



# Conservative Care of Kidney Failure

Helping  
you to  
make an  
informed  
choice

**BOOK 7**



The Irish  
**Hospice  
Foundation**

Striving for the best care  
at end of life for all

Plain   
**English**  
Approved by NALA





## Patient Information

The **Irish Kidney Association (IKA)** have six patient information books which you can get free from the IKA Head Office and Support Centre. You can also download them from [www.ika.ie](http://www.ika.ie)

**BOOK 1** - Kidney Disease; **BOOK 2** - Haemodialysis and Peritoneal Dialysis; **BOOK 3** - Kidney Transplantation; **BOOK 4** - Thinking About Donating a Kidney?; **BOOK 5** - Living with Chronic Kidney Disease; and **BOOK 6** - Emotional Wellbeing.

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### Acknowledgements

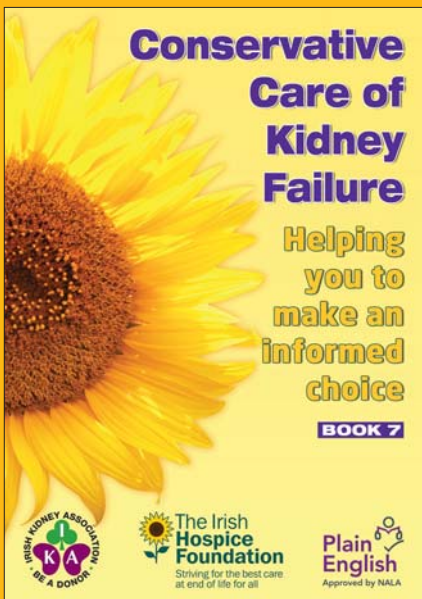
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Thanks to the **Renal Resource Centre, New South Wales, Australia** for allowing use of material from their Conservative Care of Advanced Kidney Disease Booklets.

The information in this book was correct at time of going to press. Please use this book only as a guide - always speak with your doctor or nurse if you have concerns.

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# Introduction



**T**his book is a support for anyone who faces the serious health problem of kidney failure. It is aimed at those having to make treatment choices around whether or not to start dialysis. It is also appropriate for those on long-term dialysis who are considering stopping their dialysis treatment.

Dialysis can be life-saving. It can improve your quality of life and help you live longer. However, the dialysis treatment can be complicated, time-consuming and difficult. In most cases it will not improve other conditions that you may suffer from. Dialysis is a treatment that each person with kidney failure may choose to accept, refuse or stop.

This book explains what the treatment option of conservative care of kidney failure means and the significance of choosing this treatment option.

If you are reading this booklet for the first time, you may find it upsetting. If possible, try and have a family member or members of your renal team around to support you, as you come to terms with the issues involved in conservative care of your kidney failure.

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# Chapter 1

## What is Conservative Care?



Conservative care is sometimes called conservative management or supportive care of kidney failure. It doesn't treat the causes of kidney failure. Instead, it focuses on treating the symptoms of kidney failure as they arise.

Conservative care aims to preserve kidney function for as long as possible but will not stop the decline in kidney function. Conservative care does not **replace** kidney function.

Choosing conservative care means that you accept that your loss of kidney function will progress and there is a high probability that this will lead to your death.

Treatment of the symptoms of your kidney failure will continue in the hospital outpatient clinic and your kidney function will be closely monitored. **You will be actively treated** for any complications of your kidney failure, with a focus on making sure you experience the best quality of life possible.



# Choosing conservative care

**The decision to choose conservative care is always made following lengthy discussion with your renal consultant. It may be a better choice for you if dialysis is unlikely to improve your quality or length of life, or if dialysis may significantly reduce your overall enjoyment of life.**



**Conservative care is an accepted treatment option when your kidneys fail.**

The aim of conservative care is to manage the symptoms of kidney failure without using dialysis. Conservative care includes medical, emotional and practical support. Studies have shown that conservative care of frail elderly people with kidney failure can achieve a similar life span and quality of life when compared to frail elderly people on dialysis. In other words, if you are frail and elderly and have a complicated medical history, you may live just as long with conservative care as you would with dialysis treatment.

It is important that you do not rush into making a decision about the treatment options available to you. Gather as much information as you can through reading and through discussions, with your healthcare team, at your hospital visits.

When weighing up the advantages of each treatment, you should discuss, in detail,

what each treatment can offer. This way you can be sure you are fully informed and have thoroughly explored all possibilities. Be guided by your renal doctor and nurses and your GP, all of whom know your medical and social history. However, it is likely that you and your family will need help when making decisions about which treatment will suit you best. Try not to make a decision to decline dialysis when you are feeling depressed or you are not fully aware of the consequences of your decision.

There are many reasons why you might decide not to start

dialysis treatment. You may feel that dialysis will have too great an effect on your life and the likely benefit from dialysis treatment may not be worth it. You may feel that travelling to and from a dialysis unit, often in addition to other hospital appointments, will be too demanding and will interfere with your lifestyle and normal daily activities. Also, you may feel that you have lived your life and that you are now too elderly or too frail to benefit from treatment, even though age is not usually a barrier to starting dialysis.

## The aims of conservative care

- To prevent and treat the symptoms of kidney failure
- To preserve remaining kidney function
- To achieve the best quality of life
- To spend less time in hospital
- To give practical and emotional support
- To let you voice your future treatment wishes

Sometimes your renal doctor may think that the burden of dialysis, in addition to your kidney failure and other serious medical conditions, outweigh the benefits of starting dialysis treatment. If this is the case, he or she may recommend conservative care as the best treatment choice for you.

At other times medical staff and your family may recommend dialysis treatment, when you would prefer a more conservative approach. Reaching a decision on what treatment choice suits you can be very difficult.

Family members may have unrealistic expectations of what dialysis can achieve for you and may be reluctant to accept your

decision not to have dialysis or to accept your doctor's recommendations for conservative care. They may believe that they should defend your right to access dialysis, no matter what its effect on your quality of life and overall well being.

Family meetings with medical and nursing staff are useful in helping you and your family to understand all the factors involved and to weigh up the pros and cons of dialysis treatment against conservative care. If there is any disagreement, your comfort, dignity, wishes and values should be respected and supported by your family and healthcare team.

No matter how you have come about to making a decision to choose conservative care, your choice will be documented and supported.

Having reached a decision, your emotional reaction and those of your family can be very intense. This is a time when you may feel fearful, depressed, angry and confused, even hopeless. You and your family may have concerns that need to be addressed and resolved. Your healthcare staff can help clarify any questions you may have and can talk with you about your thoughts and feelings. Some hospitals may have access to trained professionals who can help you through this difficult time.


## Compare your options

	Start or continue dialysis	Refuse or stop dialysis
<b>What is usually involved?</b>	You start or continue to get dialysis treatments several times a week at a dialysis unit close to you.	Your body will start to shut down, and you will experience normal changes from the dying process.  You may need the support of a palliative care team as your kidney failure will, in due course, lead to your death.
<b>What are the benefits?</b>	Dialysis keeps you alive longer so you don't have to deal with dying yet.  When you start dialysis you may feel better than you did before you started treatment.  You may be able to return to normal activities.  Treatment may allow you to achieve plans that you have set for yourself.	You no longer have side effects or problems from dialysis.  You no longer need to limit what you eat and drink.  The time you have left is your own to spend with friends and family, not on dialysis treatments.  Your quality of life may be better.
<b>What are the risks ?</b>	Dialysis won't cure you.  Dialysis may involve frequent travel to and from where you have treatments.  Dialysis takes a lot of time and can affect your quality of life.  Dialysis has risks, including infection, low blood pressure, fever, abnormal heart rhythm, and muscle cramps.	You will probably die within a few weeks, if you have stopped dialysis treatment or within months if you have declined dialysis treatment.  As you near death, you'll face end-of-life issues that may be hard to deal with.



## Chapter 2

# Choosing to stop dialysis treatment



This chapter is for anyone who is currently getting dialysis treatment and who feels that the burden of dialysis outweighs their existing quality of life.

When you started dialysis treatment you were aware that it replaced your kidney function and kept you alive. At the beginning you may have felt much better. However, dialysis does not cure other serious medical conditions you may have, and it will not stop you getting older and frailer.

Dialysis is meant to improve your quality of life, it is not meant to cause you distress. If you find that you are unwell during or after treatment, you might feel that life on dialysis has become a day to day struggle and is too difficult to cope with. Sometimes changes to dialysis treatment or to medications can improve things but if your health gets worse, due to other medical conditions, it may not be possible to make things easier for you. At this point you may consider stopping dialysis treatment.

***Dialysis is meant to improve your quality of life and not cause pain and suffering.***



## Ending dialysis treatment

The process of deciding to stop dialysis treatment is complex as there are many difficult things to consider and think through.

When you have been adequately informed and understand the consequences of your actions, it is medically, ethically and legally acceptable for you to choose to withdraw from a life sustaining treatment such as dialysis.

### When you choose to end dialysis treatment

If you feel that stopping dialysis is the right choice for you, you should tell your family or any member of your medical and nursing team. This will open discussion on the implications of your decision to stop.

If members of your healthcare team are concerned that your request to stop dialysis may be due to emotional or social issues, they will recommend a consultation with a psychiatrist. The psychiatrist will assess your emotional state and social circumstances to see if you have an undiagnosed or untreated depression, or other distressing emotional or social problems that can be addressed.

Treatment and counselling for mental health and other personal matters may give you a more positive outlook on life and help you decide to continue your dialysis treatment.

If you are not depressed or you don't have another mental illness, your decision to end dialysis treatment will be respected. If you later change your mind and decide to continue

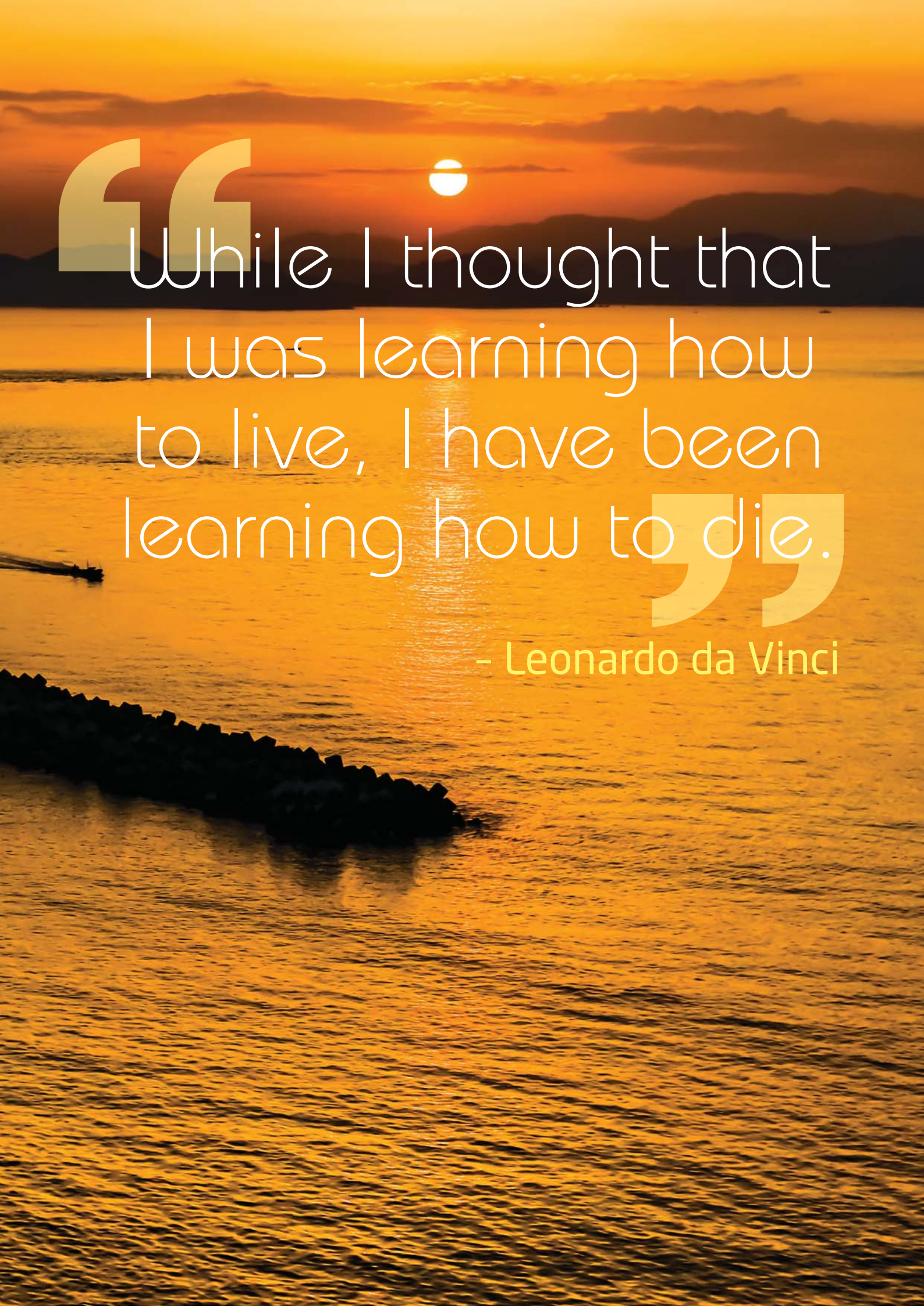
treatment, this decision will also be respected. The guiding principle is to make sure your medical and other care needs are met while maintaining your comfort and dignity.



### When your doctor and medical team recommend dialysis treatment should end

Sometimes your renal team may advise you that your dialysis treatment is no longer helping you and should stop. This may happen if your health has got much worse due to other serious medical conditions and your doctors do not expect you to recover or your quality of life to improve. In such circumstances, dialysis will not improve your health and going through dialysis treatment may even worsen your health and quality of life.





“While I thought that  
I was learning how  
to live, I have been  
learning how to die.”

- Leonardo da Vinci



# Symptoms and treatment of kidney failure

**When kidney function is severely damaged and is less than 15% of normal function, you will experience some symptoms of kidney failure. These symptoms may range from relatively minor to quite severe symptoms.**

Symptoms of kidney failure that you may experience include itch, nausea, loss of appetite, tiredness, pins and needles in your hands or feet, bruising, fluid retention with ankle swelling and shortness of breath. Dialysis generally improves some of these symptoms but others usually need additional drug treatments.

If you choose conservative care instead of dialysis, most of these symptoms can be successfully managed with medications and changes to your diet.

However, your health will decline as your kidney function gets worse.

It is not possible to predict how long you will live if you choose conservative care. Your doctor will check your bloods at each clinic visit to measure and monitor the rate of decline of your kidney function and the development of any new complications. Your doctor will tell you about your level of kidney function and health status at each visit.







***Most symptoms of kidney failure can be identified and well managed.***

## **Symptoms and treatment of kidney failure**

**You may experience these symptoms at different times and their severity may vary. Your healthcare team are experts in managing and reducing these symptoms so that you remain comfortable.**

### **Uraemia**

Uraemia is a serious life-threatening complication of kidney failure. It occurs when urea and other waste products build-up in the body because your kidneys are unable to remove them. These wastes become poisonous to the body at high levels. Uraemia can make food taste differently, often described as leaving a metallic taste in your mouth. This can turn you off certain foods and can cause you to lose weight. Uraemia can also cause a sweet ammonia smell on your breath. Mouthwashes and good oral hygiene can help these symptoms.

### **Nausea and vomiting**

Nausea and vomiting can happen as your kidney function declines and uraemic increases. The renal dietician will help you to get the nutrients and calories you need. Your doctor can prescribe medications to treat the nausea and vomiting.

### **Itchy skin**

Itchy skin is a common symptom of kidney failure, usually due to high mineral blood levels, like phosphate. Medications to improve mineral balance and reduce nerve impulses, as well as skin creams to treat dry skin, can help.

### **Lack of energy and tiredness**

The kidneys make erythropoietin (EPO), a hormone that helps the bone marrow to make red blood cells. As kidney function declines, the amount of EPO produced by the kidneys decreases and the number of red blood cells is reduced. This is called anaemia.

Anaemia can cause tiredness, sleepiness and sometimes breathlessness. EPO is available as an injection and regular doses may improve your energy levels and reduce other anaemia-related symptoms. Your renal doctor will also treat other causes of anaemia such as low iron, folate or vitamin B12 levels. Most people who use EPO are also given iron (either by injection or as tablets) to prevent low iron levels.



### **Sleep disorders and restless legs**

You may find that your sleep may become disturbed. Sleeping more during the day, and less at night, is not unusual.

You can also experience 'restless legs'. This is when the legs ache and become 'jittery' and you may have a strong impulse to kick out. A leg massage and/or a warm bath may ease these symptoms. Exercise before bedtime can make these symptoms worse.

Your doctor can prescribe medications to minimise restless legs and to improve sleep.

### **Swelling**

When kidneys are failing, they do not remove enough fluid from the body. This can lead to swelling in your legs, ankles, feet, face and hands. Medications and drinking less can help to control this.

### **Shortness of breath**

Trouble catching your breath can be related to your kidneys in two ways. Firstly, because fluid is not being removed correctly by your kidneys, extra fluid is retained in your body and can build up in your lungs. Secondly, anaemia can reduce the oxygen levels in your blood causing shortness of breath. Your doctor can prescribe medication to reduce fluid retention and to treat the anaemia.

### **Drowsiness and confusion**

As kidney failure advances over weeks or months, confusion may become noticeable and making decisions can become difficult. As waste products build-up in your blood stream your memory and concentration can sometimes be affected. Drowsiness is common and happens often as kidney function declines.

### **Pain**

Kidney failure is, in general, painless. However, some patients with other medical conditions may experience pain. Your doctor will assess and manage any pain with medications and other pain-relieving methods.

# Chapter 4

## Emotional impact of choosing conservative care or stopping dialysis



### Emotional responses

Knowing that you face kidney failure can trigger a range of emotions and feelings. You and your family may experience a variety of responses at different times throughout the course of your kidney disease.

You may find it difficult to talk to loved ones about refusing or stopping dialysis treatment and worry about how they will feel and react. Your doctor, nurse or spiritual advisor can help you to begin this discussion. It is often easier to speak first with

someone you trust and who makes you feel comfortable.

Although you may find it hard, the best approach is to discuss your thoughts and feelings openly with your family and loved ones. It will become easier if you can all be honest and acknowledge and accept each other's opinions and feelings. If you wish, a family meeting, with your doctor and nurse present, can be arranged to give all of you an opportunity to hear and discuss each other's opinions.

Whether it is your own decision, or the recommendation of your doctor and healthcare team to decline or stop treatment, you and your family may experience a range of emotions. These are all perfectly normal and to be expected. They include:

- Confusion
- Shock
- Sadness
- Anger
- Fear
- Depression
- Anxiety
- Relief
- Acceptance
- Peace

Reaching a decision can be very difficult, especially if you are uncertain about what to do, or if family members are struggling to accept your point of view or the opinion of your renal doctor. It can be an emotionally overwhelming and draining time for you and your loved ones. Yet for many people, making the decision to refuse or stop treatment can bring a great deal of relief and peace of mind.



## Some questions you may have

### **What can I expect if I choose *not to start dialysis*?**

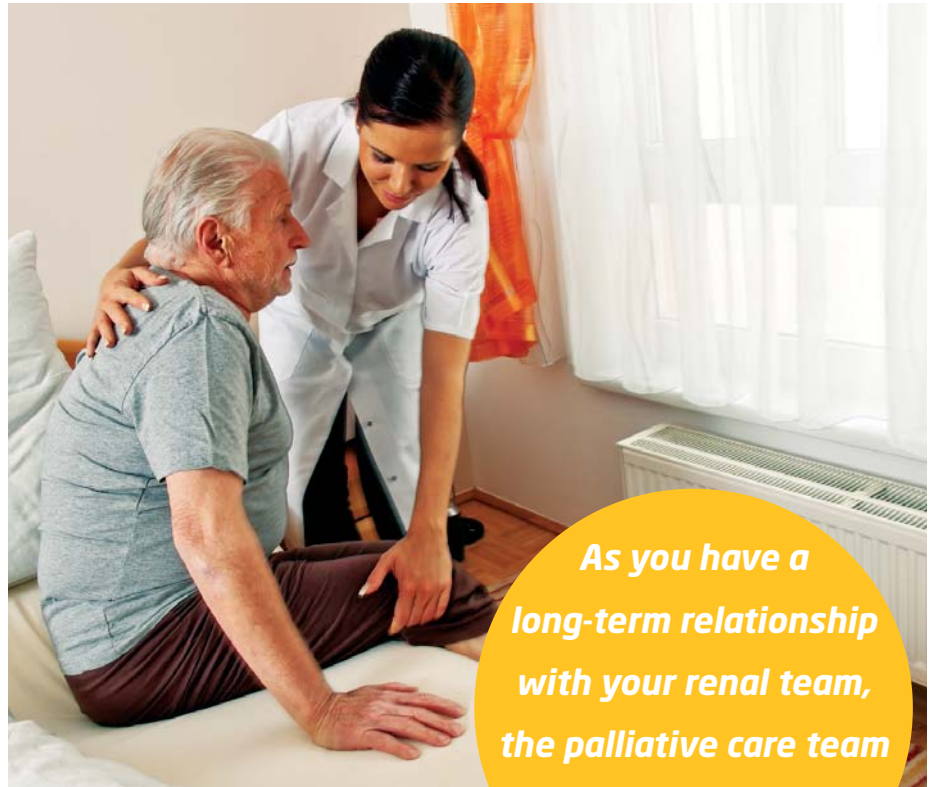
There is no certain answer to this question but we know that without dialysis treatment people with kidney failure will ultimately die. As everyone's situation is different, predicting how long you will live is difficult and depends on many things. The amount of kidney function that you have left, the rate of decline in your kidney function and your overall health will all play an important role the length of time you have left.

### **What can I expect if I choose *to stop dialysis treatment*?**

Without dialysis treatment, toxins will build up in the blood causing uraemia, which is always fatal. You will lose energy and become sleepy and lethargic. Over time, you will slip into a deeper and deeper sleep and gradually lose consciousness completely. It is hard to know how long this will take. However, if you stop dialysis treatment, you will die within days to weeks.

### **Is death from kidney failure *painful*?**

Most people who die from kidney failure will be kept comfortable and free from pain. Some people may experience pain from other illnesses or as a result of complications from their kidney failure. There are many very effective treatments for controlling pain in these circumstances.



*As you have a long-term relationship with your renal team, the palliative care team will work very closely with them.*

### **Will my doctor and nurses still be involved in my care?**

Your doctor and nursing staff will remain in close contact and available to you and your family. You may continue to attend the hospital outpatient clinic for as long as you wish.

Usually, your renal doctor will recommend that you see a palliative care doctor. As you already have a long-term relationship with your renal doctor and nurses, the palliative care team will work closely with them to meet your needs.

### **Will I have a choice about where I will die?**

Sometimes people choose to die in the comfort of their own homes. If this is your wish, your

local primary care staff such as the public health nurse and your GP will become involved in your care. They will discuss all options available to you, taking into account your preferences, and advise you and your family about the suitability of each for you.

### **Will I be able to eat and drink whatever I like?**

Typically, there can be some relaxation of your renal diet, so you can enjoy some special treats. However, drinking too much liquid can cause breathing difficulties and distress. Your doctor and dietitian will advise you about how to best manage your diet and what you can eat and drink.

# End-of-life care



**Palliative care is an approach that improves the quality of life of patients facing life-threatening illness and their families. Palliative care prevents and relieves symptoms by assessing and treating physical, psychosocial and spiritual needs.**

You may wish to die at home surrounded by those you love. For this to happen, you will need support and resources. Good co-operation and communication between your renal team and those looking after you in the community is the most effective way to deliver the care to meet your needs. In most communities, there is a co-ordinated approach to end-of-life care. You will be cared for by your primary care team which includes the public health nurse, occupational therapist, physiotherapist and others.

Palliative care is provided by specialist doctors, nurses and other healthcare professionals.

This care can be given at home, in a nursing home or in a hospital.

Palliative care always focus on maintaining a good quality of life for you by controlling any symptoms you may have and by providing psychosocial and spiritual support. They can help you and your family to make the important decisions associated with the latter stages of your kidney failure.

Admission to a specialist palliative care unit or hospice is only considered or advised when symptoms are very complex and difficult to manage or life expectancy is short.

If you have to go to a hospital emergency department for any reason, the most suitable on-going care arrangements will be made in consultation with you and your family. These may include admission to hospital, transfer to another healthcare facility or discharge home with appropriate nursing and community services.

We will do all we can to make sure you are cared for according to your wishes.



*Treasure the time you have when you are prepared for your final days. The time remaining can be spent in companionship, reminiscing, laughing and crying. Many people never have the chance for closure nor the chance to express affection and say goodbye.*

## Pastoral Care

Pastoral Care Departments operate on an multi-faith basis and are staffed accordingly. They provide full pastoral care services to patients and their families. If at any time you would like to speak to them, ask any member of staff to contact them for you

**Pastoral care can offer you:**

- A space for reflection
- A listening non-judgmental ear
- Hope and healing
- Prayer
- Help with worry, fear and anxiety

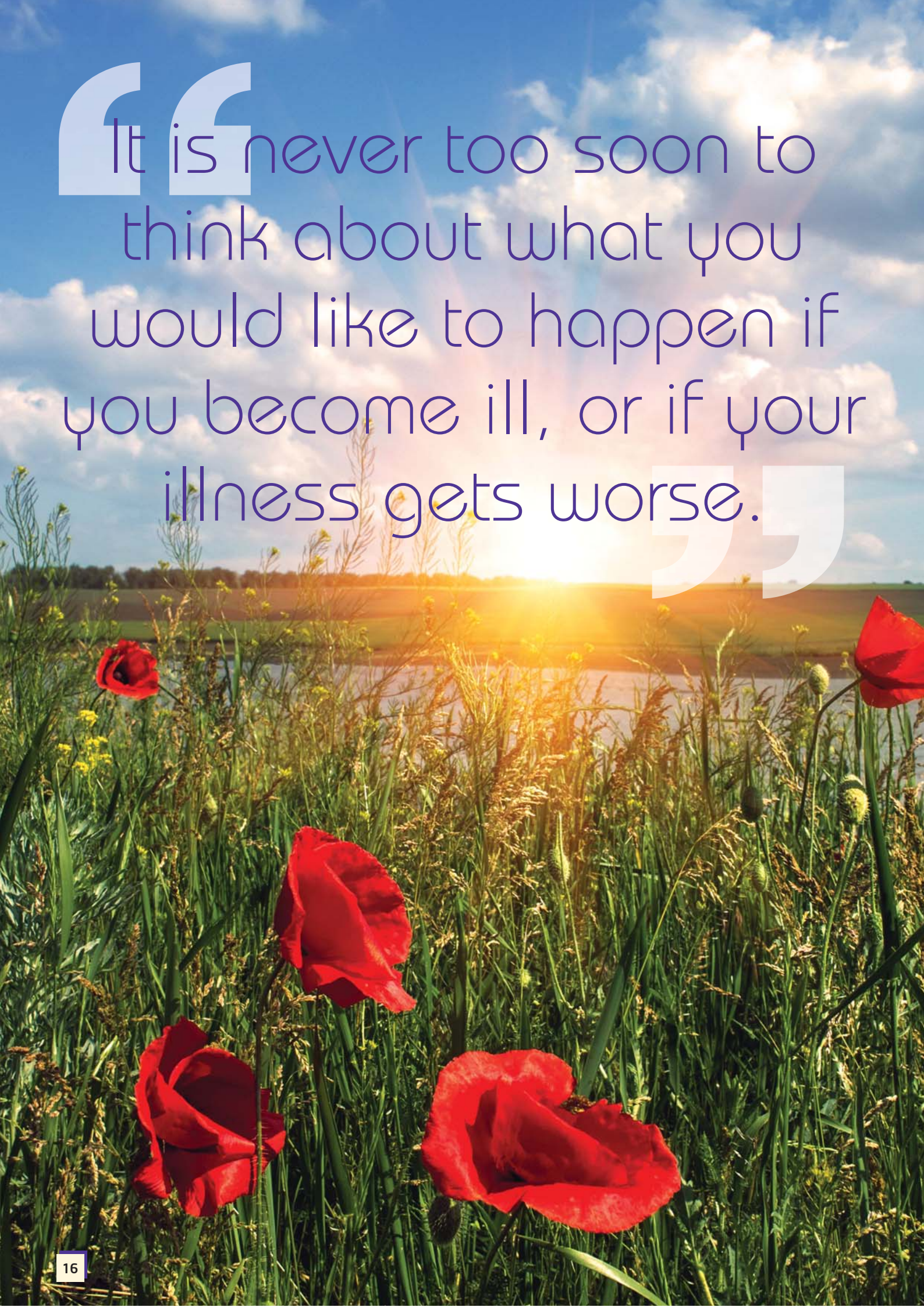


# HospiceFriendly HOSPITALS

Putting Hospice Principles into Hospital Practice.

Many hospitals around Ireland are part of the Hospice Friendly Hospitals programme. This means that the hospital staff have been trained to be aware of the needs of patients and families as they face their final journey.





“It is never too soon to think about what you would like to happen if you become ill, or if your illness gets worse.”



## Planning for the future

Thinking about end-of-life issues can be difficult for anyone, especially when their health is still good and the possibility of developing a serious illness is remote.

However, kidney failure is a very serious condition. At this point, you need to plan for the future.

If you have stopped dialysis treatment, you will know that you have a limited time to address what happens to your property and possessions. Discussing and planning for this can be especially fraught, as it requires taking some action. However, people often feel a sense of relief once these issues have been discussed and plans have been made. This is because much of the uncertainty that was causing the anxiety has been removed.

It is wise to plan for future care while you are still able to think clearly and rationally and are able to make your own wishes known.



The National Council of the Forum on End of Life has created a planning document that you can use to record your preferences, in the event of serious illness or death.

The document, called *Think Ahead, Speak for Yourself*, is available from your renal team or from the Irish Hospice Foundation.

### Planning for the future may include:

- making a will
- putting your personal affairs in order
- identifying those who will have your authority to act on your wishes should you lack the ability to do so (this is called 'power of attorney')
- advance care planning
- writing an Advance Healthcare Directive

## Putting your personal affairs in order

It is sensible to make sure your personal and financial affairs are in order.

You should contemplate talking with your solicitor and/or financial advisor about wills, estates and power of attorney. By doing this, you will have a say in directing what happens to your property and possessions after your death.

Having your affairs in order will give peace of mind to you and your family. It can also prevent a lot of emotional distress and conflict for your family after your death.

### We recommend that you:

- Prepare a last will and testament
- Discuss any special intentions or bequests with beneficiaries (the people to whom you are leaving your property and possessions)
- Discuss an Advance Care Plan (see below) with your renal doctor, nurse or family
- Arrange enduring power of attorney (this means nominating someone you trust to make decisions on your behalf when you are no longer able to)
- Organise your financial records – bank accounts, insurance policies, property, and so on
- Ensure a nominated person has the contact details of people who will be involved in the settlement of your estate such as your solicitor, accountant and the executor of your will
- Discuss your preferred funeral arrangements and service with your family or spiritual advisor

## Advance Care Planning



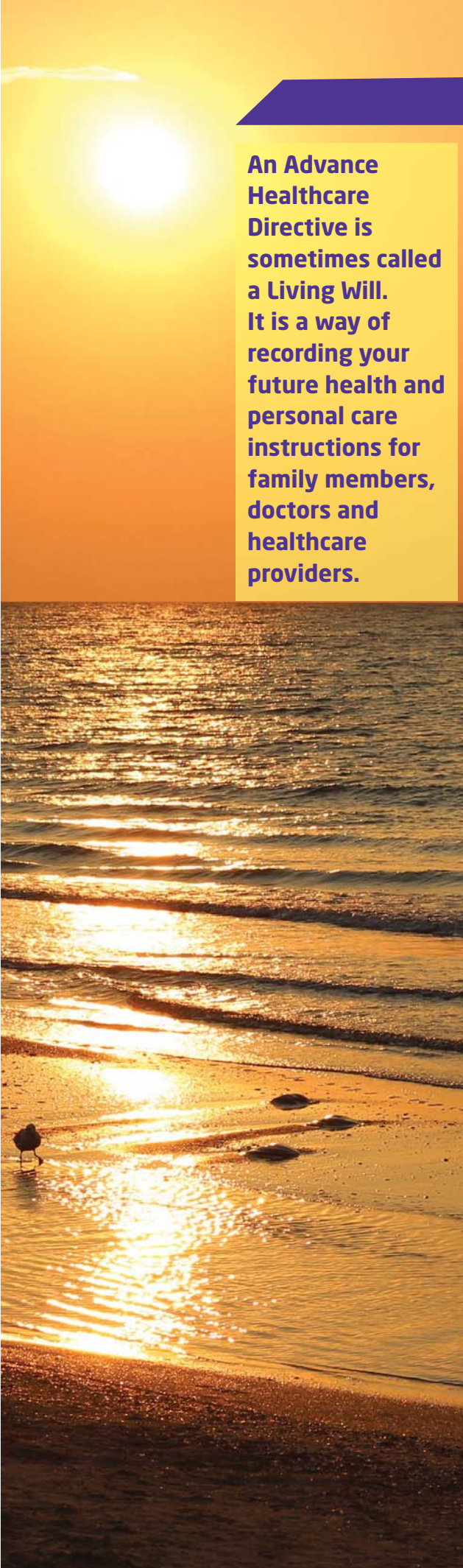
***Most families find it is a relief to have a plan in place for your future care.***

Advance Care Planning involves careful consideration of your values about your life and future health and medical treatments. It allows you to plan and communicate how you would like to be medically treated in the future if you are unable to make those decisions yourself. Advance Care Planning can be as simple as discussing your wishes about your future healthcare with your doctor or nurses, your family, your friends and other important people in your life.

An Advance Care Plan lets you say now what life-prolonging medical treatment you would, and would not, want in the future. It tells your doctor and family how you would like to be treated and removes any doubt about your preferences.

You may make your wishes known through these discussions or you may put your wishes and instructions in writing – this is called an *Advance Healthcare Directive*.





## Advance Healthcare Directives

**An Advance Healthcare Directive is sometimes called a Living Will. It is a way of recording your future health and personal care instructions for family members, doctors and healthcare providers.**

An Advance Healthcare Directive lets you record the type of care and treatment you would want if, in the future, you are unable to communicate or if you lose the ability to make decisions for yourself. It also enables those close to you to communicate your wishes with confidence.

An Advance Healthcare Directive is only used if you are unable to communicate or if you no longer have the ability to make decisions for yourself.

You can compose the Advance Healthcare Directive yourself or you can use the *Think Ahead, Speak for Yourself* form. You can record your wishes and instructions about the treatment and care you would prepare. The directive should be clear and up-to-date and written specifically to guide medical care. You can change the directive at any time and it is a good idea to review it regularly.

The Advance Healthcare Directive will only come into force when you become seriously ill and can no longer make decisions on your own behalf.

Discussing these matters with your family and doctor in advance means that your intentions are clear to those who love and care for you.

### What happens if I do not have an Advance Healthcare Directive?

The situation is a little different if you have not expressly recorded your care preferences and you face an emergency, are unable to give consent to treatments, or are unable to make your own decisions about your treatment preferences. In these situations, your doctor will make every effort to consider the benefits that dialysis treatment would give you.

Your doctor will also try to find out what your preference would have been by asking your relatives and friends. This does not mean that your relatives can decide on your behalf. It is only to help your doctor to make a careful and thoughtful judgement call on your behalf while keeping your best interests at heart. Healthcare staff are currently guided by the HSE Consent Policy.



Speak for Yourself

## The benefits of thinking ahead

### Things to consider:

- What if a day comes when you are unable to make decisions for yourself?
- What if you are suddenly taken ill, are involved in an accident or lose your ability to think clearly or independently?
- Do your closest family members or friends really know your wishes?

The image shows the cover of the 'Think ahead MY FORM'. The background is a dark green with several lighter green circles of different sizes. In the top left corner is the 'Think ahead' logo with the tagline 'Speak for Yourself'. In the center, there is a white rectangular box titled 'MY FORM' with a line for 'Name:'. At the bottom, there is a horizontal bar with five icons and labels: 'THINK' (speech bubble), 'TALK' (two speech bubbles), 'TELL' (mouth), 'RECORD' (document with pencil), and 'REVIEW' (document with magnifying glass).

***The purpose of Think Ahead is to guide members of the public in discussing and recording their preferences in the event of emergency, serious illness or death.***

The **Think Ahead** form is a planning document to use when you are well. It guides you in thinking about, discussing, and recording your preferences about all aspects of end of life.

It encourages you to make sure that those closest to you are aware of your preferences so that, should a time come when you are unable to express them yourself, your wishes will be clear to those caring for you or managing your affairs.

You do not have to fill out the complete form. It is entirely voluntary so only fill out those sections you are comfortable with. The most important information to give is:

- details about your identity (your name, address, and so on), and
- who you would like contacted in an emergency.

We recommend that you take your time and complete the form over several sittings.



Medical care is a very personal thing. Our preferences are shaped by our beliefs and values. Unless you expressly record your care preferences, your family members or medical team will not know your wishes and may disagree on your care. You can avoid this by completing section 2 of the *Think Ahead, Speak for Yourself* form which focuses on your medical care preferences.

Generally, your GP or treating doctor will be central to your care and we encourage you to discuss your care preferences with them.

However, in an emergency, the doctor treating you may be completely unfamiliar with you and your care preferences. In those situations, a record of your wishes can be very useful.

Finally, your preferences may change over time, depending on your age, illness or other factors. This is why it is important to review and update your wishes regularly. We encourage you to view this form as a living document that can change to reflect your preferences.





A photograph of an elderly couple sitting on a wooden bench on a promenade. They are seen from behind, looking out over a blue sea towards a distant coastline with hills. The sky is blue with scattered white clouds. The bench is made of light-colored wood with dark metal legs. The ground is a light-colored paved path.

# *A Final Note*

## **Reviewing Your Life**

Reading this book may have stirred many thoughts and emotions about your life, your family and your spiritual beliefs. Speaking with your doctor, nurse or spiritual advisor may help to clarify these thoughts and feelings, and reduce anxiety.

An issue as complex as the choice to decline or end dialysis treatment can take time to think through and reach a decision. For this reason, you may revisit it several times. If you cannot reach a decision, don't worry. Your treatment will continue until you are more certain what to do.

Write down any questions you have after reading this book. You can use these to guide your discussion with your doctor, nurse or family, whose opinions and advice you may value.

## Your Questions and Notes...





## Useful Contacts and Websites



**Aware** 72 Lower Leeson Street, Dublin 2

**Tel:** (01) 661 7211 **Web:** [www.aware.ie](http://www.aware.ie)

### **All Ireland Institute of Hospice and Pallative Care**

Adult Pallative Hub, Central Resource for Information, Guidance and Services

**Web:** [www.aiihpc.org/pallative-hub/adult-public](http://www.aiihpc.org/pallative-hub/adult-public)

### **Beaumont Hospital Kidney Centre**

**Web:** [www.beaumont.ie/kidneycentre](http://www.beaumont.ie/kidneycentre)

**Carers Association** Market Square, Tullamore, Co. Offaly

**Tel:** 1800 240 724 **Web:** [www.carersireland.com](http://www.carersireland.com)

### **Citizens Information**

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

### **Department of Justice and Equality**

Information on *Assisted Decision Making*

[www.justice.ie/en/JELR/Pages/Assisted\\_Decision-Making\\_\(Capacity\)\\_Act\\_2015](http://www.justice.ie/en/JELR/Pages/Assisted_Decision-Making_(Capacity)_Act_2015)

**Dying Matters**, UK website resource

**Web:** [www.dyingmatters.org](http://www.dyingmatters.org)

**Free Legal Aid Centres (FLAC)** 13 Lower Dorset Street, Dublin 1, Ireland

**Tel:** 1890 350 250 **Web:** [www.flac.ie](http://www.flac.ie)

### **HSE National Counselling Service**

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

### **Irish Hospice Foundation**

**Web:** [www.irishhospicefoundation.ie](http://www.irishhospicefoundation.ie)

Information on *Assisted Decision Making*

[www.hospicefoundation.ie/programmes/advance-care/assisted-decision-making-2](http://www.hospicefoundation.ie/programmes/advance-care/assisted-decision-making-2)

**Think Ahead, Speak for Yourself** planning document

**Web:** [www.thinkahead.ie](http://www.thinkahead.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)

### **Money Advice and Budgeting Service (MABS)**

**Web:** [www.mabs.ie](http://www.mabs.ie)

### **Northern Ireland Kidney Patients Association (NIPKA)**

PO Box 85, Carrickfergus, Co. Antrim, BT38 OAT

**Email:** [info@nipka.org](mailto:info@nipka.org) **Web:** [www.nipka.org](http://www.nipka.org)

### **Support and Advocacy for Older People (SAGE)**

**Web:** [www.thirdageireland.ie/sage](http://www.thirdageireland.ie/sage)



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Striving for the best care  
at end of life for all

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