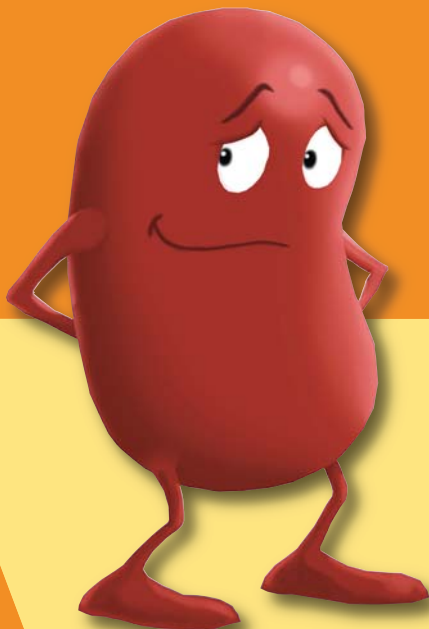




# EMOTIONAL WELLBEING

A Guide for  
Kidney Patients  
and their Families

**BOOK 6**



**THIS BOOK WAS FUNDED BY:**

**Irish Kidney Association**

**Beaumont Hospital Foundation**

**Trinity Health Kidney Centre, Tallaght Hospital**



*The information contained in this book is correct at time of going to press. This book should be used as a guide and reference tool only - always speak to your doctor if you have individual concerns.*

© This book has been produced by the **Irish Kidney Association, Beaumont Hospital Foundation** and **Trinity Kidney Health Centre**, and, save where otherwise specified, the content of all pages is copyright to them. No matter may be reproduced or stored in any way without the written consent of the Editors.

*The book has been printed and distributed by the Irish Kidney Association. Further copies are available from IKA, Donor House, Park West, Dublin 12. Ph: 01-6205306.*

# INTRODUCTION



**T**his is the sixth book in a series of six, the previous books having focused on helping patients deal with the physical aspects of chronic kidney disease, and how kidney disease is managed medically.

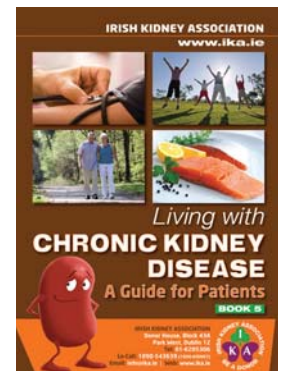
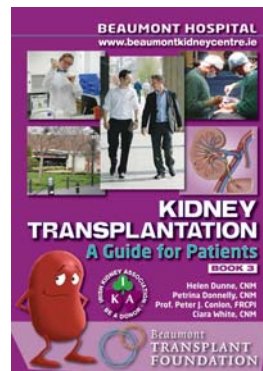
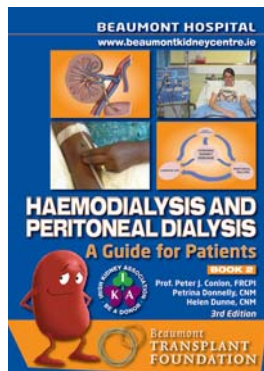
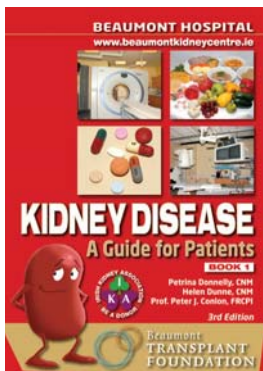
The aim of this book is to help patients and families maintain their emotional health in the face of what can be a serious illness.

You will read about reactions to your diagnosis, impact of illness within families and relationships, managing stress and anxiety, to mention just a few of the chapters. This book will also point the direction to resources and services that can help you cope with your illness.

This book was written by an inter-agency group of professionals, who all work daily with the psychological aspect of illness, and because of this, it brings great wealth to the series of books available to kidney patients and their families.

I would encourage you to read this through as you feel the need, and hope that it brings benefit to you and your family.

**Professor George Mellotte**  
**Consultant Nephrologist**  
**Tallaght Hospital**



**The information in this book was compiled and written by:**

**Mike Kelly**, Co-ordinator of Counselling Services, Irish Kidney Association

**Vicky Fourie**, Social Work Team Leader, Renal Medicine, AMNCH

**Margaret Hanna**, Renal Counsellor, SRN, Beaumont Hospital

**Tara Power**, Senior Medical Social Worker, Beaumont Hospital

**Diane Gillan**, Psychologist, Beaumont Hospital

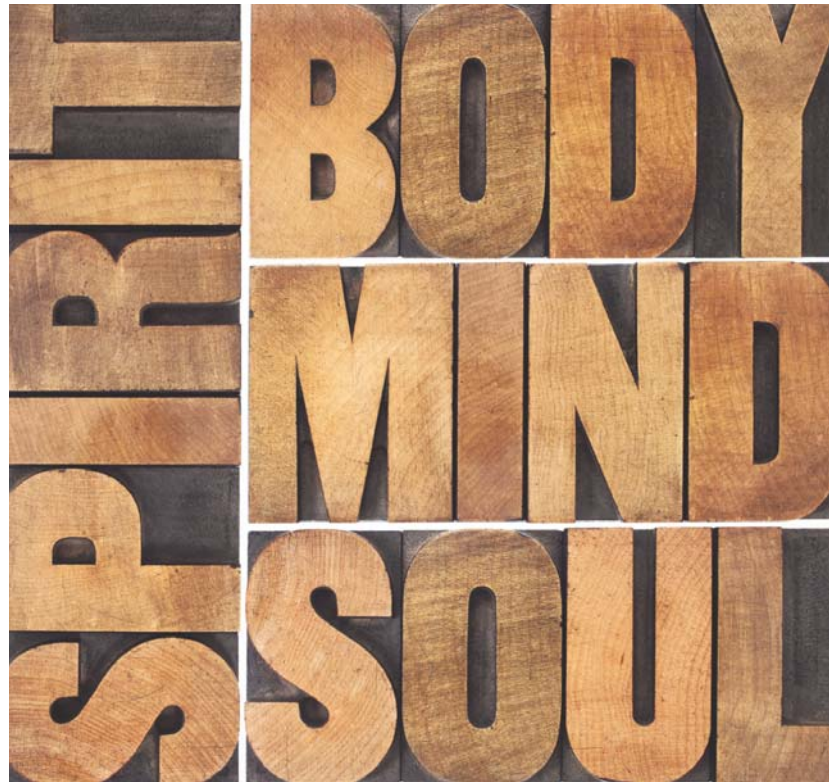
## ACKNOWLEDGEMENTS

We would like to acknowledge and thank **Evelyn Casey, Paul Holmes, Alison Larkin** and **Ciara Casey**, and all who have shared their experience and thoughts with us over the course of our work with them, much of which informs and enriches this publication.



# CONTENTS

- 3** **FOREWORD**  
By Dr Siobhan McHale
- 4** **CHAPTER 1**  
Common reactions to diagnosis
- 6** **CHAPTER 2**  
Becoming a self-manager
- 11** **CHAPTER 3**  
Communicating with your healthcare team
- 13** **CHAPTER 4**  
The impact on families
- 15** **CHAPTER 5**  
Talking to my children/grandchildren
- 17** **CHAPTER 6**  
Fatigue
- 18** **CHAPTER 7**  
Body image
- 20** **CHAPTER 8**  
Sexuality



- 22** **CHAPTER 9**  
Stress and anxiety
- 26** **CHAPTER 10**  
How do I ask my family or friends for a kidney?
- 29** **CHAPTER 11**  
Adjusting to life with a kidney transplant
- 32** **CHAPTER 12**  
Dialysis or no dialysis

# FOREWORD



It is with great delight that I welcome such a valuable addition to this well-established series of information books for patients who are living with Chronic Kidney Disease (CKD), and their families. Living a healthy life with any chronic illness requires courage, stamina, enhanced self-management skills and good relationships with health care givers. Add to this the particular demands of chronic renal failure, with associated challenges ranging from adjusting to the rigors of dialysis, to waiting for the phone to ring to say a suitable kidney is available, and it is clear that providing support for the associated emotional journey is important to integrate in all areas and stages of renal care.

The emotional and mental health demands of CKD and/or transplantation are considerable. Patients who have already endured chronic ill health have an unpredictable wait for a donor organ, during which time they face a significant decline in health. Once a donor is found, they are confronted with a major surgical procedure. They must then commit to a life-long regime of immunosuppressive medication and be perpetually vigilant to symptoms of possible infection or graft rejection. Many transplant recipients have significant difficulties adapting to life post-transplant, particularly the major adjustments which may be required in marital, family and occupational roles.

In a minority of patients, the stress of living with Chronic Renal Failure and/or transplantation can trigger psychiatric disorder, most commonly depression, anxiety or adjustment disorders. Depression can lead to problems such as poor appetite, weight loss, withdrawal, lack of motivation and poor compliance with medical treatment, which can increase the risk of physical complications.

The importance of supporting patients with these co-morbid, treatable health conditions cannot be underestimated. We now have excellent interventions available to treat these disorders, both in helping to develop more adaptive coping strategies around lifestyle management, along with medication if needed. No patient should have to cope with additional suffering that can be alleviated by good multidisciplinary team care.

This book has been developed by experts in the field. It encourages communication of the important emotional factors intrinsic to this challenging journey. Along with helping patients, carers and staff to accept that all significant health problems have both a physical and mental health component, it encourages a language around acknowledging this to ones self, sharing it with others and finding strategies to help manage difficulties. We know that this improves not just the patient's quality of life but has direct implications for improving physical and mental health outcomes.

**Dr Siobhan MacHale**  
**Consultant Liaison Psychiatrist,**  
**Renal Transplant Team, Beaumont Hospital**

# CHAPTER 1

## COMMON REACTIONS TO DIAGNOSIS



**P**eople use different words when they are first told their kidneys are failing and that dialysis (renal replacement therapy) is required. Some describe it as a “shock”, others as a “blow” or as a “bolt out of the blue”.

Whatever word or phrase is used it indicates an emotional reaction to unexpected news. This causes an emotional change which is a normal reaction when ‘bad’ news is received.

### HOW DO PEOPLE RESPOND EMOTIONALLY?

*Each person is different but the more common responses are:*

#### **DENIAL**

A common expression of denial is “I don’t want to think about it”. While this may have some advantages as a short-term strategy, if it persists for a long period it becomes detrimental to your health, both physical and emotional.

#### **ANGER**

A common and normal reaction. Anger can be both positive and negative. Its positive face allows you to harness energy that can help you respond in a healthy way to diagnosis. In its negative form it can be quite destructive and can affect behaviour.

Unhealthy anger can alienate those nearest and dearest to you. Another common unhealthy expression of anger is missing hospital appointments or not adhering to medication or diet.



## FEAR

A very common reaction which manifests itself in many different ways: fearing I am going to die, fear of losing control, fearing loss of independence, and a growing perception that life is getting worse. Fear can paralyse as you move from what is known and certain to what is unknown and uncertain. Fear can bring about a sense of powerlessness, making it hard to know where to turn or what to do.



## DEPRESSION

Why do some people become depressed? There are many reasons, and a diagnosis of kidney disease may be one of them.

When depressed you withdraw into a world perceived as safe and secure. It is your way of coping with a feeling of unbearable loss. It leads to distance, isolation and fear of engaging with others.

If the depression is mild it may act as an aid to adjustment to this new situation. However, if it becomes long-term and pronounced or if you experience suicidal thoughts, medical advice or counselling should be sought.

### HOW LONG WILL THESE REACTIONS LAST?

*Each person is an individual with a unique history and experience. People move in and out of moods, sometimes quickly, sometimes it takes longer. Some just 'get on with it', while others become stuck and need emotional support to move on.*

## SOME PEOPLE...

*Have a sense of relief that a diagnosis has been made.  
Know that treatment is available.*



# CHAPTER 2

## *Coping with Chronic Kidney Disease (CKD)*

# BECOMING A SELF-MANAGER

**A**djusting to a diagnosis of chronic kidney disease (CKD) can be an overwhelming experience, resulting in people facing a wide range of emotions: anger, frustration, shock, fear, upset or depressed mood among other feelings, all of which are normal. Reactions run from the mild to the severe in people. Many people also experience changes in their roles at work, in their family or in their social life.

At first you may notice that a lot of energy will be directed toward your treatment and physical health. But looking after your emotional well-being is just as important as looking after your physical health. You can live a satisfying life with CKD, just as millions of people around the world are doing at present. To live well with CKD, it is important to care for both the physical and emotional changes that you may experience. Once you adapt more with your illness, you may learn to be proactive about your well-being, and go on to experience a new "normal life", filled with activities and enjoyments that make you feel emotionally fulfilled.

*Here are some strategies to help you move forward and live well with CKD and become a self-manager*



### **EMPOWER YOURSELF**

Empower yourself by being proactive and educating yourself about CKD and how to manage it.

Knowledge is power. Ask questions, the renal team will be happy to help you.

### **SET REALISTIC GOALS AND PLANS**

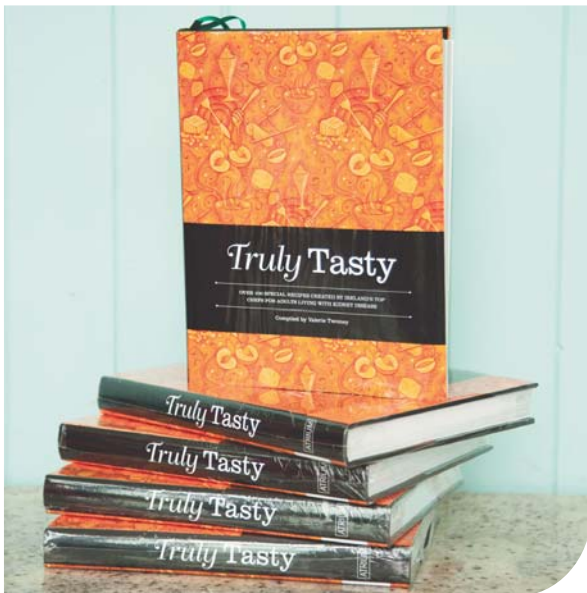
Be patient and set realistic goals in adjusting to CKD. Try not to let dialysis take over your life. Deciding on specific, achievable goals can give you a sense of purpose and control over your life that is important for living well with CKD. Keeping these objectives in mind can help you get through the more difficult times and motivate you to keep moving forward in a positive way even when difficulties arise. If you are not able to return to your job, ask a social worker about occupational or educational options.





## MAINTAIN A HEALTHY ATTITUDE

This may be difficult at times, but it is important to stay hopeful, optimistic and keep your sense of humour. **Focus on what you can achieve or enjoy rather than on what you cannot.** However, there will be times when it is helpful and necessary to express frustration, upset or anger, and this may be what you need to do to move forward. Healthy adjustment sometimes involves accepting that you will not be able to change aspects of your situation. In these circumstances the best approach is to learn to change your response to the situation. Talking to the right person, whether friend, family member or professional, often helps to sort out your feelings around troubling issues, and they can help you find a way to adjust more easily in times of stress.



### HEALTHY LIFESTYLE

Make sure to eat a kidney friendly diet and be mindful of the renal team's advice regarding dietary restrictions. Maintaining a good sleep pattern will also enhance overall well-being.

### KEEP ACTIVE

Stay active as much as possible and be guided by your doctor's recommendations. We all know that exercise has great benefits for the body and mind, including boosting mood, strengthening your immune system and improving your overall health.





## KEEP UP INTERESTS AND ACTIVITIES

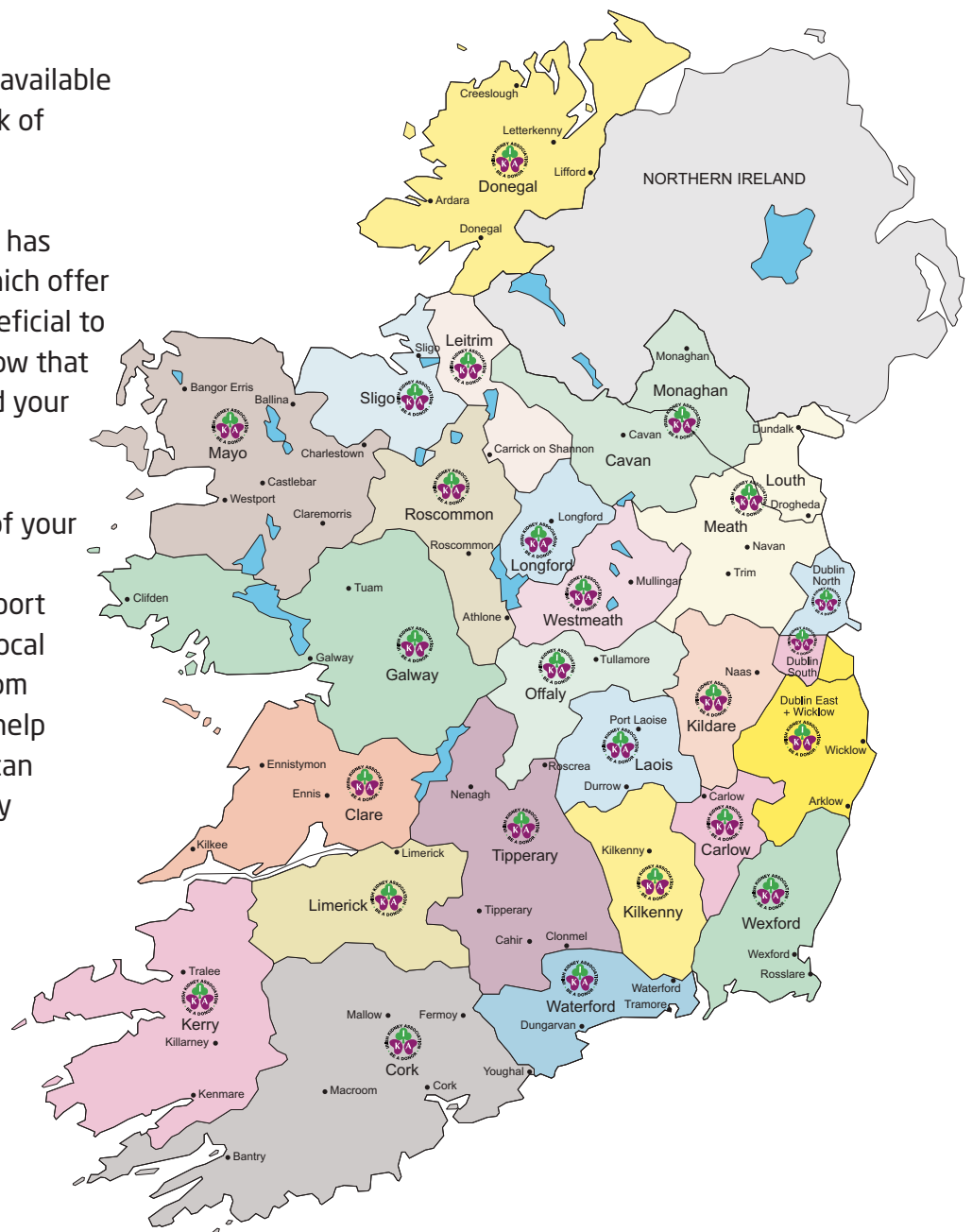
As much as possible, keep up your normal routines, interests and activities such as socialising, going for walks, visiting friends, fulfilling family obligations and relaxing. See yourself as a whole person with values, interests and passions, not just someone who has CKD.

## SEEK SUPPORT

There are support networks available for you besides your network of health professionals.

The Irish Kidney Association has branches in every county which offer support and it would be beneficial to join. It is often helpful to know that others share and understand your situation.

You can also ask a member of your healthcare team to give you suggestions as to other support groups or networks in your local community. Seek support from family and friends who can help out with practical issues or can provide emotional support by listening.



*Seek support  
from family  
and friends who  
can help out with  
practical  
issues*



## TAKING CARE OF YOURSELF

Make sure you take time out of your day to relax and reflect on your day. There are stress management techniques such as muscular relaxation, controlled breathing and mindfulness meditation exercises available on the website for the Mindfulness and Relaxation Centre (MARC) at [www.beaumont.ie/marc](http://www.beaumont.ie/marc)

And do not forget to treat yourself to something nice every once in a while.



## WATCH FOR NEGATIVE THINKING

We all have beliefs and patterns of thinking that are unhelpful or self-defeating, e.g. an overly negative focus that ignores or misinterprets the positive of a situation. You may also tend to focus more on your limitations rather than your strengths. This style of thinking filters out the positive and leaves you seeing only the negative which in turn can make you feel sad, helpless or frustrated.

These negative beliefs or biased thinking can be challenged and discussed with the support of a counsellor, particularly when they become troublesome or overwhelming. The way to address self-defeating ways of thinking is to become aware of them. This can be difficult at first as these thoughts are often automatic and we are often

unaware they are happening.

The next step is to gently challenge these biased thoughts by using realistic 'self-talk' e.g. *"OK, so I've been feeling really tired most days and I feel like everything is going wrong, but maybe I'm ignoring the fact that there are times I have felt good and I've actually made small progress with my energy levels"*.

There are self-help booklets for all kinds of emotional issues available on...

[www.getselfhelp.co.uk](http://www.getselfhelp.co.uk) or  
[www.helpguide.org](http://www.helpguide.org)

Alternatively, sitting down with a psychologist or therapist could be an option if you wanted help in examining your thought processes in more detail.



**People draw support from many places, healthcare professionals, family and friends**



## KNOWING WHEN TO SEEK PROFESSIONAL HELP

Adjusting to CKD and its treatment can be difficult, particularly in the early phase after diagnosis. There may be a natural process of grieving for the “old” you and your previous lifestyle. It is not a sign of weakness to seek professional therapeutic support. Some treatment centres have access to therapeutic support, for example; counsellors, psychologists, social workers. For those units where such services are not available, the Irish Kidney Association (IKA) provides a counselling service accessible in the person’s local area.

There are many issues that might warrant professional help, including but not limited to the following issues: relationships, high levels of anxiety or worry, persistent low mood, irritability or hopelessness, loss of interest in activities you used to enjoy, or difficulties with substance abuse.



## CHAPTER 3

# COMMUNICATING WITH YOUR HEALTHCARE TEAM

**H**ave you ever left an appointment with your healthcare professional and wished you had asked certain questions? Or have you felt that you have not been understood or you did not understand fully what the healthcare professional was trying to say?



Poor communication between a healthcare professional and their patient can lead to a number of emotions such as frustration, anger and hopelessness. It can contribute to misunderstanding, isolation and difficulty following your treatment plan.

Good communication can help create trust and promote the sharing of information, and it encourages discussion with the result that the patient feels more informed and in control and more likely to participate in their medical care.

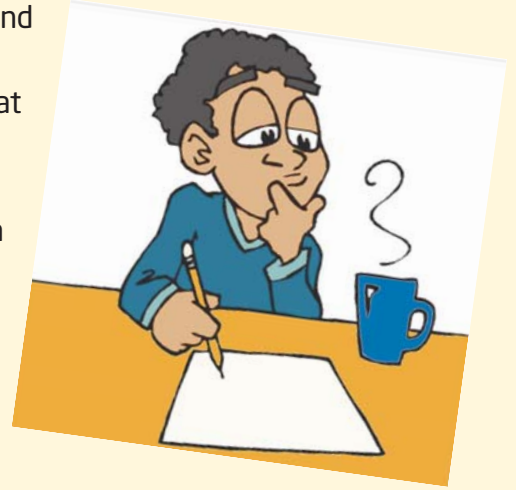
### **WHAT CAN I DO TO PROMOTE GOOD COMMUNICATION?**

Many healthcare professionals are under tight time schedules, so in order to use the time spent with them most efficiently, we suggest some of the following:



## PRIOR TO YOUR APPOINTMENT

- **Write** a list of questions/concerns that you want addressed and prioritise those you wish to discuss.
- **Record** your symptoms, when they occur, for how long, what makes them better or worse.
- **Bring** a list of your medications and the dosage.
- **Invite** a family member/friend to accompany you to act as a second listener. Give them your list of concerns, so they can prompt you if required.
- **Understand** your family may also have questions themselves.
- **Bring** something to read, if you have to wait for your appointment.
- **Inform** your healthcare professional if you have any language, literacy or vision/hearing problems, so they can accommodate you. Tell them in advance if you need an interpreter.



## DURING THE VISIT

- Make notes of the most important issues/action plan.
- Keep the discussion focused.
- Seek clarification if you do not understand any part of the discussion. This clarification can help correct misunderstandings/ miscommunication.
- Be honest about how you feel, particularly if you are having difficulty sticking to your treatment plan. Sometimes you may feel frightened or unsure. Discussing your feelings and asking questions may help you prepare for treatment or ease your worries. This may help to clarify expectations and help you feel more in control.
- If you do not understand any medical term that the healthcare professional uses, ask them to use lay person's terms.
- Tell your healthcare professional if you are unable or do not want to follow their advice /treatment plan. They may be able to provide you with an alternative treatment plan, which will fit with your values and daily habits.

*Remember it is in your best interest to develop the skills to ensure that the communication with your healthcare team is as effective as it can be*

*Good, clear, open communication is the cornerstone to building a trusting partnership between you and your healthcare team*

- At the end of your visit ensure you are clear with regards to what will happen next. Example: when is your next appointment? What symptoms should you watch out for?
- Before you leave you may wish to briefly repeat back to the healthcare professional some of the key points of the discussion to ensure you understood.
- Ask your healthcare professional to write down any instructions or recommend any reading.
- If you feel you need support around other issues which may be impacting on your ability to cope with your illness, ask for extra support. Your healthcare professional may be able to refer you to a counsellor, psychologist or social worker for support around emotional, practical, financial, and other issues etc.



## THE IMPACT ON FAMILIES

**A** diagnosis of a chronic condition, like kidney failure, affects not only the person diagnosed but also the family. Families can find themselves thrust into a new, unexpected and often unprepared for role: that of carer. What level of care will be required will differ from individual to individual. For some it will be minimal, for others it will be significant. Either way it will impact on family life. One carer put it this way; **“Every carer’s story is different but the experiences can be similar.”**

### DISRUPTION TO THE RHYTHM AND ROUTINE OF FAMILY LIFE

Every family has a particular routine when it comes to the more common illnesses experienced on a regular basis (e.g. colds, flu). People adopt roles such as carer, helper or provider. As these illnesses are of short duration the impact on family life is minimal. Not so when the illness is chronic. It may introduce significant and long-lasting changes to family life.

Hospital appointments or admissions, frequent visits to the pharmacy, increase in medication and changes in diet all have to be factored in to the family routine. If the person diagnosed can no longer work due to illness, it may involve a change in family roles with the husband/wife or partner having to find employment. Children may find themselves taking on additional roles within the family, roles not anticipated or expected.

### BREAKDOWN IN COMMUNICATION

Following diagnosis communication can be the first thing to be affected. Family members may find themselves inhibited in what they can say.



Often their fears and worries are kept to themselves out of fear they will further ‘upset’ the person diagnosed or further disrupt the family structure. Family members either do not know what to say, or feel they cannot say what they feel. Rather than express their concerns or worries, a silence descends resulting in communication becoming more problematic and difficult.

### THE INITIAL SHOCK OF DIAGNOSIS

With diagnosis and the shift for some into the role of carer, the realisation gradually dawns that life is never going to be the same again. Plans and dreams, hopes for the future may now look different. At this initial stage support and help may come from many quarters but as the caring or supportive role continues or increases, the level of support experienced may diminish.

Stress levels can be very high at this initial stage with the predominant emotions experienced of; fear, shock, anger, loss and anxiety. Family members often find they put their lives on hold in

order to care for the person diagnosed. While understandable at an early stage it is not advisable that this should continue long-term. The family member needs to care as much for themselves as the person diagnosed, otherwise they run the risk of carer fatigue or burnout.

## KEEPING THE BALANCE BETWEEN DOING AND NOT DOING

One of the temptations many family members give in to is to do too much for the person they are supporting or caring for. This is often done out of concern but it has two major pitfalls. Firstly, it renders the person being supported redundant as if they feel useless and dependent. Secondly, in time, the family member can become resentful at the lack of initiative or effort of the person they are supporting. This resentment contributes to carer fatigue making caring unsustainable in the long-term.

Even though caring or supporting can be demanding and difficult it is important to acknowledge that it also can be rewarding and life enhancing. For this to occur two things have to happen.

## ADJUST TO THE REALITY

This may eventually happen in time but the road towards adjustment can be long and difficult. To achieve it may involve seeing the

person they are supporting in a different light. It includes enabling the person to do what they can. With time the family member will develop their knowledge and skills to enable them to care in a way that keeps a balance between the needs of the person being supported and of the needs of the family member themselves.

Family members should seek support and help when they feel they need it.

*Family members should seek support and help when they feel they need it.*

## SEEING CARING FROM A POSITIVE PERSPECTIVE

Often this revolves around three elements.

- **Acting** as a unit. In this case adjustments or changes are made in tandem with the person diagnosed. The person feels included and the family member feels their needs are also taken into consideration.
- **Mutual support.** In this case it is the person diagnosed who offers support and care thereby creating an atmosphere where both parties support each other.
- **Carer's personality,** that is, the growing belief that they can cope even though they were uncertain whether they could or not.



***All the support services listed at the back of this book are accessible for families too. Alternatively most treatment centres are happy to support you also or link you to a local support service.***

# TALKING TO MY CHILDREN/GRANDCHILDREN

*Children often 'know' that things are changing for a parent or grandparent without being told*



**W**hen you start trying to adjust to your illness often your reaction is to protect your children from upset. It can be hard to know whether you should tell children about your illness or what and how much to tell them.

Even though you know your children or grandchildren best, you may be surprised at how well they deal with the news. We cannot stop children from feeling sad at difficult news. However by giving them information and helping them understand their own reaction we can support them.

Children often 'know' that things are changing for a parent or grandparent without being told. For that reason it is important that they do not feel

isolated by the lack of conversation around the changes that they see or hear about. Children who are included in what's going on are less likely to have problems adjusting to your illness, though it may still be hard learning to adjust.

### **WHEN SHOULD I TELL THE CHILDREN/GRANDCHILDREN?**

You may need to come to terms with the news yourself before you talk with your children. Often there is not a right time. Children can feel more included in the treatment plan if they are informed in the early stages of the illness. A good time to talk with them is before some obvious change occurs, like significant fatigue, hospital admissions or commencing dialysis.



## WHO SHOULD TELL MY CHILDREN/ GRANDCHILDREN?

The information should come from someone who is close to the child, you or your partner or a close relative.

## HOW CAN I TELL MY CHILDREN/ GRANDCHILDREN?

This can take some time and thought, and it can help to rehearse what you are going to say. Try to use the most clear and simple explanations possible; it can help to link the information with things they have already observed or been told.



## WHAT SHOULD I TELL MY CHILDREN/GRANDCHILDREN?

- Use the correct words for the illness, e.g. renal or kidney failure, dialysis.
- Explain how your health may be affected, e.g. tiredness, feeling sick sometimes, needing dialysis.
- Give some information on how the treatment works in simple, clear language.
- Reassure them about their daily routine and that as a family you will all continue to make each day as good as it can be.



In talking with your child or grandchild about your illness you are trying to remove some of the mystery, and for some, the fear that they can associate with illness and hospitals. You can do this through conversation, allowing them to ask questions, and at times, showing and explaining the dialysis machines to them.

For those doing home dialysis it is important the children get to see the dialysis machine and have it explained to them in language they can understand. For haemodialysis patients, older children could be invited to attend the unit and a dialysis session. With the support of a healthcare professional, or just on your own, children can have comforting and helpful conversations about what renal disease is and how the dialysis treatment works.

**If you feel you would like help talking with your children/ grandchildren, then ask for support from a member of your healthcare team.**

# CHAPTER 6

## FATIGUE

**A**s a kidney patient one of the symptoms you experience is a profound feeling of fatigue or tiredness. This fatigue can significantly affect your capacity to complete tasks, tasks that were completed without effort in the past.



### WHY DO I FEEL SUCH FATIGUE?

Many people diagnosed with kidney disease suffer from fatigue. Anaemia is one possible reason your body is not producing sufficient red blood cells. Red blood cells have a very important role in that they carry oxygen around our body. When your blood cell count is low symptoms include; fatigue, breathlessness, irritability, poor appetite and a reduction in your sex drive.

### HOW WILL THIS FATIGUE AFFECT ME?

All of us know that when we are tired or fatigued we become less patient and more irritable. Our normal way to reduce our levels of fatigue is through rest. However, what happens if the fatigue we feel is permanent, never ending and something that has to be battled on a daily basis?

You have probably said on more than one occasion: "I feel so tired ALL THE TIME". You may find your emotions are more raw and you may experience mood swings, irritability, anger and frustration, as it becomes more and more difficult to do ordinary everyday tasks you once did without effort.

### WILL OTHERS NOTICE?

If your behaviour changes, others will notice. Remember fatigue in itself is **invisible**. More often than not it is expressed in how you react to what you can or cannot do. Its danger lies in its capacity to isolate you as you may find it more difficult to engage in the normal daily activities of life. You

may, for example, find yourself turning down invitations from family or friends because you are constantly tired.

### IS THERE ANY TREATMENT FOR FATIGUE?

Fatigue can be a symptom of anaemia. You will be treated for anaemia and this will result in an increase in your energy levels although they may not return to the levels you experienced before diagnosis.

### MANAGING YOUR ENERGY

Planning ahead can help in managing your energy. Try keeping a diary so that you can work out when you feel the most fatigued during the week. In so far as you can, use your energy for the things that are most important to you. Spread your 'jobs' throughout the week, doing a little often rather than a lot in one go.

#### *Some tips that may be of help to you:*

- Do a little bit of housework each day rather than trying to do it all in one day.
- Ask others to do heavy work for you.
- Ask others to shop for you, or shop online or use a delivery service.
- Do whatever chores you can while sitting.
- Try cooking simpler meals that can make triple portions.
- Exercise a little and often.
- Keep sleep routines normal and get enough sleep.

# CHAPTER 7

## BODY IMAGE

**C**oping with health problems caused by kidney failure can be difficult. It is easy to get caught up with the medical side and ignore the enormous impact it can have on your psychological wellbeing.

One issue that can be overlooked is body image. How we look to others is important to most people, yet we often feel uncomfortable or embarrassed to talk about it.



### WHAT IS BODY IMAGE?

**Body image** is how you see and feel about your physical appearance which includes your personal perception of the way others see you. The way you view your body is linked to your self-esteem and involves how much you value yourself and appreciate your own worth.

If you are uncomfortable with your physical appearance it is most likely that this is how you feel about yourself in general.

---

***Kidney disease, whether in the predialysis, dialysis or transplant stages will bring changes. These changes may make some people feel unattractive and insecure. They may even view their body as letting them down.***

---



## HOW CAN YOU ADAPT TO THESE CHANGES?

We have different ways of experiencing emotions and change. Your **self-esteem** is a major part of your overall well-being; it is important to strengthen it.

- Keep **communication** open and be honest with your healthcare team, family and friends. At first it might feel difficult talking about feelings, however most people report a sense of relief when they share how they feel. Communication is vital for relationships to flourish especially intimate relationships. Talk to your partner about what is happening to you physically and emotionally and allow them time to share their feelings with you.
- **Peer Support:** Sharing your feelings with others with chronic kidney disease in person or online, may help you realise that what you feel is quite normal. You may find some of the coping strategies they used to integrate the physical changes into their lives useful.
- Emphasise the **deeper qualities** you possess, focus on your unique strengths, abilities and personality.
- Remember what your body **can do** rather than focusing on the things you cannot do.
- **Take good care of yourself.** Get active and improve your nutrition. There are many benefits to exercise, for example, developing a positive feeling towards your body strength and ability, which will enhance your body image and improve your well-being.



*Communication is vital for relationships to flourish, especially intimate relationships*

- **Self talk:** Observe and acknowledge the way you think, paying particular attention to your patterns of automatic thoughts and asking; are they distorted? Keeping a journal may help you to identify your negative thought patterns and open other ways of thinking about your situation.
- **Use** relaxation techniques, such as meditation, visualisation, mindfulness, etc.
- Seek **additional support**, if appropriate, from a member of your healthcare team.

There are steps you can take to manage the way you view yourself. Some people have even reported making secondary gains from kidney disease, for example, discovering a potential or strength that they did not previously recognise.

There is no right or wrong way to feel when you are dealing with changes in your body. However, how you feel about yourself is greatly influenced by how much support you receive. Accepting and talking about your feelings is one of the best ways of dealing with them.

***Remember - your worth is not defined by how you look***

# CHAPTER 8

## SEXUALITY

**S**exual difficulties are common complications related to chronic kidney disease, affecting both sexes. It is a problem that can cause real concern, impacting on your sense of self-worth and self-confidence. Yet while this is well-known, it is often the one issue that is avoided by both patients and their healthcare professionals. Keeping silent helps no one, especially the patient who may feel completely isolated and unsupported.



### WHAT ARE SOME OF THE CAUSES OF SEXUAL DIFFICULTIES?

There are multiple causes of sexual difficulties in those diagnosed with or on treatment for kidney disease.

#### SOME OF THE PHYSICAL CAUSES

- ***Loss of libido***
- ***Difficulties with sexual arousal***
- ***Fatigue***
- ***Erectile dysfunction***
- ***Hormonal imbalance***
- ***Anaemia***

#### SOME OF THE EMOTIONAL CAUSES

- ***Guilt***
- ***Feelings of dependence***
- ***A lowering of self-esteem***
- ***Feelings of anger***
- ***Depression***

**Body image** can be a major issue for many, especially younger people on treatment. The PD catheter or the fistula can be viewed as unsightly and a 'turn off', leaving the person wondering if they are still attractive and desirable.

**Impotence** is an issue for many men on treatment. This can have a dramatic effect on self-image and self-esteem and impact significantly on their sexual relations.

There are many causes of impotence, for example: anaemia, medication and fatigue. It is often a subject men have difficulty bringing up, usually out of embarrassment but sometimes out of denial. Treatment for impotence is available. Discussing it with your doctor or health care professional is helpful.

Many people on treatment complain of chronic fatigue which affects their interest in sex and sexual performance.

### **Partners**

Not only do partners have to come to terms with a loved one who is ill they also have to deal with the sexual difficulties that accompany the illness. This can be a demanding time for partners. It is not uncommon for partners to feel powerless, wanting so much to support and help but fearful of a negative reaction. Much will depend on the stability of the relationship and their level of open communication prior to diagnosis as to how the issue is dealt with. Many partners interpret their partner's disinterest in sex as a loss of interest in them, ushering in the question about their desirability and attractiveness.

### **Patients**

Many patients feel that they are no longer attractive or desirable. These feelings are genuine and must not be overlooked or dismissed. Yet they are often based on a belief of how one's partner 'sees' them. Whether this belief is valid or not is something that needs to be checked out.



## **WHAT CAN HELP?**

### **Discuss the issue of sexual difficulty**

The first step is to acknowledge the issue of sexual difficulty with your partner and later with your healthcare professional. Acknowledging that there is a difficulty is a beginning and can help in allowing patients, partners and their healthcare professionals discuss possible treatment options.

### **Challenge your beliefs**

Open and honest communication is essential to challenge the beliefs that abound when changes related to illness occur.

- Am I desirable?
- Am I still attractive?
- What does your distance mean?
- How are all these changes going to affect me, us?

Partners may need support to enable them to understand that the sexual disinterest of their partner may have nothing to do with them but is part of their illness. Failure to do so contributes to stress and ultimately may be detrimental to the relationship.

### **Treatment is available**

Sexual difficulties experienced by patients can profoundly affect their sense of wellbeing. Yet treatment and support is available. Discussion with your healthcare professional can begin a process that may help alleviate some of the difficulties you experience.

**Sexual difficulties are common among men and women diagnosed with, or on treatment for kidney disease. Sexual difficulties may remain hidden or acknowledged. When one partner is diagnosed with a chronic illness, it is only natural that this can cause stress in the relationship.**

**Raising the issue, communicating both within the relationship and with appropriate healthcare professionals allows for treatment options to be considered. Failure to acknowledge or express the difficulties may result in arguments and resentments thus adding extra stress, when what is desired is support and understanding.**



# CHAPTER 9

## STRESS AND ANXIETY

**T**his chapter will highlight some coping strategies which you may find helpful in terms of minimising the impact of stress and anxiety, thereby increasing your resilience.

### WHAT IS STRESS?

Stress is an everyday fact of life. Before you can start managing your stress, you need to understand what stress is.

Stress is the body's way of rising to a challenge and preparing to meet this challenge.

Walter B. Cannon, a physiologist, described it as a number of biochemical changes that prepare a person to deal with threats or danger. The human body prepares itself by activating the nervous system and releasing hormones such as adrenaline and cortisol which increase the speed of your heart, breathing, metabolism and blood pressure. Blood is directed away from your extremities and digestive system in to the larger muscles that can help you to fight or run.

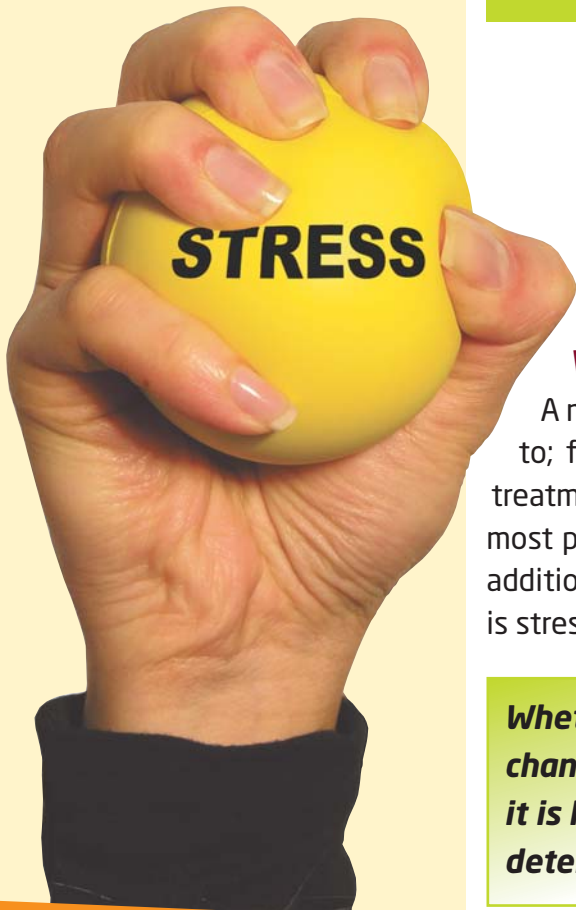
***This stress response happens regardless of whether the threat is real or perceived.***

- These changes are intended to be temporary to enable us to handle the stressful situation we are in. The body then needs to return back to its normal relaxed state.
- Constant stress however causes the body to remain in a stressed state for prolonged periods of time, and this has a significant negative impact on our health.

### WHAT CAUSES STRESS?

A major cause of stress is change, even a change that we look forward to; for example moving house raises stress. When diagnosed or on treatment for a chronic illness you have to deal with more change than most people. Adjusting to changes of lifestyle, medical treatment etc, in addition to coping with the physical and emotional effects of your illness, is stressful, and will impact on your relationships.

***Whether the stress you experience is the result of major life changes or the accumulative effect of minor every day worries, it is how you interpret and respond to these experiences that determine the exact impact stress will have on your life.***



## COPING WITH STRESS - IMPROVING RESILIENCE

People react to stress differently.

### UNHELPFUL STRATEGIES

- Smoking
- Over eating /under eating
- Drug/alcohol misuse
- Zoning out watching TV
- Occupying every minute of your time to avoid facing a problem.
- Isolating yourself from others.

### HELPFUL STRATEGIES

- **Learn to overcome your unhelpful thoughts and beliefs.**

The way in which you think about things makes a vital difference to how you feel about them.

- **Two kinds of thoughts are important in stress.**

The way you weigh up the situation that creates the stress.

The way in which you weigh up your ability to cope with it.

- **When you are stressed it is easy to think in a very negative way.**

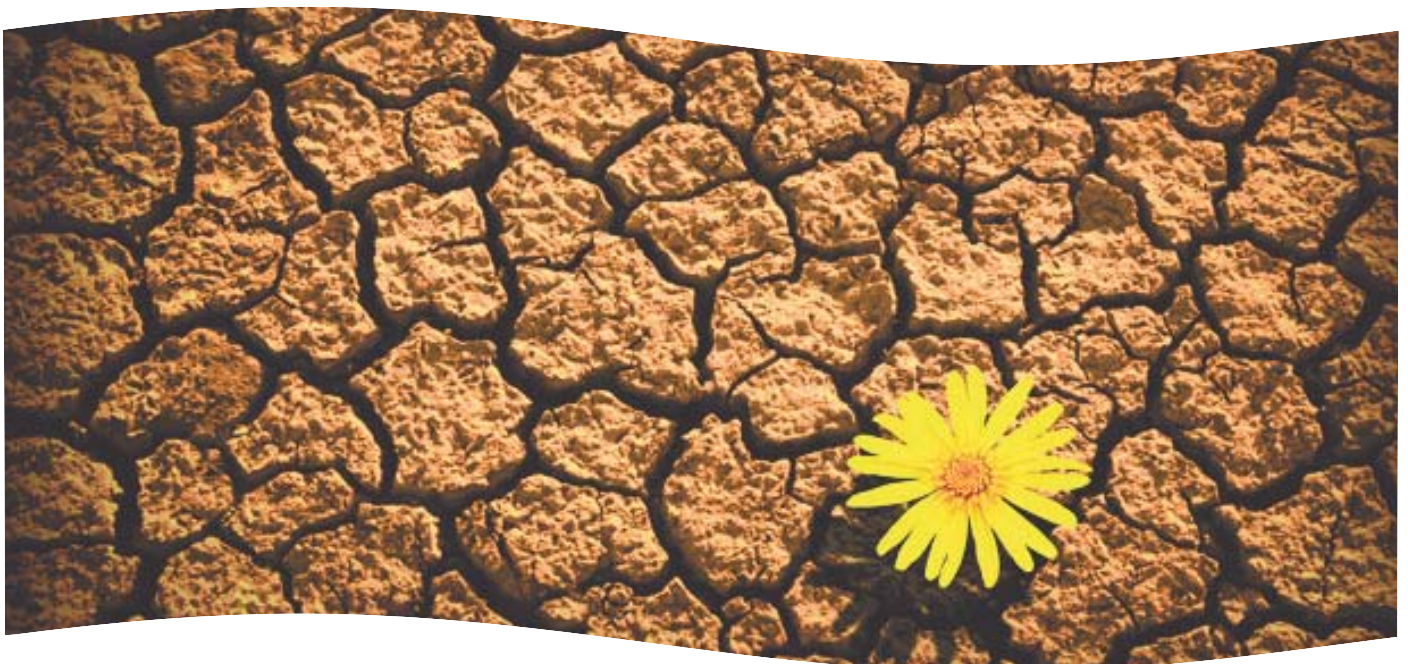
Your stressful thoughts are often rather unfair and unrealistic in the sense they are often based on guesswork and estimation.



You can forget how you have managed to cope before, and you tend to see the worst in everything and ignore aspects of the situation that might not be so bad.

### RESILIENCE

*"Capacity to see the options, and to adapt effectively to meet and overcome challenges."*



## STRESSFUL THOUGHTS - HOW THEY AFFECT YOU

Stressful thoughts are so automatic we tend to accept them as facts. The first step is to become aware of your thoughts and notice their effect on your mood and behaviour.

## HOW TO COMBAT STRESSFUL AUTOMATIC THOUGHTS

### Recognise and acknowledge

Every time you notice you are getting stressed write down:

- The time and date
- Your present situation; what has happened to make you feel stressed?
- What was going through your mind? What are your thoughts?
- The emotions you feel.



### Question your stressful automatic thoughts

Having identified your stressful automatic thoughts you can learn to examine the situation from a more objective view point:

- What is the evidence that this automatic thought is true/not true?
- Is there an alternative to your view that might be more realistic?
- What would other people say? Would they agree that the evidence supports your thoughts?
- Are you setting realistic standards for yourself and others?
- Are you underestimating your ability to cope. Have you dealt with this problem or similar ones in the past?

Everyone has good and bad days. Chronic kidney disease (CKD) brings its own challenges and difficulties which will naturally cause you upset and concern from time to time. Sometimes you can manage and cope with these challenges. However, there will be times when your worries become such that you begin to feel very anxious.

## WHAT ARE SOME OF THE SIGNS THAT POINT TO ANXIETY?

### Thoughts

- Constant worrying thoughts about treatment or other things.
- Dread; feeling that the worst will happen, most of the time.
- Stressful thoughts constantly intruding.

### Feelings

- Feeling tense or wound up, unable to relax.
- Agitation/restlessness.
- Panic/Intense fear that seems to come "out of the blue".
- Fear of losing control.

### Body Sensations

- Butterflies; unexplained tummy upset/diarrhoea.
- Dizziness/feeling faint.
- Awareness of heart beat.
- Panic/sudden rapid breathing

A certain level of anxiety is essential to help motivation. If your anxiety gets out of hand, you may become overwhelmed, causing you to freeze and feeling unable to cope.

***Everyone has good and bad days. Chronic kidney disease brings its own challenges and difficulties which will naturally cause you upset and concern from time to time***



## WHY IS IT IMPORTANT TO DEAL WITH ANXIETY?

Anxiety can interfere with the ability to deal with your treatment. For this reason it is important to keep anxiety levels in check. The interesting thing is that the more you learn and understand about your treatment, the more in control you feel. Avoidance tends to cause an increase in anxiety levels.

## WHAT YOU CAN DO ABOUT IT?

Positive coping strategies (already discussed in this book) can help you cope with distress so that it does not become a serious problem. If you are answering "yes" to a lot of the symptoms of anxiety you may need specialised help. Talk to someone on your health care team that you trust. They are used to working with people in distress and can also refer you to other support networks, for example, a referral to a counsellor, psychologist or a social worker.



## DOES COUNSELLING HELP?

Yes, it can help. You speak to someone you can trust, in a confidential space, where you are not judged. It is preferable to make the contact before you reach a crisis. The counsellor can help you understand what's happening to you and support you through your present difficulties. It is often the case that the issue you may wish

to talk about is not related to your health but to the everyday stresses of life.

## WILL I NEED TO TAKE MEDICATION?

In some circumstances anti-anxiety medication may be useful to get you through a difficult period. Some people find it useful to join self-help groups (see list at back of this book).



## PROBLEM-SOLVING

**Adapt a systematic problem-solving approach:**

- Try to be objective, break down your problem into smaller more manageable parts.
- Avoid procrastinating. If something is worrying you, take some kind of action no matter how small. This will provide you with a sense of control
- Learn to say no and do not over-extend yourself.
- Adopt good time management skills.
- Limit your perfectionism, set reasonable standards for others and yourself.
- Establish good social support.
- Ask for help, express your feelings rather than bottling them up. This may mean finding a good listener, either a good friend, family member or a member on your renal team.

***In chapter two we have highlighted other strategies which will help you cope with stress/anxiety and build your resilience.***

***Each one of us is unique. Different strategies will work for different people and different situations. Remember change takes time and long-term habits are hard to break. Try some of the different strategies, but in doing so be patient with yourself and acknowledge the effort that you are making.***

# CHAPTER 10

## HOW DO I ASK MY FAMILY OR FRIENDS FOR A KIDNEY?

**T**his is probably one of the most difficult questions anyone on dialysis will face. Asking someone, usually a loved one, to undergo surgery to give you one of their internal organs is difficult! For some patients, donation from a family member is something they will not consider. For others it is their first preference.

### WHERE TO START?

Before you consider asking someone it is important to understand, for you, exactly what it is you are asking of them. Educating yourself is the first step. Read the literature available, check out websites and write down any questions you may have.

A member of your renal team may be able to help answer the questions you have. If your unit has a renal counsellor, make an appointment to discuss the issues you may have about asking for and accepting a kidney from a family member. Remember knowledge is power and the knowledge you gain will give you confidence to approach family and friends.

One of the reasons people find it difficult to ask directly is the thought that "if they wanted to give me a kidney, they would have offered". However what may be helpful is a conversation beginning with you sharing your story/experience of your



illness. How treatment is affecting your life and what are your best options.

Once you have shared this information, wait! It may take some time for family/friends to absorb and process the information. Be ready for questions.

In any discussion with potential donors, to further help them understand your situation, the following key questions should be addressed:

- How you are feeling now.
- Why you need a transplant.
- Why a transplant will help you.
- Where transplanted kidneys come from i.e. waiting list/ living donation.
- Why living donation is preferable.
- How people are matched.
- The surgical procedure (information/videos) are available on the Beaumont website: [www.beaumont.ie/kidneycentre-home](http://www.beaumont.ie/kidneycentre-home)

*One of the reasons people find it difficult to ask directly is the thought that "if they wanted to give me a kidney, they would have offered."*

**Open communication is the key to avoid unnecessary tension or misunderstanding within the family.**



It is preferable that a potential donor does not make a decision on the spur of the moment. If they do, you must always offer an "opt out", to allow them have a change of mind. If someone offers a kidney you should not eliminate others. This person may not be suitable.

With any live related donation, stress within the family is to be expected. Some patients feel they cannot discuss their illness with their families just in case it is perceived as asking them to donate. Alternatively, if some members of the family are tested and more than one is found to be a match, which of them donates? Open communication is the key to avoid unnecessary tension or misunderstanding within the family.

Studies show that patients are more comfortable accepting from family members or friends who have taken the initiative and volunteered. However for some patients the initiative has to come from them.

**"It is not easy to ask for a kidney. It is not easy to accept the offer of a kidney."**

## **A NUMBER OF QUESTIONS CAN ARISE ONCE AN OFFER HAS BEEN ACCEPTED**

**"Are they feeling under pressure to do this?"**

**"Will this compromise their health?"**

**"Will it cause inconvenience and pain?"**

**"Will it compromise the relationship?"**

Exploring these issues with a trusted healthcare professional may help.

## **WHAT DONORS SAY ABOUT DONATION?**

**"I gave my dad a kidney; I think we're a lot closer now."**

*"I donated a kidney to my son; it did not change our relationship at all. I think my having a very positive personality helped me. I was positive from the word go and I think my son was as well. Looking back on it now, it was a very emotional experience. Two months post-operation there is a real good feel-good factor."*

**"I gave a kidney to my brother. I never felt under pressure from anyone. Up to the day before, my brother did not want me to go through with it. I feel very fortunate as I had to lose three stones to undergo surgery. Having had a medical NCT I now know I'm healthy."**

*"It left me with the feeling I had done something positive. It's amazing to see the change in him."*

**"I had to take my time to think about donating as I had so many questions. I found 'Thinking About Donating A Kidney' (Book 4) really helpful."**





## WHAT RECIPIENTS SAY ABOUT RECEIVING A KIDNEY?

**Dr Duncan Thomas, whose kidneys failed and who had a successful live donor transplant wrote:**

*"Observing a family member looking unwell and in pain immediately post-operation was difficult. It was what I had chosen to do (I did not have many choices) so it was something I had to accept. As we both improved physically, the emotional impact remained. In particular how do you ever say 'thank you'? In truth I do not believe a person can ever fully appreciate the gift of a kidney, but I believe it is through this humility and an understanding that an individual can never fully say 'thank you' for the transplanted kidney, which creates a sense of responsibility to comply to any and all requirements to ensure the gift lasts for as long as possible."*

**(Quote taken from article written by Dr Duncan Thomas  
Journal of Renal Care, Vol.36, No.3, Sept. 2010)**

***"Many of my  
questions truly had  
no answers. It was my  
faith and trust in  
others that  
I turned to."***

There are no guarantees for donor or recipient in this process; this is what makes it so scary. Some family members and patients express concern that the transplant may fail. This is a common and understandable concern. It would seem recipients worry most, feeling totally responsible for what might happen. These feelings need to be processed before surgery. If this is done successfully, the recipient will approach surgery less anxious and more confident.

A positive attitude and the courage to face the unexpected are essential.



# CHAPTER 11

## ADJUSTING TO LIFE WITH A KIDNEY TRANSPLANT

**T**ransplant is not a cure, it is another form of treatment. While family, friends, co-workers may think the recipient is now “good as new” and is cured, this is not the case. Medication has to be taken regularly to preserve the transplant and this will be lifelong. There will be regular visits to the transplant clinic and uncertainty about the longevity of the new kidney.

While improved health and well-being can seem like a miracle after, perhaps, years of illness, unrealistic expectations can leave the recipient feeling overwhelmed. There are both physical and emotional changes to cope with following a successful transplant. Recipients sometimes feel they have to “bottle up” their feelings as everyone around them

*“I should not be feeling like this, I should be happy, I’m so lucky.”*



sees them as “cured”. Some become self-critical, thinking; “I should not be feeling like this, I should be happy, I’m so lucky”.

Many recipients find it reassuring to know what is commonly experienced. Many find themselves dealing with weight gain and fluid retention, a common reaction to anti-rejection medication. Medication can also cause mood swings and emotional changes that are difficult to predict and hard to deal with. The symptoms usually diminish once the proper dose is established.

### WHAT TO EXPECT AFTER YOUR TRANSPLANT?

Good communication between you, the members of your transplant team and all your healthcare providers is vital. There are what seems like countless questions, some big, some small, some feel silly, some complex. They need to be answered, not only for the benefit of your health but also, at times, just to put your mind at ease. Write down your questions to be discussed at your next visit. Transplantation is something new to you; feel free to bring up any issue causing you concern.



Often it is fellow recipients who understand what you are going through. There are huge benefits to being able to say it “as it is”, rather than always feeling under pressure to keep up a front to suit others.

### ***“I feel pressure to be happy all the time after the transplant, is this common?”***

Transplant brings an end to dialysis treatment and to the schedule that often accompanied dialysis. Although it might sound bizarre, immediately following transplant routine can be “topsy turvey”. Some patients miss the chat with the driver, the company of other patients they have befriended and also the constant support from nurses and carers. Post transplant routine is very different, and can be daunting for people who find change difficult.

A new routine will develop and evolve in time. Decisions may have to be made regarding work / retraining. It is important to have a realistic vision of what you can change in your life and what you cannot.

Recipients often speak of the desire to return to normal. Often this is couched in terms of feeling and being as they were before diagnosis. This is unrealistic. Just as we cannot return to being a child, much as we may want to at times, we cannot turn the clock back. A transplant radically alters life, and, while aspects of life will return to “normal”, it cannot return life entirely to the way it was.

### ***“Is it normal to think about my donor and their family?”***

It is interesting how different patients process this. Some agonise about having someone else’s kidney before making the decision to enter the transplant pool. A period of counselling can often help in processing these feelings. Having dealt with it pre-transplant, they rarely worry about it afterwards.

Emotions run high following surgery. Most recipients will think about their donor and the



family. When all the drips and drains are out, it helps to record some of these thoughts. At a later date you may consider writing to your donor family, through the transplant co-ordinator. Having a record of your thoughts and emotions will make it easier



to do this. It is natural to wonder about the donor and even to dream about them. Since the donor is anonymous, there will always be an element of mystery. The Irish Kidney

Association facilitates thanksgiving services for both recipient and donor families. These services can be emotionally harrowing but hugely freeing for everyone involved.

### ***“I worry a lot about rejection!”***

It can be scary living with uncertainty. The challenge for transplant recipients is to make a realistic assessment of what is involved in living with a transplant, clarifying what you can change (behaviour/ thoughts) and what you accept, for now and for the future.



## WHAT RECIPIENTS SAY

"Don't let yourself become a permanent patient whose life is defined by being on the illness track. You need not be defined solely by your transplant, but by many other things. Organ transplantation is a life-changing, transformative event that can, if you allow it, become a springboard into vibrant living"

"Find what you can do in your new circumstances

and capitalise on that. Even going one step further; find what you want to do and pursue that dream"

"Take the meds as prescribed. Listen to your body. Eat right. Exercise as much as you can. Work. Learn everything about transplant. Get involved. Read books. Have fun. Travel. Be competitive at work and play. Don't let anyone push you around. Go back to school. Learn how to use the internet".

## STRESS FOLLOWING TRANSPLANT

Life is stressful for everyone; transplantation does not dissolve other problems in life. The bills must be paid, relationships have to be managed, children are a constant worry, etc. The important thing is to find constructive ways of dealing with it. Some people find stress reduction through counselling, music, gardening, mindfulness, or even a good book. Others seek time-out for themselves or seek out a person who will really listen. If you would like a referral for counselling, contact a member of the transplant team or the counsellor at the Irish Kidney Association.

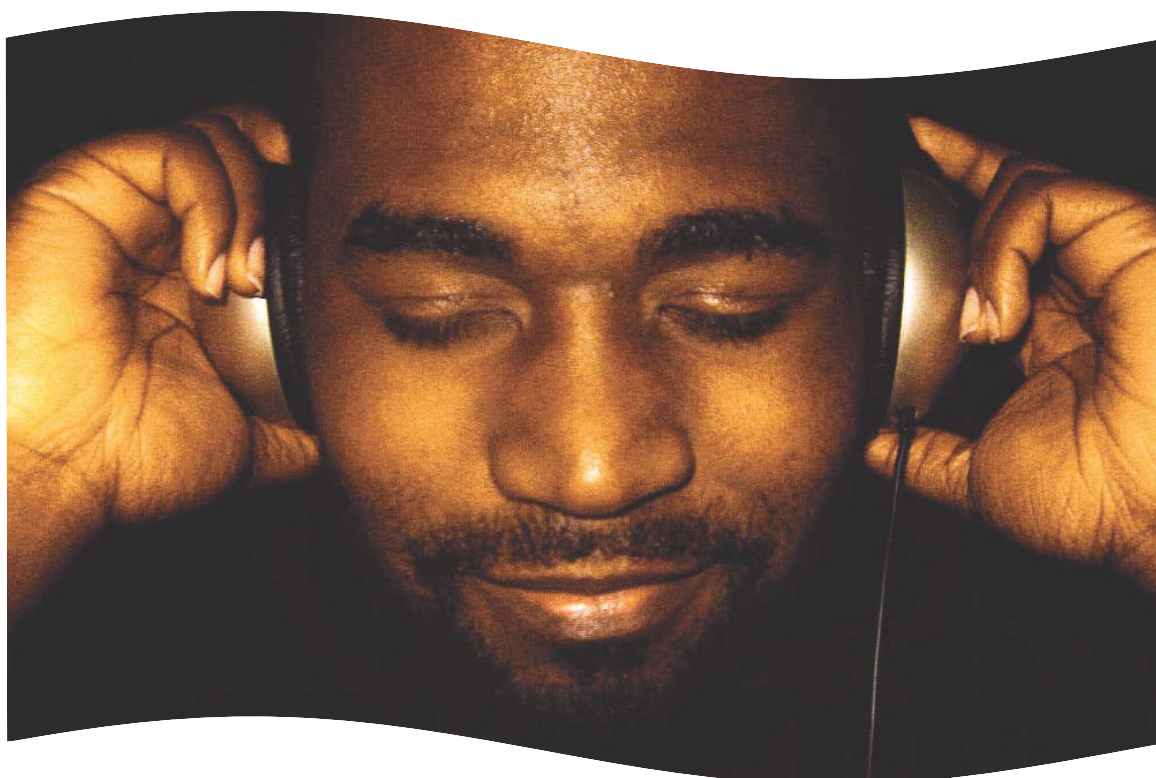
Exercise is vital post-transplant. It helps maintain bone and muscle strength, and also helps alleviate

stress. Choose an exercise you enjoy - that way you'll stick with it.

### ***A final word from a recipient***

***"I would not wish this on anyone, but it's too bad we all can't experience it, because it is the most incredible life experience anyone can go through."***

*Quotes taken from booklet "From Illness to Wellness/Life after Transplantation, available to download from National Kidney Foundation website...[www.kidney.org](http://www.kidney.org)*



# CHAPTER 12

## DIALYSIS OR NO DIALYSIS

### WHAT IS CONSERVATIVE MANAGEMENT?

**N**ot all patients do well on dialysis. For some there is a marked deterioration in quality of life, though it is not entirely predictable. Some people may experience dialysis as an excessive burden, providing no benefit at all. Patients who are struggling with many health problems may reasonably wonder if dialysis will make their life any better or will it prolong suffering.

If you decide not to start dialysis, your care will be managed under a programme called Conservative Management. This means you receive all aspects of kidney care i.e. regular clinic visits, diet management, with the exception of dialysis. Your GP may also be involved in your care.

### WHAT IS THE FIRST STEP I SHOULD TAKE?

Write down your hopes and concerns. Making notes may help clarify the reasons behind your thinking, leading to a more informed choice.

### WHO SHOULD I TALK TO?

The primary people you should talk to are your family and your consultant. Your written notes re: concerns/hopes can act as a basis for the discussion.

### TALKING TO YOUR FAMILY

- This may be difficult, as your family may not agree with your decision. If you feel it would help, consider having a facilitator present (someone you trust, or someone from the renal team, if they are agreeable).
- Using your notes, outline the reasons for your decision.
- Listen to your family, acknowledge their concern and reply in a calm manner.
- You are aiming to reach a point where your family understand the reasons you are making this decision. However be prepared, they may not all be in agreement with you.

### TALKING WITH YOUR CONSULTANT

- Try to avoid using a clinic appointment to discuss such complex issues. If possible make an appointment for another time, where you will have adequate time to explore all your options.
- Your notes will guide you. It is important to have your questions written down in front of you.
- It may be helpful to have a family member accompany you to this meeting..

### CAN MOOD INFLUENCE MY DECISION?

If depression is suspected your doctor will suggest an assessment, to ensure a depressive episode is not a contributory factor to your decision. If depression is diagnosed, appropriate interventions in the form of therapy with or without medication, will be discussed with you.

*"Is the option of dialysis a burden to be faced or an opportunity to prolong life?"*

### WHAT IF I CANNOT DECIDE

If you cannot decide, you can opt for a trial of dialysis. It can be for 6 weeks, 3 months or whatever you decide with your doctor. After a trial, you may decide to continue with dialysis or discontinue dialysis altogether.

*"Is the onset of end stage kidney disease a sign that natural life is coming to an end?"*

### IS THERE ANYONE ELSE I SHOULD TALK TO

Some people find it helpful to talk through their thinking with a social worker, psychologist, counsellor or a representative from their faith community, e.g. vicar, priest.



### 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.

### KEY QUESTIONS TO KEEP IN MIND

- Do I not want to have treatment or stop treatment?
- Do I fully understand what will happen if I decide not to have treatment or stop treatment?
- Have I discussed this with my family?
- Are my consultant and family clear about what I want or do not want done should my condition deteriorate suddenly?





## SUPPORT SERVICES

**Aware** 72 Lower Leeson Street, Dublin 2  
**Tel:** 01-661 7211 **Web:** [www.aware.ie](http://www.aware.ie)

**Irish Kidney Association** Donor House, Block 43A, Park West, Dublin 12  
**Tel:** 1890-543 639 **Email:** [info@ika.ie](mailto:info@ika.ie) **Web:** [www.ika.ie](http://www.ika.ie)

**Carers Association** Market Square, Tullamore, Co. Offaly  
**Tel:** 1800-240 724 **Email:** [info@carersireland.com](mailto:info@carersireland.com) **Web:** [www.carersireland.com](http://www.carersireland.com)

**HSE National Counselling Service**  
Counselling in Primary Care - is available through your GP (for medical card holders only)

**Grow (World Community Mental Health Movement in Ireland)**  
(Network of Support Groups nationwide)  
**Tel:** 1890-474 472 **Email:** [info@grow.ie](mailto:info@grow.ie) **Web:** [www.grow.ie](http://www.grow.ie)

**Northern Ireland Kidney Patients Association (NIPKA)**  
PO Box 85, Carrickfergus, Co. Antrim, BT38 0AT  
**Email:** [info@nipka.org](mailto:info@nipka.org) **Web:** [www.nipka.org](http://www.nipka.org)

**Citizens Information**  
**Web:** [www.citizensinformation.ie](http://www.citizensinformation.ie)

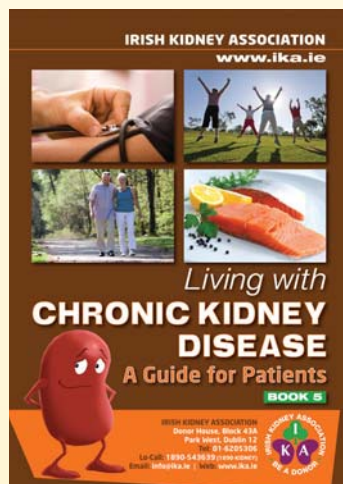
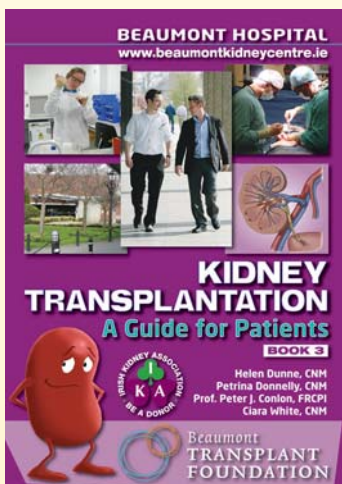
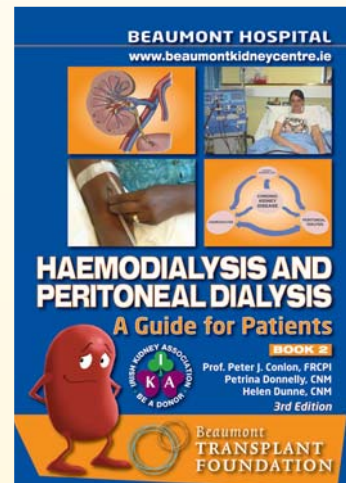
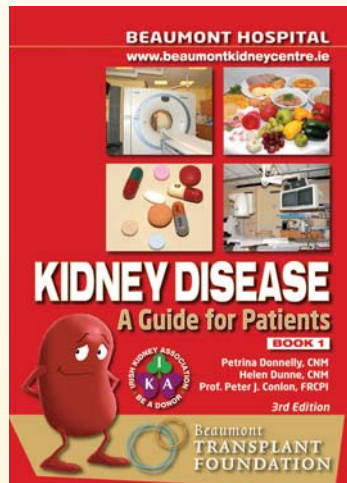


## WEBSITES

[www.getselfhelp.co.uk](http://www.getselfhelp.co.uk)  
[www.helpguide.org](http://www.helpguide.org)  
[www.mind.org.uk](http://www.mind.org.uk)  
[www.amnch.ie](http://www.amnch.ie)

[www.beaumontkidneycentre.ie](http://www.beaumontkidneycentre.ie)  
[www.lhatedialysis.com](http://www.lhatedialysis.com)  
[www.medicine.tcd.ie/thkc](http://www.medicine.tcd.ie/thkc)  
[www.kidneyfriends.net](http://www.kidneyfriends.net)

# Patient Information Books



The IKA has five other patient information books in print format and they are available free from the IKA Head Office and Renal Support Centre or they can be read or printed from the website... **www.ika.ie**

**BOOK 1** deals with the functions of the kidney, types of kidney disease, diagnostic tests and medicines used to treat kidney conditions. **BOOK 2** deals with haemodialysis and peritoneal dialysis. **BOOK 3** covers kidney transplantation in more depth. **BOOK 4** addresses the area of the 'living donor' programme whilst **BOOK 5** 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).

*Four of the books were produced in conjunction with the Beaumont Transplant Foundation.*

# Notes

USE THIS PAGE TO RECORD ANY QUESTIONS YOU MAY HAVE  
FOR YOUR DOCTOR OR ANY MEMBER OF THE TEAM.



# IRISH KIDNEY ASSOCIATION (IKA)

The Irish Kidney Association (IKA) is a national voluntary organisation of patients, family carers and supporters which offers support for all patients with end stage kidney disease. Throughout its 25 local branches, patients can meet other kidney patients and share experiences, problems and, most importantly, solutions.



The IKA provides the following services to patients and their families;

- **Holiday homes in Tramore and Tralee** for patients who are either receiving dialysis or are transplanted.
- **Holidays Abroad:** the IKA holiday co-ordinator will help those patients wishing to go abroad with sourcing dialysis.
- **Renal Support Centre:** situated in the grounds of Beaumont Hospital, offers 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
- **Health Promotion Through Sport:** caters for all ages and abilities of people who have experienced organ failure. A wide range of sports are offered. The programme encourages people to be actively involved in enhancing their own health.

## IKA RENAL SUPPORT CENTRE



Beaumont  
Hospital,  
Beaumont,  
Dublin 9

**Phone:**  
01-837 3952

**Email:**  
[renalcentre@ika.ie](mailto:renalcentre@ika.ie)



- **Counselling Service:** available to patients and family members through the IKA counsellor based in Donor House and a network of locally based counsellors.
- **Patient Support Officer:** deals with those welfare issues that concern patients and their families
- **SUPPORT magazine:** produced four times a year and is posted free to members and people who have requested a copy.

## MULTIMEDIA

[www.ika.ie](http://www.ika.ie)

The IKA website is a valuable source of up-to-date information about renal disease and national and international developments.

We also have many followers on **FACEBOOK** and **TWITTER**



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



<https://twitter.com/IrishKidneyAs>



#### BEAUMONT HOSPITAL FOUNDATION

Beaumont Hospital, Beaumont Road, Beaumont, Dublin 9.  
Tel: 01-809 2161 | Email: [friends@bhf.ie](mailto:friends@bhf.ie) | Web: [www.bhf.ie](http://www.bhf.ie)



#### BEAUMONT HOSPITAL

Beaumont Hospital, PO Box 1297, Beaumont Road, Beaumont, Dublin 9.  
Tel: 01-809 3000/837 7755 | Web: [www.beaumont.ie](http://www.beaumont.ie)



#### Tallaght Hospital

#### AMNCH

Nephrology Department, Tallaght, Dublin 24.  
Tel: 01-414 2000 | [www.amnch.ie](http://www.amnch.ie)



#### IRISH KIDNEY ASSOCIATION

Donor House, Block 43A, Park West, Dublin 12  
Tel: 01-6205306 | Lo-Call: 1890-543639 | Email: [info@ika.ie](mailto:info@ika.ie) | Web: [www.ika.ie](http://www.ika.ie)  
Charity No. 20011260