

BEAUMONT HOSPITAL

www.beaumont.ie/kidneycentre



THINKING ABOUT DONATING A KIDNEY?

BOOK 4

3rd Edition





IRISH KIDNEY ASSOCIATION (CLG)

The Irish Kidney Association CLG, Company Limited by Guarantee, is a national voluntary organisation of patients, family carers and supporters which offers support to people living with and affected by end stage kidney disease. Through its 25 local branches, patients can meet other kidney patients and share experiences, problems and, most importantly, solutions.

The Irish Kidney Association Head Office is located in 'Donor House' in the west of Dublin. The office is the main administrative and service centre for the Association. The staff is made up of Chief Executive, Accountant, Patient Support Manager, Office Manager and Personal Assistant to CE, National Advocacy & Projects Manager, Coordinator of Counselling Services, Dialysis Holiday Coordinator, Digital Media Coordinator, Receptionist, Support Centre staff and Administration staff. Individual names and email addresses for the staff are available on the IKA website.




Our Support Centre, in the grounds of Beaumont Hospital, which offers on-campus accommodation for kidney patients and their families attending any Dublin hospital and short-term accommodation for the families of seriously ill patients from outside the Dublin area.

IRISH KIDNEY ASSOCIATION CLG

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 [IrishKidneyAssociation](https://www.facebook.com/IrishKidneyAssociation)

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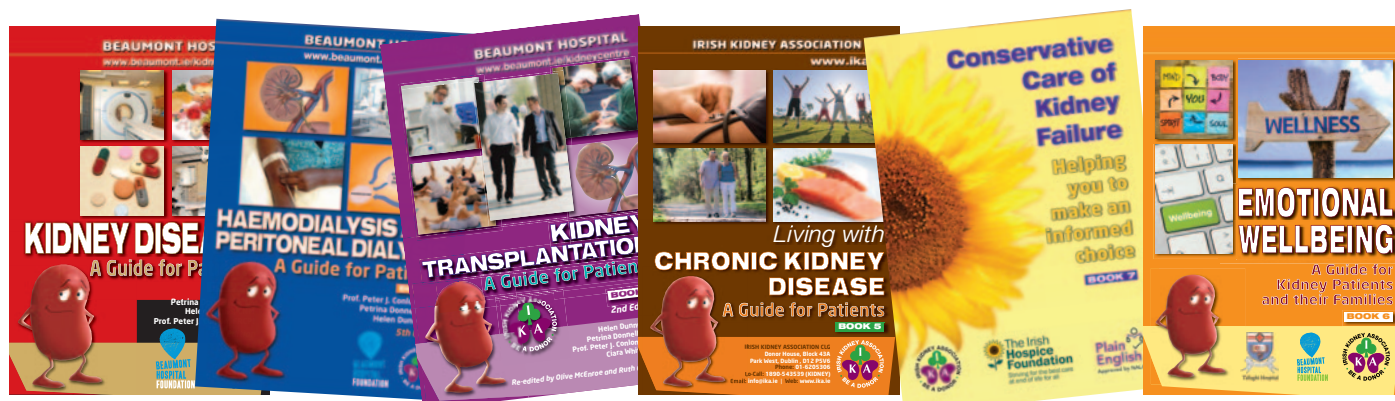
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PREFACE

For people with kidney disease, the treatment options are dialysis and, for suitable patients, transplantation. Kidneys for transplantation come either from people who have donated their organs after death or from a living donor. A living donor is usually a relative, spouse, or close friend.

This is the third edition of **BOOK 4**, which addresses the area of the 'living donor' programme. It has been written so that people who are considering living donation can have the opportunity to read about the risks, benefits, investigations, procedures and follow-up associated with donating a kidney. Everything covered in the book will be discussed with you, in person, by the medical staff. The book is in no way a replacement for face-to-face communications between the transplant team, the potential donor, the recipient and their families.



If you wish to learn more about chronic kidney disease, dialysis or transplant treatment options, you can consult the other books in this series addressing these topics. **BOOK 1** deals with the functions of the kidney, types of kidney disease, diagnostic tests and medicines used to treat kidney conditions. **BOOK 2** deals with haemodialysis and peritoneal dialysis. **BOOK 3** covers kidney transplantation in more depth whilst **BOOK 5** is aimed at helping patients with kidney disease learn more about their illness and is specifically written for people who have been informed that they have impaired (or reduced) kidney function and are classified as having Chronic Kidney Disease (CKD). **BOOK 6** aims to help patients and families maintain their emotional health in the face of what can be a serious illness and **BOOK 7** explains what the treatment option of conservative care of kidney failure means, helping patients make an informed choice.

More information is available from the transplant team at Beaumont Hospital, Phone: (01) 8093119 or from: <http://www.beaumont.ie/kidneycentre>

We do hope you find it helpful.



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IKA Renal Support Centre

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The books have been printed and distributed by the Irish Kidney Association (CLG). Further copies are available from IKA, Donor House, Parkwest, Dublin, D12 P5V6. Phone: 01-6205306 or 0818-543639.

The information contained within this book is correct at time of going to press. This book essentially pertains to the practices at Beaumont Hospital. Other Kidney Units may use different practices. This book should be used as a guide and reference tool only.

CHAPTER 1

LIVING DONATION

A successful kidney transplant is often the best treatment for people with end stage kidney disease (ESKD). A kidney transplant provides the best opportunity for good long-term health. It can also offer better long-term outcomes than dialysis, which is the other major treatment option for people with end stage kidney disease.

In Ireland, the majority of transplanted kidneys come from people who have been declared brain-stem dead. This occurs in hospital intensive care units and is often the result of an individual's sudden death. When a person's organs are offered for donation, after their death, that person is known as a 'deceased donor'. Research suggests that living kidney donation might offer a number of advantages to the recipient when compared to a deceased donor transplant (*see list below*).

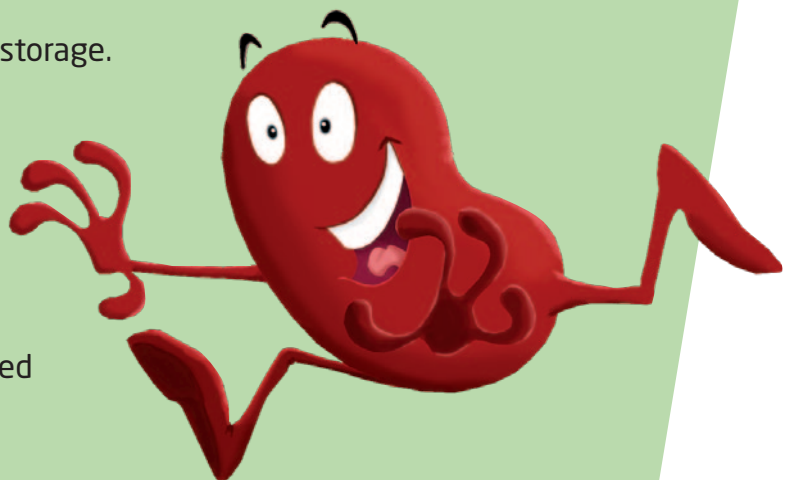
Since the genetic make-up of families can be similar, or more rarely identical (as in the case of identical twins, the chances of the recipient's body rejecting the donated kidney is less with a donor kidney from a family member. Some of these advantages of living kidney donation are also true

for donors who are not genetically related to the recipient, such as husbands or wives. It is, therefore, worth exploring the possibility of a non-related living donor if this is an option for a person in need of a kidney transplant.

"A kidney transplant provides the best opportunity for good long-term health."

SOME OF THE ADVANTAGES OF LIVING DONATION ARE AS FOLLOWS:

- The transplant can be planned in advance.
- The transplant can occur earlier, so the recipient may spend less time on dialysis or even avoid dialysis altogether.
- The donated kidney spends less time in storage.
- Donor-recipient tissue matching can be better, which might mean a lower chance of the kidney being rejected by the recipient's body.
- Long-term results are better for the recipient, when compared with a deceased donor kidney.



WHAT DOES A POTENTIAL LIVING DONOR NEED TO CONSIDER?

Someone who is thinking about donating one of their kidneys to help a loved one has many things to consider. The medical staff will need to do a complex series of tests, which may take quite a long period of time. This is to make sure that the donor is in good physical and mental health and that their kidney is suitable for transplantation.



"One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will adversely affect them in later life."

One of the most frequent concerns of potential living kidney donors is whether the loss of one kidney will adversely affect them in later life.

A healthy person can live a completely normal life with only one kidney; indeed, some people are born with only one kidney. If a kidney is removed, the remaining kidney increases slightly in size and capacity, and can carry on the function of two kidneys. This means that it is possible to remove one kidney from a **healthy** living person and transplant it into someone who needs it, with minimal ill effects on the donor other than the surgery itself.

THE RISKS AND BENEFITS

Studies have concluded if donors are carefully selected and screened the risk of experiencing serious problems (such as kidney disease later in life) from donating a kidney is very low. There is sometimes a slight rise in blood pressure or increased loss of protein in the urine for the donor, but this does not usually impact on the donor's health in the long-term.

The renal unit at Beaumont Hospital plans to follow-up all living donors, on an annual basis, for life so that any health issues can be detected at an early stage. These issues will be discussed in more detail throughout this book.

It is worth remembering, however, that the operation to remove a healthy person's kidney carries the same risk as any major surgical procedure. Although all possible precautions are taken, there are always risks when undergoing surgery.

There are also practical issues that need to be considered, such as the time taken off from work for the investigations and after the operation. It is also important to consider domestic responsibilities and practical arrangements, such as looking after children.

In addition, a number of investigations are performed that may uncover a previously unknown medical condition

PEER PRESSURE

Pressure on the donor from other family members can be an issue. There may be pressure to donate a kidney to a family member who is unwell, even if the donor is not entirely sure that it is the right thing for them to do.

For donors, it is therefore important to **consider all these issues before you even volunteer for the initial tests**. It can be harder to think clearly about the issues once, for example, you are told that your kidney could be a suitable match for the recipient.



WHO CAN DONATE A KIDNEY?

RELATIONSHIP

A wide range of people can consider becoming a living donor for a loved one. These include a close relative, spouse, partner, or close friend who has demonstrated a long-standing emotional relationship with the recipient.

Donors are usually brothers, sisters, partners or parents of the recipient, and, less often, they are relatives such as uncles, aunts, grandparents, sons or daughters.



AGE AND WEIGHT

Potential donors should preferably be 25 years of age, or older, though in some circumstances donors aged from 23 years may be considered. There is no strict upper age limit for potential donors, but an older person is less likely to pass the medical examination for potential donation, given that advancing age can bring more medical issues. The outcomes are generally better for recipients when the donor is similar in age to them. Similarly, a slight person who is of low body weight might not be the best donor for a large person of strong build. Each case will be considered on an individual basis by the transplant team and decisions made accordingly.



FAMILY ISSUES

Although one might think that most family members would want to give a kidney, life is not always so simple. Donation between siblings, for example, can present a variety of family and emotional issues.

The problems are usually less complex for parents donating to children, but even here, loyalties may be divided between a desire to provide for one child, whilst inevitably depriving other children of one parent for a period of time.

This is not a trivial consideration, since the transplant operation might come after a long illness for the affected child, during which time other children may have felt deprived of their share of parental love.

Parents, as with all donors, must also face up to the possibility that the kidney might not function. This can be a very difficult complication for both donor and recipient.

Finally, there may be conflict between the parents as to who should give a kidney.

THE TEAM'S PERSPECTIVE



The transplant team is fully aware of all the issues (psychological or otherwise) involved in living kidney donation.

Therefore it is very important that, before volunteering, and throughout the assessment process, close members of the family fully understand the process and consider all the risks and implications.

It is important to openly discuss how everyone feels, especially how people might feel if the kidney were to fail and the disappointment that may cause.

It is also important to consider the financial implications of donation, such as salary protection whilst out of work, life insurance, and mortgage repayments. The government has

introduced a scheme to reimburse some out-of-pocket expenses associated with being a living kidney donor.

For further details on this scheme see page 30-31.

CHAPTER 2

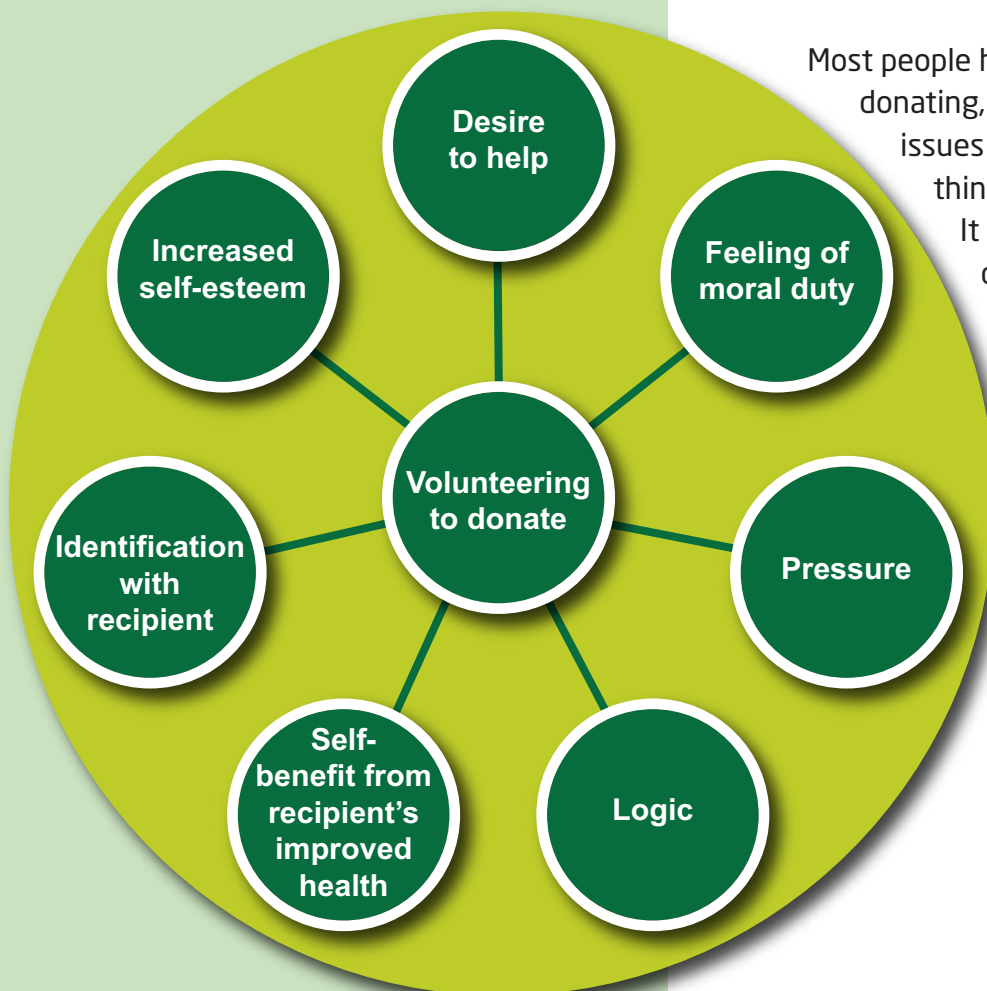
WHY BECOME A LIVING DONOR?

Individuals volunteer to donate a kidney for a variety of reasons. Often donors are motivated by watching someone close to them wait a long time for a transplant or seeing a loved one suffer in some way as a result of kidney problems.

Other reasons for wanting to donate a kidney include: feeling a duty to do something for a loved one who is unwell or feeling that it will benefit the donor's life to have their loved one free of dialysis. Research shows the reasons for donating can vary, as shown in the chart below.

While all these motives might be acceptable reasons to be a donor, more complex reasons can also be involved, such as:

- Offering to donate a kidney because of feeling **pressure** from others (e.g., family members), perhaps because the situation seems urgent, or it appears that the ill person has no other options.
- Offering to donate because of **feelings of guilt**, or feeling that it is your duty as a close relative/friend.
- Offering to donate to **"right" past wrongs**, to feel good about yourself, or to feel closer to the person to whom you are donating.



Most people have a number of reasons for donating, and it is normal for different issues to come up when you are thinking about becoming a donor. It is important that these are discussed openly during your donor work-up, and this discussion forms part of your meeting with the team, particularly the psychologist.

"Individuals volunteer to donate a kidney for a variety of reasons."

HOW CAN I VOLUNTEER?



Direct personal communication is the key to making sure the process of assessment for living kidney donation goes smoothly. This is true both for donors and for recipients.

If you want to be considered as a potential kidney donor, for a friend or family member, you will need to make direct contact with the Kidney Transplant Office at Beaumont Hospital and ask to speak with one of the Kidney Transplant Co-ordinators.

Phone number is **01-8093119**.

It is important to be aware that we will not commence the evaluation of a potential living donor until the recipient has been evaluated by the transplant team. This usually means that a potential recipient must be suitable for transplant and must be on the active waiting pool **for a deceased donor kidney**. It is important to discuss your wish to donate a kidney with the potential recipient, since we cannot evaluate a potential donor until we have the consent of the recipient to do so.

WHAT MAKES A SUITABLE LIVING DONOR?

Before the medical staff can agree to anyone becoming a living donor, they must be satisfied that the donated kidney is unlikely to be rejected by the recipient's body. They also need to ensure that the person, willing to be a donor, is unlikely to suffer ill health as a result of making the donation.

BLOOD GROUPS

Most people are familiar with the fact that red blood cells have a specific type or group: A, B, AB, or O. In general, for successful direct transplantation, the blood group of the potential donor must be compatible with that of the proposed recipient. So, before anything else, the blood group compatibility of donor and recipient must be tested.

The different pairs are shown below:

Recipient Blood Group O	Recipient Blood Group A	Recipient Blood Group B	Recipient Blood Group AB
Donor Can be	Donor Can be	Donor Can be	Donor Can be
O	O or A	O or B	O, A, B, or AB

If you are not a compatible blood group with your recipient it is still possible to donate a kidney to help your loved one by way of paired kidney exchange.

See page 27-28 or ask your transplant co-ordinator to discuss this with you.

TISSUE MATCHING

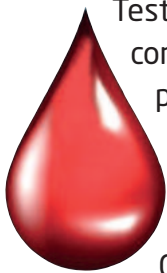
Once blood group compatibility has been confirmed, the donor has to be tested for tissue compatibility. The tissue type of the donor and recipient will be determined in the transplant laboratory by way of a blood test. This process may take up to six weeks. In general, the better the match between the recipient and the donor the better the long-term success of kidney transplantation.

You are tested for HLA antigens on up to 12 different markers, which can have thousands of different combinations. A donor/recipient pair that has matches on each of these 12 markers has a so-called 'full house match', sometimes called 'zero mismatch'. Donor/recipient matching is important because a better match often results in better success of the transplant, and because poor matching can make kidney transplantation, the second or third time, a lot more difficult.



The long-term success of a kidney transplant can be excellent, even when the donor and recipient tissue-match is less than perfect.

OTHER BLOOD TESTS



Tests to check the donor for viruses are completed quite early in the assessment process. A potential donor's blood is examined for the presence of previous exposure to certain viruses, such as Hepatitis B & C, HIV and Cytomegalovirus (CMV).

With the exception of CMV, if these viruses are detected, transplantation cannot normally take place due to the risk of disease transmission. CMV can be transmitted during transplantation. Recipients can be affected with flu-like symptoms which can usually be controlled by modern anti-viral drugs.

In summary, donors generally need to meet the following standards;

- Donors need to be fit enough to undergo the operation.
- They need to be capable of living normally with just one kidney.

- They must be in excellent physical health.
- Their medical history needs to be relatively "clear" or uneventful.
- They must be relatively free of pressure to donate as well as having a positive relationship with the potential recipient.
- They must have some positive coping skills and supportive relationships.
- They must be relatively free of current emotional distress or disturbance.
- They must demonstrate a clear and realistic understanding of what is involved in living kidney donation.

If tests show evidence of poor kidney function or, if investigations show the possibility of the donor being medically unsuitable, the offer of a donation may be declined. The team recognises that this can be difficult news for those who are motivated to donate a kidney to a loved one.



CHAPTER 3

RISKS AND BENEFITS

FOR THE RECIPIENTS

BENEFITS

- The main benefit to the recipient of a successful kidney transplant is usually **freedom from dialysis**, energy levels returning to normal and feeling 'well' again.
- Although a transplant recipient will always have to take medications to prevent the rejection of the kidney, **most aspects of their lives can return to normal**. The majority of recipients return to their normal activities of daily living and even full-time work.
- Long-term kidney **transplant survival rates are very good** for kidneys from living donors, often lasting 10-20 years and more.
- In general, the only way a patient with severe kidney disease can avoid a long period of time on dialysis is if they receive a living or deceased donor kidney. This varies slightly but the average waiting time for a deceased donor transplant is 35 months. A living kidney transplant can sometimes be organised in 4 to 6 months and may be planned prior to the person commencing dialysis treatment.



RISKS

- As with any surgical procedure, there are risks for transplant recipients. This includes the **risk of death**, which is less than two to three cases per thousand living transplant recipients.
- Poor blood supply to the kidney or **severe rejection can cause failure and great disappointment** to everyone. It is estimated, however, that 95% of living kidney transplants are still functioning at one year and many patients are fit and well twenty years after surgery.
- Relationship and emotional problems can arise within the family for the potential recipient as well as the donor. Potential recipients may feel under pressure from other family members - even the donor - to go ahead with the procedure. It is a topic that needs to be discussed, at length, with all members of the family. The recipient might feel a sense of guilt about the donor and this needs to be recognised and spoken about.

BENEFITS

- A potential donor is likely to have experienced some changes to their own lifestyle due to a family member's illness (e.g., as a sibling these could include greater domestic responsibilities). A successful kidney transplant may mean the **balance of roles/ responsibilities change in a positive way in a family**, when a formerly ill person may be able to contribute more to family life.
- Spousal transplantation offers the potential for considerable **improvement in quality of life for both parties**; if the transplant is a success spouses and families are free of the burden of dialysis.
- The **main benefit of donating a kidney is purely an emotional or psychological one**. The sense of satisfaction, at giving a loved one a kidney, can sometimes be thoroughly rewarding for the donor.

RISKS

- **Approximately one in eight donors who come forward to be tested will be considered suitable as an actual donor**. Donors who have gone through testing and found to be unsuitable may be left feeling helpless and disappointed.
- Any patient who has a general anaesthetic or a major operation runs a **slight risk of problems**, though the tests that are done before the

operation try to ensure that this risk is made as small as possible.

- The removal of a kidney involves a rather more **difficult and uncomfortable operation** than the transplant operation. It involves a degree of post-operative pain and discomfort which can be partly controlled by painkillers. The potential donor should keep in mind that they are likely to feel less well than the recipient in the first few weeks after the operation.
- The tests involved in the process could reveal an abnormality or health problem that the donor was unaware of before volunteering as a potential living donor.
- After the operation, the donor may experience **a sense of anti-climax and may be at a slightly higher risk of depression**, particularly if he or she or the recipient has post-operative problems.
- An emotional difficulty for the donor may be the worry around how they will face their future with one kidney; the donor may worry that they do not have the 'assurance' of the second, in case of serious accidents or illness.
- The risk of the surgery not working out needs to be seriously considered. As we know, no matter how many tests are undertaken beforehand, there is **still a risk that the transplanted kidney will fail** and the recipient will have to return to dialysis.
- Young women need to consider if they should postpone being a kidney donor until after they have had their family. There is evidence that women who have donated a kidney are more likely to have high blood pressure or pre-eclampsia in subsequent pregnancies. Nonetheless most kidney donors will have successful pregnancies after donating a kidney.
- There is a possibility that, as a result of tissue type testing, we will discover that one of your parents or other potential donors is not in fact your blood relative. You need to think about how you could cope with this news before you embark on becoming a living kidney donor.

- One of the most common emotional challenges a recipient may face is fear – particularly **fear that the transplant will not work out**. This can be especially difficult for recipients as they are aware that the donor has made a sacrifice on their behalf. By discussing these issues as openly as possible, difficult situations such as the transplant not working out can be handled in a sensitive and supportive way by all involved.

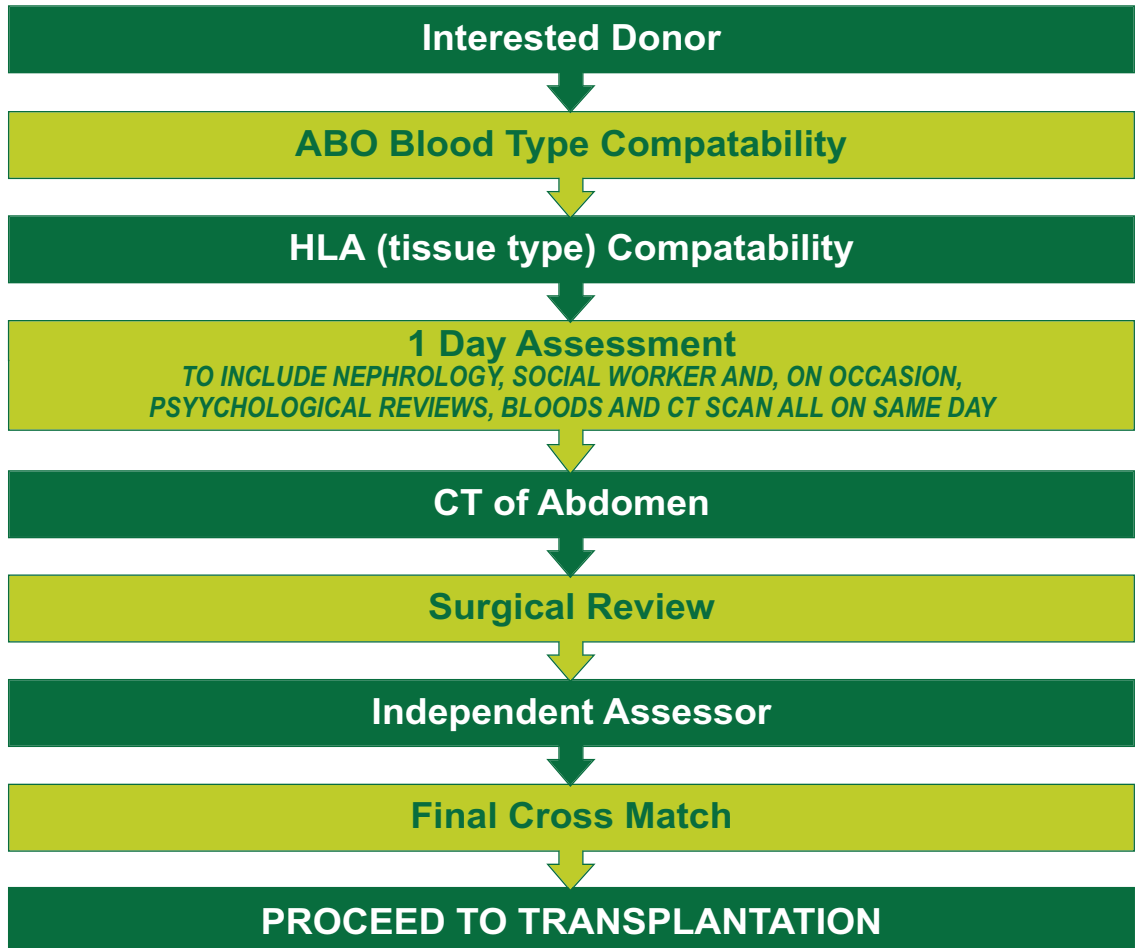


IN SUMMARY, THE MAIN RISKS OF THE SURGERY FOR DONORS ARE AS FOLLOWS:

1. The risk of **death** (approximately one in every three thousand procedures).
2. **Negative reaction** to anaesthetic or other drugs.
3. The **general complications of major abdominal surgery**:
 - a) Blood **clot**
 - b) Intra-abdominal **bleeding** and infection
 - c) **Wound** complications
 - d) **Chest** complications
 - e) Urinary retention/**urinary infection**
 - f) The possible need for blood **transfusions**
 - g) Risk of adhesions and **blockage of the bowel**
4. The possibility of short and long-term **wound pain**.
5. The need for a **recovery period of between 4-12 weeks**. Potential donors should check their sick leave entitlement with their employers.
6. The possibility of an **increase in blood pressure** and protein in the urine.
7. The possible **emotional consequences of donation**: the risk of the donor feeling pressure from family, feeling worried about the future with one kidney, or feeling upset after surgery.
8. The possible **family and relationship consequences of donation**: the risk that tensions can arise in families around the surgery or that the balance in a donor-recipient relationship can change after surgery (e.g., a recipient feeling like they "owe" something or are indebted to a donor).
9. The **emotional and psychological impact on the donor** of the recipient dying suddenly or the transplanted kidney failing.
10. Young women should consider if they would prefer to donate a kidney after they have had their family
11. The risk that surgery may impact on the current or future **insurability of the donor**. This has to be checked by the donor with their own insurance company.

CHAPTER 4

A summary
of the
various
stages of
assessment
involved in
the
evaluation
of potential
living
donors



INITIAL DONOR ASSESSMENT AND INFORMATION SESSION

THE FOLLOWING IS A SUMMARY OF WHAT HAPPENS, AT THE BEGINNING OF THE JOURNEY TOWARDS BECOMING A LIVING KIDNEY DONOR:

- The potential donor **contacts the transplant co-ordinators' office** for general discussion of living kidney donation. The donor's **blood group compatibility** is now assessed and he or she is given the living donor **information book**. Blood may also be taken for tissue typing tests. You will be encouraged to watch the living kidney donation video. You should watch this video on www.beaumont.ie/kidneycentre-home before you come to the clinic for evaluation.
- **Tissue typing results take approximately six weeks to process** and are reviewed at a large meeting of different professionals.
- Once your tissue typing results are available, you will be phoned by a co-ordinator to advise you of the results. You will be offered an appointment for a one-day donor assessment. This will involve you coming to Beaumont hospital and having a lot of blood and urine tests and a number of scans.

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You will be examined by a kidney specialist and have an opportunity to discuss any aspect of this during this meeting. You need to think carefully how you want to receive these results. If, for example, you hear in the presence of your other family members that you are the only potential donor, you might feel great pressure to proceed with donation. In the first instance, **the nephrologist will only discuss your results with you.** They will not discuss them with any other family member.

- Once results are given, the donor who wishes to proceed is asked to **contact the transplant office** for an appointment to start their work-up as a potential donor.
- It is important to realise that if you are not directly compatible to donate to your loved one it may still be possible to do this by way of paired kidney exchange or desensitisation. See page 27-28.



Outpatient Clinic

DETAILED POTENTIAL DONOR ASSESSMENT

After the initial assessment and information session, the following stages are usually followed as part of the detailed evaluation of potential living donors



ONE DAY DONOR ASSESSMENT

Once you have been identified as potentially suitable to be a kidney donor you will be invited to come to Beaumont Hospital for a detailed assessment. During this busy day you will have many tests done and meet many members of the transplant team.

- **A transplant nephrologist (kidney doctor) evaluates the donor** with a full history and physical assessment. They again discuss in detail the risks and benefits of living donor kidney transplantation.

- **A transplant co-ordinator arranges for the following tests to be performed:** Multiple blood and urine chemistry tests. Blood testing for viruses including hepatitis and HIV (AIDS) and syphilis. At this stage a second tissue type test will be taken. There will also be a chest x-ray, abdominal ultrasound, CT scan

of kidneys and ECG. You will also have a special test called an Isotope GFR test. In this special test, to precisely measure your level of kidney function, a very small dose of radiation will be injected into you and then over the subsequent 4 hours you will have blood tests drawn to carefully measure your level of kidney function. Any **special investigations** are also ordered at this stage.

- You will meet with the **Social Worker** who will inform you about the Living Organ Donor Reimbursement Scheme. The Social Worker will also discuss some of the practical, financial and emotional issues that may arise throughout the donation process.



"The donor has another meeting with his or her surgeon and a date for surgery is booked."

- Depending on your particular situation you may be offered an appointment to meet our transplant **psychologist** or transplant **psychiatrist**.
- After this one-day assessment all your investigations will be reviewed by the transplant team. The team may well request other specific follow-up tests.
- Potential **donors are then discussed at the multi-disciplinary meeting**. If everything is satisfactory they are referred to the donor surgeon.

- The potential donor is **reviewed by the donor surgeon and anaesthetist**.
- The donor is reviewed by the **Independent Assessor**.
- Final tissue typing tests are completed. Consent forms for surgery are signed and a date for surgery is agreed.



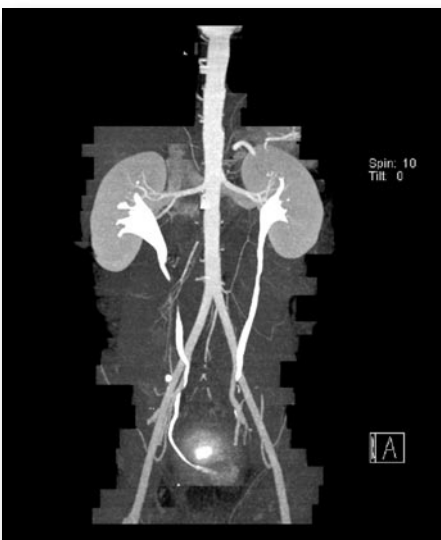
INDEPENDENT ASSESSOR INTERVIEW

All donors and organ recipients are required to see an **Independent Assessor (IA)** who is a person trained in transplantation but independent of the Transplant team. The IA interviews the donor and recipient separately, and together, and is independent of the healthcare teams who are involved in the donation process.

The purpose of these interviews is to ensure that donors are not forced to do something against their wishes, to ensure that no reward has been sought or offered and to ensure that the donor has the capacity to make an informed decision.

Depending on complexity, most interviews range in time from 30 minutes to one hour. Donors and recipients will be asked to bring proof of their identity and proof of their relationship.

These interviews take place after the donor has been approved for donation at the multi-disciplinary team meeting. The decision of the Independent Assessor is final and is not subject to appeal.



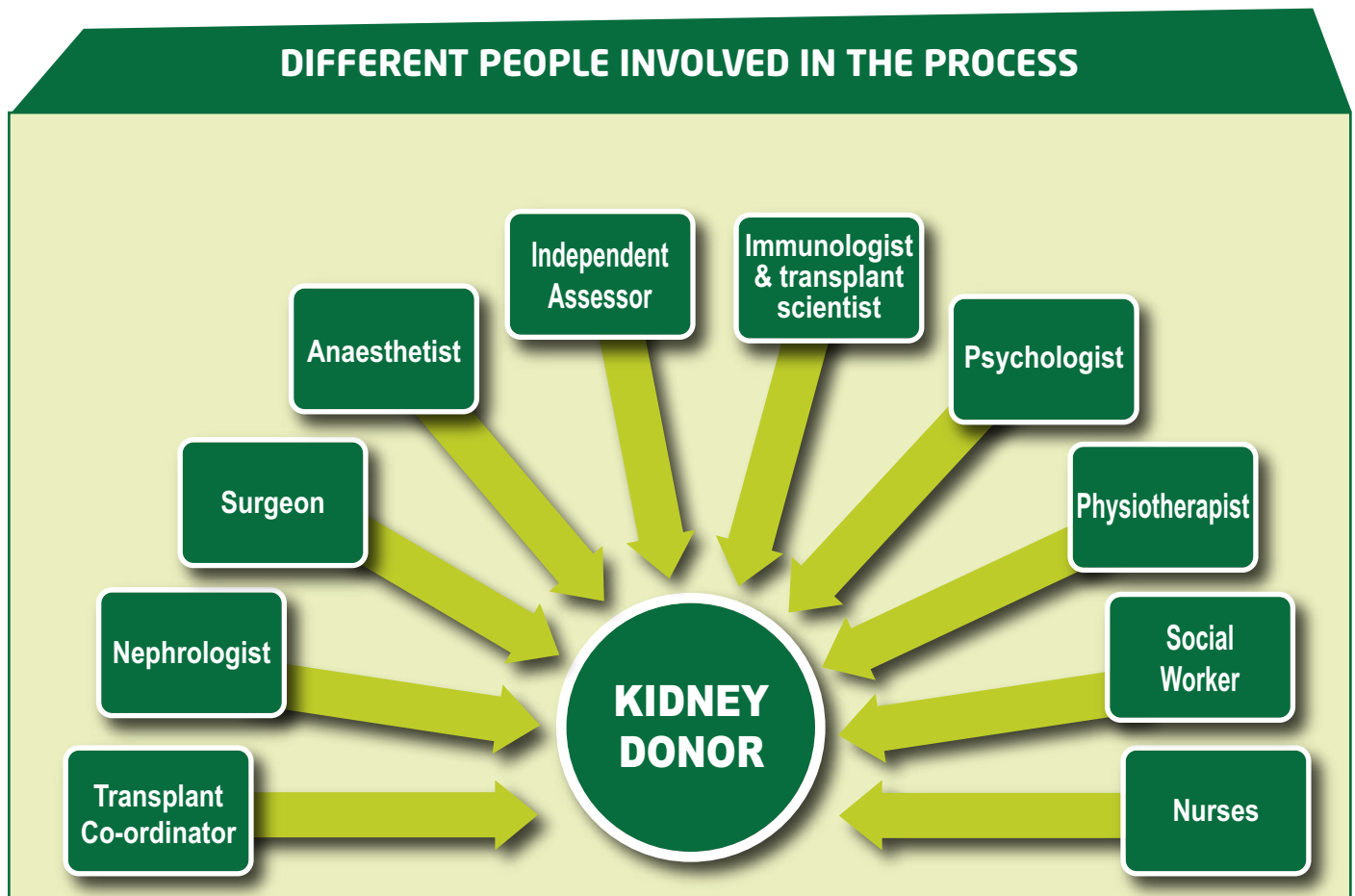
CHAPTER 5

WHO MAKES THE FINAL DECISION?

Before the living kidney transplant surgery, both donor and recipient have to agree that they want the surgery to proceed. All test results will then be reviewed by the multi-disciplinary consensus team.

This team consists of the consultant transplant surgeons, nephrologist, immunologists, anaesthetists, transplant co-ordinators, psychologist, psychiatrist and social worker. It is only when the results of all the tests are approved by this group that you will be referred to the independent assessor. Once the independent assessor gives approval a date will be set for surgery and consent forms signed.

DIFFERENT PEOPLE INVOLVED IN THE PROCESS



THERE ARE MANY DIFFERENT PEOPLE IN THE TRANSPLANT TEAM AND EACH HAS A SPECIFIC ROLE

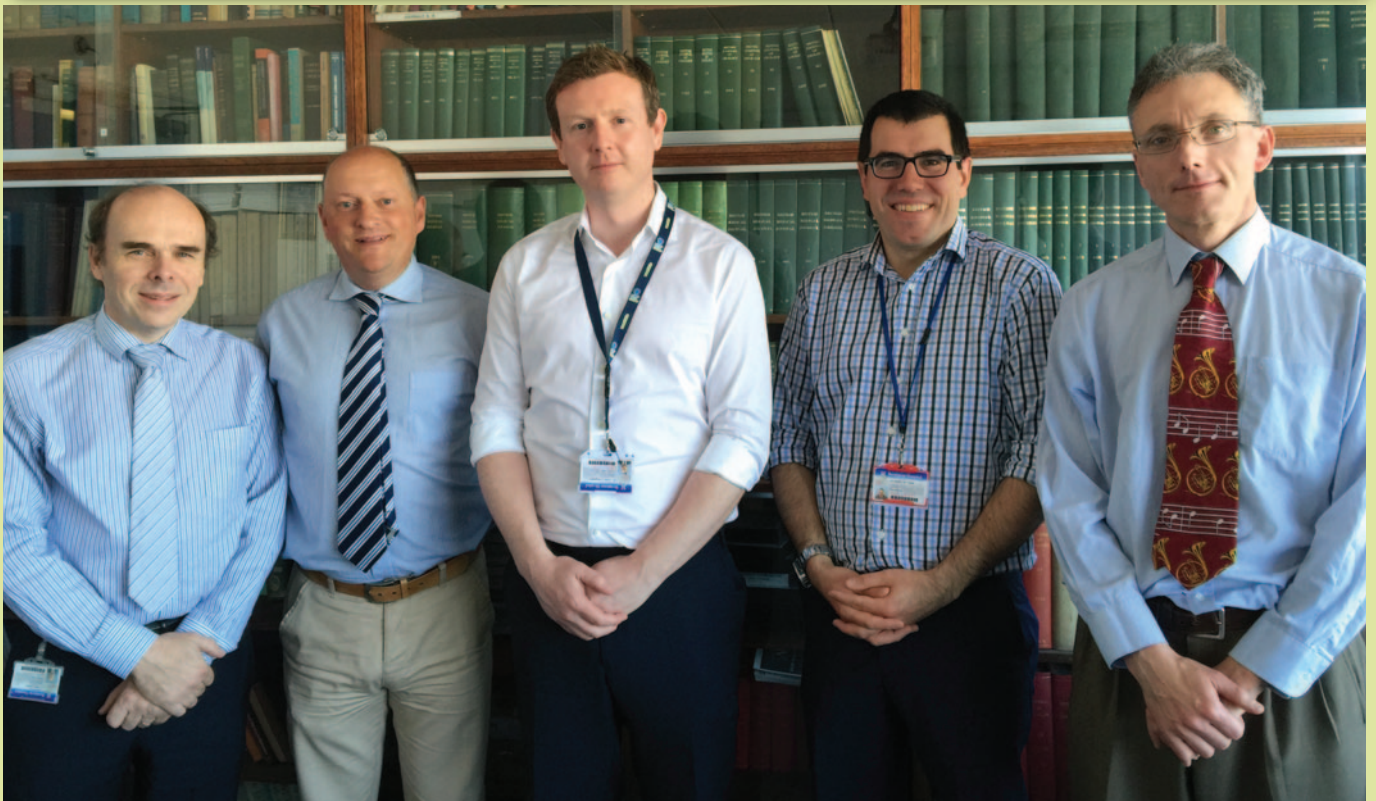
TRANSPLANT CO-ORDINATORS

The Co-ordinator is responsible for **ensuring that the individual aspects of the donor's care, including pre-donation assessments and the surgery itself, run as smoothly as possible.** The co-ordinator is aware of what stage each donor is currently at in their assessment, and whom is responsible for each part of the process. Simply put, he/she co-ordinates the different aspects of the process, from initial assessment to post-operative care, to ensure it runs as smoothly as possible.



*TRANSPLANT CO-ORDINATORS
Laura Lynch, Laura Austin, Andrea Fitzmaurice*

CONSULTANT NEPHROLOGIST



Prof. Peter Conlon, Dr. Mark Denton; Prof. Conall O'Seaghdha; Prof. Declan DeFreitas and Dr. Colm Magee

The consultant nephrologist is the person who, together with the consultant transplant surgeon, has to **be sure that the transplanted kidney is likely to restore the health and reasonable lifestyle of the intended recipient and that the donor's health would not suffer as a result.**

Donors and recipients will generally each have a different nephrologist.

TRANSPLANT SURGEONS

A team of senior transplant surgeons, one for the donor and one for the recipient, with another surgeon to assist, will perform the operation.

The transplant surgeons must ensure that all the results of tests point to a successful transplant. They must also be sure that the donor and recipient are fit to undergo surgery with the minimum risk.

The surgeon who removes the kidney **carries overall responsibility for ensuring the safety of the donor.**



*Ms. Dilly Little
Surgeon*



*Mr. Ponnusamy Mohan
Surgeon*



*Mr. Richie Power
Surgeon*



*Mr. Gordon Smyth
Surgeon*

PSYCHOLOGIST

Many important emotional relationship issues need to be considered in a living kidney donation. The psychologist is there to discuss these with the potential donor and **offer support** to donors at any stage in the process.

The psychologist also has responsibility for considering whether a potential donor is under undue pressure or stress in relation to donation.

The psychologist also examines whether potential donors are currently **emotionally stable** and how they are likely to cope with major surgery.

SOCIAL WORKER

The Social Worker will explain the Reimbursement Scheme and discuss and offer support around the practical, financial, and emotional aspects of the donation process.



*Tara Power
Social Worker*

CONSULTANT IMMUNOLOGIST AND MEDICAL SCIENTISTS



It is unlikely that you will meet the consultant immunologist and medical scientists, but there is a large group of people, in the laboratory, that are

members of the transplant team. These scientists analyse your blood in detail to maximise the chances of transplantation success.

CONSULTANT ANAESTHETIST



It is the responsibility of the anaesthetist to administer the anaesthetic and to ensure the health of both patients **during the surgical procedure.**

PHYSIOTHERAPIST



After any form of surgical procedure, **returning to full activity** can be an uphill struggle. The physiotherapist can frequently advise on methods of making rehabilitation easier.

CHAPTER 6

THE SCIENCE IN MORE DETAIL

WHAT ARE ANTIBODIES?

The body makes millions of antibodies, which are primarily intended to fight off disease. However, when people have a blood transfusion, pregnancy, previous transplant or some infections, they can produce so-called 'HLA antibodies' which react with donor tissue and possibly damage it.

It is therefore **preferable to find a kidney against which you do not have antibodies.**

You will hear the doctor talk about **PRA** or **PGEN**. This is a measure of the probability of having antibodies against 1,000 Irish donors; it is a measure of how hard it will be to find a suitable compatible donor. If the recipient has a PGEN of 0% then they have no antibodies and should not have difficulty finding a suitable donor. Conversely, if the recipient has a **PGEN of 100%**, **they will have great difficulty finding a suitable kidney donor** and will most likely have



"If the recipient has a PGEN of 0% then they have no antibodies and should not have difficulty finding a suitable donor."

a prolonged wait on dialysis. If the recipient has a sibling, who is a 'perfect match', then antibodies are generally not important. However, even patients with 100% PRA can be

"If the recipient has a sibling who is a 'perfect match', then antibodies are generally not important."

"The levels of antibodies in the recipient may fluctuate."

transplanted if the right donor comes along.

When the recipient sees the transplant surgeon, at the pre-transplant assessment clinic, they will be told what their PGEN is and this will give them some assessment of how long the likely wait will be to receive a transplant.

There are no effective strategies to take away antibodies that give good long-term results.

The levels of antibodies in the recipient might fluctuate, and so it may be possible that the initial screening for donor specific antibodies is favourable but, later screening in the donor workup may show that the donor is in fact not suitable. This can cause significant disappointment to the donor who may be in an advanced stage of the workup process.



"The process of checking the suitability of a donor is a long, but in-depth one."

continued next page



WHAT ARE ANTIBODIES? contd.

When testing donor and recipient compatibility, one of the **main problems that has to be avoided is giving a patient a kidney to which they have formed antibodies**, as this carries a high risk for the early failure of the transplant.

The process of checking the suitability of a donor is a long, and **in-depth** one. To be as certain as possible that the transplant will be successful, for both recipient and donor, this **extensive procedure is necessary** and also gives the potential donor plenty of time to consider his/her options.



SUMMARY OF TESTS INVOLVED

A sequence of tests are necessary to thoroughly examine the health of the potential living donor and the function and anatomy of the donor kidney. A potential living donor can expect:

TEST	PURPOSE
Blood Pressure	Excludes high blood pressure.
Urine Analysis	Identifies any underlying conditions.
Blood Tests	For routine analyses. Another blood test will be taken from both the potential recipient and the potential donor to check the recipient does not have antibodies which may react to the donor. This test will be repeated just before the operation.
Isotope Kidney Function Test	If the kidneys are not functioning well, the creatinine level rises. In order to get a precise measure of the level of your kidney function a tiny dose of radiation will be injected into you and then blood samples will be drawn for up to 4 hours later. This test gives a more precise measure of the level of your kidney function.
X-rays	Ensures normal function, especially of the chest area.
ECG	A cardiograph of the heart function is recorded to exclude heart disease.
Ultrasound	Checks the size and shape of the kidneys and excludes any anatomical abnormalities.
Spiral CT Scan	Looks in detail at the kidneys and blood vessels going to the kidneys. After this test, the surgeon will discuss with the donor which kidney is recommended for removal.

EMOTIONAL ASPECTS

SUPPORTS AVAILABLE AND DIFFICULTIES THAT CAN ARISE



WHAT SUPPORT CAN I GET BEFORE TRANSPLANT SURGERY?

As a living kidney donor, you volunteer to go through surgery that carries certain risks and might not be of any direct benefit to you. This is why the living donor team go to such lengths to ensure we are not putting you at any unacceptable risk in agreeing to take a donated kidney from you. It also means that the assessment process is long and sometimes difficult. The psychologist is available to support you when issues arise such as:

- You **change your mind** about being a donor because you realise being a living donor is not for you, or you are feeling too nervous about the surgery. The donor team recognises that this can be a difficult experience for potential donors, and they will do their best

"The assessment process is long and sometimes difficult."

to **support you** through the process, in such a way that changing your mind would have minimal impact on your relationships/family.

- You might be **frustrated by the assessment process**, perhaps because you find the wait difficult or you have other concerns.
- You feel **worried about the surgery** or about living life with one kidney after surgery.
- **Your offer of donating a kidney is declined** because the team are concerned about your medical suitability or the risks to your health. This can be a very disappointing experience for potential donors, particularly if it happens after you have gone through a number of assessments and your expectations have built up.

WHAT SUPPORT CAN I GET AFTER KIDNEY DONOR SURGERY?

If you get to the point of going through living donor surgery, the team will be there to look after you throughout the process.

The psychologist will be available to support you, because recovery can bring up all kinds of issues for donors and their loved ones, including:

- The donor finding it **difficult to be in the unfamiliar sick role**. This can be especially difficult because the recipient often recovers more quickly than the donor after the surgery.
- The donor can sometimes feel an **anti-climax** or a sense of loss or sadness after the surgery. This is normal, and might be partly due to the anaesthetic or the **physical exhaustion** of surgery. It can also be a result of feeling upset at being dependent and unwell in a hospital bed.
- The living donor may worry about the donated kidney being **rejected** by the recipient's body. If the kidney is rejected, donors can feel huge disappointment and even despair and often need a lot of support.

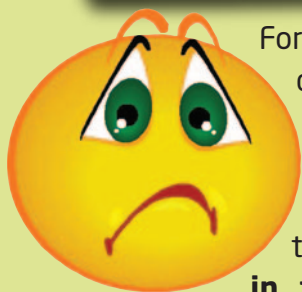


Of course, living donors can also experience positive outcomes from giving a kidney, including:

- The **practical benefits** of not having a spouse or child on dialysis: the recipient is more able to get involved in family life.
- The **'feel-good factor'** the donor gets knowing that they have made a positive difference to someone else's life, by donating a kidney, and perhaps feeling closer to the recipient as a result of the surgery.

"The psychologist is also available to support you, because recovery can bring up all kinds of issues for donors and their loved ones."

WHEN DIFFICULTIES ARISE...



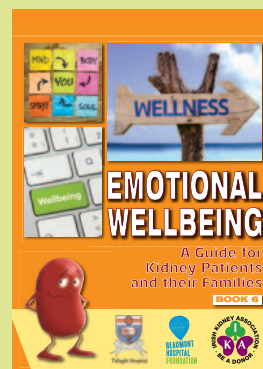
For the most part, living kidney donors do not regret going through the surgery. The research shows that for most donors, one year after surgery there is **no significant change in their quality of life, self-reported health, anxiety or depression**.

A **minority of people regret donating** however, and this is linked with a negative outcome for the donor and/or the recipient. **Complications** for the donor or the recipient leading to long-term consequences such as chronic

pain, place the donor at a **slightly greater risk of mental health problems** (e.g., anxiety or depression) because of the strain.

This also explains why it is **important to donate for the right reasons**. A strong bond between donor and recipient can help both parties to get through post-operative difficulties, whereas if the relationship breaks down, the donor may be left with regrets about donating.

See also book six of this series
- 'Emotional Wellbeing'.



THE OPERATION

THE DONOR NEPHRECTOMY (Removal of kidney)

Under general anaesthetic, the donor kidney is removed by an operation in the same way as if the kidney was diseased. The kidney can be removed through an incision in the side or keyhole surgery is now becoming more popular. The kidney is located at the back wall of the abdomen behind the bowel and the stomach.

Generally, for purposes of living kidney donation, the surgeon chooses to remove the left kidney as it has slightly longer blood vessels, which facilitate the transplant. Sometimes kidneys have more than one blood vessel, or there may be a slight discrepancy in the size of the kidney, and, therefore, the right kidney might be removed. The donor is always left with the “better kidney” of the two.

If the left kidney is to be removed, the bowel is first put to one side out of the way and then the fat around the kidney is cleared away. The kidney is immobilised and the artery, vein and ureter (drainage urine tube) are identified and dissected free.

Neighbouring structures to the left kidney are the spleen, the adrenal gland, the pancreas, the colon and small bowel and the stomach.

Neighbouring structures to the right kidney are the liver, the adrenal gland, the inferior vena cava (a very large vein) and the bowel.

The surgeon takes great care not to injure any of these adjacent structures as they free up the kidney. They will then divide the ureter to go with



the donor kidney.

The artery, bringing blood to the kidney, comes off the main artery of the body - the aorta.

The donor kidney vein comes off the main vein in the body - the inferior vena cava. When the blood vessels are clearly identified and dissected, to give maximum length by dividing any branches not supplying the kidney, the surgeon first secures the artery, either by tying it off or stapling it shut. The vein is then tied off in a similar fashion and the donor kidney is removed.

Once the artery is tied off, the kidney is removed as quickly as possible, as the blood in the kidney can clot while it is not circulating. Once the kidney is removed, the surgeon checks that there are no areas of bleeding and then closes the wound.

KEYHOLE SURGERY

Depending on the donor's anatomy and preference and the surgeon's decision, the surgery might be performed through an incision below the ribs or by a 'keyhole' incision. The advantage of the keyhole incision is that it allows the incision to remove the kidney to be sited lower down in the abdomen, which is generally not as sore post-operatively. This incision also allows the surgeon to place their hand into the abdomen to facilitate the dissection of the kidney.

However, if the keyhole method is adopted and the surgeon has to convert to the traditional open surgical method, for whatever reason, then the donor will have the standard scar below the ribs and a second scar lower down on the abdomen. The surgeon's first priority is always to ensure the safety of the living donor.

The kidney is lifted out of the wound and flushed with a cold solution to wash out blood and slow the metabolism before being carried into the adjacent operating theatre in which the recipient is waiting.

The incision(s) is/are then sewn up and the donor is transferred to the recovery room and, subsequently, the ward. Sometimes a temporary

ST DAMIEN'S RENAL TRANSPLANT WARD



drain is fitted near the wound. Fluids can be administered via a drip, and because the incision can be painful afterwards, infusions of pain killers can be added to this. Alternatively, the anaesthetist may insert an epidural catheter to administer medication close to the spinal cord to help with post-operative pain. This is usually removed on the second or third day post-operatively.

A catheter is inserted in the bladder. Tubes are usually removed, after the first day, and the donor is encouraged to get up and sit in a chair.

A donor's stay in hospital is usually between 4-6 days. He or she can expect to be out of bed the day

after the operation and home in less than two weeks. The stitches are removed approximately 10 days post-surgery. The wound may remain sensitive for several weeks.

Sometimes a small area of numbness may be noticed on the skin of the abdomen, because small nerves have been cut by the incision at the side. However, the scar should be the only permanent reminder of the donor operation. The donor will usually have to take 4 weeks off from work to recuperate, depending on the individual and his or her occupation.



CHAPTER 9

RESUMING NORMAL ACTIVITIES

DRIVING

There are no hard and fast rules with regard to driving again. In the main, if the donor feels okay and their doctor agrees to it, a donor can return to driving when they feel capable - usually after 4-6 weeks. The donor must be aware, however, that long journeys could be difficult and that he/she should not over-stretch.



EXERCISE

Maintaining a healthy lifestyle is as important, after donation, as beforehand. Any post donation exercise programme should begin slowly with the length of time spent exercising, and the effort involved, being increased over a period of time.



SEXUAL RELATIONSHIPS

There is no standard typical period before sexual intercourse can be considered. Donors should be able to resume their usual sexual relationships as soon as they feel comfortable. It may take a few months before normal activities can be undertaken, but this depends on the individuals and their recuperation.



FOLLOW-UP

After living kidney donor surgery, an outpatient clinic appointment will be offered to you, for follow-up at 6 weeks and 3 months, by the donor surgeon. Annual follow-up will be offered to you by a nephrologist closer to where you live. You will need to ensure that you make appointments for annual follow-up. You should bring blood and urine test results with you or have them done on the day you come to the clinic.



CHAPTER 10

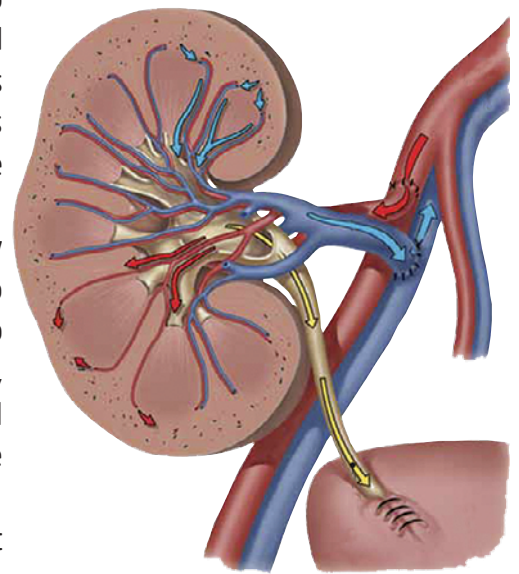
GENERAL INFORMATION

THE RECIPIENT'S TRANSPLANT

The kidney is put into the outer pelvis – protected by the hip bone – low down and to one side of the bladder. The blood vessels of the kidney are joined to the large blood vessels supplying the leg. The kidney lies here away from the intestines and their covering and the ureter can more easily be sewn into the bladder.

The recipient should be out of bed within a day or two. After only a few days, most or all of the tubes will be removed. Medicines to suppress the immune system will be necessary. These drugs help the recipient's body to tolerate a 'foreign' organ. In the early stages, the medication may be in the form of infusions. Later this will change to tablets. This medication will have to be taken, by the recipient, for the entire life of the transplanted kidney.

The most anxious time for both donor and recipient is the 'wait to see' if the new kidney functions well. Depending on how successful the transplant has been, the recipient can expect to leave hospital between one and three weeks post-surgery. By this time, he/she will usually be feeling the benefit of the kidney transplant. Initially, recipients will have to be seen quite frequently in the out patients' clinic but this becomes less frequent as time progresses.



WHAT CAN I DO IF I AM NOT A MATCH?

If you are not a match for the recipient because of blood group or antibody reasons there are a number of possibilities.

If the recipient is *not highly sensitised* (PGEN < 70%) and has a blood group incompatible donor, the best option to consider would be to enter into a paired kidney exchange. That is where the patient's donor gives his/her kidney to a compatible recipient and another donor gives a kidney to our patient.

An example could be a brother who wants to donate a kidney to his sister but is unable to because of a difference in blood type. If this

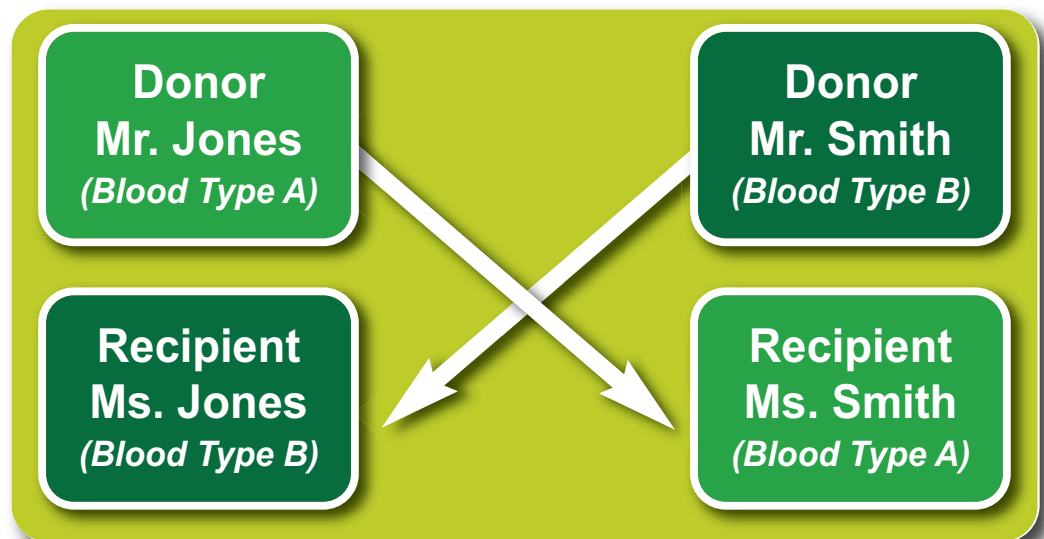
recipient/donor pair consents to participate in the paired kidney exchange programme, an attempt would be made to match them with another recipient/donor in the same situation willing to "exchange" kidneys. An example is if Mr. Jones who is blood type A wants to donate a kidney to Ms. Jones who is blood type B and another donor-recipient pair, Mr. and Mrs. Smith, have the opposite circumstance (blood type B donor who wants to donate to blood type A recipient). The donor kidneys could be exchanged and both groups would undergo a transplant procedure which would not otherwise happen.



IN ORDER TO MAXIMISE THE POTENTIAL OF FINDING A SUITABLE MATCH WE PARTICIPATE IN A PAIRED KIDNEY EXCHANGE SYSTEM WITH THE UK. THE POTENTIAL DONOR AND RECIPIENT MAY THEREFORE BE REFERRED TO A HOSPITAL IN ENGLAND OR BELFAST TO BE ENTERED INTO THE PAIRED KIDNEY ARRANGEMENT.

If the recipient is *highly sensitised* (PGEN > 70%) and they have an ABO incompatible donor but well HLA-matched donor, it might be possible to enter into a programme to remove the recipient's ABO antibodies and proceed ahead with the kidney transplant.

Some patients with high antibody levels may have to wait a long time to obtain a suitable match. Effective technology does not currently exist to remove high levels of antibodies to allow successful long-term outcomes.



MORE INFORMATION ABOUT PAIRED KIDNEY EXCHANGE

Paired kidney exchange allows the recipient to get the best possible outcome from a donated kidney by finding a kidney to which they do not have antibodies. In this process the transplant nephrologist will refer the donor and recipient files to a hospital in England or Belfast. Both donor and recipient will then be invited to be reviewed by the UK transplant team.

The details of the donor and recipient are uploaded onto a UK computer system. Four times a year the computer checks to find suitable matches. If a match is found you will be notified. It is important to realise that not everyone will find a match and it may take a number of years before a suitable match is found.

Once a potential match is found both donor and recipient will likely need some additional testing to confirm suitability. It is also possible at this stage

that a difficulty will arise to stop the transplant going ahead.

If a suitable match is found both donor and recipient will need to go to either the Belfast or England hospital. Both donor operations will go ahead at the same time to minimise the possibility of either donor pulling out.

Once the donor and recipient have recovered from the surgery they will return to Ireland for follow-up.

It should be noted that there are financial and practical issues to consider for patients who travel to England. In particular the donor and recipient will have to spend a period of time as an outpatient and they will have to organise their own accommodation. The Social Worker is available to discuss any issues or concerns you may have and to provide you with support.

LIVING ORGAN DONOR REIMBURSEMENT SCHEME

This scheme was introduced to address some of the costs incurred by potential living donors participating in the Living Donor Programme in Ireland, during the pre-operative and post-operative period.

The scheme applies to any potential donor who has been invited to attend a one-day assessment, by the Living Donor Programme at Beaumont Hospital, and those donors who have been referred to the Paired Kidney Exchange programme.

THE REIMBURSEMENT SCHEME COVERS THREE MAIN AREAS:

- Travel
- Accommodation
- Loss of earnings associated with organ donation

The scheme is currently under review by the Department of Health. Further details will be available on Beaumont Hospital's website...www.beaumontkidneycentre.ie or the Irish Kidney Association's website...www.ika.ie

Travel and accommodation expenses up to a maximum value of €6,000 are reimbursable but such expenses must relate to a hospital visit/stay in relation to organ donation and must be supported by relevant documentation.

If a person donates, they may be entitled to reimbursement of earnings lost as a result of their inpatient stay for the purpose of donation and up to a maximum of 12 weeks post-operative period. The amount reimbursable is capped at €10,000 and must be supported by relevant documentation.

An application form for the Living Organ Donor Reimbursement Scheme can be obtained by contacting the Living Organ Donor Reimbursement Scheme Office on 056-7784579 or 056-7784551.

In cases where a donor is selected but later deemed unsuitable he/she can claim reimbursement for this period only.

Living Organ Donor Reimbursement Scheme



1. PERIOD OF COVER

Reasonable travel and accommodation expenses incurred from when the donor has been selected as a potential donor through to the in-patient stay when the donation takes place and for up to 12 weeks post-donation are eligible for reimbursement. Loss of earnings incurred from the time the donor is selected as a suitable donor through to the in-patient stay, when the donation takes place, and for up to 12 weeks post donation (12 weeks inclusive) are eligible for reimbursement. Any reimbursement claim for loss of earnings may not exceed 12 weeks in total (eg if a donor claims for 1 week loss of earnings pre-donation they may only claim a maximum of 11 weeks post donation).

2. ELIGIBLE EXPENSES

General

- Only those expenses that are directly attributable to the organ donation will be considered for reimbursement. This includes the cost of obtaining medical certificates.
- The best evidence available should be submitted by the living donor - i.e. receipts, invoices, statements.
- In line with the HSE's National Financial Regulations, payments may not be made without the supporting documentation. Therefore it is incumbent on each person seeking reimbursement to ensure original receipts are obtained, kept and submitted.
- Reimbursements will be net of any other reimbursement paid or due to the donor through any other method or scheme - e.g. health insurance, life assurance, employee

assistance scheme, long term illness insurance, financial support from a charity or voluntary organisation.

3. LOSS OF EARNINGS

Loss of earnings incurred by a selected salaried/waged donor or a self-employed donor for up to 12 weeks pre/post-donation (12 weeks inclusive) may be considered for reimbursement, up to a cap of €10,000, on the provision of relevant supporting documents.

Salaried/Waged Donors

Salaried/waged donors must submit a letter from their employer detailing how much the employer will pay the donor for the period up to 12 weeks pre/post-donation (12 weeks inclusive). If the donor will be fully paid by their employer during this period, they will not be eligible for any reimbursement for loss of earnings.

In cases where a selected salaried/waged donor will not be paid by their employer for any, or for a portion, of the 12 week period pre/post donation (12 weeks inclusive), they must submit details from the Department of Social Protection, or any income continuance plan or other similar policy, detailing what benefits, if any, they will be entitled to during the period.

Salaried/waged donors must provide their most recent P60 and payslips for the 6 months preceding donation. In exceptional circumstances, payslips for the preceding 3 months will be accepted.

continued next page

OR

A self-employed donor can make a claim for the expense of a person to replace them in their business for a period of up to 12 weeks pre/post donation (12 weeks inclusive), up to an upper limit of €10,000. Any claim must include receipts supported by documentary evidence that will need to be provided to the HSE's Living Donor Reimbursement Office.

Where a self-employed donor is using this option and the person replacing them is already an employee then it will be necessary to demonstrate the additional hours that employee is incurring in his duties to replace the employer. Only the additional hours will be eligible for reimbursement. A self-employed donor can only make a claim for loss of earnings or the expense of a person to replace them in their business, not both.

Only the difference between the donor's average net pay¹ and the total of any payments made by their employer, the Department of Social Protection or on foot of any insurance policy etc., will be eligible for reimbursement.

The maximum period for which a donor may claim for reimbursement of loss of earnings is 12 weeks. If the donor is out of work for longer than 12 weeks, they will not be eligible for reimbursement of loss of earnings after the 12 week period.

All donors will be required to submit medical certificates from their treating consultant or GP as well as written confirmation of the date of return to work from their employer. Overtime payments, shift allowances or other similar payments will not be eligible for reimbursement, irrespective of whether they comprise a regular portion of the donor's salary. Every effort will be made to reimburse the donor according to their usual pay cycle i.e. weekly, fortnightly or monthly payments.

Self-employed Donors

Self-employed donors must submit a Notice of Assessment on the Revenue Commissioner's Form 11. Reimbursement for a 12 week period will be calculated on the basis of 12/52 of the donor's income in the preceding 12 months tax period.

As some donors may return to work earlier than 12 weeks post-donation, a medical certificate and a return to work certificate from the donor's GP or treating physician must also be submitted.

4. DEPARTMENT OF SOCIAL PROTECTION SCHEMES

A donor who is in receipt of a payment from any Department of Social Protection Scheme will continue to have this payment made (provided such payments are in line with their normal rules and regulations) for a period of up to 12 weeks from donation.

The Living Donor Programme at Beaumont Hospital or the Living Donor Reimbursement Office, as appropriate, will make the necessary arrangements with the Department of Social Protection in consultation with the donor.

5. TRAVEL EXPENSES

Reasonable travel expenses, incurred by an individual in relation to the living donor process will be considered for reimbursement. As a general rule, the most economically advantageous mode of transport should be

¹ For the purpose of this Policy, net pay is the average pay received over the 6 months preceding donation following statutory deductions. Overtime and other non-standard payments will not be recognised in this regard.

used. Standard class fare only will be considered for reimbursement.

The donor must submit original receipts which must coincide with an appointment date with the Living Donor Programme in Beaumont Hospital or, in the case of paired or direct kidney donation, receipts must coincide with an appointment date in the relevant hospital. Likewise for living liver donations receipts must coincide with an approved appointment with the relevant hospital.

When a donor travels by car, reimbursement will be calculated with reference to the AA Routeplanner, calculated on the day the claim is processed. This website provides calculations of the distance travelled and the average fuel cost. Please see www.theaa.ie/routes. Hospital parking and toll charges will also be considered for reimbursement. Receipts must be submitted.

6. ACCOMMODATION

If overnight accommodation is required, this must be approved in advance by the Living Donor Programme or the Living Donor Reimbursement Office. Only the vouched cost of

the accommodation (bed and breakfast) will be considered for reimbursement up to a maximum of €110 per night. The donor must submit the original receipt which must coincide with an appointment date with the Living Donor Programme in Beaumont Hospital or an appointment date approved by the Treatment Abroad Scheme.

Where a donor wishes to extend his/her stay for any reason, including to remain with the recipient of the organ, all costs associated with this period will not be reimbursed.

7. CHILDCARE COSTS

Childcare costs that would not have otherwise been incurred by the donor may be reimbursed up to an upper limit of €5,000 subject to certain criteria being met. Reimbursement will only be considered for children placed with childminders or centre based childcare providers who are registered with Tusla, the Child and Family Agency, in line with the Child Care Act 1991, as amended (Early Years Services) Regulations 2016 and the (Registration of School Age Services) Regulations 2018.

All correspondence should be addressed to:

**LIVING ORGAN DONOR REIMBURSEMENT SCHEME OFFICE,
ST. CANICE'S HOSPITAL COMPLEX, DUBLIN ROAD, KILKENNY.**

Contributors

*We would like to extend special thanks
to the following members of the Renal Team at Beaumont
for their contribution to this book:*

**Peter Conlon, Aileen Counihan, Phyllis Cunningham,
Mark Denton, Molly Eng, Diane Gillan, Mary Keogan,
Dilly Little, Colm Magee, Olive McEnroe,
Siobhan McHale, Louise McSkeane, Ruth O'Malley,
Derek O'Neill, Tara Power**

*Kidney Cartoons: **KegKartoonz** (Noel Kelly)*



Contact Numbers

Beaumont Hospital	01-809 3000
Transplant Co-Ordinators	01-809 3119
St. Peter's Ward	01-809 2285 / 2290
St. Mary's Ward	01-809 2292 / 2293
St. Damien's Ward	01-809 2294 / 2761
Renal Day Care	01-809 3144
Patient Care Co-Ordinators	01-809 2727 / 2834 / 2532 / 2488
Renal Nurse Counsellor	01-828 2751
Ambulatory Nurse Specialist	01-809 2321 / 8395
Prof. Conlon's Secretary	01-809 2747
Dr. Magee's Secretary	01-797 4701
Dr. Denton's Secretary	01-809 3080
Prof. de Freitas's Secretary	01-809 3357
Prof. O'Seaghdha's Secretary	01-809 2567
Home Therapies	01-852 8152

Other sources of useful information

BEAUMONT RENAL UNIT - www.beaumont.ie/kidneycentre

IRISH KIDNEY ASSOCIATION - www.ika.ie

IRISH HEALTH WEBSITE - www.irishhealth.com

AMERICAN ASSOCIATION OF KIDNEY PATIENTS - www.aakp.org

NATIONAL KIDNEY FOUNDATION USA - www.kidney.org

IRISH KIDNEY ASSOCIATION RENAL SUPPORT CENTRE

The Irish Kidney Association Renal Support Centre is located in the grounds of Beaumont Hospital, just 100 metres walk from the main hospital entrance, is open all year round and provides free accommodation for all its residents, who include:

- Families of renal patients from outside Dublin. It is available to all renal families no matter what Dublin hospital their family member is attending.
- Renal patients who have to travel long distances to see their consultant as an outpatient may stay overnight when accommodation is available.
- The Centre arranges counselling service as required by outpatients and their families. The counselling service is managed from the IKA Head Office: Donor House.
- Preference for accommodation is given to families of patients receiving transplants and families of the seriously ill.



FACILITIES

Thirteen en-suite bedrooms some of which can sleep up to four persons. All rooms are on ground floor level and have satellite TV, hairdryer, refrigerator and ironing facilities.



Comfortable sittingroom/dayroom with satellite TV. Fully fitted kitchen where meals can be prepared by residents. Complimentary tea and coffee is provided by the Association for residents and guests. Soft drinks and snacks are available from vending machine.

Laundry room with washing powder supplied. Parking for overnight residents only.

The Centre is owned and funded by the IKA. Donations from residents and fundraising initiatives are most welcome.

The Centre is open to residents all year round. Day facilities are available Monday to Friday from 8.30am to 4.30pm, Saturday and Sunday 12pm-4pm.



For further information contact:

IKA Renal Support Centre, Beaumont Hospital, Dublin, D09 Y5R3.

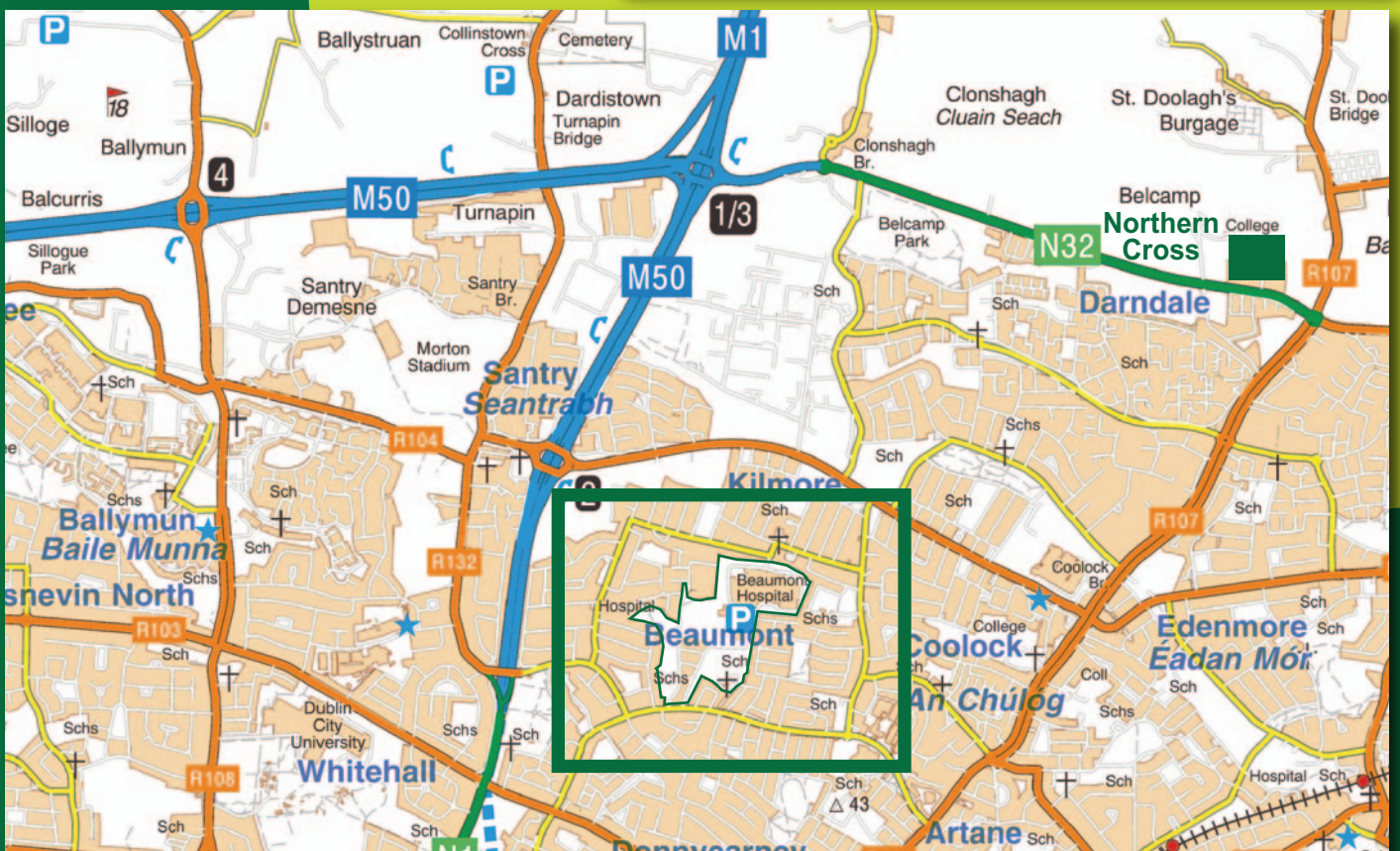
Telephone: 353-1-837 3952. Out of hours (Emergency only): **087-416 9907**

Email: renalcentre@ika.ie

Beaumont Hospital



Beaumont Hospital
Beaumont Road, Dublin 9
www.beaumont.ie



Beaumont Hospital Foundation

Established over twenty years ago, **Beaumont Hospital Foundation** is a registered charity that works to inspire charitable donations and promote support for its activities amongst patients, their families and friends, and locally and nationally from communities who access the services of Beaumont Hospital.

Funds raised by the Foundation are used to upgrade and purchase new, essential equipment that helps to ensure better care for patients and families.

As the National Renal Centre and home to the National Kidney Transplant Service, Beaumont Hospital is active in several areas of research to improve the lives of patients with kidney disease. **Active areas of research include:**

- The Irish Kidney Gene Project, which studies the genetic causes of kidney disease and operates a renal genetics clinic to help diagnose and treat those patients with hereditary kidney disease.
- A randomised trial of an app designed in Beaumont to improve fluid management in dialysis patients.
- Development of an app to improve potassium and phosphate control in dialysis patients.
- Development of an app to empower patients to better manage their kidney transplant.
- Observational studies of kidney transplant outcomes in Ireland.
- Observational studies of dialysis outcomes in Ireland.
- Clinical trials of novel biologic treatments for kidney disease.

All of these vital projects require funding in order to continue. If you would like to support a specific project, or make a general donation to Beaumont Renal research, you can do so online through our website or by phone on 01 - 809 2161.



www.beaumont.ie/kidneycentre



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