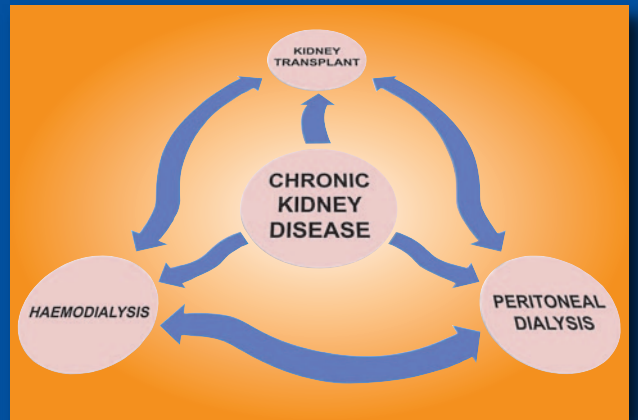
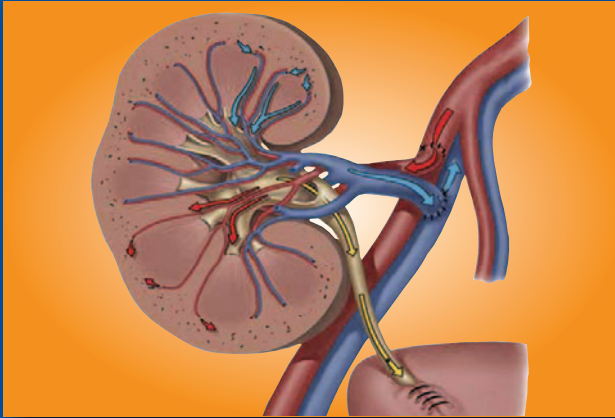


BEAUMONT HOSPITAL

www.beaumont.ie/kidneycentre



HAEMODIALYSIS AND PERITONEAL DIALYSIS

A Guide for Patients

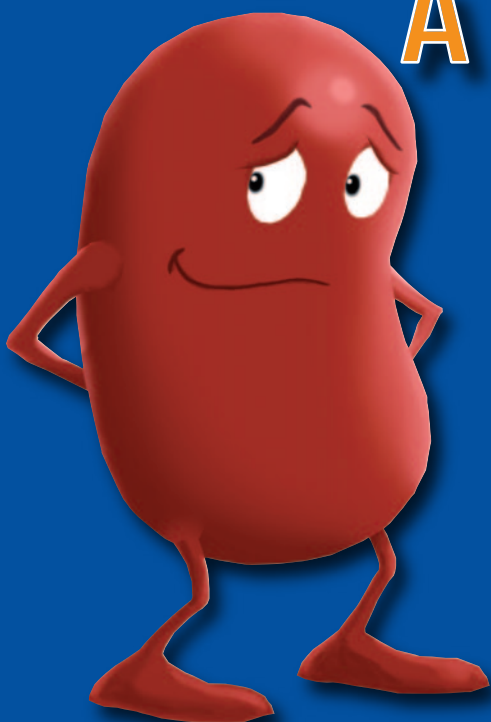
BOOK 2

Prof. Peter J. Conlon, FRCPI

Petrina Donnelly, CNM

Helen Dunne, CNM

5th Edition





IRISH KIDNEY ASSOCIATION (CLG)

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

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




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


IRISH KIDNEY ASSOCIATION CLG

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


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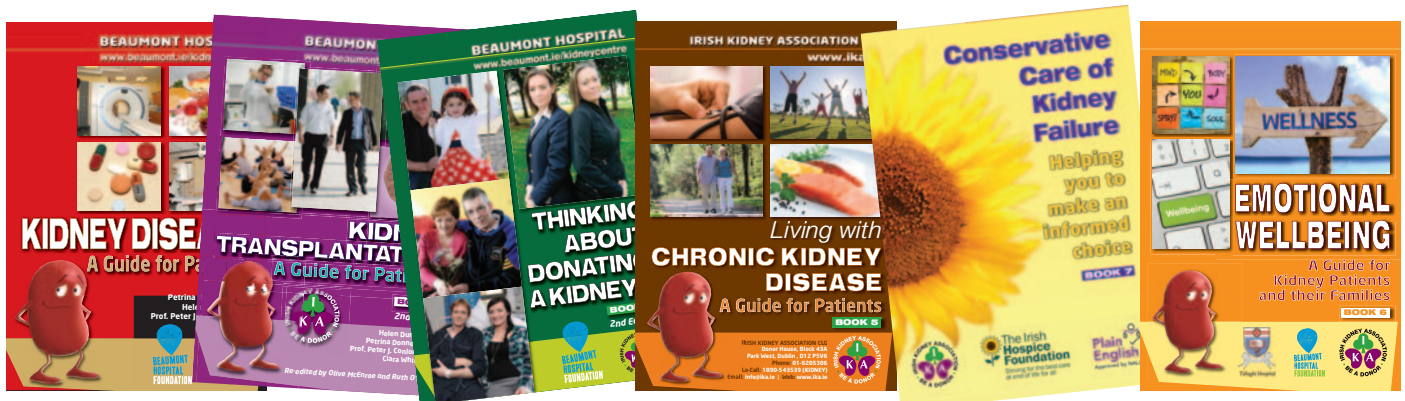
 renalcentre@ika.ie

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 primary educational book for patients experiencing kidney disease. Since then, technology concerning the treatment of kidney disease, has changed radically. As a result, we have produced this series of books, which we regularly update, to assist patients and their families when diagnosed with kidney disease.



This is the fourth edition of **BOOK 2** in a series of seven books, aimed at helping patients with kidney disease learn more about their illness. Book 2 outlines the different forms of kidney replacement therapies, including Haemodialysis, Peritoneal Dialysis and 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 3** covers Kidney Transplantation in more depth, whilst **BOOK 4** addresses the area of the 'living donation' programme. **BOOK 5** is aimed at helping patients with kidney disease learn more about their illness and is specifically written for people who have been informed that they have impaired (or reduced) kidney function and are classified as having Chronic Kidney Disease (CKD). **BOOK 6** aims to help patients and families maintain their emotional health in the face of what can be serious illness and **BOOK 7** explains what the treatment option of conservative care of kidney failure means, helping patients make an informed choice.

Please use these books as a guide and reference tool. 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 Hospital Foundation together with the Irish Kidney Association.

We do hope you find it helpful.



Prof. Peter J Conlon FRCPI
Petrina Donnelly CNM
Helen Dunne CNM

August 2021

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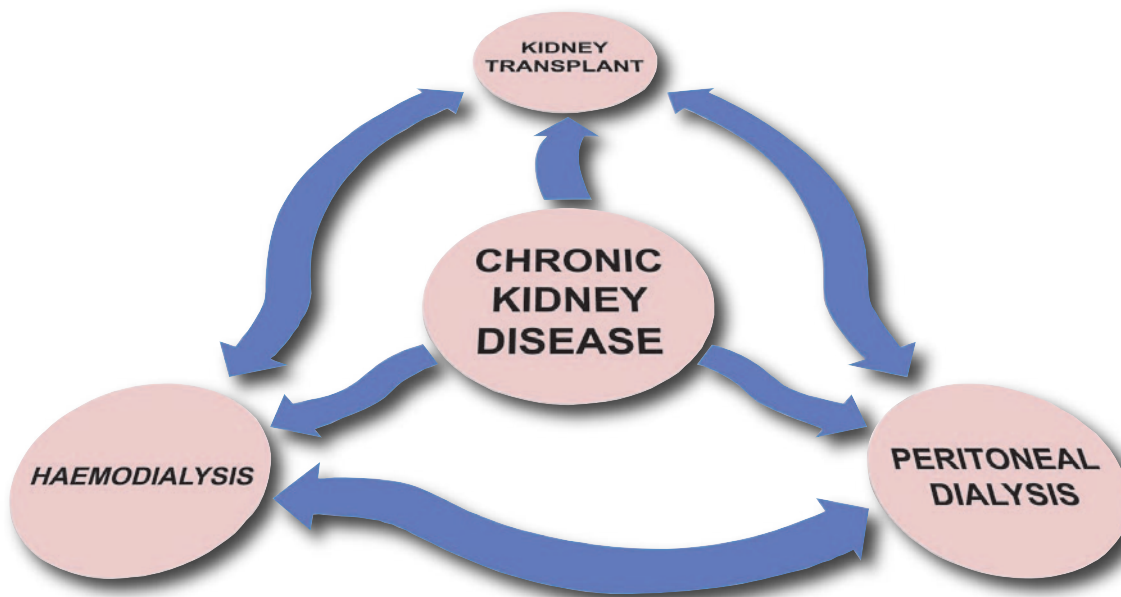
The information contained within this book is correct at time of going to press. This book essentially pertains to the practices at Beaumont Hospital. Other Kidney Units may use different practices. This book should be used as a guide and reference tool only.

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

CHAPTER 1

KIDNEY REPLACEMENT THERAPY



Kidney function is essential to sustain life. If your kidneys are showing signs of failure, your doctor and nurse will discuss options with you.

These include:

- Haemodialysis (HD)
- Peritoneal Dialysis (PD)
- Kidney Transplantation
- Conservative Management of Kidney Disease.

In general, your doctors and nurses will discuss these options many months or years before you actually need them, as planning your treatment can make your journey more straightforward. Remember knowledge is power; the more information

you have, the more able you are to make a decision about the best form of treatment suitable for you.

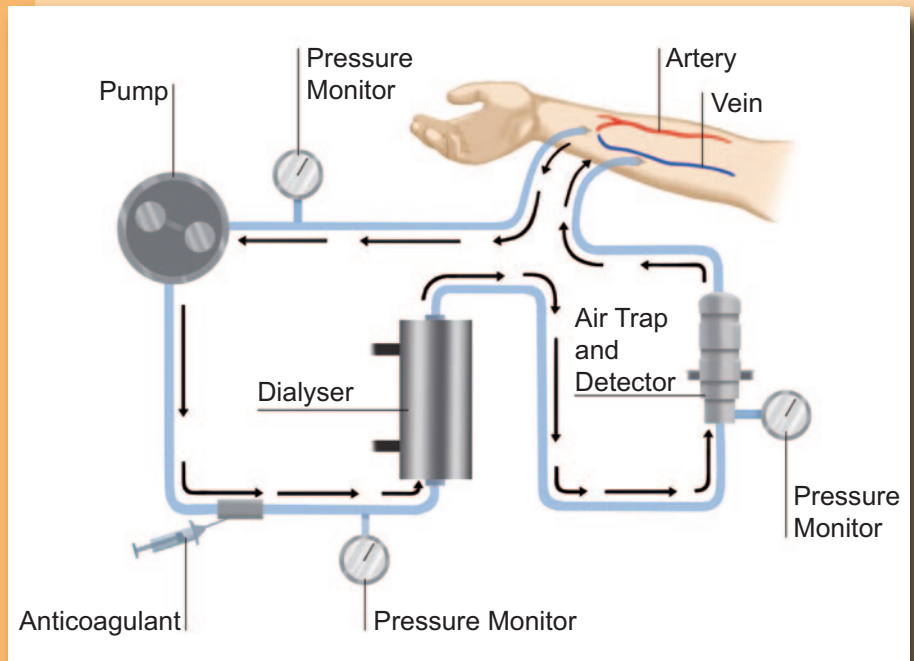
Dialysis is a process in which your blood is filtered to remove waste products and excess fluid which build up because your kidneys are not working properly. Dialysis uses a filter (membrane) and a special solution (dialysate) to remove the fluid and waste.

DIALYSIS: THE THEORY

Here comes the science bit. Dialysis is essentially an exchange, within the body of fluids and chemicals, made up of the normal waste products our bodies produce. The two ways that the body can do this are called Diffusion and Ultrafiltration. Dialysis aims to mimic these.

DIFFUSION

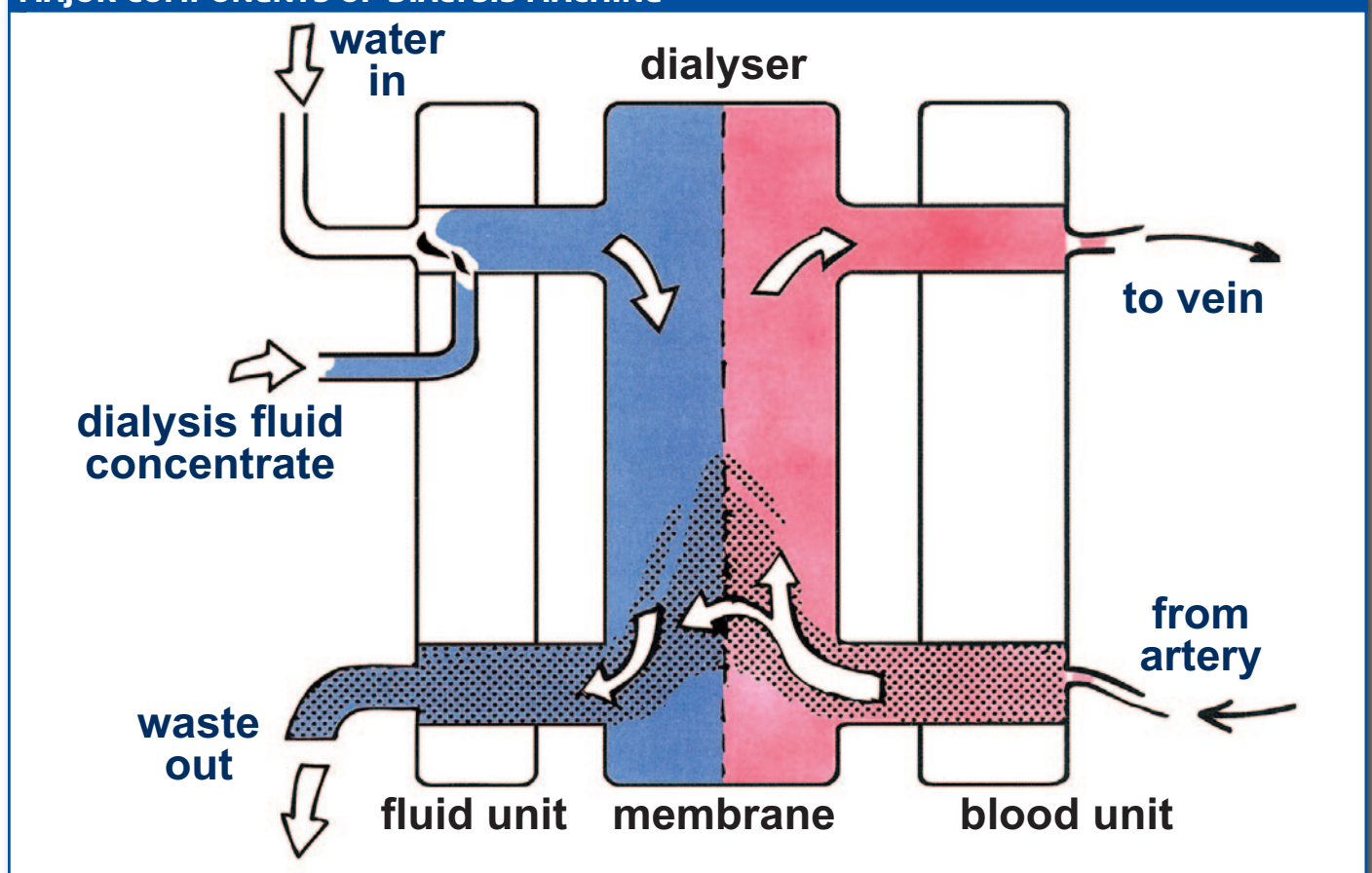
Diffusion is the process which removes the waste products from your blood. Chemicals will move across a semi-permeable membrane from where they are in high concentration to an area in which they are in low concentration. In your case, chemicals are in high concentration in your blood and in low concentration in the dialysate fluid. The semi-permeable membrane is either the dialyser (Haemodialysis) or your peritoneum (Peritoneal Dialysis).



ULTRAFILTRATION

Ultrafiltration is the removal of water from the blood. Ultrafiltration requires an extra force in order to remove the fluid. In the case of Peritoneal Dialysis, the glucose in the dialysate provides the extra force. The haemodialysis machine is programmed to provide the extra force.

MAJOR COMPONENTS OF DIALYSIS MACHINE



CHAPTER 2

STARTING ON HAEMODIALYSIS



Usually, when you start on dialysis you will be admitted to hospital. Most people have 3 sessions over a three-day period, starting with a two-hour session; this is increased at the next session to two and a half hours and then 3 hours. This allows your body to get gradually used to the procedure and the toxins are removed slowly.

It is quite normal to feel anxious when first starting on dialysis. Discussing your feelings with the nursing staff may help to ease these feelings and give you an opportunity to address any concerns you may have at this time.

One of the patients said:

"I was really worried as the machine kept beeping, I thought it was not working. The nurse told me the machine can beep frequently, throughout the treatment, and that it was nothing for me to worry about."

"I was really worried as the machine kept beeping, I thought it was not working."

When you have your first treatment, the nurse will connect you to a blood pressure monitor and cardiac monitor. This is routine for all new patients.

HAEMODIALYSIS & DIALYSERS EXPLAINED

Generally speaking, the dialyser is essentially a filter. It is a cylinder that contains very thin plastic fibres that act as a *dialysis membrane*. Your blood runs along the middle of the fibres and the dialysis fluid is pumped on the outside of the fibres. There is no contact between the blood and the dialysis fluid.

In the dialyser, toxins and excess water (which are the equivalent of the urine produced by the healthy kidneys) pass from the blood into the

dialysis fluid (dialysate). The cleansed blood is then returned to the body at the same rate at which it is removed; approximately 200-300mls per minute.

In the dialyser the blood flows along one side of a semipermeable membrane made of cellulose or a similar product, with the dialysate flowing on the other side.

The different molecules pass through the dialyser, at different rates, until a suitable concentration is achieved.

Dialyser



MONITORING ON DIALYSIS

Each month, "monthly bloods" are taken to ensure you are receiving the best possible treatment. These tests include:

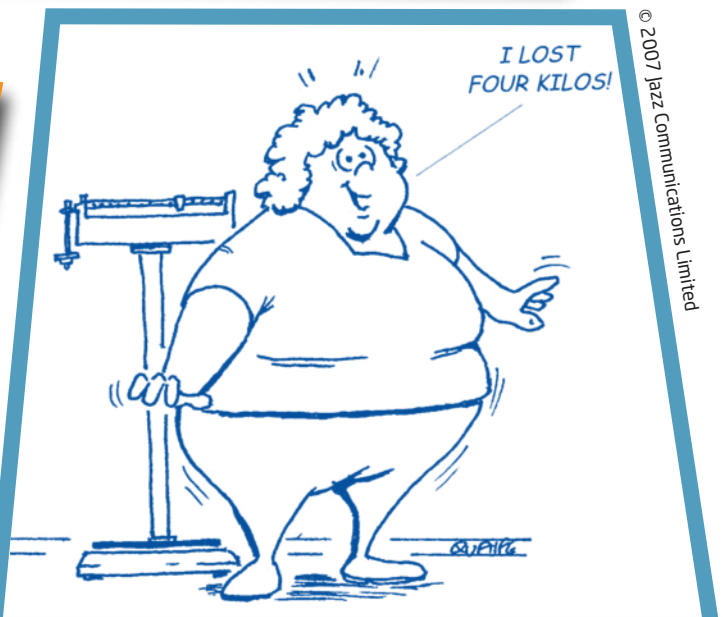
- Haemoglobin levels
- Iron studies
- Urea and electrolyte and calcium and phosphate levels.

FLUID AND WEIGHTS EXPLAINED

Dry weight is the weight that you are with no excess fluid accumulated in the body. Your weight may drop if you have been unwell or not eating. It can also rise if you have had an increase in appetite and gained body weight. Before and after your dialysis treatment you will be weighed.

This monitoring of your pre- and post-dialysis weight allows the nurse to calculate how much fluid needs to be removed from your body. During dialysis the fluid you accumulate between dialysis sessions is called the **intradialytic weight gain**. For example: If you gain 1kg of weight we would aim to remove 1.5 litres of fluid. This is because 1kg

Esmeralda was one of the few who really liked dialysis



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of weight gain is equal to 1 litre of fluid. The extra 0.5 litre is to account for the fluid you receive during your treatment.

Your dry weight will be adjusted regularly, based on how much you are eating, your blood pressure and if there is swelling (fluid) on your ankles.

Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

One of the most important means of controlling your blood pressure, when you are on dialysis, is by adjusting your dry weight. If your blood pressure rises, your doctor may advise that you have your dry weight reduced. If you are feeling dizzy and light-headed after dialysis or having cramps, your doctor may increase your dry weight.

The amount of fluid to be removed is individualised and depends on how you are feeling,

"It is important to limit your fluid intake as discussed with your team."

the amount of urine you may pass, your blood pressure and how much fluid removal you can tolerate.

Each person can tolerate different amounts, depending on a number of different factors. It might be useful to measure the cup/glass that you use at home, and this will help you to limit your fluid intake as discussed with your team. It is important that you adhere to the advice given by your dietitian and limit the intake of fluids.

WHAT HAPPENS WHEN YOU ARRIVE FOR DIALYSIS?

The senior dialysis unit nurse will arrange transport for you to and from the unit, if you require it. This may be either by minibus or taxi. When you come into the dialysis unit you will meet your nurse who will discuss with you any difficulties since your last treatment. All patients have a medical file which is kept up-to-date with all relevant information.

When you arrive for dialysis, ensure you empty your bladder if you still have a urine output. You will be asked or helped to weigh yourself. It is important to wash your hands prior to starting your

You will be asked or helped to weigh yourself



Arteriovenous Fistula

treatment, after which you will sit in a dialysis chair/bed, according to your preference, in order to receive your treatment. The nurse will carefully clean your dialysis access: the skin, if you have a fistula, or the end of your permcath.

contd...

If you have a fistula, two needles will be carefully inserted which is necessary to connect you to the dialysis machine. As the blood pump starts, you will see your blood going into the machine and then returning to you. The dialysis process will take 3 to 4 hours. During this time you should relax, read a book, or watch television. Throughout the dialysis treatment, you will be monitored closely: Your blood pressure and pulse being measured frequently. If you feel weak, you should let your nurse know straight away as this can be quickly corrected by giving you some extra fluids. When the dialysis treatment is complete, your dialysis needles will be removed and pressure applied to the sites until the bleeding stops, or your dialysis catheter will be redressed. It is important not to jump up or stand up quickly, after your treatment, as some patients' blood pressure can

drop and can cause them to feel dizzy.

You will then be weighed again to determine how much fluid has been removed during the treatment. It is advisable to stay in the dialysis unit for a short period before you go home.

After each use the dialysis machine is carefully chemically disinfected to prevent any transmission of blood borne infections between patients.

WHAT TO DO IF YOU ARE FEELING UNWELL

If you are unwell at home, you should contact the hospital/dialysis unit and explain your symptoms. You will be advised on what to do (contact numbers are located at the back of this book).



Fistula needles

MAINTENANCE DIALYSIS

Once you have settled into a pattern of dialysis that is right for you, you will be given a fixed schedule of treatment times. Most patients have dialysis three times a week, every second day, Monday, Wednesday, Friday or Tuesday, Thursday and Saturday.

When you are discharged, every effort will be made to ensure that you will be given dialysis times that suit your needs. However, staff may have to change your times based on the physical needs of other patients. If you need to change times, for a special occasion, please ask the nurse manager who will try to facilitate you.

Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

Dialysis Therapy Centre



Fresenius Northern Cross



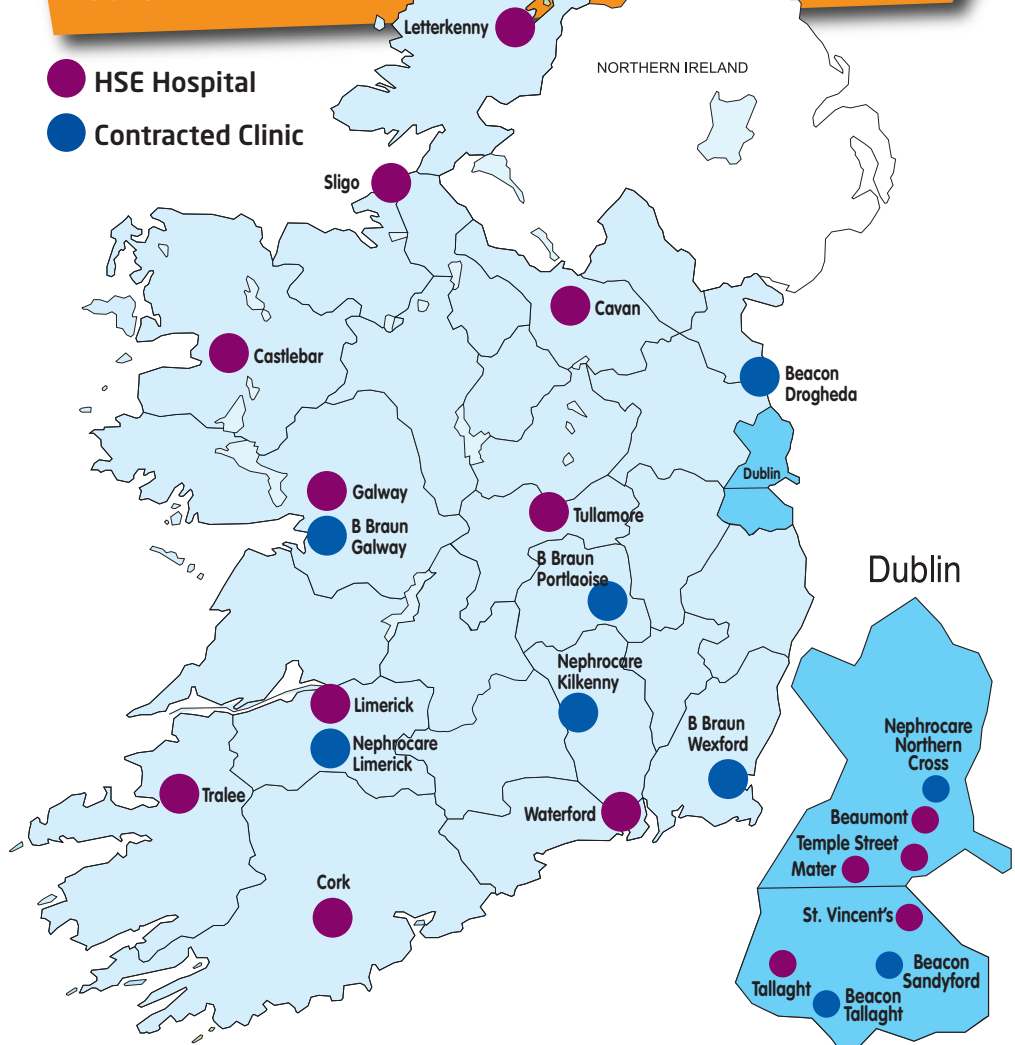
Once you have commenced haemodialysis, you will be allocated a specific time and day for your dialysis treatment. This is normally a fixed appointment, although the hospital can change the times and days, either as a one-off for a specific reason, or if the allocated time does not suit you.

Within Beaumont Hospital, the Dialysis Therapy Centre is divided into two units; DTC Unit 1 and DTC Unit 2. We also supervise patients in the Northern Cross Haemodialysis Unit. This is an off-site unit, run by Nephrocare who are a large dialysis provider.

Northern Cross provides the same dialysis treatment as Beaumont Hospital, under the supervision of the Consultants from Beaumont Hospital. Dietetic and counselling services are also provided to Northern Cross patients from Beaumont Hospital staff.

You may discuss your dialysis unit preference with your Consultant or Patient Care Coordinators. They will do their best to accommodate your requirements.

Map of Haemodialysis Units used by Patients from the Republic of Ireland



CHAPTER 3

COMPLICATIONS OF HAEMODIALYSIS

HYPOTENSION (Low blood pressure)

Hypotension means low blood pressure. When on dialysis this is related to the speed and amount of fluid removed from your blood. Giving you some intravenous fluids can easily reverse this. Symptoms can vary. Tell the nurse if you experience dizziness, nausea, cramps in legs or any 'funny feeling'. The best way to prevent this is for you to *stick to the fluid restrictions that are set for you* so that you avoid gaining too much fluid/weight between dialysis sessions.

FLUID OVERLOAD

Between sessions, patients can sometimes develop a condition called fluid overload. This is due to excess fluid building up in your body. Fluid overload can be mild and manifest itself as swollen ankles, or high blood pressure, or severe breathlessness.

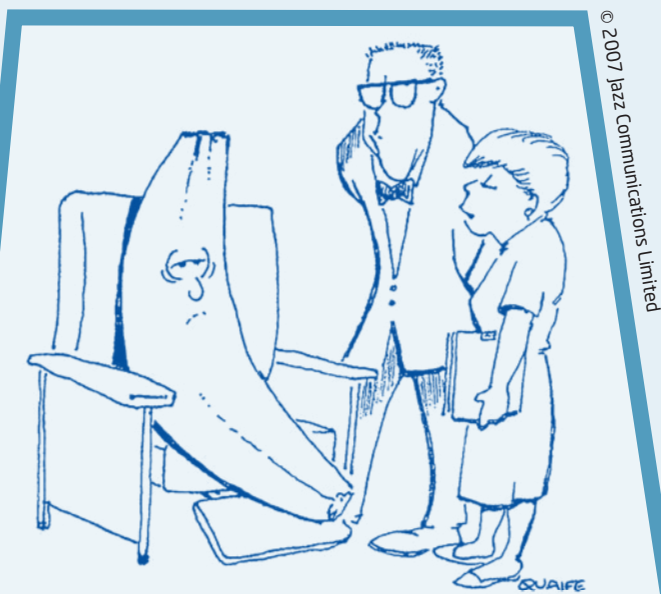
Constantly becoming fluid overloaded is not good for you, as it causes the blood pressure to rise and eventually damages the heart. If you think you are overloaded, contact the dialysis unit to organise extra dialysis to remove the fluid. If you are breathless or unwell, do not delay in contacting the dialysis unit.

BLEEDING FROM YOUR ACCESS SITE

After dialysis, the needles will be removed from your fistula or graft. Your nurse will take every care to ensure that bleeding has stopped before you leave the unit. If you should develop further bleeding, from your access site, apply a dry dressing to the site, apply gentle pressure to the area, and **return to the unit immediately**. If possible, call the unit to let them know.

INFECTION

See information in Chapter 6, Book 1.



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We're a little concerned about your potassium levels

HIGH POTASSIUM

In medical terms, this is known as hyperkalaemia. This means that there is too much potassium in the blood. This can be dangerous and life-threatening.

High potassium can affect the muscles of the body including the heart, which could cause the heart to stop beating.

By sticking to the diet, that the dietitian has prescribed for you, you can avoid this serious complication.

(See section on Dietary Advice in Book 1, Chapter 4).

Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

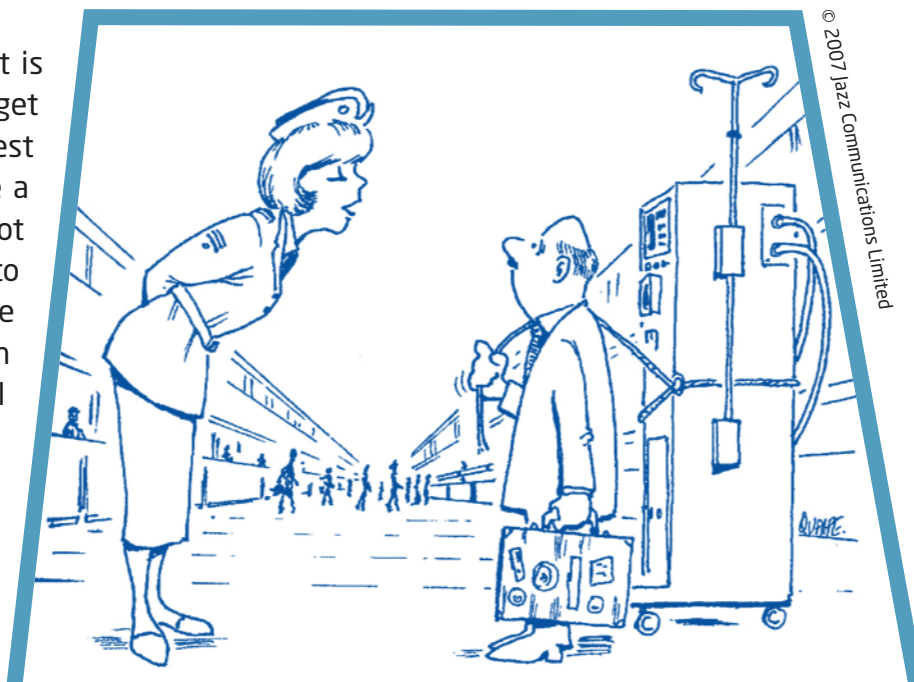
HOLIDAYS ON DIALYSIS

Once you start on dialysis, it is essential that you continue to get your dialysis treatment for the rest of your life or until you receive a kidney transplant. This does not mean that you cannot continue to take a holiday. You will still be able to take a holiday within Ireland and abroad. This will require prior planning so that you can receive your dialysis while you are away. Your dialysis Nurse/Patient Care Co-ordinator will help you to make arrangements and identify a suitable dialysis unit close to your holiday destination. They will send the necessary information to the unit, prior to your journey. This will include a recent Hepatitis B + C blood level and HIV level.

There may be a charge for holiday dialysis. This can be discussed further prior to your holiday.

It is essential that a minimum of two months notice is given to staff prior to your travel.

The Irish Kidney Association also provide respite holidays for patients on dialysis and patients with a kidney transplant. These holidays are available in the form of holiday homes in Tramore, Co. Waterford and Tralee and Killarney, Co. Kerry. Please speak to the staff in your unit, who will give you further details.



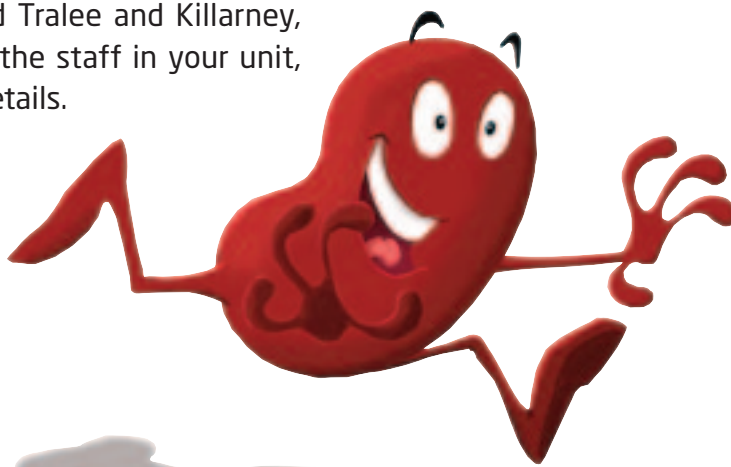
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I do sympathise with you, sir, but I'm afraid it cannot be viewed as 'carry on' luggage

"On your return from holidays it is necessary to obtain further Hepatitis blood levels"

On your return from holidays, it will be necessary to obtain further Hepatitis blood levels. This will need to be checked once a month for three months.

If you are away, for more than 14 days, on return to Beaumont Hospital you may need to have dialysis in isolation until the blood results become available.



CHAPTER 4

ACCESS FOR HAEMODIALYSIS

To perform haemodialysis, an access must be created. An access is a site from which blood can be safely removed and returned to your body. The access site is often referred to as your 'lifeline'.

There are two main types of haemodialysis access - arteriovenous fistula and central venous catheters.

PERMANENT ACCESS OPTIONS

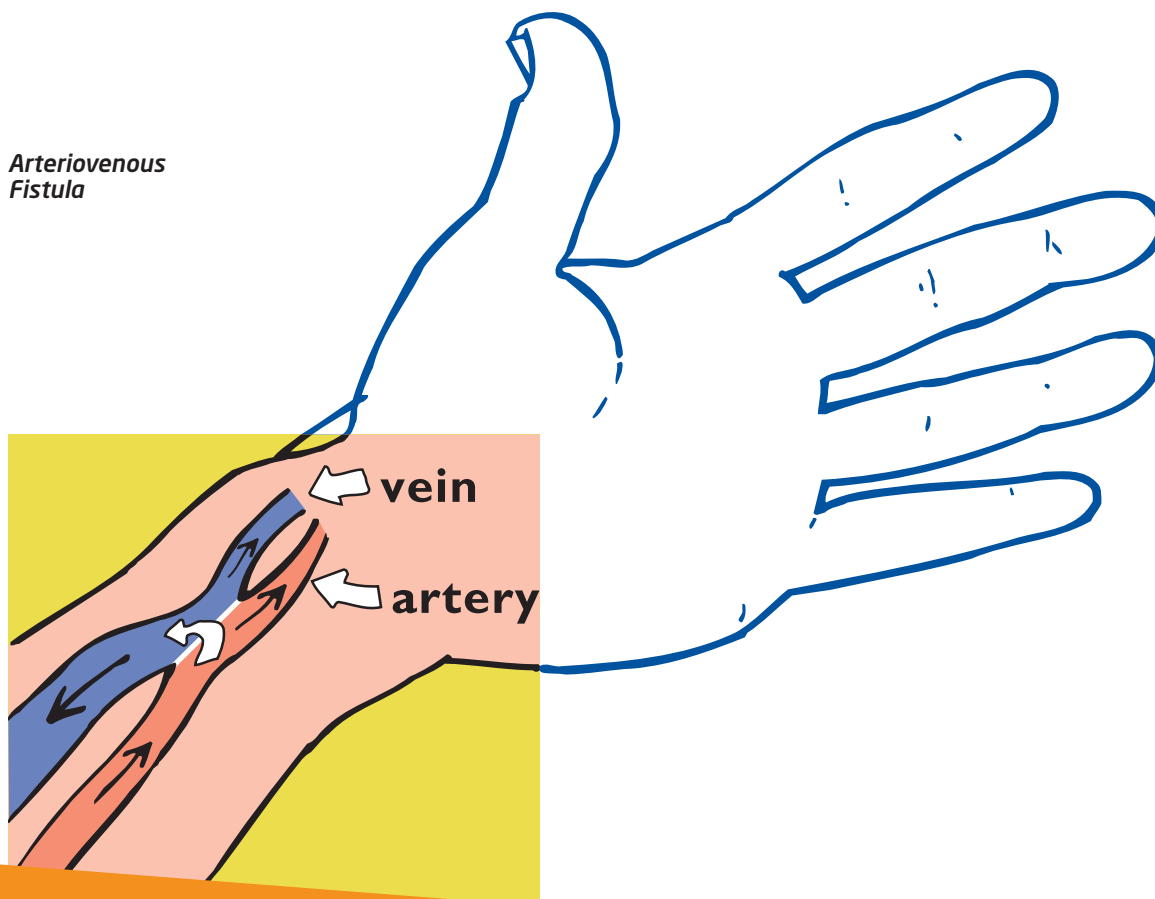
The *arteriovenous* or AV fistula is a type of vascular access, involving a direct connection between an artery and a vein. This connection is made underneath the skin with a surgical procedure that will only require a short stay in hospital. The connection between a vein and artery allows for adequate blood flow during dialysis. This increased blood flow leads

ONE PATIENT REPORTED:

"I've had my fistula for 22 years - the entire time I've been on dialysis. I make sure to take care of it because it's my 'lifeline' and it allows me to receive dialysis."

to larger and stronger veins and makes repeated needle insertions easier. Fistulas are the preferred vascular access for long-term dialysis patients because they last longer than any other vascular access and are less prone to infection and clotting.

Arteriovenous
Fistula



Kidney Disease

– Haemodialysis and Peritoneal Dialysis Explained

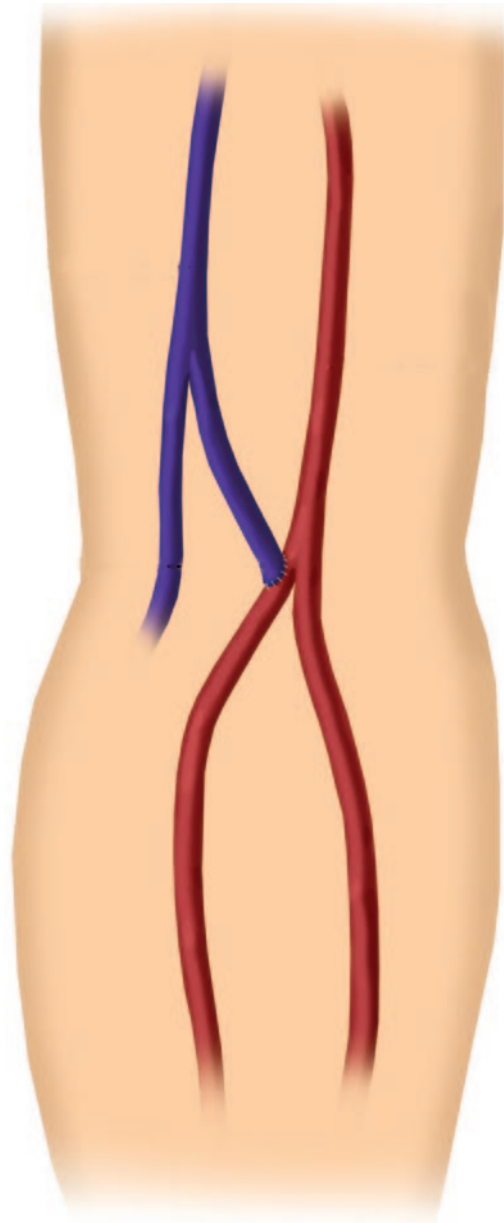
The fistula is usually placed in the forearm. AV fistulas may also be placed in the upper arm, if a previous AV fistula has failed or if the arteries or veins in the forearm are unsuitable for the creation of a fistula. It is preferred that the fistula be placed on the 'non-dominant' arm or the arm that you do not use as frequently.

8-12 weeks is usually needed to allow the fistula to properly develop, although it may take longer in some cases. Once the fistula has developed, you are ready to commence haemodialysis treatment.

A nurse will insert two needles into the fistula, one for withdrawing blood from the body and the other to return dialysed or filtered blood to the body.

Not everyone is suitable for an AV fistula. It can be difficult to create, in some patients, due to small veins and other medical conditions. Your surgeon may order a test to show the blood flow in your arms, to determine the suitability for a fistula.

"Not everyone is suitable for an AV fistula. It can be difficult to create in some patients due to small veins and other conditions."



Upper arm primary fistula

PROS AND CONS OF AN ARTERIOVENOUS FISTULA

PROS

- Best overall dialysis performance
- Considered the best vascular access
- Less chance of infection than other types of access
- Tend to last many years
- Predictable performance

CONS

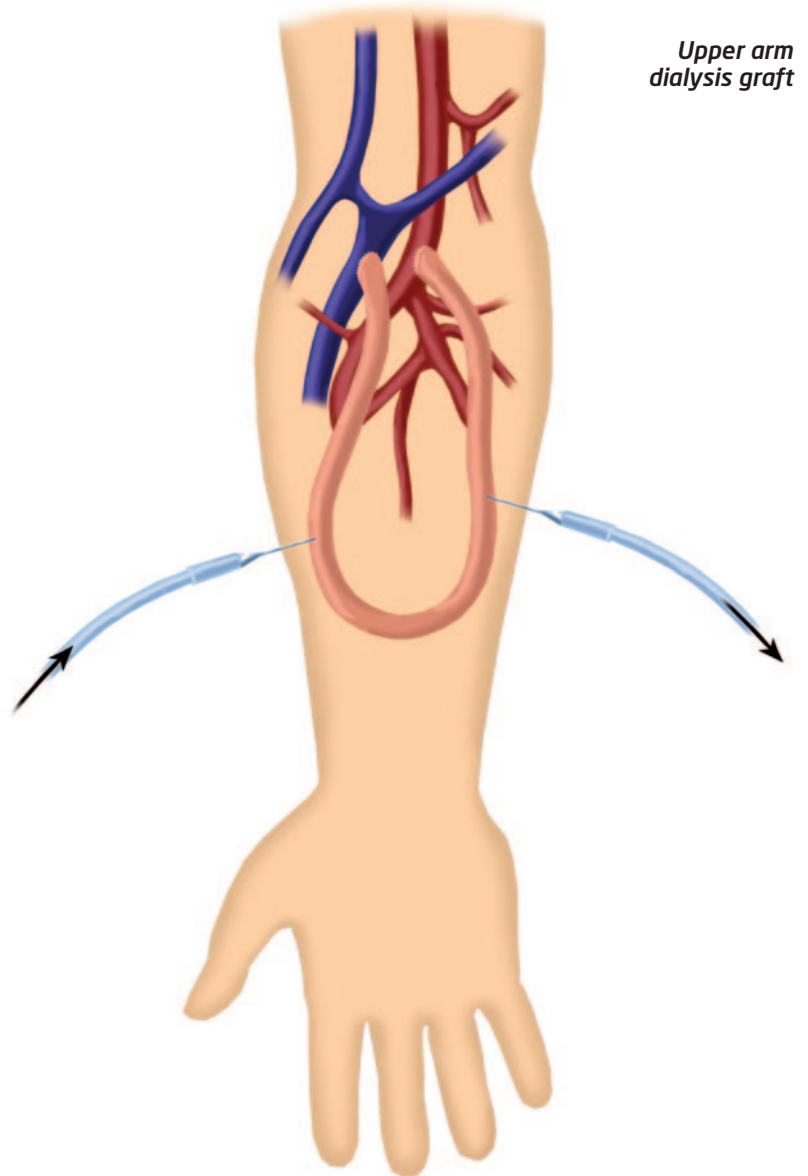
- Visible on the forearm
- May take time to develop
- May require temporary access while fistula matures
- May bleed after dialysis needles are removed
- Some fistulas may fail to mature
- Steal Syndrome - Poor circulation

GRAFTS

Grafts are similar to AV fistulas. Unlike the fistula, which is created by the direct connection of the artery to the vein, the graft is formed by using a synthetic tube to connect the artery to the vein. Therefore, grafts are typically used when patients have small or weak veins that will not develop properly into a suitable fistula. Like a fistula, this type of access is usually implanted under the skin in your arm. A surgeon performs a brief procedure, in order to properly place the graft.

The graft is usually a soft, synthetic tube that connects to an artery at one end and a vein at the other. The tube acts like a natural vein, allowing blood to flow through it.

Following the surgery, you may experience pain and swelling in the area over the graft for three or four weeks. You will be prescribed pain relief to take during this time. The arm should be kept elevated. After the swelling goes down, the graft can be used for haemodialysis. Grafts can be used repeatedly for needle insertion during dialysis.



PROS AND CONS OF A GRAFT FOR ACCESS

PROS

- Can be readily implanted.
- Predictable performance.
- Can be used faster than an AV fistula (within 3 to 4 weeks).

CONS

- Increased potential for clotting.
- Increased potential for infection.
- Does not usually last as long as a fistula.
- Steal Syndrome.

Vascular access steal syndrome is a syndrome caused by ischemia (not enough blood flow) resulting from a vascular access device (such as an arteriovenous fistula or synthetic vascular graft-AV fistula) that was installed to provide access for the inflow and outflow of blood during haemodialysis.



Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

RISKS OF AV FISTULA OR GRAFT

Not every fistula or graft will work first time. The success rate when creating a fistula is about 70%. Some patients have to come back to have a new fistula made a second or third time.

Occasionally, when a fistula is made it takes too much blood from the hand, resulting in what's called 'steal syndrome'. If this happens, it may require that the fistula be reversed and another access created for dialysis.

A graft may be prone to developing an infection. If this does develop, you will require a prolonged period of IV antibiotics.

Occasionally, a fistula or graft will clot and it will not be possible to use for dialysis. If this occurs it may be necessary for the surgeon to remove the clot to ensure your access functions again.

Care for Fistulas and Grafts

The following information is important to remember in order to ensure your fistula stays working for the longest time possible.

- Do not wear constrictive clothing or watch straps on the fistula arm.
- Avoid trauma to the fistula arm, such as cuts and abrasions.
- Do not allow anyone to take blood samples, blood pressure readings or insert an IV cannula (drip) into your fistula arm.
- Avoid dehydration. This may occur if you lose excessive amounts of fluid (for example, if you develop diarrhoea or are unwell and unable to drink your fluid allowance).
- Maintain a high standard of hygiene. It is preferable to have a daily shower. Before and



A patient receives dialysis treatment using an arteriovenous fistula.

after your dialysis treatment, your fistula arm must be washed well up to the elbow with Hibiscrub (pink solution), which is located at all sinks within the dialysis unit.

- Should you develop any signs of infection such as redness, swelling, pain, tenderness or discharge from your fistula, contact your dialysis unit immediately.
- You will be shown how to assess your fistula. If you notice the buzz is gone, contact the unit immediately.
- Do not sleep with your access arm under your head or body.
- Do not lift heavy objects or put pressure on your access arm.
- Learn how to properly hold the gauze after the dialysis needles are removed. If your fistula starts bleeding, apply pressure to the fistula site until bleeding stops and contact your unit immediately.
- To ensure safety, during your dialysis treatment, your fistula should be in view of nursing staff at all times.

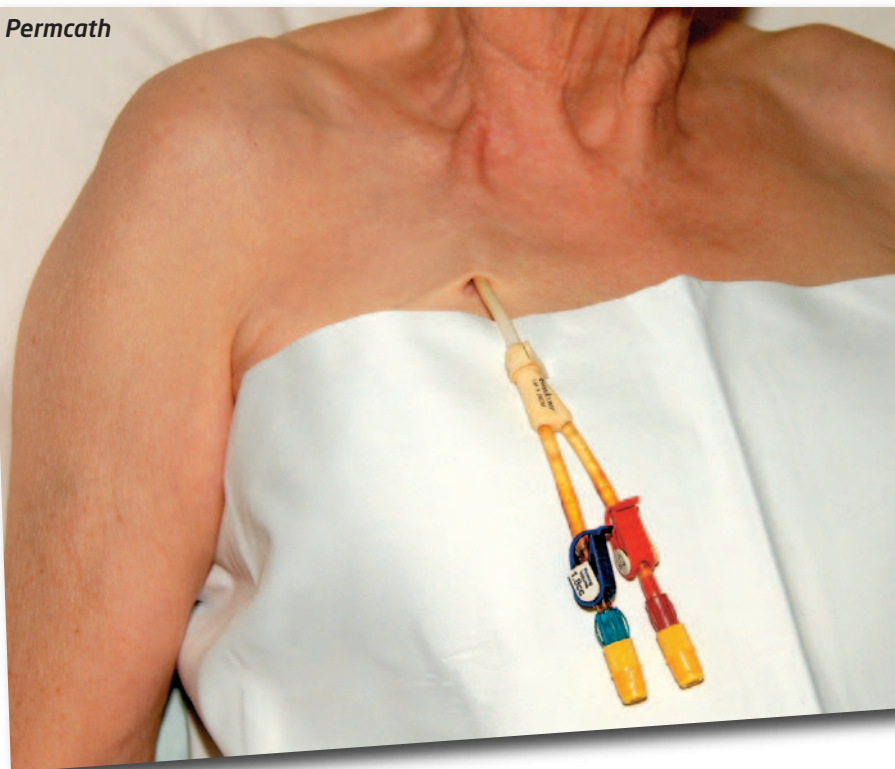
TEMPORARY ACCESS

A dialysis catheter is a flexible, hollow tube which allows blood to flow in and out of your body. They are most commonly used as a temporary access for up to three weeks. This is often undertaken when a patient first needs dialysis immediately and is waiting for a fistula or graft to mature.

They are also used when a permanent access fails and a patient is too unstable to delay treatment. Catheters can be placed in a number of different locations, including the neck, upper chest or upper leg (femoral vein).

After a catheter has been placed, needle insertion is not necessary to receive haemodialysis treatment, dialysis lines are directly connected onto the catheter.

Permcath



CARE OF YOUR DIALYSIS LINE

Protecting your dialysis access is crucial to you.

PROS AND CONS OF A DIALYSIS CATHETER

PROS

- Dialysis can be performed immediately.
- Easy removal and replacement.
- Avoids needle insertion for each treatment.

CONS

- Not ideal as permanent access.
- May cause narrowed central veins.
- High infection rates.
- Blood flow may not be sufficient to complete your dialysis treatment.



Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

The following tips will help you care for your dialysis line.

- The dialysis staff will change your line dressing at the end of each dialysis session.
- Most daily activities are not affected by having a dialysis line. However, you should avoid swimming and contact sports.
- Take extreme care when dressing and undressing to avoid pulling accidentally on your catheter.
- If you have a bath, do not allow the dialysis catheter or dressing to come into contact with the bath water.
- If you have been taught how to dress your own exit site by dialysis staff, then you may take a shower and redress the line as shown.

IMPORTANT POINTS TO REMEMBER AFTER INSERTION OF YOUR DIALYSIS LINE

When you are discharged home from hospital you will be given an emergency pack containing:

- Blue dialysis clamps
- Gauze dressings
- Spare dressings

Please keep this pack with you at all times. In the unlikely event that the **catheter becomes damaged or leaks**, lie flat with your legs elevated. Place the blue clamp from the emergency pack above the leak as close to your exit site as possible and **contact the unit immediately**.

Remember - keep sharp objects such as razors or scissors away from your dialysis line.

In the unlikely event of your dialysis **catheter falling out**, lie flat with your legs elevated, place gauze or a clean towel over the area and apply pressure for at least 5 minutes or until the bleeding has stopped. **Contact the unit immediately**.

Never open the clamps or sealing caps between treatments.

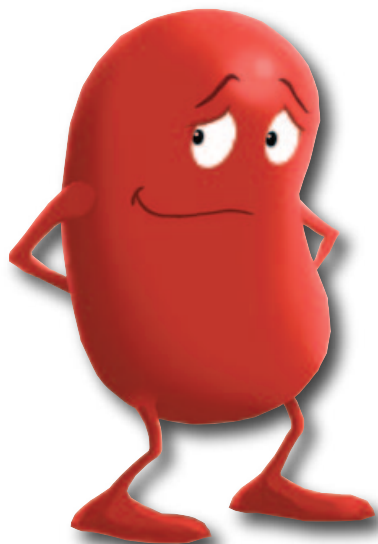
If you feel or observe fever, chills, redness, swelling, pain at exit site or, feel generally unwell, **contact the unit immediately**, as you may have a catheter infection that will need to be treated.

LONG TERM RISKS OF CATHETERS

Catheters can cause a number of long-term risks including infection. Catheters that have been in place for a long time, may cause narrowing or blockage of the central veins in the body, interfere with the functioning of a fistula or cause swelling of an arm or the face. This is called central venous stenosis. If this occurs, it may be necessary to have a new line inserted.

Poor flow - Catheters may develop a small clot, at the tip, causing poor flow of blood in the line. This can lead to inadequate dialysis and result in you feeling poorly.

In rare cases, catheters that are in place for a long time can become embedded, making their removal very difficult.



*"Remember -
keep sharp objects
such as razors or
scissors away from
your dialysis line."*

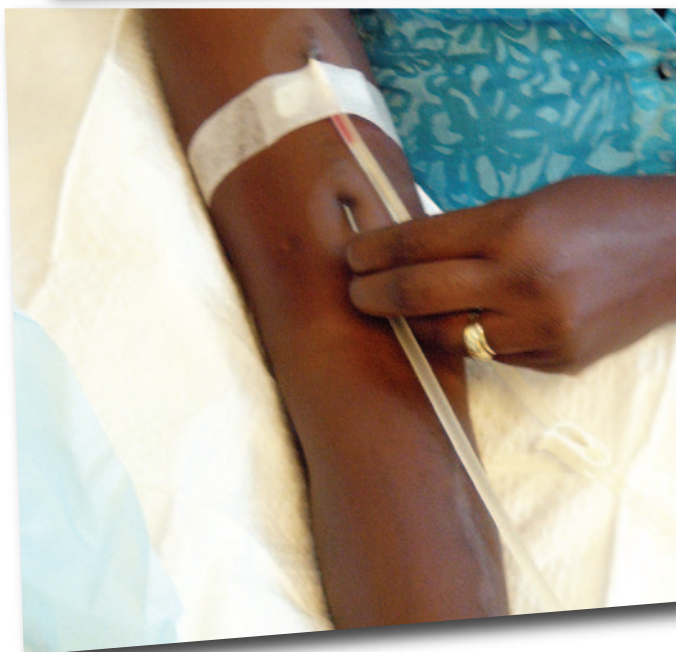


CHAPTER 5

HOME THERAPIES

If you choose to perform dialysis at home, you have two options - **Home Haemodialysis** or **Peritoneal Dialysis**. These options allow you to manage your condition and meet your health goals at home. These therapies will be outlined in more depth in this chapter.

HOME HAEMODIALYSIS



Home Haemodialysis (HHD) is an option of kidney replacement therapy. This is an ideal therapy for people who are motivated and have an interest in doing their own dialysis in the home setting.

Once you have discussed this option with your consultant, you will be referred to the home therapies team. An appointment will be made with you to discuss this option in more detail. This discussion usually takes about an hour. A partner or friend is encouraged to attend this appointment with you, both for support and to listen to the information being delivered to you.

Prior to starting Home Haemodialysis, you must have a functioning arterio venous fistula and the skill to self-needle your fistula (this skill will be taught to you, over a period of time in your dialysis unit). You can also be referred if you have a central

venous catheter (CVC) line or an AV graft.

It will be necessary for a house assessment to be carried out to assess the suitability of room size, electric and plumbing access and water quality. This assessment is completed by the service provider and a member of the haemodialysis training team. The water testing results take up to six weeks to be reported on and it is essential to have these results before training commences. When they are available, the team will organise a date to start training.

When you arrive at Hospital to commence your training, it will take place in a designated HHD room and one-to-one care and training will be provided. Training takes place on Monday, Wednesday and Friday at 08.00am for approximately 6 weeks. The first five weeks of training will take place in hospital, and, if you and the team feel you are ready, the last week (week 6) is provided in your home. Depending on where you live, the days and times may vary. During your training in Beaumont, you will also meet with the renal nurse counsellor and the dietitian.

WHAT PATIENTS SAY:

"Self-needling is a 'mind-set', and 'mind-sets' are made to be conquered"

"Self-needling is rarely a technical problem."

"The rest is practice and repetition."

Haemodialysis and Peritoneal Dialysis

- A Guide for Patients

Your house conversion will commence on the second week of your training. This involves creating an electricity supply, water and drainage access in the room chosen as your dialysis area. A shower tray, for the dialysis machine to stand on, is fitted and the floor will have lino fitted, which is required as part of the hygiene, health and safety standards. The conversion is essential to safely perform this therapy in your home. There is no cost to you for this conversion.

The service provider will also organise and set up all the required equipment in your home prior to week 6. This will include:

- Home Haemodialysis Machine;
- Dialysis chair;
- Dialysis table;
- Weighing scales;
- Waste disposal equipment including a sharps bin, healthcare risk waste bags and a wheelie bin.

There must be a designated area to store the necessary stock for your treatment.

Your first week (or longer if required) at home is fully supervised and supported by the home therapy nurse. This is a good opportunity to troubleshoot any problems you may encounter during your treatment at home. The service provider has a 24 hour, 7 days a week helpline and your clinical support team have an 8am to 8pm (Monday to Friday) and 8am-5pm (Sat and Sun) helpline.

Once you are settled into a routine of home dialysis, it will be necessary to attend Beaumont clinic, once a week initially for review, and to have an opportunity to express any worries or concerns. Other support staff (for example a dietitian or nurse counsellor), will be available to you as you require. To help with the reviews it will also be necessary to send bloods to the home therapy team on a monthly basis. This is an essential part of your



treatment and will help the team make decisions about your therapy.

If you decide this is the right mode of treatment for you, you will benefit by:

- Not needing to travel to and from the hospital 3 times a week for dialysis.
- Having your dialysis when it suits you, as discussed with your home dialysis team.
- Choosing to have longer dialysis sessions and, more often than the three times weekly. This will certainly benefit your health and you can be more flexible with what you eat and drink.
- Taking more control of your condition.

Nocturnal dialysis is now also an option for home dialysis. This is performed 8 hours 5 nights per week, and is considered the gold standard of treatment. It is gaining popularity due to the benefits associated with it.

Some disadvantages to HHD therapy include:

- You have to set up and dismantle your own dialysis machine for each treatment.
- You require a dedicated space in your home for storage of dialysis equipment.

Home Haemodialysis may not be right for you at this time. You may want to think about self-care dialysis in a unit, perhaps then deciding to make the move to home haemodialysis.

PERITONEAL DIALYSIS

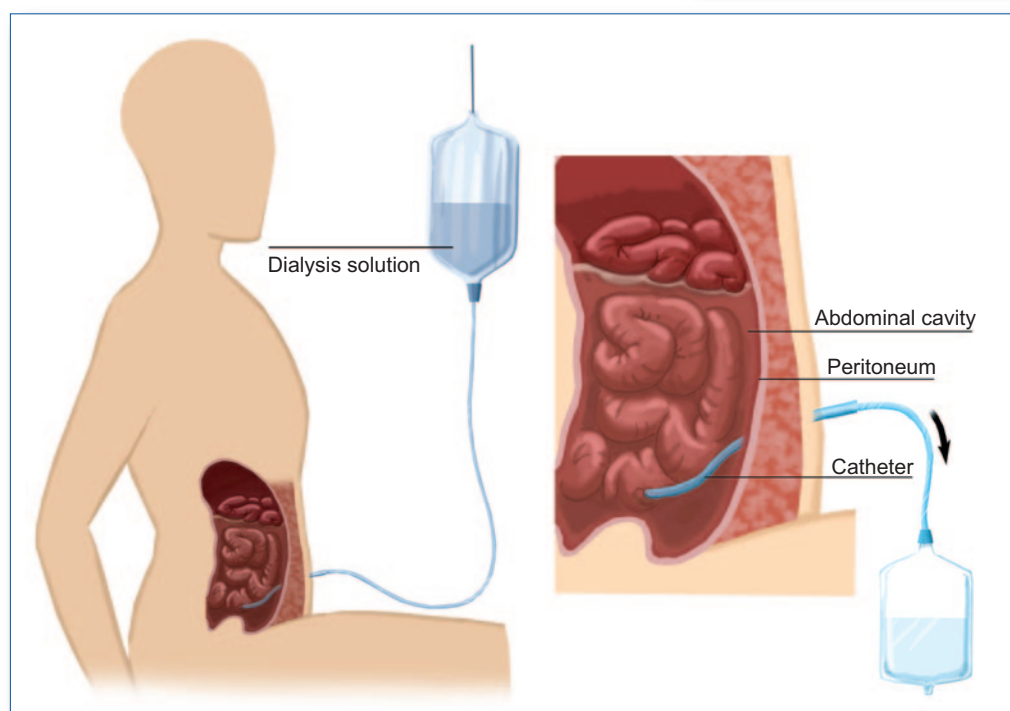
Peritoneal dialysis is another form of kidney replacement therapy. The peritoneum is a membrane which lines the abdominal cavity. Surrounding and protecting many of the body's internal organs, it has a rich blood supply, making it an ideal area in which to carry out dialysis. Peritoneal dialysis involves the use of the peritoneal membrane, as a filter, to remove waste products from the body and to correct body fluid and biochemistry.

This is achieved by inserting a catheter (tenckhoff) into the peritoneal cavity by way of a minor operation. About 15 cms of the catheter remains outside of the body, providing a means for attaching a bag of special dialysis fluid (dialysate). The dialysate fluid and the peritoneum work together to remove waste and excess fluid from your body.

Peritoneal dialysis exchanges can be performed by the patient themselves during the day time (Continuous Ambulatory Peritoneal Dialysis) or by a small machine at night while you sleep (Automated Peritoneal Dialysis).



Continuous Ambulatory Peritoneal Dialysis (CAPD)



Both methods are easy to learn. Once trained by the peritoneal dialysis staff, dialysis is carried out in your own home. Patients will be assisted by their renal team in choosing the dialysis therapy that best suits their medical and personal needs.

Haemodialysis and Peritoneal Dialysis

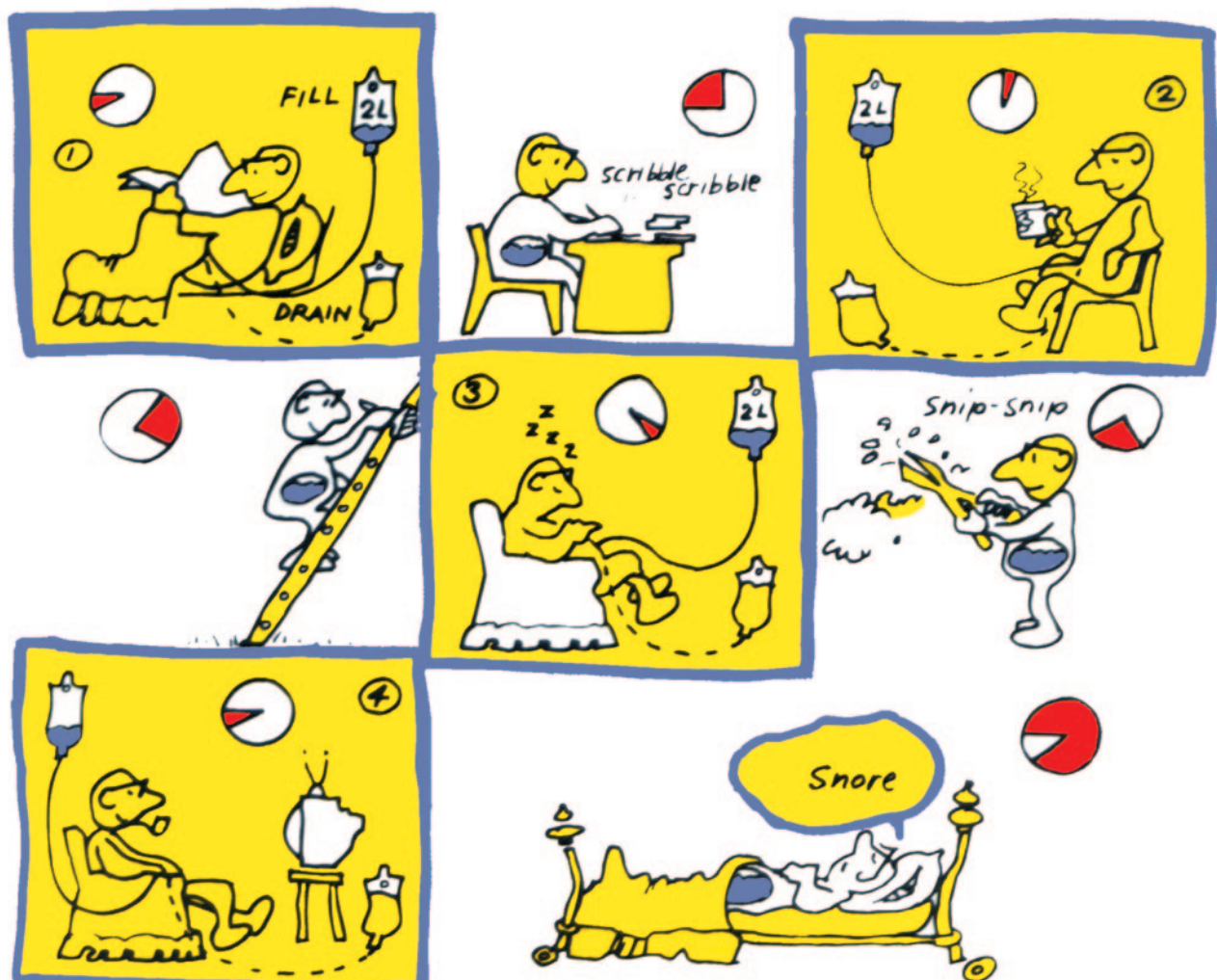
- A Guide for Patients

SHOULD I CHOOSE PERITONEAL DIALYSIS (PD) OR HAEMODIALYSIS (HD)?

Both peritoneal dialysis and haemodialysis are equally effective for treating kidney disease in the short to medium term. Your choice of treatment depends on the way you want to live your life.

- In haemodialysis (HD), you receive your treatment every second day. You will have 4 days off every week. With peritoneal dialysis (PD), you need to do your treatment daily in either four 20 minute exchanges or 8-10 hours overnight whilst you sleep.
- In HD, the nurses carry out the procedure when you come into the unit (unless you opt for Home Haemodialysis). PD is a self-care treatment.
- With PD, it is sometimes easier to work or have a good quality family life. Your treatment is performed at home. Therefore, you are not making as many trips to the hospital.
- It is often easier to arrange a holiday on PD. Your dialysis fluids can be delivered to your destination, home or abroad.
- PD often works well for people who have had difficulties with dialysis access.
- PD allows you to drink more fluids, as the excess can be taken off each day.
- With PD, you need to have reasonable eyesight and manual dexterity to carry out the exchanges.
- Patients who have had extensive abdominal surgery will generally not be suitable for PD.

Your nephrologist will sit down with you and discuss in detail which form of dialysis best suits your situation. It is often possible to switch from PD to HD or HD to PD after a period of time, on each treatment, if it does not agree with you.



WHAT DOES PD INVOLVE?

The process of PD depends on whether you choose CAPD or APD.

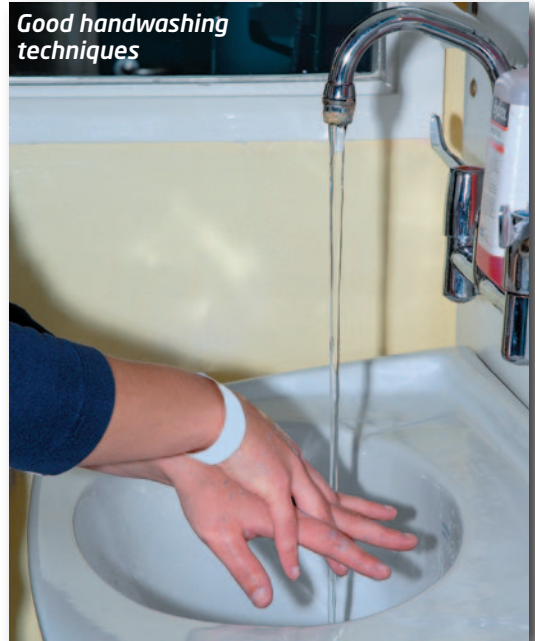
If you decide to opt for peritoneal dialysis, a small operation is needed to place the catheter into your abdomen.

The catheter is allowed to rest for a few weeks before it can be used.

Once the catheter is ready for use, you will either be admitted to the hospital to receive the training required to carry out peritoneal dialysis or it may be possible to receive the training as an outpatient.



Equipment required to perform a dialysis exchange



Good handwashing techniques

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS (CAPD)

With PD, dialysis is taking place inside you without you being aware of it. CAPD is a process by which 2-2.5 litre bags (depending on your prescription) of dialysis fluid are instilled into your peritoneum, four times a day, via your Tenckhoff catheter. Different strengths of dialysis fluid are available, and your doctor and PD nurse will explain which fluids best suit you.



Tenckhoff catheter in situ



Sr. Nora McEntee demonstrating how to connect the dialysis fluid to the Tenckhoff catheter



Tenckhoff catheter



Haemodialysis and Peritoneal Dialysis

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AUTOMATED PERITONEAL DIALYSIS (APD)

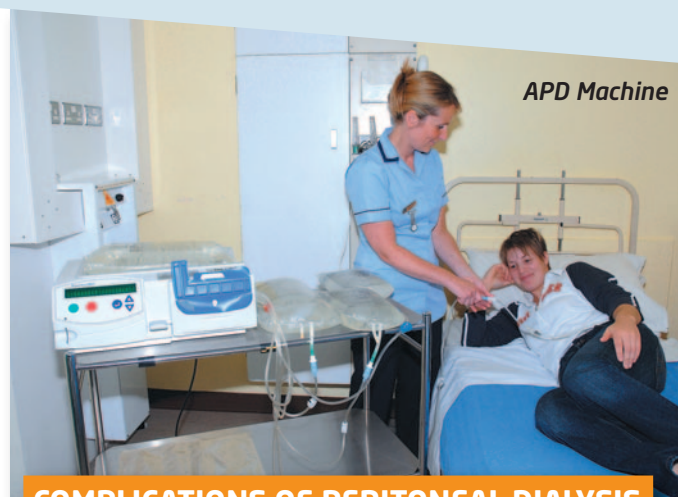
APD is an overnight treatment for 8-10 hours, 7 nights per week, and uses a machine to perform the dialysis whilst you sleep. The machine works by instilling and removing fluid throughout the night and is very easy to set up. Some people require fluid to stay in during the daytime for some extra dialysis. You will have a memory card with your details and prescription on it. This will record your sessions. When you attend the PD clinic the dialysis nurses will download the information. The machine is portable for holidays and has a carry case which can be taken abroad.

CONTROL OF FLUID AND DRY WEIGHT ON PD

As a patient on dialysis, it is very important to be careful about the amount of fluid you drink. Your doctor/nurse will inform you of the amount of fluid you can take on a daily basis. This amount is reviewed regularly, as it may change taking into consideration urine output. However, most patients lose their urinary output within the first year of dialysis treatment. The amount of fluid removed, at each session is determined by the type of dialysis bag that is used. By increasing the concentration of glucose in the bags, more fluid can be taken off.

The three main types of fluid used in Beaumont are 1.36% (light bags), 2.27% (medium bags), and 3.86% (heavy bags). There is also a very strong bag called Extraneal, which has the strongest fluid removal capacity. You and your doctor will develop a prescription of the PD treatment, using, for example, three light bags and one extraneal bag, or one light bag, two heavy, and an extraneal at night. The prescription will be individualised for you and may change over time.

It is important to record your dialysis prescription, weight and the amount of fluid that is



COMPLICATIONS OF PERITONEAL DIALYSIS

PD, like any form of dialysis, carries a risk of a number of complications, which are rare.

The major complications include:

- | | |
|------------------------|------------------|
| ● Peritonitis. | ● Loss of |
| ● Exit site infection. | ultrafiltration/ |
| ● Fluid leak. | inadequate |
| ● Catheter blockage. | dialysis. |

removed on a daily basis. This shows clearly how well dialysis is working for you. It is important that these records are brought along to clinic appointments, so that your team can review them, and make changes in your treatment if required.

FOLLOW-UP

If you select PD as your treatment choice, you will have continued support from the kidney team. You will be reviewed by your consultant at a special PD Clinic once, every 2 months or sooner if needed. However, you have the choice to contact the kidney ward at any time to speak to staff. PD staff are available from 7.45am to 8.30pm. A home visiting service is also available from the Beaumont PD staff.

CHAPTER 6

SUPPORTIVE CARE OF KIDNEY FAILURE

When dialysis was first introduced, its availability was reserved for the younger, fitter and employed person. Over time, these restrictions were lifted, and dialysis is now offered to all patients, regardless of age or co-morbidity (having other health problems). This has resulted in many patients enjoying a longer life than would have been possible years before.

If you are reading this article, it probably means that you, or one

of your family members, are facing the prospect of your kidney function advancing to the stage that a decision is required as to whether or not you/ they will need dialysis to prolong life.

Before making that decision, get as much information as you can about what is involved in dialysis, what to expect, and how it might affect you.

Not all patients do well on dialysis and for some, there is a marked deterioration in quality of life, though this is not entirely predictable. Some patients may

experience dialysis as an excessive burden, which provides no benefit. People who are already struggling with health problems, over many years, may reasonably wonder if dialysis will make their life any better or will it prolong their suffering.

Is the onset of end stage kidney disease a sign that natural life is coming to an end? Is the option of dialysis a burden to be faced or an opportunity to prolong life?

"Is the onset of end stage kidney disease a sign that natural life is coming to an end? Is the option of dialysis a burden to be faced or an opportunity to prolong life?"

The best way to make these very important choices is preferably in discussion with your doctor and medical and nursing team. This includes your GP, your Nephrologist (kidney specialist) and their team, and the specialist nurses. They

will be in a position to give you the facts relating to your individual situation. It is also advisable to include your family in the discussions as, obviously, your welfare will be of concern to them and their support will be important to you, whichever decision you make.

POSSIBLE REASONS WHY PEOPLE MAY OPT NOT TO HAVE DIALYSIS

- **Age / Frailty** – "Am I too old?"
- **Co-morbidity** – "I already have heart disease, or diabetes, or chronic lung disease or many other conditions."
- **Malignancy** – I have cancer. How will dialysis affect that?
- **Psycho social issues** – "I live alone, how will I manage? Who will help me?"

Many patients with some, or all of these questions, do quite well on dialysis, so use this list to help you make the right decision, rather than to steer you away from dialysis.

No one can predict the specific time/date of death of another, but it may be helpful to ask your doctor how long you might be reasonably expected to live with or without dialysis.

Haemodialysis and Peritoneal Dialysis

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WHAT IF I CANNOT DECIDE?

If you find it difficult to decide, you can opt for a trial of dialysis. This means that, for an agreed period, such as 6 weeks, 3 months, or whatever you decide with your doctor, you will have dialysis treatment to see how you get on with it. After a trial, you may decide to continue with dialysis or stop dialysis treatment altogether.

WHAT IF I DECIDE NOT TO GO ON DIALYSIS AT ALL?

The doctor and his/her team will respect your decisions and make plans to continue your care under a programme called Conservative Management. This means that you will receive all other aspects of kidney care, with the exception of dialysis.

Before this commences, the doctor will want to discuss your decision with you, to ensure that all possible interventions have taken place and to optimise your medical management. It is also likely that an assessment, for depression, will be offered to ensure that a depressive episode is not a contributory factor to your decision. Sometimes, an assessment of cognitive function and capacity is required.

Symptoms will be reviewed and appropriate medications prescribed to manage these. Your GP will be notified regarding your care and depending on your circumstances, e.g., distance from the hospital, it might be beneficial for your care to be managed by your GP regularly, with access to the kidney team for support as the need arises.

You will be guided through what to expect by the Ambulatory Care Sister whom you will meet at the clinic. She will liaise with the Patient Care Co-ordinator and your Public Health nurse will be notified. Help and support from your local health

service will be requested as and if you require them.

WHEN WILL I DIE?

This is a very difficult question to ask and to think about. It is also a difficult subject to talk about with your family. The sad reality is that death will eventually be the outcome of kidney disease, without dialysis. The timing of death will be different for everyone, depending on what kidney function you have, other medical problems, your age and other factors. People, managed conservatively with chronic kidney disease, have lived from 5 years to a few weeks.

Being in a position to make decisions for yourself about what you want, when the time comes, can actually be a help. Most people would choose to die at home, and this is possible with support from family and community nursing. Other options include hospital or local hospice care, depending on which area of the country you live.

Patients already resident in nursing homes may remain there and be cared for to the end of life. What is important to know is that you will not be alone. You will continue to be offered expert medical advice regarding management of your condition and its progress.

Specialist Palliative Care is available if your condition becomes complex. The aim of conservative management is to keep you as comfortable as possible until natural death occurs, supported by family and community services.

"This means you will receive all other aspects of kidney care, with the exception of dialysis."

"You will continue to be offered expert medical advice regarding management of your condition and its progress."

PEACE OF MIND

To ensure your peace of mind, it is advisable at this time, to consider the following:

1. Making a will.
2. Discussing with your family personal preferences about your future care, in the event that you were unable to make decisions for yourself. Given that you may live for a number of years with conservative management, would you want to be resuscitated if you suffered a cardiac or respiratory arrest? Would you want to be put on a ventilator?

These are very difficult questions but by you giving them some attention now, you might prevent a very difficult situation for your family.

- Should you decide not to opt for resuscitation, this will be clearly documented in your chart.
- You have the right, at all times, to change your mind and opt for dialysis and/or resuscitation if this is medically feasible.

HOW WILL I DIE?

This is impossible to predict. As time goes on and as the end gets closer, some people become progressively weaker and may slip into a coma. Symptom management will be adjusted to provide maximum comfort at this stage.

WHAT ABOUT MY FAMILY?

Help and support will be offered to your family throughout your on-going conservative management, as required. Contact details will be provided at the kidney clinic.

IF I START DIALYSIS, CAN I STOP IT?

Yes. Any patient who opts for dialysis is entitled to stop dialysis if it becomes too much for them. Sometimes, the patient comes to this decision first and other times it may be suggested, by the medical team, if it is apparent that dialysis is no longer suitable or beneficial to the patient.

"Any patient who opts for dialysis is entitled to stop dialysis if it becomes too much for them."

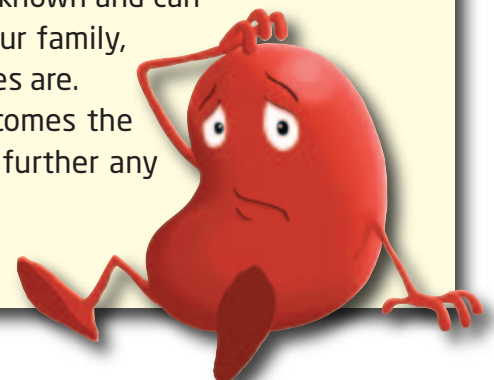
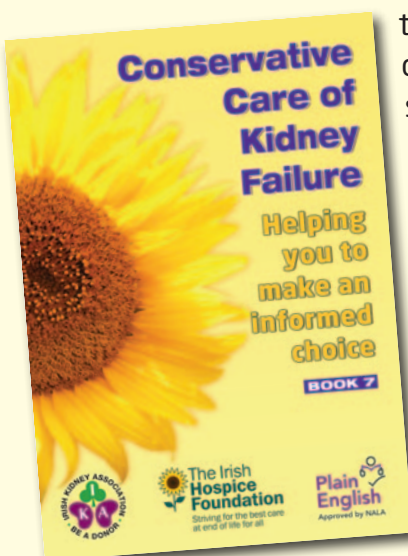
WITHDRAWAL OF DIALYSIS

If dialysis treatment is no longer possible or tolerable, the aim will be to make you as comfortable as possible, by carefully managing symptoms and supporting you and your family through all stages of the dying process. No two people will experience discontinuation of dialysis in the same way, so each person's circumstances will be supported as appropriate to them. Some people will opt to die at home, supported by their GP and community nursing services. Others may prefer to be in hospital when the time comes.

While talking about end of life issues is difficult, many people experience a sense of relief at bringing the discussion into the open. It helps ensure that your wishes are known and can be honoured. It is also helpful, to your family, to know beforehand what your wishes are.

The staff of the kidney unit welcomes the opportunity to discuss and explain further any issues raised in this article.

See more information in Book 7.

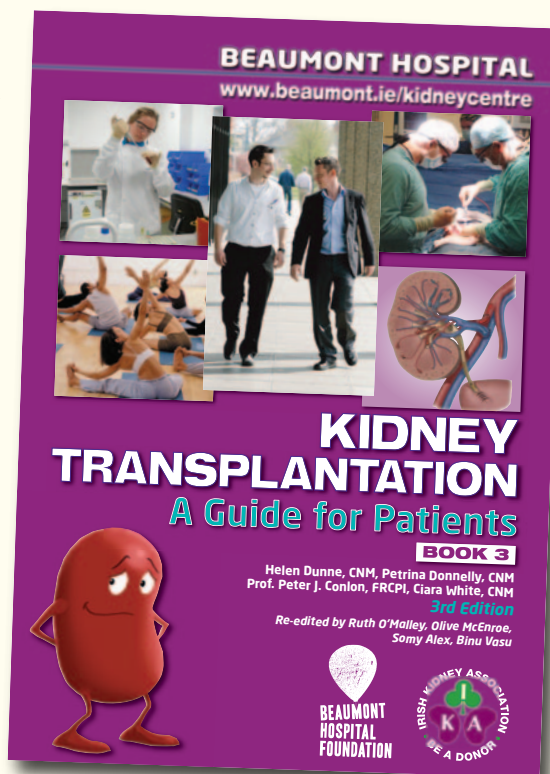


CHAPTER 7

KIDNEY TRANSPLANTATION

Kidney transplantation is a very big area with lots to learn about. We have published a booklet '*Kidney Transplantation - A Guide for Patients*' that tells you all you need to know about receiving a kidney transplant. Your nurse will give you a copy of this on request.

A kidney transplant is undoubtedly the best long-term treatment for patients who have developed irreversible kidney disease. While this sounds very daunting at first, the procedure is performed fairly frequently with excellent long-term results. However a kidney transplant is not for everyone. Very elderly patients, or those with significant problems such as heart or lung disease, might not be medically suitable to undergo transplantation. Your team will discuss the best options for you.



THE TRANSPLANT PROCESS

To receive a kidney transplant you must be in reasonable general health apart from kidney disease. To determine your health, you will need to undergo a complete medical evaluation. This will be undertaken by your own kidney team and will include an extensive list of blood tests, including tissue typing bloods, hepatitis B test, HIV test and many others. There will also be a test of your kidneys and cardiac function. It is possible to begin the process of going on the kidney transplant list, before your kidneys have failed completely, although your kidney function does need to be less than 20%.

Once these tests are completed, your

kidney team will refer you to Beaumont Hospital where you will be asked to come and meet the Beaumont transplant team. At this visit, the pros and cons of a kidney transplant will be discussed. You will be given the opportunity to discuss any issues you have at this point. If all your test results are acceptable, you will be placed on the kidney transplant waiting pool. It is very important that, while you are on the transplant waiting pool, you remain contactable. A suitable kidney may become available at any time of the day or night. You must let the transplant co-ordinators know if you are away or change your contact details.

contd...

While you are on the transplant waiting pool, you must send blood samples to the transplant laboratory, at Beaumont, at least every 3 months. If you are on dialysis, this will probably be done automatically for you but, if you are not yet on dialysis, you will be sent a letter to organise an appointment for you to have your bloods taken. It is your responsibility to ensure that these samples are taken, by your doctor/nurse, and sent to the hospital every month.

If these blood samples are not kept up-to-date, your name will be suspended from the transplant waiting pool.

When you receive a call, regarding the possibility of a suitable transplant, it is of vital importance to travel to Beaumont Hospital as quickly as possible.

You will be asked to fast from that point. You will go to St. Damien's Ward on the fourth floor.

In St. Damien's you will again undergo many different blood tests, x-rays and heart monitor, etc. You will also be seen by the surgeon and anaesthetist.

Only after all these evaluations are available will the final decision be made to go ahead with the transplant.

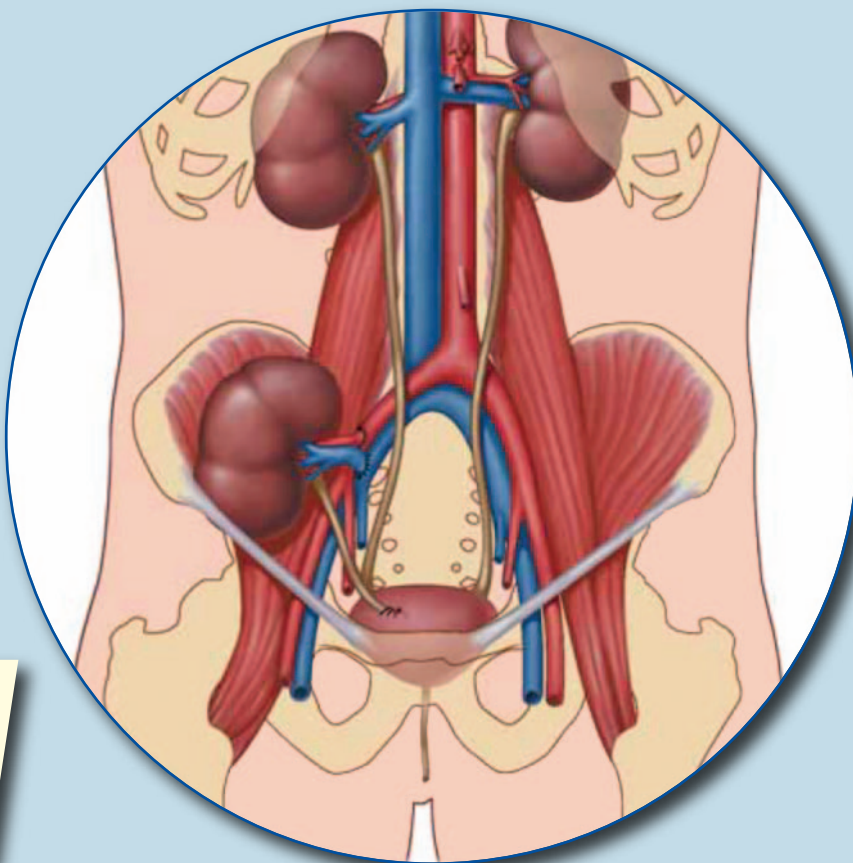
In some situations, the cross-match test will come back **positive**, which means that this kidney is not suitable for you. This can be extremely difficult and disappointing for you and your family. The kidney team will be there to support you through this time in the hope that a better match for you appears next time.

THE TRANSPLANT OPERATION

If the kidney is making lots of urine and the serum creatinine is falling, it implies that the kidney is functioning well. About 10% of patients will experience a rejection episode, where the body attacks the transplanted kidney, resulting in a rise in creatinine. If this happens, you will probably need to have a transplant biopsy and then undergo a 'boost' of high dose intravenous steroids for 5 days. The good news is that the vast majority of rejection episodes respond to this treatment.

Kidneys for transplantation can be from:

- Deceased donors
- Living donors



Haemodialysis and Peritoneal Dialysis

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DECEASED KIDNEY TRANSPLANTATION

At present, in Ireland, this is the most common form of kidney transplant. A person who has had an irreversible brain injury, usually from an accident or brain haemorrhage, can become a kidney donor. In Ireland this is only done with the consent of the patient's relatives. The brain stem is responsible for the capacity for consciousness. If the brain stem is irreversibly damaged, this constitutes brain stem death, which constitutes death of the person.

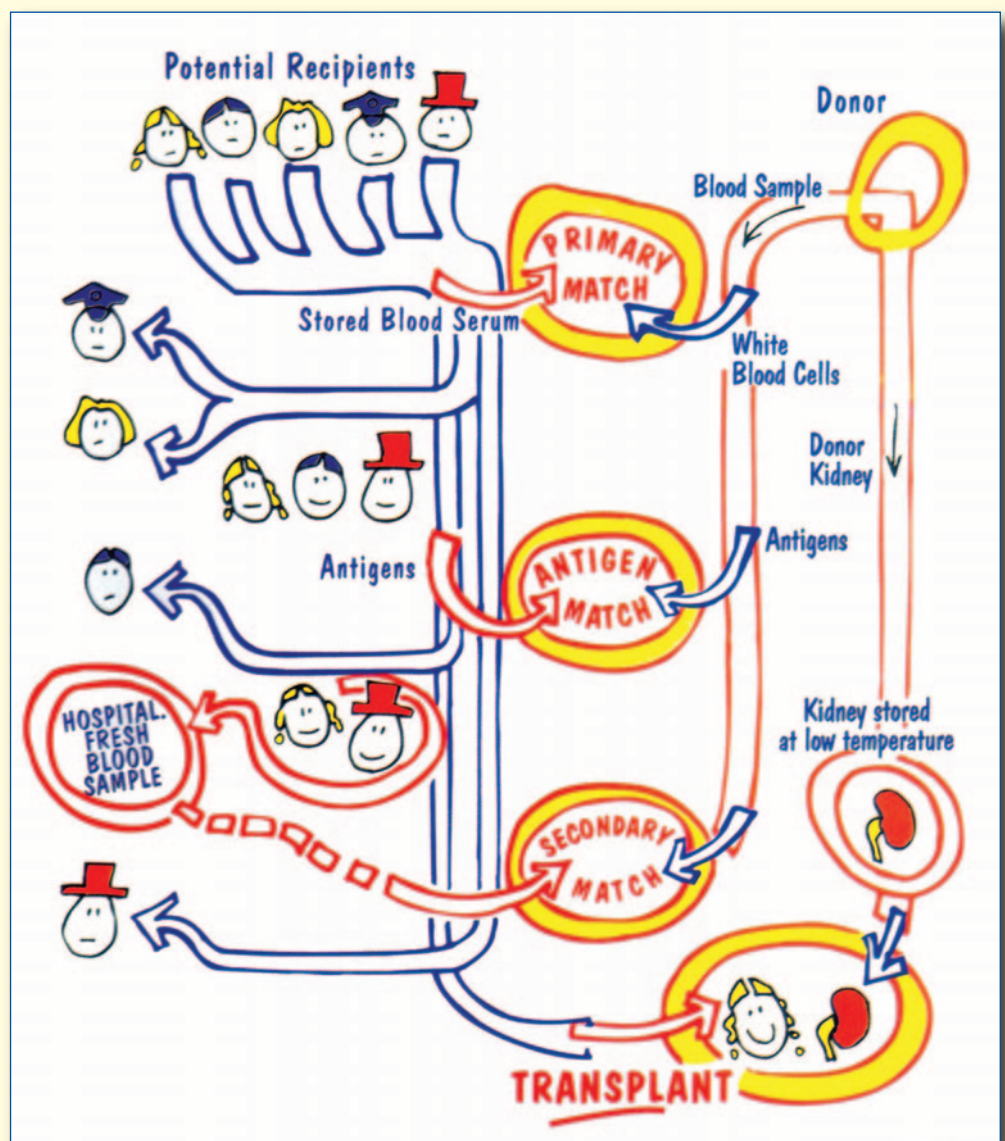
The donor is taken to theatre, where their kidneys and frequently many other organs, are

removed for transplant purposes.

The problem with this approach is that there are far more patients in need of a kidney transplant than there are kidneys available for transplant. The average waiting time for a kidney transplant is two, to two and a half years, although there can be enormous variation, with some patients waiting less than 6 months and some patients waiting more than 5 years because of the difficulty of matching the new kidney to particular needs.

To access the transplant list, fairly strict rules are in place. Priority is given to patients with a perfect match between the donor and recipient. After that, the major criterion used to allocate kidneys is the length of time patients have been waiting. Children are also prioritised, and patients with very difficult life-threatening clinical situations occasionally are considered as priority. On average, the one year success rate of a kidney transplant is 92% and, on average, a cadaveric kidney lasts 14 years.

For patients with Type 1 Diabetes it is also possible to receive a combined kidney/ pancreas transplant. You should discuss, with your kidney team, if you think you might be suitable for this.



LIVING DONATION

This is the best solution for the long-term treatment of kidney disease. It provides the best long-term results, in terms of patient and graft survival, and commonly means the patient does not need an extended period of dialysis. The disadvantage is that a live healthy person needs to undergo a very significant operation to have one of their kidneys removed. This procedure carries risks to the donor. These risks include the occasional risk of the donor dying in the process. This is extraordinarily rare but does happen about one in every three thousand procedures. There are a few essential rules that the donor must fulfil before being considered a potential living donor.

- They must be a compatible blood group
- They must be fully informed of the risk and benefits of the procedure, and be willing, of their own free will, to undergo the procedure
- They must be in perfect health
- The final cross match test must be negative.

The potential living donor will have to volunteer themselves and make contact themselves with the Transplant Office phone: 01-8093119. The donor will undergo a very extensive medical and psychological evaluation to determine that they are suitable. This will include a number of special investigations and examinations by an independent doctor.

The one-year success rate of a living donor kidney is about 95% and, on average, a living donor kidney will last 16 years. However, if your donor is a 'perfect match', on average such a kidney will last 28 years.

Please see Book 4 '*Thinking About Donating a Kidney?*'.



TRANSPLANT MEDICINES

Following the transplant, you will need to remain on transplant medicines for the rest of your life. The actual dose that you take will change from time to time, particularly in the early months. After the transplant, they will be rapidly reduced. **If you ever stop taking the transplant medicines, you will lose your transplanted kidney through rejection.**

There are many transplant medicines, such as Prednisilone, Prograf (Tacrolimus) and CellCept (Mycophenolate Mofetil). These medications, while effective, cause a number of side effects.

Steroids can make you gain weight, become puffy around the face, increase your blood

pressure, and sometimes increase the risk of diabetes.

Prograf is a powerful immuno-suppressant. It can, however, make you more susceptible to infections. Other side-effects include skin cancer and other cancers, and in the long-term can cause kidney damage. Your doctor will try to achieve a balance between using the lowest possible dose to avoid rejection, and to minimise the risk of kidney damage and other side effects.

CellCept is also a powerful immuno-suppressant. It has many of the side effects of Prograf, but it does not damage the kidney. It can cause diarrhoea and stomach upset initially.

COMPLICATIONS OF KIDNEY TRANSPLANTATION

- A kidney transplant does not last forever. On average, it lasts 14 to 16 years. If the transplant fails your doctors will aim to put you back on the transplant list for another kidney transplant.
- The transplant operation is a significant undertaking and the risk of dying from the procedure is about 0.03%.
- Infection is an important problem after transplantation. In the first 6 months, you are at risk of developing a viral infection called CMV. If your doctor determines, by a blood test, that you are at risk of CMV, he will prescribe a 3 month course of Valgancyclovir, which is very effective at preventing it. You will also be prescribed a 3 month course of Septrin to prevent you developing a lung infection call Pneumocystis (PCP). Even after the first 3 months there is an increased risk of bacterial infections of the skin, lungs and urine.
- **Cardiovascular Disease.**
After a kidney transplant, you are at a higher risk than the general population of

developing heart disease. Your kidney team will, therefore, take great care to ensure that your blood pressure and cholesterol are kept in the normal range. This may frequently require you to take medications.

- **Cancer**

After a kidney transplant, the risk of most forms of cancer is increased compared to the general population. There are two particular forms of cancer which are of particular concern - skin cancer and lymphoma (a form of cancer of the lymph glands).

Skin cancer will develop in up to 25% of kidney transplant recipients, mostly in sun-exposed skin on the hands and face. This is usually easily treated with local excision or by freezing it. This form of cancer can be dramatically reduced by avoiding sun exposure and wearing high factor sun block.

The other form of cancer that causes concern is lymphoma, which occurs in about 1 in 200 transplant patients (0.5%). This is a serious problem that requires reduction or elimination of immunosuppressant drugs and might also require chemotherapy and radiotherapy.

CHAPTER 8

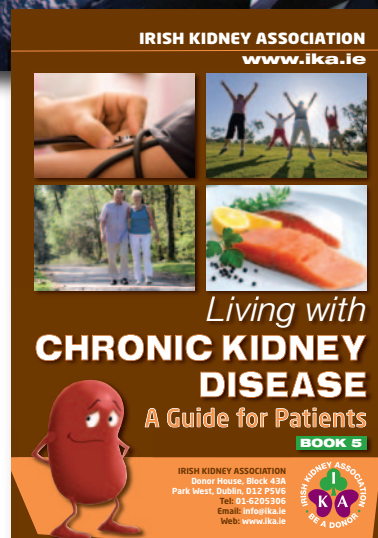
PRE-DIALYSIS SUPPORT AND EDUCATION



The Patient Care Co-Ordinators, along with Ambulatory Care and other members of the kidney team run Education Sessions three times a year in Beaumont Hospital. These sessions are specifically aimed at patients who are at stage 4 to 5 of Chronic Kidney Disease (CKD) (see page 8, Book 1 – *Kidney Disease – A Guide for Patients*) or (page 5, Book 5 – *Living with Chronic Kidney Disease*). The aim of the afternoon is to provide a structured programme of education in an informal environment which focuses on the needs of individuals living with CKD.

A PATIENT REPORTED:

"Good to see other people's concerns and great to talk to people who have been on dialysis..."



The first half of the day is dedicated to short presentations delivered by the different members of the team.

Firstly, the renal Counsellor invites attendees to introduce themselves. Following this, Ambulatory Care discuss functions of the kidney, followed by a nutrition session by the renal dietitian who introduces the rationale of the renal diet through practical means.

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*Olive McEnroe, Ruth O'Malley
and Louise McSkeane,
Ambulatory Care Nurses*



A PATIENT REPORTED:

*"It was informal enough
to be comfortable to ask
questions..."*

A PATIENT REPORTED:

*"It helps to be reminded of the fact that there are
others in the same boat, also that there is always
someone to help."*

The final talk is delivered by the Patient Care Coordinator who discuss their role, along with some practical advice relating to benefits and entitlements, as well as providing on-going support to the patient and their family.

Following a light lunch the second half of the day is dedicated to dialysis options delivered in the form of

workshops.

The group is divided to facilitate further discussion with the relevant support staff working in the different areas of dialysis. The patient will have the opportunity to see the different machines involved in dialysis as well as speak to other patients

who are currently receiving their therapies.

The informal setting of the workshops is of great benefit to the patient and is considered by many to be the most beneficial part of the day.

For more information contact 01-8092730.



L-R): Brenda Groarke, Jane Ormond and Andrea Scully, Patient Care Coordinators

CHAPTER 9

COPING WITH DIALYSIS

Maintaining or returning to good health involves more than medical matters. It involves accepting chronic kidney disease, learning to live with it, and getting on with your life. To adjust to living with kidney disease, you are going to need the help and understanding of your family, your friends, and your healthcare team.

But, the most important person is YOU, the person with kidney disease.

Successfully living with kidney disease takes a positive attitude, a commitment to succeed, and a determination to maintain your usual lifestyle and the results are worth it.

To help you with this process, we are going to discuss:

- Learning to live with chronic kidney disease
- Sexual issues
- Staying healthy and enjoying life

For many people, discovering that their kidneys have failed comes as a great shock. For others who have known, for years, that they have kidney problems, it is perhaps less of a shock. But still, being told you have end-stage kidney disease is never welcome news. It takes time to accept this fact and to adjust to it.

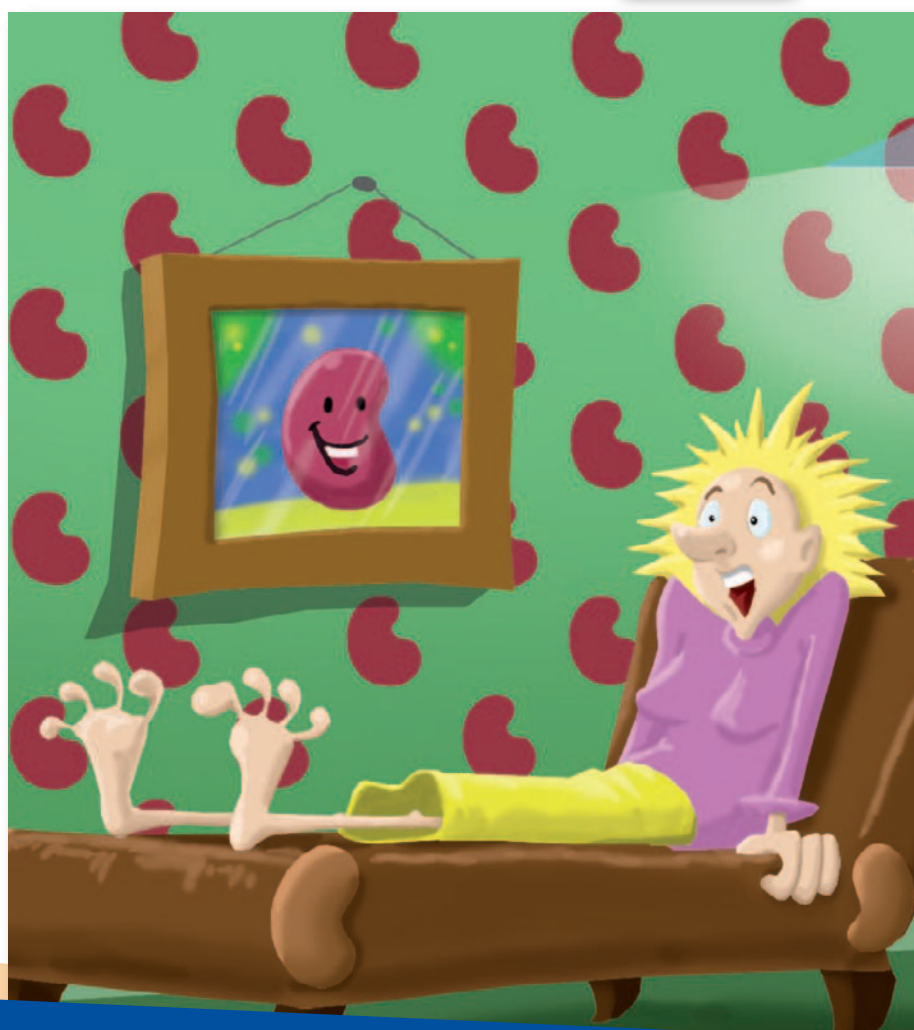
STAGES OF ACCEPTANCE

Many people go through a number of emotional stages after being told their kidneys have failed. Of course, not everyone goes through the same stages, or in the same order. These stages may include denial, anger, bargaining, depression, and acceptance.

Read the following descriptions and see if you recognise any of them. You will be happy to know that, with time, most people adjust emotionally to chronic kidney disease and return to their former outlook on life.

Denial

At first, many people deny they have chronic kidney disease and might need kidney replacement therapy. They cannot believe this is happening to them. Some are convinced that the laboratory has mixed up their blood test with someone else's. For many, this is the first chronic, irreversible disease they have ever had to face, and they are not able to accept it right away.



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The people who have the most difficulty accepting their diagnosis are usually those who have had the least warning. One day they may be feeling fine; the next day they are told their kidneys have failed. That is a big mental hurdle to overcome.

Those who have the least difficulty are usually those who have known for years that this was a possibility and have prepared themselves, emotionally, for this day. With time, most people get over this stage and accept that their kidneys are failing or have failed.

Anger

Anger is a common response for many people when told their kidneys have failed. They are angry at themselves for getting sick or angry at their doctor because the problem was not diagnosed

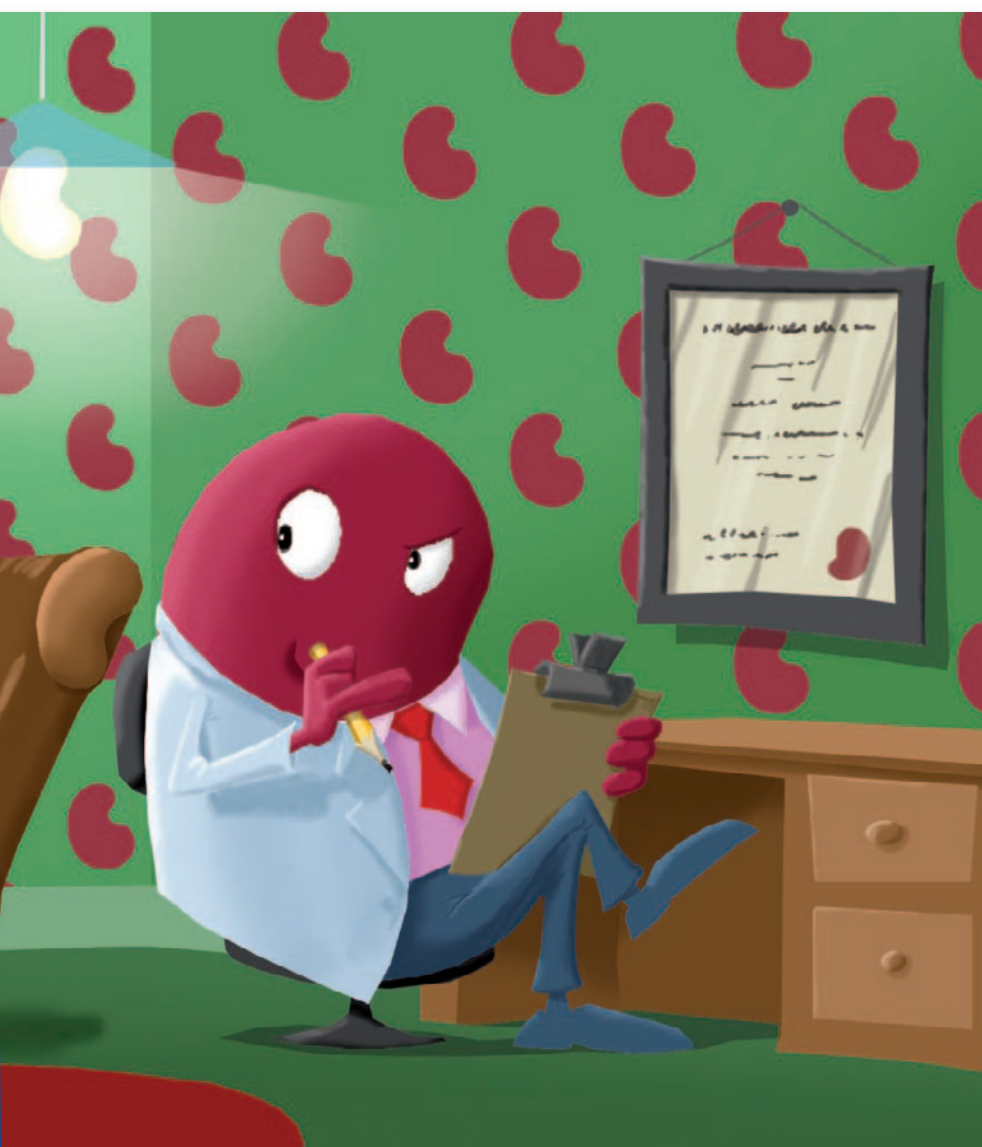
sooner or cannot be cured. Sometimes, they are angry at everyone, including their friends, family and healthcare team, simply because they feel angry.

Of course, no one's really to blame – not you, your doctor or anyone else. There is probably nothing you could have done to prevent the disease, and your treatment would probably have been the same, even if your doctor had diagnosed the problem sooner. This stage does not usually last very long. Anger fades, as you adjust to living with chronic kidney disease.

Bargaining

Most people respond to bad news by trying to bargain their way out of it. So it is not surprising that, when some people are told their kidneys are failing or have failed, they try to bargain their way out of the situation. They promise themselves that if they can have working kidneys again, they will go on a diet, exercise regularly, and give up smoking and drinking. Though these changes are likely to benefit your health, they will not change the diagnosis of kidney disease. Unfortunately, chronic kidney disease is one of those things you cannot bargain your way out of – no matter what you promise.

At this stage, it is often helpful to find out as much information as you can about kidney disease and the different treatments available. There have been recent advances in treatment strategies, for kidney disease, prior to kidney replacement therapy. There have also been advances in dialysis and transplant technology. There are many reasons why you should be able to live a productive and enjoyable life.



Depression

Many people feel depressed when they discover their kidneys have failed. Even after dialysis treatment has started and you are feeling much better physically, the thought of having regular dialysis, might leave you feeling depressed.

You may feel dependent on others for the first time and this may affect your ability to live the life you once enjoyed. Emotional support, from family and friends, may also decrease as the shock of diagnosis fades. You might have difficulty accepting their support or they might not know how best to offer it.

However, with time and increased understanding of kidney disease, people do adjust. Each person has different ways of adapting. However, if depression continues for some time, it is a good idea to speak to your healthcare team because depression can be effectively treated.

Acceptance

Fortunately, most people learn to live with chronic kidney disease. Although they would rather have healthy kidneys, they realise that, with the proper treatment and lifestyle changes, they will be able to live as usual.

Acceptance does not always come quickly or without help. Many people find it useful to talk to someone besides family and friends about their feelings. If you feel you need a person to talk to, do ask a member of your healthcare team to recommend someone. It can make a big difference.

Being told you need to go on dialysis comes as a great shock. People naturally worry about how they are going to cope. Common emotions felt at this time are:

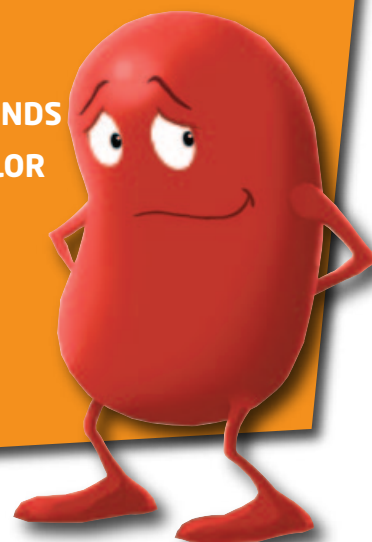
Fear about the treatment, death, the future, the unknown.

Anger "Why did this happen to me?" "It is not fair." "Why now?"

Denial "It can't be true." "There must be some mistake." "I feel fine."

PEOPLE TO TALK WITH

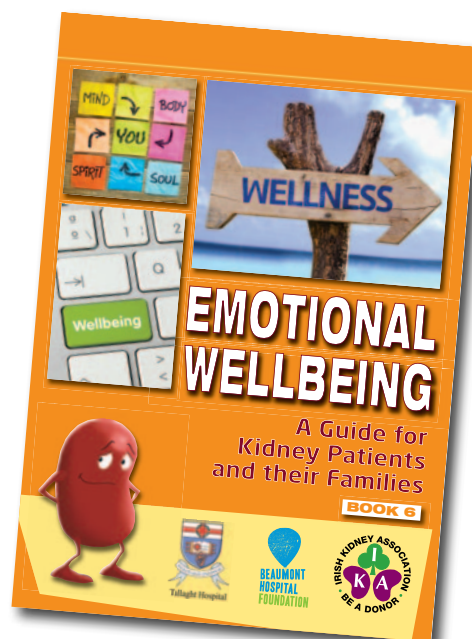
- NEPHROLOGIST
- FAMILY DOCTOR
- FAMILY AND FRIENDS
- RENAL COUNSELLOR
- NURSES
- PATIENT CARE COORDINATOR
- CLERGY
- DIETITIAN



Anxiety about what to expect - prolonged periods of feeling uneasy and finding concentration difficult.

Worry about how the treatment will affect your life, your plans, your future, your family.

While most people will experience some or all of these emotions, the actual experience of being on dialysis is unique to each individual. The good news is that, after the initial shock, most people do come to terms with it and cope effectively in their own way. The more support and help a person has, the easier it is to adjust.



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ADJUSTING TO LIFE ON DIALYSIS

Adjusting to life on dialysis can be achieved by the following:

Educate yourself - Find out as much as you can about dialysis and the treatment options available. Ask questions; the renal team is there to help you. It can be difficult to take it all in at first because there seems so much to learn.

Seek support - Be prepared to talk about how you feel and your concerns. The renal team comprises members who can offer specialist advice and support, and their roles are explained in this book. Counselling is available for both you and your family and can be arranged by speaking to any member of the renal staff.

Maintain relationships - Being on dialysis at first can make you feel 'different' from your family and friends. Remember that they do not know what to expect any more than you do. Talk to them and stay involved with them.

Do not let dialysis take over your life - Yes, changes are inevitable, because adjustments have to be made to facilitate dialysis in your life. However, it does not mean you have to put your life 'on hold'.

Despite the restrictions on your time, stay involved as much as practically possible with your other interests such as family activities, work, education, leisure pursuits.

Try to stay positive - This can seem a difficult task. However, if you work at it, it can be managed. Try to concentrate on what you can do rather than what you cannot. Do things that help you

to relax.

Take control - Take charge of yourself. Familiarise yourself with your treatment, your drugs, and your diet and fluid restrictions. There are prescriptions to keep you well, and if you work with them, rather than fight against them, they will help you cope and feel better.

The Irish Kidney Association - Support from the patients' association is very helpful and it is advisable to join. Even if you cannot actively attend local meetings, you can be informed about forthcoming events and other support services for patients and family members in their quarterly magazine.

Healthy lifestyle - Do not forget the basics. Keeping well means taking care of yourself physically, emotionally, socially and spiritually. Eating well and healthily within your dietary restrictions, getting enough sleep, taking some exercise, getting fresh air and relaxation are all important. Also, not smoking and alcohol consumption, in moderation within the fluid/dietary restrictions, will all help you to cope.

Seek help - If you feel unable to cope talk to a member of staff and consider counselling. Counselling provides a one-to-one confidential opportunity to talk about your problems and receive help to cope. Counselling is available for you and your family.

DO I HAVE TO GO ON DIALYSIS?

Yes, if you want to keep living. However, for some people who may be coping with other serious or chronic illnesses or have a poor quality of life due to illness, the option of dialysis might appear to offer prolonged suffering rather than relief. Dialysis is a treatment choice, not a cure for kidney disease. You have the right to choose not to go on dialysis, or to have dialysis for a trial period, to see how you get on with it. You have the right to stop dialysis if you feel it is not for you.

This is a very difficult decision to make, and one, which affects you and your family. The kidney team is available to discuss all options with you.

GLOSSARY

TERM	DEFINITION
AKD - Acute kidney disease <i>ALSO CALLED</i> AKI Acute kidney injury	A sudden loss of kidney function that is often reversible.
AVF - Arteriovenous fistula	Vascular access for dialysis; joining an artery and vein together.
Anaemia	A shortage of red blood cells in the blood. One of the functions of the kidneys includes EPO (erythropoietin) production. When the kidneys fail, EPO is not made leading to anaemia.
ANCA - (Anti-neutrophil cytoplasmic antibody)	A type of antibody that is associated with vasculitis conditions.
APD - Automated peritoneal dialysis	Also known as CCPD. This is a form of peritoneal dialysis which is carried out overnight.
Arteries	Blood vessels that carry blood from the heart to the rest of the body.
Blood Tests	A blood test that is used to measure many substances in the body to ensure they are within normal/safe range.
Blood Pressure (B/P)	The pressure that the blood exerts against the walls of the arteries as it flows through them.
CAPD - Continuous ambulatory peritoneal dialysis	Infusion of fluid into the peritoneum, prolonged dwell period and then drainage.
Central Venous Catheter (CVC)	Also known as permcath. A catheter with two ports inserted into a major central vein for the purpose of haemodialysis.
Creatinine	A waste substance produced by the muscles when they are used. The higher the blood creatinine level, the greater the indication of kidney disease.
Chronic kidney disease (CKD)	Slow onset of kidney disease which is irreversible.
Dehydration	Not sufficient water in the body to maintain normal function.
Dialysis (HD)	An artificial process, which removes chemical substances and water from the blood, by passing it through an artificial kidney.
End Stage Kidney Disease (ESKD)	Advanced kidney disease.
Erythropoietin (EPO)	Hormone involved in production of Red Blood Cells.
Fluid Overload	The body contains excess fluid. This occurs in kidney disease as one of the functions of the kidney is to remove excess fluid.

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GLOSSARY

TERM	DEFINITION
Graft	A type of access for dialysis. A small plastic tube that connects an artery to a vein.
Haematuria	Blood in the urine.
Hepatitis	An infection of the liver. Can be passed on by blood contact.
Kidneys	Two bean-shaped body organs (approximately the size of your fist) where urine is produced. Functions of the kidney include removal of toxic waste, removal of excess fluid, controls blood pressure helps to produce red blood cells and helps to keep bones strong and healthy.
Nephron	Small filtering unit in the kidney, made up of blood vessels and tubules.
Oedema	A build up of fluid causing swelling, especially ankles and the lungs.
Oliguric	Passing low levels of urine.
PD Catheter	Also known as tenckhoff. A tube that is inserted into the peritoneal cavity for the purpose of peritoneal dialysis. A small operation is required to insert the catheter into the abdomen.
Peritoneum	A natural membrane that lines the inside of the wall of the abdomen and that covers all the abdominal organs.
Peritonitis	Infection of the peritoneal cavity of patients who have a PD catheter insitu. Most episodes are easily treated with antibiotic medication.
Potassium	A mineral that is normally present in the blood. Too much or too little can cause complications.
Semi-Permeable Membrane	A membrane which will not allow certain products to pass through.
Steal Syndrome	Condition where the blood supply to an area has been decreased/minimised.
Subclavian Vein	Large vein positioned behind the collar bone.
Transplantation	The replacement of an organ that is not working in the body with another donor organ.
Tunnel Infection	An infection that occurs when an exit site infection spreads into the tunnel of the catheter.
Ultrafiltration (UF)	Removal of excess water from the blood during dialysis treatment.



Contact Numbers

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

Useful Information Websites

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

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Kidney Dialysis Centres

BBraun Wellstone, Galway

Tel: 01-709 1844

BBraun Wellstone Midlands Renal Care Centre, Portlaoise, Co. Laois

Tel: 01-709 1880

BBraun Wellstone, Wexford

Tel: 01-709 1830

Beaumont Hospital, Dublin

Tel: 01-809 3000

Beacon Renal, Sandyford Dublin

Tel: 01-906 5628

Beacon Renal, Tallaght Dublin

Tel: 01-906 5624

Beacon Renal, Drogheda Dublin

Tel: 041-972 0111

Cavan General Hospital

Tel: 049-437 6032

Cork University Hospital

Tel: 021-492 0883

Daisyhill Hospital, Newry

Tel: 0044-28 3756 2407

Limerick Regional Hospital

Tel: 061-482 377/482 400

Mater Misericordiae Hospital Dublin

Tel: 01-803 2400/803 2405

Mayo General Hospital

Tel: 094-904 2414

Merlin Park Hospital, Galway

Tel: 091-775 575/775 574

Nephrocare Kilkenny

Tel: 056-778 3030

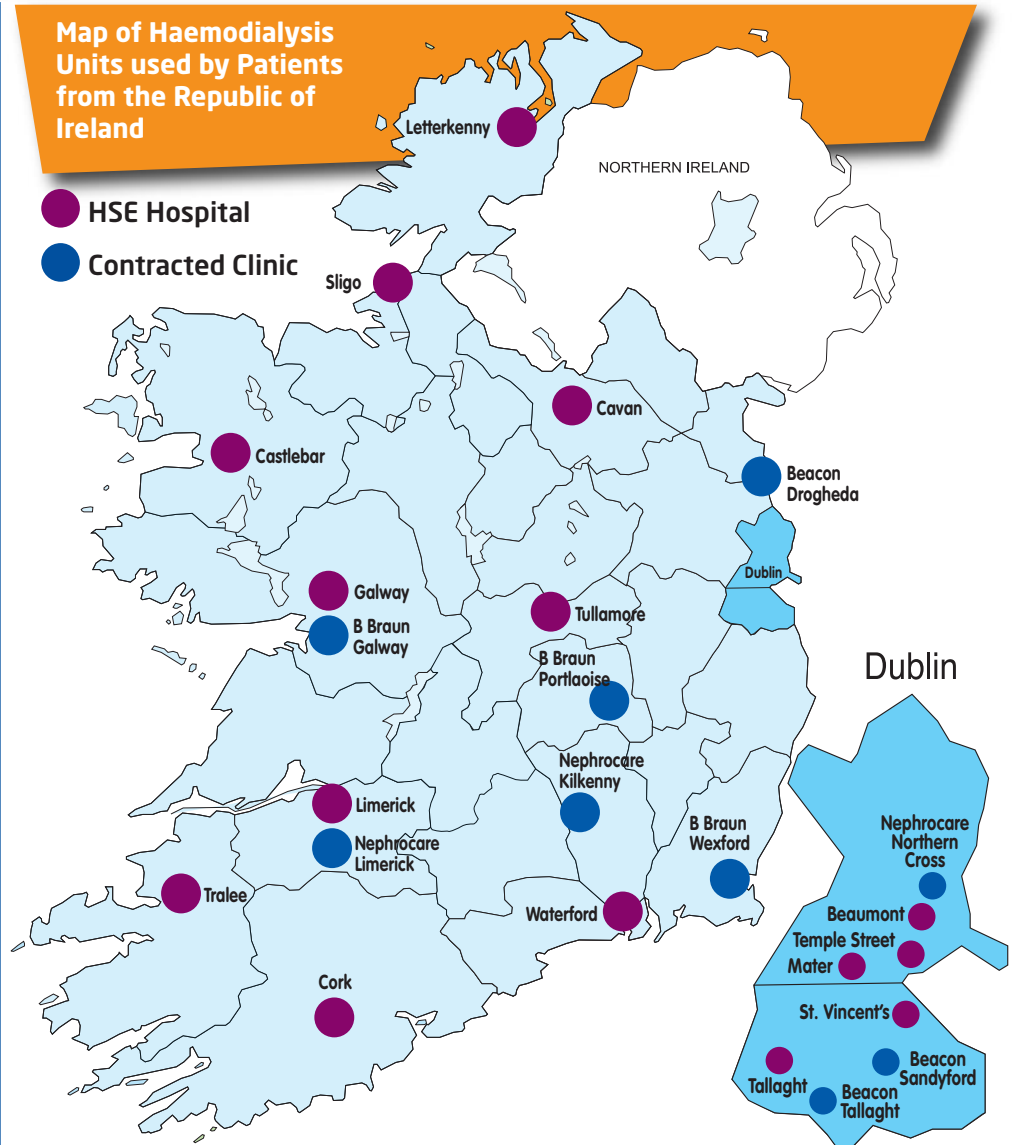
Nephrocare Dock Road Limerick

Tel: 061-498 040

Nephrocare Northern Cross Dublin

Tel: 01-866 1314

Map of Haemodialysis Units used by Patients from the Republic of Ireland



Letterkenny General Hospital

Tel: 074-912 3544

Our Lady's Children's Hospital, Crumlin, Dublin

Tel: 01-409 6029/409 6948

Sligo General Hospital

Tel: 071-917 4598

St. Vincents University Hospital Dublin

Tel: 01-221 4427/221 3089

Tallaght Hospital, Dublin

Tel: 01-414 2358/414 2350

Temple Street Children's Hospital, Dublin

Tel: 01-878 4757

Tralee General Hospital

Tel: 066-718 4330 / 718 4090

Tullamore Regional Hospital

Tel: 057-935 8743 / 935 58740

Tyrone County Hospital, Omagh

Tel: 0044-28-828 33320

University Hospital Waterford

Tel: 051-842 753

IRISH KIDNEY ASSOCIATION RENAL SUPPORT CENTRE

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

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



FACILITIES

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



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

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

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

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



For further information contact:

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

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

Email: renalcentre@ika.ie

Tax relief on medical expenses incurred by kidney patients

In the interests of making the tax system more user friendly the Revenue no longer requires a Med 1 form to be completed. Instead, taxpayers looking to reclaim tax on medical expenses do so by completing an income tax return.

This can be accessed online through "my account" on www.revenue.ie and involves the following steps:

- Click on "review your tax" link in PAYE services
- Request a statement of liability
- Click on "complete Income tax return"
- In the "tax credits and reliefs" page select "health and health expenses"
- Complete and submit the form

Qualifying health expenses to the extent that they are not covered by health insurance can be claimed at the standard rate of 20%. The following are considered to be qualifying:

- Doctor and consultant services
- Drugs and medicines
- Physiotherapy or similar treatment which includes chiropractor, osteopath or bone setter.
- Special diet expenses for diabetics

To qualify the health care must be carried out or advised by a registered practitioner such as a doctor or dentist. Relief is not allowed for routine dental care or eye tests.



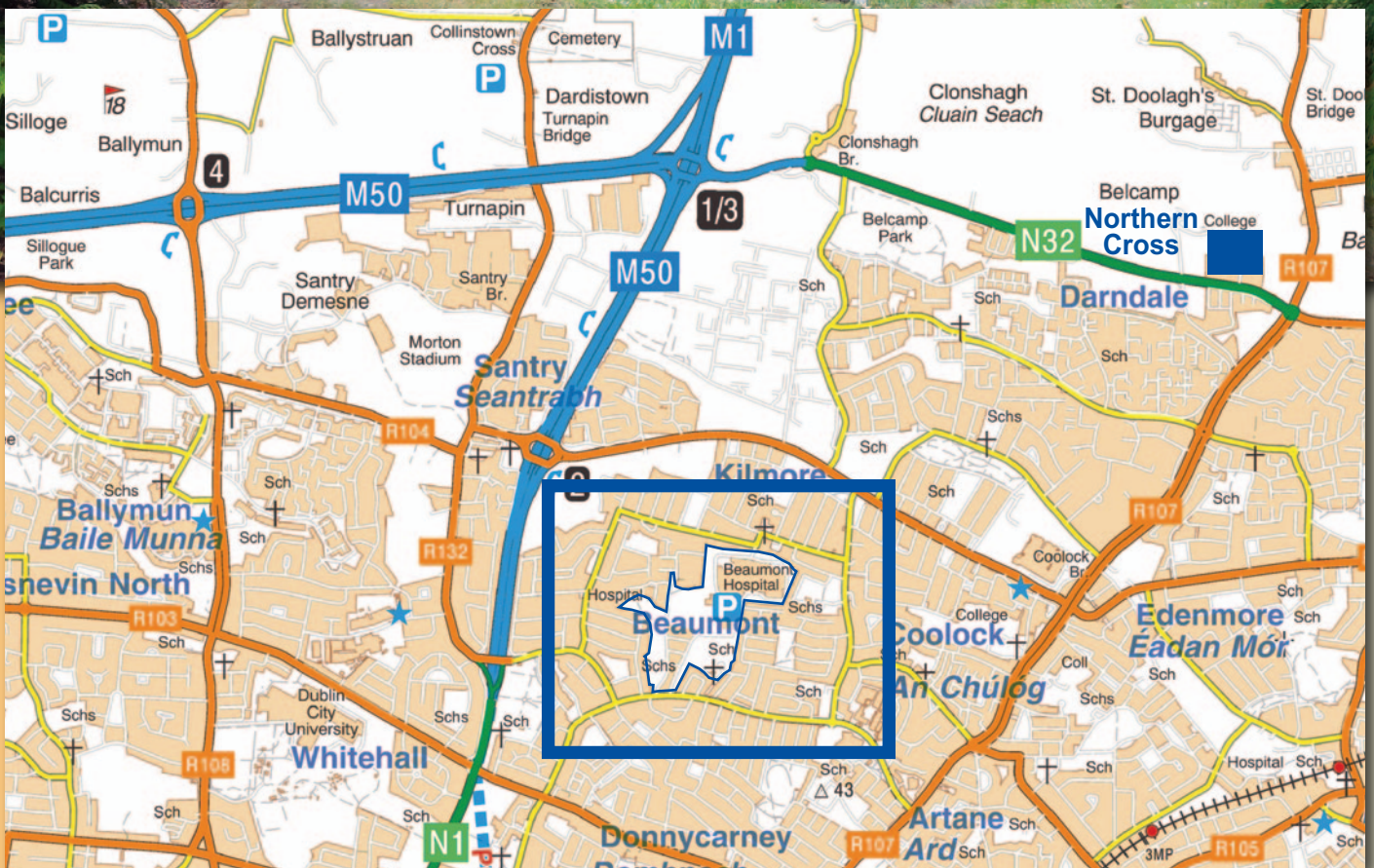
In addition, the following reliefs apply to kidney patients:

- Travel for dialysis. Travelling to and from hospital for dialysis can be claimed at €0.29 per mile or €0.17 per kilometre. This allowance does not apply where a claim has already been made from the HSE
- Home dialysis where the patient uses an APD or haemodialysis machine at home. Here relief is allowed up to €1,900 for electricity, €1,945 for laundry and protective clothing and €310 for telephone
- Chronic Ambulatory Peritoneal Dialysis (CAPD) where the patient has treatment at home without the use of an APD machine. Here relief is allowed up to €1,505 for electricity and €310 for telephone

Relief can be claimed for past qualifying expenditure going back four years.

A full list of all allowances and reliefs can be found at www.revenue.ie or by contacting Gary at Email: gary@ika.ie or go to <https://www.revenue.ie/en/personal-tax-credits-reliefs-and-exemptions/health-and-age/health-expenses/index.aspx>

Beaumont Hospital



Contributors

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

Prof. Peter Conlon, Petrina Donnelly, Helen Dunne, Annmarie Casey, Noreen Casey, Sheila Donlon, Nora McEntee, Johanna McWilliams and Dr. Darren Pachaippan

Cartoons and Illustrations:

KegKartoonz (Noel Kelly), Jazz Communications Ltd., and www.netterimages.com

Also, to the patients and staff who took time to contribute to editing this book.

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



BEAUMONT HOSPITAL FOUNDATION

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Phone: 01-8092161

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