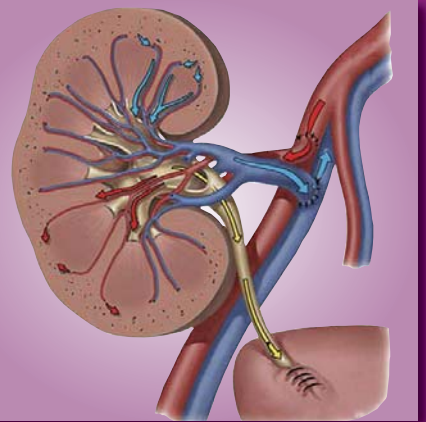


BEAUMONT HOSPITAL

www.beaumont.ie/kidneycentre



KIDNEY TRANSPLANTATION

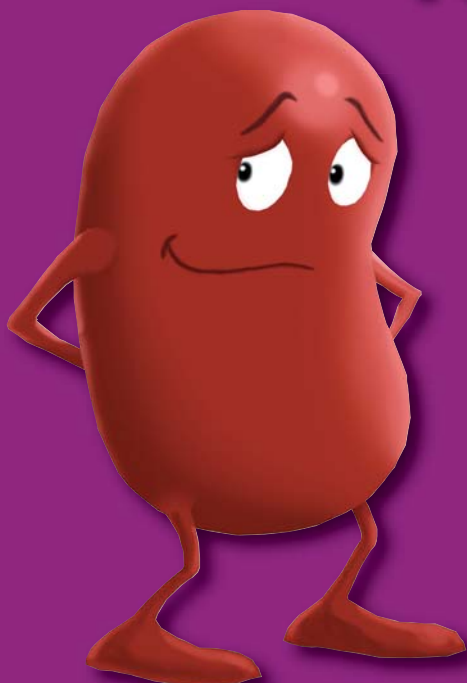
A Guide for Patients

BOOK 3

Helen Dunne, CNM, Petrina Donnelly, CNM
Prof. Peter J. Conlon, FRCPI, Ciara White, CNM

3rd Edition

*Re-edited by Ruth O'Malley, Olive McEnroe,
Somy Alex, Binu Vasu*





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 for all patients with 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 the west of Dublin, named 'Donor House'. The office is the main administrative and services centre for the Association. The staff is made up of Chief Executive, Accountant, Patient Support Office, Office Manager and Personal Assistant to CE, National Projects Manager, Renal Counsellor, Dialysis Holiday Co-ordinator, Receptionist, IT Developer, Social Media Co-ordinator and the Support Centre Managers. Individual names and email addresses for the staff are available on the IKA website.



The IKA provides holidays every year, for kidney patients who are either receiving dialysis treatment or are transplanted. It also has a 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, Donor House, Block 43A, Parkwest, Dublin, D12 P5V6

Phone: 01-6205306. Email: info@ika.ie. Web: www.ika.ie

CHARITY REGISTRATION NUMBER: 20011260



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IKA RENAL SUPPORT CENTRE

Beaumont Hospital

Beaumont, Dublin, D09 Y5R3

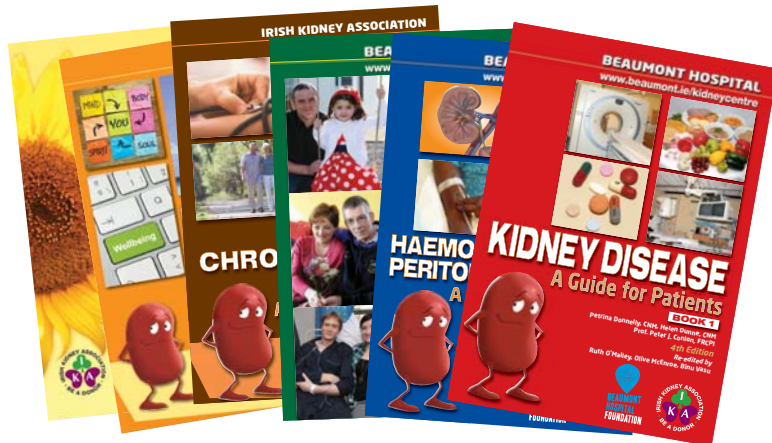
Phone: 01-837 3952

Email: renalcentre@ika.ie

PREFACE

In 1983, Dr Michael Carmody wrote the first edition of *Living with Kidney Disease*. For more than 20 years this book was used as the major patient education booklet for patients experiencing kidney disease. During the last 20 years, the technology concerning the treatment of kidney disease, has changed radically. As a result, we have produced this series of books to assist patients and their families when diagnosed with kidney disease.

This is the third edition of **BOOK 3** which deals in more depth with Kidney Transplantation. It will provide information on receiving a kidney transplant, the process that is involved, how to get a place on the transplant waiting pool, and the benefits and risks associated with kidney transplantation.



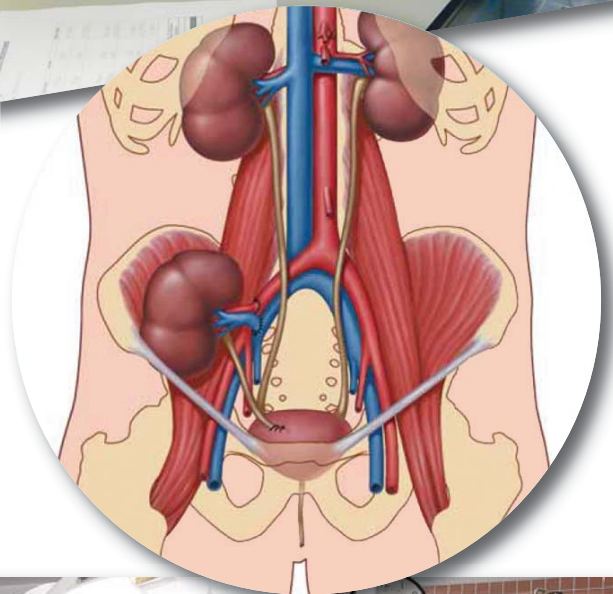
BOOK 1 deals with the functions of the kidney, types of kidney diseases, diagnostic tests and medicines used to treat kidney conditions. **BOOK 2** deals with Haemodialysis and Peritoneal Dialysis. **BOOK 4** addresses the area of the 'living donor' programme; **BOOK 5** is aimed at patients living with Chronic Kidney Disease; **BOOK 6** - Emotional Wellbeing and **BOOK 7** - deals with the Conservative Care of Kidney Failure.

Please use these books as a guide and reference tool, but any worries or issues you have should be discussed with your medical team. The text includes contributions from many members of the Beaumont Hospital Renal Unit team and has been supported by the Beaumont Transplant Foundation together with the Irish Kidney Association.

We do hope you find it helpful.

Prof. Peter J Conlon FRCPi
Ruth O'Malley, Olive McEnroe
Somy Alex, Binu Vasu

February 2019



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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.

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The books have been printed and distributed by the Irish Kidney Association. Further copies are available from IKA, Donor House, Parkwest, Dublin, D12 P5V6. Ph: 01-6205306.*

CHAPTER 1

OVERVIEW OF KIDNEY TRANSPLANTATION

When you are diagnosed with End Stage Kidney Disease (ESKD), also known as kidney failure, there are a number of treatment options available - Haemodialysis, Peritoneal Dialysis and Transplantation.

The Haemodialysis and Peritoneal Dialysis options are discussed in detail in Book 2 - *Haemodialysis and Peritoneal Dialysis - A Guide for Patients*.

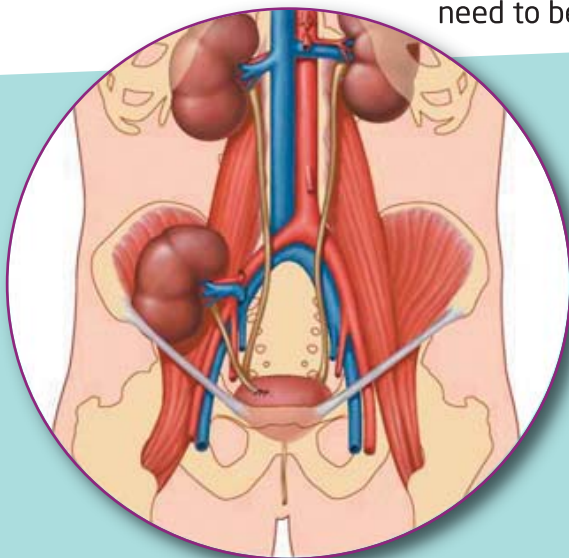
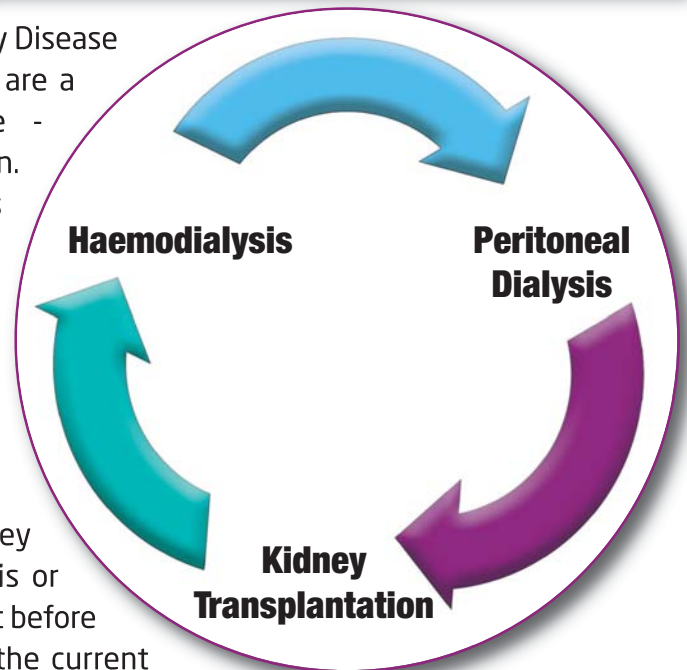
Kidney transplantation, if you are suitable, is the best treatment option for long-term health, but there are a number of factors that must be considered as it is not without potential complications. This book will discuss these factors in detail.

Most people, who are waiting to receive a kidney transplant, will be on dialysis - either haemodialysis or peritoneal dialysis. It is possible to receive a transplant before commencing on dialysis; however, it is rare due to the current waiting times for transplant kidneys.

Transplanted kidneys do not last forever and you may need to return to dialysis or undergo a repeat kidney transplant if your kidney fails.

A kidney transplant involves connecting the kidney artery and veins from the transplanted kidney to the recipient. The tube carrying urine, called the ureter, also needs to be connected to the recipient's bladder. The transplanted kidney is generally placed in the lower abdomen on the right or left.

In general, the surgeons do not interfere with your own kidneys unless there are specific problems that need to be dealt with.



WHERE DO KIDNEYS TO TRANSPLANT COME FROM?

Deceased Donors

- From people that have died suddenly

Living Donors

- From a living person, usually a relative

CHAPTER 2

DECEASED DONOR KIDNEY TRANSPLANTATION

Deceased donor kidneys are donated by families that have suddenly lost a close relative. There are two types of organ donors. Donors from brain death (DBD's), mainly from accidents or a brain haemorrhage. These donors have had a severe and irreversible brain injury that they cannot recover from and are declared 'brain dead' (that is their heart and body is kept alive by a breathing machine but their brain has died). The other type of organ donors are donors from cardiac death (DCD's). All donor families are asked to give consent for their relative's organs to be used for transplantation after cardiac death.

Unfortunately, the need for kidneys is higher

than the number of kidneys available for transplant. Currently, there are approximately 400 people waiting for a kidney transplant and between 140 and 170 deceased donor transplants are performed annually.

Deceased donor kidney transplantation has an advantage in that a living donor does not need to undergo a kidney donor operation which has associated discomforts and risks. The disadvantage, however, is that there is a world-wide shortage of kidneys to transplant and people have to wait quite long periods of time for one to hopefully become available. Currently, the Irish average waiting time for a deceased donor kidney transplantation is about 3 years.

IS A TRANSPLANT FOR EVERYONE WITH KIDNEY DISEASE?

While a kidney transplant can be a very successful operation, it does require a major operation lasting up to 3-4 hours. Not all patients with kidney disease will be medically fit to cope with this procedure. Patients with severe heart disease, history of stroke or peripheral vascular disease are often better served by continuing on dialysis rather than having a kidney transplant.

Patients that have had a history of cancer (except skin cancer) generally need to wait five years, after definitive treatment for the cancer, before going on the transplant waiting pool.

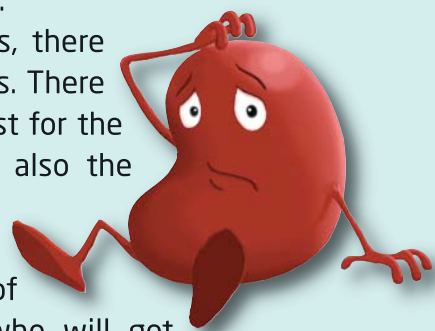
There is no upper age limit for kidney transplantation but, as a general rule, patients over 70 years of age, who do not have other associated illnesses such as heart disease, history of stroke or peripheral vascular disease, will be accepted on the

transplant waiting pool.

In allocating kidneys, there are competing priorities. There is a need to do the best for the individual patient but also the best for society in general, by allocating the scarce supply of kidneys to patients who will get many years of success.

Patients who have certain forms of kidney disease that may recur in the transplanted kidney may be better suited to dialysis rather than having to endure repeat transplantation.

Your nephrologist will discuss your individual case with you, and will help you make the right decision regarding transplantation.



RISKS AND OUTCOMES ASSOCIATED WITH KIDNEY TRANSPLANTATION

Kidney transplantation is a major surgical procedure with a success rate of about 95%. That is, 95% of kidneys transplanted will be functioning one year after the surgery.

Viewed another way, about 5 people in a 100 will not have a successful outcome from kidney transplantation. In general, about 3 patients in 100 will die, either during the operation, or shortly afterwards. Pre-operation testing, minimises these risks; nonetheless, you should be aware that there are significant risks associated with transplant surgery.

"Kidney transplantation is a major surgical procedure with a success rate of about 95%."



Other risks associated with transplant surgery will be discussed later in this book, but the transplant medicines necessary for the transplant to function, can cause side effects including diabetes, increased risk of infection, weight gain, increased risk of skin cancer and, rarely, lymphoma, (a form of cancer). There is also approximately a 10% risk of transplant rejection, which can be treated with courses of medicine, but still represents a risk to your new kidney. By following your doctor's instructions, and having regular medical check-up's you can help minimise the risk of your new kidney failing.



The outcome of kidney transplantation needs to be compared with the alternative, which is dialysis and the lifestyle restrictions it brings. In general, kidney transplantation results in more than doubling of life

expectancy, when compared to remaining on dialysis.

Deceased donor kidney transplants function for an average of 15 or 16 years. A live donor transplant functions for an average of 17 to 20 years and a best matched live donor kidney transplant functions for an average of 32 years.

"The outcome of kidney transplantation needs to be compared with the alternative, which is dialysis and the lifestyle restrictions it brings."

NEPHRON DOSING

The nephron is the functional unit of the kidney where all filtration takes place. A healthy kidney has approximately one million nephrons. The goal of transplantation is to deliver the "healthiest" kidney to the recipient.

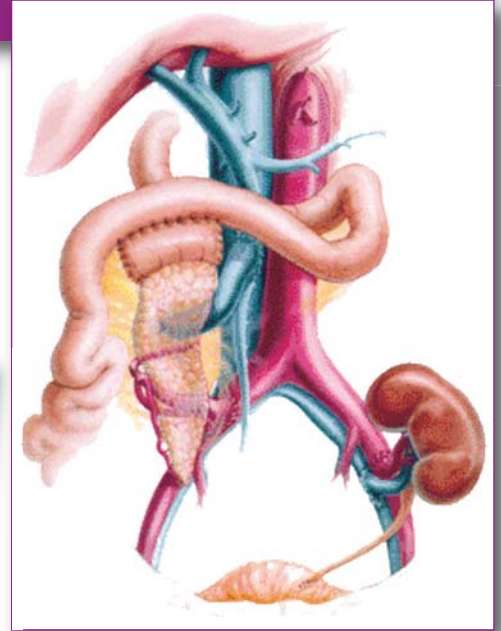
In a small number of cases, usually if the donor is an older individual, both kidneys are transplanted into a single recipient to maximise the number of nephrons delivered. This type of transplant is called "nephron dosing."

A kidney is placed on either side of the lower abdomen resulting in two scars. This operation takes longer than a single transplant and the recipient has a longer hospital stay. These kidneys can also be 'slow to start.' The decision to carry out a nephron dosing transplant is made on a case-by-case basis and is discussed with the potential recipient prior to surgery.

KIDNEY PANCREAS TRANSPLANTATION

Patients who have developed kidney disease due to Type 1 diabetes may benefit from having a simultaneous pancreas and kidney transplant (SPK). This option is only suitable for Type 1 diabetes. It is not suitable for Type 2 diabetes.

Type 1 diabetes results from the body's failure to produce insulin and presently requires the person to inject insulin.



Type 2 diabetes results from insulin resistance, the cells fail to use insulin properly.

During a SPK procedure a whole pancreas is stitched onto the vessel going to one leg and the kidney transplant onto the blood vessel going to the other leg. It is important to realise that a SPK transplant is a much bigger and more difficult operation than

a kidney transplant alone.

Currently the results of SPK transplantation are very good with a one year survival of 95% and a 5 year survival rate of 90%. Kidney pancreas transplantation should be considered the treatment of choice for all otherwise, well, young patients with renal failure from Type 1 diabetes. SPK transplantation is conducted in St. Vincent's University Hospital, Dublin 4.

Advantages of kidney/pancreas transplantation

- Improved quality of life
- Improved blood sugar control
- Probability of freedom from insulin injections
- Improved long-term survival
- Reduced long-term complications of diabetes

Disadvantages of kidney/pancreas transplant

- Longer, more difficult operation
- Possibly longer waiting time than for kidney alone
- More possibility of complications developing related to the surgery

LIVING DONOR TRANSPLANTATION

A living donor kidney transplant means that the donor kidney comes from a living person. Such a person, who volunteers to donate a kidney, is generally a brother, sister, parent, close friend, child or spouse of the person with kidney disease. The donor needs to have a close personal relationship with the recipient. A living donor kidney transplant must be seen as a 'no strings attached gift' to the recipient.

"A living donor kidney transplant must be seen as a 'no strings attached gift' to the recipient."

It is against the law to purchase or sell a kidney for transplantation. There is a reimbursement scheme for living donors expenses and loss of wages. Much more detail on the process of becoming a living kidney donor is available in book four of this series - *'Thinking About Donating A Kidney?'*



From a transplant recipient's perspective' live kidney donation has particular advantages which include:

Much shorter waiting time

The average wait in Ireland, at present, for a deceased donor transplant is about three years. A live donor transplant can be organised sooner if a suitable one is available.

The possibility of avoiding dialysis altogether

In general, it is possible to avoid dialysis completely only if you have a willing and suitable living donor who can be prepared, in sufficient time, prior to the progression of the kidney disease. As the average waiting time for a deceased donor transplant is three years, most patients will have progressed to dialysis, prior to receiving a deceased donor transplant.

Living donor transplantation generally results in better long-term success than a deceased donor transplant. For some groups of living donors this

improved success can be very considerable. For example, if you have a 'full-house' match sibling, who is willing to donate, the new kidney can last up to twice the length of time compared to a deceased donor kidney.

For some groups of patients, a live transplant from a sibling may be the only reasonable prospect of receiving a kidney transplant. This situation particularly applies to patients with a high percentage of antibodies, where a perfectly matched kidney, from a sibling, may be the only prospect of a transplant in a short period of time.

The major disadvantage of live donor transplantation is that a healthy living person has to undergo a major operation to donate a kidney, with all the associated risks and discomforts that are associated with major surgery.

LIVING KIDNEY DONATION

Living kidney donors are usually blood relatives, such as brothers, sisters or parents. Less often, close relatives, such as uncles, aunts, sons or daughters, or close friends.

Whoever becomes a donor must be over 21 and, preferably, in their middle 20's. Each potential donor is evaluated individually.

There is no strict upper age limit in donating a kidney, but there is less chance that an older donor will pass the medical examination necessary before donation is judged to be safe. (See Book 4 - *Thinking About Donating a Kidney?*).

Once a person has been accepted onto the transplant waiting pool, any potential living donor can contact the Transplant Co-ordinators to discuss their possible donation.

A living kidney donor needs to have a compatible blood group to the recipient. This will be one of the first tests that a potential donor will undergo to assess their suitability.

Checking DNA
for donor typing



*"Once you have been accepted
onto the transplant waiting pool,
any potential living donor can
contact the
TRANSPLANT CO-ORDINATORS
to discuss donation."*



The phone number
for the
**Transplant
Co-ordinators**
is....

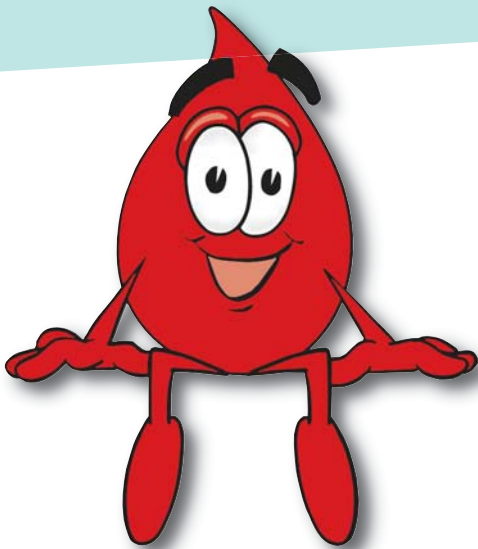
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BLOOD GROUPS AND DONOR/RECIPIENT COMPATIBILITY FOR KIDNEY TRANSPLANTATION

From this table, you will see that blood group O donor can be considered a universal donor i.e., they can give a kidney to anyone and blood group AB recipient is a universal recipient, i.e., they can receive a kidney from anyone.

These are important rules in the process of transplantation.

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

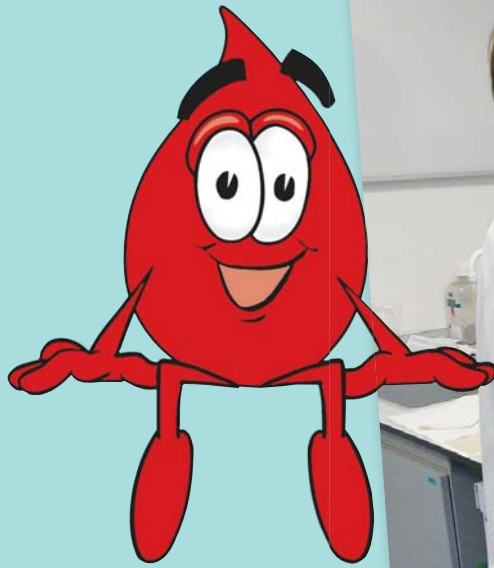


Once blood group compatibility has been confirmed, the donor has to be tested for tissue type compatibility. The tissue type of the donor and recipient will be determined in the tissue typing laboratory by way of a blood test. This process may take up to six weeks. The better the match between the recipient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

Cross matching a potential donor against their recipient



"Once blood group compatibility has been confirmed, the donor has to be tested for tissue type compatibility."



"The best match is where all 6 sets of markers are identical, and this is referred to as a 'full house' or 'zero mismatched graft'."

Your blood is tested for tissue markers called HLA antigens to determine your tissue type. Potential donors are tested for 6 different sets of markers, and you will be informed of how similar your tissue type is to the recipient.

The best match is where all 6 sets of markers are identical, and this is referred to as a full house or zero mismatched graft.



Donor and recipient matching is important for two reasons. Firstly, because a better match often results in better success of the transplant. Poor matching can make kidney transplantation for a second or third time much more difficult.

Secondly, it is also important to realise that there are many more factors that go into the success of kidney

transplantation than just tissue type matching and, it is entirely possible, to get excellent long-term kidney transplant success with a poorly-matched kidney.

When testing donor and recipient compatibility, we have to avoid giving a patient a kidney to which he or she has formed antibodies, as this would result in the early failure of the donor kidney.



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.

We are aware that if we give a donated kidney to somebody that has HLA antigens, against which they have HLA antibodies, there is a higher risk of the kidney failing due to rejection. 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 or easy 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



*Mary Keogan
(Consultant
Immunologist)
signing out the
final cross match report*

PGEN of 100%, they will have great difficulty finding a suitable kidney donor and will most likely have 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 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**

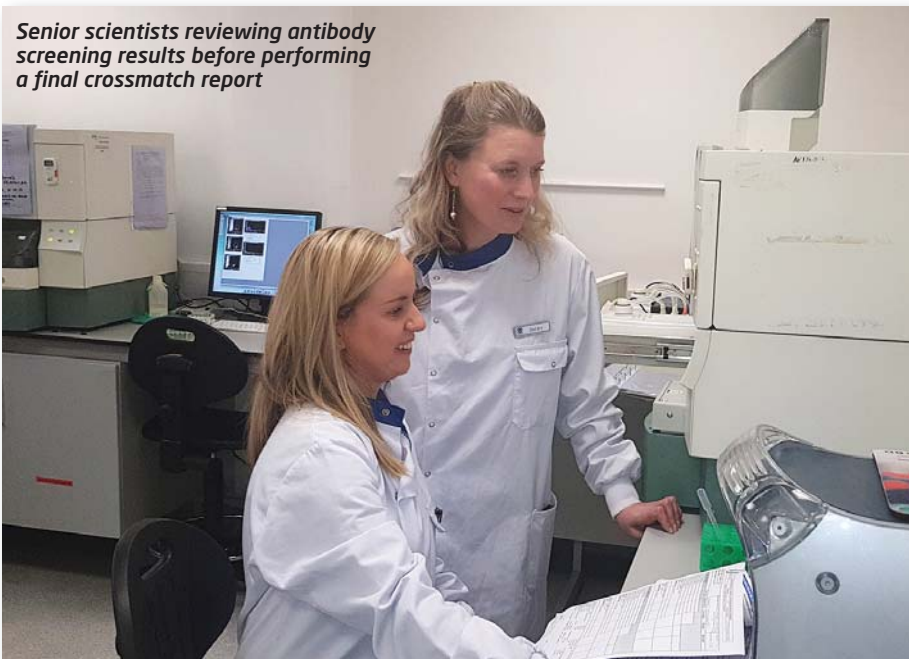
effective strategies to take away antibodies that give good long-term results.

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 potential donor workup shows that the donor is not suitable. This can cause significant disappointment to the donor who may be in an advanced stage of the workup process.

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 transplanted kidney.

The process of checking the suitability of a potential donor is a long, but **in-depth** one. To be as certain as possible that the kidney 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.

Senior scientists reviewing antibody screening results before performing a final crossmatch report



WHAT CAN I DO IF MY LIVING DONOR IS NOT A MATCH?

If you have a living donor willing to donate a kidney to you, but they are not a match 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

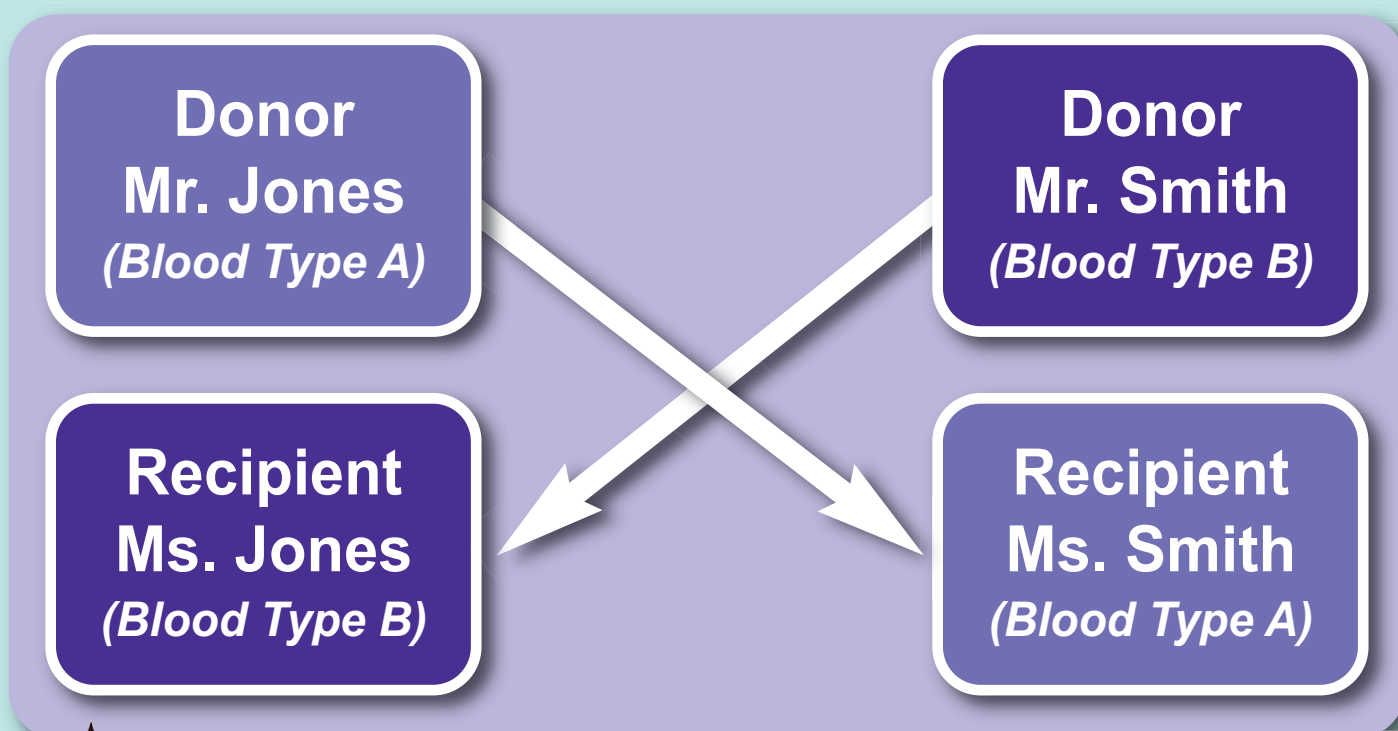
into a paired kidney exchange programme with others in a similar predicament.

This is where your donor gives their kidney to a compatible recipient and the recipient's donor gives you their kidney. Obviously, this depends on both kidneys being matched and suitable for transplantation.

INCOMPATIBLE DONOR EXAMPLE 1

Mr. Jones is blood type A and wants to donate a kidney to Ms. Jones who is blood type B. Mr. and Mrs. Smith, have 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 living donor and transplant procedure.



IT IS IMPORTANT TO POINT OUT THAT SUCH AN ARRANGEMENT IS NOT YET AVAILABLE IN IRELAND BUT SUITABLE IRISH BASED PATIENTS ARE WELCOME TO JOIN THE UK PAIRED EXCHANGE PROGRAMME. YOUR TRANSPLANT TEAM MIGHT BE ABLE TO ARRANGE FOR YOU TO BE REFERRED TO THE UK, WHERE SUCH PROCEDURES TAKE PLACE, PAID FOR BY THE HSE TREATMENT ABROAD SCHEME.

INCOMPATIBLE DONOR EXAMPLE 2

If, on the other hand, 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 ABO antibodies and proceed with the kidney transplant, across incompatible blood groups. Your nephrologist will discuss this in more detail if necessary.

It is however, important to appreciate that some patients with high antibody levels may have to wait a very long time to get a suitable donor match. Effective technology does not currently exist to remove HLA antibodies to allow successful transplantation.

CHAPTER 4

TRANSPLANT WAITING POOL

To be considered for a kidney transplant there are a number of steps that you must go through. You must be placed on the national kidney transplant waiting pool. When a deceased potential donor is identified the pool is consulted for potential matching recipients.

STEPS INVOLVED IN KIDNEY TRANSPLANTATION

1. Evaluate if you are healthy enough to receive a kidney transplant.
2. Prepare you for the operation.
3. Refer you to the Transplant Department at Beaumont Hospital.
4. List you on the transplant waiting pool.
5. Find a suitable kidney for you.
6. Perform the kidney transplant operation.
7. Help you stay healthy after your kidney transplant.

ARE YOU A GOOD CANDIDATE FOR KIDNEY TRANSPLANTATION?

Once your kidney function falls below 20%, your doctor should begin the process of working you up for a kidney transplant. Before you embark on transplant surgery, they need to be sure that you are fit enough for a transplant. You will only be placed on the transplant waiting pool when your

kidney function has fallen to 15% or less. There is no

point in putting you on the transplant waiting pool too early. You will only be put on this pool if you are ready to receive a kidney transplant.

Patients can be evaluated for a kidney transplant prior to

actually starting dialysis. Your nephrologist will arrange for a number of tests to be performed, prior to you being referred to Beaumont Hospital, where you will be evaluated by the transplant team. The tests that will be required will depend on a number of factors, including your age and cause of renal disease.

"It is possible that the results of these tests may determine that you are not a suitable candidate for a kidney transplant."

Tests that will be required include:

- Blood tests to establish your tissue type and blood group and blood tests for Hepatitis B, C and HIV (AIDS test) and other viruses. Depending on the results, you may be offered vaccination for protection against Hepatitis B or Chicken Pox (Varicella) if you are not already immune.
- Chest x-ray.
- ECG.
- Cardiac Echo Scan.
- Abdominal ultrasound scan.
- Dental evaluation (by your own dentist).
- Smear test (for women).
- Prostate test (for men).
- Older patients, patients hoping to receive a second transplant, or patients with diabetes will also require a coronary angiogram.
- You might also require more specialised tests relating to your bladder or other organ systems, as decided by your nephrologist.

Some of these tests might determine that you require further procedures to be performed before you are referred to the transplant centre.

PSYCHOLOGICAL CONSIDERATIONS

Some people might have concerns regarding a kidney transplant and might wish to discuss these, in confidence, with a counsellor. If your unit does not have a counsellor as part of its staff, counselling can be made available to you locally, through the

Irish Kidney Association.

It is helpful to talk to someone about your expectations of transplantation and to have realistic views of what to expect afterwards, and how you might cope.

REFERRAL TO THE TRANSPLANT DEPARTMENT AT BEAUMONT HOSPITAL



TRANSPLANT CO-ORDINATORS (l-r): Laura Lynch, Laura Austin, Andrea Fitzmaurice, Grainne Lambe, Emma Harte

Once your nephrologist has gathered together the results of all these tests, he or she will write a letter to the Transplant Department at Beaumont Hospital.

You will then receive an appointment to see one of the transplant surgeons and transplant co-ordinators, who will discuss, in detail, the pros and cons of kidney transplantation and make a final decision as to your suitability for a kidney transplant. The transplant team might ask that you undergo some more tests, or be reviewed by some other doctors, before you are placed on the transplant waiting pool.

At this appointment with the transplant surgeon and co-ordinator you will be examined and have the opportunity to discuss your

"Once you are approved for the transplant waiting pool, you will receive a letter from the Transplant Department confirming that you are on the waiting pool."

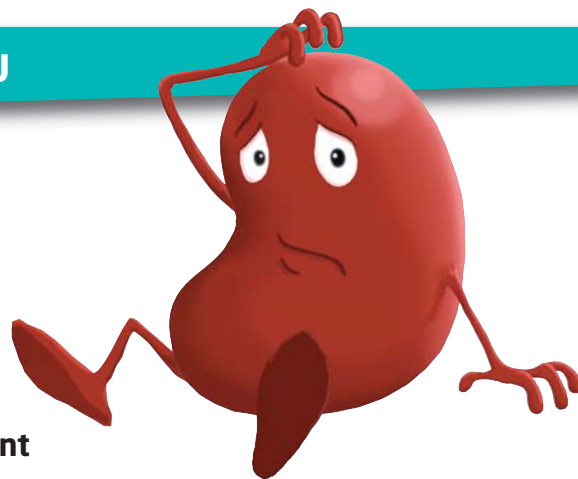
questions or concerns about the transplant process. After this meeting, your details will be noted and your case discussed at the monthly transplant consensus meeting. It is only after this meeting, where all the details of your case will be discussed by the entire transplant team, that you will be activated on the national kidney transplant waiting pool. You might be asked to come back to Beaumont Hospital to see an anaesthetist, based on the results of your investigation. Once you are approved for the transplant waiting pool, you will receive a letter from the Transplant Department confirming that you are on the waiting pool.

Once you are on the kidney transplant waiting pool you can ask any one who wishes to be considered as a living donor, to contact the Transplant Office themselves to request an evaluation as a potential living donor.

The phone number for the Transplant Co-ordinator is

01-8093119

FINDING A SUITABLE DONOR KIDNEY FOR YOU



The next step involves finding a suitable kidney for you. Sometimes this can take a long time. How long it takes will depend on many factors. On average, patients in Ireland presently wait about three years for a deceased donor kidney transplant, but **it might be a lot shorter or a lot longer**. While you are waiting for your transplant you should stay as healthy as possible. **Every 2 years on the transplant pool you will require a new echo, ECG and CXR.** Also, even though you are on the waiting pool prior to going on dialysis, you will probably start dialysis before you receive a transplant. It is not wise to delay going on dialysis in the hope that your kidney transplant will come soon. You need to be in the best shape possible the day you are called for a transplant.

Every 2 years on the transplant pool you will require an echo, ECG and CXR.

To find a suitable kidney, many considerations need to be taken into account. We will try to match a kidney for you from the deceased donor pool that is the best tissue match (see subsequent chapters), from a compatible blood group, and from a donor of similar age and

"On average, patients in Ireland presently wait about three years for a deceased donor kidney transplant, but it may be a lot shorter or a lot longer."

weight. To be fair to everyone on the waiting

pool we also take into account waiting time. Those waiting longest (all else being equal) will get priority. (See 'Criteria for Allocating Deceased Donor Kidneys' - on page 16).

It is very important that we find a compatible kidney for you because, if you receive a kidney that is not compatible, it might fail rapidly and complicate further transplantation.

If you are placed on the transplant pool before you commence dialysis (pre-emptive), you will receive blood sample bottles for testing your antibody levels every three months. You will receive instructions on how to take these bloods. **It is essential that these samples are taken and returned to Beaumont Hospital for testing.**

The Transplant Office MUST be able to contact you AT ALL TIMES, so if you change phone, move house or go on holidays, let the Transplant Office know beforehand.



Once you get a phone call from the Transplant Co-ordinator informing you of a potential kidney transplant, you need to make your way to Beaumont Hospital AS QUICKLY AS POSSIBLE.

Your family can contact the IKA's Renal Support Centre on the grounds of Beaumont Hospital if they require accommodation. (See page 49)

IF YOU HAVE A LIVING DONOR

Once your living donor has completed their evaluation, transplant surgery will be scheduled in a much more planned manner, compared to deceased donation, at a mutually agreed date.

CRITERIA FOR ALLOCATING DECEASED DONOR KIDNEYS

All patients requiring a kidney transplant in Ireland have their medical details maintained on a computer at Beaumont Hospital. The factors that decide who is selected as a suitable recipient for the kidney transplant are: blood group of the donor and recipient, length of time people have been waiting on the transplant pool, and the match between the donor and potential recipient. Other factors that have an influence are the age of donor and recipient, and antibody level of the recipient.

Patients who have had pregnancies, a previous renal transplant or blood transfusions might develop antibodies. A transplant can only be given from a donor to whom the recipient does not have antibodies. If you ask your doctor, he will tell

Blood Group
Compatibility



Tissue Type
Match



Waiting
Time



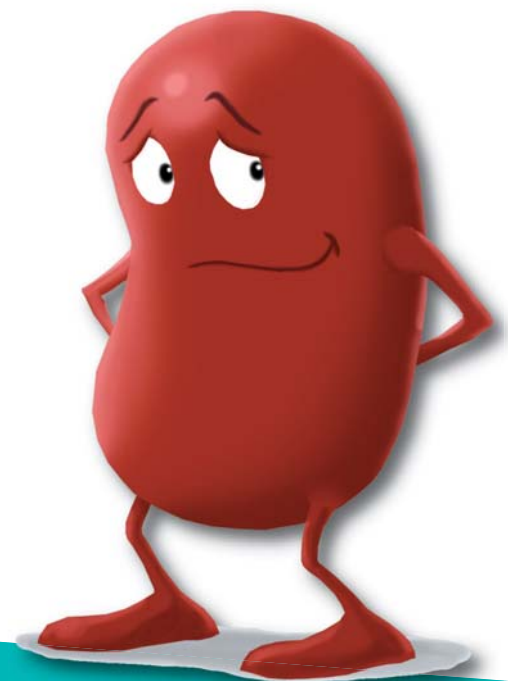
Match donors/
recipients age
and weight

People on the transplant pool, in severe life threatening clinical need, are considered by a panel of doctors and may be prioritised

you what percentage of antibodies you have, which will give you some idea how long you may have to wait on the transplant pool. People with high levels of antibodies generally have to wait longer for a suitable donor kidney than people with no antibodies.

People on the transplant pool, in severe life threatening clinical need, are considered by a panel of doctors and may be prioritised.

"Patients who have had pregnancies, a previous renal transplant or blood transfusions might develop antibodies."



TRANSPLANT PROCEDURE AND FOLLOW-UP

PREPARING FOR A KIDNEY TRANSPLANT

When you receive a phone call to tell you that a potential suitable deceased donor transplant is available for you you must make your way to Beaumont Hospital as quickly as possible. Bring a bag with a change of clothes, toothbrush, toiletries, pyjamas, and whatever you may need during your stay. You must not eat or drink from the time you are told to come to Beaumont, as you must be fasting prior to surgery. Please note that when you are called for a transplant there is no guarantee that you are going to receive a kidney. There will be a number of further tests that will need to be done after you arrive at Beaumont. These tests might show that this particular kidney is not suitable for you.

You will have blood tests, an ECG and a chest x-ray. You may also need to have a dialysis session prior to the surgery depending on when you were last dialysed and your blood test results. If you are

on peritoneal dialysis, you will be asked to drain out your fluid at home or at Beaumont.

The kidney transplant operation has been perfected over many years. All adult kidney only transplants, in Ireland, are performed in Beaumont Hospital and all children's kidney transplants are performed in the National Children's Hospital, Temple Street by the Beaumont transplant surgery team. All kidney and pancreas transplants are performed in St. Vincent's University Hospital.

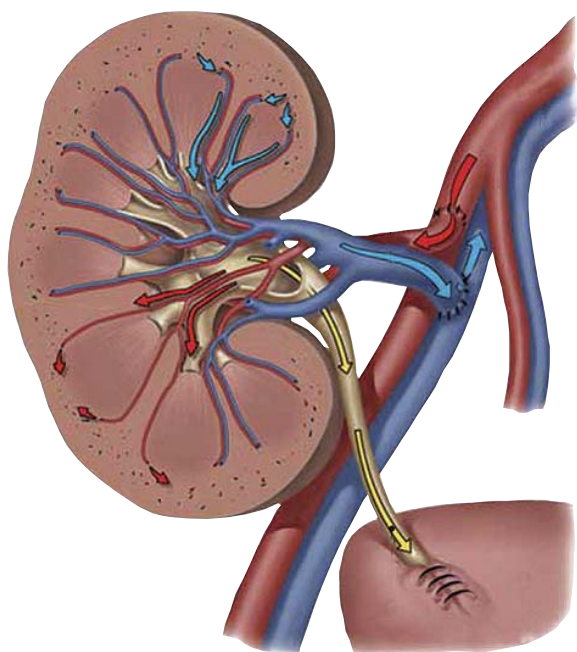
WHAT HAPPENS DURING THE OPERATION?

The transplanted kidney is placed in a different location to your existing kidneys. It will be placed in the right or left side of your lower abdomen, just above the hip bone. The arteries of the new kidney are connected onto the blood vessels, going to your legs, and the tube from the new kidney is connected to your bladder. The transplant operation takes about 3 to 4 hours. Normally your native kidneys will be left where they are.

AFTER THE OPERATION?

After the operation, you will be taken to the specialist high dependency transplant ward where you will remain until discharge.

When you wake up after the operation, you will have a number of tubes connected to you. You will have a tube in your bladder called a catheter and a number of drips in your arm or neck, supplying you with fluids. Also you will have oxygen supplied to you by a mask. Pain relief is given by Patient Controlled Analgesia (PCA) for the first 24-48 hours. After that, oral medication is usually enough to keep you comfortable.



The day after the operation most people will be out of bed, sitting in a chair, and will be allowed to gradually start eating a light diet. The catheter in your bladder will stay in place for up to five days. Sometimes a small plastic tube, called a stent, will be left near your bladder for 3-4 weeks. This will be removed through the bladder at a later date by a small procedure conducted as a day case. This involves a small camera being inserted via the urethra into the bladder. If you have been on dialysis for a long time, the bladder will be smaller which means you will probably have to urinate very often. This will improve with time.

Your length of stay in the hospital will depend on your health and how quickly your new kidney begins to work. Most patients spend between 7 and 14 days in hospital, after the transplant.

It is not unusual for your kidney not to work straight away, and you might need dialysis after your transplant. This does not mean the newly donated kidney is not going to work. It may take 2 or 3 weeks to work fully.

Your doctors will monitor many factors relating to your new kidney. In particular, they will measure your creatinine level and drug (immunosuppression) levels each day. The lower your creatinine level, the better your new kidney is working. If your creatinine does not come down as low as your doctors would like, they might recommend a kidney biopsy.

A kidney biopsy is a procedure where the doctor puts a needle into the kidney to take out a small piece of tissue to examine exactly what is going on



St. Damien's Ward

in the kidney. In particular your doctor wants to know if there is rejection developing in the kidney. An ultrasound machine is used to locate the kidney and the skin in the area is numbed with a local anaesthetic. A small needle is inserted through the skin, into the kidney.

The risks associated with performing a kidney biopsy are small. The main risk is bleeding after the biopsy. The risk of bleeding, such that you would need a blood transfusion, is about 1 in 100 and it is about 1 in 700 that it would bleed badly enough to require surgery.

If you develop some rejection, you will be prescribed a high dose of steroids for between 3 and 5 days. This almost always reverses the rejection. Occasionally, patients develop a severe rejection that requires a special drug treatment called Anti-Thymocyte Globulin (ATG). It is also possible to develop a form of rejection called humoral rejection that requires a special treatment called Plasmapheresis.



Dialysis machine

EMOTIONAL REACTION

It is quite normal to feel emotional after a transplant. Feelings can range from elation to tearfulness, from joy to sadness. People can feel vulnerable emotionally and even overwhelmed. These feelings usually settle down quickly.

Counselling will be available.

If you are being treated for depression, prior to your transplant, it is advisable to continue taking your anti-depressant medication. Your doctor will advise you about this.

POST-TRANSPLANT MEDICATION

After your transplant, medications will play an essential role in keeping your new organ working properly and maintaining your general good health. You will need to take some medications for the rest of your life. Other medications will be necessary only for a limited time. From time to time, the amount of a medication you take may change, or you may be switched from one medication to another. The medications that you will be taking are designed to prevent a number of problems:

- Transplant medicines (immunosuppressants) to prevent rejection
- Medicines to prevent infection
- Medicines to deal with other common problems after kidney transplant, such as cholesterol and blood pressure tablets.



Immunosuppressants

Immunosuppressants are medications that help prevent rejection of your transplanted kidney. They are called immunosuppressants, because they work by suppressing your immune system. These are powerful medications that affect other parts of your body too.

The goal of immunosuppressant therapy is to find the right balance between preventing rejection while minimising side effects and reducing the risk of infection. Many of the side-effects are more severe when the dosage of the anti-rejection medication is highest, just after the transplant. In the weeks and months following your transplant the dosage may be reduced and some of the side-effects may become less troublesome or might even disappear. If you experience side-effects tell your doctor or transplant nurse who might be able to adjust your dosage or switch you to another medication.

Anti-rejection medications work only within a very narrow range in your body- too little, and you risk rejection; too much, and they can be poisonous or toxic to your body. **That is why you must take these medications exactly as instructed.** Never take more, never take less, and never, ever, skip a dose. If you do forget to take a dose, take it, if remembered, within 4-6 hours of the prescribed time, but never take a double dose, unless you are specifically told to by your doctor. In order to be certain that you are getting precisely the right amount of anti-rejection medication, you must be monitored regularly with routine blood tests, which measure the drug level within your body.

You must take these medications for the rest of your life. Even if you have had a rejection episode or your doctor has reduced your dosage, you must not stop taking these very important medications. **If you stop taking your medication, you will lose your kidney transplant. It is that simple.**

TYPES OF IMMUNOSUPPRESSANTS

Anti-rejection medications are taken orally (by mouth) and form the mainstay of your post transplant treatment.

All patients take a combination of the following three groups of medications:

- Prednisolone
- Prograf (Tacrolimus) or Advagraf
- Mycolat (Mycophenolate Mofetil)

TRANSPLANT MEDICATION COMBINATIONS

Tacrolimus
(Prograf or Advagraf or Envarsus)

OR

Cyclosporin
(Neoral)

AND

Mycophenolate
(Mycolat or Cellcept or Myfortic)

AND

Prednisolone

Prednisolone

Prednisolone is a steroid drug, available in 5mg tablets, and should be taken once daily, in the morning, and always with food. The dose of Prednisolone may be high at first, usually starting at 20mg daily, but will be tapered down over the first three months. Never stop taking this medication abruptly.

Some side effects of this medication include: increased appetite, weight gain, bone density loss, increased risk of infections, acne, elevated blood sugars, joint pain and muscle weakness, increased sensitivity to the sun, mood changes, increased blood pressure, cataracts and glaucoma.

Prograf (Tacrolimus)

This medication is available in oral capsules, strength 0.5mgs, 1mg and 5mgs. Take Prograf in two doses at the same time each day, twelve hours apart. Take Prograf on an empty stomach, one hour before or two hours after meals. Grapefruit and grapefruit juice will interact with Prograf and must be avoided. Possible side effects of this medication include: tremor, headaches, nausea, vomiting or diarrhoea, high potassium levels, hypertension, hair loss and diabetes.

You transplant team will measure the level of Prograf in your blood each time you come to the clinic. For the first 3 months, after transplant, your doctor will adjust the dose to achieve a level of 6 to 12mg/ml. After 3 months they will be aiming for a lower level of around 6 to 10mg/ml and after 6 months they will aim for a level closer to 6 to 8mg/ml. A high level of Prograf may result in a higher serum creatinine. Other drugs may interfere with Prograf. If your GP, or any other doctor prescribes a medication, check with your transplant team before starting it. Your nephrologist may prescribe you Advagraf. This drug is in the same family as Prograf but unlike Prograf it is taken once a day, in the morning. You may be switched from Prograf to Advagraf when your kidney function is stable.



Mycolat (Mycophenolate Mofetil)

This medication is available in 250mg oral capsules and 500mg oral tablets. Take Mycolat in two doses, at the same time each day, twelve hours apart. Possible side effects of this medication include: diarrhoea, vomiting or nausea (diarrhoea associated with Mycolat mainly improves after 2-3 weeks), abdominal pain, decreased white cell count and platelets. Report any signs of bruising or bleeding to your doctor.



Myfortic (Mycophenolic Acid)

This medication is available in 180mg and 360mg oral tablets, which are enteric-coated. This medication works in a very similar way to Mycolat and has similar side-effects.



Women who want to become pregnant will need to come off Mycolat or Myfortic and use a different medicine BEFORE they even plan to become pregnant.



Imuran (Azathioprine)

This medication is available in 25mg and 50mg oral tablets. Take this medication, at the same time every day, with food. Some side effects include: nausea or vomiting, low white blood cell and platelet count. You will be monitored very carefully to detect any complications.

Neoral and Sandimmun (Cyclosporine)

This medication is available in soft gelatine capsules in 25mg, 50mg and 100mg doses. An oral solution is also available. Grapefruit and grapefruit juice will interact with Cyclosporine and must be avoided. Side-effects of this medication include: hypertension, increased hair growth, enlarged gums, tremors, high potassium levels and elevated blood sugars.



Rapamune (Sirolimus)

This medication is available in 1mg and 2mg tablets. Grapefruit and grapefruit juice will interact with Sirolimus and must be avoided. Side-effects of this medication include: high cholesterol, hypertension, rash or acne, mouth ulcers, bone pain, respiratory problems and delayed wound healing.

INFECTION-FIGHTING DRUGS

The medications you take to stop your body from rejecting your new kidney also reduce the normal ability of your body to fight bacteria, viruses, and other germs. As a result, you are at an increased risk of getting an infection. Your doctor may prescribe one or more drugs to protect you from infection or to control infection. The following are some of the more commonly used antibiotics (antibacterial drugs), antiviral drugs, and antifungal medications.

Septin (Co-trimoxazole)

Septin is used to prevent and/or treat, pneumonia and other infections. Transplant patients have more risk of getting pneumonia, because of the drugs taken to avoid rejection, which reduce their body's ability to fight infection.

- Your transplant team will decide the right dosage and length of time for you to take Septin.
- Take plenty of fluids with this medication. Check with your transplant team about the amount.
- Main side effects include nausea, rash, itching, and increase risk of sunburn.



Valganciclovir (Valcyte)

Valcyte may be given to help prevent or treat infections that are caused by a virus called Cytomegalovirus (CMV).

It is given orally in 450mg tablets. It is generally given once daily, in the morning. You will be asked to take this medicine for 3 to 6 months.

Contraception needs to be used by men and women whilst on this medication as it is teratogenic. This means it can cause abnormal development of a foetus.

Valacyclovir (Valtrex)

Valacyclovir is used to prevent or treat herpes simplex and shingles. Valacyclovir will not get rid of the herpes virus, but it will lessen the pain and help heal the sores. Valacyclovir is also used to prevent and decrease the severity of other viral infections in patients at higher risks.

The lowered ability of your body to fight infection, puts you at more risk of getting a serious fungus infection. This may take the form of thrush, or, in women, vaginal yeast infections.

Various drugs are used to treat or prevent fungus infections. Nystatin (Mycostatin) and Fluconazole are the most commonly used. Fluconazole and related antifungal drugs can interact with some anti-rejection medications, so an adjustment will be made in your medications when you start and stop taking the antifungal drugs. Nystatin oral suspension does not interact. Your transplant team will decide the right dosage and length of time for you to take antifungal medications.

Main side effects include nausea, vomiting, diarrhoea and an unpleasant taste.



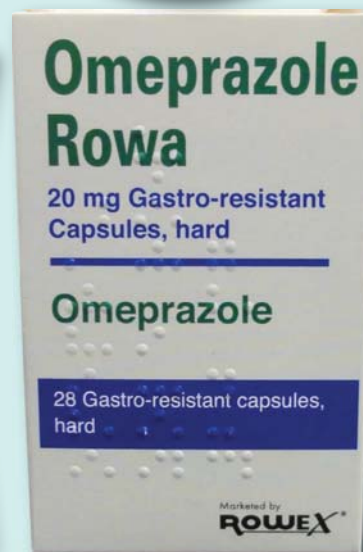
DRUGS THAT PROTECT YOUR DIGESTIVE SYSTEM

Because some medications you are prescribed can cause stomach ulcers, you may need to take other medication to help protect your digestive system. These drugs will be prescribed by your transplant team, when necessary.

ANTACIDS/ANTI-ULCER MEDICATIONS

Ranitidine (Zantac), Famotidine (Pepcid), and Omeprazole (Losec), are medications used to prevent and sometimes treat stomach ulcers.

- It is important to follow instructions about meals and other medications when taking any of these drugs.
- Your transplant team will decide the right medication, dosage, and length of treatment time for you.
- Do not take these drugs with other medications unless your transplant team has told you to do so.



"Because some medications you are prescribed can cause stomach ulcers, you may need to take medication to help protect your digestive system."

OVER-THE-COUNTER MEDICATIONS

The following is a list of common complaints with recommended over-the-counter medications that you can take. Please check this list before taking any over-the-counter medication. The addition, of any other medications or change in your current medications, must be made through your transplant centre.

Constipation – Fybogel and Senekot are medications that you may take. Increase fluids and fibre in your diet (bran, fresh fruits and vegetables). If constipation remains a problem, be sure to contact your GP.



Diarrhoea – Imodium is a medication that you may take. Increase fluids to prevent dehydration until diarrhoea goes away. If diarrhoea persists, for more than 2 days, contact your GP.

Headache, Muscle Aches, other Aches and Pains – If headaches persist, or are accompanied by fever, please notify your transplant centre immediately. Paracetamol or Solpadeine are medications that you may take.



DO NOT TAKE Ibuprofen (Brufen, Nurofen), Diclofenac (Difene/Voltarol)



These medications are known as non-steroidal anti-inflammatory drugs (NSAIDs) and interact with your immunosuppressants and may harm your kidneys. There are many other NSAIDs, known by many different names, always check with a health professional if unsure. Your pharmacist can assist you.



Common cold symptoms

Call your transplant centre if symptoms persist or worsen. Over-the-counter medications that you may take include Lemsip.

“Check with your transplant team before taking any nutritional supplement.”

NUTRITIONAL SUPPLEMENTS

Your transplant team may recommend you take vitamin and/or mineral supplements if your diet is not providing enough of the nutrients you need. Check with your transplant team before taking any nutritional supplement.

CAUTION: HERBAL PRODUCTS OR HERBAL TEAS Since there is little information about drug interactions between herbals, and anti-rejection drugs, it is not recommended that transplant patients



take herbal products. Herbal products are not regulated by any government agency. This means that they are not tested for safety, side-effects or drug interactions. St. John's Wort, for example, is a herb known to increase the risk of rejection by decreasing the amount of the anti-rejection drugs in your blood. Other products that may 'enhance your immune system' may lead to rejection as well.

REFILLS

Running out of medication is careless, dangerous and unnecessary. Keep a regular count of your medications. Don't wait until you've run out, or are on your last pill, before ordering. Refill your prescriptions early. Your immunosuppressive medications are initially prescribed on a high-tech prescription. This prescription is different to your other medical prescriptions. Because of the high cost of the medicines it is funded differently by the HSE. **Your pharmacy will require an up-to-date high-tech prescription every six months. If you do require a high tech prescription, ask and remind your doctor at your clinic visit.**

Many local pharmacies do not keep regular stocks of some transplant medications and will need time to order them. Try to keep at least a two-week supply of all medications, at all times. Use only one pharmacy. If the pharmacy has a complete record of all your medications, they can be sure to stock each of the medications you require, when you require them. Always check your medications when you receive them from the pharmacy. Look at each label and medication. If there is anything that appears different than usual, call the pharmacist immediately, as mistakes can and do happen. Take charge of your medications and see explanations for any changes in your order.

STORING YOUR MEDICATIONS

- Keep your medications in a place that is dry, dark and neither too hot or cold. Never store

medications in the refrigerator, unless instructed specifically to do so.

- Keep medications where you will remember to take them. Once the foil outer packaging surrounding Prograf and Advagraf is opened the drug only has an expiry of 12 months, especially important from 0.5mg strength as may not be used on a regular basis.
- Keep all medications out of the reach of children and separate from other peoples' medication.

For most patients, stopping, dialysis after a transplant, means certain medications will no longer be needed. Medication such as phosphate binders and quinine are usually discontinued.

Activated Vitamin D medicines, such as One Alpha, are also likely to be discontinued unless you have had a surgical parathyroidectomy carried out to control parathyroid hormone levels.

A successful transplant should help correct anaemia caused by end stage kidney disease (ESKD) so that erythropoietins and iron supplements may not be needed after transplant.

If you are unsure about the need for any of your medications. ask your doctor.

"Check your medications when you receive them from the pharmacy. Look at each label and medication. If there is anything that appears different than usual, call the pharmacist immediately as mistakes can and do happen. PLEASE NOTE PACKAGING CAN AND DO VARY."



GENERAL TIPS

- Tell any other doctor, dentist or surgeon looking after you, what medications you are taking and show them your Renal Transplant Passport.
- Anti-rejection medications can interact with many other medications, both prescription (especially certain antibiotics) and over-the-counter medications. These interactions can cause you to get too much or too little of the required medication.
- Never take any medication, including herbals, tonics or supplements, without first discussing it with your transplant doctor, nurse or pharmacist.
- Most pharmacies sell medicine organisers - plastic containers that are designed to help you organise your medications for a whole day or a whole week. Try not to prepare more than a week's supply of medication in advance. These are easy to carry, and many patients find them to be very helpful.



CHAPTER 7

AFTER THE TRANSPLANT

The following information is designed to help answer some of the questions you might have following your kidney transplant. This information is only a guide. You should discuss any worries or concerns you have with your doctor or transplant nurse.

After your transplant, you will need to take medication every day and return to the hospital for regular check ups.

GOING HOME

Going home after a kidney transplant is usually a happy and emotional occasion, but this feeling of joy may also be accompanied by a significant level of anxiety for the first few weeks. It is important to realise that recovery following the transplant is a process that can take many weeks or months.

For both the patient and their family it can take a while to adjust to the new way of life. Once the vulnerable early period of about three months has passed, most kidney transplant recipients enjoy recovery to a full and active life.

Renal Day Care, Dialysis Therapy Centre



OUTPATIENT FOLLOW UP

Before discharge from hospital, kidney transplant recipients are given a medical diary called a **Renal Transplant Passport**. It will have all your blood results and any changes made by the doctor to your medication regime. You must bring this book with you to all your visits to the hospital.

After discharge, patients from Cork will be followed up at the Cork Renal Unit, whilst patients from Kerry will be followed up at the Tralee Renal Unit. All other patients will initially be followed up at Renal Day Care, at the Dialysis Unit in Beaumont Hospital. Before discharge, you will be given an appointment for Renal Day Care. In the beginning, you will attend the hospital once or twice a week. In time, these visits will become less frequent. Once the doctor is happy with your progress, you will be transferred to the outpatient department and may be transferred back to your referring hospital for long-term or 'shared care', where you will have regular follow-up with your own nephrologist and medical team.

CLINIC VISITS (including Renal Day Care Visits)

Outpatient clinic visits are an essential part of your treatment. During these visits, you will have:

- Blood samples taken and tested.
- Your medications adjusted, if necessary.
- Physical examination.
- An opportunity to ask the transplant nurses or doctors any questions.

The blood tests are vital to detect any problems, such as rejection or infection, even before you have any physical symptoms.

Other blood tests are taken to monitor your drug levels.



Dialysis Therapy Centre reception

Renal day care staff will contact the patient the following day regarding blood results and medication changes.

For patients attending clinics

the staff will contact you only if there is a change in medication, otherwise you can assume 'no change'.

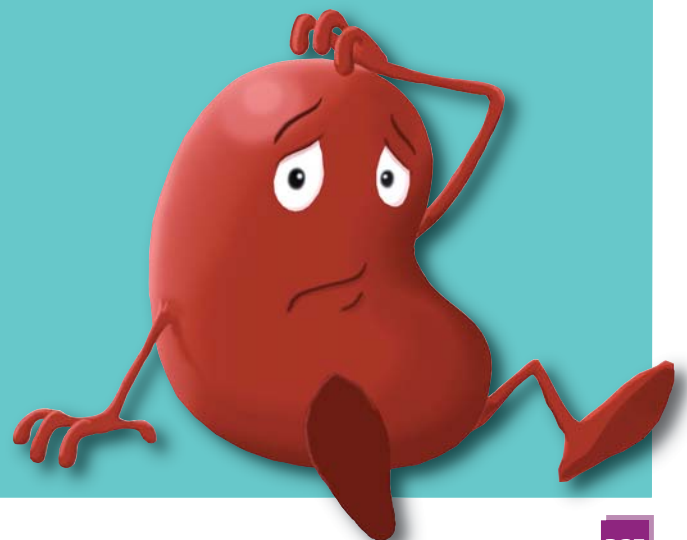
PSYCHOLOGICAL ISSUES

Adjusting to life with a kidney transplant may be challenging for some. Counselling is available, at any time following transplantation, to you or your family should you wish to talk, in confidence, about anything that is worrying you.

Contact **Mike Kelly, Renal Counsellor, Irish Kidney Association, Donor House, Park West, Dublin, D12 P5V6, Tel: 01-6205306.**

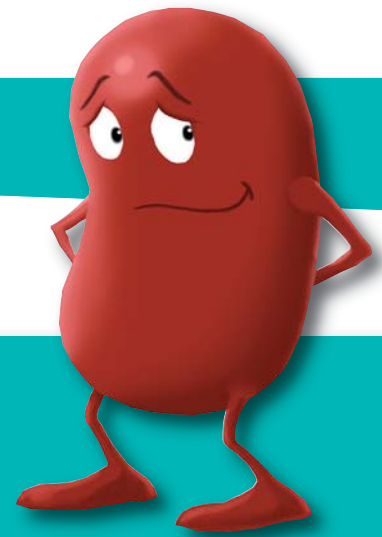


Alison Larkin, Renal Counsellor



CHAPTER 8

TRANSPLANT COMPLICATIONS



Any patient who has undergone major surgery can experience postoperative complications. In the first few weeks following transplantation, the majority of patients experience some kind of complication including:

1. Delayed Graft Function 'Sleepy Kidney'

The functioning of your kidney transplant might be delayed, causing a need for dialysis until the kidney 'wakes up'. Delayed function might last from several days to several weeks.

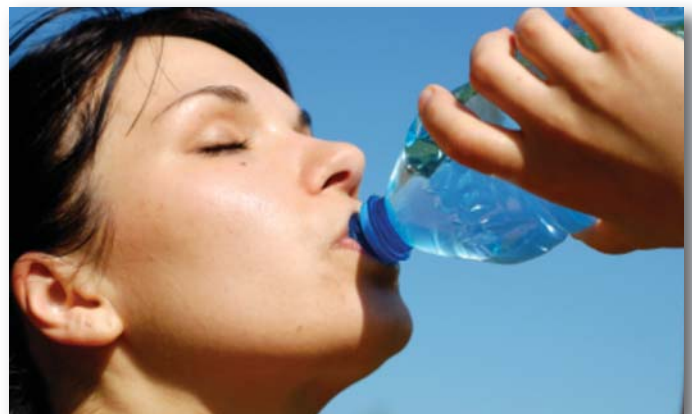
2. Wound Problems

Your incision may not be completely healed when you go home. Keep the wound clean and dry. Do not take a bath or swim until your wound is fully healed. If you have staples or stitches, they will be removed by the transplant nurse. Steristrips (paper stitches) will dry and fall off on their own. Examine your incision every day. Notify your doctor or nurse immediately if you notice any *redness, swelling, tenderness at the site or liquid seeping from the site*.



Transplant wound

While we want you to be physically active, there are some things you should not do during the first two to three months after your transplant. Do not do any heavy lifting, pushing or pulling for at least two months. Do not do any exercises that drag or pull the tummy muscles. We recommend that recipients do not drive for six weeks following transplant, but there is no evidence to suggest that wearing a seat belt can harm your transplanted kidney.



3. Dehydration

One of the best ways to keep you and your kidney healthy is to drink plenty of fluids. Fluids will flush medication from your system, make you feel less hungry, and prevent your skin from becoming dry. Normally you should drink more than 2 litres of fluid each day (please check with your doctor regarding your fluid allowance). If you are dehydrated, you may experience some of the following symptoms: thirst, dry skin, dizziness, feeling light-headed, decreased urine output, dark urine, headache, hunger and weight loss.



4. Infection

Transplant patients are at a greater risk of infection because of their need for immunosuppression medications, which weakens the immune system and its ability to fight infection. While it is important for you to limit contact with potentially infectious situations it is not necessary to become a recluse! There are some relatively simple measures which you can take to reduce the risk of infection, without unduly limiting your lifestyle.

Infections are caused by viruses, bacteria and fungi and come from these sources:

- **Environment** – For example, contaminated food or cooking utensils, uncooked food or animals.

- **People** – Colds, influenza and a range of viral illnesses.

- **Bacterial Infections**

Urinary Tract Infections (UTI) is one of the most common infections seen in kidney transplant recipients. If not properly treated, the infection can spread and harm your new kidney. The symptoms of a UTI are: cloudy urine, blood in the urine, frequent urination, burning upon urination, difficulty urinating, strong smell from the urine, and high temperature.

"If you suspect you may have an infection contact your doctor or transplant nurse"

INFECTIONS MAY CAUSE THE FOLLOWING SYMPTOMS

- High temperature, sometimes accompanied by chills
- Diarrhoea, nausea and vomiting
- Loss of appetite
- Fatigue
- Shortness of breath
- Difficulty or discomfort when urinating
- Appearance of a skin rash
- Unexplained pain

THINGS TO DO AND AVOID TO PREVENT INFECTIONS

- Get enough rest and eat a healthy well-balanced diet.
- Reduce close contact with anyone who has an active infection or any children who have been recently vaccinated.
- Wash hands with soap and water frequently throughout the day.
- Do not touch open sores. Keep any wounds clean and covered.
- Wear gloves when gardening or during any other dirty jobs.
- Avoid close contact with pets.
- Wash fresh fruit and vegetables and also meat, fish and poultry prior to cooking.
- Never share personal items such as razors or toothbrushes.

HERE ARE SOME WAYS YOU CAN PREVENT URINARY TRACT INFECTIONS:

- Drink plenty of fluids.
- Avoid bubble baths.
- Urinate frequently.
- Wear cotton underwear.

Preventing Bacterial Infections:

Most bacterial infections can be avoided by following good common sense and good personal hygiene.

- Wash your hands frequently throughout the day using warm water and soap.
- If you get a cut, wash and treat it immediately. If it gets red or sore contact your GP.
- Cook meats thoroughly and avoid eating raw eggs, raw meat or raw fish.



Fungal Infections

The most common fungal infection, seen in kidney transplant recipients, is Candida. Thrush is a common candida infection, which occurs in the mouth. Thrush creates creamy or grey patches on the inside of the tongue or cheeks. Some women may experience vaginal thrush, which has similar symptoms. You can let your team know if you experience any symptoms.

Pneumocystis carinii

Pneumocystis carinii is a germ that is similar to a fungus, and it is normally found in the lungs of people whose immune systems are suppressed. It may cause a type of pneumonia. Early in the illness, you might have mild, dry cough and a fever. If you think that you have a cold or flu-like illness that does not get better, contact your transplant team right away. You will be prescribed Septrin (Co-trimoxazole) to prevent this infection, for up to six months post-transplant, when you are most at risk.

● Viral Infections

Although there are many viruses that can cause infection in transplanted patients, the ones that most often cause problems belong to the herpes group.

Cytomegalovirus - CMV

As previously discussed, CMV is a member of the herpes family and is present in more than half of all adults, before they reach middle age. For most people CMV causes only mild symptoms including a low fever and tiredness. Although these symptoms disappear, the virus remains in the body forever.

When the immune system is suppressed, following a kidney transplant, the CMV could be reactivated and can cause a range of serious infections such as pneumonia, eye infections or gastrointestinal disease.

To prevent this, many patients are prescribed a prevention medication such as Valganciclovir for three to six months post-transplant.

Varicella Zoster

Varicella virus is the cause of chickenpox in children. As with CMV, the virus continues to live on in the body. If someone has previously had chicken pox, the virus will/can reactivate in the form of shingles.

If you never had chicken pox and come into contact with shingles then you may develop chicken pox which is the primary form of Varicella. If you never had chicken pox and come into contact with chicken pox then you will get chicken pox.

For the last ten years patients have been tested for Varicella prior to going on the transplant pool and before going on the pool will be vaccinated if their test is negative.

Measles, Mumps and Rubella are all highly contagious viral diseases that can be severe, if caught by anyone taking immunosuppressants. The vaccines against these diseases, as well as the oral polio vaccine, are made from live viruses and can cause an immunosuppressed person to catch the disease. Avoid these vaccines and anyone who has recently received them.



Herpes Simplex Type 1 and Type 2

Herpes Simplex Type 1 causes painful cold sores on the lips or mouth or it can appear as an eye infection. It is known that exposure to strong sunlight and stress can contribute to these attacks.

Herpes Simplex Type 2 causes sores in the genital area and is usually transmitted through sexual intercourse.

Even after the mouth sores heal, it is still possible to infect others for up to seven days afterwards. Genital herpes is contagious for up to twelve days and although using a condom is a safe practice, it does not protect you or your partner from spreading herpes. It is best to abstain during this period.



Polyoma infection (BK Virus)

This is a viral infection that only affects transplant patients and can cause slow damage to the kidney. Fortunately if the condition is diagnosed early enough it is possible to reduce the amount of transplant drugs you are taking and allow the infection to clear up before severe damage has occurred in the transplant kidney.

You will require regular blood tests to check for the first 12 months post transplant. A schedule of these tests is printed inside your passport.

5. Rejection

Rejection is the natural process of your body trying to protect itself from anything that is foreign. Kidney transplant rejection means that your immune system is 'confused' and attacks your kidney, thinking it is attacking a group of bacteria, infecting your body. Rejection may sound quite dramatic but, in fact, it is very common and, fortunately, in most cases, when rejection is discovered and treated early, it can be controlled.

There are things you can do to reduce your risk of rejection:

- Take your medication as directed;
- Learn the early warning signs of rejection, and
- Attend all scheduled clinic and doctor visits.

TYPES OF REJECTION

There are three types of rejection:

- **Hyper acute rejection** – happens very suddenly, usually during the transplant surgery or the first few hours after. This form of rejection is, thankfully, rare due to careful tissue type matching, but is very difficult to treat.
- **Acute rejection** – is the most common kind and develops over a short period of time, a few days or weeks. The risk is highest during the first 2 to 3 months, but can also happen a year or more after transplant.
- **Chronic rejection** – is a process that occurs slowly and over a long period of time. It may begin immediately after the transplant, but the visible signs of chronic rejection are rarely seen within the first year. It is not known why it occurs, but the risk of chronic rejection is reduced when patients continue to take all their medications exactly as prescribed.



SOME WARNING SIGNS OF REJECTION CAN INCLUDE:

- Flu-like symptoms, such as chills, headache, fatigue, dizziness or vomiting.
- High temperature - over 38°C (You should have a thermometer at home, as an increase in temperature is an important sign of possible rejection or infection).
- Any signs of fluid retention, such as rapid weight gain or swelling of the ankles.
- Pain or redness over the transplant site.
- Reduction in the amount of urine you are producing.

IF YOU EXPERIENCE ANY OF THESE SYMPTOMS, CALL YOUR TRANSPLANT UNIT IMMEDIATELY!

WARNING SIGNS OF REJECTION

Sometimes, when rejection starts, you may feel fine, with no symptoms. More often, there will be signs to alert you to possible rejection. If these occur, you should immediately contact your transplant team. Quick action can make the difference between keeping and losing your transplant.

Although you may experience symptoms of rejection, it is also possible to have no symptoms at all. That is why it is so important that you have all of the tests indicated by your transplant team. Blood tests are the best way to monitor kidney function and catch early warning signs of rejection. A rise in the patient's creatinine level may often be the first sign of rejection.

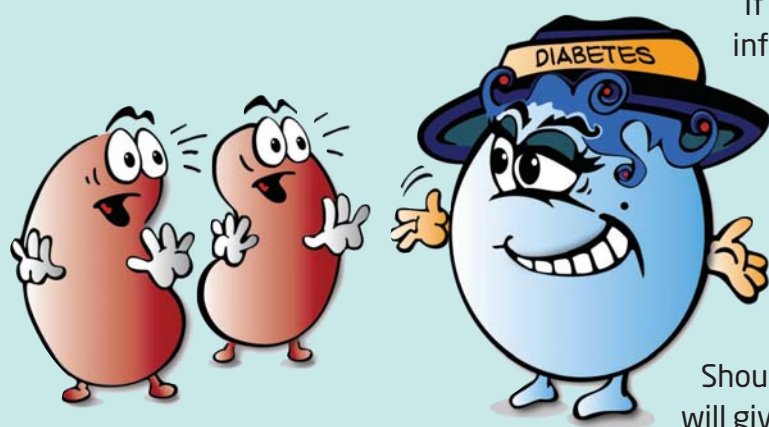
TREATING REJECTION

When rejection is suspected, it is usually confirmed by a kidney biopsy, as this is the most precise test to diagnose rejection. The earlier rejection is detected, the better the chance of reversing it. Most commonly a mild to moderate episode of rejection is treated successfully, with a 3 to 5 day course of Methylprednisolone (steroid). Where a rejection episode is very severe, more potent forms of immunosuppression, such as ATG, are sometimes used. Some forms of rejection (antibody mediated), however, need to be treated with a course of plasmapheresis.



6. Diabetes

Glucose is a simple sugar and is the main source of energy in the body's cells. A condition called diabetes mellitus occurs if glucose accumulates, because your body is not using it properly and/or not enough insulin is produced. Some of your prescribed anti-rejection medicines may cause diabetes. The onset of diabetes post-transplant is usually mild and early signs can include: tiredness, thirst, weight loss, excessive production of urine, blurred vision and confusion.



If you have any of these symptoms you should inform your transplant team. You will be monitored, in clinic, for this condition by regular blood and/or urine tests. Post-transplant diabetes is often resolved, by reducing some of your anti-rejection medicines or converting you to different ones, though you may need a specific oral diabetic medicine or insulin injections.

Should you develop diabetes, your transplant team will give you specific advice. Careful diet, weight loss and exercise are all helpful in controlling this condition. If you were diabetic, prior to your transplant, you may have problems with blood sugar control following your surgery. This will be discussed with you on an individual basis.

7. High blood pressure

High blood pressure (Hypertension) is a very common complication following kidney transplantation, particularly during the early months. This is why your blood pressure will be checked more frequently, during this period. It is vital to control high blood pressure; if left untreated, you will be at an increased risk of heart disease or of having a stroke.

Often high blood pressure does not produce symptoms. Some patients complain of headaches or blurred vision. It can be associated with several problems, which include fluid overload, rejection and narrowing of the renal transplant artery (renal artery stenosis). It can also be a side-effect of some of your medicines. There are many different ways of treating high blood pressure:

- If your doctor thinks you are fluid overloaded, you will be given a diuretic (water pill) which will drive your kidney to increase your urine output and thus help lower your blood pressure.
- Blood pressure medicines - There are many different types of blood pressure medicine including vasodilators, beta-blockers and calcium channel blockers; your doctor will choose the most appropriate one for you. Many patients will need a combination of more than one blood pressure medicine.
- If your doctor suspects you have a rejection episode, or renal artery stenosis, the appropriate diagnostic tests will be performed and treatment initiated.
- If your high blood pressure is caused by a side effect of your anti-rejection therapy, you may be switched to a different type of medication.

"It is important that you do not stop or change your prescribed medicines without discussion with your transplant doctors."



Blood Pressure Equipment

Home Automated BP Monitor



8. Cancer

Transplant patients are at increased risk for certain types of cancers, especially lymphoma, skin and cervical cancer. Fortunately Lymphoma is very rare. Skin cancer, however, is very common, but if detected early, is very easily treated.

Several factors influence the types of cancers seen in transplant patients.

These include:

- i) viral infections acquired either before, or after, transplant.
- ii) Use of immunosuppressive therapy to prevent rejection of the kidney.

THERE ARE DIFFERENT TYPES OF SKIN CANCERS

ACTINIC KERATOSIS



Actinic Keratosis

These lesions predispose to skin cancer. They are usually pink or red spots with a jagged surface. They most frequently appear on sun exposed sites such

as hands, face or neck. Early treatment may prevent progression to skin cancer.

BASAL CELL CARCINOMA (BCC)

Most BCC present as a lesion, that never heals completely, and may bleed occasionally. This may look like a scaly red flat mark or a lesion with a white rim surrounding a central dip. If left untreated it may become ulcerated.



Basal Cell Carcinoma

SKIN CARE

Taking good care of your skin is vital for kidney transplant recipients because, once you receive a transplant and begin taking immunosuppression, you are more at risk for developing skin cancer. This risk also increases with time. Immunosuppressive drugs prevent rejection of your kidney, by reducing the immune system's natural capacity to repair or destroy sun damaged cells. These cells can develop into cancer.

Some patients will be at higher risk due to other factors such as: fair skin that burns easily, light coloured eyes, blonde/red hair, numerous freckles, outdoor working environment, previous skin cancer, or prolonged sun exposure in the past

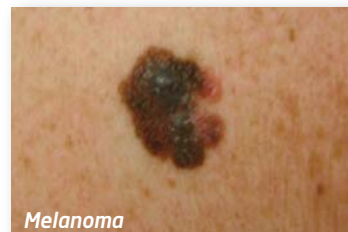
SQUAMOUS CELL CARCINOMA (SCC)

This is the most common type of skin cancer in transplant recipients. Again, it usually appears on sun exposed sites. It may appear as a scaly area of skin with a red inflamed base. Both BCC & SCC are usually painless.



Squamous Cell Carcinoma

MELANOMA



Melanoma

This is the most serious form of skin cancer but also the rarest. It is best described as an irregular black or brown spot. It may appear as a new lesion or occur on an existing mole.

IF YOU NOTICE ANY OF THE ABOVE LESIONS OR ANY CHANGES IN A PRE-EXISTING MOLE SUCH AS: INCREASE IN SIZE, BLEEDING OR CHANGE IN APPEARANCE, YOU SHOULD CONSULT YOUR DOCTOR.

Most skin cancers can advance rapidly in kidney transplant patients but if detected and treated early they are curable.

THERE ARE A NUMBER OF WAYS TO TREAT SKIN CANCER

SURGERY: An injection is given to numb the skin and the lesion is cut away.

CRYOTHERAPY: The lesion is frozen with liquid nitrogen

TOPICAL CREAM: Medicated cream is applied to the lesion.



Cryotherapy

PHOTODYNAMIC THERAPY: A cream is applied to the lesion followed by a special light that destroys the lesion.

In some cases radiotherapy can also be used where x-rays are directed at the lesion to destroy it. In serious advanced cases of skin cancer your doctor may recommend that you stop taking your immunosuppressant.

If your doctor suspects a lesion may be cancerous, a small portion of your skin may be excised and further examined. This is called a skin biopsy and is performed under local anaesthetic.



Photodynamic Therapy

PROTECTING YOUR SKIN

Exposure to the sun or its ultraviolet rays is the main cause of skin cancer in transplant patients. Exposure to the sun does not just mean sunbathing, by just being outside you are exposed to the sun. This includes walking, gardening, outdoor work etc.

You should take simple precautions to protect yourself:

- **Cover Up** – wear a wide brimmed sun hat and long sleeves,

- **Stay in the shade** during peak times of sun intensity (11am-3pm)



- **Never, ever,** use sun beds

- Wear a high intensity sun cream, Sun Protection Factor (SPF) 30 or higher with a 3 or 4-star rating. Ensure the sun cream protects against UVB and UVA rays.

- If planning to travel to Australia, purchase sun cream when you get there, that is designed specifically to protect against UVC rays.



CERVICAL CANCER

The Cervix is the neck of the womb and is prone to develop cancer. This form of cancer is very treatable but it needs to be detected early. For this reason all sexually active female transplant recipients should have a smear test annually. Your

GP or practice nurse can arrange this but you need to remind them. The Department of Health and Children is currently providing vaccination to young girls who have not been exposed to the human papilloma virus which can cause cervical cancer.

HEART DISEASE

Hypertension and raised cholesterol levels can occur as a result of some of the immunosuppressive drugs. This leads to an increased chance of heart disease. At each clinic visit your blood pressure and cholesterol level will be measured. Your doctor may prescribe medication to control your blood pressure or decrease your cholesterol level. However, regular exercise and keeping to a low-fat, low salt diet with plenty of vegetables, as advised by your dietitian, are ways by which you can help control your blood pressure and cholesterol levels.

CHAPTER 9

CREATININE LEVELS

Every time you come to the clinic you will have a blood test which will measure, amongst other things, your serum creatinine. A creatinine level gives a very good idea of how well your kidney is working. A very well functioning renal transplant should have a serum creatinine of around 100 to 120 $\mu\text{mol/L}$.

If your creatinine level starts rising, your doctor may order some investigations to establish what is the reason for this. There are a number of reasons for a rise in creatinine including:

- A mechanical problem with the flow of urine from the bladder or kidney.
- High Prograf or Cyclosporine level.
- Acute Transplant rejection.
- Chronic Transplant Rejection.
- A viral infection called Polyoma virus.
- Recurrence of original disease in the transplanted kidney.
- Transplant artery narrowing (stenosis).



Problem with the flow of urine from the bladder or kidney

Clearly, for the donor kidney to function well, the urine has to be able to flow out of the body. Sometimes, after transplant surgery, a blockage in urine flow can occur. This may arise as a result of narrowing in the tube that joins the kidney to the bladder called the ureter. The diagnosis of narrowing of the transplant ureter (ureteric stenosis) will usually be made by ultrasound scan of the kidney. If Transplant Ureteric Stenosis develops, it will usually be treated by inserting a nephrostomy tube into the kidney. A nephrostomy is a drainage tube that is inserted directly into the kidney and allows the urine to drain into a bag. A subsequent operation will usually be required to bypass the blockage in the transplant ureter.

It is also possible that the reason the transplant is not draining properly is because a lymphocele has developed. A lymphocele is a collection of fluid, which can develop around the transplant and compress the ureter, stopping the urine from flowing properly. If this problem develops it will require a small operation to make this fluid drain internally.

In men, enlargement of the prostate gland can affect bladder emptying. This can be treated medically or surgically.



High Prograf or Cyclosporine level

Even though Cyclosporine, Rapamune and Prograf allow renal transplants to be successful, these drugs can damage the kidney over time. There is a very fine line between giving you enough medication to prevent rejection and not too much to cause kidney damage. Sometimes this problem can be solved by measuring the drug levels in your blood, but a kidney biopsy may be performed to determine if there is chronic damage to your kidney from medication. Your doctor may recommend changing your medication.

Acute transplant rejection

Acute (sudden) transplant rejection might occur in the first three months after the transplant but it can happen at any stage after transplantation. The diagnosis of acute transplant rejection will require a kidney biopsy and the treatment usually involves 3 to 5 cycles of high dose steroids given intravenously.

Chronic transplant rejection

Even with modern immunosuppression, chronic transplant rejection may still develop. Chronic rejection is more likely to develop if you previously had an episode of acute transplant rejection. Chronic transplant rejection and chronic Prograf or Cyclosporine damage can be very difficult to distinguish. The treatment of chronic rejection may involve adjustment of your transplant medicines and the addition of another immunosuppressant; Cellcept or Sirolimus.

Polyoma infection

Polyoma infection is a virus which can cause damage to the transplanted kidney causing raised creatinine levels and reduced function of the kidney.

Further information on Polyoma infection is on page 31.

Recurrence of original disease

Certain diseases, that originally caused kidney disease, may return in the new transplanted kidney slowly causing damage to it. The most common disease to return, in new transplants, are FSGS (Focal Segmental Glomerulosclerosis) and MPGN (Membranoproliferative Glomerulonephritis). Even when these diseases do recur after kidney transplantation, they generally only cause very slow deterioration of the transplanted kidney.

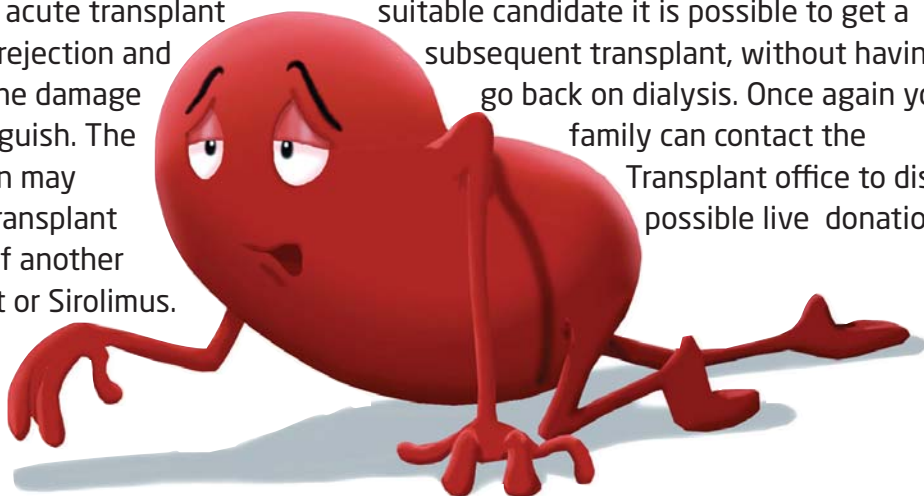
Transplant artery stenosis

Some patients develop a narrowing of the transplant artery, where it is stitched onto the blood vessel going to the leg. If this happens it may cause severe high blood pressure and a rise in the creatinine level. This condition will generally be diagnosed by an MRI scan or Angiogram. Transplant artery stenosis can be treated, by a balloon dilation of the narrowed artery and, sometimes, the placement of a metal tube called a stent to keep the artery open. It may occasionally require an operation to remedy the problem.

What happens if the kidney transplant fails

If the kidney transplant shows progressive signs of failing, and nothing can be done to reverse the situation, your doctor will discuss plans for you to go back on dialysis and, indeed, to go back on the kidney transplant pool. If you are a suitable candidate it is possible to get a subsequent transplant, without having to go back on dialysis. Once again your family can contact the Transplant office to discuss possible live donation.

"Acute (sudden) transplant rejection usually occurs in the first three months after the transplant but it can happen at any stage after transplantation."



CHAPTER 10

HEALTHY EATING AFTER TRANSPLANTATION

After your kidney transplant you will have a lot more freedom with your diet. However, it is very important to have a healthy well-balanced diet to help protect your new kidney. When you go home, YOU become the most important member of your transplant team.

The first few days after transplant

Depending on how well your new kidney is working you may need to continue to restrict certain foods for a short time. Your dietitian, or medical team, will let you know if this is necessary.

It is important that you try to eat well during this period to help your wound heal. If you are finding it difficult to finish your meals inform the ward staff or the dietitian. The big difference for you will be the ending of your fluid restriction and you will be encouraged to drink a lot of fluids.

What to do when you go home

Once your kidney is working well you will no longer need to be on a special diet but it is important that you still watch what you eat and have a healthy balanced diet.

This is particularly important as your transplant medications can increase your blood pressure, cholesterol and blood sugar levels. These medications can also weaken your bones so you need to have a good intake of calcium and vitamin D.

What is a healthy diet?

A healthy diet is what the whole family should have. It means eating a wide variety of foods, in the correct amounts, to ensure good health and a healthy weight.

Continue a low salt diet

Almost all of us eat too much salt. About 80% of the salt we eat comes from processed foods, fast food, and canteen and restaurant food. About 10-15% is added at home and only 5% occurs naturally in food.

To reduce your salt intake, you need to use less salt in cooking and at the table, eat more fresh foods and less processed and ready-made foods. Avoid using salt substitutes, for example: *Lo-Salt* and *So Low*.



LIMIT THE AMOUNT OF FAT IN YOUR DIET

- Choose a low fat spread instead of butter, e.g., *Flora Light*, *Golden Olive* or *Kerry Low-Low*.
- Use low-fat instead of full fat milk.
- Choose low fat or diet yoghurts.
- Choose low fat cheese, e.g: Cottage cheese, half-fat cheddar or Edam. Limit portion size to 2oz per week.
- Avoid deep frying foods - bake, boil, steam, microwave or grill instead.
- Use a small amount of olive, rapeseed or sunflower oil if frying food.
- Trim fat off meat and remove skin from chicken before cooking.
- Limit high fat snacks such as chips, crisps, chocolate, cakes and biscuits.

EAT MORE FRUIT AND VEGETABLES



- Fruit and vegetables are the perfect snack food. They are high in fibre, vitamins and minerals and low in fat.
- Aim to eat 4-5 portions of fruit and vegetables each day. Fresh, frozen, dried or tinned all count!
- Include a wide variety of fruit and vegetables.
- A small glass of fruit juice (unsweetened) can count as 1 portion each day.
- Choose fruit tinned in natural juice instead of syrup.
- Dried fruit contains a lot of sugar and should be consumed in small quantities.
- Avoid adding salt, butter, oils or rich sauces to vegetables.
- Grapefruit and grapefruit juice is best avoided if you are taking: Cyclosporin (Neoral/Sandimmun), Prograf (Tacrolimus) or cholesterol lowering drugs.

Increase your fibre intake

A high fibre diet is good for health. Fibre can help lower your cholesterol levels and can help maintain a healthy weight. It is found in grains, cereals, pulses (beans, peas, lentils), fruit and vegetables.

Try to choose:

- High fibre breakfast cereals, for example: Branflakes, Shredded Wheat, Weetabix.
- Wholemeal, granary or wholegrain bread.
- Brown rice and wholegrain pasta.
- Remember: when taking more fibre in your diet, it is important to drink more. Suitable fluids are water, sugar free squash, fruit juice, weak tea or coffee.



Include calcium and vitamin D rich foods:

Adequate calcium and vitamin D are essential for healthy bones. Aim to have 3 to 4 portions of high calcium foods each day. One portion is:

- ½ pint / 200 ml of low fat or Super milk.
- 1 carton of low fat or diet yoghurt.
- 1 oz / 25 g of cheddar/hard cheese.
- ½ tin of salmon or sardines (with soft bones).

Foods rich in vitamin D include: oily fish like salmon, herring, mackerel, sardines and trout. Eggs, and fortified foods such as milk, margarines and breakfast cereals.

Probiotics

Probiotics are 'good bacteria' that claim to have certain health benefits when consumed. They can be found in different forms, such as tablet supplements, or they can be added to certain foods such as yoghurts.

High dose probiotic supplements (for example, those found in tablet form) should be avoided after your transplant. This is because the high levels of bacteria in the tablets may be a potential source of infection. However, the amounts of probiotic bacteria added to foods such as yoghurt are found in much lower doses and are less likely to cause harm. These include any yoghurt or other dairy products labelled 'Bio'. Therefore, they can be used with caution in your diet.*

*As per food safety recommendations, always avoid any dairy products that have not been pasteurised (heat treated).

Choose foods low in sugar

Too much sugar can cause weight gain and increase your triglyceride and blood sugar levels.

- Use artificial sweetener, for example: Canderel, Splenda or Hermesetas, instead of sugar.
- Have diet minerals, sugar-free squashes or cordials instead of regular drinks.
- Limit cakes, biscuits, puddings, sweets and chocolate.

LIMIT ALCOHOL INTAKE

Alcohol is high in calories and sugar. Excessive alcohol can lead to weight gain and increased triglyceride levels.

- Have 2 -3 alcohol free days each week.
- Do not exceed recommended limits:

Men	17 units per week
Women	11 units per week
One unit =	1 small glass (100ml) of wine
or	1 measure (35.4ml) of spirits
or	½ pint of beer/stout/cider
or	1 Alco pop (275ml)
- Use sugar free mixers, e.g., slimline tonic or diet minerals.

Food safety

It is important to follow some simple food safety guidelines after your kidney transplant; this is because your treatment requires immunosuppressant tablets.

What you should do:

- Wash hands thoroughly before preparing food, after going to the toilet or after handling pets.
- Prepare and store raw and cooked food separately.
- Cook food well. Follow the instructions on the pack. If you re-heat food do make sure it is piping hot.
- Check 'use by' dates and use within the recommended period.
- Avoid food containing uncooked egg and store eggs in the fridge.
- Avoid unpasteurised milk or dairy products e.g., soft ripened cheeses like brie or Camembert. You should also avoid paté.
- Avoid smoked meats, fish and sushi.

SUMMARY

- Eat three main meals each day.
- Avoid salty, processed foods and adding salt to food.
- Eat 4-5 portions of fruit or vegetables.
- Take 3-4 portions of dairy each day.
- Eat more fibre rich foods.
- Limit sugary foods and sweetened drinks.
- Aim to include 2-3 portions of oily fish each week.
- Avoid fried and fatty foods.



- Include exercise as part of your daily routine.
- Maintain a healthy weight.



CHAPTER 11

GENERAL ADVICE

EXERCISE

Now that you have your transplant, regular exercise is one of the keys to putting you on the road to good health. It is important to have a daily exercise routine, to build up muscles weakened by a long period of illness. The exercise programme should be aiming to slowly increase the level of exercise. Walking is a good way to start exercising and hobbies such as tennis and jogging can be taken up as early as three months after your transplant. However, contact sports should be avoided.

Exercise has a positive effect on blood pressure, cholesterol levels, and the functioning of the heart and lungs, even if you don't lose weight. Exercise can also improve your psychological health and can be achieved with low to moderate levels of physical activity.

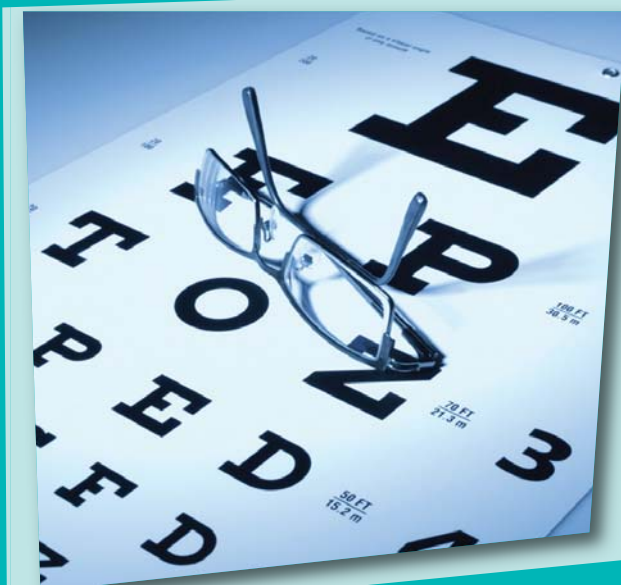


The **Irish Kidney Association** promotes an active year-round sports programme for transplant recipients and people on dialysis. The programme is open to all levels of ability and interest, with an emphasis on participation and enjoyment. Regular open sessions are held, with family and friends always welcome.



The Association organises national teams for events such as the World Transplant Games (biennial - odd years) and the European Transplant & Dialysis Games (biennial - even years). The team is open to all abilities as the Transplant & Dialysis Games experience is worthwhile and about so much more than sport!

Why not contact the IKA to find out more and get involved in a new wonderful family?



EYE CARE

It is common to experience changes in your vision, for the first few weeks, after your transplant. It is recommended that you wait about six months for your vision to stabilise before considering a change in your glasses. Your transplant medications may increase your risk of developing cataracts, glaucoma and eye infections. Do visit an ophthalmologist at least once a year. Be certain to inform them that you are taking immunosuppressive medications.

WORK

If you were employed up to the time of your transplant, you should be able to return to work, within three months, after your surgery. It really depends upon you and your job – how well you feel, and what are the physical demands of your work. If your job requires heavy lifting, it may require more time. If your job is not physically difficult, it can be sooner. The important thing is to be realistic. Pushing yourself too soon, can lead to problems that would delay your return to a full work schedule. If you have not worked for some time, due to your illness, do speak to your transplant nurse or patient care co-ordinator, as there may be training or employment opportunities for you in your community.



DENTAL CARE

Good mouth and dental care are essential to prevent infections after your transplant. It is best to wait about three months after your transplant, or if you have recently been treated for a rejection episode, before you have a routine dental check-up, including cleaning. Brush and floss your teeth twice a day. Be gentle when flossing, as this can irritate your gums and cause bleeding. A waxed floss slides more easily between the teeth. Use fluoride toothpaste and a soft nylon or electric toothbrush. You should see a dentist every six months. Be certain that your dentist knows that you are a transplant patient and taking immunosuppressive drugs. You do not need extra antibiotics just because you have had a transplant.





SMOKING, ALCOHOL AND DRUGS

Smoking tobacco, marijuana or using any unprescribed drugs is harmful to everyone but especially so for transplant patients. Smoking damages the lungs and puts you at greater risks of contracting lung infections and cancer. Your transplant team will assist you to give up smoking.

Any form of so-called 'recreational drugs', such as cocaine, speed or ecstasy can have a serious negative effect on your body and mind. These drugs can also interfere with your medication

If you have normal liver function, moderate amounts of alcohol should not cause you any problems. Some of your medications can reduce liver function so it is best to limit the amount of alcohol you drink. Alcohol can also cause dehydration and depression.



STAYING HEALTHY CHECK LIST

- Always take your medication as prescribed.
- Attend renal clinics regularly.
- Keep track of your serum Creatinine.
- Take regular exercise and do not become overweight.
- Monitor your skin for changes and skin lesions.
- Women should have a smear test annually.
- Women more than 50 years should have a mammogram every 3 years.
- Bowel cancer screening every 2 years for those between the age of 55 and 74.
- Keep your cholesterol under 5.
- Get the flu vaccine in September from your GP.
- Get the pneumococcal vaccine from your GP every 5 years.
- Do not smoke.

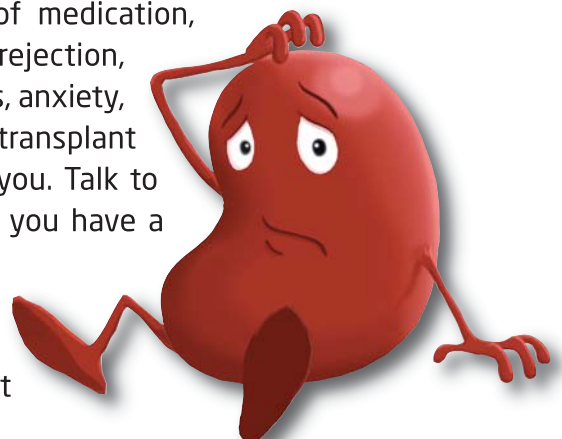
DEALING WITH YOUR EMOTIONS

Some people may think – "You got a transplant, a new lease on life. Be happy. Don't worry!" But, in reality, the time after transplantation can be emotionally difficult for many patients.

First of all, some of the medications can cause mood swings, sleep disturbances, or even depression. These kinds of problems are even more troubling because you cannot understand why you feel the way you do. If you experience any of these effects, talk to your doctor or transplant nurse. And, remember, never change your dose of medications without permission from your doctor.

Very Important!! If you are feeling depressed, do not take any medications or herbal preparations without medical advice. St. John's Wort, for example, is known to interact negatively with immunosuppressive medications.

Transplant patients often have concerns about changes in relationships, work, finances, staying healthy, side-effects of medication, and the possibility of rejection, which may cause stress, anxiety, fear or sadness. Your transplant team is there to help you. Talk to them. Tell them when you have a problem. You can also avail of the renal nurse counselling service available at Beaumont Hospital.



WRITING TO YOUR DONOR FAMILY



Many transplant recipients ask how they might acknowledge the gift of their new donor organ. There is no right or wrong time, and no right or wrong way to say 'thank you' to your donor family.

Some ways that patients may express their thanks include writing:

- a letter;
- a thank you card, or
- a mass card.



Donor families receive a letter from the transplant co-ordinators, within a month of their loved-one's death, thanking them for consenting to organ donation. Donor families are not given any information which may identify you.

We recommend that you allow some time to elapse, after your discharge, before expressing your thanks to the donor family. Your 'thank you' may be written, at any time, after your transplant. It will always be greatly appreciated by your donor family. The letter should not identify you. It is preferable that you do not date the letter or card as it may be some time before it may be

forwarded to the family. Please do not seal the envelope as the Transplant Co-ordinators will need to check the letter, for confidentiality purposes, before passing it on.

The letter normally starts with "Dear Donor Family" or "Dear Friends". You may like to include details such as:

- your age;
- length of illness;
- whether you are male or female and some family details.

Most people describe how their lifestyle was prior to the transplant, and describe their contrasting quality of life since receiving their transplant. Everyone expresses their thanks to donor families in their own way. In nearly all cases, transplant patients say it is the most difficult letter that they have ever written and that they had to rewrite it, many times, before getting it right.

You can give this letter or card to your transplant nurse or transplant co-ordinators.

SERVICE OF REMEMBRANCE & THANKSGIVING

This service is hosted every year, in the Autumn, by the Irish Kidney Association (IKA). Many kidney transplant recipients and, indeed, other organ recipients, join with donor families, at this service, to remember the donors. It is a special way of expressing gratitude in an anonymous manner.

Do view the IKA *SUPPORT* magazine for more details or website www.ika.ie



TRAVEL AND VACCINATIONS



One of the things that many patients look forward to after transplant is the freedom to travel.

Patients should advise their doctor if they intend travelling abroad. It is important to consider your destination as some exotic locations may have

higher risks, including impure water or insect bites. If you require

any vaccinations, you must consult your doctor.

Always pack enough medications for the entire journey and a little extra in case of delays. Ensure that your medications are not exposed to extreme heat or cold. If you fly, keep your medication with you in your hand luggage.

Carry your Renal Transplant Passport with you.

Pack plenty of sunblock and use it!

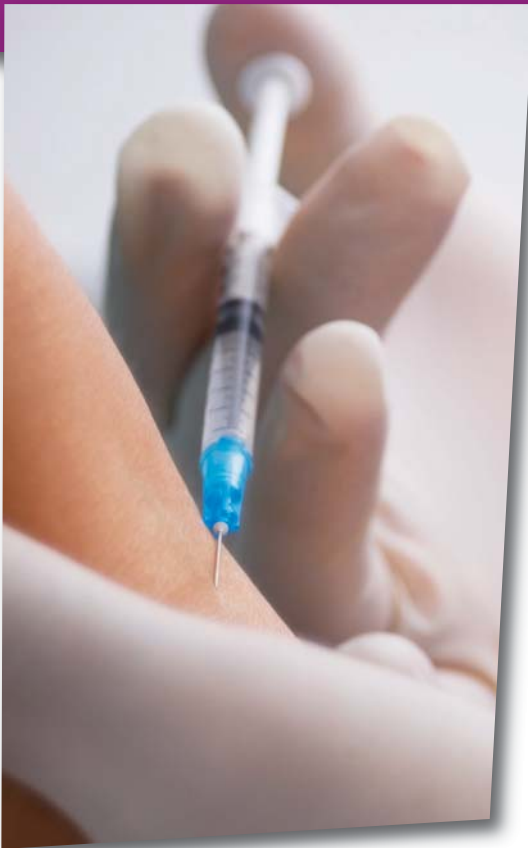
On long journeys, get up and walk around at least every two hours, and ensure you drink plenty of water.

On long distance flights, it is recommended that you wear flight stockings.

In warm weather, ensure that you keep yourself well hydrated.



IMMUNISATIONS AND TRAVEL ADVICE



Exotic destinations may include potential exposure to infections that are rare in your country of origin or that you have never been exposed to before. When considering foreign travel, it is worth assessing your potential destination with regard to water supply, general standard of hygiene and access to medical services.

If you are planning foreign travel you should consult with a travel medical specialist, in good time, before you plan to travel. You should also comply with vaccines and medications that are prescribed for you. You should also ensure that you have adequate supplies of medication and adequate health insurance cover. Many travel insurance packages do not cover existing illnesses - check before you buy a policy. In Europe the European Health Insurance Card (EHIC) Card, available from the HSE is a 'must have'. It is your entitlement to public health care in all EU countries, Switzerland and Norway. You can obtain it from the HSE online at www2.hse.ie/services/ehic

Vaccination is a highly effective way of preventing disease. Most vaccines take some time before they are fully effective, so you should plan consultation with doctor and actual vaccination, weeks before you plan to travel.

You should ensure your vaccination schedule is up-to-date. Additional vaccines may be prescribed, depending on the area of travel and any special risks you may encounter.

If you are travelling to a malaria endemic area you should also take appropriate malaria medication and precautions.

Patients who do not have immunity against chicken pox (Varicella virus) will need to get the chicken pox vaccine before going on the transplant list. Most people are immune so only a very small number of people need this vaccine.



**The Government has recently announced plans to roll out the HPV vaccine for boys.*

VACCINATION AND KIDNEY TRANSPLANT

Routine Vaccinations	Travel Vaccinations
Haemophilis	(AS APPROPRIATE FOR AREA YOU ARE TRAVELLING TO)
Meningococcal vaccine	Typhoid vaccine
Annual Influenza vaccine	Hepatitis A and B
Pneumococcal vaccine every 5 years	Rabies
Human Papillomavirus (HPV)* vaccine (Girls under 16)	Diphtheria
Tetanus vaccine	Yellow Fever
Inactivated Polio vaccine (salk)	Cholera

VACCINATIONS TO AVOID AFTER KIDNEY TRANSPLANTATION

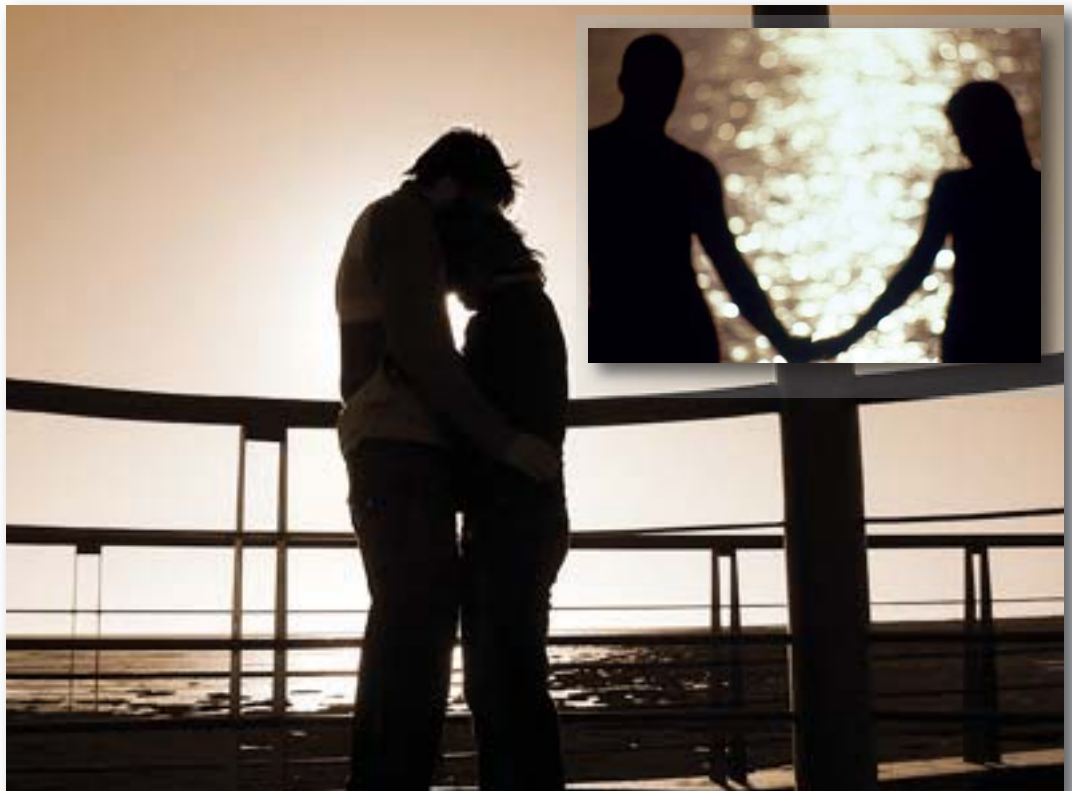
Measles, mumps and rubella
Oral Polio
Oral Typhoid
Small Pox, Yellow fever
BCG
Chickenpox

It is beyond the scope of this book to discuss each vaccine individually. The HSE website www.immunisation.ie and the NHS website www.fitfortravel.nhs.uk are very useful resources that lists specific vaccines needed for each country. You should consult with your doctor if you plan to travel to a destination that requires vaccination.

SEXUALITY AFTER TRANSPLANTATION

There are many factors that influence sexuality after transplantation - how you feel physically and how you feel about yourself. Sexual intimacy can begin any time after surgery, as long as you have the interest and feel well. However, wait 4-6 weeks to have sexual intercourse. This will allow time for your incision to heal. Communication is the most important factor in any relationship.

Wherever there is a problem share your feelings and fears with your partner. Nursing and medical staff recognise that you may have difficulties, in sexual relationships, and will gladly talk to you and your partner. Professional guidance can help – all that may be needed is a little reassurance.



MEN

Difficulty with sexual function, for men, is not uncommon after kidney transplantation as the body gets used to being healthy again. Much of the time this is a psychological difficulty rather than any specific physical problem.

Diabetes, or some blood pressure medication, can cause impotency. If this happens discuss it with your doctor, as there are now very effective medications which can resolve these issues. As men get older the prostate gland may become enlarged resulting in difficulty passing urine, with poor flow or having to get up at night. Again, there are very effective medications or a small operation may be needed which can deal with these problems if you discuss them with your doctor.

WOMEN

Most women usually stop menstruating while on dialysis. Following kidney transplantation, many women find that their periods return within a couple of months. However, sometimes they will be irregular for the first few months. If you persist being very irregular let your doctors know and they may arrange for you to see a gynaecologist.

"It is important to be aware that you may become pregnant at any stage post-transplant if you are sexually active and do not take precautions."

It is important to be aware that you may become pregnant at any stage post-transplant if you are sexually active and do not take precautions. We advise that you do not become pregnant for 2 years after kidney transplantation. If you plan to become pregnant discuss it with your doctor before you stop any contraceptive measures.

All transplanted women, who are sexually active, need to have a smear test annually

CONTRACEPTION

When you have a kidney transplant you need to discuss your contraceptive requirements carefully with your transplant nurse or doctor. Generally, the pill is not suitable for transplant patients because of the risks of blood clots and blood pressure. The most suitable forms of contraception are either for the man to wear condoms or for women to use the Progesterone only pill or the DepoProvera contraception injection.

The Mirena coil can also be considered.

HAVING A BABY AFTER KIDNEY TRANSPLANT

If your transplant is functioning well and your blood pressure is well controlled, and you do not have much protein in the urine, then you may well be able to safely have a baby. There have been thousands of babies successfully born to transplant patients across the world.

However, you should not plan to become pregnant until one year after transplant.

Many of the medications that you are on may interfere with a baby's growth so

your doctor should switch these around prior to you becoming pregnant. It is also important to take vitamins, like iron and folic acid, prior to becoming pregnant.



BREAST SCREENING

Breast cancer is no more common after a kidney transplant than in the general population. It is nonetheless, common in women in general. The best way to treat breast cancer is to diagnose it early.

Mammography is available for women between the ages of 50 and 65. If you are offered a free mammogram you should keep the appointment.



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
Renal Nurse Counsellor	01-828 2751
Ambulatory Nurse Specialist	01-809 2321
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
Dr. 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 located at 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
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

IRISH KIDNEY ASSOCIATION

LOCAL BRANCHES

The **Irish Kidney Association** has evolved to become a network of twenty-five IKA branches (three covering the Dublin area and twenty-two covering the rest of the country).

This service is supported by their staff in Head Office, who facilitate and assist their local branch volunteers in dealing with patient requests for practical support. Communicating with local social services, statutory bodies and employers empowers the patient and the family to develop their confidence and independence to deal with the traumatic changes that have occurred in their lives.

The progress on branch activities is controlled by regular meetings and supplemented by the quarterly reports from the branches to their Board of Directors. The detailed quarterly financial returns, from the Branches, are inclusive of analysis of activities and events, outcomes and results, and their related expenditure.

This on-hand local IKA presence, with support from Head Office, leads to an easier adjustment of patients to their life-changing circumstances. It also assists in their accessing new areas of local support, within the community and back-to-work schemes previously unknown to them prior to their illness.

IRISH KIDNEY ASSOCIATION LOCAL BRANCHES:

CARLOW
CAVAN/MONAGHAN
CLARE
CORK
DONEGAL
DUBLIN EAST + WICKLOW
DUBLIN NORTH
DUBLIN SOUTH
GALWAY
KERRY
KILDARE
KILKENNY
LAOIS
LEITRIM
LIMERICK
LONGFORD
LOUTH/MEATH
MAYO
OFFALY
ROSCOMMON
SLIGO
TIPPERARY
WATERFORD
WESTMEATH
WEXFORD



The Irish Kidney Association
website
www.ika.ie
has up-to-date contact details
for each branch

GLOSSARY

Acute Rejection	A rejection episode that happens suddenly and usually responds to steroids.
Anaesthetic	A drug that provides unconsciousness for an operation.
Anaesthetist	A doctor who specialises in giving anaesthetics.
Antacid	Medicine to correct the acidity of the stomach.
Antibiotic	Drug that fights infection by bacteria.
Antibody	Natural substances in the blood that attack microorganisms.
Antifungal agent	Drug that fights fungal infection.
Antigen	A substance that provokes the formation of antibodies (e.g a protein from a micro-organism, or from a transplant organ).
Antiviral agent	Drug that fights against infections by viruses.
Azathioprine	A type of immunosuppressants.
Bacteria	A type of micro-organism, made of a single cell.
Biopsy	Removal of a small part of tissue to be examined under the microscope.
Blood Groups	There are 4 major blood groups which need to match between a transplant recipient and the donor.
Blood Tests	To check the composition of the blood, for instance, oxygen, iron, or infection.
CAPD	Continuous Ambulatory Peritoneal Dialysis (A form of kidney dialysis).
Catheter	Tube.
Cell	The tiny building blocks that living creatures are made of.
Chronic	A persistent or recurring condition.
Chronic rejection	A long-term rejection episode unresponsive to steroids.
CMV (Cytomegalovirus)	A type of virus that can cause problems after transplantation.
Corticosteroid	A type of steroid.
Creatinine	A waste product of the kidneys.
Crossmatching	A method of ensuring good compatibility between transplant donor and recipient.
Cyclosporin	A type of immunosuppressant.
Diabetes	Excess glucose in the blood caused by lack of insulin.
Dialysis	A method of removing waste products from the blood if the kidney is not functioning.
Dietitian	An expert in nutrition, who advises on your diet.
Diuretic	Drugs that increase urine production by the kidney.
Donor	The person whose organ is used in transplant.
ECG	A test which measures the electrical currents of the heart in order to check its function.
Echocardiogram	An ultrasound test to check the function of your heart.

GLOSSARY

Febrile	Having a high temperature above 37.5°C.
Glomerulus	Small structure in the kidney that passes fluid from blood to kidney.
Glomerulonephritis	A disease in which the glomerules are damaged.
HLA antigens	Tissue markers are 'sign posts' that determine your tissue type
Hypertension	High Blood Pressure.
Immune System	The body's natural defences against bacteria and viruses.
Immunosuppressant	Drugs that suppress the body's immune system.
Immunosuppression	Suppression of the immune system.
Infection	Invasion of the body by harmful micro-organisms, such as bacteria or viruses.
Intravenous (IV)	Into a vein.
Kidney	An organ involved in filtering waste products from the blood, and producing urine.
Mycophenolate Mofetil (MMF)	Mycolat - A type of immunosuppressants.
Orally	Taken by mouth.
Organ	A part of the body with a specific function such as heart, brain or kidney.
Pharmacist	Prepares medicines and advises on their use.
Radiologist	A specialist in ultrasound scans and x-rays.
Registrar	A hospital doctor involved in the ward round and clinics.
Rejection	The immune system's attack on a transplanted organ.
Renal	Relating to the kidney.
Steroids	A group of immunosuppressants.
Tacrolimus (Prograf/Advagraf)	A type of immunosuppressant.
Tissue Typing	A method of classification that helps to find the best match between transplant recipient and donor, based on antigens within the body.
Transplant	The new (transplanted) organ.
Transplantation	The transferral of an organ, such as a kidney, from one body to another
Ultrasound	Obtains images within the body using high-frequency sound waves.
Urine	Waste fluid produced by the kidneys.
Viral infection	Attack on the body by viruses.
Virus	A group of micro-organisms smaller than bacteria.
White blood cells	Type of cells in the blood, including lymphocytes, which fight against infections.

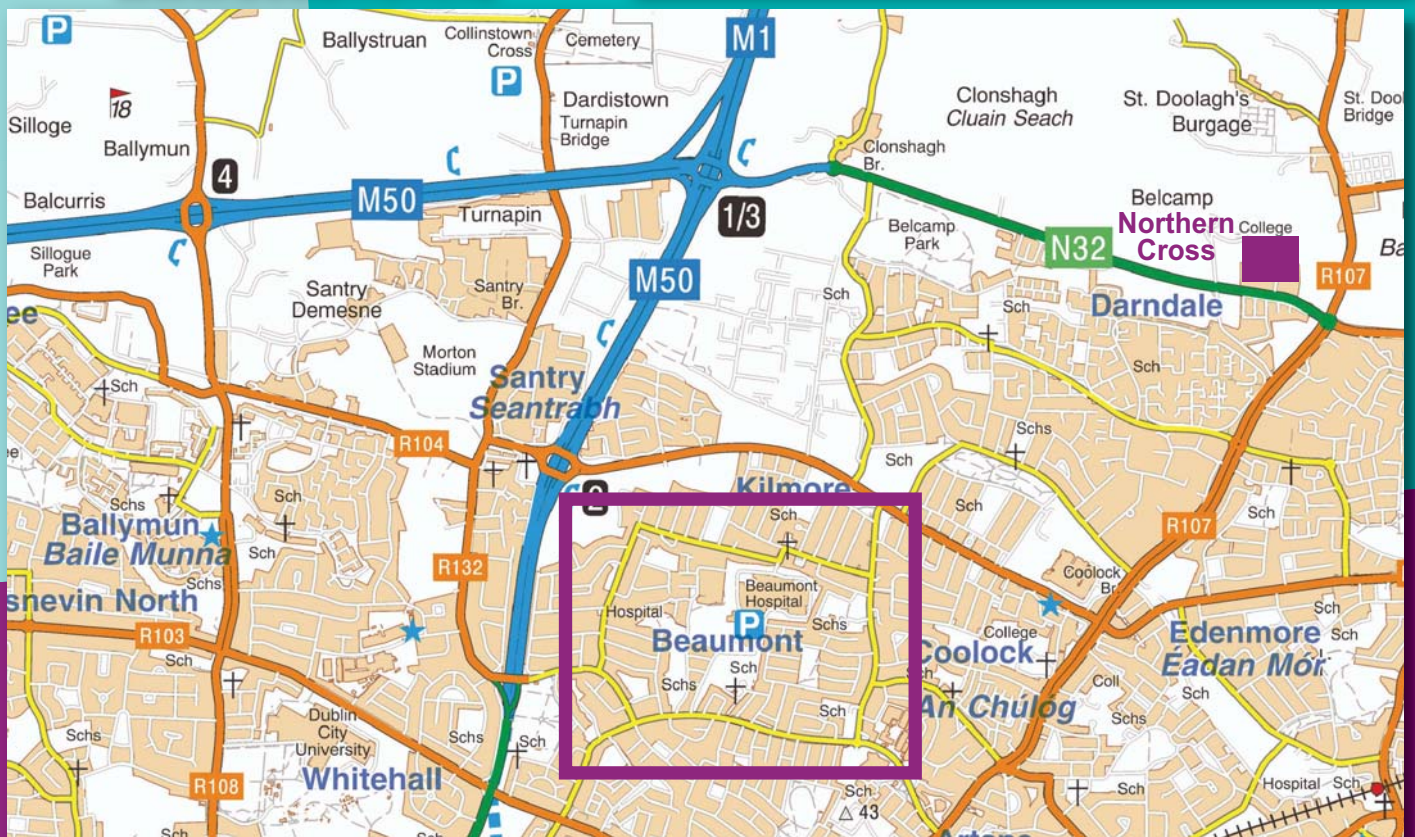
We would like to extend special thanks to the following members of the Renal Team at Beaumont for their contribution to this book:

Helen Dunne, Prof. Peter Conlon, Petrina Donnelly, Martin Ferguson, Oonagh Deeney, Ciara White, Ruth O'Malley, Olive McEnroe and Binu Vasu.
Also, to the patients and staff who took time to contribute to editing this book.

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.

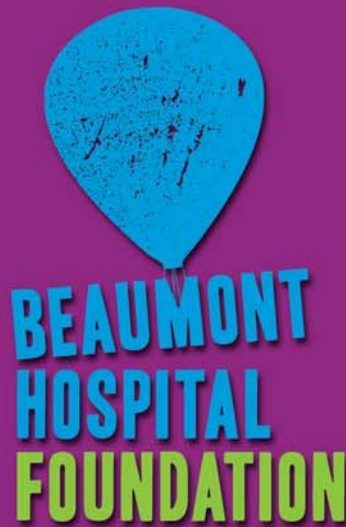


Beaumont Hospital Foundation,
Beaumont Hospital, D 9
Tel: 01 - 809 2161 **Email:** hello@beaumont.ie



www.beaumontfundraising.ie

www.beaumontkidneycentre.ie



BEAUMONT HOSPITAL FOUNDATION

Beaumont Hospital, Dublin, D09 V2N0

Telephone: 01-8092161

Email: hello@beaumont.ie

Web: www.beaumontfundraising.ie

CHARITY REGISTRATION NO: 11538



IRISH KIDNEY ASSOCIATION

Donor House, Block 43A, Park West, Dublin, D12 P5V6

Telephone: 01-6205306

Email: info@ika.ie

Web: www.ika.ie

CHARITY REGISTRATION NO: 20011260