate for donating a kidney to a relative;
- the donor may be the father or mother of the recipient, a spouse, a brother or sister, a child, a grandparent, an uncle or aunt, a cousin, or any person providing proof that they have lived together with the recipient for at least two years, or that they have had a close and stable emotional relationship with the recipient for at least two years;
- the donation is freely consented to with no reward in exchange;
- a full pre-transplant medical check-up is carried out to ensure compatibility and the absence of risk for the donor and recipient.



**For the donor, the transplant involves:**

- the risk of chronic kidney disease, which is higher than in the general population but remains very low at around 0.1%;
- the surgical risk, which is virtually zero and under control;
- no additional costs, as the cost is covered by the hospital centre where the kidney for transplant is removed and the national health service;[2]

- lifelong follow-up with nephrologists.

For more detailed information, please consult the specific information booklet for living donors. Don't hesitate to ask the healthcare team for it. You can also listen to or watch the podcast series on living donation using the QR code opposite:

## WHAT WILL THE BENEFITS OF THE TRANSPLANT BE?

**Stopping dialysis:** dialysis is no longer necessary when the transplanted kidney starts working. The new kidney performs the functions of your old kidneys. This means you'll generally have more energy.

**Improved quality of life:** having a kidney transplant can give you more time and more freedom than dialysis. It will be easier to take part in social and sporting activities, or to travel.

**Return to an almost normal diet.**

**Longer life expectancy.**

## WHAT ARE THE RISKS?

**However, it is also important to understand that, although a transplant is an excellent treatment option, there are side effects and risks.**

This treatment requires surgery and several days in hospital.

You will need to take medicine **called anti-rejection medication every day, once or twice a day at set times, as prescribed by your doctor**, to allow your body to accept the new kidney and not reject it. This is lifelong treatment, in any case for the duration of the transplanted kidney's life. It must never be stopped without medical approval.

These anti-rejection drugs have side effects.

**Post-transplant diabetes:** this is a frequent complication. Diabetes can develop or become unbalanced as a result of the medication. This situation may be temporary and regress after three months by making lifestyle and dietary changes (adapted diet) and adapting the medication. However, it can also be permanent, requiring chronic anti-diabetic treatment. In this case, it is highly likely that prediabetes already existed before the transplant but was masked by your end-stage kidney disease.

**Infections:** anti-rejection medication lowers the immune defences so that they do not reject the transplanted kidney. At the same time, lowering your immune defences increases your risk of developing an infection. However, it remains lower than in dialysis. That's why we strongly advise you to keep your vaccinations up to date, take preventive medication such as Bactrim®, and have regular blood tests to check for reactivation of certain viruses.

**Skin cancer:** this is the most common cancer in kidney transplant patients. The best treatment is still prevention, which combines effective, regular sun protection, avoiding exposure to the sun during the hottest hours of the day, and an annual visit to the dermatologist. This annual visit is an essential part of your post-transplant follow-up.

Finally, it is also essential to understand that transplanted kidneys have a limited lifespan and that **it is possible to receive several kidney transplants in the course of a lifetime**.

After fifteen years, 50% of kidney transplants are still working.

**To keep your new kidney in good health**, it is vital that you take an active role in your treatment.

This means taking your medication strictly every day, particularly your anti-rejection drugs, and having regular medical check-ups.

# 3 - PRE-TRANSPLANT ASSESSMENT

The pre-transplant assessment ensures that you have no contraindications to transplantation. **It is organised by your dialysis or transplant centre.** It can be carried out as an outpatient or day patient. It includes exhaustive blood tests, and a considerable number of imaging tests and scans.

After these examinations, the patient's situation is discussed by the referring pre-transplant nephrologists, the transplant coordination team, the psychologist, the anaesthetist and the urologist in order to give final approval for the transplant.

**The coordination team is there to plan, check and monitor this assessment.**

Coordination is provided by a team of nurses, the coordinators. Their role is central to organisation of the transplant. They are responsible for providing you with information, carrying out your pre-transplant assessment and ensuring that the pre-transplant process runs smoothly. It can be a long and complex process, but it is crucial to your future transplant. They will be with you every step of the way, from registration to transplant. They will put you on the waiting list and liaise with the Agence de la biomédecine, the French body which manages the entire kidney transplant waiting list and the allocation of transplants. They conduct some of the pre-transplant consultations.

They are your key contacts.

A coordinator is specially appointed to provide information, to answer questions and handle administrative problems relating to living donation.

Their contact details are (see ‘Useful contacts’ at the end of the brochure, p. 33):

**They can be contacted**
(see the “Useful contact” list at the end of the brochure) **:**

By telephone : **+33 (0)1 49 81 44 09** | **+33 (0)1 49 81 44 54**

By email : **coordination-de-greffe.nephrologie.hmn@aphp.fr**

By fax : **+33 (0)1 49 81 44 04**

**Each patient has a doctor and a nurse coordinator who corresponds with the referring doctor. However, any doctor or coordinator can answer your specific questions.**

The following documents are essential for your registration:

- a copy of your identity document;
- a copy of your ‘carte Vitale’ (French national health insurance card) or proof of health cover;

- a signed commitment to register exclusively at the Henri-Mondor transplant centre.

**Once your documents have been registered, your registration will become official and you will receive confirmation by post from the Agence de la biomédecine.**

## SPECIAL CASES

Depending on your blood type or pathologies, you may be offered other transplants to improve your access to a kidney transplant and reduce your waiting time for a transplant.

If you have blood group B, you may have to wait a long time. This protocol gives you access to a group A subtype 2 transplant if you have low levels of natural anti-A antibodies. These levels need to be monitored every three months to enable you to be included and remain in this protocol. This type of transplant does not increase the risk of rejection.

If you are a treated hepatitis C virus carrier (negative viral load), you may benefit from a transplant from a donor who is a treated hepatitis C virus carrier (negative viral load). There is no risk of transmission from the donor, and the results of transplants using these grafts are the same as those without hepatitis C.

If you are a treated HIV carrier (negative viral load), you may be able to receive a transplant from a donor who is a treated HIV carrier (negative viral load). There is no risk of transmission from the donor, and the results of transplants using these grafts are the same as those without the HIV virus.

These protocols will be proposed to you and are subject to your acceptance. Of course, not accepting will not affect your pre-transplant follow-up.

## FOLLOW-UP APPOINTMENTS

**These appointments can be carried out by the transplant coordinator or your referring doctor.**

First appointment: pre-transplant information, meeting with the coordinator, appointment with the referring doctor, blood tests and creation of the pre-transplant file.

Second appointment three to four months after the first to finalise the pre-transplant file.

Then every year to keep your pre-transplant file up to date. If your state of health requires it, these appointments may be more frequent.

In addition, a urology consultation is essential every one or two years, with an abdominal and pelvic scan less than two years old and a PSA test less than one year old for men over 50.

Lastly, an annual consultation with an anaesthetist is also essential with a cardiology check-up (transthoracic echocardiogram (TTE) less than one year old, a Doppler of the lower limbs and supra-aortic trunks, and myocardial scintigraphy less than two years old for patients over 50 or annually for diabetic patients).

**It is essential that you inform the transplant coordinator of any change in your state of health** (dialysis, hospitalisation, surgery, infections, etc.) **or of a change of postal address or telephone number.**

The pre-transplant file must be complete and up to date at all times while you are waiting for a transplant, as the transplant call may come at any time. If it is not up to date, the transplant cannot go ahead. The coordination team in collaboration of your dialysis centre are therefore there to help you update it, **but you remain the central figure in your transplant journey.**

# 4 - DAILY LIFE BEFORE THE TRANSPLANT

## ORGANISING YOUR MEDICAL FOLLOW-UP

**Each appointment is a special time** when you can express your questions and ask for support from the healthcare professionals working with you. The entire coordination team, nephrologists, psychologists, surgeons and other medical specialists are at your disposal during the difficult period of waiting for a transplant.[5]

**So that you don't find yourself worrying about unanswered questions or with anxiety, you can write down anything that concerns you between appointments,** for example:

- current symptoms (side effects, pain);
- questions about the treatment to come (fatigue, precautions to take, possible continuation of work, etc.);
- questions about the transplant itself (donation, waiting time, operation, results, etc.);
- previously unanswered questions (sexuality, family situation, employment, role of family members, etc.).

**Preparing for your appointments: Three practical tips**

- Write down all your questions in black and white before your appointments
- Don't be afraid to raise any subject at all with the healthcare team
- Ask the professionals to explain anything that is not completely clear again

# 5 - MANAGING THE WAIT

Coping with the uncertainty and anxiety associated with waiting is undoubtedly the main issue. However, we're here to support you and help you get through this period in the best possible way.

While you're waiting, never hesitate to:

- seek support from the department psychologist or patient associations;
- ask questions about the process, such as:
  - the protocol;
  - the donation;
  - the waiting times;
  - the return to normal life;
  - rejection: the best way to avoid this will be to take the treatment properly every day. To keep up with this new rhythm, you need to be prepared! You can discuss it with the medical teams. The more prepared you are, the easier it will be.

Our department organises meetings where you can discuss all these issues, for example in pre-transplant therapeutic education workshops.

You can make the most of this waiting time by taking part in therapeutic education workshops on the disease, future treatment, monitoring and on how the waiting list is managed.[9]

They are defined according to your needs. You can contact us if you feel you need to, or if you're simply curious to find out more.

**Several workshops are available:**

- 'Waiting for my transplant';
- 'Care plan to life plan (from dialysis to transplant)';
- 'My daily anti-rejection treatment';
- 'A balanced diet, weight and pleasure post-transplant';
- 'My 1st transplant anniversary';
- 'Women's health'.

Another workshop entitled 'The living donor journey' is also available.

Three times a year, we also organise a **donor café** on Saturday mornings for anyone who would like to find out more about the living donor process: patients on the transplant waiting list, potential donors, carers, relatives, etc.

The aim is to bring together people who have donated a kidney, or who are in the process of becoming a living donor, or who are wondering about the possibility of living donation. The donor café is an informal opportunity to share experiences about the unique experience of living kidney donation.

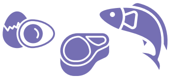
The presence of medical or paramedical staff guarantees the quality of the information provided.

**Staying in good shape while you wait**

- Try to be physically active
- Eat as healthily as possible
- Limit alcohol consumption
- Take all your treatments properly

## DAILY LIFE...

**To prepare your body during the wait,** you may be advised to adopt a diet adapted to end-stage chronic kidney disease, as shown in the diagram.

| KIDNEY FUNCTIONS | CONSEQUENCES | DIETARY ADVICE | |
|---|---|---|---|
| Remove waste products | Anorexia, nausea, vomiting | Limit your protein intake |  |
| Balance water and salt levels in the body | Rapid weight gain, oedema, shortness of breath, high blood pressure | Limit your salt and potassium intake |  |
| Maintain healthy bones and mineral levels | Arterial calcification and bone disorders | Limit foods that are high in phosphorus |  |

Adopt a balanced diet wherever possible, adding vegetables and fruit to your diet.

To protect your heart and arteries and make surgery easier, it is advisable to reduce fatty and sugary foods.

At the same time, regular exercise will help you stay in shape.

Control how much salt you eat.

These rules are important to adopt, and will become good habits you should continue after the transplant.

It's also important **to avoid putting on weight**. Surgery is more difficult if the patient is overweight, and being overweight can also contraindicate a kidney transplant if the body mass index (BMI) is over 35. A brochure giving advice on diet and physical exercise while waiting for a transplant is available.

In addition, to combat the cardiovascular risk and the risk of cancer, consider **giving up smoking now and maintaining or resuming regular physical exercise** (adapted to your age and physical condition).[6]

To help cope with material, administrative and financial constraints, it is important to find logistical and practical assistance during this waiting period. A transplant requires frequent medical care, hospitalisation and often prolonged leave from work. Certain treatments and transport may be reimbursed in full if you have been declared as suffering from a long-term illness.

It is therefore important to:

- **check that you have good health cover** (compulsory health insurance and top-up health insurance) and that everything is up to date for your declaration;
- **anticipate as much as possible** (professionally and financially) the sick leave required by the transplant (a minimum of three months).

You can meet the social worker at the hospital or transplant centre to review your health insurance (100% cover) and support paid by your top-up health insurance (in particular the daily rate for each day of hospitalisation), to plan for the period when you are off work (insurance covering your lost wage, etc.), to obtain home help or financial aid[7], etc. A local social worker (in France, from the Caisse centrale des activités sociales [CCAS], Conseil général (regional council), Sécurité Sociale (social security office), etc.) or a member of an association can also meet with you to discuss these issues.

### Social support

Remember to make a note of the department's social worker and contact them at the start of your process to discuss your rights with them.

- **find organisations to help you.** Whether you need help with shopping, housework or childcare, you can find help by discussing your difficulties with your GP, the hospital team or a patient association. It's vital to save your energy!

**Where can you find them?** Your team will be able to advise you on local organisations. Talking to other people waiting for a transplant is always beneficial and can allow you to share experiences, find out information and not ignore any of the problems that may arise throughout the process.[8]

**Associations can also be a great help in obtaining information on local aid, so don't hesitate to ask them:**

Renaloo

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# 6 - THE TRANSPLANT CALL

## HOW LONG WILL I HAVE TO WAIT FOR A TRANSPLANT?

From the moment you are registered on the transplant list (letter received at home), there are a number of rules that must be followed at all costs.

### The waiting time

**It varies greatly** depending on the transplant indications and the severity of your illness.

You will be monitored **at least every three months** (consultation, blood tests +/- imaging tests) by your referring doctor.

**If you have any problems,** consult your GP and/or nephrologist. They can keep the transplant team informed.

## BE REACHABLE AROUND THE CLOCK

**When you're waiting for a transplant, it must be possible to contact you** within a reasonable time. When the transplant call comes, you have a few hours to get to the transplant centre.

Even so, the fact that you are waiting for a transplant should not dissuade you from going away from time to time for a business trip, a holiday or a weekend.

## PLAN YOUR TRANSPORT FOR THE DAY OF THE TRANSPLANT

It is strongly recommended that you are taken to the transplant centre by your own means (with a relative), by taxi or by non-emergency patient transport. As soon as you are on the list, make sure your means of transport is available day and night.

If you are planning a trip further afield, it may be useful to contact your transplant centre in advance to inform the team of your travel plans.[10]

### The call

Being called does not always mean being transplanted.

## PRACTICAL ADVICE TO PREPARE FOR THE CALL

**Nobody knows exactly when the call will come.**

To prepare for the transplant call:

Make sure that the **transplant** and **dialysis centre** has **your number** and possibly **that of a relative**.

**Answer** your phone **every time it rings**. **Answer blocked** calls and calls from **numbers you don't recognise**.

**Continue** your **dialysis treatments**

**Plan** your **transport.**

**Think** of **who** might come **with you.**

**Pack** a hospital **bag**

### Checklist

Before leaving for the transplant, make sure you have:

- Your **Carte Vitale** (French national health insurance card)
- Your **top-up health insurance card**
- Your **identity document**
- The list of your **current treatments**
- Your **toiletries**
- Your **personal belongings**

## WHAT IF THE CALL DOESN'T COME?

There may be several reasons for this, but you should be aware that your place on the waiting list remains valid indefinitely.

It may happen that temporary contraindications prevent you from being on the active waiting list, which means that you are not eligible for a transplant. The team will of course do its utmost to eliminate any contraindications and return you to the active waiting list.

The waiting time varies according to your blood group and percentage immunisation, i.e. the number of anti-HLA antibodies you have, which may be present as a result of a previous pregnancy, transfusion or other transplant. The allocation of transplants is decided by a national algorithm which takes into account the date of registration on the list, the date of commencement of dialysis, your compatibility with the donor, your blood group and anti-HLA antibodies, among other factors.

**The shortage of donor organs requires a great deal of patience and means that you need to keep up your annual assessment to ensure that your file is always up to date. Never forget the possibility of living donation.**

# 7 - THE SURGICAL ASPECTS OF TRANSPLANTATION

Kidney transplant surgery takes place under general anaesthetic and lasts between two and three hours.

Once you are asleep, a urinary catheter will be inserted.

The surgical incision is usually made in the lower abdomen on the right. In order to carry out a kidney transplant, three ‘tubes’ need to be connected, a process known as anastomosis, so that the graft can function properly. The first two anastomoses involve the blood vessels, namely the renal vein and renal artery, which will be sutured to the external iliac vein and external iliac artery (large vessels in the lower abdomen). This will enable the blood to circulate in the transplanted kidney and keep it working. The third and final anastomosis involves the urinary tract of the transplanted kidney, which will begin to produce urine. The ureter of the transplanted kidney will be sutured to the bladder. As this suture is fragile, it is protected by inserting a small, flexible silicone stent, called a ‘double J stent’, into the ureter to help drain urine from the new kidney and aid the healing process. This double J stent is entirely internal and cannot be seen from the outside. It is removed after one month. This procedure is carried out during a urology consultation, by means of a bladder fibroscopy performed under local anaesthetic.

When you wake up, in addition to drips, you will have your urinary catheter and a Redon drain, which is placed in contact with the transplanted kidney and takes the form of a plastic tube coming out near the scar and connected to a collection bottle. The purpose of this Redon drain is to collect and drain away the various secretions (lymph, blood) and prevent them building up around the transplanted kidney. It can be easily removed on the ward by a nurse when it no longer collects much fluid.

The bladder catheter should be kept in for five days. It allows precise measurement of your urine output to check how the transplanted kidney is working, as well as keeping the bladder empty for five days so as not to stress the urinary anastomosis and thus promote healing.

Depending on the circumstances of the surgery, the scar may be closed with staples that will be removed on day 10 by a nurse, or with a self-absorbing thread.

After the operation, it is important not to carry heavy loads or take part in sport for a month to allow the muscle wall around the scar to heal properly.

# 8 - THE IMMEDIATE POST-TRANSPLANT PERIOD

The first few days after the transplant require continuous monitoring (medical, paramedical, blood and urine tests and ultrasound scans). Access to your room will be restricted to nursing staff for the first five days to minimise the risk of infection.

In some cases, the transplanted kidney may not start working again immediately after surgery, making it necessary to continue dialysis temporarily.

The average hospital stay is one to two weeks, sometimes longer in the event of complications. This will be an opportunity for you to meet the new team who will be looking after you after the operation.

## THE KEY POINTS OF THIS NEW PHASE

Anti-rejection or immunosuppressive medication is started on the day of transplantation (day 0) before you are taken to the operating theatre. It involves a combination of three different categories of drugs that work together to prevent your body from rejecting the transplanted kidney. These tablets are to be taken daily at set times throughout your transplant life. Rejection can occur despite treatment. This does not mean that the kidney stops working. Various drugs are available to treat this rejection.

## A HEALTHY LIFESTYLE

To avoid certain risks and complications associated with immunosuppression (anti-rejection drugs), precautions are recommended:

- maintain good hygiene (body, clothing, environment and use of hydro-alcoholic gel) to avoid infections;

- eat a balanced diet, eliminating sugary foods (especially in the first few months after the transplant) to prevent the onset of diabetes and weight gain;
- exercise as much as you can;
- avoid exposure to the sun and reduce or stop smoking and drinking alcohol to prevent cancer.

# 9 - FOR THREE MONTHS AND BEYOND

## ON LEAVING HOSPITAL

You will be closely monitored for the first three months. A nephrologist/advanced practice nurse (APRN)* will be responsible for your follow-up. Consultations and examinations are held at least once a week.

The weekly consultation is used to monitor your clinical and biological parameters and ensure that your treatment is well tolerated (clinical examination, weighing, blood pressure measurement).

Biological monitoring includes blood and urine tests and anti-rejection assays.

If an abnormality is detected, further tests may be required and hospitalisation is always possible, and quite common at this stage of the transplant process.

The nephrologists and APRNs work very closely together to provide you with optimum, individual care tailored to your needs.

* APRNs (nurses who have completed two additional years of study) carry out monitoring, guidance, prevention, screening and health education work, and help to improve access to care and the quality of patient care.

## AFTER THE FIRST THREE MONTHS

Your nephrologist will then determine the frequency of your follow-up according to your state of health.

From this stage onwards, you will be offered alternating follow-up with the nephrologist who treated you before the transplant.

Every year, you will return to the department for a major check-up - the ‘annual check-up’ - during which blood and urine tests will be carried out, as well as a Doppler ultrasound of the transplanted kidney and a chest X-ray. Other complementary examinations may be carried out outside the clinic.

# 10 - KIDNEY TRANSPLANT COORDINATION

## PRE-TRANSPLANT ASSESSMENT

A large number of tests must be carried out at the start of the transplant process and throughout its duration. These tests are necessary to detect and treat other diseases before the transplant:

- **chest x-ray**;
- **abdominal ultrasound**;
- **sinus scan** with an ENT appointment;
- **panoramic dental x-ray** with an annual appointment with a dentist;
- **cardiac ultrasound** to be performed annually before each appointment with the anaesthetist;
- **myocardial scintigraphy** every two years (for patients over 50) or every year for diabetics;
- **Doppler of the lower limbs and supra-aortic trunks** every two years;
- **abdominal and pelvic CT scan without injection** (with CD) every two years or every year depending on your state of health;
- **a haemoccult test** (colorectal cancer screening) to be carried out every two years (for patients aged over 50). The test is sent to the patient's home by the health service or provided by the GP;
- **PSA levels** (men over 50);
- **cervical smear** every three or five years;
- **mammography** every two years (women over 50);
- **viral serology tests** every year;

- **anti-HLA antibody tests** every three months (collected by the dialysis or transplant centre if the patient is not on dialysis).

## BEFORE THE CALL

Whether you have a living kidney donor or are on the waiting list for a kidney from a deceased donor, you need to be prepared for the day of the call for a deceased donor transplant. Here's a checklist of things to remember before that long-awaited call.

### 1 Make sure you are easy to reach

for a deceased donor transplant

**Give the transplant and dialysis centres your contact details and inform them of any changes in numbers. Add an emergency contact** and the number of reliable friends or family members.

**Answer your phone every time it rings.** Answer blocked calls and calls from numbers you don't recognise. It is absolutely vital not to miss that call.

### 2 Talk to the most important people in your life to get everything organised

Talk to your family and friends about your journey.
Ask them to organise a communication plan to keep each other informed of your progress during your future recovery.
If you are a religious person, consider talking to a religious leader in your community.

### 3 Make sure your finances are in order and organise important documents

Call your insurer to find out exactly what is covered.

Discuss financial issues with the social worker at your transplant centre or with a welfare worker to get help.
**Prepare a folder with all your important documents.**

### 4 Contact your employer

Let your human resources (HR) team and your manager know that you will be away.

Talk to them about how to maintain your insurance and benefits related to your job while you're away.

You should also find out about short- and long-term medical leave, family-related leave and the resources to which you are entitled in your specific case.

### 5 Take care of yourself and your home

Pack a hospital bag. Pack comfortable clothes, books and anything else you might need for your stay.

Ask a friend or family member to collect the mail, water your plants, look after other members of the household, look after your pets, etc. while you're away.

### 6 Make a plan when you receive the call

**Keep a notepad and pen next to your phone in case you need to take notes.**

Contact your family immediately to let them know that a kidney is available.

**Plan your transport.** Think of scenarios such as receiving a call in the middle of the night or when you're on holiday.

## ON THE ROAD TO YOUR TRANSPLANT!

As soon as you're on the waiting list, everything will revolve around that long-awaited call that will change your life. You need to do everything you can to be psychologically and physically ready.

### Day by day

Schedule medical follow-up appointments.

Organise your meals to comply with the lifestyle and diet rules that have been explained to you.

Plan activities, outings and get-togethers with friends and family to avoid isolation and make sure you get daily physical exercise.

Inform your GP and your coordination team of any changes in your state of health.

## Preparing for the transplant call

Be reachable day and night.

Inform your medical team if you are away for more than 24 hours.

Have a small bag ready for the hospital stay.

Know who to contact in an emergency to get you to hospital if necessary.

## Organise appointments and therapeutic education sessions

Check with a nurse coordinator to see what workshops are being organised in your area - there are so many!

# 11 - FURTHER INFORMATION

## USEFUL CONTACTS

| **Henri Mondor transplant department telephone numbers** | |
|---|---|
| Outpatient reception desk | +33 (0)1 49 81 21 11 extension 78109 or +33 (0)1 49 81 24 57 |
| Nursing station | +33 (0)1 49 81 22 62 |
| Day hospital | +33 (0)1 49 81 44 56<br>Day Hospital Coordinator +33 (0)1 49 81 24 74 |
| Pre-kidney-transplant coordinator | +33 (0)1 49 81 24 54 or +33 (0)1 49 81 44 09 |
| Email address | coordination-de-greffe.nephrologie.hmn@aphp.fr |
| Fax | +33 (0)1 49 81 44 04 |
| Hospital admissions desk | +33 (0)1 49 81 44 12 |
| Clinical Research Unit | +33 (0)1 49 81 44 08 or +33 (0)1 49 81 44 07 |
| Therapeutic education | +33 (0)1 49 81 44 03 or +33 (0)1 49 81 44 07 |
| On-call doctor (24 hours a day) | +33 (0)1 49 81 21 11 extension 36037 |
| Psychologist | +33 (0)1 49 81 24 61 |
| Social worker | +33 (0)1 49 81 24 71, by appointment |
| Dietician | Appointments made at the outpatient reception desk |
| Medical secretary fax | +33 (0)1 49 81 24 51 / +33 (0)1 49 81 24 52 |

## NEPHROLOGY ASSOCIATIONS

| | |
|---|---|
| **France Rein**<br>Fédération Nationale d’Aide aux Insuffisants Rénaux (French Federation for Patients with Kidney Failure) | **www.francerein.org** |
| **RENALOO**<br>Kidney disease and failure, dialysis and transplants | **www.renaloo.com** |
| **RENIF**<br>Ile-de-France nephrology network | **www.renif.fr** |
| **LRS**<br>Ligue Rein & Santé (Kidney & Health Association) | **www.rein-echo.org** |
| **AIRG**<br>Association for Information and Research on Genetic Kidney Diseases | **www.airg-france.fr** |
| **ADF**<br>French Diabetics Association | **www.afd.asso.fr** |

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