



# Informative leaflet to the public about Living Donation

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## Euro Living Donor **EULID**

European Living Donation and Public Health



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## **Kidney transplantation**

Kidney transplantation is the best treatment in renal failure. It is not the only treatment. Dialysis is the life saving procedure when the kidney function due to different kidney diseases is insufficient. When kidney transplantation a given organ is needed.

The advantage with a living donor is obvious. There is no waiting time. The recipient gets a good kidney from a healthy person. The surgery is planned and takes place when both recipient and donor are well prepared. A living donor also shortens the waiting time for the other patients on the waiting list.

## **Kidneys**

Kidneys are organs that remove waste products, salts and water from the body. The kidneys are also important organs regulating blood pressure, calcium balance in the body and formation of red blood cells that we measure as hemoglobin. Hemoglobin is needed for oxygen transportation.

Thus, when the kidney fails the blood pressure is high, the skeleton is poor in calcium giving osteopenia and the blood is anemic.

When kidney function is below 5% dialysis treatment or kidney transplantation is necessary. After a successful kidney transplantation immunosuppressive treatment is necessary to prevent rejection and this has to continue.

## **What does it mean to give a kidney? Can you live a normal life with one kidney?**

Most of us are born with two kidneys but there are some born with one. To have 2 kidneys means that there is a reserve capacity. If one kidney is removed the remnant kidney takes over and instead of 50% capacity, the kidney increases to get 75% capacity. This occurs immediately but recent research also shows that the capacity continues to increase during many years. There is no greater risk to catch a kidney disease having one kidney and the expected lifetime is normal or even longer compared to average people.

## **Who can donate a kidney?**

Today almost anyone who is legally competent can donate but this requires a clear motivation and a healthy donor according to the rather strict pre-donor investigations. The donation has

to be of free will and the kidney is a gift. It is not allowed to sell an organ for transplantation purposes according to law.

The most common donors today are:

- Parents
- Siblings
- Spouses

Less common are:

- Other relatives like uncles, aunts, grandparents, daughters, sons, cousins
- Friends
- Work mates
- Anonymous

Every transplantation centre has its rules for acceptance depending on cultural climate, experiences, policy.

The important thing is that the potential donor is taken seriously and if diseases or unwillingness appear during the investigation period fully respect and integrity is taken not to damage the donor and/or the relationship with the potential recipient.

### **Risks for the donor**

This is, of course, the crucial question. Should a healthy person be subject to a major operation such as removal of a kidney without any benefit to him-/herself? Operations always involve a risk. There is a mortality rate, estimated at around 0.03%. The most serious and life-threatening complications are major bleedings, blood clotting in the lungs, intestinal damage and heart attack. Published data show an incidence of such life-threatening of approximately 0.5-2%.. Less serious complications include urinary tract infection, wound infection, pneumonia, nerve damage, psychological problems, depression, severe post-operative pain, distal vein thrombosis, allergic reactions, heart problems, constipation, hernia and minor liver involvement. These occur in 15-40% of the cases, pain being the most common complication. The most important measures are those aimed at preventing such complications and treating them as quickly as possible when they occur.

Certain donors with high-risk jobs like divers, firemen should be considered with special care since the physical health is of utmost importance going back to their physical demanding jobs.

### **What are the long-term implications?**

With the flank technique to remove a kidney a few percent have developed long-standing pain. With the new technique removing a kidney with laparoscopic technique, long term pain is eliminated. After a couple of years donors can develop high blood pressure. Whether or not this is caused by the donation is an unanswered question. The incidence of high blood pressure, defined today as blood pressure over 140/90 mm Hg, increases with age and it is a higher incidence among males. Due to decreased renal function some donors get problems with gout and uric acid is high. The most important thing is that the reserve is lost. Looking at survival after a donor nephrectomy Scandinavian data has shown that “Living donors live longer”. The truth behind this finding is probably that the donors are a selected group of healthy people and it does not look like having one kidney shortens the life.

### **Are there any positive aspects of kidney donation?**

There are studies showing that donors have increased levels of self esteem. It is difficult to say whether this results from the donations themselves or is simply characteristic of people who are willing to donate. Life satisfaction is also related to transplant success. If everything went well, the donors felt better than people in general; if there were problems, the donors felt no better or worse than others.

### **Could really everyone be living organ donor of a kidney?**

No, of course not. You have to be healthy without any chronic disease. The potential donor cannot have:

- Kidney disease
- Subnormal kidney function
- Hypertension
- Cancer
- Heart disease
- COL chronic obstructive lung disease
- Hepatitis B or C or HIV
- Psychiatric disease
- Severe obesity
- Systemic disease like diabetes type I or II

### **Investigation- when and who does this?**

The investigation can start when the recipient has a chronic end stage disease and with a low function (around 15-20% of normal) but not necessarily in dialysis. It is the nephrologist of the recipient who knows who does the donor investigations. The first screening is made by measuring blood pressure, weight, height, and some blood and urine tests are generally taken. You are investigated by a doctor. He/she wants to know about your present health and if there have been any medical problems or events. The program is then usually run during several weeks with more sophisticated blood and urine tests (total 50 tests) and investigations (total 10). The investigations are focused on the kidneys and then heart-lungs, bleeding and thrombosis risks since a donor operation is major surgery.

A new visit to the doctor is made for information in an interactive way, when most investigations have been made. Information is also given by the social worker for social-economic subjects (see separate chapter). There should be no costs from your side. The time you spend away from work during investigations and later at surgery and convalescence should be compensated.

### **Donor investigations**

Blood pressure, height, weight, BMI

#### **Blood tests**

Blood group, cross-match, HLA-type

**Different blood status tests:** Hemoglobin, platelets, white blood cell counts

**Liver tests:** Enzymes, bilirubin

**Different kidney tests:** Creatinine, urea, Cystatin C, Electrolytes

**Different infection tests:** SR, CRP,

HCV, HBV, HIV, VZV, CMV (Different virus)

**Coagulation tests:** APC resistance, protein S, protein C, etc

**Other tests:** Cholesterol , Blood sugar

#### **Urine tests**

Status to catch sugar, hematuria, proteinuria, Urinary electrophoresis- for sub analysis of proteins in the urine, Microalbuminuria test, Culture

### **Investigations**

**Clearance-** to measure the renal function with an exact technique. A substance is injected and a blood test is taken after 3-4 hours. The clearance should at least be above 80 ml/min, higher in younger.

The substance injected is only eliminated through the kidneys.

**Split function-** to measure if the function is similar in left and right kidney. It is usually measured with a radionuclide substance injected. The substance is followed with a camera, screening the kidneys and the urinary pathways to the bladder. If one kidney has lower function this kidney is preferred for donation. It is important to drink fluid before the investigation.

**Ultrasound of the kidneys** – a simple test for screening the kidney size, presence of abnormal changes or cysts.

**CT angio Computed Tomography** of the kidneys. This is one of the last investigations to describe the number of vessels both arteries and veins to the two kidneys. It is made at the X-ray department. The results are important for the surgeons when deciding which kidney and what technique used at nephrectomy. The investigation also get information about the ureters at both sides, the bladder and the urine flow at both sides.

A kidney might have several arteries which mean technical problems not only to remove but to transplant which is the purpose.

The investigations start with injection of a contrast media usually in a vein in the arm. The contrast goes immediately to the kidneys so the investigation does not take long time.

Alternative investigation is **MR magnetic resonance** angiography. This is an investigation without X-rays but radio waves and strong magnetism. The person to be studied has to enter a long tube and when taking photos there is a strong noise. The investigation is more time consuming and is nothing for those with claustrophobia.

A third variant is the more classical **renal angiography**. In this investigation the contrast is injected in the femoral artery in the groin. There is a warm feeling when injecting and afterwards you have to rest in bed for a couple of hours with a pressure bandage at the injection site and blood pressure and pulse is usually followed.

**ECG electrocardiogram.** Simple test with electrodes on chest, arms and legs describing the rhythm and work of the heart.

**Stress-test. ECG at work.** This is a test made on persons above 50 years of age. The test person cycles a test cycle and ECG is taken during and after work. This tells us how the heart reacts when getting stressed by hard work and lack of oxygen.

**X-ray of lungs and heart.** This is a screening to find any pulmonary changes and/or heart size changes. These are usually remade day before nephrectomy as a preoperative check-up.

**Oral glucose test** – this is a test to detect if you have diabetes or tendency for diabetes. A sweet sucrose drink is served and then blood sugar tests are taken usually at certain intervals.

**Social safety- see separate chapter**

In special cases other tests could be added depending on sign and symptoms:

**Urine flow measurements:** At what velocity could the urine bladder be emptied? Also bladder scan with measurements of volume after voiding could be of value. This is to certify that there is no obstruction of urine. In men it could for instance be prostate hyperplasia.

**Lung capacity tests.** The total breathing volume and the peak flow, the velocity to exhale could give valuable information to detect obstructive lung disease. Important in smokers and ex-smokers.

**Ultrasound of the heart-** this is to detect cardiac insufficiency or different cardiac valvula problems

**Psychiatric consultation-** every donor should have a chance to talk and discuss with a psychiatrist but this is not generally done. It is made if needed and in case of friend donation or donations outside the family, for sure in anonymous donations.

## **Decision**

After all investigations you will see the doctor for a concluding talk and information. All documents will be sent to the Transplantation Unit for discussion and final decision. There is a probable statement about acceptance but the formal decision is taken by a team with the transplant surgeon, transplant physician and coordinator involved. At acceptance a suggestion of time for surgery will be given.

The aim is then that both the donor and the recipient are in good “health” at time of planned surgery. Usually both are admitted to hospital one or two days before the donation and transplantation. There is investigation of preoperative tests and X-Ray and ECG. Both have to meet the anesthesiologists, the surgeons, the physiotherapists, the nurses and the doctors in

charge of the patients at ward. You have to sign a document that You donate of free will. Usually the surgeon involved will sign the paper too. The law requires this document.

### **Acceptance criteria**

The criteria change from time to time and place to place. There are two aspects. What could you accept from a medical- risk perspective from the donor? What could you accept with the transplant success in focus?

The acceptance criteria are easy when you keep a strict policy, just accepting healthy people without any diseases or medication and good renal function. If people are accepted with treated hypertension, obesity, etc. there might be problems in the future. The donors have to be more checked. Around 1% regrets the donation and it is important the donation is of free will.

### **Surgical technique to remove the kidney**

There are two major techniques, the open and the laparoscopic, to remove a kidney.

#### **Open technique**

It is an old technique to remove the kidney through a flank incision either the left or right kidney. Big muscles are divided and sometimes a part of the rib has to be removed to get out the kidney. The known complication with longstanding pain and nerve damage occurs in 1-5%.

An anterior technique to remove the kidney is a less painful way to remove the kidney which has been preferred by many centers. The scar is more at the front of the upper abdomen.

The laparoscopic way of removing a kidney is coming more and more. Three ports in the abdomen are created: one hole for camera, one for cutting instrument and one for blood hemostasis instrument. The surgeons work in front of a camera. The abdomen of the donor is filled with gas during surgery to make the kidney visible. This could create some malaise and pain in the shoulders shortly after surgery. The kidney is removed through an incision 6-7 cm long and the kidney is removed with special instrument in a sterile sac.

#### **Postoperative ward**

The donor has pain but the recipient gets better and better each day with a new kidney getting away with all toxins.

Your general status is checked every day and you will become better and better. Blood pressure, blood tests are taken and pain relievers are given. The first day you will have drip and are not allowed to eat. The urine catheter is removed the day after surgery if possible. It is important not to stay in bed but try to move around. The personal will help you. It is good to move to decrease the risk of thrombosis and to prevent constipation which could be a problem with different pain-killers. Rather soon you can eat and feel better and come home.

### **At home again**

It takes some weeks for wound healing. You should not carry heavy things but do easy things. Taking a walk daily and relax. Most donors get very tired. They are not used being unhealthy. They get tired after very little endeavor. This is normal. Do not get panic! With time the recovery will be there. The time for sick-leave is usually a couple of weeks.

### **Is follow-up recommended?**

We recommend simple check-ups measuring blood pressure, kidney function tests and urine tests every year, body weight. It is the responsibility of the donor investigating centre to arrange this in a practical way.

### **Register**

In many countries there is now from EU –European parliament- a recommendation to keep a donor register. This register is a quality and surveillance register and every country has to organize the data gathering. Within this EULID group we have aimed to stimulate a creation of an organ donor register and the following data should the register contain:

- First initial of donor given name
- First initial of donor family name
- Gender
- Year of birth
- Donor country of residence
- Nationality of recipient
- Recipient country of residence
- Relationship of donor to the recipient
- Type of donation

- Organ donated
- Date of donation
- Centre for donation
- Centre for follow-up
- Post operative outcome

General recommended data for both living kidney and liver donors

- Date of follow-up
- Status
- Weight in combination with height

Specific recommended data for living kidney donors

- Creatinine
- Proteinuria
- Systolic blood pressure (together with diastolic blood pressure)
- GFR (calculated automatically)
- Surgical reintervention
- Pain requiring treatment
- Wound complications requiring treatment
- Psychological complications requiring treatment
- Hypertension requiring treatment
- Needed to be transplanted

Specific recommended data for living liver donors

- Total Bilirubine, AST, ALT, Alcalic Phosphatase, Gamma GT, Total protein
- INR.
- Surgical reintervention
- Pain requiring treatment
- Wound complications requiring treatment
- Psychological complications requiring treatment
- Hypertension requiring treatment
- Needed to be transplanted

Sometimes the donors feel they do not get any thank you or back-up from the society. The recipients are checked and backed-up all the time but the donors have been neglected. The donors are taken for granted.

## **Liver transplantation**

Liver transplantation is the only treatment in chronic liver failure. Also in acute liver failure with necrosis of the liver an acute liver transplantation is life saving. There is no type of dialysis for long-term use like for those having chronic kidney disease.

A liver transplantation is more demanding than kidney transplantation. The diseased liver has to be removed before the new organ is transplanted and the surgery takes many hours.

## **Transplantation with living donor**

The liver has two lobes, the right which is bigger and the left which is smaller. Due to its segmental anatomy, it is technically feasible to divide a liver. For maintaining metabolic demands and normal function, the recipient requires a liver graft of approximately 1% of the body weight or more. For a child who needs liver transplantation the lateral part of left lobe is enough. For a grown-up recipient the right lobe must often be used to provide sufficient volume.

The death hazard risk for a liver donor has been estimated to 0,5% thus the risk is 10 times higher compared with living kidney donor surgery.

Indication for living donor living transplantation is mainly small children with congenital diseases and then the parents donate a part of left lobe which is enough. Acute liver failure may also be an indication for living liver donation when it is hard to find a deceased donor quickly. In case of cancer in the liver when increased waiting time means risk for spread of cancer living donor transplantation can be of particular value. For adult recipients the larger right lobe is necessary.

## **Risks short term and long-term for the donors**

To remove left or right liver lobe is major surgery. Left lobe means removal of segment 1-2 which is around 300 mL of hepatic volume. Right lobe means removal of segment 5-8 which is around 1000 mL volume. Leakage of bile, risk of bleeding, infections, severe pain from the abdomen and thromboembolic events are early complications, which occur in 10-20% of the donors. Complications leading to death which has been reported from both USA and Europe are caused by septicemia, pulmonary embolism and severe bleeding or liver failure.

Long-term problems exist in a few percent with long standing pain, gastritis. However, the

liver is unique for its ability to regenerate. The donor liver is restituted to 95% whatever size of removed mass. This recovery occurs rapidly in the first three months after donation. Liver tests long term after a donation does not reveal that a donation has occurred. Almost every test is normal which is in contrast to a former kidney donor.

### **Investigations**

The investigations are the following:

Blood tests for liver function and general tests: ASAT, ALAT, bilirubin, ALP, albumin, INR hemoglobin, leucocytes, platelets, blood sugar, amylase, electrolytes, creatinine

Coagulation tests: APTT, AT-III, protein C, protein S, APC resistance, B-Protrombin-genotype

Blood group, HLA-typing

Virus tests: HBV, HCV, EBV, CMV; HIV

Height, weight, ordinary medical history and status including blood pressure

ECG

X-rays of the lungs

Ultrasound liver with Doppler

CT liver or MR angio liver and a MR Cholangiography to determine the size and volume of the liver and the parts to be removed

Anesthesia consultation

Consent and information from the surgeon

Information from the social worker

Preoperative physical therapy

### **Surgery**

Liver donation is usually performed through an upper subcostal incision. The liver lobes are freed from the surrounding ligaments and tissue, thereafter the major vessels and biliary structures entering and leaving the liver at the hilus is dissected and isolated at the side which is to be removed. After division of the liver tissue, the bile duct is cut and the blood vessels

are clamped and the donated part of the liver is removed and flushed with cold solution to preserve the tissue. A drain will be put in to collect any fluid collections or small amounts of bleeding at the cut surface.

### **Postoperative care**

The donor will stay in the ICU at least until the next day. After transfer to a regular surgical ward, most patients can start to drink and eventually eat gradually. It is of great importance that the patient is mobilized out of bed as early as possible. Blood tests are performed on a daily basis during the first days, and pain management is usually by epidural analgesia for the first 4-5 days, which is then gradually replaced by oral analgesics. Most patients require a hospital stay of about 7-10 days following the procedure. Skin sutures can be removed 2 weeks after the operation, but the healing of the wound requires 6 weeks. During this time, the donor should avoid lifting and strenuous work, but can maintain activities like walking to get exercise. The required length of sick leave might vary greatly between individuals, but a period of 8-12 weeks can be expected in most cases.

### **Long-term follow up**

The Liver donor should be followed at three month intervals with clinical examination, blood tests (liver function tests) and ultrasound of the liver at 3 and possibly at 6 and 12 months. If, at any time in the postoperative period, signs of complications or irregularities occur, the donor should make contact with the transplant center in order to have an extra evaluation. Thereafter, it would be optimal to have a follow-up investigation but the practice regarding long term follow up varies among liver transplant centers and we have no recommendations. The most important is optimal liver surgery.

## **Social insurance and protecting systems for the living donor**

The *living donors* should be covered within the systems and our recommendations are given separately.

Social insurance aims to provide security at every stage of life. Throughout the 20<sup>th</sup> century reforms were gradually introduced and there is still room for improvements and equal rules within EU.

### **Social protection for the living donors – practice today and guidance for tomorrow**

#### **Could the donors have sick-leave after their donation?**

Generally the donors should have right to sick-pay.

#### **Who pays?**

It is common that both employer and official authority share the paying. We recommend that there should be one paying instance for the donors.

#### **Are there any limitations to get private life insurance for a donor?**

A donation as such should not be a reason for denial of life insurance. On the contrary. With the knowledge that donors live longer this is settled.

#### **Are there any limitations to get mortgage after a donation?**

There are no limitations.

#### **Are there patient insurance systems that could be used by the donors in case of complications during surgery or afterwards?**

The patient insurance system is a system where the patients could get paid for complications that are not foreseen. Only Sweden Norway, Italy, France and UK seem to have this law. If existent, this patient insurance system could be used and should be used by the donors. Of course this is an important protection that gives all donors chance to get money in case of injury.

**What about systems for reimbursement? Does this exist for the donors?**

Reimbursement systems for the donors exist in countries with long experiences with living donors. It should exist in all countries to facilitate the treatment of living donors. They are patients for very short time and it has to work. The donors get tired after the surgery and have not the capacity to work or claim their rights.

**Should the donors get paid for the transportations to and from hospitals at the investigations and surgery and check-ups?**

Yes, every country should have this rule. The donors do their surgery not just for their beloved kidney diseased relatives or friends but also for the society saving money in the long run. The donors need this type of service.

**What about donor investigations? Who pays for these?**

We recommend that the donor should not pay at any time not even at the check-ups after the donation even the long-term check-ups. This is the payment back from the health care system.

**What about the lack of income due to investigations? Who pays for this?**

This should be compensated. This is our recommendation.

**What about costs for medication?**

The countries have different policies on this issue. We recommend cost compensation

**Is it possible to get reimbursement for social arrangements necessary around the donation procedure?**

It could be for instance farmers who need that having animals or parents who need help with household and children. As with all compensations for expenses a written verification is needed to show the costs.

Leaflet developed in the context of the EULID project, which has reached a consensus and recommendations for common European Standards to guarantee the health and safety of organ Living Donors.

## Authors

<b>Ingela Fehrman-Ekholm</b>	Sahlgrenska University Hospital	Göteborg, Sweden
<b>Pål-Dag Line</b>	Rikshospitalet	Oslo, Norway
<b>Niclas Kvarnström</b>	Sahlgrenska University Hospital	Göteborg, Sweden
<b>Danica Avsec</b>	Slovenija Transplant	Ljubljana, Slovenia
<b>Alessandro Nani Costa</b>	ISS-Centro Nazionali Trapianti	Rome, Italy
<b>Carlo De Cillia</b>	ISS-Centro Nazionali Trapianti	Rome, Italy
<b>Claudio Rago</b>	ISS-Centro Nazionali Trapianti	Rome, Italy
<b>Paola di Ciaccio</b>	ISS-Centro Nazionali Trapianti	Rome, Italy

## Project coordinators:

<b>Martí Manyalich</b>	Hospital Clínic de Barcelona	Barcelona, Spain
<b>Assumpta Ricart</b>	Fundació Clínic per a la Recerca Biomèdica	Barcelona, Spain
<b>David Paredes</b>	Universitat de Barcelona	Barcelona, Spain
<b>Jordi Vilardell</b>	Hospital Clínic de Barcelona	Barcelona, Spain
<b>Chloë Ballesté</b>	Universitat de Barcelona	Barcelona, Spain
<b>Irene Martínez</b>	Fundació Clínic per a la Recerca Biomèdica	Barcelona, Spain

## Associated partners

<b>Rosário Caetano Pereira</b>	Centro Hospitalar do Porto	Porto, Portugal
<b>Leonídio Dias</b>	Centro Hospitalar do Porto	Porto, Portugal
<b>Christian Hiesse</b>	Hôpital Necker	Paris, France
<b>Christophe Legendre</b>	Hôpital Necker	Paris, Francia
<b>Jarosław Czerwinski</b>	POLTRANSPLANT	Warsaw, Poland
<b>Agnieszka Krawczyk</b>	POLTRANSPLANT	Warsaw, Poland
<b>Dorota Lewandowska</b>	POLTRANSPLANT	Warsaw, Poland
<b>Janusz Wałaszewski</b>	POLTRANSPLANT	Warsaw, Poland
<b>Garabet Khasho</b>	Paraskevaïdon Surgical and Transplant Center	Nicosia, Cyprus
<b>George Kyriakides</b>	Paraskevaïdon Surgical and Transplant Center	Nicosia, Cyprus
<b>Andy Maxwell</b>	UK Transplant	Bristol, UK
<b>Victor Gheorghe Zota</b>	ANT Fundatia Pentru Transplant	Bucarest, Romania
<b>Rosana Turcu</b>	ANT Fundatia Pentru Transplant	Bucarest, Romania
<b>Frank Van Gelder</b>	Institute for LifeLong Learning-IL3	Barcelona, Spain
<b>Gloria Páez</b>	Institute for LifeLong Learning-IL3	Barcelona, Spain

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