KIDNEY FAILURE EXPLAINED

‘Answers everything you always needed to know but were afraid to ask’

Austin Donohoe, Chairman of Kidney Alliance, and Former Chairman of the NKF

SECOND EDITION

Dr Andy Stein and Janet Wild, RGN

COMMENDED by the British Medical Association
Comments on *Kidney Failure Explained* from readers

‘I was so impressed by the wonderful way the book is presented, in terms which everyone can understand. Our committee has recommended the book to our members.’

*Roy Bradbury, Chairman, Sheffield Area Kidney Association*

‘This is a very well written book and it should be of great value to renal patients.’

*Professor R. Wilkinson, Consultant Nephrologist, Freeman Group of Hospitals, Newcastle-upon-Tyne*

‘The book is excellent and will prove very valuable to a variety of different groups. I shall certainly be recommending it to patients and to general practitioners in particular.’

*Dr Robin Winney, Consultant Renal Physician, Department of Renal Medicine, The Royal Infirmary of Edinburgh*

‘The content of the book was realistic but positive and covered all aspects of kidney failure. I have already started recommending it to some of my patients.’

*Ros Tibbles, Pre-dialysis Sister, Department of Renal Medicine and Transplantation, The Royal Hospitals NHS Trust*

‘*Kidney Failure Explained* not only answered all the questions I wanted to ask, it also answered a lot of questions I hadn’t even thought of. Books of this kind are badly needed. Thank you for a clear and precise text, in language I can understand.’

*Dennis Jackson, CAPD patient*

‘Your book has been a tremendous help and support throughout. I think that *Kidney Failure Explained* should be offered to all renal patients.’

*J. R., Kidney donor, Northampton*
Kidney Failure Explained

Everything you always wanted to know about dialysis and kidney transplants but were afraid to ask

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CLASS PUBLISHING • LONDON
DEDICATION

This book is dedicated to the tens of thousands of patients with kidney failure in the UK. Their will to live has inspired us all.
## Contents

### Foreword to This Edition
*Austin Donohoe*  
x

### Foreword to the First Edition
*Professor John Walls*  
xi

### Acknowledgements
xii

### Introduction
xiii

### 1 What is Kidney Failure?

Introduction  
Kidneys – what and where are they?  
The kidneys’ main job: making urine  
Why make urine?  
Removing toxic wastes  
Removing excess water  
Other functions of the kidneys  
Kidney failure – what is it?  
What are the symptoms?  
How is kidney failure diagnosed?  
What causes kidney failure?  
The ‘progression’ of kidney failure  
What is ESRF?  
How is ESRF treated?  
When should dialysis be started?  
Can the need for dialysis be delayed?  
Will dialysis or a transplant solve the problem?  
Why treat kidney failure?

### 2 Toxin ‘clearance’

Introduction  
Why is clearance measured?  
How is clearance measured?  
Why measure urea or creatinine?  
Types of test  
Blood tests for urea or creatinine  
Blood creatinine before dialysis  
Starting dialysis  
Blood creatinine during dialysis  
Blood creatinine with a transplant  
Urea or creatinine clearance tests  
How is clearance measured?  
Urea or creatinine clearance during dialysis

### 3 Fluid Balance

Introduction  
Flesh and fluid  
What is the ‘target weight’?  
Control of fluid balance  
Sodium and fluid balance  
What is fluid overload?  
How is fluid overload treated?  
Dehydration  
How is dehydration treated?
9 Peritoneal Dialysis

Introduction 49
Who can be treated by PD? 49
What does PD do? 49
How does PD work? 50
The peritoneum 50
How is PD done? 51
Operation to insert a PD catheter 51
The training 51
Methods of fluid exchange 52
Fluid exchanges in CAPD 53
Fluid exchanges in APD 53
CAPD or APD? 54
Bigger bags and stronger bags 54
Alternative dialysis fluids 55
Living with PD 55
Delivery and storage of supplies 56
Possible problems with PD 56
Poor drainage 56
Leaks 57
Hernias 57
Peritonitis 57
Exit site infections 58

Single-needle dialysis 64
How much dialysis is needed? 65
Haemodialysis in hospital 65
Satellite haemodialysis 66
Haemodialysis at home 66
Living with haemodialysis 66
Possible problems during haemodialysis 67
Fluid overload and haemodialysis 67
Hyperkalaemia (excess potassium) 67
Problems with access 68
Problems for diabetics 68
Bleeding 68
Infections 68

10 Haemodialysis

Introduction 60
Who can be treated by haemodialysis? 60
What does haemodialysis do? 60
How does haemodialysis work? 60
Different dialysers and machines 61
How is haemodialysis done? 62
‘Access’ to the bloodstream 62
Dialysis catheters 62
Fistulas 63
Other types of access 64

Introduction 70
The benefits 70
Who can have a transplant? 70
New kidneys and old diseases 71
Do you have to be on dialysis first? 71
Finding a suitable kidney 71
Matching the blood group 72
Matching the tissue type 72
Testing for viruses 73
Other tests for transplant suitability 73
Cadaveric transplants 73
Other sources of kidneys 74
Xenotransplantation 74
Stem cell ‘kidneys’ 74
The transplant waiting list 74
Being ready for a transplant 75
Tests before the operation 75
The transplant operation 76
12 Living Transplantation

Introduction 77
The benefits 78
Patient survival after live transplants 78
Cadaveric or live transplant – which is best? 78
Who can donate a kidney? 79
Which donor? 79
Who will do the asking? 80
Tests for the recipient 80
Tests for the donor 80
Living unrelated transplants 81
Buying and selling organs 81
Being offered a cadaveric transplant while planning a living transplant 82
Preparation for a live transplant 82
Removing the kidney from the donor 82
Risks to the donor 83
Risks to the recipient 83
Rejection 83
Conclusion 83

13 The Transplant Operation and After

Introduction 85
The transplant operation 85
Post-operative tubes 85
After the operation 86
How long will the transplant last? 86
Survival after a cadaveric transplant 88
Possible problems after a transplant 88
The rejection process 88
Acute rejection 89
Chronic rejection 89
Immuno-suppressant drugs 90
The ‘best’ regime of immuno-suppressant drugs 90
Drug side effects 91

14 Diet

Introduction 94
Healthy eating guidelines 94
What is ‘nutritional status’? 94
Dietary protein and kidney failure 95
Diet before starting dialysis 95
Diet during dialysis 95
Gaining weight (obesity) and kidney failure 95
Losing weight and kidney failure 96
Poor appetite and malnutrition 96
Other causes of weight loss 96
Protein/energy supplements 97
Phosphate and calcium 97
Potassium 97
What about salt and fluid? 98
Vitamin supplements 98
Individual dietary recommendations 98
Diet after a transplant 99

15 Psychological Aspects

Introduction 100
Body and mind 100
Psychological needs 100
Stresses on kidney patients 100
The diagnosis 101
Initial reactions 101
Longer-term problems 101
Factors affecting the ability to cope 103
Coping strategies 105
## 16 Sexual Problems

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>106</td>
</tr>
<tr>
<td>Investigating sexual problems</td>
<td>106</td>
</tr>
<tr>
<td>Impotence: the male sexual problem</td>
<td>106</td>
</tr>
<tr>
<td>What causes impotence?</td>
<td>106</td>
</tr>
<tr>
<td>How is impotence investigated?</td>
<td>107</td>
</tr>
<tr>
<td>How is impotence treated?</td>
<td>108</td>
</tr>
<tr>
<td>Tablets (Viagra and Uprima)</td>
<td>108</td>
</tr>
<tr>
<td>Hormones</td>
<td>109</td>
</tr>
<tr>
<td>Vacuum devices</td>
<td>109</td>
</tr>
<tr>
<td>Penile injection therapy</td>
<td>110</td>
</tr>
<tr>
<td>Penile insertion (transurethral)</td>
<td>110</td>
</tr>
<tr>
<td>Penile implants</td>
<td>111</td>
</tr>
<tr>
<td>Emotional problems</td>
<td>111</td>
</tr>
<tr>
<td>Sexual problems for women</td>
<td>111</td>
</tr>
<tr>
<td>Menstrual periods and fertility</td>
<td>112</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>113</td>
</tr>
</tbody>
</table>

## 17 Death and Dying

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>116</td>
</tr>
<tr>
<td>Death from kidney failure</td>
<td>116</td>
</tr>
<tr>
<td>Where should this period be spent?</td>
<td>117</td>
</tr>
<tr>
<td>The decision not to start dialysis</td>
<td>117</td>
</tr>
<tr>
<td>Trials of dialysis</td>
<td>118</td>
</tr>
<tr>
<td>Choosing the lesser of two evils</td>
<td>118</td>
</tr>
<tr>
<td>Those who cannot make an informed</td>
<td>118</td>
</tr>
<tr>
<td>The decision to stop dialysis</td>
<td>119</td>
</tr>
<tr>
<td>Withdrawing from treatment after</td>
<td>120</td>
</tr>
<tr>
<td>Spiritual concerns</td>
<td>120</td>
</tr>
<tr>
<td>Rate of transplantation</td>
<td>126</td>
</tr>
<tr>
<td>The ‘postcode lottery’</td>
<td>126</td>
</tr>
<tr>
<td>The shortfall in UK renal services</td>
<td>128</td>
</tr>
<tr>
<td>The Renal National Service Framework</td>
<td>129</td>
</tr>
<tr>
<td>Patients’ voices, patients’ rights</td>
<td>130</td>
</tr>
</tbody>
</table>

## 18 The Future

<table>
<thead>
<tr>
<th>Topic</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>122</td>
</tr>
<tr>
<td>Survival with kidney failure</td>
<td>122</td>
</tr>
<tr>
<td>Why do people with kidney failure die?</td>
<td>123</td>
</tr>
<tr>
<td>Individuals not statistics</td>
<td>124</td>
</tr>
<tr>
<td>How good are the services?</td>
<td>124</td>
</tr>
<tr>
<td>The ‘postcode lottery’</td>
<td>126</td>
</tr>
<tr>
<td>Rate of transplantation</td>
<td>126</td>
</tr>
<tr>
<td>The shortfall in UK renal services</td>
<td>128</td>
</tr>
<tr>
<td>The Renal National Service Framework</td>
<td>129</td>
</tr>
<tr>
<td>Patients’ voices, patients’ rights</td>
<td>130</td>
</tr>
</tbody>
</table>

### Glossary

### Further reading

### Useful addresses and websites

### Index

### Priority order form
As someone with kidney failure, I have tried to find out as much as I can about my disease. Much of the information I found was confusing, too technical or just plain dull.

The first edition of this book was a revelation to me – it dealt with the issues that I wanted to know about and it did so in a way that was clear but not patronising or superficial.

This updated second edition continues and builds on that standard. There are expanded chapters on transplantation and a new chapter on living donation. There is also expanded information on the provision of services and a useful list of helpful organisations.

Even more than before, this book answers everything you always needed to know but were afraid to ask.

And why shouldn’t you? The discovery that you have kidney failure is traumatic and can deeply affect your life and the lives of those close to you. The treatment is lifelong and often intrusive, frequently including a bewildering array of options, treatments and drugs.

I’ve found that getting the right information at the right time is vital – it has given me some sense of control and helped me to cope.

This is an excellent book – if you are going to buy just one book on kidney failure, buy this one.

Austin Donohoe
Former Chairman, National Kidney Federation
For most patients, medicine is a very confusing subject, with a totally different and at times apparently alien vocabulary. To complicate matters further, within medicine there are numerous specialities, each dealing with a separate organ or system within the body, and with a different group of individuals caring for that speciality. Renal medicine, or nephrology as it is often called, has more than its share of confusion. Add to that the words ‘kidney failure’ and it is not surprising the alarm that this creates for our patients. The complexities regarding the causes of kidney disease, its complications, and the different methods of treatment, all potentially lead to further confusion and concern.

It is appropriate and timely that a book should have been written to clarify this situation. Dr Andy Stein and Janet Wild are to be complimented on their achievement. This book is written with the patient’s welfare as its first priority and succeeds in this regard. The various chapters clearly explain the subject matter and should help patients with kidney disease to understand their problem – or at least to ask the appropriate question to the appropriate person. Especially useful is the glossary of terms used in nephrology, to be found at the end of the text.

It is a pleasure to be asked to write this foreword and I would recommend this book to all kidney patients, new or old, as standard reading.

John Walls,
Late Professor of Nephrology,
Leicester General Hospital
Kidney disease is about teamwork. This book could not have been written without the combined efforts of the following people. Professor Gerry Coles (Cardiff), Dr Jo Adu (Birmingham) and Dr Tim Mathew (Adelaide, Australia) inspired Andy Stein to be a kidney doctor in the first place.

An early force behind the book was Val Said, a kidney patient, who works tirelessly as a volunteer advocate for patients with kidney failure in the UK. Her efforts have been supported by Austin Donohoe, former Chairman of the National Kidney Federation.

The late Professor John Walls (Leicester) and Professor Terry Feest (Bristol) were the first doctors to review the first edition of the book, and both devoted much time to improving it. Subsequently the book was also reviewed by Gillian Matthews (Andy’s mother), Dr Steve Nelson (St George’s, London) and Dr Phin Kon (King’s, London). The guest writers, Juliet Auer (Oxford), Gemma Bircher (Leicester), Peter Ellis (King’s, London), Jean Hooper (Gloucester) and Dr Ian Lawrence (Leicester) all took to their task keenly and with speed. Individual chapters were reviewed by Mr Paul Gibbs (King’s, London), Dr John Cunningham (The London), Althea Mahon (Bart’s, London), Professor Mike Nicholson (Leicester), Dr Ian Abbs (Guy’s, London), Mr Geoff Koffman (Guy’s, London) and Dr Roger Greenwood (Stevenage).

This edition includes new chapters on death and dying (contributed by Juliet Auer, Oxford) and living transplantation. Dr Rob Higgins, Nick West (both Coventry) and Rosemary Elwell (Leicester) contributed to the transplant chapters, especially the one on living transplants. Dr Catherine Nelson-Piercy (St Thomas’, London) is largely responsible for the sections on female fertility and pregnancy in Chapter 16. Katherine Fairhurst and Andrew Schache, both medical students from Warwick, helped with the checking of basic facts. Kitty Jager (EDTA), David Ansell (Renal Registry, Bristol) and Phil Pocock (UK Transplant) helped with the statistical information for Chapter 18. Terry Feest was, once again, the principal reviewer — this time helped by Gillian Matthews and Val Said. Their contribution cannot be over-emphasised.

We are grateful to Saheed Rashid (Baxter Healthcare), Saima Butt (Roche Pharmaceuticals), Sally Taylor and Mike Stark (Janssen-Cilag) and Tim Proger (Kimal) for raising funds for the first edition of the book.

The publisher, Richard Warner, insisted on literary excellence but never ‘pushed’ us faster than we could cope with. Darren Bennett is thanked for his clear diagrams and design, and Carrie Walker for her meticulous proof reading. Lastly, and most importantly, we thank Ruth Midgley and Richenda Milton-Thompson, editors of the two editions, for insisting on factual accuracy and clear writing for our readers. They converted this book from something that was ‘all right’ to something of which which we can be proud.
This is a book about kidney failure. It has been written primarily for people with kidney failure. But, as any partner, friend or family member of a kidney patient knows, kidney failure is a family business. ‘They’ also usually want to know as much as possible (sometimes even more than the patient) about the disease. So this book is also for ‘them’, the silent support that keeps a kidney patient alive.

The idea for this book came at the end of a dinner I had with a group of 20 or so peritoneal dialysis patients in 1995. I had gone away with them on an ‘adventure weekend’ to North Wales. It was a dark and blustery winter’s night. At the end of the meal, I asked them what they hated most about kidney failure. I expected answers like: ‘the arrogance of the doctors’, ‘having to take Calcichew tablets’, ‘the never ending drudgery of doing four peritoneal dialysis exchanges every day’. But I was wrong. The patients all said that the worst thing was the ‘lack of information on kidney failure’.

I knew I could give them what they wanted. So, that night, I promised them that I would write them a book describing all aspects of kidney failure. They said they wanted a book that was understandable, hard-hitting and truthful. They didn’t want to be patronised. They didn’t want wool pulling over their eyes. If kidney failure was to kill them, they wanted to know, and when, and why.

So I make no apologies to those kidney patients who ‘don’t want’ to know. I believe that they are only a small proportion of the total and that they probably will not buy this book anyway.

The book would never have come to fruition without my co-author, Janet Wild, who has many years’ experience as a senior kidney nurse. Janet and I have written most of the book. Five of the other chapters have been written or co-written by friends of ours, all of whom currently work in kidney medicine: Gemma Bircher (Diet), Peter Ellis (Dialysis), Jean Hooper (Psychological Aspects), Ian Lawrence and Catherine Nelson-Piercy (Sexual Problems). The new chapter on ‘Death and Dying’ has been written by Juliet Auer who has a background in social work and is currently Renal Support Manager at the Oxford Kidney Unit.

As in all aspects of medicine, different doctors favour different ways of treating patients. I have tried to present the views of the majority in this book. I have also tried to point out controversial areas – either where we don’t really understand things (for example, why kidneys fail in the first place) or where there are real differences of opinion (such as which treatment is ‘the best’, or when a treatment is available in one kidney unit but not in another). The limitation of the treatments currently available is one of the themes of the book.

Over the past few years, whenever I get frustrated about the inadequacies of the NHS or the England cricket team, my mind turns back to that dark night in Wales. I am glad that my computer somehow drew me to fulfil my promise.

Andy Stein
2002
1 What is kidney failure?

This first chapter begins by explaining how kidneys work. Then it explores what goes wrong when someone has chronic kidney failure, what causes this problem and why it should be treated.

Introduction
Chronic kidney failure is a serious, long-term medical condition. At the present time, there are approximately 30,000 people in the UK who are either on dialysis or who have received a kidney transplant to treat chronic kidney failure. This is approximately one person in 2,000, making it a very rare condition. This means that a typical family doctor will have only one kidney patient ‘on their books’.

There are approximately 5,000 new patients diagnosed with kidney failure every year.

Chronic kidney failure has many possible causes, but the effects are usually the same. The kidneys become less and less able to do their normal work. After a time, the kidneys stop working almost completely – a condition called end-stage renal failure (ESRF), end-stage renal disease (ESRD) or end-stage kidney failure. Treatment that takes over the work of the patient’s kidneys is then essential. The main treatments are dialysis – either peritoneal dialysis (PD) or haemodialysis – and transplantation. These treatments cannot ‘cure’ kidney failure, but they can improve health and prolong life.

Kidneys – what and where are they?
Most people have two kidneys. These important body organs are shaped like beans and are about 12 centimetres (5 inches) long, which is about the length of a man’s palm. They are approximately 6 centimetres wide and 3 centimetres thick. Each kidney weighs about 150 grams (6 ounces). The kidneys lie under the ribs at the back, just above the waist, one on either side of the body (see diagram on next page).

The kidneys lie deep inside the body, so you cannot normally ‘feel’ them.

The kidneys’ main job: making urine
The main job of the kidneys is to clean up the blood and make urine from the waste products they take out of it. Blood is pumped by the heart to the kidneys. Each kidney has a drainage system that takes urine from that kidney to the bladder. This drainage system is like a funnel with a tube (the ureter) that connects the kidney to the bladder (see diagram on next page). Urine
passes down the ureters (one for each kidney) into the bladder.

Urine is stored in the bladder before being passed from the body via another tube, called the urethra. The bladder holds about 400 ml (¾ pint) of urine when ‘full’. People normally pass around 2 litres of urine per day.

**Why make urine?**
The kidneys make urine in order to perform their two most important functions. These are:

1. **Removing toxic wastes from the blood** – a process called ‘clearance’. (See below for a brief description, and Chapter 2 for more details.)

2. **Removing excess water from the body** – a process called ‘ultrafiltration’. (See page 3 for a brief description, and Chapter 3 for more details.)

**Removing toxic wastes**
The kidneys play a very important role in getting rid of waste products. The food that we eat is normally digested in the stomach and the bowels. During digestion, the food is broken down into substances that can be carried around the body in the blood. These ‘good things’ in the bloodstream provide every part of the body with the energy it needs for work, and with the substances necessary for growth and repair.

When the different parts of the body make use of the various ‘good things’ in the blood, they also produce waste products. These wastes are toxic (poisonous) to the body and make people unwell unless they are removed. Like the ‘good things’, these ‘bad things’ also travel around the body in the bloodstream.

When the waste products of food in the blood reach the kidneys, it is the job of the kidneys to get rid of them in the urine. What the kidneys do is to sieve and filter the blood, removing the wastes and putting them in the urine, but leaving the ‘good things’ in the blood. Healthy kidneys generally have no problems getting rid of all the many toxins normally produced by the body.

In people with kidney failure, however, the levels of toxins build up in the blood. It is this build-up of toxins that makes people with kidney failure feel unwell. When someone is in the early stages of kidney failure, there are
usually no symptoms, because the toxin levels are not high enough to cause them. (This can be true even when the kidneys are working at less than 25% of their normal capacity.)

**REMOVING EXCESS WATER**

The second most important function of the kidneys is to remove excess water from the body. As well as getting rid of the waste products of food, healthy kidneys also remove excess fluids from the body. Like the food that we eat, the water (and tea, coffee, beer and all other liquids) that we drink is digested in the stomach and bowels and absorbed into the blood. When the blood reaches the kidneys, the normal sieving and filtering process removes any excess water and puts it in the urine. So normal urine contains not only the waste products of food, but also any excess water that has been drunk.
In people with kidney failure, water cannot so easily be put into the urine. Excess fluid can therefore build up in the body, causing it to become ‘waterlogged’ – a condition called fluid overload (see Chapter 3). This may lead to swelling of the ankles, and shortness of breath due to excess fluid in the lungs.

Other functions of the kidneys
As well as water and waste removal, the kidneys have three important ‘extra’ functions. These are:

1. **Helping to control blood pressure.** The blood pressure is finely controlled by healthy kidneys. When someone’s kidneys fail, their blood pressure usually goes up, although it is not really known why. High blood pressure is unlikely to cause symptoms unless the pressure gets very high, but it increases the risk of a stroke or heart attack, and can cause the kidneys to deteriorate more rapidly (see also Chapter 4).

2. **Helping to control the manufacture of red blood cells.** The kidneys help control the making of red blood cells in the bone marrow. The red blood cells float in the liquid part of the blood (called plasma). Their job is to carry oxygen around the body. Every part of the body needs oxygen to function properly.

   When someone has kidney failure, they make fewer red blood cells than normal. This causes them to become anaemic (i.e. they are short of red blood cells). This anaemia contributes to the tiredness suffered by most people with kidney failure – it is not only high toxin levels that cause tiredness. (See Chapter 5 for more about anaemia and how it can be treated.)

3. **Helping to keep the bones strong and healthy.** Calcium and phosphate are two minerals found in the blood and in the bones. If the bones are to stay strong and healthy, there must be a correct balance between these minerals in the body. The kidneys help to maintain this balance. When someone develops kidney failure, the normal balance between calcium and phosphate in the body is lost. The level of calcium in the blood goes down, while the level of phosphate in the blood goes up. Unless this imbalance is treated, it will result in a condition called renal bone disease. This may cause aches and pains in the bones, and even fractures. (See Chapter 6 for more information about renal bone disease and its treatment.)

Kidney failure – what is it?
In short, kidney failure is a condition in which the kidneys are less able than normal to perform their usual functions. These functions are:

- removing toxic waste;
- removing excess water;
- helping to control blood pressure;
- helping to control red blood cell manufacture; and
- helping to keep the bones strong and healthy.

This book is about the long-term condition known as chronic kidney failure or chronic renal failure. There is a separate condition, known as acute kidney failure, in which the kidneys suddenly stop working. Short-term treatment may be needed for acute kidney failure, but the kidneys usually get better on their own. This book does not tell you about acute kidney failure.

When someone has chronic kidney failure, the kidneys become less and less able to do their work. This happens gradually, usually over a period of many years. Eventually, the kidneys stop working almost completely – a condition called end-stage renal failure or ESRF. Treatment is then essential to take over the work of the kidneys and so keep the patient alive. The treatments for ESRF are dialysis or a kidney transplant (see page 1).
**What are the symptoms?**
In the early stages of chronic kidney failure, there are often no symptoms. Later, the condition may cause any of the following:

- itching;
- weakness or tiredness;
- loss of appetite;
- poor concentration;
- restless legs;
- leg cramps;
- swollen ankles;
- shortness of breath;
- poor sleeping;
- low sex drive; and
- feeling cold.

**How is kidney failure diagnosed?**
The only reliable way to diagnose kidney failure in the early stages is by measuring the levels of a substance called creatinine in a patient’s blood. Creatinine is one of the many waste products that build up in the blood when someone has kidney failure.

Creatinine level is measured by a simple blood test. The higher the creatinine level, the worse the kidney function. The normal level of creatinine is between 70 and 120 µmol/l (micromoles per litre of blood).

- **If a patient’s creatinine is over 120 µmol/l, then they have kidney failure** (see Chapter 2).

As soon as the creatinine level starts to rise, the kidney problem is already serious. A creatinine level slightly above normal (say, 150 µmol/l) may mean that the kidneys are already down to about 75% of normal function.

Creatinine testing is used not only to detect kidney failure, but also used at all stages of kidney disease – before dialysis, during dialysis and after a transplant. The amount of creatinine in the blood is the single most important piece of information that doctors and nurses require when looking after people with kidney failure.

(See Chapter 2 for more information.)

A kidney patient should know their blood creatinine level all the time.

**What causes kidney failure?**
There are hundreds of different diseases that can cause chronic kidney failure. Usually, however, kidney failure is more likely to be due to one of the following:

1. **Nephritis.** The term ‘nephritis’ covers a group of conditions in which there is long-term inflammation of the kidneys (‘neph-’ means ‘kidney’, and ‘-itis’ means ‘inflammation’). Sometimes the condition is described, more specifically, as glomerulonephritis or GN. (‘Glomerulo-’ refers to the glomeruli, which are part of the kidneys’ filtration unit.)

   The causes of most types of nephritis are unknown. Nephritis can only be diagnosed for certain by a kidney biopsy. This involves removing a small piece of kidney to be examined under a microscope (see page 41).

2. **Polycystic kidney disease (PCKD).** This is an inherited disease (a disease that runs in families) in which both kidneys become filled (‘poly-’ means ‘many’) with cysts (abnormal fluid-filled lumps). If someone has PCKD, they will have a 50% chance of passing the problem on to each of their children.

   PCKD is diagnosed by ultrasound (an investigation that uses sound waves to produce a picture of the kidneys). Polycystic kidneys, although abnormally large because of the cysts, do not work well. Most people with PCKD eventually develop ESRF.
The cysts in PCKD can remain a problem after treatment for kidney failure has started. A cyst can burst, bleed or get infected – any of which may cause pain. Occasionally, a large cyst that is particularly troublesome will have to be drained through a long, hollow needle, or removed by an operation. Sometimes, people with polycystic kidneys have to have one of them removed to make room for a transplanted kidney.

3. Pyelonephritis. ‘Pyelo-’ refers to the drainage system of the kidney (it looks like a funnel) and ‘-nephritis’ means ‘kidney inflammation’, so pyelonephritis means ‘inflammation of the kidney drainage system’. Pyelonephritis is diagnosed by ultrasound, or by a special X-ray of the kidneys called an intravenous pyelogram (IVP), in which an opaque dye is injected into the bloodstream.

Pyelonephritis can sometimes be linked to repeated kidney infections. These may have gone undetected for many years, perhaps having occurred in childhood.

Pyelonephritis is sometimes caused by a condition called reflux nephropathy (or ‘reflux’). In this condition, a valve where the ureter enters the bladder (see diagram, page 2) is faulty. This faulty valve allows urine from the bladder to flow back up the ureter to cause problems in the kidney.

4. Renovascular disease. As people get older, their arteries tend to become ‘furred’ up with cholesterol and other fats. Smoking makes this process occur at a younger age. This ‘furring up’ (which is called atheroma or atherosclerosis) gradually narrows the arteries (the blood vessels that take blood from the heart to every part of the body).

Atheroma in the arteries that supply the heart’s own muscle leads to angina and heart attacks. If the atheroma affects the arteries that supply blood to the brain, it may cause a stroke. Atheroma can also affect the arteries that supply blood to the kidneys, the renal arteries. This is called renovascular disease (‘reno-’ means kidney, and ‘-vascular’ means blood vessel). Renovascular disease is a particularly common cause of kidney failure in older patients.

5. Diabetes mellitus. Whether diabetes is controlled by insulin, tablets or diet, it can cause kidney failure. This happens most often when people have had diabetes for longer than 10 years. By this stage, they are also likely to have other long-term complications of diabetes, such as heart disease or eye problems. Diabetes is the most common cause of kidney failure in some parts of the world, where it may affect as many as 40% of dialysis patients. In the UK, an average of 15% of dialysis patients are affected by diabetes, although this does vary from one part of the country to another.

6. Obstructive nephropathy. This is a common cause of ESRF in men, especially those over the age of 60 years. It is usually due to enlargement of the prostate gland, which obstructs the urethra (hence the name ‘obstructive nephropathy’). The urethra is the tube through which the urine drains from the bladder.

Surgery to the prostate gland (even if it is enlarged due to cancer) can often reverse the kidney failure. But in some cases, especially those cases that were diagnosed late, ESRF requiring dialysis will occur even if the patient has had an operation on the prostate to relieve the blockage.

7. Unknown. In about 25% of patients with ESRF, the cause of the kidney failure is never discovered. This is because the kidneys often appear small and shrunken when shown by ultrasound. For this reason, a diagnosis of ‘two small kidneys’ is often made. ‘Two small kidneys’ really means that the kidneys are small, but doctors don’t know why. It is presumed that ‘something’ happened to the kidneys years ago, and they have slowly shrivelled up since.
**The ‘progression’ of kidney failure**

When chronic kidney failure is still at an early stage, most patients feel quite well. This is because their failing kidneys ‘overwork’ to keep the level of body waste normal. This hides the fact that the kidneys are failing. In other words, the kidneys have a lot ‘in reserve’. The body manages for quite some time to adapt to high levels of toxins and water in the blood. It does this by making the kidneys work harder.

The rate at which kidney failure gets worse varies from patient to patient. Also, the symptoms that patients get when they have similar levels of kidney function can vary considerably. Some patients get symptoms when their kidney function is 90% of normal, whereas others do not get symptoms until their kidney function is down to 1% of normal!

However, for most people with kidney failure, the following description will apply:

- When kidney function is 75% of normal, the blood creatinine (see *Chapter 2*) may be 150 µmol/l, and the patient feels fine.

- Most patients only start to feel unwell when their kidney function is down to about 10% of normal, and their blood creatinine is about 500 µmol/l.

- When kidney function is down to about 5% of normal, the blood creatinine may be over 600 µmol/l, and most patients feel very unwell. Dialysis or a transplant is then needed, but most patients should have started treatment well before this time.

If someone has chronic kidney failure – whatever its cause – it is likely that their kidneys will eventually stop working completely. Doctors do not know why failing kidneys usually get worse, or why people with chronic kidney failure almost always progress to ESRF.

**What is ESRF?**

This is surprisingly difficult to define. However, most doctors would say that ESRF has occurred when treatment by dialysis or a transplant becomes essential for life. When kidneys reach ‘end-stage’, they very rarely get better. Once someone develops ESRF, they will always have it, even after they have had a transplant (see *Chapter 11*).

If the kidneys start to fail in an older person (say, in someone over 70 years old), that person may live out their natural lifespan without experiencing any problems from their kidneys. This is because the kidneys can take up to 10 years to progress to ESRF. So, sometimes, older people never need treatment for their kidney failure. If an older person develops ESRF, however, they can still be treated by dialysis or a transplant.

**How is ESRF treated?**

ESRF can be treated by dialysis or by a kidney transplant. It is usual for a patient to undergo a period of dialysis before transplantation is considered. Dialysis and transplantation provide alternative ways of taking over the work of the patient’s failed kidneys.

1. **Dialysis.** In this treatment, some of the work of the kidneys is performed by artificial means. (See *Chapter 8* for a description of what dialysis is and how it works.) There are two main types of dialysis: PD and haemodialysis. (PD is described in detail in *Chapter 9*, and haemodialysis in *Chapter 10*.) Either PD or haemodialysis usually provides about 5% of the function of two normal kidneys.

2. **Transplantation.** This treatment involves the removal of a normal kidney from one person (the donor), and its insertion into a patient with kidney failure (the recipient). Transplantation is done by a surgeon during a transplant operation. A ‘good’ transplant provides about
50% of the function of two normal kidneys. (Transplantation is described in Chapter 11.)

**When should dialysis be started?**

Dialysis is usually started either when:

- a patient has severe symptoms of kidney failure which affect normal daily life; or
- the levels of toxins and/or water in the body are so high that they become life-threatening.

A blood creatinine level of 800 µmol/l is generally taken to indicate the onset of ESRF. However, the actual level varies from patient to patient (see Chapter 2). Most doctors now usually try to start patients on dialysis when their blood creatinine level is about 600 µmol/l (i.e. just before the onset of ESRF). However, individual decisions always take into account more than creatinine level alone.

**Can the need for dialysis be delayed?**

Once a patient has developed ESRF, dialysis should be started at once. However, if someone with chronic kidney failure has not yet developed ESRF, it may sometimes be possible to delay the need for dialysis.

The following treatments may delay the need for dialysis in some patients:

1. **Treatments to control blood pressure.** High blood pressure is known to speed up kidney failure. Doctors therefore make great efforts to keep the blood pressure of their kidney patients normal. Keeping the blood pressure really low (consistently 130/80 mmHg or less) can delay the need for dialysis by years. This is true for all patients with kidney failure – the cause of the kidney failure makes no difference. (See Chapter 4 for more about blood pressure and kidney failure.)

2. **Treatments to suppress the immune system.** When kidney failure is due to nephritis (see page 5), the need for dialysis can sometimes be delayed by tablets called immuno-suppressants. In some types of nephritis, the body’s immune system (the system that normally fights infection or foreign objects in the body) starts to attack the patient’s kidneys and stops them working properly. So tablets that make the immune system less effective – such as the steroid tablet called prednisolone – can be used to treat the kidney problem. In some patients, such treatments are very successful, and return the kidney function to normal or near normal. In other patients, these tablets are less successful. Even so, they may delay the need for dialysis by many years. (There is more information on the immune system in Chapter 14.)

3. **Use of ACE inhibitors.** This is a more controversial treatment that may delay the need for dialysis in some patients. Some people with kidney failure (especially kidney failure caused by nephritis) have a large amount of protein in the urine. Normally, there is next-to-no protein in the urine. If a kidney patient has a raised level of protein in the urine, doctors often attempt to reduce it with a type of blood pressure tablet called an ACE inhibitor. Whether this treatment in fact delays the need to start dialysis is not yet proven.

4. **Treating obstructive nephropathy.** This is the only cause of ESRF that can, in many cases, be wholly or partially reversed. Initially, this is done either by putting a tube (urinary catheter) into the bladder through the urethra; or one or more tubes (nephrostomies) through the skin, into the pelvis (drainage system) of the kidney. Depending on the cause of the obstruction, these procedures in men are usually followed by an operation on the prostate gland.
**Will dialysis or a transplant solve the problem?**

Neither dialysis nor a kidney transplant can ‘cure’ a patient with chronic kidney failure. These treatments can control the symptoms of kidney failure, but they cannot get rid of the symptoms completely nor restore the kidneys to health.

1. **Dialysis.** When someone is treated by dialysis, the symptoms of kidney failure never really go away completely. This is because either type of dialysis – PD (see Chapter 9) or haemodialysis (see Chapter 10) – can provide only about 5% of the function of two normal kidneys. So when a patient starts dialysis, they will usually have only about 10% of the function of two normal kidneys (5% from dialysis, and 5% from their own kidneys). This is simply not enough to make the person feel completely better.

   The symptoms of kidney failure will also tend to worsen if there is under-dialysis – i.e. if insufficient dialysis is given to bring the amount of creatinine in a patient’s blood down to target level (see Chapter 2 for more information).

   Even though dialysis technology has its limitations, it does do a reasonable job. So it is sensible to start treatment as early as possible – before a patient becomes very unwell. This means that some patients may feel relatively well when they start dialysis. The doctor will be able to tell from a patient’s blood creatinine and symptoms when is the best time to start dialysis.

2. **Transplantation.** A kidney transplant is more effective than dialysis at removing the symptoms of kidney failure. This is because a transplanted kidney can provide up to 50% of the function of two normal kidneys. However, transplants have their own problems. They do not last for ever and it may be necessary for a patient to have a second transplant or to resume dialysis. (See Chapters 11–13 for more information about transplantation.)

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**Why treat kidney failure?**

If someone with ESRF is not treated by dialysis or a transplant, they will develop severe kidney failure symptoms (see page 5), and then, after a few weeks, they will die.

Given the terrible result if no treatment is given, it may seem stupid to ask: ‘Why treat kidney failure?’ The answer seems obvious – ‘to keep patients alive’. To a certain extent this is true. When people have ESRF, they will die without treatment.

So, certainly, the main purpose of the treatment of ESRF is to keep patients alive. However, there is little point in keeping patients alive if their quality of life is so poor that they don’t want to be alive.

There are, in fact, several reasons why treatment is given to patients with kidney failure. Firstly, treatment prolongs life. Secondly, it aims to make patients feel better, and to return them to a good quality of life. To achieve this, the two main functions of the kidneys – removing toxins (see Chapter 2) and maintaining the body’s fluid balance (see Chapter 3) – have to be performed for the patient. Dialysis and transplantation can perform both these vital functions.
The two main functions of the kidneys are:
● removing toxic wastes;
● removing excess water.

Kidney failure is a condition in which the kidneys are less able to carry out these two functions.

Whatever the original cause of kidney failure, it tends to get worse over a period of years.

A blood test (the creatinine level) is used to measure the amount of work that the kidneys can still do.

Most people with chronic kidney failure develop a condition called end-stage renal failure (ESRF), when they will need treatment.

ESRF can be treated by dialysis or (usually better) by a kidney transplant.

For most kidney patients, good control of blood pressure is the only way to delay the onset of ESRF and the need for dialysis.

The treatment of kidney failure (by dialysis or transplantation) is effective, but it is not a ‘cure’ and may not get rid of all the symptoms.
2 TOXIN ‘CLEARANCE’

This chapter looks at ways of measuring the ability of the kidneys, or dialysis, to remove (or ‘clear’) toxins from the blood.

**Introduction**

One of the main functions of the kidneys is to remove the toxic waste products of food from the blood. This function is sometimes called ‘clearance’, because toxins are ‘cleared’ away. When someone has kidney failure, their kidneys become less efficient at clearing waste products from the blood. This leads to a build-up of toxins in the blood. It is this build-up that makes people with kidney failure feel unwell. Doctors do not know which particular toxin or toxins make people ill.

**Why is clearance measured?**

Tests that indicate the clearance of toxins from the blood are extremely important when someone has kidney failure. Clearance measurements are used:

- in the diagnosis of kidney failure;
- to assess the severity of kidney failure;
- to decide whether it is time for a patient to start treatment by dialysis;
- to monitor treatment by dialysis; and
- to assess how well a transplant is working.

Clearance provides a more reliable guide to a kidney patient’s condition than is possible from either a physical examination or an account of the patient’s symptoms. Some patients get a lot of symptoms when their kidney function is not too bad. Others get few or no symptoms even when doctors and nurses think that they need dialysis.

**How is clearance measured?**

There are tens of thousands of different substances in the blood. Fortunately, there is no need to measure most of them. The overall ability of the kidneys to clear wastes from the blood is assessed by measuring the blood levels of two particular substances. These are called urea and creatinine:

1. **Urea** is a waste product produced by the liver. When we eat protein (such as in meat and eggs), the body uses this protein to repair itself and to build muscles. The ‘used’ proteins (now in the form of substances called amino acids) are taken in the blood to the liver, where they are changed into urea. The urea then travels in the blood to the kidneys, where it enters the urine.

2. **Creatinine** is a substance created by the muscles whenever they are used. The harder our muscles work, the more creatinine they produce. This is a little bit like a
car engine producing exhaust fumes. So our muscles are like the engine which drives the car, and creatinine is like the exhaust from the engine. Like urea, creatinine is carried in the blood to the kidneys, where it enters the urine.

**Why measure urea or creatinine?**
Normal healthy kidneys can remove both urea and creatinine from the body quite well. However, when someone has kidney failure, the blood levels of both these substances rise above normal:

- **The normal blood level of urea** is between 3.3 and 6.7 mmol/l (millimoles of urea per litre of blood).

- **The normal blood level of creatinine** is between 70 and 120 µmol/l (micromoles of creatinine per litre of blood).

Urea and creatinine are not, in themselves, particularly harmful to the body. Creatinine is not even a toxin. However, tests that indicate the clearance of urea and creatinine from the body provide an indication of the clearance of all the thousands of harmful toxins that are produced by the body. In kidney failure, there is a build-up of urea, creatinine and all these toxins.

A substance which is known to indicate the presence of another substance or condition is called a ‘marker’. Urea and creatinine do not themselves make people with kidney failure feel ill. However, both urea and creatinine are markers for the many more harmful toxins that do make kidney patients feel ill.

**Types of test**
Different tests show how well or badly the kidneys (or dialysis or a transplanted kidney) are managing to clear the blood of urea or creatinine.

There are basically two types of test:

- **blood tests**, which measure the level of urea or creatinine in the blood (see page 13); and

- **clearance tests**, which measure the amount of urea or creatinine removed from the blood (see pages 14–15).
**Blood tests for urea or creatinine**

Blood tests provide a direct measurement of the levels of urea or creatinine present in a patient’s blood. These levels can then be compared with normal levels (see page 12), or with a range of expected or target levels at different stages of a patient’s illness or treatment (see page 14).

In simple terms, the higher the levels of urea or creatinine in a patient’s blood, the worse the kidney (dialysis or transplant) function. The lower the levels, the better.

In reality, the picture is not quite so simple. Blood urea tests are not always a reliable guide to a patient’s kidney function. This is because blood urea levels are affected by things other than the kidneys, such as the amount of protein in the diet. Blood creatinine tests are a generally more reliable guide to kidney function, and have now largely replaced blood urea tests.

It is also the case that blood levels of both urea and creatinine are affected by an individual’s overall size and muscle bulk. Larger and more muscular people have higher blood levels of creatinine and urea than smaller and less muscular people. This is true both when someone is healthy and at all stages of kidney failure. Overall size and muscle bulk must therefore be taken into account when looking at an individual’s blood urea and blood creatinine test results.

**Blood creatinine before dialysis**

Blood tests that measure the level of creatinine in a patient’s blood provide doctors with the information they need to decide:

- whether a patient has kidney failure; and
- how bad it is.

The normal level of creatinine in the blood is known to be between 70 and 120 µmol/l. So, if anyone has a creatinine level of over 120 µmol/l, it means that they have kidney failure.

As stated above, the normal level for any particular individual depends on their overall size and muscle bulk. For example, a healthy large man might have a normal blood creatinine of 120 µmol/l (at the top of the normal range). However, the same blood creatinine of 120 µmol/l in a small woman might indicate the start of kidney failure; her normal blood creatinine might be as low as 40 µmol/l (below the bottom level of the normal range).

At the start of kidney failure, the blood creatinine level tends to increase slowly over time. This can take months, or, more often, many years. However, when the kidneys have almost completely failed, the blood creatinine level rises more rapidly. Patients will probably feel unwell when their creatinine level gets to more than about 500 µmol/l, equivalent to about 10% of normal kidney function.

At all stages of kidney failure, large patients will have a relatively higher blood creatinine than small patients. So, for example, a large man whose kidney function is only 25% of normal could have a creatinine level of 400 µmol/l. A small woman who has 25% of normal kidney function could have a creatinine level of 250 µmol/l.

**Starting dialysis**

Dialysis is usually started when a patient’s blood creatinine is between 600 and 800 µmol/l. This level is equivalent to about 5% of the function of two normal kidneys. Unless someone with kidney failure starts dialysis at this point, they will become very unwell.

The actual creatinine level at which any patient starts dialysis will take into account their size and muscle bulk, as well as the degree to which they are troubled by symptoms of kidney failure and feeling generally unwell. Guidelines are based on the needs of an ‘average’ person, but most people are not average. So the precise creatinine level for starting dialysis is different for different patients.
BLOOD CREATININE DURING DIALYSIS

Measurement of blood creatinine continues to be important after a patient has started dialysis. This applies to patients on either type of dialysis – peritoneal dialysis (PD) (see Chapter 9) or haemodialysis (see Chapter 10).

Blood creatinine level provides vital information about how well dialysis is working. A ‘high’ level of creatinine could mean that a patient is not getting enough dialysis – i.e. dialysis is not removing enough toxins.

When planning an individual patient’s treatment, doctors and nurses aim to keep the patient’s blood creatinine at or below recognised ‘target’ levels. These targets take into account both the size of the patient and the type of dialysis.

The following table summarises the target creatinine levels for different sizes of patient:

<table>
<thead>
<tr>
<th>Weight</th>
<th>Target creatinine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 60 kg</td>
<td>Less than 600 µmol/l</td>
</tr>
<tr>
<td>60–90 kg</td>
<td>Less than 800 µmol/l</td>
</tr>
<tr>
<td>More than 90 kg</td>
<td>Less than 1000 µmol/l</td>
</tr>
</tbody>
</table>

A blood creatinine of 800 µmol/l is the accepted target level for a person of average size and muscle bulk. As explained below, this target applies all the time for average-sized PD patients, and before dialysis for average-sized haemodialysis patients:

**1. PD patients.** The blood creatinine of a PD patient remains almost constant. This is because PD patients have dialysis treatment every day. Their treatment therefore aims to keep the creatinine level permanently below 800 µmol/l.

**2. Haemodialysis patients.** The blood creatinine of a haemodialysis patient does not stay at a constant level. Patients on haemodialysis usually have treatments 2 or 3 times each week. This means that their blood creatinine rises in the days between dialysis sessions, and falls during dialysis. The goal is to keep the creatinine below 800 µmol/l before dialysis, and below 300 µmol/l after dialysis. In other words, a haemodialysis session should cut the creatinine level by at least two thirds.

The fact that the creatinine target levels are the same for PD and haemodialysis (before dialysis) indicates that the two techniques provide roughly the same amount of dialysis. One is not ‘better’ than the other.

If dialysis does not achieve creatinine target levels over a period of time, the patient will be in danger of, once again, developing the symptoms of kidney failure. This problem is called under-dialysis.

Under-dialysis is corrected by increasing the amount of dialysis. Ways of doing this are described in later chapters (see Chapter 9 for PD, and Chapter 10 for haemodialysis).

**BLOOD CREATININE WITH A TRANSPLANT**

Ideally, the blood creatinine of an average-sized person with a transplanted kidney should be less than 120 µmol/l (i.e. the upper limit of normal). However, even if a transplant is working well, the blood creatinine may not return to normal level. A creatinine level of below 200 µmol/l is generally considered satisfactory for a patient in this situation, so long as it is stable.

If a transplanted kidney starts to fail, the patient’s blood creatinine level will rise again. When it exceeds 600 µmol/l, it is probably time to start dialysis again. The creatinine level for restarting dialysis is therefore the same as the level at which a patient who is new to kidney failure would start on dialysis. This is because the period in which a transplant fails is very similar to the period before dialysis is first started.

**UREA OR CREATININE CLEARANCE TESTS**

Most renal units now use tests called urea or creatinine clearance tests in addition to blood tests for measuring
their patients’ kidney (dialysis or transplant) function.

Urea or creatinine clearance tests are sometimes preferred to simple blood tests because they link the amount of urea or creatinine in a patient’s blood to the size of the patient’s muscles. In some situations, this may make these tests a more reliable measure of the severity of a patient’s kidney failure.

The test used to measure the clearance of urea is called urea kinetic modelling. The amount of urea clearance is expressed in terms of Kt/V (pronounced ‘K…t…over V’). (See Chapter 10 for more details.)

The clearance of creatinine is measured in millilitres per minute (ml/min) or litres per week (l/wk).

- **The normal creatinine clearance level** is about 120 ml/min or 1200 l/wk.

A healthy person’s blood, therefore, is ‘cleaned’ about 35 times a day. The fact that 120 is the normal level of urea and creatinine clearance and also the upper limit of normal for blood creatinine is a coincidence.

Blood tests measure the levels of toxins remaining in the blood. So, when blood urea or blood creatinine is measured, the lower the number the better. High numbers reflect poor kidney (dialysis or transplant) function.

The opposite is true for urea and creatinine clearance measurements. Low numbers reflect poor kidney function. This is because clearance tests measure the amount of toxin removed from the blood. So, for clearance test results, the higher the number, the better. A low number indicates poor functioning of the kidneys (or dialysis or transplant).

When the blood creatinine is down to 600 µmol/l (at the onset of ESRF), the creatinine clearance is usually down to about 5 ml/min (i.e. about 5% of normal).

Dialysis provides about 5 ml/min of creatinine clearance (i.e. about 5% of normal). So, when a patient starts dialysis, the combined effort of the kidneys and dialysis is only about 10% of what two normal kidneys can do. This is why patients with kidney failure rarely feel perfectly well on dialysis. Neither PD nor haemodialysis is good enough at clearing toxins.

**HOW IS CLEARANCE MEASURED?**

Different methods for measuring the clearance of urea or creatinine are used for different patients, depending on their type of treatment:

1. **Patients not on dialysis.** Clearance of urea or creatinine in these patients (either pre-dialysis or with a transplant) is measured by comparing:
   - the amount of urea or creatinine passed in the patient’s urine over a period of 24 hours; with
   - the amount of urea or creatinine in the patient’s blood.

   To provide accurate results, it is essential that the collection of urine is done very carefully. Every drop of urine collected in the 24-hour period must be collected, otherwise the information will be less reliable than that obtainable from simple blood urea or blood creatinine tests.

2. **PD patients.** The method used for measuring clearance in PD patients is much more accurate than that used for patients who are not on dialysis. In PD patients, clearance is measured by comparing:
   - the amount of urea or creatinine in 24 hours’ worth of the patient’s used dialysis fluid (and also in the urine that they might pass); with
   - the patient’s blood urea or creatinine level (taking into account the patient’s size).

3. **Haemodialysis patients.** For haemodialysis patients, the most accurate method is to compare:
   - the patient’s blood urea or blood creatinine level before dialysis; with
• the patient’s blood urea or blood creatinine level after dialysis.

When measuring clearance in dialysis patients, it is also necessary to take into account patient size, as well as the urea or creatinine passed in any urine. Urine production dwindles, making it necessary to increase the amount of dialysis about 1 year after starting dialysis.

**UREA OR CREATININE CLEARANCE DURING DIALYSIS**
When monitoring urea or creatinine clearance in a dialysis patient, doctors and nurses will compare that patient’s levels with generally accepted levels for patients on dialysis. The current guidelines state that:

**PD patients** should have:
- a creatinine clearance of 60 l/wk (litres per week); and
- a urea clearance (Kt/V) of 1.7/wk.

**Haemodialysis patients** should have:
- a creatinine clearance of 100 l/wk; and
- a urea clearance (Kt/V) of 1.2 for each dialysis session.

These goals are the same for all patients as they take into account size and build, as well as the amount of waste that patients can get rid of through their own kidneys.

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**KEY FACTS**

1. Creatinine and urea are two waste products that are normally passed in the urine.

2. The levels of urea and creatinine in the blood are an indication of how well the kidneys (or dialysis or a transplant) are working. Blood creatinine level is a more reliable guide than blood urea level.

3. The higher the level of urea or creatinine in the blood, the worse the kidney (dialysis or transplant) function. Generally speaking, the lower the number, the better.

4. Larger people may have higher blood creatinine levels than smaller people because they have bigger muscles.

5. Urea and creatinine clearance may be more accurate ways of measuring the efficiency of dialysis. This is because these tests take each patient’s body size into account.

6. The higher the urea or creatinine clearance, the better the kidney (or dialysis) function. So, the higher the clearance number, the better.

7. Kidney function continues to deteriorate after starting dialysis, making it necessary to increase the dialysis dose, usually after one year.
**INTRODUCTION**

One of the two main functions of the kidneys is to remove excess water from the body. Water comes into the body from drinks, and also from food, especially high-liquid food such as soup, jelly and ice-cream. By removing excess water from the body, the kidneys are able to control the body’s water content. This is called fluid balance. To understand fluid balance, it helps to know a bit about how the body is made up.

**FLESH AND FLUID**

The body is made up of two main parts: flesh and fluid. The flesh is all the solid parts of the body, such as bone, muscle and fat. Most of the fluid part is simply water, such as the water in blood, urine and saliva. Men have approximately 60% of fluid to 40% of flesh in their bodies, whereas women, whose bodies contain a higher proportion of fat, have approximately 55% of fluid to 45% of flesh (see diagram).

The easiest way to see a change in the amount of fluid in the body is to measure body weight. The known weight of 1 litre of water is 1 kilogram. So, if you weigh yourself, then drink 1 litre of water, then weigh yourself again, your weight will show an increase of 1 kilogram.
**What is the ‘target weight’?**

The term ‘target weight’ means the weight that the doctor considers to be the ‘best’ weight for an individual patient. At this weight, there will be neither too much nor too little water in the body. Men will have about 60% fluid to 40% flesh, and women about 55% fluid to 45% flesh. A kidney patient’s target weight may have to go up or down as flesh weight is gained or lost. Flesh weight increases if a person eats too much, or may decrease due to dieting or illness.

Weight also changes according to how much fluid is in the body. If a person has too much water in their body (i.e. is fluid overloaded, see below), they will weigh more. The target weight, therefore, is the ideal weight when the person is neither ‘wet’ (fluid overloaded) nor ‘dry’ (dehydrated).

Judging the amount of water in the body is difficult. But with practice, patients can learn to ‘feel’ when they are at their target weight.

**Control of fluid balance**

Normal healthy kidneys can control the amount of water in the body with ease. If you do not have kidney failure, you do not have to think about your fluid balance because your kidneys control the amount of urine you pass.

If a person drinks 10 pints of water (or beer), they will usually pass about 10 pints of urine. Similarly, if they drink three cups of tea per day, they can expect to pass the equivalent of about three tea cups of urine.

Fluid is also lost from the body in other ways – as you breathe, when you sweat and in your faeces (see diagram). If someone becomes very hot, they will sweat more. To control fluid balance, they will then need to compensate for the sweat lost by passing less urine.

In kidney failure, it is different. Many kidney patients do not pass any urine at all. Others pass exactly the same amount of urine every day, no matter how much they drink. This means these patients are unable to control how much water is in the body. If someone with kidney failure drinks too much, they may keep that fluid in their body. This is called fluid overload (see below for more details). Conversely, if someone with kidney failure drinks too little, or loses too much water from the body (say, through sweating), they will become dehydrated (see page 19). Finding the balance is not easy.

**Sodium and fluid balance**

Sodium is a mineral that plays a part in helping to control the body’s fluid balance. Too much of it can contribute to high blood pressure. Table salt contains sodium, so dialysis patients should avoid eating salty foods such as bacon, crisps and many pre-packed foods, and to avoid adding salt to their food either at table or in cooking. Also, eating salty foods makes people want to drink more fluid. If people with kidney failure drink too much, they may develop fluid overload.
**What is fluid overload?**

This is a condition in which there is too much water in the body. It is caused by drinking too much fluid, or not losing enough. Fluid overload often occurs with high blood pressure (see Chapter 4). High blood pressure may not cause any symptoms.

When the water content of the body reaches a very high level, excess water collects in and under the skin. The problem usually first shows as swelling around the ankles. This is called ankle oedema. The reason the ankles are affected first is simple – gravity tends to make fluid fall to the bottom of the body.

If fluid overload is not treated, the swelling due to excess fluid slowly creeps up the body into the thighs, and then into the lower abdomen and lower back. Hopefully, by this stage, the patient will have asked for medical help. If not, fluid will continue to spread up the body, and eventually settle in the lungs. Fluid in the lungs, which causes shortness of breath, is called pulmonary oedema. It is a very serious condition, and can be life-threatening.

Occasionally, people with kidney failure suddenly develop pulmonary oedema, without going through the ‘warning stages’ of ankle and leg swelling. This can happen if they drink a lot of fluid very quickly. When pulmonary oedema comes on this quickly, it needs urgent treatment. And urgent means exactly that – treatment straight away.

Fluid overload tends to occur mainly in kidney patients on dialysis. However, it can be a problem for pre-dialysis patients too, and also for people who have had a kidney transplant.

**How is fluid overload treated?**

Remember, ‘what goes in has to come out’. Therefore the first treatment of fluid overload for all people with kidney failure is simply to drink less. However, this is not usually enough. It is also important that they cut down on salt in their diet, since salt increases thirst. Additional treatments depend on whether or not a patient is on dialysis:

1. **In patients not on dialysis.** If patients are pre-dialysis, or if they have a failing transplant, they will usually be given tablets called diuretics or ‘water tablets’ to treat fluid overload. These patients are usually able to pass urine, and the tablets work by increasing the amount of urine that is passed every day. A combination of passing more urine and drinking less usually does the trick. Two commonly used diuretic drugs are frusemide and bumetanide. Stronger diuretics, such as mefruside and metolazone, may be given as well.

   If taking diuretics and drinking less does not get rid of all the fluid, it may be necessary to have some dialysis. This may be for just a few days. However, sometimes the difficulty in getting rid of fluid is a sign that kidney failure is well advanced and that dialysis may need to be permanent.

2. **In patients on dialysis.** Dialysis patients with fluid overload should also drink less. However, because people on dialysis usually pass little urine, diuretics don’t normally work for them. A different treatment for fluid overload is needed. These patients need a combination of drinking less (usually a daily limit of 1 litre for haemodialysis patients and 1.5 litres for PD patients), and removing more water by dialysis.

**Dehydration**

Dehydration is the opposite of fluid overload. It occurs when there is too little water in the body. Dehydration may occur if someone does not drink enough, or if they lose fluid as a result of sweating, diarrhoea or vomiting.

It can be difficult for people to judge when they are dehydrated. However, dehydration is almost always accompanied by low blood pressure. This is easier to
identify than high blood pressure. Low blood pressure makes people feel weak and dizzy when they stand up.

**HOW IS DEHYDRATION TREATED?**
Any patient with kidney failure who is suffering from dehydration needs to drink more.

If a patient (pre-dialysis or with a failing transplant) takes diuretics, these should be reduced or stopped. If the dehydration is severe, admission to hospital for intravenous fluids (via a drip) may be necessary.

For dialysis patients, a reduction in the amount of water removed by dialysis may be needed. If haemodialysis patients are severely dehydrated, they can be given a lot of intravenous fluid during a dialysis session.

**KEY FACTS**

1. Fluid balance is the balance between water coming into the body, from drinks and food, and water leaving the body, mainly in the urine or by dialysis.

2. Too much water in the body is called fluid overload. This may cause swelling of the ankles.

3. If patients eat salty foods, such as bacon, crisps and many pre-packed foods, they will become very thirsty and will not be able to control their fluid intake. So control of salt intake is vital for control of fluid intake.

4. The treatment of fluid overload is to drink less, and to remove more fluid from the body. This is done by taking diuretics (water tablets), or by increasing the amount of water removed by dialysis.

5. If fluid overload is not treated, shortness of breath due to fluid in the lungs may develop. This condition – known as pulmonary oedema – needs urgent treatment in hospital.

6. Judging the amount of water in the body is difficult. But, with practice, patients can learn to ‘feel’ when they are on their target weight – i.e. their ideal weight when they are neither ‘wet’ (fluid overloaded) nor ‘dry’ (dehydrated).

7. When there is too little water in the body (dehydration), dizziness may occur.

8. The treatment of dehydration is to drink more, and to remove less water from the body. This is done either by stopping diuretics, or by reducing the amount of water removed by dialysis.
4 Blood Pressure

This chapter looks at the link between blood pressure and kidney failure. It also explains the importance of blood pressure control and how this is achieved.

Introduction
The control of blood pressure is one of the important ‘extra’ functions performed by the kidneys. The term ‘blood pressure’ means the pressure of the blood on the artery walls. This pressure goes up and down as the heart continuously squeezes and relaxes to pump blood around the body. Although the kidneys are known to help control the blood pressure, exactly how they do this is not clearly understood.

High blood pressure and kidney failure
High blood pressure is very common in people with kidney failure. The connection between these two conditions is two-way. High blood pressure can cause kidney failure, and kidney failure causes high blood pressure. It is often difficult to know for certain whether a patient’s high blood pressure has caused their kidney failure, or whether kidney failure has caused their high blood pressure.

High blood pressure can occur in kidney patients who are pre-dialysis, who are on dialysis, or who have had a transplant. Many patients with kidney failure are taking one, two or even three types of blood pressure tablet.

Many patients with kidney failure have to take an injection treatment called erythropoietin (EPO) for anaemia. This drug can make blood pressure worse. It is better, however, to stay on the drug if the patient needs it, and to take more blood pressure tablets, than to stop the drug.

Low blood pressure and kidney failure
Some people with kidney failure have a different blood pressure problem. Their blood pressure is lower than it should be. Low blood pressure is less serious than high blood pressure, but it also needs to be treated.

Circulation of the blood
The main function of the blood (and the blood vessels through which it flows) is to carry things around the body. Blood carries ‘good things’ to parts of the body where they are needed, and also removes ‘bad things’ so that they can be got rid of, mainly by the kidneys via the urine.

Adults have about 5 litres (10 pints) of blood travelling around their body all the time. The heart acts as a pump to drive the blood through the blood vessels. There are two main types of blood vessel: arteries and veins. The arteries take blood that is rich in oxygen from the heart to all parts of the body. This oxygen, combined with the food that is eaten, provides the different parts of the body with the energy they need to do their work. The veins then take the blood (now with most of its oxygen used up) back to the heart. From there, the blood goes to
the lungs to get more oxygen. It then goes back to the heart, and so the process goes on (see diagram above).

**Measuring Blood Pressure**

The blood pressure is measured using a using a piece of equipment known as a sphygmomanometer (or sphyg, pronounced ‘sfig’). There are various different types of sphygmomanometer, but all of them measure blood pressure in units of millimetres of mercury (mmHg).

Two readings are taken. The first reading shows the pressure of the blood when the heart squeezes, and is called the systolic blood pressure. The second reading is the pressure of the blood when the heart is relaxed between squeezes. This is called the diastolic blood pressure.

The systolic pressure is always higher than the diastolic pressure, and is always recorded first. So, for example, a blood pressure of 140/80 mmHg (known as ‘140 over 80’) means that the systolic pressure is 140 and the diastolic pressure is 80.

A reading of 140 mmHg means that the blood pressure has raised the top of the mercury (Hg) column inside the sphygmomanometer to a height of 140 millimetres.
What is ‘normal’ blood pressure?

There is no such thing as normal blood pressure. Both the systolic and the diastolic blood pressure go up naturally as people get older. So there is only a normal range of blood pressure for your age. Most doctors accept the following values as the normal range for different age groups:

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Blood Pressure (in mmHg)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Systolic</td>
</tr>
<tr>
<td>Under 30 years</td>
<td>100–120</td>
</tr>
<tr>
<td>30–60 years</td>
<td>110–130</td>
</tr>
<tr>
<td>Over 60 years</td>
<td>120–140</td>
</tr>
</tbody>
</table>

The blood pressure varies continuously throughout the heart’s pumping cycle. This means that during each cycle, the systolic blood pressure is, say, 140 or 180 for only a fraction of a second.

Blood pressure also varies according to the time of day – tending to be higher in the morning and again in the early evening. And there is a difference between one arm and the other. Slight variations may also result from using different sphygmomanometers, or from how different people use the same piece of equipment.

If there is doubt about whether or not a patient has high blood pressure, a 24-hour blood pressure test can be organised. This involves a patient carrying a cuff on their arm for 24 hours. Every hour, the cuff automatically inflates and deflates, giving the doctor a better idea of the average blood pressure over the 24-hour period.

Does anxiety affect blood pressure?

Anxiety is definitely not a major factor in high blood pressure. Although anxiety can put the blood pressure up a little, it is a mistake to blame repeated high blood pressure readings on, for example, ‘the stress of the journey’ or a ‘fear of seeing the doctor’.

How do you know that your blood pressure is high or low?

You don’t. Some people with very high blood pressure suffer from headaches. But the fact that you do not have headaches does not mean that you do not have high blood pressure. The only reliable way of finding out your blood pressure is to have it measured.

If your blood pressure is very low, you may feel weak or dizzy, especially when you stand up. But there are many other causes of weakness and dizziness. So, as with high blood pressure, you cannot rely on your body to tell you that your blood pressure is low. You have to have your blood pressure checked.

Why treat high blood pressure?

There are several important reasons to treat high blood pressure (see overleaf). However, there is little point in treating someone for high blood pressure unless the
related problems of high cholesterol levels in the blood, being overweight and smoking are also addressed. All these factors worsen the effects of high blood pressure.

High blood pressure increases the likelihood of a stroke or a heart attack by damaging the blood vessels. There are also ‘kidney’ reasons to treat high blood pressure. If blood pressure is high for a period of time, a patient with kidney failure may have to start dialysis sooner than would otherwise be necessary. This is because uncontrolled high blood pressure can accelerate kidney failure.

In fact, controlling blood pressure is the only thing proven to delay the need for dialysis in all kidney patients, whatever the cause of their kidney failure. Good blood pressure control does not mean they will never need dialysis, but it may mean that dialysis does not need to be started so soon. It may also prolong the life of a transplant.

**What determines blood pressure levels?**

A person’s blood pressure is affected by the following two important factors:

1. **The amount of water in the body.** If there is too much water in the body (fluid overload), the blood pressure will go up. If there is too little water in the body (dehydration), the blood pressure will go down. (Both fluid overload and dehydration, and their treatments, are described in Chapter 3.)

2. **The width of the arteries.** The arteries are constantly changing in width as blood flows through them. The narrower the arteries, the higher the blood pressure.

**How is high blood pressure treated?**

There are three different ways of treating high blood pressure:

1. **Reduce the amount of water in the body.** If someone has fluid overload, their blood pressure will increase. This is because their blood contains more water than normal, which increases the pressure on the blood vessels. Correcting fluid overload (see Chapter 3) will reduce the blood pressure. Eating a lot of salty foods and adding extra salt to meals makes people thirsty and leads to them drinking more (see page 18). So people with kidney failure should cut down on salt as well as fluid.

2. **Vasodilator drugs.** Blood pressure tablets called vasodilators lower the blood pressure by causing the arteries to widen. There are several different types of vasodilator drug:
   - ACE inhibitors (e.g. captopril, enalapril, ramipril, perindopril and lisinopril);
   - alpha-blockers (e.g. prazosin, doxazosin and terazosin);
   - calcium antagonists (e.g. amlodipine, nifedipine and diltiazem);
   - angiotensin II antagonists (e.g. losartan, telmisartan, irbesartan, candesartan); and
   - other tablets (e.g. hydralazine, methyldopa, minoxidil and moxonidine). Minoxidil is probably the strongest drug available, and can be extremely useful for kidney patients with very high blood pressure.

3. **Beta-blocker drugs.** These tablets reduce the heart rate (the number of heart beats per minute). They also lower the blood pressure, although it is not clear how they do this. Commonly used examples of beta-blockers are atenolol, labetolol, metoprolol and propranolol.
**ARE THE BLOOD PRESSURE TABLETS WORKING?**

As blood pressure has to be very high before it causes symptoms (such as headaches), most people cannot ‘feel’ that their blood pressure is raised. Not surprisingly, therefore, they also cannot tell whether or not their blood pressure tablets are working. The only reliable way of knowing a person’s blood pressure, and discovering whether it is responding to tablets, is for the blood pressure to be measured.

**DOES SALT IN FOOD AFFECT BLOOD PRESSURE?**

Too much sodium (salt) in the body can increase the blood pressure. This is because a salty diet causes thirst and makes people drink more. However, salt is not the only thing that causes high blood pressure (see above). People who have high blood pressure will therefore be asked to eat less salt and take tablets to help keep it under control.

**WHAT ABOUT LOW BLOOD PRESSURE?**

Low blood pressure is not as common as high blood pressure. It is normally less serious and easier to treat. This is partly because people can often feel that their blood pressure is low. So they can also feel when it is back to normal.

Low blood pressure in people with kidney failure is usually due either to dehydration, or to taking too many blood pressure tablets. Therefore, the treatment is either to drink more to correct the dehydration, or to alter the dose of blood pressure tablets or stop the tablets.

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**KEY FACTS**

1. High blood pressure is very common in people with kidney failure.
2. Kidney failure causes high blood pressure, and high blood pressure can cause kidney failure.
3. The injection treatment for anaemia, called erythropoietin, can increase the blood pressure.
4. High blood pressure also increases the likelihood of a stroke or a heart attack.
5. You cannot reliably ‘feel’ your own blood pressure, especially when it is high. You have to have it checked.
6. High blood pressure can be controlled by removing fluid from your body and by taking blood pressure tablets.
7. Too much salt in the diet may make the blood pressure higher.
This chapter explains what anaemia is, and how the drug erythropoietin (EPO) has revolutionised its treatment. EPO is probably the most important drug taken by patients who need it.

**INTRODUCTION**

Many patients with kidney failure have a condition called anaemia. This means that they have a lack of red blood cells in their body. Blood cells are produced in the bone marrow, the ‘runny’ bit in the middle of some bones. An important ‘extra’ function of the kidneys is to help control the manufacture of red blood cells in the bone marrow.

**WHAT IS ANAEMIA?**

Anaemia is the term for a lack of red blood cells in the body. The main symptoms are tiredness, shortness of breath, pale skin, poor appetite, irritability and low sex drive. Anaemia is probably the most important complication of kidney failure. It is the main reason why dialysis patients feel weak and tired. In fact, many of the symptoms of kidney failure are not caused by kidney failure itself, but are actually due to anaemia.

Red blood cells are needed to carry oxygen around the body. Oxygen enters the lungs when we breathe in. From the lungs, oxygen is taken around the body in the blood. Each red blood cell contains a substance called haemoglobin. It is the haemoglobin that carries oxygen around the body. Oxygen combines with the nutrients taken in from food to provide energy.
Measuring the level of haemoglobin (or ‘Hb’) in the blood provides a guide to the number of red cells present. The higher the Hb, the more red blood cells there are in the body. As it is red blood cells that are able to carry oxygen round the body, in general the higher the Hb the better (but see page 28).

Normal Hb levels are 11.5–17 g/dl (grams of haemoglobin per decilitre of blood). If a person’s Hb is below 11.5 g/dl, they are said to have anaemia, or to be anaemic.

**Composition of the blood**

Blood is made up of two parts: a liquid part and a more solid part. The liquid part is called plasma. It accounts for about 60% of the blood’s volume, and is mainly water. The amount of water in the plasma is increased in fluid overload and decreased in dehydration. (Both these conditions are described in Chapter 3.)

The other 40% of the blood is made up of blood cells, which are so tiny that they can only be seen through a microscope. There are various different types of cells: red cells (which carry oxygen around the body), white cells (which fight infection) and platelets (involved in blood clotting). Most of the blood cells are red cells. It is these cells that give the blood its red colour. Each one looks rather like a tiny doughnut. Red cells are smaller than white cells, and larger than platelets. You have about 5 billion red cells in one drop of blood.

**Why do people with kidney failure develop anaemia?**

The main reason that kidney patients develop anaemia is this. One of the jobs that the kidneys do, in addition to their main job of making urine, is to manage the production of red blood cells in the bone marrow. To do this, the kidneys make a substance called erythropoietin (EPO).

EPO travels in the blood from the kidneys to the bone marrow, where it constantly reminds the bone marrow to keep producing red cells. When someone has kidney failure, the kidneys usually make less EPO than normal. So the bone marrow ‘goes to sleep’ and makes fewer red cells. As a result, anaemia develops, and the patient becomes weak and tired.

Some patients with kidney failure develop anaemia even though their EPO level is normal (or even high). This probably means that their bone marrow has a problem responding to EPO, rather than that the kidneys
are not making enough EPO. Although a lack of EPO is the main cause of anaemia in people with kidney failure, other things may contribute. For example, red blood cells do not live as long as normal (120 days) in people with kidney failure, and so must be replaced more rapidly. Also, blood may be lost during haemodialysis, or through frequent blood tests.

**PROBLEMS WITH BLOOD TRANSFUSIONS**

In the past – before the introduction of EPO injections (see below) – blood transfusions were the only treatment for anaemia in kidney patients. Many patients had to have transfusions every couple of months, since each transfusion could reduce anaemia for a few weeks only.

Blood transfusions can cause serious problems for patients on dialysis. These include fluid overload (see Chapter 3), and the storage of surplus iron in the liver (which can lead to liver failure). Another problem is that whenever a transfusion of blood is received, the body produces substances called antibodies. These antibodies stay in the blood for years and can cause problems if the patient is then given a transplant. The antibodies can attack (and cause the body to reject) the new kidney.

The risk of contracting hepatitis B, hepatitis C or HIV (the virus that causes AIDS) from a blood transfusion is small in the UK. Even so, if someone does not need a blood transfusion, it is better not to have one.

Blood transfusions are still sometimes needed by kidney patients – for example, after severe bleeding. In general, however, treatment with EPO has turned regular blood transfusions into a thing of the past for kidney patients.

**EPO – THE ‘WONDER DRUG’**

Synthetically produced EPO became available as an injection in the late 1980s – probably the most important advance in the treatment of patients with kidney failure. By the turn of the millenium, 90% of haemodialysis patients and 60% of PD patients were on EPO. This drug works well in most patients, and usually gets rid of the tiredness and other symptoms caused by anaemia.

EPO is generally given in the form of an injection under the skin (called a subcutaneous injection). This is needed one to three times a week. Some patients may be asked to give their own injections. The aim of the treatment is to raise the Hb level in the blood to between 11 and 12 g/dl. Without this treatment, most patients with kidney failure will have an Hb between 6 and 8 g/dl.

A patient’s response to EPO depends on how much they are given. The higher or more frequent the dose, the higher the patient’s blood Hb level will go. However, there is no point in making the Hb go above 11 to 12 g/dl – the patient will feel no better. In fact, problems may occur if the Hb goes over 14 g/dl. So, patients should only take EPO as prescribed.

**WHO NEEDS EPO?**

Patients who are on dialysis – either PD (see Chapter 9) or haemodialysis (see Chapter 10) – often need EPO. In most patients, anaemia actually begins long before they need to start dialysis. Therefore many doctors now give EPO before the start of dialysis. EPO may also be given if a transplant is failing, as anaemia often returns at this time. However, there are some doctors who prefer to delay starting treatment with EPO until 3 months after the start of dialysis. This is because the start of dialysis will sometimes ‘cure’ a patient’s anaemia – perhaps because dialysis removes toxins that may interfere with the way the bone marrow works.

Treatment with EPO has been found to be very useful even in those kidney failure patients who have anaemia without having a reduced EPO level. It is not known why giving very high doses of EPO to these patients should make such a difference to their anaemia, but it does.

Some patients with kidney failure – especially those with polycystic kidney disease (see page 5) – do not
become anaemic, as their kidneys continue to produce EPO, even when on dialysis. They therefore do not usually need EPO treatment.

**Are there any side effects?**
The only common side effect of EPO is worsening of high blood pressure. This is most likely in patients who have had severe high blood pressure in the past, or in patients who are on more than one type of blood pressure tablet. If the blood pressure does increase, more blood pressure tablets may need to be taken. A combination of EPO and high blood pressure can sometimes cause fits, but this problem can usually be prevented by treating the high blood pressure.

**Poor response to EPO treatment**
Most, but not all, patients respond to regular treatment with EPO. However, EPO may not work if other conditions are present. These include infections – especially repeated peritonitis in PD patients, and dialysis catheter site infections in haemodialysis patients. It also may not work if there is under-dialysis (failure of dialysis to achieve target creatinine and urea levels), renal bone disease (see Chapter 6) or iron deficiency.

Iron deficiency is the most common reason for EPO not to work. EPO causes the body’s iron stores to be used up more quickly than usual. In an attempt to spot the onset of iron deficiency, patients are given regular blood tests to measure a substance called ferritin (see page 40). Blood ferritin levels provide a guide to the amount of iron stored in the body and low levels of ferritin indicate iron deficiency.

If iron deficiency is discovered, the doctors should investigate why the patient lacks iron. One important cause could be bleeding (that may not have been noticed by the patient) from somewhere in the bowel.

If such causes of iron deficiency can be ruled out, it can sometimes be treated with iron tablets (usually a type called ferrous sulphate). Other patients need regular iron injections. These days, iron injections rather than tablets are usually given.

If EPO stops working – for whatever reason – the Hb will return to the ‘normal’ low level in people with kidney failure (usually 6–8 g/dl). The symptoms of anaemia will then return.

**Anaemia and transplantation**
After a kidney transplant, the new kidney will start making EPO for the patient and the problem of anaemia usually goes away. Injections of EPO will then no longer be needed. However, if the transplanted kidney ever fails, anaemia will usually return, and EPO injections may be needed again.

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**Key facts**

1. Many dialysis patients have a condition called anaemia.
2. Anaemia is the major reason why dialysis patients are weak and tired.
3. The severity of anaemia is measured by a blood test called a haemoglobin (or ‘Hb’) test.
4. The lower the Hb level, the more anaemic and tired the patient will be.
5. Anaemia is easy to treat with injections of a substance called erythropoietin (EPO).
6. The target Hb is 11–12 g/dl in most patients.
7. Patients on EPO treatment may need additional iron, in the form of either tablets or injections.
**INTRODUCTION**
Most people with kidney failure have some degree of renal bone disease. This is because one of the ‘extra’ functions of the kidneys is to help make the bones strong and healthy. For the bones to be strong, the kidneys must be able to maintain a healthy balance of various substances – including calcium, phosphate and vitamin D – in the body. Kidney failure results in abnormal levels of these substances, and so leads to renal bone disease.

**DEVELOPMENT OF RENAL BONE DISEASE**
Blood tests will reveal abnormal levels of calcium, phosphate and vitamin D in a patient’s blood very early in kidney failure, long before dialysis is required. The calcium and vitamin D levels will be lower than they should be, while the phosphate level will be too high.

Abnormalities in calcium, phosphate and vitamin D levels do not usually lead to problems that a patient is likely to notice until after the start of dialysis. However, treatment should be started at an early stage to prevent weakening of the bones. This may also help the heart.

**WHAT CAUSES RENAL BONE DISEASE?**
There are three main causes of renal bone disease:

1. **Low calcium levels in the blood.** Calcium is a mineral that strengthens the bones. It is obtained from some foods, especially dairy products, eggs and green vegetables. In our bodies, calcium is stored in the bones. There is also some calcium in the blood. The kidneys normally help to keep calcium in the bones. In people with kidney failure, calcium drains out of the bones and is lost from the body. This leads to a fall in the level of calcium in the blood.

   The normal blood calcium level is between 2.2 and 2.6 mmol/l (millimoles per litre of blood). In kidney patients, the level of calcium in the blood may fall below 2.0 mmol/l. Treatment can keep the calcium level up quite easily.

2. **High phosphate levels in the blood.** Phosphate is another mineral that strengthens the bones. Foods that contain phosphate include dairy products, nuts and meat. Like calcium, phosphate is stored in the body in the bones and is also present in the blood. The kidneys normally help to keep the right amount in the blood –
not too much, not too little. In people with kidney failure, phosphate builds up in the blood.

The normal level of phosphate in the blood is 0.8–1.4 mmol/l. In kidney patients, it is common for the blood phosphate level to be high, rising to more than 2.0 mmol/l. Unfortunately, it is quite difficult to keep phosphate levels normal. High phosphate levels are thought to cause itching.

3. Low vitamin D levels in the blood. Vitamin D is needed in the body so that calcium from the diet can be absorbed into the body and used to strengthen the bones. Vitamin D is found in some foods, especially margarine and butter. However, most of our vitamin D is made by the skin (a process that only occurs if the skin is stimulated by sunlight). Unfortunately, vitamin D from food and from the skin are in a form which the body cannot use directly. The kidneys are responsible for transforming vitamin D into a usable substance.

Blood levels of the usable form of vitamin D are not usually measured, as the blood test is expensive and difficult to do. If they were measured, they would be low. It is quite easy to provide additional vitamin D as tablets or injections, although not all kidney patients need it. Often, it will be enough just to control the levels of calcium and phosphate.

A combination of causes

Doctors do not know which of the three main causes of renal bone disease comes first. Nor do they know what leads to what. They do know, however, that although any one of these causes can lead to problems, a combination of the three is usually present in people with kidney failure. More importantly, each of the causes tends to have a ‘knock-on’ effect, worsening the other two abnormalities. For example, a high phosphate level tends to lower the calcium level, and vice versa. It is important, therefore, to treat all three causes (see page 31).

Parathyroid hormone and kidney failure

Parathyroid hormone (PTH) is a substance produced by four tiny glands called the parathyroid glands. These glands are situated in the front of the neck (see diagram). When someone has kidney failure, the parathyroid glands become over-active and produce too much PTH.

How is renal bone disease monitored?

The levels of calcium and phosphate in a kidney patient’s blood can tell us what is happening in the bones at the time of the test. However, these levels provide little information about the future.

The best guide to the progress and severity of renal bone disease is the amount of PTH in the blood. PTH tells us much more about the long-term health of the bones. Changes in blood PTH can tell us about what will happen to the bones in the future – the lower the PTH, the better.
Renal bone disease begins very early in kidney failure. It is therefore a good idea for doctors to measure a patient’s blood PTH even before dialysis is necessary. Once dialysis has started, most doctors will measure the blood PTH every 6 months or so. A high level indicates a problem with the bones. Doctors will then start a range of treatments to help prevent any worsening of the problem. Even very high PTH levels can usually be lowered with the right tablets.

**HOW IS RENAL BONE DISEASE TREATED?**

Treatment may be needed for each of the three main causes of renal bone disease.

**1. Raising low calcium levels.** Patients on dialysis can obtain some extra calcium from the dialysis fluid. This happens because there is more calcium in some dialysis fluids than there is in the blood. Calcium passes from the stronger solution (the dialysis fluid) into the patient’s blood (the weaker solution) by a process called diffusion. (See *Chapter 8* for more information on diffusion.)

For many kidney patients, extra calcium from dialysis is not enough. They also need calcium in the form of a drug. This drug is calcium carbonate (commonly taken in a preparation called Calcichew). Calcium carbonate tablets may need to be taken every day to look after the long-term health of the bones.

Although the main job of calcium carbonate in kidney patients is to reduce blood phosphate levels (see below, point 2), calcium carbonate also has the effect of raising blood calcium levels. Blood calcium levels are also raised by treatment with vitamin D (see below, point 3).

Treatment is most successful when blood calcium levels are driven to the upper limit of normal. So the target blood calcium level for someone with kidney failure should be 2.5–2.6 mmol/l (given the normal range of 2.2–2.6 mmol/l). This target applies all the time for a peritoneal dialysis (PD) patient, and before dialysis for a patient on haemodialysis.

**2. Lowering high phosphate levels.** Dialysis removes some phosphate from the blood, but it does not do this very efficiently. Most patients therefore need further treatment to control the phosphate level.

To lower their blood phosphate levels, kidney patients are usually given tablets called phosphate binders. The most commonly used phosphate binder is calcium carbonate (see above, point 1). Aluminium hydroxide used to be given as a phosphate binder too, but is rarely used these days. To be effective, any type of phosphate binder needs to be taken just before food, and not together with iron tablets.

If the combination of dialysis and phosphate-binding tablets fails to control a patient’s phosphate level, then it may be necessary for the patient to have more dialysis, or to eat fewer high-phosphate foods (see Chapter 14, page 97), or both of these.

Even with treatment, a kidney patient’s blood phosphate rarely returns to the normal level of 0.8–1.4 mmol/l. So the target blood phosphate level is not normal: it is a level of less than 1.8 mmol/l. This target applies all the time for a PD patient, and before dialysis for a haemodialysis patient.

**3. Raising low vitamin D levels.** In a few patients, renal bone disease continues to be a problem even when the blood calcium and phosphate levels are brought under control. Treatment with a vitamin D preparation is then needed. The most commonly used type is called alfacalcidol. Vitamin D treatment works in two ways: it provides the vitamin D that is lacking and it increases blood calcium levels (see above, point 1). PD patients receive vitamin D in the form of a tablet. Haemodialysis patients receive it either as tablet, or as an injection given during dialysis.
Parathyroidectomy
In most patients, correcting the blood levels of calcium, phosphate and vitamin D is enough to control renal bone disease, and to cause PTH levels to fall.

In a few patients, however, this treatment plan is not sufficient, and blood PTH levels continue to rise. When this happens, the blood calcium tends to rise to above normal (it is usually low in kidney failure). At this stage, the blood phosphate is usually very high. This combination of an extremely high PTH, a high calcium and a very high phosphate level cannot be treated by dialysis and tablets alone. It is then necessary to carry out an operation to remove the parathyroid glands. This operation is called a parathyroidectomy.

If an operation is not performed, the blood vessels can become ‘furred up’ with calcium, which can be very dangerous. Calcium may also be deposited in the eyes (making them red and itchy) or in the skin (which can cause parts of the skin to go black and die). A parathyroidectomy is a very effective operation. It returns blood calcium levels to normal, and can prevent these complications.

A parathyroidectomy operation takes 1–2 hours, and requires a hospital stay of 5–7 days after the operation. For the next few weeks, frequent blood calcium checks will be needed. This is because blood calcium can fall to a very low level after the operation. It is often necessary for patients to take high doses of calcium carbonate and/or vitamin D after a parathyroidectomy. These can usually be stopped at a later date.

Bone pain due to dialysis amyloidosis
Renal bone disease is not the only cause of bone pain in patients with kidney failure. Bone pain can also be caused by a condition called dialysis amyloidosis.

This condition seems to develop 10 years or so after the start of kidney failure. It is caused by a poor removal by dialysis of a protein called amyloid. This causes a build-up of amyloid in the body, which continues even when a patient starts dialysis. After a time, amyloid is deposited in the joints all over the body, especially in the wrists and shoulders. This leads to joint and bone pain.

At present, there is no effective treatment for this condition in dialysis patients. Its progress is halted – to an extent – by transplantation.

Transplants and renal bone disease
If a patient receives a transplant and the new kidney works well, the blood levels of calcium, phosphate, vitamin D and PTH will usually return to normal, or near normal. Renal bone disease then improves, although it never really goes away completely.

If a transplanted kidney never functions properly, or if it starts to fail after working well, renal bone disease will become a problem. It is therefore important to pay attention to the calcium, phosphate and PTH levels even after a transplant.
Key facts

1. Renal bone disease is an important complication of kidney failure.

2. Without treatment, renal bone disease can cause bone pain and fractures, and may also affect the heart.

3. Renal bone disease starts early in kidney failure but does not usually cause problems until after dialysis has begun.

4. Renal bone disease is caused by low levels of calcium and vitamin D in the blood, and by high blood levels of phosphate.

5. A combination of dialysis and tablets usually reverses these problems.

6. The level of parathyroid hormone (PTH) in the blood is the best long-term indicator of the health of the bones.

7. If dialysis and tablets fail to control renal bone disease, an operation called a parathyroidectomy may be necessary to remove the parathyroid glands in the neck.
The 'figures' is commonly used in hospitals to refer to the biochemistry blood test that most kidney patients have at the end of every clinic appointment.

The biochemistry blood test is not really a single test. It includes measurements of a whole range of different substances in the blood. Most patients with kidney failure tend to focus on two of them: creatinine and potassium. This is a good choice, as they are probably the two most important tests. Both of them indicate how well dialysis is working.

However, looking at blood test results can give a person a lot of information about their body. They can tell the patient (and the doctors) about the levels of minerals in the body, the acidity of the blood, the state of the bones, how well nourished the person is, and how well the liver is working.

The dozen or so substances usually measured in a biochemistry blood test for kidney patients can be divided into two groups: dialysable and non-dialysable.

The tests for dialysable substances

The first group of substances measured in the biochemistry blood test for kidney patients are all dialysable. This means that they can pass from the blood into the dialysis solution, and vice versa. The direction in which a dialysable substance travels during dialysis depends on the amount of substance in the blood and in the dialysis solution. Substances always pass – by a process called diffusion – from a stronger to a weaker solution. (See Chapter 8 for a more detailed description of this basic principle of dialysis.)
By putting more or less of different substances in the dialysis fluid, compared with the blood, it is possible to remove substances from the blood, or to add them to the body. The biochemistry test measures blood levels of several substances that may be removed from the body by dialysis – potassium, creatinine, urea and phosphate. It also measures the levels of some useful substances that are given to patients in the dialysis fluid – bicarbonate and calcium. Two other dialysable substances – sodium and glucose – are also measured, although the blood levels of these substances are not usually affected by dialysis.

1. **Potassium.** The chemical symbol for potassium is K. It is a dialysable mineral that is usually present in the blood. The normal level of potassium in the blood is 3.7–5.0 mmol/l (millimoles per litre of blood). Potassium helps the heart to function properly.

Patients with kidney failure tend to have too much potassium in the blood, although there are some patients who have too little. Either too much or too little potassium can be dangerous, causing the heart to stop and the patient to die. Problems are especially likely if the blood potassium is more than 7.0 mmol/l, or less than 2.0 mmol/l.

There is no potassium in peritoneal dialysis (PD) fluid, and only a small amount (usually less than 2.0 mmol/l) in haemodialysis fluid. Because of the basic principle of dialysis (by which substances pass from a stronger to a weaker solution), potassium therefore usually flows out of the blood into the dialysis fluid. Dialysis therefore normally removes potassium from the body.

Controlling the level of potassium in the blood can be quite difficult, especially in patients who are being treated by haemodialysis. Because of this, it may be necessary for some haemodialysis patients to restrict their intake of potassium-rich foods (see also Chapter 14, page 97). Despite the difficulties, a normal potassium level can usually be achieved.

2. **Creatinine.** Creatinine is a waste substance produced by the muscles whenever they are used. Like thousands of other body wastes, creatinine is carried around the body in the blood until it is normally filtered out by the kidneys and passed in the urine (see page 1).

Creatinine is not itself harmful to the body, but it is a very important ‘marker’, which provides a valuable guide to the levels of other, less easily measured substances in the blood. If there is a build-up of creatinine in the blood, there will also be a build-up of many other more harmful substances. The higher the creatinine level, the worse the kidney, dialysis or transplant function (see Chapter 2 for more details).

The normal level of creatinine in the blood is 70–120 µmol/l (micromoles per litre of blood). There is no creatinine in dialysis fluid. Because creatinine is dialysable, it will therefore pass out of the blood, through the dialysis membrane (see Chapter 8) into the dialysis fluid.

Creatinine levels can never be normal when someone is on dialysis. This is because dialysis – whether PD or haemodialysis – can provide only about 5% of the function of two healthy kidneys.

For a patient of average size who is on PD, the target creatinine level is below 800 µmol/l. For a similar patient on haemodialysis, the target is below 800 µmol/l before dialysis, and below 300 µmol/l after dialysis. Larger, more muscular people produce more creatinine than smaller, less muscular people. Because of this, individual creatinine targets are adjusted to take account of body and muscle size. Provided this adjustment is made, the creatinine level is a very reliable guide to a patient’s kidney (dialysis or transplant) function (see Chapter 2 for more details).

3. **Urea.** Urea is a waste product of food. It is made in the liver and then travels in the blood to the kidneys, where it normally goes into the urine for removal from the body. Like creatinine, urea is a ‘marker’ for other,
more harmful substances in the blood. A build-up of urea in the blood also indicates a build-up of many other substances. The higher the blood urea level, the worse the kidney (dialysis or transplant) function (see Chapter 2 for more details).

The normal range for urea in the blood is 3.7–8.1 mmol/l. There is no urea in dialysis fluid. Again, because urea is dialysable, it will pass out of the blood into the dialysis fluid. Urea levels can never be normal when someone is on dialysis. Neither type of dialysis is good enough at getting rid of it. For patients on PD, the usual target level for urea is below 25 mmol/l. For haemodialysis patients, the usual target levels are below 25 mmol/l before dialysis and below 9 mmol/l after dialysis.

Blood urea levels provide a less reliable guide than blood creatinine levels to a patient’s kidney, dialysis or transplant function. This is because the amount of urea in the blood is also affected by what a patient eats and by how much fluid there is in the body.

4. Phosphate. The normal level of phosphate in the blood is 0.8–1.4 mmol/l. In normal quantities, phosphate helps calcium to strengthen the bones. Healthy kidneys help to keep the right amount of phosphate in the blood. When someone has kidney failure, the level of phosphate in the blood rises. (See Chapter 6 for more information about phosphate and the bones.)

Phosphate is a dialysable substance, and the aim is to reduce the amount of phosphate in the blood of people with kidney failure. This is the reason that there is no phosphate in dialysis fluid. Phosphate therefore passes from the patient’s blood into the dialysis fluid (because of the basic principle of dialysis, by which substances pass from a stronger to a weaker solution).

The target phosphate level for dialysis patients is less than 1.8 mmol/l. It is not usually possible to achieve normal phosphate levels in dialysis patients. Dialysis is simply not good enough at removing phosphate from the blood.

If dialysis does not keep blood phosphate at the target level, it may be necessary to take calcium carbonate tablets (as Calcichew, for example). Not only do these tablets give calcium to a patient, they also reduce the level of phosphate in the blood.

5. Bicarbonate. The normal level of bicarbonate in the blood is 21–29 mmol/l. If the blood bicarbonate is lower than normal, this means that there is too much acid in the blood. Acid is a waste product of food; like other wastes in the blood, it is normally removed by the kidneys. When someone has kidney failure, the level of acid in the blood goes up and the level of bicarbonate (the body’s natural alkali) falls. If acid levels in the blood are not adequately corrected over a period of time, this may contribute to malnutrition (loss of flesh weight, see Chapter 14, page 97 for more information). Malnutrition is a common problem in dialysis patients.

The target level for bicarbonate is normal, preferably high-normal, say 26 mmol/l or over. For haemodialysis patients, this target applies after dialysis. It does not matter if the bicarbonate is consistently just above normal.

In order to keep the acidity of the blood normal, dialysis fluid contains an alkali (a substance that is the opposite of an acid). In haemodialysis fluid, the alkali is either bicarbonate (at a concentration of 35 mmol/l) or acetate (at a concentration of 40 mmol/l). In PD fluid, the alkali is lactate, at a concentration of either 35 or 40 mmol/l. Both acetate and lactate are changed into bicarbonate inside the body.

The level of alkali in the dialysis fluid is higher than the level of alkali in the blood. Because alkali is dialysable, and because of the basic principle of dialysis, alkali passes from the dialysis fluid into the patient. In the blood, the alkali neutralises the acid and produces normal blood bicarbonate levels.
6. Calcium. Calcium is a mineral that strengthens the bones. One of the functions of the kidneys is to help to keep calcium in the bones. When someone has kidney failure, calcium passes out of the bones. There is also a fall in the level of calcium in the blood. (See Chapter 6 for more information about calcium and the bones.) The normal level of calcium in the blood is 2.2–2.6 mmol/l. Calcium is a dialysable substance. This means that it can be given to kidney patients in the dialysis fluid. If there is a higher concentration of calcium in the dialysis fluid than there is in the blood, calcium will pass into the patient’s blood during dialysis.

The level of calcium in dialysis fluid ranges from 2.0 to 3.5 mmol/l. Different doctors prefer different levels of calcium in the dialysis fluid – all have their advantages. Most dialysis fluids allow calcium to flow into the blood.

The target level for calcium is 2.5–2.6 mmol/l. This level, at the top of the normal range, has been found to be better for kidney patients than a calcium level in the middle of the range. If the dialysis fluid does not give a patient enough calcium to achieve the target level, it may be necessary to take calcium carbonate tablets (as Calcichew, for example) or vitamin D tablets (usually as alfacalcidol).

7. Sodium. Sodium is one of the minerals normally present in the blood. Its name is sometimes written as Na (pronounced ‘N…a’), which is the chemical symbol for sodium. The normal level of sodium in the blood is 136–144 mmol/l. Sodium keeps water in the body, and helps to control the blood pressure.

Sodium levels are not usually a problem for people with kidney failure. However, sodium is a dialysable substance. To keep blood levels normal, it is therefore necessary to prevent it from being lost from the blood into the dialysis fluid. This is done by having a concentration of sodium in the dialysis fluid similar to that in the blood. (PD fluid contains 132 mmol/l of sodium; haemodialysis fluid contains 132–145 mmol/l.) Because the levels of sodium in the dialysis fluid and the blood are similar, dialysis does not have much effect on the blood sodium level.

Controlling the level of sodium in the blood is quite easy when someone is on dialysis. A normal level is usually achieved.

8. Glucose. The normal level of glucose in the blood is 3.0–7.8 mmol/l. Glucose is a type of sugar, and it provides the body with energy. The amount of glucose in the blood is controlled by a substance called insulin, which is made in the pancreas (a gland in the upper abdomen). When someone has diabetes mellitus (‘sugar diabetes’), their pancreas makes either no insulin, or not enough, and their blood glucose level tends to be high.

Blood glucose levels are only usually a problem for those patients with kidney failure who also have diabetes. Blood glucose problems in these patients are due to the diabetes itself, rather than to the kidney failure that was caused by the diabetes.

For kidney patients who do not have diabetes, it is usually easy to achieve a normal blood glucose level. So blood glucose is not something that most dialysis patients have to worry about.

Although glucose is a dialysable substance, it does not do what people might expect it to do during dialysis. Firstly, for haemodialysis, the dialysis fluid contains an amount of glucose similar to that in the blood (about 5 mmol/l). As expected, given the basic principle of dialysis, very little glucose passes between the blood and the dialysis fluid.

Secondly, the dialysis fluid used for PD contains a lot of glucose. Even a weak bag will contain about 75.5 mmol/l (which is more than 10 times the normal blood level of glucose). In this case, it might be assumed that glucose would pour into the patient and cause problems, but in fact, the body deals quickly with the sudden inflow of glucose. As soon as the glucose enters the bloodstream, the pancreas can usually produce
enough insulin to bring the level of glucose in the blood back down to normal.

However, if a PD patient uses a lot of ‘strong’ bags (containing 3.86% glucose, compared with 1.36% in weak bags), the amount of glucose entering the blood may be too much for the pancreas to cope with. This extra glucose may make any patient (diabetic or not) put on body weight, usually as fat. If a patient has diabetes, it may also upset diabetic control, making it necessary to inject more insulin, or to take more tablets.

Given that glucose sometimes causes problems for PD patients, you may wonder if it is really necessary to include it in the dialysis fluid. In fact, the glucose in the PD fluid is there to perform one of the two major tasks of the kidney, i.e. to remove water from the body (ultrafiltration).

**Tests for non-dialysable substances**

The next group of blood tests to be looked at in this chapter are those which measure blood levels of various non-dialysable substances. Like the tests already described, these tests – measuring blood levels of albumin, and various substances such as bilirubin that show liver function – form part of the regular biochemistry test for patients with kidney failure.

**Albumin.** Albumin is a type of body protein. It is made in the liver and is present in the blood. The normal level of albumin in the blood is 34–48 g/l (grams per litre of blood).

The level of albumin in the blood is measured because of the information this provides about whether a patient is eating enough (especially enough protein). Kidney failure tends to reduce appetite. Also, during dialysis, some albumin and other proteins are lost into the dialysis fluid. Many kidney patients have a lower than normal blood albumin level. If a patient’s blood albumin level is always low, malnutrition (loss of flesh weight, see Chapter 14, page 96) may have become a problem.

Unfortunately, the information obtained by measuring the blood albumin level is not very reliable. One difficulty is that the blood albumin decreases very quickly whenever someone is ill. This means that it is not possible to tell whether or not the malnutrition diagnosed by the test is really a long-term problem. Another problem with the test is that the blood albumin tends to fall whatever is wrong with a patient, no matter how well nourished they are. A further problem with this test is that even if a fall in the blood albumin level is identified, there are no specific treatments to bring it back up again. The target level, for what it is worth, is normal.

**Liver function tests**

The results of a group of tests called liver function tests (LFTs) often appear at the bottom of biochemistry test results. Most doctors do not mention these, or brush over them, saying ‘Oh, don’t worry about them, they are just liver tests’. So why are they measured? The main reason is that biochemistry tests are generally done by a machine, which includes the liver tests automatically.

Having said that, patients with kidney failure can get liver problems. Haemodialysis, blood transfusions or a kidney transplant puts patients at increased risk of catching a viral infection (such as hepatitis B or C) that can cause liver failure. Also, some of the drugs that are used to suppress the immune system after a kidney transplant can affect the liver. So here is a quick guide to common LFTs:

**1. Bilirubin.** This is the most important of the LFTs. (It is the liver function equivalent of the creatinine test.) Bilirubin is produced when worn-out red blood cells are broken down for removal from the body. The normal range of level for bilirubin in the blood is 4–25 mmol/l. Raised bilirubin levels show that the liver is not working properly. If the blood bilirubin goes above 50 µmol/l, the patient will develop jaundice (go yellow in colour).
2. **Aspartate transaminase**. The normal range for aspartate transaminase (AST) in the blood is 8–40 iu/l (international units per litre). Raised levels indicate that the liver cells have been damaged by disease.

3. **Alkaline phosphatase**. The normal range for alkaline phosphatase (alk. phos.) in the blood is 30–120 iu/l. This test measures how well bile (a liquid made by the liver) drains from the liver. Bile contains the waste products from the liver. It is drained into the bowel, and leaves the body in the faeces. In patients with kidney failure, a high alk. phos. level can also indicate renal bone disease.

4. **Gamma-glutamyltransferase**. The normal range for gamma-glutamyltransferase (gammaGT) in the blood is 10–70 iu/l. Like alkaline phosphatase measurements, this test measures how well bile drains from the liver. It also rises if a patient drinks alcohol heavily long term.

**Other blood tests**

Kidney patients are also given a number of other blood tests in addition to the tests that make up their usual biochemistry test. The substances measured by these tests – haemoglobin (Hb), ferritin, cholesterol and parathyroid hormone – are all non-dialysable. Kidney patients have their Hb level measured each time they have a biochemistry blood test. Their blood levels of ferritin, cholesterol and parathyroid hormone are measured less often, usually every 6 months or so.

1. **Haemoglobin**. Most patients on dialysis have anaemia. Anaemia means that there is not enough of a substance called haemoglobin in the blood. Haemoglobin is important because it carries oxygen around the body. Every part of the body needs a regular supply of oxygen. (See Chapter 5 for more information about anaemia in kidney patients.) The normal level of Hb is 11.5–17 g/dl (grams per decilitre of blood). If the Hb level is below 11.5 g/dl, the patient is said to be anaemic.

   There is a very good treatment for anaemia called erythropoietin (EPO), which is given as an injection one to three times per week. Dialysis patients who are not being treated with EPO may have an Hb of only 6–8 g/dl, which is very low. The aim of EPO treatment is to increase the Hb level to 11–12 g/dl. (See Chapter 5 for more information on EPO.)

2. **Ferritin**. For EPO (see above) to work well, it is necessary to have enough iron in the body. The best guide to how much iron there is in the body is a blood test that measures the level of a substance called ferritin. The more iron there is in the body, the higher the level of ferritin in the blood.

   For EPO to work, it is important to have a ferritin level of at least 200 µg/l (micrograms per litre of blood). The normal level of ferritin is 15–350 µg/l, but 200 µg/l is generally considered an adequate level.

   To keep the ferritin above 200 µg/l, many patients on EPO need to take iron tablets, or have regular iron injections. Some renal units now give iron injections to all patients with kidney failure, whether they are on EPO or not.

3. **Cholesterol**. Cholesterol is a form of fat present in the blood. High levels are thought to put people at risk of heart attacks and strokes. Currently, it is recommended to keep the level below 5 mmol/l of blood.

   If the level of cholesterol in the blood is high, it can be reduced in some patients by going on a low-fat diet. However, many patients also need to take a tablet called a statin to control the levels.

4. **Parathyroid hormone**. Parathyroid hormone (PTH) is a hormone (a chemical messenger) that is made by four glands in the front of the neck. These glands are too small to see or feel. If someone with kidney failure has
low levels of calcium and/or high levels of phosphate for a long time, these glands grow and start producing too much PTH.

It is important to measure the level of PTH in the blood of patients with kidney failure because of the information this test provides about a patient’s bones. The amount of PTH in the blood is the best long-term guide to how much damage kidney failure has done to the bones. Blood levels of calcium and phosphate tell you what is happening now; PTH also tells you what will happen in the future.

Different renal units use different tests for measuring PTH, and different doctors have different views about PTH targets for kidney patients. A PTH level that is less than three times the upper limit of normal is generally considered to be satisfactory. As with phosphate levels, it is often hard to achieve normal PTH levels in people with kidney failure. (See Chapter 6 for more information about PTH and renal bone disease.)

**OTHER TESTS**

There are a number of other tests that patients are likely to experience at some time in the course of their life with kidney failure. The more common tests are described below. For more information about tests while preparing for a transplant, see Chapter 11, pages 75–6.

**FINDING OUT ABOUT KIDNEY FAILURE**

1. **Kidney biopsy.** This test involves a hollow needle being used to remove a very small piece of the kidney, which can then be studied under a microscope. Biopsies are sometimes used to find out the cause of kidney failure. They are also used to check whether a transplanted kidney is being rejected.

   Before a biopsy, local anaesthetic is used to numb the area where the needle will be inserted. After a biopsy, the patient will need to rest for 6–12 hours, but it is usually possible to go home the next day (or even later on the same day, in some units).

   Kidney biopsies are not without risk. There is a 1 in 20 chance that not enough of the kidney tissue will have been taken, meaning that the procedure will need to be repeated. There is a 1 in 100 chance of seeing blood in the urine after the biopsy. This usually clears up on its own, but in 1 case in 1,000, the bleeding is so severe that the kidney has to be removed in an operation. There is also a 1 in 10,000 chance of a biopsy causing the patient’s death.

2. **X-rays.** Various types of X-ray are used to investigate kidney problems. X-rays may be taken of the kidneys, of the bladder – an *intravenous pyelogram (IVP)*, *intravenous urogram (IVU)* or *micturating cystourethrogram* – or of the blood vessels to the kidneys (renal angiogram, see below). These special X-ray tests usually require the use of radio-opaque dye (fluid which shows up on X-ray film), which may be injected into the bloodstream or flushed into the bladder during a cystoscopy (when a telescope is put into the bladder). There is also a small risk of worsening kidney function, or even of causing death, with all of these techniques.

3. **Renal angiogram.** For this test, a special tube is passed into the femoral artery (a blood vessel in the groin). This plastic tube is fed up the artery, towards the kidney, and a special dye that shows up on X-rays is injected into it. The dye makes it possible to take X-ray pictures of the blood vessels of the kidney, which will show the doctors if there is anything blocking them.

   A renal angiogram is a complex procedure which carries a degree of risk. Possible side effects include bruising in the groin (not uncommon) and pain. The X-ray dye is toxic to the kidneys and may damage them. There is a 5% risk that a renal angiogram will make the
### Summary of Normal and Target Blood Test Results for Patients on Dialysis

<table>
<thead>
<tr>
<th>Substance</th>
<th>Relevance</th>
<th>Normal level</th>
<th>Target level</th>
<th>Units</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dialysable substances</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Potassium</td>
<td>Heart health</td>
<td>3.7–5.0</td>
<td>normal</td>
<td>mmol/l</td>
</tr>
<tr>
<td>Creatinine</td>
<td>Toxin clearance</td>
<td>70–120</td>
<td>less than 800</td>
<td>µmol/l</td>
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<tr>
<td>Urea</td>
<td>Toxin clearance</td>
<td>3.7–8.1</td>
<td>less than 25</td>
<td>mmol/l</td>
</tr>
<tr>
<td>Phosphate</td>
<td>Bone health</td>
<td>0.8–1.4</td>
<td>less than 1.8</td>
<td>mmol/l</td>
</tr>
<tr>
<td>Bicarbonate</td>
<td>Acid balance</td>
<td>21–29</td>
<td>high–normal (26–29)</td>
<td>mmol/l</td>
</tr>
<tr>
<td>Calcium</td>
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<td>high–normal (2.5–2.6)</td>
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<td>Sodium</td>
<td>Fluid balance</td>
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<td>normal</td>
<td>mmol/l</td>
</tr>
<tr>
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<td>Blood sugar</td>
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<td>normal</td>
<td>mmol/l</td>
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<tr>
<td><strong>Non-dialysable substances</strong></td>
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<tr>
<td>Albumin</td>
<td>Nutritional status</td>
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<td>normal</td>
<td>g/l</td>
</tr>
<tr>
<td>Bilirubin</td>
<td>Liver function</td>
<td>4–25</td>
<td>normal</td>
<td>mmol/l</td>
</tr>
<tr>
<td>AST</td>
<td>Liver function</td>
<td>8–40</td>
<td>normal</td>
<td>iu/l</td>
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<tr>
<td>Alk. phos.</td>
<td>Liver function</td>
<td>30–120</td>
<td>normal</td>
<td>iu/l</td>
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<tr>
<td>GammaGT</td>
<td>Liver function</td>
<td>10–70</td>
<td>normal</td>
<td>iu/l</td>
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<tr>
<td><strong>Other (non-dialysable) substances</strong></td>
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<td>Haemoglobin</td>
<td>Blood health</td>
<td>11.5–17</td>
<td>11–12</td>
<td>g/dl</td>
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<tr>
<td>Ferritin</td>
<td>Iron in blood</td>
<td>15–350</td>
<td>more than 200</td>
<td>µg/l</td>
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<tr>
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<td>Heart and brain health</td>
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<td>Parathyroid hormone</td>
<td>Bone health</td>
<td>1.1–4.2</td>
<td>less than 15</td>
<td>pmol/l</td>
</tr>
</tbody>
</table>

How do your test results compare? Although your hospital may use slightly different figures, they should be similar to those given here. If any of your figures do not seem to be on target, find out why.
kidney function worse, but this can be as high as 10% in patients who have diabetes or a degree of kidney failure before the test. There is a 2% chance of the dye causing so much damage that the person will need dialysis earlier than expected, and a small number of people may be allergic to the dye. Complications following an angiogram can be fatal in around 1 in 1,000 cases.

4. Computed tomography (CT) scan. This is another special type of X-ray. It uses a machine to send X-rays around the area being looked at, in order to build up an image of the ‘slice’ of body being scanned. The patient needs to lie inside the machine for a CT scan to take place. Radio-opaque dye is sometimes required for a CT scan. If it is, there is a small risk of worsening kidney function or, in rare cases, causing death.

5. MRI scan. MRI stands for magnetic resonance imaging – a scanning technique which uses magnetism, radio waves and a computer to produce high-quality pictures of the inside of the body. The patient lies inside a large machine that sends signals to a computer. The computer then builds an image of the inside of the body. No X-rays are used.

   An MRI scan allows doctors to see good pictures of the inside of the kidney, which will help them discover the cause of problems.

6. Ultrasound scans. This is the type of test used on pregnant women to check on the baby in the womb. It is also used to help discover the cause of kidney problems – either when kidney failure is first discovered, or if there appear to be problems after a transplant. It uses sound waves, so is completely safe.

   Jelly is spread on the skin and an ultrasound probe moved over the abdomen and sides of the body, allowing the kidneys to be seen on the screen. Sometimes, the person carrying out the test may print photographs of certain images seen on the screen. The test is quick and painless for the patient, and tells the doctor if a kidney is shrunken, enlarged or even missing. Ultrasound scans may be used to allow the doctor to locate the kidney before taking a biopsy.

Tests for people on dialysis

1. Adequacy test. Adequacy is a general term that refers to how well dialysis is working. Adequacy tests are basically clearance tests, as described in Chapter 2, pages 14–16.

2. Peritoneal equilibration test (PET). This is a test for patients who are being treated by peritoneal dialysis (see Chapter 9). The test measures how quickly waste products and fluid are removed from the blood during dialysis. It is an important test in determining the correct prescription for peritoneal dialysis. The test takes 4 hours, and involves taking samples of dialysis fluid and a blood test. Other similar tests include the peritoneal function test (PFT) when samples are taken from each bag used.

3. Residual renal function (RRF). When patients first start treatment, their own kidneys may still be working, but at a reduced level. The amount they are still working will vary from patient to patient and is known as ‘residual renal function’. The longer a patient keeps their RRF, the healthier they will be. Over time, it is likely the RRF will decline, and in many patients, it eventually disappears altogether. As the RRF declines, the dialysis prescription should be adjusted to make up for the reduced function. A creatinine clearance test, which measures the amount of creatinine cleared by the kidneys and put into the urine (see Chapter 2, pages 14–16), is used to assess RRF.
**Key facts**

1. The term ‘figures’ is used to refer to the biochemistry blood test that most kidney patients have at the end of every clinic appointment.

2. The biochemistry test is not a single blood test. It measures the levels of a dozen or so different substances in the blood. The results tell the patient about the levels of minerals in the body, the acidity of the blood, the state of the bones, how well nourished the person is, and how well the kidney is working.

3. The substances that are measured can be divided into two groups, dialysable and non-dialysable.

4. Dialysable substances can pass from the blood into the dialysis fluid and vice versa. Substances pass from a stronger to a weaker solution. This basic principle of dialysis determines the direction in which a substance travels during dialysis.

5. Potassium, creatinine, urea and phosphate are dialysable substances that are taken out of the body during dialysis.

6. Calcium and bicarbonate are dialysable substances that are usually put into the body during dialysis.

7. Non-dialysable substances measured by blood tests include albumin, various substances that measure liver function, haemoglobin, ferritin, cholesterol and parathyroid hormone.

8. Patients with kidney failure should know the values of most of their blood tests all the time.

9. Patients with kidney failure may have other tests to find out about the extent to which their kidneys have failed, tests to see how well dialysis is working and tests to prepare them for a transplant.

10. Tests for finding out about kidney failure and dialysis include biopsies and angiograms, clearance tests and various types of imaging and X-ray.
INTRODUCTION
This is the first of four chapters which explain the treatment options available to people with kidney failure. There are basically two ways of treating kidney failure: dialysis (see also Chapters 9 and 10) and transplantation (see Chapter 11). There is currently no cure.

WHAT IS DIALYSIS?
Dialysis is an artificial way of doing the work of the kidneys. It clears waste products from the blood, and it also removes excess water. Dialysis thus performs the two main functions of the kidneys: toxin clearance (see Chapter 2) and maintaining fluid balance (see Chapter 3).

There are two different types of dialysis: PD (see Chapter 9), and haemodialysis (see Chapter 10).

HOW DOES DIALYSIS WORK?
Even though, at first sight, PD and haemodialysis may seem quite different, they work in similar ways:

- Waste products are cleared from the blood by a process called diffusion (see page 46).
- Excess water is removed from the blood by a process known as ultrafiltration (see page 47).
- Wastes and water pass into a special liquid – called the dialysis fluid or dialysate – for removal from the body.
- A thin layer of tissue or plastic, known as the dialysis membrane, keeps the dialysis fluid and blood apart.

THE ROLE OF THE DIALYSIS FLUID
Both of the key processes involved in dialysis – i.e. diffusion and ultrafiltration – depend on the use of a dialysis fluid. Body wastes and excess fluid can only pass from the blood if they have somewhere to go. The dialysis fluid provides the ‘container’ in which they are removed from the body. The dialysis solution is slightly different in each type of dialysis, but it does the same job.

The chemical content of the dialysis fluid affects the flow of substances between the blood and the dialysis fluid. During dialysis, body wastes and excess fluid pass from the blood into the dialysis fluid. Other substances, such as calcium, will usually flow in the opposite direction, from the dialysis fluid into the blood.

THE DIALYSIS MEMBRANE
Dialysis solution is toxic to the body if it flows directly into the blood. It is important therefore to keep the dialysis fluid separate from the blood. This is done by using a dialysis membrane, which looks similar to a very thin piece of ‘cling film’.

The dialysis membrane has thousands of tiny holes in it. These holes are big enough to let water, body wastes and various other substances through, yet small enough
to keep the blood cells and proteins inside the blood vessels. So the dialysis membrane acts as a ‘leaky barrier’ between the blood and the dialysis fluid.

In haemodialysis, the membrane used is artificial, made from a type of plastic. The membrane, folded over many thousands of times, is situated in an artificial kidney (called a dialyser). Dialysis takes place outside the patient’s body, in the artificial kidney.

In PD, a natural membrane inside the abdomen, called the peritoneum, is used. The peritoneum lines the inside wall of the abdomen, and covers all the abdominal organs (the stomach, bowels, liver, etc.). It is a thin layer of tissue, rather like a thin balloon in appearance and texture.

**WASTE REMOVAL BY DIFFUSION**

Diffusion is one of the key processes involved in dialysis. It is a process by which substances pass from a stronger to a weaker solution.

Diffusion works in the same way as a tea bag. When hot water is poured over a tea bag, the tea comes out of the bag and into the water. The surface of the teabag is like the dialysis membrane, as it lets tea drain out of the tea leaves, but does not let the tea leaves out themselves. The tea mixes with the water until the tea is the same colour throughout the cup.

People with kidney failure have a lot of body wastes in their blood. If the blood is put next to a dialysis fluid that does not have any of these wastes in it, the wastes will pass from the blood into the dialysis fluid. So, if we want to remove unwanted substances (such as urea or creatinine) from the blood, we need a dialysis fluid that contains little or none of those substances.

As dialysis proceeds, there comes a point at which there are equal amount of wastes in the blood and in the dialysis fluid (as when the tea stops changing colour). The process of diffusion then stops, and no more wastes will move across. This is the basic principle underlying dialysis.
Diffusion also works the ‘other way’ round. If the amount of a substance is higher in the dialysis fluid than in the blood, then that substance will pass from the dialysis fluid into the blood. So if we want to add useful substances (such as calcium) to the body via the blood, we use dialysis fluid that contains a lot of those substances.

**Fluid removal by ultrafiltration**

Ultrafiltration – the other key process involved in dialysis – occurs at the same time as diffusion. It is the process by which excess fluid (mainly water) is drawn out of the blood during dialysis. Ultrafiltration happens in slightly different ways in haemodialysis and PD.

In haemodialysis, the water is ‘sucked’ from the blood by the kidney machine. The amount of water to be removed during a session of haemodialysis can be varied, from a lot to a little, depending on how the machine is set up.

In PD, a substance is put into the dialysis fluid which ‘sucks’ the water from the blood. The most commonly used substance is glucose (i.e. sugar). The way the glucose sucks water from the blood is the same way as a tree draws water up from the ground to its highest leaves. It depends on a process called osmosis.

Osmosis occurs when a liquid from a weak solution (e.g. water in the blood) passes through a semi-permeable membrane (e.g. the dialysis membrane) into a stronger solution (e.g. one of glucose in the dialysis fluid). By this means, water is lost from the blood, and the glucose solution is diluted.

The amount of water drawn from the blood depends on the amount of sugar in the solution – the more sugar, the more water will be removed. Hence in PD, there are different strengths of dialysis bag – with ‘strong’ bags containing more sugar than ‘weak’ bags. The choice of bag depends on how much water needs to be removed from the patient’s blood: a strong bag will remove more water than a weak bag.
**PD or haemodialysis?**
Both methods of dialysis are equally effective. Haemodialysis works much more quickly than PD, and so only has to be done in short sessions (taking 3–5 hours), two or three times a week. PD is a much gentler form of dialysis, and so needs to be performed every day.

Some doctors think it is better to start off with PD so, if the technique ever fails, the patient’s veins are in a better state for haemodialysis at a later date.

In the UK, approximately 65% of the patients on dialysis are treated by haemodialysis, and the remaining 35% by PD. In fact, it is possible for most patients to have either type of treatment. Indeed, many patients will experience both during their life with kidney failure.

In most other developed countries, PD is not quite so common as it is in the UK. For example, only about 12% of patients in the USA are treated by PD. This difference could be due in part to the fact that doctors in some countries are paid according to how many patients they treat by the different types of dialysis. Doctors in these countries often receive more money for haemodialysis patients than they do for patients on PD.

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**Key facts**

1. Dialysis is the word used to describe the removal of body wastes and water from the blood.

2. There are two types of dialysis: haemodialysis and peritoneal dialysis (PD). Both work in a similar way.

3. There are two main processes involved in dialysis: diffusion and ultrafiltration. Diffusion removes the body wastes, and ultrafiltration removes the excess water.

4. In the UK, approximately one third of patients on dialysis have PD, and the other two thirds have haemodialysis.

5. Most patients can have either type of dialysis.
This chapter concentrates on peritoneal dialysis (PD), the newer of the two types of dialysis that may be used to treat people with kidney failure.

**INTRODUCTION**

Peritoneal dialysis (PD) is one of the two types of dialysis that may be used to treat people with kidney failure. In PD, the process of dialysis (see Chapter 8) takes place inside the patient’s body, using the peritoneum (the natural lining of the abdomen) as the dialysis membrane. PD has been available in the UK since the late 1970s. It has proved to be a highly successful alternative to the ‘traditional’ form of dialysis known as haemodialysis (see Chapter 10).

**WHO CAN BE TREATED BY PD?**

PD is a suitable treatment for most people with end-stage renal failure (ESRF). However, there are a couple of requirements:

1. **A non-scarred abdomen.** People who have had several major abdominal operations may not be able to have PD. This is because a scarred peritoneum may not be an effective dialysis membrane.

2. **Commitment.** PD requires a lot of commitment from kidney patients and their families. Kidney patients on PD are responsible for exchanging their own dialysis fluid (see page 52). They perform these exchanges in their own homes. For this reason, PD is not recommended if patients are unable to care for themselves and do not have someone available full-time to help them with their exchanges.

**WHAT DOES PD DO?**

PD (like haemodialysis) takes over some of the work that is normally done by the kidneys. It removes the waste products of food (toxin clearance, see Chapter 2), and removes excess water from the body (see Chapter 3). It can also be used to give people various substances that they are lacking, such as calcium or bicarbonate.

PD and haemodialysis are equivalent techniques in terms of the amount of dialysis they can deliver (about 5% of the function of two normal kidneys). Both relieve the symptoms of kidney failure, and both enable patients to go back to work.

Currently, PD is less likely than haemodialysis to be used for patients who are elderly or frail, such as people in nursing homes. At present, a very small number of nursing homes in the UK employ a nurse who can do the PD exchanges for patients. Even if an area does not have such a home, it might be possible to persuade a good nursing home to provide this service. If it is possible to find, or create, this facility within a nursing home, PD may still be an option where patients and their families are unable to give the commitment usually needed. This is useful if, for example, the patient’s close relatives are not in a position to give up full-time work.
**How does PD work?**

The basic principles of dialysis are the same for PD and haemodialysis. (These principles are explained in detail in Chapter 8.) Briefly, both types of dialysis use a special liquid (called the dialysis fluid, dialysis solution or dialysate) and a membrane (called the dialysis membrane) to do some of the work of the kidneys. In PD, the dialysis membrane is the patient’s own peritoneum (see below).

The dialysis fluid provides the ‘container’ in which waste products and excess water can be removed from the body. The dialysis membrane acts as a filter. It keeps the dialysis fluid and the blood separate from each other, but it allows certain substances and water to pass through it. During dialysis, substances pass from the blood into the dialysis fluid (and vice versa). They do this by a process called diffusion, by which substances pass from a stronger to a weaker solution (see page 46). At the same time, ultrafiltration occurs (see page 47). Excess water passes from the blood into the dialysis fluid by a process called osmosis, in which liquid in a weaker solution passes into a stronger one.

**The peritoneum**

The essential difference between PD and haemodialysis is that, in PD, the dialysis process takes place inside the patient’s abdomen, using a natural membrane – the peritoneum – as the dialysis membrane. It is from the peritoneum that PD (peritoneal dialysis) gets its name.

The peritoneum is a natural membrane that lines the inside of the abdominal wall and covers all the abdominal organs (the stomach, bowels, liver, etc.). It resembles a balloon in appearance and texture but has lots of extremely tiny holes in it. These holes allow the peritoneum to be used as a dialysis membrane. As blood flows through the blood vessels in the peritoneum, it flows past the holes. Although the holes are extremely tiny, water and toxins can easily pass through, but blood cells are too large. In this way, the peritoneum in PD works as a ‘natural filter’, performing the same function as the ‘artificial filter’ used in haemodialysis.

The peritoneum has two layers – one lining the inside of the abdominal wall, the other lining the abdominal organs. Between these two layers is a space. This space is called the peritoneal cavity. During PD, it is the peritoneal cavity that is used as a reservoir for the dialysis fluid. Normally, the peritoneal cavity contains only about...
100 ml of liquid. In fact, it can expand to hold up to 5 litres of liquid, as women who have been pregnant know.

**How is PD done?**

PD needs to be done every day. It consists of the following three stages:

1. The peritoneal cavity is filled with 1.5–3 litres of dialysis fluid from a dialysis bag. (The amount varies, depending on a patient’s individual needs and the type of dialysis fluid used.)

2. The dialysis fluid is left inside the peritoneum to allow dialysis to take place. (The length of time it is left there varies, from between 1 and 8 hours, depending on individual requirements and the type of PD.)

3. The ‘used’ fluid, containing the water and toxins that the kidneys would normally have passed into the urine, is drained out of the body and discarded, usually down the toilet.

**Operation to insert a PD catheter**

To receive PD, a kidney patient first needs to have a small operation. During the operation (which is performed using a local or a general anaesthetic), a plastic tube is permanently inserted into the abdomen (see diagram). This tube is called a PD catheter. It is about 30 centimetres (12 inches) long and as wide as a pencil.

The PD catheter is placed through the lower abdominal wall, into the peritoneal cavity. Half of the catheter lies inside the abdomen, and half lies outside. It comes out on the right or the left, under the navel (tummy button). The PD catheter acts as a permanent pathway into the peritoneal cavity from the outside world. It is the PD patient’s dialysis ‘lifeline’.

Patients are usually allowed to go home 1 or 2 days after the operation. The catheter is ‘left alone’ for 5 days or more after the operation before it can be used for dialysis. This allows it to ‘settle in’ and gives the abdominal wound time to heal.

PD catheter operations are not always successful – only 75% of those inserted end up being used reliably. So some patients need two or more operations to get a PD catheter working.

**The training**

PD is performed by patients themselves, in their own homes. They therefore need proper training to perform their own dialysis fluid exchanges. This training is usually given to patients two weeks after their PD catheter operation.
Before anyone is expected to carry out their own dialysis, they will be trained in all aspects of their care by specialist nurses. Most patients can become competent in the exchange technique in 3–14 days. Some hospitals train patients as an in-patient, some as an out-patient. When patients first go home and have to do the exchanges by themselves, they may find it a bit daunting. However, within a few weeks most patients find that they are doing the dialysis by themselves with no problems.

METHODS OF FLUID EXCHANGE

The way that the dialysis fluid is exchanged depends on the type of PD.

There are two main types of PD, which differ only in the way that the dialysis fluid is exchanged. The two different types of PD are:

1. **Continuous ambulatory peritoneal dialysis (CAPD).** ‘Continuous’ means ‘all the time’ and
ambulatory’ means ‘while you walk around’. In this form of PD, patients walk around with the dialysis fluid in their abdomen. At the end of each period of dialysis, they have to change the dialysis fluid themselves (see below and diagrams on page 52).

2. Automated peritoneal dialysis (APD).
‘Automated’ means that a machine changes the dialysis fluid for the patient. The patient remains connected to the machine while dialysis is taking place, usually at night (see below).

**Fluid exchanges in CAPD**
When patients are on CAPD, they do their own fluid exchanges. They drain 1.5–3 litres of dialysis fluid into their abdomen, leave it there for 4–8 hours, and then drain it out. This is done four or five times a day – every day. It is as simple as that. With practice, an exchange of fluid can be done in about 30 minutes. Exchanges are simple to do and can be performed almost anywhere.

The dialysis fluid is kept in sealed plastic bags. The bags are connected and disconnected to the peritoneal catheter with a system of tubes and clamps. (How this is done is shown in the diagrams on page 52.)

There are no ‘set’ times to carry out the exchanges. However, a four bag regime ‘fits’ into a typical day. For example, the first bag might be exchanged before breakfast, the second before lunch, the third before the evening meal, and the fourth before going to bed (leaving the fluid for the last exchange in through the night). It is easy for patients to adapt the timing of exchanges to their own individual needs. For example, a patient who wants to go out for the day could delay the mid-day exchange, and do two ‘quick bags’ (say, 3 hours apart) after coming home. It may be safe to miss the occasional bag, but this is certainly not recommended on a regular basis.

**Fluid exchanges in APD**
APD uses a machine to do the dialysis fluid exchanges for the patient. The machine is usually placed in the bedroom and does the exchanges while the patient is asleep. Some APD machines are only the size of a video recorder (see below) and make it possible for patients to do exchanges in different places.

Most patients need to spend 8–10 hours attached to the machine every night. This enables the machine to perform an average of six exchanges of 1.5–3 litres of dialysis fluid each night. The length of time that PD fluid is left in the abdomen before it is exchanged by the machine varies between about 1 and 3 hours. After spending the night on the machine, most people on APD keep fluid inside their peritoneum during the daytime without needing to exchange it.

A few patients can afford to miss one night’s dialysis per week. However, they should always check first with the doctor or nurse at the renal unit to see whether this is safe.
**CAPD or APD?**

In most renal units in the UK, about 65% of the PD patients currently do CAPD, and 35% do APD. However, the number of patients doing APD is growing all the time. Different patients may be better suited to either CAPD or APD for a number of reasons:

1. **How the peritoneum works.** The main medical reason why a doctor may choose either CAPD or APD for a patient relates to the way the patient’s peritoneum works during dialysis.

   Some patients, called ‘high transporters’, have a peritoneum which works best with more frequent exchanges of dialysis fluid. High transporters are usually more suited to APD, because the machine is able to do rapid exchanges of dialysis fluid while they sleep.

   Other patients, called ‘low transporters’, will get more dialysis if the fluid is left inside them for longer periods. Low transporters are generally better suited to CAPD. A test has been developed to find out whether patients are ‘high’ or ‘low transporters’. This test is called a peritoneal equilibration test (see page 43), and is usually performed in hospital by a nurse. It takes 4 hours to complete, and involves doing just one CAPD exchange. The test measures how quickly the toxins move out of the patient’s bloodstream and into the dialysis fluid. If the toxins move quickly, the patient is called a ‘high transporter’. If the toxins move slowly, the patient is a ‘low transporter’.

2. **Patient size.** APD can also be particularly good for patients who require a lot of dialysis – for example, large people, especially those who no longer pass urine. This is because the machine can do more fluid exchanges than patients are able to do themselves with CAPD. Also, as the patients are lying down, they may be more able to tolerate bigger volumes of dialysis fluid. In these ways, APD can remove more waste toxins than CAPD. Even so, for some very large patients, APD during the night may not be enough. Such patients commonly need an additional CAPD exchange at tea-time.

3. **Patients with a carer.** APD is a possible treatment option for patients who need a carer to perform dialysis for them, such as the elderly, infirm or very young.

4. **Employment reasons.** Since APD exchanges are done during the night, this form of dialysis can be particularly suitable for patients who work or who are in full-time education.

**BIGGER BAGS AND STRONGER BAGS**

Whatever the type of PD (either CAPD or APD), the ability to remove toxins (i.e. more clearance) can be raised by increasing either the volume of fluid used, or the number of exchanges, or both. A larger bag will remove more toxins (and a little more water) than a smaller bag. The dialysis needs of patients depend partly on their body size (see Chapter 2). Big people usually need ‘big bags’ (2.5 or 3 litres of dialysis fluid).

The ability of PD fluid to remove water (i.e. to do ultrafiltration) is affected by the amount of glucose (sugar) in the bag – the more glucose in the bag, the more water is removed. There are three different strengths: a ‘strong’ bag (3.86% glucose solution), a ‘medium’ bag (2.27% glucose) and a ‘weak’ bag (1.36% glucose). When there is too much water in the body (a condition called fluid overload, see page 18) the patient will be advised to use more strong or medium bags. These will remove more water than weak bags.

The strength of the bag is different from the size of the bag. A strong bag has more glucose in it than a weak bag, but it is no larger. Patients are advised to consider the weak bag as their ‘standard’ bag, and to try to use a minimum number of strong bags.
**Alternative dialysis fluids**

There are a number of new ‘special’ dialysis fluids which are sometimes prescribed for patients with particular problems:

1. **Icodextrin.** This fluid contains a glucose polymer (in which the glucose molecules are stuck together), rather than ordinary glucose. Icodextrin may be recommended for PD patients who are diabetic or overweight. This is because the glucose polymer in Icodextrin is less likely than ordinary glucose to be absorbed into the body to cause problems with sugar balance or weight gain. Icodextrin has also been shown to benefit patients who have been on PD for a long time and whose peritoneums do not work very well for dialysis.

2. **Amino acids.** Some other dialysis fluids use amino acids rather than glucose. As amino acids are the building blocks of protein, and as some of the amino acids are absorbed into the blood, it is thought that these dialysis fluids might also act as food supplements. It is claimed that dialysis fluids containing amino acids are useful for patients who do not eat well or who have malnutrition (see Chapter 14 for information on diet).

3. **Bicarbonate.** A bicarbonate-based dialysis fluid has been developed to help patients who have problems regulating the level of acid in their bodies. The solution is very similar to that of the human body (it is ‘biocompatible’), and is thought to preserve the patient’s peritoneal membrane. This solution may also be good for people who experience pain when the fluid is drained in.

**Living with PD**

Once people develop ESRF, they will have it for the rest of their lives. Without treatment – by PD, haemodialysis or a kidney transplant – people with ESRF will die within a few weeks. With treatment, they will be able to do all or most of the things they did before they became ill. PD does affect a person’s lifestyle – especially because of the need for daily dialysis – but the limitations are often less of a problem than many people might expect.

1. **Flexibility.** PD is a flexible treatment which can be performed almost anywhere. The dialysis supplies can be delivered to most parts of the world, and some APD machines are portable.

2. **Responsibility and independence.** People on PD usually do their own dialysis, usually in their own homes. This gives many PD patients a greater sense of responsibility and independence than is possible for the majority of haemodialysis patients (who receive their dialysis from nurses or dialysis technicians in a hospital).

3. **Sport and exercise.** Most types of sport and exercise are possible for people on PD. Even contact sports are possible (although not always recommended). PD patients who want to play sports such as rugby, judo and karate are advised to wear a protective belt around their abdomen.

4. **Swimming/baths/showers.** Before a swim (or bath or shower), PD patients need to cover their PD catheter with a special plastic dressing, which they can get from either the hospital or their family doctor. After a swim (or bath or shower), patients should clean the exit site of their catheter and, whenever possible, should also do a fluid exchange.

5. **Sexual activity.** Sex is very possible for people on PD. Some people may find it uncomfortable to have sex with the dialysis fluid in, but they can drain it out first and use a new bag afterwards. Patients on APD can have sex either off the machine or while they are on it (the connecting lead is very long).
**Delivery and Storage of Supplies**

PD is performed by patients themselves in their own homes. They therefore need to have supplies of fluid delivered to them and to be able to store these supplies in a convenient place. The bags of dialysis fluid come in boxes of four or five, and so a month’s supplies can be as many as 40 boxes. These can be stored in a cupboard under the stairs, a spare bedroom, the shed or even the garage.

Most people receive a delivery of supplies once a month, although patients with very small houses or flats may be able to arrange fortnightly deliveries. The people who deliver the supplies deliver to many other dialysis patients, and are specially recruited and trained to go into patients’ homes. They will move the supplies to exactly where a patient wants them, and will even move boxes around so that fluid from previous deliveries gets used before the new stock.

**Possible Problems with PD**

PD is not always entirely trouble free. Patients may experience various psychological and physical problems:

1. **Feelings of restriction.** Some kidney patients feel that PD is more restrictive than haemodialysis because it never goes away. PD patients have to do dialysis every day. Haemodialysis patients, on the other hand, do at least have some ‘let up’ from it – they do have ‘days off’.

2. **Body image problems.** Some PD patients do not like the way PD affects their appearance. The abdomen tends to get stretched by PD, giving it a rounded appearance. Young people in particular may be very conscious of their body shape, especially if they are slim. Keeping fit and doing exercises to strengthen the abdominal muscles will help.

   The PD catheter can also cause body image problems. PD patients now have to come to terms with the fact that they now have a piece of plastic tubing permanently sticking out of their abdomen. Some people find this very difficult to cope with, and feel they have been severely mutilated. They may also worry that the catheter might put off a sexual partner. (See Chapter 15 for more information about the psychological aspects of kidney failure.)

3. **Sexual problems.** Sexual problems – such as reduced sex drive, impotence and problems with fertility – are common among people with kidney failure. However, not all kidney patients have sexual problems, and for those who do, a range of treatments is available (see Chapter 16).

4. **Fluid overload.** The amount of ‘used’ fluid that is drained out of the body after PD is about 1.5 litres per day more than the amount of fresh dialysis fluid that is put in. This extra fluid – in effect, the PD patient’s urine – does not increase in quantity however much the patient drinks. This means that PD patients have to restrict their drinking to 1.5 litres a day in order to avoid problems due to fluid overload (see Chapter 3 for details).

5. **Discomfort.** Some PD patients find that the dialysis fluid in their abdomen is uncomfortable. It may also lead to backache.

6. **Wearing out.** The peritoneum does not actually ‘wear out’ but, in a small number of patients, it may in time cease to be effective as a dialysis membrane. Newer PD solutions, such as those that contain bicarbonate, may help to preserve the membrane for longer.

**Poor Drainage**

One of the most common problems with PD – especially among new PD patients – is poor drainage of the dialysis fluid. The PD catheter may become blocked with a
substance called fibrin, which is a form of protein. It looks like tiny strands of cotton wool and is completely harmless. A patient may be able to clear the catheter simply by squeezing the tubing to dislodge the fibrin. Alternatively, a nurse will be able to clear the catheter by injecting water, saline (a salt solution) or a de-clotting agent, called heparin, down the catheter. This is a simple procedure and will not need an operation.

The most common reason for poor drainage is constipation. If a PD patient becomes constipated, the bowels press against the catheter and make the dialysis fluid drain very slowly. The fluid may also get trapped in pockets of bowel, preventing it from draining properly. So it is very important to avoid constipation, perhaps by taking regular laxatives.

Another reason for poor drainage might be that the catheter is in the wrong position. There is no single ‘right’ position for a PD catheter. As they are free to roam around the tummy, they can settle in almost any position and they may move into different positions from week to week. A ‘good position’, however, is one that enables the catheter to work well. Sometimes a displaced catheter will ‘float’ back into a good position naturally. If this does not happen, an operation may be required to move it.

Leaks
In most PD patients, the ‘seal’ around the catheter exit site (where the catheter leaves the abdomen) works properly. PD fluid drains in and out of the abdomen through the tube without any leakage. However, in some patients, the PD fluid leaks out around the catheter, wetting the dressing over the exit site.

If a leaking catheter is ‘rested’ (not used for dialysis) for 2–4 weeks, it will usually ‘seal up’ again, and become water-tight. Occasionally, however, a leak may recur even if the catheter is rested. It may then be necessary to have an operation to take out the leaking catheter.

A new catheter, at a different site, is usually put in during the same operation.

In some men on PD, fluid leaks into the scrotum and causes swelling of the genitals. This is called a scrotal leak. If a scrotal leak occurs, PD must be stopped temporarily until the leak has healed.

Hernias
A hernia occurs when a wall of muscle weakens and lets an organ or tissue bulge through from inside. Hernias can cause difficulties for PD patients. If a patient has a hernia before the PD catheter is put in, it can become more of a problem afterwards. The daily draining of PD fluid into and out of the abdomen can cause the hernia to become bigger (and more painful).

If nothing is done, the bowel can become ‘stuck’ inside the hernia, thereby blocking the bowel. This will require an emergency operation. If an existing hernia is noticed by the surgeon during an operation to insert a PD catheter, it will be repaired during the same operation to stop it causing problems in the future.

If a hernia occurs at a later date, it should also be repaired. This may require a 4–6 week period of haemodialysis while the operation heals.

Peritonitis
Peritonitis is an infection of the peritoneum. It is usually caused by one of two types of bacteria (called *Staphylococcus epidermidis* and *Staphylococcus aureus*). In rare but serious cases, peritonitis in PD patients is caused by a fungus (usually a type called *Candida albicans*).

The most common reason why PD patients get peritonitis is that they touch the connection between the bag of fluid and the catheter. However, even if PD exchanges are scrupulously clean, infection can still enter the abdomen from the outside world through the
PD patients can expect to get on average less than one attack of peritonitis every 18 months, so it is not that common. Indeed, some patients never get it. Patients on APD are less likely to get peritonitis than those on CAPD, probably because fewer catheter connections are required.

A patient will know when they have peritonitis because the dialysis fluid that drains out will be cloudy. This fluid is normally ‘see-through’. Patients sometimes – but not always – have abdominal pain and a fever as well. The treatment is simple and effective – usually one or more antibiotics given either as tablets or added to the fresh dialysis fluid. Patients are shown how to do this – i.e. they treat peritonitis themselves in their own homes.

A patient will not be offered a transplant if a kidney becomes available during an attack of peritonitis. This is because the drugs that are given after a transplant to prevent kidney rejection (see Chapter 13) may make the peritonitis worse. These drugs, which are called immunosuppressant drugs, make it harder for the body’s immune (defence) system to fight any type of invader (including germs as well as transplanted organs).

Occasionally, a patient may get several attacks of peritonitis in a row. The doctor may then decide that an operation to replace the PD catheter is needed straight away. The old catheter can be removed and replaced with a new one, at the same operation. Alternatively, the doctor may decide that it is better to remove the old catheter, and ‘rest’ the abdomen by not using it for PD for a period of 4–6 weeks. The catheter will then be replaced in a second operation. If this happens, the patient will usually need to have haemodialysis until PD is resumed.

If peritonitis is caused by a fungus such as Candida, it will be treated straight away – by an operation to remove the PD catheter. Drugs are not very effective against fungi, but the problem soon goes away if the catheter is removed. The catheter can still be replaced at a later date.

Patients who have had many bad attacks of peritonitis may find that PD is no longer suitable for them. They then have to change to haemodialysis as their long-term treatment.

Exit site infections
PD patients may also get another type of infection, called an exit site infection. This causes a red tender area around the exit site (the point where the PD catheter comes out through the skin). Also, when a person has this type of infection, squeezing around the exit site may produce some pus.

Some PD patients get exit site infections regularly, whereas others never get them. Keeping the catheter taped down to the skin will help reduce the risk of an exit site infection, especially when the catheter is new.

Exit site infections respond well to antibiotics, usually given either as tablets or creams. Sometimes, a single intravenous injection of an antibiotic called vancomycin is needed. There is usually no need to remove the PD catheter.

Occasionally, an exit site infection spreads down the catheter ‘tunnel’ (the route taken by the catheter through the abdominal wall). This type of infection is called a tunnel infection. Antibiotics are not always effective when someone has a tunnel infection. An operation to remove the catheter will then be necessary. It is usually possible to insert a new catheter at the same operation.
In peritoneal dialysis (PD), the process of dialysis takes place inside the patient’s abdomen.

PD is suitable for most people with ESRF.

The patient’s peritoneum (abdominal lining) acts as the dialysis membrane.

Dialysis fluid from a bag is drained into the peritoneal cavity, left there until dialysis has taken place, and is then drained out.

Patients are trained to do PD themselves, in their own homes.

One advantage of PD is the independence it gives patients.

Storage space in the home is needed to accommodate bulky supplies of dialysis fluid.

Peritonitis is the main problem with PD. Patients know they have peritonitis when their used dialysis fluid becomes cloudy.
INTRODUCTION
Haemodialysis is the older of the two types of dialysis. This treatment became available in the 1960s, and since then has enabled large numbers of kidney patients to lead almost normal lives. The main difference between haemodialysis and the other type of dialysis – called peritoneal dialysis or PD (see Chapter 9) – is that in haemodialysis, the process of dialysis (see Chapter 8) takes place outside the body, in a machine.

WHO CAN BE TREATED BY HAEMODIALYSIS?
Almost all patients with end-stage renal failure (ESRF) can be treated by haemodialysis. The only real requirements are:

- It must be possible to gain good access to a patient’s bloodstream (see page 62). (Access can be a particular problem for kidney patients who have diabetes, see page 68.)

- Patients must be able to withstand major changes in blood pressure and toxin levels. (Most people have no problems with this, but some patients with heart problems are unable to cope.)

WHAT DOES HAEMODIALYSIS DO?
Haemodialysis takes over some of the work that the kidneys can no longer manage when a person has kidney failure. Like PD, haemodialysis removes the waste products of food (toxin clearance, see Chapter 2) and removes excess water from the body (ultrafiltration, see Chapter 3). It can also be used to give people with kidney failure various substances that they may be short of, such as bicarbonate and calcium.

Either haemodialysis or PD can provide dialysis that is equivalent to about 5% of the work done by two healthy kidneys. This is enough to relieve most of the symptoms of kidney failure, and to enable people to do all, or most of, the things they could do before they became ill.

HOW DOES HAEMODIALYSIS WORK?
The basic principles of dialysis – which apply to both haemodialysis and PD – are explained in detail in Chapter 8. Briefly, both types of dialysis use a special liquid (called the dialysis fluid, dialysis solution or dialysate) and a membrane (called the dialysis membrane) to do some of the work of the kidneys.

In haemodialysis, the process of dialysis occurs in a machine. This machine is called a dialysis machine or kidney machine (see top diagram, page 61). Blood from the patient is pumped through the machine so that dialysis can take place. Dialysis fluid and water are also pumped through the machine.

The dialysis machine contains a special filtering unit called the dialyser or artificial kidney (see bottom diagram, page 61). The dialyser is a cylinder that
contains thousands of very small hollow tubes. Each of the tubes is made from very thin plastic, which acts as the dialysis membrane. The patient’s blood is pumped through the middle of the tubes. Meanwhile, the dialysis fluid is pumped around the outside of the tubes. The process of dialysis takes place through tiny holes in the tubes. Various substances and water can easily pass through the holes, but blood cells cannot.

During dialysis, body wastes (such as creatinine and urea) pass from the blood into the dialysis fluid. They do this by a process called diffusion, by which substances pass from a stronger to a weaker solution (see page 46). Meanwhile, other substances that are needed by the body (such as bicarbonate and calcium) can be supplied to them from the dialysis fluid. Again, it is diffusion (now working in the opposite direction) that makes this possible.

The second main function of the kidneys (and therefore of dialysis) is to remove water. The way that this is done in haemodialysis is not the same as in PD. (In PD, water is removed by a process called osmosis, see page 47). In haemodialysis, it is the action of the dialysis machine that removes the water. The machine applies a sucking pressure that draws water out of the blood and into the dialysis fluid. This process is known as ultrafiltration (see also page 47) or ‘….f….ing’. Instructions about the amount of water to be removed and the rate of ultrafiltration are entered into the machine at the start of each dialysis session.

**DIFFERENT DIALYSERS AND MACHINES**
There are many sorts of dialyser available, and different renal units tend to have their own preferences. Although the dialysers may look quite different from one another, the way in which they work is the same. The same applies to dialysis machines. Manufacturers opt for different colour schemes and shapes. Also, different machines display information in different ways, but they all tell much the same story.
HOW IS HAEMODIALYSIS DONE?
To do haemodialysis, the patient must be connected to a dialysis machine. The machine may be in a hospital renal unit, in a satellite dialysis unit or, less commonly, in the patient’s own home (see page 66).

Haemodialysis is done by taking blood from the body and pumping it around a dialysis machine and through a dialyser. In the dialyser, toxins and excess water – which are the equivalent of the urine produced by healthy kidneys – pass from the blood into the dialysis fluid. The cleansed blood is then returned to the body at the same rate at which it is removed. Meanwhile, the ‘used’ dialysis fluid (full of toxins and extra water) is pumped out of the dialysis machine and down the drain.

Haemodialysis is usually done two or three times a week, for 3–5 hours each session. The exact length of the sessions will depend on the amount of waste that an individual patient produces; bigger people generally need longer dialysis sessions than smaller people. Longer sessions may also be needed by patients who do not pass any urine.

Most renal units use a new dialyser at each dialysis session, but some units – especially in the USA – clean the dialysers after use and re-use them several times on the same patient.

‘ACCESS’ TO THE BLOODSTREAM
The term ‘access’ soon becomes familiar to patients on haemodialysis. It refers to the method by which access is gained to the bloodstream, so that dialysis can take place.

During haemodialysis, large quantities of blood must be rapidly removed from the body, and (at the same time) just as rapidly returned to it. Therefore, in most cases, access has two ‘sides’. One of these (often called the ‘arterial side’) is used to take blood out of the patient’s body. The other (often called the ‘venous side’) is used to return blood to the patient after dialysis.

There are two main types of access:
- a dialysis catheter, which is usually a double-barrelled plastic tube (see below); and
- a fistula, which is formed from the patient’s own blood vessels by joining a vein to an artery (see page 63).

DIALYSIS CATHETERS
A haemodialysis catheter is a plastic tube, usually with two separate barrels, one for removing blood from the body, and the other for returning it after dialysis. The catheter, which needs to be half in and half out of the body, is inserted during a short operation. This operation may be performed under either a general or a local anaesthetic. The catheter is inserted into a large vein either at the side of the neck, under the collar bone, or at the top of the leg next to the groin (see diagram, next page). Names sometimes used for catheters in these different places are a ‘jugular line’ (at the side of the neck), a ‘subclavian line’ (under the collar bone), and a ‘femoral line’ (in the groin).

Dialysis catheters may be temporary or semi-permanent. Temporary catheters are often used while patients are waiting for a fistula to be created. Other patients – particularly those with diabetes – have blood vessels that are not strong enough for a fistula, and will need a semi-permanent catheter for haemodialysis access.

Semi-permanent catheters are tunnelled deeper under the skin than temporary catheters. They also have small cuffs around them, just under the skin, to help keep them in place, and to help keep germs out of the body. Semi-permanent catheters also tend to be softer and more flexible than most temporary catheters.

After each dialysis session, saline (salt dissolved in water) is injected into the line to remove any blood. The inside of the catheter is then filled with a drug called heparin. Heparin stops the formation of blood clots,
which could block the catheter. This keeps the catheter clear of clots between dialysis sessions. Access is the haemodialysis patient’s lifeline, and catheters must always be treated with great care by doctors, nurses and patients. Between dialysis sessions, patients are asked to keep their catheter clean and dry, and to ensure that it has a dressing on it at all times.

**Fistulas**

The usual form of access for haemodialysis is the arteriovenous fistula or AVF (often simply called a fistula). Fistulas are the preferred method of haemodialysis access because they are less likely to get infected and will generally last longer than a catheter. However, some people are unable to have a fistula formed because they have very thin or delicate veins that are unsuitable for this.

Fistulas are made by a surgeon in a small operation, which may be performed under a general or a local anaesthetic. In this operation (see diagram, next page), a vein (a blood vessel that carries blood back to the heart) is joined to an artery (a blood vessel that carries blood away from the heart). This can be done under the skin, usually at either the wrist or the elbow.

The blood pressure in arteries is always higher than the blood pressure in veins. When a fistula is formed, blood from the artery flows into the vein, and causes it to enlarge a little. Once the fistula has ‘matured’ (i.e. grown) it will be ready for dialysis. This usually takes about 6 weeks.

Fistulas are not always successful: 90% of brachial fistulas (fistulas at the elbow) but only 60% of radial fistulas (at the wrist) grow into something that can be used for dialysis. However, although the success rate is lower for a radial fistula than for a brachial one, doctors will usually try a radial fistula first. This is because once a person has had a brachial fistula, they cannot then have a radial one, but if they have had a radial fistula first, and it ceases to work, it may still be possible for them to have a brachial fistula created.

Whenever a fistula is used for haemodialysis, a local anaesthetic may be applied to the area and then two large needles are inserted into the fistula. These needles provide access to the bloodstream for dialysis, and are removed at the end of the session. Fistulas are a better form of access than catheters because they do not use any plastic, and so are less likely to become infected.

The creation of a fistula means some blood that would otherwise have gone to the hand (or arm) in the artery used for the fistula, instead bypasses the hand or arm and goes up the fistula. This does not normally cause any problems. However, occasionally, the hand or arm becomes cold and painful because of the blood that is ‘stolen’ from it by the fistula. This is called steal syndrome. Severe steal syndrome may mean that the fistula has to be ‘tied off’ – i.e. permanently blocked off – by a surgeon during another small operation.
Steal syndrome is more common in brachial (elbow) fistulas, which is a disadvantage of that type of fistula, even though the initial success rate is high. When a fistula is touched, a buzzing sensation is felt. This is known as a bruit (pronounced ‘broo-ee’). Patients with fistulas are advised to check for the buzz every day. They should do this gently as fistulas can be fragile. If there is no buzz when a fistula is touched, this probably means that the fistula has become blocked by a blood clot. Often this occurs at night and is caused by accidentally sleeping on the fistula arm. If no buzz can be felt, it is important to contact the hospital as soon as possible as it may be possible to clear the clot and save the fistula.

**Other Types of Access**

There are other types of access available, which are used when the two main types (double-barrelled catheters and fistulas) no longer work. This usually happens in patients with fragile blood vessels.

1. **Grafts.** A graft is a plastic connecting tube that joins an artery to a vein, inside the patient’s arm or leg. (It is therefore different from a fistula, in which the patient’s artery and vein are joined directly without a plastic connector.) The graft must be inserted by a surgeon during an operation. Grafts are made of a special self-sealing material (for example, Gortex) through which dialysis needles can be inserted. A graft can be used many hundreds of times.

2. **Single-barrelled catheters.** It is sometimes necessary to use a single-barrelled catheter. This is inserted into the same sites that would have been used for a double-barrelled catheter. Recent studies suggest that 60% of grafts are still working at the end of 1 year – a success rate similar to that for a radial fistula. The advantage, however, is that they can usually be used more quickly – usually within 1–2 weeks of being inserted. Doctors in the USA tend to favour grafts over fistulas.

**Single-needle Dialysis**

It is also possible to do haemodialysis using a single needle to remove and return the blood (rather than the two needles used for ‘normal’ dialysis). The single needle is inserted into a fistula or a graft. Alternatively, a single-barrelled catheter can be used. Single-needle dialysis is
sometimes used for patients who have developing fistulas or grafts, or if a patient’s fistula never enlarges properly. It is not nearly as effective as normal, two-needle dialysis.

**How much dialysis is needed?**
In most hospitals, it is the nurses in the renal unit who are responsible for working out how long kidney patients need to spend on the dialysis machine, and also what size of dialyser they will use. There are different sizes of dialyser – bigger ones remove more toxins than smaller ones (provide better clearance). Longer dialysis sessions will also remove more toxins.

As a rule, the bigger or more muscular the patient, the more dialysis they will need. In order to change the amount of dialysis that a patient receives, the nurse can choose to alter the size of the dialyser and/or the length of time that the patient spends on the machine.

The dialysis dose can be worked out simply by comparing the levels of wastes (such as urea or creatinine) in the patient’s blood before and after dialysis (see Chapter 2), and making sure that there is a significant reduction. Some units still use this method, but it is now more common to use one of the newer methods of working out dialysis doses. The first of these uses a calculation called the urea reduction ratio; the other is a method called urea kinetic modelling. With each of these methods, dialysis target figures are the same whatever the size of the patient.

The urea reduction ratio is really just a more formal way of comparing urea levels in the blood before and after dialysis. As before, the patient’s urea levels are measured in millimoles per litre (mmol/l) of blood, but now the measurements before and after dialysis are used to calculate a percentage reduction in blood urea. (For example, if the blood urea before dialysis was 30 mmol/l, and after dialysis it was 15 mmol/l, then the percentage reduction in urea during dialysis was 50%.) Such information allows adjustments to be made at future dialysis sessions in order to achieve the current urea reduction target of at least 65% per session.

Urea kinetic modelling also compares the levels of urea in the patient’s blood before and after dialysis. However, this method also takes into account the size of the dialyser (called ‘K’), the time the patient will need on the machine (called ‘t’) and a number that reflects the patient’s body weight (called ‘V’). This produces a figure called the Kt/V (pronounced ‘K...t...over V’). Because a patient’s Kt/V figure refers to the amount of urea cleared from the body, the higher the number the better (see also page 14). Recent recommendations state that Kt/V should be more than 1.2 for each dialysis session.

Some patients on haemodialysis believe that it is the amount of fluid that needs to be removed which determines the length of time that they must spend on the dialysis machine. This is wrong. The most important factor affecting the length of dialysis is the amount of toxins that need to be removed. However, if a patient has a lot of fluid to remove, they may need to spend extra time on the machine to achieve this.

**Haemodialysis in hospital**
Most haemodialysis patients receive their treatment in a specially designed kidney unit within a hospital. This is called unit haemodialysis.

Patients attend the hospital two or three times a week to use one of the unit’s dialysis machines. Unlike PD (see Chapter 9), in which patients have almost total responsibility for their dialysis, unit haemodialysis still tends to be done on behalf of the patient, by nurses, healthcare assistants and technicians. Patients therefore have very little responsibility for their dialysis sessions – other than turning up at the right time. This may suit some patients for various personal and medical reasons.

For other patients, however, the lack of control over their own treatment is not satisfactory. To address this problem, many kidney units now encourage their more
able patients to become involved in their own care. This may mean simply having patients check their own blood pressure before dialysis, but it may go as far as teaching patients to put themselves on to, and taking themselves off, the dialysis machine.

Visiting the hospital regularly for haemodialysis sessions does have its advantages. It helps patients to avoid the feelings of isolation that may occur when dialysis is done at home (either PD or home haemodialysis, see below). Unit dialysis also gives patients with ESRF frequent and regular access to medical and nursing expertise, education and support. It also gives them an opportunity to chat to other patients who are ‘in the same boat’.

**Satellite Haemodialysis**

Many hospitals now offer what is called satellite haemodialysis. This takes place away from the main hospital, in a ‘satellite unit’. At the satellite unit, a small number of the hospital’s healthier patients are treated by relatively few nurses. The patients generally do some of the dialysis preparation themselves. This allows patients to feel more in control of their treatment than is often possible in hospital-based units.

Satellite units can be more convenient for patients as they tend to be nearer to residential areas than many hospital buildings, making them more accessible by car or public transport. It may also be possible to arrange haemodialysis sessions after normal working hours.

**Haemodialysis at Home**

Some kidney patients can do haemodialysis in their own homes (‘home haemodialysis’). The dialysis machines used today have many safety devices built into them, so it is usually quite safe to dialyse at home.

Whether or not a patient can have home haemodialysis depends partly on the hospital and partly on the patient. Some kidney units are more willing than others to provide home haemodialysis. Even if a unit is willing, the money must be available to supply the dialysis machine, to convert a room in the patient’s home to be used for dialysis and to put in a special water supply.

To be considered for home dialysis, patients must:

- be quite fit, with no access problems;
- be able to learn to do dialysis, and be able to solve the various problems that might occur during a dialysis session; and
- have someone around to help every time they are on the machine.

As long as these conditions are met, home haemodialysis can be an ideal option for kidney patients who value their independence and who perhaps need to fit in haemodialysis around a busy work schedule.

**Living with Haemodialysis**

The need to do haemodialysis regularly has an inevitable effect on lifestyle. Having to make frequent trips to the hospital can be an irritation, and may interfere with the patient’s family or work life. Home haemodialysis may be less disruptive, but still involves a long-term regular commitment to the treatment by the patient and other members of the family.

Doing haemodialysis can restrict a kidney patient’s holiday choices. Holidays can sometimes be difficult to arrange because of the need for patients to find a dialysis centre that is willing to treat them while they are away from home.

Haemodialysis patients are less likely than PD patients to have body image worries. Some haemodialysis patients need a semi-permanent catheter to provide access, and they may feel unhappy about the effect this has on their appearance. However, the more usual form of access for haemodialysis is the fistula,
which is much less visible. (See Chapter 15 for more information about the psychological aspects of kidney failure.)

**POSSIBLE PROBLEMS DURING HAEMODIALYSIS**

Haemodialysis, like all medical procedures, is not without its problems. Most of the problems that occur with haemodialysis are related to the speed with which water is removed from the bloodstream during dialysis. Removing water from the bloodstream quickly is a bit like letting the air out of a balloon. When air is released from a balloon, the pressure inside it drops, and it becomes less rigid. In humans, when water is let out of the blood over a short period of time, the blood pressure falls. Haemodialysis is a more ‘aggressive’ form of dialysis than PD. In haemodialysis, all the dialysis is crammed into two or three sessions a week, each one lasting only 3–5 hours. In other words, the balloon is let down very quickly. The rapid changes in blood pressure (usually a fall), and in the blood levels of water and body wastes that occur during a haemodialysis session, can make some patients feel quite unwell, either during or after the session. Fainting, vomiting, cramps, temporary loss of vision, chest pain, fatigue and irritability can all occur.

The best way to avoid problems caused by rapid physical changes during haemodialysis is for patients to stick to recommended fluid intake limits. For most haemodialysis patients, the recommended daily fluid intake is about 1 litre of fluid. (PD patients can usually have 1.5 litres.)

Some kidney units use a technique called sodium profiling to prevent problems caused by the rapid removal of water. However, not all kidney doctors and nurses agree that this is useful. Although sodium profiling does help in the removal of fluid and does stop dizziness and cramps during dialysis, it may also make patients more thirsty after dialysis – and so more likely to need more fluid removing at the next dialysis session. For this reason, some people believe that sodium profiling creates a vicious circle of excessive drinking and fluid removal.

**FLUID OVERLOAD AND HAEMODIALYSIS**

Between dialysis sessions, haemodialysis patients sometimes develop the condition called fluid overload (see page 19). This causes excess fluid to collect first in the skin at the ankles and then elsewhere in the body, including the lungs.

Problems with fluid overload are usually due to drinking too much. However, the problem is not always the patient’s fault. It can also occur when the person in charge of a dialysis session does not set the controls to take off enough fluid, or misjudges a patient’s target weight.

If a patient thinks that they may have fluid overload between dialysis sessions, they should contact the hospital at once. It may be necessary for such a patient to have an extra dialysis session to remove the excess fluid. Constantly being fluid overloaded causes the blood pressure to rise. Like a balloon which contains too much air, the heart muscle stretches, and will eventually weaken.

The best way for patients to avoid the complications associated with fluid overload is to stick to the fluid restrictions they have been given.

**HYPERKALAEMIA (EXCESS POTASSIUM)**

Another problem that may occur between haemodialysis sessions is hyperkalaemia. In this, there is too much potassium in the blood (see also Chapter 14). A raised level of potassium in the blood may cause the heart to flutter, and even stop. Hyperkalaemia can be very dangerous. It requires urgent medical treatment, and sometimes immediate dialysis. If hyperkalaemia is a problem for a patient on haemodialysis, they may be...
asked to restrict their intake of foods that contain a lot of potassium.

**PROBLEMS WITH ACCESS**

There may also be problems with the different types of haemodialysis access.

The usual type of haemodialysis access is a fistula (see pages 63–4). If a fistula works well, it makes haemodialysis technically easy. However, not all fistulas work perfectly. Some never develop into a vein that is large enough for the blood flow to be adequate. Some function for months or even years, then suddenly stop working. In either case, a surgeon will then have to make a new fistula (or sometimes a graft) in another part of the body. Unfortunately, there are only a certain number of veins that are suitable to be used in this way. If patients require haemodialysis for many years, they may eventually run out of suitable veins.

To use a fistula (or graft), it is necessary to insert needles into it at the start of each dialysis session. Even with a local anaesthetic, some patients find this painful.

Because of the limited 'life' of fistulas, grafts and dialysis catheters, haemodialysis may eventually become impossible. This can be a particular problem for patients with diabetes mellitus (sugar diabetes).

Dialysis catheters may also cause problems. Some patients find it difficult to cope with their changed body image (see Chapter 15). Another problem is that dialysis catheters sometimes stop working because they have become blocked by a blood clot. If a catheter stops working, it will have to be replaced. Again, as for fistulas and grafts, there are only a certain number of veins suitable for plastic tubes. Dialysis catheters are more likely to become infected than either fistulas or grafts.

If a graft becomes infected, this can be very serious. It may be necessary to have another operation to remove the graft.

**PROBLEMS FOR DIABETICS**

The blood vessels of people with diabetes can be very narrow. This can make it almost impossible to form a fistula in some patients. Inserting plastic tubes into the veins can also be very difficult. For this reason, some doctors recommend PD rather than haemodialysis for kidney patients with diabetes, especially when they first start dialysis.

There is also a fear that the drug heparin, which is normally given during haemodialysis to prevent blood clotting, can cause bleeding at the back of the eye (as well as other sites). By the time they need dialysis, most diabetics with kidney failure are prone to this type of bleeding (a condition called diabetic retinopathy), which can cause blindness. It may therefore be better to avoid having to use heparin.

However, not all doctors think that haemodialysis is inadvisable for this group of kidney patients. Some consider that haemodialysis is just as good as PD, does not worsen vision, and may indeed have some advantages for many people with diabetes.

**BLEEDING**

Haemodialysis patients may have problems with bleeding either during a dialysis session or, more commonly, after dialysis when the fistula needles are removed. Sometimes bleeding can result from using heparin during dialysis. So most centres now try to use as little heparin as possible, and some people have heparin-free dialysis. To try to stop the bleeding after dialysis, it is common for the heparin to be turned off at least 1 hour before the end of the dialysis session.

**INFECTIONS**

There is always a risk that a patient will pick up an infection during a dialysis session. Germs may enter the patient’s blood either from the haemodialysis access or
from the lines of the machine. During sessions of dialysis, fevers often become worse and there may be rigors (shivering attacks).

Infections can usually be treated with antibiotics, but it is better to avoid getting an infection in the first place. This can be achieved by strict attention to hygiene. Care is needed both with personal hygiene and when the dialysis machine and access lines are set up. Fistulas are much less likely to get infected than dialysis catheters.

Patients may sometimes develop an infection where the haemodialysis catheter comes out from under the skin. This is called an exit site infection, and causes the area around the catheter to become sore and inflamed. Most exit site infections respond well to antibiotics.

The inside of the catheter can also become infected. This is called a line infection, and can make patients very unwell, causing fever and rigors. If a patient develops a line infection, their catheter will usually be removed and replaced after the fever has settled. Temporary catheters are more likely to become infected than semi-permanent ones, and for this reason temporary catheters should be replaced after about 3 weeks of use even if they are not obviously infected. This helps to prevent line infections.

### Key Facts

1. In haemodialysis, the process of dialysis takes place inside a machine.
2. Haemodialysis is suitable for most people with kidney failure.
3. In a haemodialysis session, blood is taken from the body, pumped into the dialysis machine, cleaned by an artificial kidney (dialyser), and pumped back into the body.
4. Haemodialysis is usually done two or three times a week, each session lasting 3–5 hours.
5. In order to do haemodialysis, it is necessary to gain direct access to the patient’s bloodstream. The usual types of access are a dialysis catheter or a fistula (made by joining a vein to an artery).
6. Most patients have haemodialysis in a hospital, but some have it in a satellite dialysis unit or at home.
7. Some patients may feel sick or dizzy during a haemodialysis session. This is usually due to the rapid removal of water and toxins, which results in a rapid drop in blood pressure.
8. Haemodialysis patients have a stricter fluid restriction than PD patients.
9. Because of the limited life of fistulas, grafts and dialysis catheters, haemodialysis may eventually become impossible for some patients.
INTRODUCTION
A successful kidney transplant is a more effective treatment for kidney failure than either peritoneal dialysis (see Chapter 9) or haemodialysis (see Chapter 10). However, not all patients are suitable for transplantation, and not all suitable patients are suitable all the time.

Also, before a transplant can take place, it is necessary to find an appropriate donor kidney, which may not be easy.

THE BENEFITS
A kidney transplant can deliver the best quality of life to people with end-stage renal failure. There is no doubt that for the right patient at the right time, a transplant is the best treatment option. A ‘good’ transplant provides about 50% of the function of two normal kidneys (compared with only about 5% from either type of dialysis).

The most obvious advantage of a transplant to people with kidney failure is freedom from dialysis. If a transplant works well, dialysis becomes a thing of the past. There are also no particular fluid or dietary restrictions after a transplant. Erythropoietin and calcium tablets, such as Calcichew, can usually be stopped. Most people who have had a transplant feel better and have more energy than they did on dialysis. They are more able to cope with a job, and many find their sex lives improve. Women are more likely to get pregnant and have a healthy baby.

WHO CAN HAVE A TRANSPLANT?
Up to 40% of patients with kidney failure are suitable for a transplant, provided a suitable donor kidney can be found (see next page). Patients who will probably not be considered suitable include anyone with serious heart or lung disease, or with many types of cancer.

Most kidney units do not have an age limit for kidney transplantation. Patients are considered on merit (i.e. their suitability for a transplant) rather than age. However, having said that, most units would think very seriously before transplanting a patient over 70 years old.

Doctors do not believe that transplanting an older patient ‘wastes’ a kidney that a younger person would get ‘more benefit’ from. The main reason for limiting transplants among older patients is that they often do not tolerate the operation very well. Also, the drugs that are needed after a transplant (see page 90) are often too strong for older patients.
NEW KIDNEYS AND OLD DISEASES

Patients who are having kidney transplants sometimes worry that the original cause of their kidney failure might make the new kidney fail too, but this would be very unusual for most people. An exception, however, is where the original kidneys failed because the patient had a condition called focal and segmental glomerulosclerosis (FSGS). This is a type of glomerulonephritis, and it comes back in 10–30% of patients who have had it before. Patients who have lost one kidney due to recurrent FSGS have a 40–50% chance of losing another one.

There are a few other types of glomerulonephritis and related conditions that may also come back. These include mesangiocapillary glomerulonephritis (20–80%, depending on type), Goodpasture’s disease (25%), haemolytic uraemic syndrome (10–25%), membranous nephropathy (10–25%), IgA nephropathy (10%), Henoch-Schönlein purpura (10%), and lupus nephritis (1%). But these conditions, if they do recur, do not necessarily lead to loss of the kidney. However, if FSGS or one of these other conditions were to recur in two consecutive kidneys, causing their failure, doctors would probably not recommend a third transplant.

Patients who are affected by any of these conditions, should ask their doctor about the likelihood of the original disease recurring, and damaging a kidney transplant.

DO YOU HAVE TO BE ON DIALYSIS FIRST?

Most kidney units will not put patients onto the national waiting list for a transplant kidney (see page 74) until they are stable on dialysis. However, a few units will put patients onto the list before this point. This is usually done when the blood creatinine is about 400 µmol/l (micromoles per litre of blood) – i.e. about 6 months before dialysis will be needed. Also, if someone has a transplant that is failing, they may be put onto the list at this same point, and given a new kidney before they have to go back on dialysis.

The national waiting list is for what is known as a cadaveric transplant (see page 74). This type of transplant uses a kidney that has been removed from someone who has died; 80% of the kidneys transplanted in the UK come from this source. The remaining 20% are what are known as living related transplants or LRTs, and living unrelated transplants or LURTs (see page 81). For some patients, the possibility of obtaining a transplant kidney from a living donor will be the best chance of having a transplant operation before dialysis is needed.

Given that it is possible for people with kidney failure to be given a transplant before they need dialysis, you may wonder why all hospitals don’t do this. The reason is that most doctors think that because there is such a shortage of kidneys for transplantation, it is better if patients all around the UK start waiting for a kidney at an equivalent time point, i.e. when they start dialysis. This makes it fair for everyone.

However, some kidney units are undoubtedly better organised in terms of transplantation than others. So some units do carry out more transplants before dialysis. Some units also make more effort to obtain kidneys than others and do more transplants, and some units are keener on living transplants than others. For all these reasons, patients in some units may wait less time for a transplant, and be more likely to have a transplant before they need dialysis, than is usual in other units. You have a right to ask the doctors, nurses or managers about the performance of your unit.

FINDING A SUITABLE KIDNEY

For a kidney transplant to be successful, it is better that the tissues of the new kidney are fairly similar (i.e. ‘matched’) to the patient’s original kidney. If the new kidney is not a good enough match, the patient’s
immune system (natural defence system) will be more likely to attack and reject it. (See page 88 for a description of the rejection process.)

Before a suitable kidney can be looked for, it is necessary for patients to have a number of tests. The most important of these are to find out the patient’s blood group (see below) and tissue type (see page 73). The results will then be checked against the results of similar tests carried out either on an available kidney, or on a relative or other person who is considering donating one of their kidneys to the patient.

**Matching the Blood Group**
The blood group is an inherited characteristic of red blood cells. It stays the same throughout your life. There are four main blood groups. These groups are called A, B, AB and O. Group O is the most common, followed by group A – except in Asian patients, in whom group B is the most common.

The blood group that you belong to depends on whether or not you have certain substances called antigens (types of protein) in your body. Two different antigens – called A and B – determine a person’s blood group. If you have these antigens, they will be on the outer surface of all your cells, not just on your blood cells. If you have only antigen A, your blood group is A. If you have only antigen B, your blood group is B. If you have both antigen A and antigen B, your blood group is AB. If you have neither of these antigens, your blood group is O.

The function of the blood group antigens is not known exactly. They may act as a ‘friendly face’ for the cells, so the rest of the body can recognise the cells as their own, and leave them alone. A person’s immune system will attack any cells that have a foreign antigen. This means a patient can only be given a transplant kidney if the patient’s and donor’s blood groups are matched as follows:

<table>
<thead>
<tr>
<th>Patient</th>
<th>Donor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group O</td>
<td>Group O</td>
</tr>
<tr>
<td>Group A</td>
<td>Group A or group O</td>
</tr>
<tr>
<td>Group B</td>
<td>Group B or group O</td>
</tr>
<tr>
<td>Group AB</td>
<td>Any group (O, A, B, or AB)</td>
</tr>
</tbody>
</table>

**Matching the Tissue Type**
The principle of matching for tissue type is similar to that for matching for blood group. Again, the patient and the donor kidney or potential donor are matched using a blood test. The tissue typing test shows a person’s genetic make-up (a type of ‘genetic fingerprint’).

The tissue type is an inherited set of characteristics (antigens) on the surface of most cells. It stays the same throughout your life. You have only one tissue type (just as you only have one blood group), but your tissue type is made up of six different tissue type characteristics.

There are three main sorts of tissue type characteristic, called A, B and DR. Everyone has two of each (one from each parent) – making six in all. Just to make it more complicated, there are many different types of A, B and DR characteristic. In fact there are 20 or more different versions of each A, B and DR characteristic. This means that there are hundreds of different possible tissue types. So, for example, a tissue type could be A1/A2, B7/B8, DR2/DR3.

As there are so many possible tissue types, matching tissue types is a little more complicated than matching blood groups. However, basically the more of these that are the same for both patient and donor kidney, the better will be the chances that the transplant kidney will work.

Given the large number of tissue type possibilities, it is very unusual to get an exact match (known as a ‘6 out of 6 match’ or ‘full-house match’) between a patient and donor. Most units will offer a transplant if the patient and donor have three or more of the six tissue type
characteristics in common, and there is at least one DR match. In terms of tissue typing, it is more important that the DR characteristics are matched than the A or B types. So, for example, a transplant might be offered in the following situation:

<table>
<thead>
<tr>
<th>Patient:</th>
<th>A1/A2</th>
<th>B7/B8</th>
<th>DR2/DR3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor:</td>
<td>A1/A3</td>
<td>B7/B12</td>
<td>DR2/DR7</td>
</tr>
</tbody>
</table>

As the A1, B7 and DR2 characteristics are the same in this example. It would be called a ‘3 out of 6 match, including one DR match’.

The more characteristics that match the better. So a ‘6 out of 6 match’ is better than a ‘3 out of 6 match’. The better the match, the more likely it is that the body will accept the kidney ‘as its own’, and not try to reject it. Unfortunately, it cannot be guaranteed that even a ‘6 out of 6’ match will not be rejected. This is because the blood group and tissue type are not the only cell surface characteristics that are important. However, these other important characteristics have not all been identified.

**Testing for Viruses**

Before a patient can be put forward for a transplant, they will have to be tested for various viruses. These include HIV (the virus that causes AIDS), hepatitis B, hepatitis C and cytomegalovirus (CMV). It is important to test for these viruses because they may be dormant (‘sleeping’, causing no symptoms) in a patient’s body. After the transplant, they may be ‘woken up’ and cause illness. This is especially true of CMV.

Patients who refuse to have any of these tests, such as the HIV test, will not be able to have a transplant. If a patient has one of the viruses, it does not mean that they will not get a transplant, it just means the doctors will have to be more careful.

**Other Tests for Transplant Suitability**

Other tests are also necessary before a patient can have a transplant. These include an electrocardiogram (ECG, an electric recording of the heart beat), a chest X-ray, and sometimes an echocardiogram (ECHO, a sound-wave picture of the heart) and an ‘exercise test’ (a test in which the patient has to walk on a moving walkway, to test their fitness, and stress the heart). Some kidney units also insist that kidney patients who are diabetic also have a cardiac catheter test (a special X-ray picture of the heart). This cardiac test has some risk, causing death in 1 in 1,000 patients.

If results of all these tests are satisfactory, the patient can then be put on the national waiting list (see [page 74](#)) for a cadaveric transplant, or considered for a possible transplant from a living donor.

**Cadaveric Transplants**

The term ‘cadaveric transplant’ is used to describe a transplant kidney that has been removed from someone who has died. More than 80% of transplant kidneys in the UK come from this source.

Most of these donors have been killed in car accidents or died from a stroke, and have been on a life support machine (ventilator) in an intensive care unit. The ventilator is breathing for them. Their kidneys can only be removed after they have been diagnosed ‘brain dead’. This means the part of the brain called the brainstem, which controls breathing, has permanently stopped working, and the patient is legally certified as dead. The doctors then record this in the medical notes.

Once brainstem death is diagnosed, this is irreversible, and the ability to breathe for themselves will not return. An individual who is brainstem dead cannot remain on a life support machine indefinitely, as their heart will stop relatively soon.

If the person on the life support machine is not going to be a donor, their machine would be switched off at
this point. If they are going to be a donor, their kidneys for donation are usually removed immediately after the donor’s heart has stopped beating, which occurs shortly after the life support machine has been switched off. For this reason, these donors are sometimes called ‘heart-beating donors’.

**Other sources of kidneys**

Because of the shortage of donors, some kidney units are obtaining transplant kidneys from people who have died up to 30 minutes previously. These donors – called non-heart-beating (or asystolic) donors – are people who have died very suddenly, usually from a heart attack. Their hearts have stopped beating, and they are dead. They have not necessarily been put on a life support machine.

Patients who are offered a transplant can ask whether it is from a heart-beating or non-heart-beating donor. They have a right to know this, even though they will not be told any other details about the donor. After receiving a cadaveric kidney, patients may write to the donor’s family, via the transplant co-ordinator, if they wish, but it is essential that both donor and recipient remain anonymous. Patients should feel free to discuss these issues with their transplant co-ordinator after the transplant.

Patients who have kidneys from non-heart-beating donors are quite likely to have a period of dialysis after the transplant. This does not normally affect the long-term results.

If someone is on the national waiting list (see below) for a cadaveric kidney, they can still ask a relative, partner or friend to give them a kidney. These living related (and unrelated) transplants are described more fully in Chapter 12. It is not as important to have a well-matched transplant if the donor is a living person (see page 78).

**Xenotransplantation**

The term ‘xenotransplantation’ refers to the possibility of using organs (such as kidneys) taken from animals (especially pigs) for transplantation into humans. A certain amount of research has been done in this area, but the problems are currently considered to be too great. One major concern is the risk of passing on animal viruses to humans.

**Stem cell ‘kidneys’**

Research is also being carried out to see if kidneys can be grown or repaired using stem cells. These are very simple cells taken from an adult (or human foetus) that can be programmed to grow into more mature (kidney-like) cells. Although this research has received considerable publicity, and might change the face of kidney failure in years to come, it is doubtful it will help people with kidney failure in the near future.

**The transplant waiting list**

At present, not enough cadaveric kidneys are donated to meet the demand. Changes in seat-belt laws and improvements in medicine mean that fewer people now die from the accidents or illnesses that would have made them suitable donors.

So people who are waiting for a cadaveric kidney are put on to a waiting list. Their details, including their blood group and tissue type, are put onto a national computer at United Kingdom Transplant (UKT) in Bristol. When surgeons remove two kidneys from a patient who has died, UKT finds the most suitable patient for each kidney – either locally or in the rest of the country.

A nationally agreed ‘scoring system’ decides where the kidneys go. It is based on a combination of blood group and tissue type matching, and the length of time the patient has been on the waiting list, and some other
factors. Even though it is as fair as it can be, some patients are disadvantaged – especially Asian people. This is partly because Asian people have different blood groups from white people, and there are few suitable Asian donors. It is particularly important therefore for Asian patients to find a living donor in their family, as they may have to wait a very long time to get a cadaveric kidney in the UK.

The waiting list works on the basis of finding the ‘right’ dialysis patient for the ‘right’ kidney, when one becomes available. It does not work on a ‘first-come-first-served’ basis. Transplants are allocated to the patient who is the best match for the kidney in terms of blood group and tissue type. In other words, the patient does not join a queue, knowing that his or her name will come up after a reasonably fixed time. It is not really a waiting list, more of a register. The average waiting time for a transplant is about 2 years. It is important to note that this is an average: it can be 2 days, or 20 years – or never.

It may sometimes be necessary to take a patient off the transplant list. This may be done, for example, if someone develops a serious infection or a heart problem, or if they need a major operation. The decision is not made lightly. Any patient who is being removed from the list should be told about the decision, and informed whether removal from the list is temporary or permanent. Patients who are unsure whether or not they are ‘on the list’ should ask their kidney doctor or nurse.

**Tests before the operation**

Patients called in to the hospital for a transplant are not guaranteed to receive it. Before the operation can go ahead, it is necessary to check that the patient is well enough to have the operation, and that they will not reject the transplant kidney:

1. **Physical examination.** The patient is first given a thorough physical examination by a doctor. The purpose of this is to check that it is safe to proceed with the operation. For example, if a patient has a heavy cold, it may be considered too much of a risk for them to have an anaesthetic. If the patient ‘fails’ this assessment, they will be sent home, and put back on the waiting list.

2. **The cross-match.** This test is the final hurdle before the operation. The cross-match is a blood test that checks the patient has no antibodies (substances that normally help the body to fight infection) that would react with the donor kidney. High levels of such antibodies in the blood mean that the new kidney is likely to be rejected as soon as it is put into the patient, even if it seems a good match.

   A cross-match is done by mixing a sample of the patient’s blood with blood cells from the donor. If there is no reaction (i.e. if the patient’s blood does not start attacking the donor’s cells), it is assumed that the patient will be less likely to reject the new kidney when it is transplanted. This is called a negative cross-match, and means that the operation can go ahead.

**Being ready for a transplant**

Patients who are on the waiting list for a transplant will not be given very much notice that a kidney is available for them. So they need to be prepared to go to the hospital at short notice. Some patients are given a ‘bleep’ so that they can be contacted more easily. It may be sensible to invest in a mobile phone and leave it on 24 hours a day.

When patients are on the transplant waiting list, it is largely up to them to make themselves contactable at all times, day and night. If a patient cannot be found, the kidney will be offered to someone else. When a patient ‘gets the call’, they should go to the hospital at once and not have anything to eat or drink (in preparation for the anaesthetic).
If the cross-match is positive (i.e. there is a reaction between the patient’s blood and the donor’s cells), the patient will be sent home and put back on the waiting list. This can be very disappointing, but it is much better to return to dialysis for a while than to be given a kidney that doesn’t work, and which may make the recipient extremely ill.

**The transplant operation**

Undergoing an operation to have a kidney transplanted is a major procedure, and afterwards all patients have to take certain medicines and other precautions for the rest of their lives. This applies whether the transplanted kidney was from a cadaveric donor or from a living donor. More details about the operation itself, and life after transplantation, are given in Chapter 13.

**Key facts**

1. For the right patient at the right time, a transplant is the best treatment for kidney failure.
2. If a transplant works well, the patient will be totally free from dialysis, able to eat and drink normally and go back to work, and their sex life may improve.
3. Suitability for a transplant is more important than age. Up to 40% of patients with kidney failure may be suitable to receive a transplant.
4. Transplants are matched to the patient in terms of blood group and tissue type.
5. Transplant kidneys come from three sources: cadaveric transplants, living related transplants and living unrelated transplants.
6. The transplant waiting list works on the basis of finding the ‘right’ kidney for the ‘right’ person – i.e. patients do not join a queue.
7. Patients have to wait on the transplant waiting list for an average of about 2 years. Asian or Black patients may have to wait longer, so should certainly consider a living transplant if a suitable donor is available.
8. Patients who are called in to hospital to receive a kidney transplant need to undergo a series of tests before the operation to make sure the kidney is suitable for them.
In this chapter we discuss the issues surrounding living transplantation, the procedures and processes involved, the benefits of living transplantation, and some of the possible problems.

**Introduction**

The first successful kidney transplant was a living transplant. It was performed on 23 December 1954 by Joseph Murray and his team at the Peter Bent Brigham Hospital, Boston, USA. A kidney was removed from one man and transplanted into his genetically identical twin brother.

Although, in the UK, the majority of kidneys for transplantation are donated by people who have died (cadaveric transplants), a significant proportion (currently about 20%) are donated from a relative or someone close to the person who has kidney failure. Human beings do not need two kidneys – quite why we have a ‘spare one’ is not known. The loss of one kidney will not usually cause any harm to the donor, providing the other one is healthy and functioning. The proportion of living transplants is increasing every year, and, in some UK units, accounts for as many as 30–40% of all transplant operations. In countries, such as Japan, where cadaveric transplantation is almost unheard of, living transplant offers the only real option to coming off or avoiding dialysis. In countries such as Norway, nearly 50% of all transplanted kidneys come from living donors.

A living transplant can have many benefits. For most patients, the possibility of a transplant kidney from a living donor will be the best chance of having a transplant operation before dialysis is needed. If a loved one is donating a kidney, the whole transplant procedure will be planned, and both donor and recipient are usually well prepared for the operation.

However, there are risks with the procedure. Just as with a cadaveric transplant, the kidney may not work – in fact, 1 in 20 are not working a year after the transplant operation. So it is worth considering the emotional aspects of living transplantation before embarking on the process.

A growing number of units now have a transplant coordinator whose main job is to organise living transplants. This is part of the reason why these transplants are becoming more common.

Anyone who is on the list for a cadaveric transplant can have a live transplant.
THE BENEFITS
Accepting a kidney from a loved one means that the wait for a transplant may be shorter than the wait for a cadaveric transplant. In some circumstances, the transplant may take place before you need to start dialysis. The transplant operation can also be planned, on a date which is suitable for everyone involved, whereas cadaveric transplants often happen at very short notice.

A kidney from a live donor is likely to function for longer than a cadaveric kidney. Approximately 70% of live transplants still work after 5 years, and 55% after 10 years. This is in contrast to only 60% of cadaveric transplants at 5 years, and 35% after 10 years.

No one really knows why a live transplant usually lasts longer. Certainly, a kidney being transplanted from a live donor is usually of better quality than a cadaveric kidney. This is because live donors are carefully screened for any diseases that might affect their kidneys, such as hypertension or diabetes. The donor’s kidneys are also checked to make sure that they function perfectly, and are not likely to fail in the future.

Also, the time in which the kidney is outside a human body after it has been removed from the donor (i.e. ‘still fresh’) – called the cold ischaemia time – seems to be a crucial factor. This is less than 1 hour for a live transplant, but 12–36 hours (the average is 20 hours) for a cadaveric transplant. The benefits of transplanting the kidney as soon as possible after it is removed from the donor seem to be much more important than other issues such as tissue type for the success of the transplant.

A live transplant may improve the relationship between donor and recipient, as there is a common bond between the two. There is also some evidence to suggest that the recipient of a live transplant is more likely to take the medication required after the transplant, perhaps because the recipient feels more of a responsibility towards the new kidney.

If your kidney failure is diagnosed at an early stage, you could be considered for live kidney transplant up to 6 months before you need dialysis. At this point your creatinine level is likely to be about 400 µmol/l (micromoles per litre of blood). If you already have a transplant that is starting to fail, you could have a live transplant before you need to return to dialysis. But this is up to your own kidney unit’s individual policy.

PATIENT SURVIVAL AFTER LIVE TRANSPLANTS
There is also evidence that patients who have a living transplant will live longer than those receiving cadaveric transplants – having a 98%, 90% and 80% chance of being alive at 1, 5 and 10 years after the transplant. This compares with a 95%, 80% and 60% chance for a patient with a cadaveric transplant at the same time points. In other words, there is a particular benefit at 5 and, more particularly, 10 years. The reasons for this are not clear.

CADAVERIC OR LIVE TRANSPLANT – WHICH IS BEST?
It is difficult to give firm advice on which is the ‘best’ type of transplant, even though there are clear medical benefits of a live transplant to the recipient. These benefits, outlined above, are in terms of the likelihood of both the kidney working and the patient being alive at 5 and 10 years after a transplant. There are, however, significant risks to the donor.

Nonetheless, it is the view of the authors that if both sides are willing, and understand and accept the risks, then it is ‘better’ for most patients that their first transplant is a living transplant. This is especially important in families, such as Asian and Black families, where a suitable cadaveric kidney is likely to be harder to come by. If this first transplant ever fails, they should then have another live transplant, or a cadaveric transplant. Not all people, however, would agree with this view.
In the end, it is up to each donor and recipient pair to make the decision, having taken in the type of information put forward in this chapter, and discussed this with their doctors and the rest of their family.

**WHO CAN DONATE A KIDNEY?**

Almost anyone can donate a kidney to a loved one.

The best donor is an identical twin, as the tissue type is identical. Unfortunately, most people do not have an identical twin waiting to give them a kidney. A kidney from a non-identical twin may also be suitable, but again, few patients have non-identical twins. If a kidney patient has a friend, partner or relative who is at least 16 years old, healthy, and willing to give them a kidney, they should speak to the transplant co-ordinator (or other senior nurse or doctor) at their unit.

The most suitable donor is usually a brother, sister, father, mother, son or daughter, but other more distant relatives may be suitable – uncle, aunt, nephew, niece, cousin, grandparent or grandchild. In fact, the donor does not necessarily have to be a blood relative. The patient’s wife, husband, partner or close friend may also be suitable. About 50% of people, blood relatives or otherwise (if they are fit), may be suitable to donate a kidney to any given patient.

As human beings do not need two kidneys to be healthy, the donor is unlikely to come to any harm by losing a kidney. However, even if a kidney comes from a loved one, it is important that both the donor and the patient understand that the kidney is not guaranteed to work.

However, there are some situations where live kidney donation would not be possible. These include people with the following conditions:

- HIV or AIDS-related infection;
- hepatitis B or C infection;
- major heart or breathing problems;
- diabetes (either type);
- significant kidney disease;
- most cancers;
- very high blood pressure;
- intravenous drug abuse;
- extreme obesity;
- pregnancy;
- having only one kidney;
- evidence of financial or non-financial coercion;
- inability of a potential donor to give informed consent; or
- age below 16 years.

In addition, doctors would think very seriously before allowing anyone to donate a kidney if any of the following applied:

- age over 70 years;
- age below 18 years;
- intellectual impairment but able to give informed consent;
- mild obesity;
- family history of diabetes;
- psychiatric disorders; or
- mild high blood pressure.

**WHICH DONOR?**

Sometimes, when patients are told they will need a transplant to treat their kidney failure, they can be inundated with offers from their family and friends. Each potential live donor will be assessed for their medical suitability to donate a kidney, and to ensure they are well both before, during and after the operation. If more than one person is a suitable donor, it can be difficult to decide which one to accept a kidney from.
But if a patient has a parent and a brother or sister, both of whom are willing (and able) to donate, it might be ‘better’ to accept the kidney from the parent now, and then ‘keep’ the sibling’s kidney for later in life, if the first transplant ever fails. However, there are no ‘hard and fast’ rules – as for different patients, different people are closest to them . . . not necessarily the closest relative.

There is no evidence that a woman of child-bearing age will be at any more risk than anyone else who is offering to be a donor. Nor is there any evidence that it will affect her chance of getting pregnant, or put a future pregnancy at risk.

**WHO WILL DO THE ASKING?**

It is up to kidney patients to ask their friends or family to see if they are willing to donate a kidney. Doctors will not usually ask a patient’s loved ones for them, but they will talk to anybody who is willing to donate a kidney.

**TESTS FOR THE RECIPIENT**

These are the same as those outlined in Chapter 11 (pages 75–6).

**TESTS FOR THE DONOR**

As with a cadaveric transplant, the first and perhaps the most important test, to see if the potential transplant might work, is a simple blood test to find out the blood group of the donor. If the patient’s blood group and the donor’s blood group are not compatible (according to the rules outlined on page 72), no further tests will be carried out. The transplant will not be able to go ahead, so the transplant tests will be stopped immediately.

If the test is all right, blood samples will be taken to test the donor’s liver and kidney function. If these prove satisfactory, the next stage of the screening process can then go ahead.

The donor will need to have a thorough medical examination. This is usually done by two separate doctors – a kidney doctor (usually a different one from the doctor responsible for the patient), and the surgeon who will perform the operation. The doctors will check to make sure that the donor has a normal blood pressure. If their blood pressure is found to be high, the doctors will monitor it for 24 hours – this is because it may only be high at certain times of the day or in certain circumstances. In some cases, the doctors may still agree to go ahead with the transplant, even if the donor has high blood pressure, just as long as it is well controlled using only one tablet.

An ultrasound scan will then be used to make sure that the donor has two kidneys, and that both are functioning equally well. The function of the individual kidneys can be assessed by a renogram test, in which photographs of the kidney are taken a few hours after a small amount of a harmless radioactive dye has been injected into a vein. Each should be providing 50% of the total kidney function. It is no good if one kidney is undertaking 70% of the work while the other kidney only does 30% of the work. If the surgeon then removed the kidney that did 70% of the work, this could be disastrous for the donor.

The potential donor will also have an ECG (a heart trace, see page 134) and a chest X-ray to ensure there are no problems with their heart or breathing. They may also be given an exercise tolerance test to see how their heart reacts under light exercise.

Blood tests will be carried out for infections such as HIV and hepatitis B and C. Blood samples will also be used to test the donor’s genetic compatibility with the recipient (tissue type). This is necessary for all live related transplants so that the genetic relationship between donor and recipient can be proven. Tissue matching is also undertaken in live unrelated transplantation to find out if the donor and recipient are well matched. However, as discussed above (page 78), close matching is not necessary in living transplants.
In addition, there will also be a cross-match test (as in cadaveric transplantation) between donor and recipient. As with cadaveric transplantation, if the cross-match is negative, this means the transplant work-up can continue, but if the cross-match is positive, the transplant cannot go ahead.

Most units also carry out a psychological assessment of both donor and recipient. This is to make sure that both are happy about the procedure, and the effects it may have on them and their families. The psychologist will make sure that both people are able to cope if the transplant fails or anything happens to either the donor or the recipient.

Finally, to help the surgeons decide which kidney (left or right) to remove, the blood vessels to each kidney must be examined using either a type of computed tomography (CT) scan that takes a special look at the blood vessels to the kidneys (a CT angiogram), or a normal renal angiogram. The CT angiogram is safer but does not produce quite such good pictures.

**Living unrelated transplants**

Most live donor transplants are performed using kidneys from people who are related to each other, such as genetically related family members. These are called living related transplants (LRTs).

However, an increasing number of live kidney transplants use the organs from people who are not genetically related to each other, although they do have a 'relationship' with each other. This could either be through marriage, co-habitation or a long-standing friendship. Whatever the circumstances, before any live transplant can go ahead, the relationship must be proven. These are called living unrelated transplants (LURTs).

If the donor and the recipient are from the same family, the relationship can be proved from blood samples. If the relationship is an emotional one (husband, wife, partner or friend), it must be proved in other ways. In these situations, each case must be reported to the Unrelated Living Transplant Regulatory Authority (ULTRA), a Department of Health-regulated authority. ULTRA’s role is to ensure that the kidney is being donated freely and for no other reason than to benefit the recipient’s health. ULTRA has a panel of members consisting of a medical director and two elected lay members, all of whom will assess the suitability of each individual application.

ULTRA can only authorise the transplant if the relationship can be proven. The doctors looking after the potential recipient and donor have to prepare a report for ULTRA to support the proposed reason for the transplant. An independent third party specialist doctor, who is not involved with the care of either the recipient or the donor, will also need to submit a report. This doctor must interview both people separately and together in order to prepare the report. The reports need to be supported by documentary evidence such as a marriage certificate, photographs of the donor and recipient together, or evidence of co-habitation.

Although it only usually takes about 2 weeks for ULTRA to grant permission for the transplant to go ahead, collecting all the evidence may take much longer.

**Buying and selling organs**

In the UK, it is illegal to buy or sell kidneys for transplant. There must be no pressure put on to any potential donor to donate, or recipient to accept. It is also illegal for a person (no matter how well meaning) to donate a kidney to a stranger.

Even though it is illegal to offer payment to enable the live transplant to take place, it is legal for the donor to be repaid reasonable costs incurred due to travelling (even from abroad) or loss of earnings. This facility is included in the Human Organ Transplant Act (1989). The renal social worker should know how to obtain this money from the Health Authority or Primary Care Trust.
**BEING OFFERED A CADAVERIC TRANSPLANT WHILE PLANNING A LIVING TRANSPLANT**
If the patient is on the cadaveric waiting list, and is having the necessary tests for a living transplant, they may be lucky enough to be offered a cadaveric organ. They will then have to make the difficult decision whether or not to accept the organ. This decision is made harder by the fact that it is possible that the living transplant may have better results. If the cadaveric organ is not a good match, or it is not a particularly ‘good’ organ, it may be better to ‘say no’, and proceed with the living transplant. But ultimately, the decision is a personal one for the patient to discuss with their family, the donor and the doctors.

**PREPARATION FOR A LIVE TRANSPLANT**
The length of time it takes to prepare the donor and recipient for a live kidney transplant can vary from one unit to another, depending upon a variety of factors:

- **The process will be quicker if there is a full-time dedicated live transplant co-ordinator.**
- **The process may be delayed if it is necessary for either donor or recipient to have additional pre-transplant tests as a result of initial screening.**
- **If the donor is not a blood relative of the recipient, it will be necessary to contact ULTRA for permission to carry out the operation. This usually takes about 2 weeks, although getting all the necessary information together can take considerably longer.**

On average, it can take around 3–6 months to prepare for a live transplant. Sometimes, the time is deliberately long so as to give both parties sufficient time for careful consideration.

It is important that the donor allows for time off work before the transplant as well as after, so that the relevant tests can all be done.

**REMOVING THE KIDNEY FROM THE DONOR**
There are two ways a live kidney can be donated, either by open surgery, or laparoscopically (using keyhole surgery). The removal of a kidney is called a nephrectomy:

1. **Open nephrectomy.** Open surgery is the more usual method of removing the kidney. The surgeon makes a cut from the middle point of the side of the chest to the side of the abdomen. Part of a rib may also need to be removed. This method leaves a much larger scar than keyhole surgery. It also takes longer for the donor to recover after the operation. However, using conventional surgery significantly reduces the risk of complications during the operation.

2. **Laparoscopic nephrectomy.** Some kidney units remove the kidney using keyhole surgery. A small cut is made above the pubic hairline (a ‘bikini’ or ‘low bikini’ cut). The kidney is located and removed with the help of a small camera that helps the surgeon to see inside the body without cutting the patient right open. The benefit of this procedure is that the patient has a smaller scar and a quicker recovery time. But there are some disadvantages. There is an increased risk of complications, such as potential damage to the kidney being donated.

Whichever method is used to remove the kidney, the surgeon takes great care not to damage the organ in any way. The surgeon also removes the blood vessels and tubes surrounding the kidney, as they will be used for the recipient.

If the kidney is removed using laparoscopic nephrectomy, the donor will be in hospital for about 3–5 days, but after open surgery this could be 6–9 days.
How soon the donor returns to work will depend on the type of work and their general fitness before the operation. If the work is physically demanding, the donor will probably need a longer recovery time than someone who has sedentary work.

If the kidney is donated by laparoscopic nephrectomy, the donor can probably return to work within 3–4 weeks of the operation. With open surgery, it is advisable to remain off work for about 12 weeks.

**Risks to the Donor**

Although any surgical procedure carries with it a small risk (there is about a 1 in 2,000 risk of dying as a result of an operation), the risks to a healthy donor should be minimal if all the pre-operative tests have been carried out. The donor should be aware, however, that the more invasive tests (such as the angiogram) do themselves carry some risk. Anyone who donates a kidney will be seen regularly after the operation. Most units recommend kidney donors should be seen by a kidney specialist every year for life. There is some evidence to suggest that kidney donors live longer than other people on average – nobody knows why this might be so.

There will be some pain and discomfort after the operation, which should get better after a few days. One in 25 patients, however, get long-term pain in the site of the wound. This can usually be controlled by injections given from time to time.

There is usually a 10–20% rise in the donor’s creatinine level after losing a kidney.

Some donors may suffer from protein in their urine (proteinuria) after the operation, and about 10% of all donors may develop high blood pressure. This is the same as the incidence of high blood pressure within the general population.

A major problem of donating a kidney to a loved one is the potential emotional upset if a live transplant fails at an early stage.

**Risks to the Recipient**

For the recipient, a live kidney transplant operation carries the same risks it would do for a cadaveric transplant (see page 88).

Also (as mentioned on page 71) some patients may find their original disease, especially a type of glomerulonephritis called focal and segmental glomerulonephritis, may return in a transplant. This is a problem in both cadaveric and live transplants, but will not necessarily cause the transplant to fail.

**Rejection**

Unless the live transplant has come from a genetically identical donor (an identical twin), there will be a risk of rejecting the kidney. Around 40% of patients may experience rejection at some point in the first year after a transplant (not necessarily leading to loss of the kidney). This is about the same as the risk for people who have had a cadaveric transplant. It means that it is very important for patients to take their immuno-suppressant medication very carefully, to help avoid this problem. More information about rejection and immuno-suppressant medication is given in the following chapter.

**Conclusion**

Live transplants are becoming more common in the UK, but there is still a large shortfall in the number of kidneys available. Hopefully, with better awareness of the higher success rate of live transplants, the number will continue to rise.
**Key facts**

1. Although the majority of kidneys transplanted in the UK are from people who have died, around 20% are given by a living relative, partner or friend of the patient.

2. All would-be donors will be carefully assessed to ensure they are fit enough to donate a kidney. Nonetheless, there are risks to both the donor and recipient.

3. Most live donors are related to the patient (LRTs), but an increasing number of kidneys are now being given by partners or friends (LURTs).

4. Live unrelated transplants (LURTs) cannot take place without authorisation from ULTRA, the Unrelated Living Transplant Regulatory Authority.

5. Benefits of live transplants include shorter waiting times and the potential for advance planning. The kidneys are likely to last longer than cadaveric ones, and the patient also has a better chance of living longer after a live transplant than after a cadaveric transplant.

6. It is illegal to buy or sell kidneys for a transplant in the UK.

7. A person who has had a live transplant will be at risk of rejection like any other transplant patient, so will have to take the same immuno-suppressant drugs very carefully, for the rest of their lives.
This chapter describes what happens during a kidney transplant operation, and what to expect afterwards. The importance of continuing treatment, and possible side effects of drugs, are addressed.

**Introduction**

Transplanting a kidney is a straightforward operation, with a good success rate. The principles have not changed much since the 1950s, when the first kidney transplants were being performed in America. After a transplant, patients will need to take drugs daily for the rest of their lives. If a transplant fails, patients can go back to dialysis or possibly have another transplant.

**The transplant operation**

An operation to transplant a kidney requires a general anaesthetic and lasts about 2–3 hours. The surgeon makes a diagonal incision (cut) into the abdomen, on the right or the left, below the navel (see page 87, diagram 1).

The patient’s own kidneys are usually left in place. The transplant kidney is placed lower down in the abdomen, just above the groin (see page 87, diagram 2). The transplant kidney has its own artery (to take blood to it), vein (to take blood from it) and ureter (to take urine to the bladder).

The artery belonging to the new kidney is attached to the patient’s main artery supplying blood to the leg on that side of the body. The vein belonging to the new kidney is attached to the main vein carrying blood from that leg. These leg blood vessels are big enough to be able to send blood to and from the new kidney without affecting the blood supply to the leg. The transplant kidney’s ureter is attached to the patient’s own bladder. A small plastic pipe (called a double J stent) is usually inserted into the ureter (see page 87, diagram 3) to help prevent the ureter from becoming blocked after the operation. At the end of the operation, the patient’s abdomen is closed with stitches.

**Post-operative tubes**

When the patient wakes up from the anaesthetic, they will have several tubes coming out of them. These will include:

- a urinary catheter (a tube into the bladder);
- a central venous pressure (CVP) line (which is placed under the collar bone or in the side of the neck, and measures the pressure of blood inside the heart);
- an intravenous drip in the arm (to give the patient fluid and drugs if necessary); and, probably,
one or more surgical drains coming out of the abdomen (to drain off any fluid that gathers around the kidney after the operation).

These tubes will be removed one by one over the next few days. The urinary catheter is usually left in place for 5 days or more. The double J stent is usually removed during a small operation (under local or general anaesthetic) about 3 months after the transplant. PD patients may also have their catheter removed at the same time. Some haemodialysis patients find their fistula stops working at some stage after the transplant. This does not matter, provided the transplant is working well.

**After the operation**

The first few days after the operation are critical, and patients are monitored very closely. Particular attention is paid to blood pressure, fluid intake and urine output. Most patients are able to drink and eat small amounts and also to sit out of bed the day after the operation.

Patients will have their blood creatinine level measured every day. This shows whether or not the transplant kidney is working. The amount of urine that the new kidney makes is not a reliable indicator, as people who have just had a transplant may produce a large volume of urine that does not contain many toxins. In about one third of kidney transplant patients (more if the kidney has come from a non-heart-beating donor – see page 74), the kidney does not produce any urine in the first few days (and sometimes weeks) after the transplant. This does not mean that the transplant will never work. If the transplant does not work at the start, patients will need to continue dialysis and play a waiting game until the kidney starts working.

A ‘good transplant’ is one that is working well after 1 year, not 2 weeks.

Patients will usually stay in hospital for about 2 weeks. After leaving hospital, they will need to go to the clinic very frequently for many months, initially two or three times per week, then once a week, then once every 2 weeks, etc. When the doctors are satisfied that the kidney is working well, the patient’s appointments may be extended to once every 3 months or so.

It usually takes 3–6 months for patients who have had a kidney transplant to return to normal activities, including work. Transplant patients are recommended not to drive for at least 1 month after the operation. The function of the kidney, and the risk of infection, will not be affected by having sex. However, it is probably best not to resume sexual activity until about 4 weeks after leaving hospital.

**How long will the transplant last?**

A kidney transplant does not last for ever. The average lifespan of a transplanted kidney is 8 years for a cadaveric kidney, and about 11 years for a living related transplant. The average for a living unrelated transplant is somewhere between the two. So the ‘best’ (longest-lasting) kidney transplant is one from a relative, then a friend or partner, then a dead person.

Another way of looking at how long a transplanted kidney is likely to last is to look at the percentage chance that the kidney will be working at set time points. A transplanted cadaveric kidney has, on average:

- a 90% chance of working 1 year after the operation;
- a 60% chance of lasting 5 years; and
- a 35% chance of lasting 10 years or more.

The chances that a kidney from a non-heart-beating donor will still be working at the same time points are similar. The chances that a kidney donated by a living person will be working at these times are higher – on average:
Transplant operation

1. Incision sites (see Note below)
2. New kidney position (right side insertion)
3. Double J stent tube (shown in position)

Note:
Only one cut will be made, either on the left or right side of the abdomen, depending on which side the new kidney will be inserted.
- a 95% chance of working 1 year after the operation;
- a 70% chance of lasting 5 years; and
- a 55% chance of lasting 10 years or more.

So younger patients may need two or more transplants in their lives. If a transplant fails, the patient can restart dialysis, and most can go back on the transplant waiting list.

**SURVIVAL AFTER A CADAVERIC TRANSPLANT**

The chances of the patient being alive are 95% at 1 year after a transplant, 80% after 5 years and 60% after 10. This may not seem that good, as most patients have their transplant when they are quite young. But these numbers should be compared with what would happen if the patient stayed on dialysis. For example, 20–25% of patients are dead within 1 year of starting dialysis. This is a not entirely fair comparison though, as transplant patients are younger and so would be expected to live longer. While doctors may not necessarily believe transplants are more likely than dialysis to improve survival for patients with kidney failure, there is general agreement that they can offer a better quality of life.

**POSSIBLE PROBLEMS AFTER A TRANSPLANT**

Although a transplant is an excellent treatment for most people with ESRF, it is not problem-free. Some people who have had a transplant experience a problem called rejection (see below). Rejection is part of the reason why transplants do not last for ever.

Other problems that a patient may experience after a transplant include drug side effects (see page 91), infection (see page 92), heart disease (see page 92) and cancer (see page 92). It must also be repeated that within 1 year of any transplant, around 5% of patients die.

**THE REJECTION PROCESS**

‘Rejection’ means that the patient’s body recognises that the transplanted kidney is not ‘its own’ and tries to ‘reject’ it from the body. Even when patients and transplant kidneys are apparently ‘well matched’ (in terms of blood group and tissue type, see pages 72–3), some degree of rejection is common. The severity of rejection varies from patient to patient. Rejection may be either acute or chronic (see page 89).

The body system that is responsible for the rejection process is called the immune system. The immune system is the body’s natural defence system. It is located all over the body, and has many different parts. It includes organs (such as the spleen and appendix), lymph nodes (including the ‘glands’ in the neck) and specialist white blood cells (called lymphocytes).

The usual task of the immune system is to fight foreign invaders. These include germs (such as bacteria and viruses) and foreign objects (such as splinters or thorns embedded in the skin). The immune system also fights cancer. An individual’s immune system does not usually attack that person’s own cells because these all have a ‘friendly face’ (consisting of special proteins called antigens on the outer surface of the cells). The immune system recognises the friendly face and knows to leave the cells alone. Germs and foreign objects do not have this friendly face. Nor do cancer cells, which have developed in an abnormal way.

Normally, the immune system is a ‘good thing’, as it protects the body from dangerous infections, foreign bodies and cancer. However, after a transplant it can be a ‘bad thing’. If the immune system recognises that the new kidney does not have the usual friendly face of the body’s own cells, it will become overactive and send lymphocytes to attack (reject) the kidney. The body is actually trying to protect you from the kidney, which it perceives as a danger. Luckily, there are drugs – called immuno-suppressant drugs (see page 90) – that can help prevent and treat the rejection process.
Acute rejection

‘Acute’ means short term, coming on quickly and needing immediate action. Acute rejection can happen in the first few months (particularly the first few weeks) after a transplant. It is very common – about 40% of patients experience acute rejection in the first year after a transplant. If acute rejection hasn’t occurred within 1 year of the operation, then it is unlikely to happen, as long as patients take their drugs correctly. However, if a patient doesn’t take their immuno-suppressant drugs, acute rejection can occur at any time. This is why taking these medicines as prescribed, on a regular basis, is so important.

Acute rejection may sometimes cause pain and fever, but usually there are no symptoms. Doctors will suspect that a patient has acute rejection if the blood creatinine level is either not coming down after a transplant, or if it has started to fall and then remains stable or increases again. However, acute rejection is not the only reason why there may be problems with blood creatinine level after a transplant, and these other possibilities are usually looked for first.

1. Investigation. Tests that might be performed include an ultrasound scan (see page 43). This will show whether the patient’s ureter (the tube that takes urine from the kidney to the bladder) is blocked. Other possibilities are specialist scanning techniques called a radio-isotope scan and a Doppler scan. Either of these will show if there are any problems with the blood supply to the new kidney.

The only way to be sure whether a transplant kidney is being rejected is to do a test called a biopsy. This test is described in more detail on page 41. It is common for patients who have had a kidney transplant to have two or more biopsies in the weeks after the operation.

A kidney biopsy is an invasive procedure, and therefore there are some risks involved with having one. For more information about the risks involved, see page 41.

2. Treatment. If the biopsy shows signs of rejection, then the patient will usually be given a high dose of a steroid drug, either prednisolone or methylprednisolone. The drug is given by tablet or intravenous injection, once a day for 3 days. These short-course, high-dose treatments are called ‘pulses’. Very often, this steroid treatment will suppress the rejection process, and the blood creatinine will start to decrease. Occasionally, a patient may need two courses of this (or a similar) drug.

If pulse prednisolone or methylprednisolone does not work, there are various options. For example, one of the immuno-suppressant tablets may be changed to a similar but slightly ‘stronger’ drug. An example might be tacrolimus replacing cyclosporin (see page 91). Alternatively, the patient may be given a 5–10 day course of a stronger intravenous injection, such as anti-lymphocyte globulin (ALG), anti-thymocyte globulin (ATG) or orthoclone K T-cell receptor 3 (OKT3) antibody.

These treatments almost always work, and the rejection process goes away. However, all of them can have fairly severe side effects, especially OKT3, which can cause fever, diarrhoea, joint and muscle pain, wheezing, and shortness of breath due to fluid on the lungs (pulmonary oedema).

Chronic rejection

‘Chronic’ means long term and of slow onset, not necessarily requiring prompt action. Some doctors think that the term ‘chronic rejection’ is misleading. The condition it describes is very different from acute rejection. In chronic rejection, there is no real rejection process taking place. The patient’s immune system does not attack and reject the transplant kidney in the same way as it does in acute rejection.

Chronic rejection is more like a slow ageing of the new kidney. The cause is uncertain. If it happens, it will usually be more than a year after the transplant.
operation. Doctors may suspect chronic rejection if a patient’s blood creatinine starts to rise slowly after it has been stable for some time. As with acute rejection (see above), the only sure way to diagnose the condition is to do a biopsy. There is no treatment for chronic rejection.

The severity of chronic rejection varies. Mild chronic rejection is not usually a problem. However, more severe chronic rejection will eventually lead to failure of the kidney (and therefore a need to go back to dialysis or have another transplant). Chronic rejection may take years to happen, but it is much the most common cause of transplant failure after the first year.

**IMMUNO-SUPPRESSANT DRUGS**

All patients who have a kidney transplant need to take drugs called immuno-suppressant drugs. As the name ‘immuno-suppressant’ suggests, the function of these drugs is to suppress the immune system. The aim is to dampen down the immune system sufficiently to stop it rejecting the transplant kidney, while still keeping it active enough to fight infection. Finding the balance can be difficult.

The most commonly used immuno-suppressants are currently cyclosporin, azathioprine and prednisolone (a steroid), but newer drugs, such as tacrolimus (FK506), and mycophenolate are increasingly being used. We are also now gaining experience with even newer drugs, such as the tablet called sirolimus and an injection treatment called basiliximab. Other drugs are currently being developed.

Usually, patients no longer need to continue taking EPO or calcium tablets after a transplant (see page 29). However, it is vital for them to take two or three different kinds of immuno-suppressant drugs every day. This is because, if they stop taking these drugs, the immune system ‘fights back’. If a patient is unable to take these immuno-suppressant drugs, either because they have run out or because they are suffering from diarrhoea or vomiting, they should go to the hospital at once. The immune system does not forget that there is a ‘foreign’ kidney in the body. It is always waiting for a chance to attack and reject it.

Many other medications (both prescribed and ‘over-the-counter’) can interact with immuno-suppressant drugs, especially with cyclosporin and tacrolimus, both of which are very ‘sensitive’ drugs. New medications can cause either of these immuno-suppressants to work too well, increasing toxicity, or work less well, risking rejection. Either of these interactions can cause the creatinine level to go up. So patients should always check with the kidney unit pharmacist, or hospital doctor (not their GP), before taking any new medication. Patients should never assume that just because a medicine or tablet is common and easily available (like aspirin, for example), it is necessarily ‘safe’ to take if they have a transplant.

**THE ‘BEST’ REGIME OF IMMUNO-SUPPRESSANT DRUGS**

There is no best regime of immuno-suppressant drugs. Many drugs are now available. However, there is no proof that any one combination of drugs is better than any other combination, in terms of transplant success rate. Every transplant unit uses the drugs in a slightly different way. For example some units start with cyclosporin and azathioprine (both ‘older’ drugs) and others with tacrolimus and mycophenolate (both ‘newer’ drugs). These differences do not seem to be important.

If a patient experiences side effects from a particular drug, the drug can be changed for an alternative. Examples might include changing cyclosporin for tacrolimus and vice versa, or azathioprine for mycophenolate and vice versa.

The choice of drugs is influenced by the cost of some of the newer drugs, which are generally more expensive. Also, the long-term side effects of these newer drugs are not fully understood.
**Drug side effects**

All of the most commonly used immuno-suppressant drugs have their problems:

1. **Cyclosporin and tacrolimus.** These are the most important drugs used to prevent kidney rejection, and work in a similar way. Unfortunately, if patients are given too much of either, both are toxic (poisonous) to the kidney, and can prevent the transplant from working. This condition is called cyclosporin (or tacrolimus) toxicity. To reduce the risk of problems, patients on both will have the amount of the drug in their blood monitored regularly. If problems do occur, these can usually be reversed, either by stopping the drug or reducing the dose. Of course, taking too little of either can increase the risk of rejection. Finding the balance is not easy.

Some patients who take cyclosporin for a long time develop a condition called gum hypertrophy (i.e. swelling of the gums). This is an excessive growth of the gums, which can be unsightly. It is less likely to develop if patients practise good dental hygiene, including regular flossing between the teeth. Another possible side effect of cyclosporin is excessive growth of hair on the face and body. Tacrolimus does not cause gum swelling or increased hair growth, but can cause hair loss and trembling. Both drugs can cause diabetes, but tacrolimus does so much more often (in up to 10% of patients). If diabetes occurs, it may lead to a lifelong need for insulin injections twice a day.

Both cyclosporin or tacrolimus can also damage the liver and nervous system.

2. **Sirolimus.** This is a new drug that works in a similar way to the above two, but without their toxicity to the kidney. However, other side effects are seen – especially a very high cholesterol (a type of lipid or fat) level in the blood.

3. **Azathioprine and mycophenolate.** The main problem with azathioprine and mycophenolate is that they can suppress activity in the bone marrow, where blood cells are made. By affecting blood cell production, they can cause a number of serious problems. If too few red blood cells are produced, the patient will suffer from anaemia, causing tiredness. If there are too few white blood cells, the patient will develop a condition called neutropenia. This lack of white blood cells will affect the patient’s ability to fight infection. If too few of the blood cells called platelets are produced, the resulting problem is thrombocytopenia, which can cause an increased tendency to bleed.

   Patients taking either of these drugs may suffer from any or all of the above problems. However, stopping the drug or reducing the dose will normally put matters right.

   There are also other side effects. Azathioprine can cause damage to the liver, usually picked up by blood tests. Mycophenolate can cause abdominal pain and diarrhoea.

4. **Prednisolone.** This drug is a steroid, and, like other steroid drugs, it can cause thinning of the skin (leading to easy bruising) and facial swelling (giving a red and rounded appearance to the face). These problems may lessen if the dose of the drug is reduced.

   Like cyclosporin and tacrolimus, prednisolone can also cause diabetes mellitus (‘sugar diabetes’). At worst, this might mean that the patient will have to take tablets or give themselves insulin injections twice a day.

   A further possible problem with prednisolone is that it can cause crumbling of the joints, especially the hip joints. Pain in either hip, even in the first 3–6 months after a transplant, should be taken seriously. Replacement of one or both hips may become necessary. In the longer term, patients on prednisolone are also at increased risk of thinning of the bones (osteoporosis).

   Some doctors try to withdraw steroid tablets after the first 6–12 months because of these side effects on the joints and bones. This usually causes the creatinine to...
rise by 10 µmol/l (micromoles per litre of blood) or so, which is not usually a problem. But it does carry a very small risk of rejection (or even loss) of the kidney.

**Infection**

Although immuno-suppressant drugs help prevent transplant rejection by making the immune system less efficient, their effect on a patient’s ability to fight infections is generally less than might be expected. So people taking immuno-suppressant drugs do not necessarily get one infection after another.

Having said that, there is one infection that is a particular problem after transplantation. It is called cytomegalovirus (CMV) infection. For most people who are not taking immuno-suppressant drugs, CMV is a mild infection that causes a ‘flu-like illness. However, in patients who have just received a transplant, CMV infection can be quite a severe illness.

If a transplant patient does ever get CMV, there is a very effective treatment for it. This is called ganciclovir, and is given as a course of injections.

**Heart Disease**

Heart attacks and problems with the circulation (such as stroke and reduced blood flow to the legs) are much more common after a transplant. This is partly because of the effects of kidney failure on the circulation before a transplant. It is also due to other new problems after a transplant. These may include high blood pressure, a high cholesterol level in the blood, diabetes (which can start after a transplant, as it is a side effect of many immuno-suppressant drugs) and increased risk of clotting (‘thickening’) of the blood. The risk of these problems may be reduced if the patient does not smoke, keeps fit, and keeps their weight under control.

A transplanted patient should also work with their doctor to keep their blood pressure down (under 120/70 mmHg), diabetes (if new) under control, cholesterol low (under 5 mmol/l), and perhaps have their blood thinned. This may mean taking more medicines. Tablets or insulin injections may be needed to control diabetes. A group of tablets called statins are particularly good at controlling the cholesterol level in the blood. Aspirin can be used to thin the blood, although it will not necessarily be suitable for all transplanted patients.

It is important to ask the doctor why such tablets are not being prescribed, if they are indicated, as having a heart attack or stroke, say 5 years after a transplant, makes it hardly worth the patient going through such a major operation.

**Cancer**

One of the functions of the immune system is to fight cancer. By making the immune system less efficient to help prevent transplant rejection, immuno-suppressant drugs unfortunately increase the likelihood of getting some types of cancer. A research study has shown that 25% of transplant patients who live for 25 years after a transplant develop some type of cancer.

For example, transplant patients are three times more likely than other people to get skin cancers after a transplant. This makes it very important for people who have had a transplant to use a strong ‘sun block’ cream to avoid sunburn. Exposure to the sun greatly increases the risk of developing skin cancer. (In Australia, where skin cancer is particularly common, the increased risk to transplant patients rises to 40 times the average.) Provided that skin cancers are diagnosed in good time, they are not usually a major problem. This type of cancer does not usually spread to other parts of the body, and can be easily removed.

Transplant patients are no more likely than anyone else to get the other more common serious problems, such as breast or lung cancer.
**Lymphoma**

A small but significant number (2–5%) of transplant patients develop lymphoma, which is a more serious (leukaemia-like) cancer of the bone marrow and immune system – often within a year of the operation. It is more common in patients who have had stronger immuno-suppressant drugs. About 60% of cases occur in the first year after transplant. The average time from transplant to developing lymphoma is about 9 months. These ‘early’ cases are particularly serious.

Lymphoma is treated with high doses of chemotherapy. In some cases, the immuno-suppressant drugs given for the transplant are stopped, which can lead to loss of the kidney. Although these treatments can be successful, 30–50% of people who develop lymphoma after a transplant die within 2 years of the diagnosis.

**Key facts**

1. A transplant operation lasts 2–3 hours, and involves staying in hospital for about 2 weeks after the operation.
2. A transplant does not always last for ever. Transplants from living relatives last longest.
3. If a transplant fails, the patient can go back onto dialysis. Most can go on to have another transplant.
4. Patients have to take immuno-suppressant drugs daily to prevent their body rejecting a transplant. Not taking them correctly can lead to loss of the kidney. However, these drugs do have side effects.
5. It is important for patients to stay fit after a transplant. For example, they should not smoke, should keep their weight down, and should monitor their blood pressure, cholesterol and (if necessary) blood sugar.
6. Transplant patients have an increased risk of developing some types of cancer – especially skin cancer – and lymphoma, which can be fatal.
This chapter explains why it is important for people with kidney failure to watch what they eat. It also describes the different dietary advice that they are likely to be given as their condition and treatment change.

**Introduction**

One of the questions most frequently asked by kidney patients is, ‘Why does the advice given to me about my diet keep changing?’ Well, it isn’t because the dietitian got it wrong in the first place. The reason is that patients’ dietary needs change as their condition changes. So, just as drug therapy and other treatments may need to be altered, diet may also need to be revised to stay in line.

**Healthy eating guidelines**

It is a good idea for all patients with kidney failure – whether pre-dialysis, on dialysis or with a transplant – to follow ‘healthy eating guidelines’.

These guidelines are:

- to eat some high-fibre foods (such as wholemeal bread and cereals);
- to eat only moderate amounts of fats (which should be mainly polyunsaturated); and
- to avoid adding ‘extra’ salt to foods if you have high blood pressure.

**What is ‘nutritional status’?**

The term ‘nutritional status’ is used by doctors, nurses and dietitians to describe a patient’s state of nourishment. A person with a poor nutritional status is not receiving enough of the right kinds of food. There is no single reliable method of measuring nutritional status: there is no nutritional equivalent of the blood creatinine test (see Chapter 2).

Doctors, nurses and dietitians usually assess the nutritional status of a kidney patient by:

- asking how the patient is feeling;
- asking about the patient’s diet (perhaps including asking the patient to keep a record for a while of everything they eat and drink);
- measuring the level of albumin (a type of protein) in the blood (see page 39), as a low level of this is linked to malnutrition;
- measuring the size of the patient’s muscles; and
- monitoring the patient’s body weight.

Research has shown that nutritional status is an important factor in survival. A study of 12,000 haemodialysis patients in the USA showed that patients who had a very low blood albumin when they started...
Dialysis were 17 times more likely to die during the first year of dialysis.

**Dietary Protein and Kidney Failure**

Protein is an essential nutrient, which enables the body to build muscles, and to repair itself. The main sources of protein in the diet are meat, fish, dairy products and pulses (such as beans and lentils). Everyone – including people with kidney failure – must eat appropriate amounts of protein if they are to avoid serious nutritional problems.

When protein is digested, waste products are formed and enter the blood. One of these wastes is called urea (see page 11). Normal healthy kidneys are quite good at getting rid of urea and other wastes from the blood. However, as kidney failure develops, the kidneys become less and less able to remove wastes from the blood (see Chapter 2). Even so, this does not mean that people with kidney failure should stop eating protein (see below).

**Diet Before Starting Dialysis**

People with kidney failure who have not yet started dialysis should follow normal healthy eating guidelines. This includes continuing to eat foods that contain protein even after the level of urea in their blood has started to rise.

If people with kidney failure restrict their intake of dietary protein, their urea level will not rise so rapidly. For this reason, it has been suggested that reducing the amount of protein in the diet might delay the need for dialysis. However, such use of protein restriction is controversial, since lower levels of urea in the blood may indicate that patients are becoming malnourished – i.e. they do not receive enough protein to maintain their flesh weight (see page 18).

When the time for dialysis draws closer, some patients do not feel as hungry as they used to – and some foods, particularly meat products, may taste ‘funny’. Special dietary supplements may help such patients to maintain adequate protein, energy and vitamin intakes. A diettitian will be able to provide advice about these supplements.

**Diet During Dialysis**

Several aspects of diet and nutrition are very important for patients on dialysis. All kidney patients are at an increased risk of developing malnutrition (see below).

It may also be necessary to pay special attention to a dialysis patient’s intake of phosphate, calcium, potassium, salt, fluid and vitamins (see pages 97–8). In some cases, there may also be other specific individual dietary recommendations (see page 98).

**Gaining Weight (Obesity) and Kidney Failure**

Even though weight loss is problem that causes particular concern in kidney failure (see page 96), weight gain can be almost as serious.

Obesity can actually contribute to the development of kidney failure. This is largely because being overweight makes a person much more likely to develop diabetes mellitus, which is one of the major causes of kidney failure.

Reversing obesity (losing weight by dieting) will not cure kidney failure. Nevertheless, the other health advantages, such as reducing blood pressure and strain on the heart, are well worth achieving. At the very least, patients on the transplant waiting list are more likely to cope physically with a transplant operation if they are a healthy weight and do not have raised blood pressure.

More specifically, obesity can cause practical problems for people on dialysis. Overweight people with fat arms can have particular problems with access for haemodialysis. Their veins can be difficult to reach, or
weak, and therefore difficult to make a fistula from (see pages 63–4). And PD is less likely to work for patients who have a fat or distended tummy. Very obese patients will be too unfit to be offered a transplant.

If obesity is a problem, healthy eating guidelines may help. Overweight patients should ask to be referred to a dietitian for advice.

**Losing weight and kidney failure**

Some kidney patients find they lose a lot of weight and become very thin. This is usually because they are not eating enough (especially foods providing protein and energy). Such patients rapidly become malnourished. Malnutrition is the most important, and most dangerous, nutritional problem that can develop in patients on either type of dialysis. So, to prevent malnutrition, patients on dialysis will be asked to increase their food intake (especially their intake of protein).

Doctors are not entirely sure why kidney patients have an increased risk of malnutrition, and why they need extra protein in their diet. A combination of causes seems most likely.

**Poor appetite and malnutrition**

The most important cause of malnutrition in kidney patients is probably the simplest one – poor appetite. This is one of the major symptoms of kidney failure, and is often the reason why people go to their family doctor in the first place.

When someone is pre-dialysis (or has a failing transplant), worsening of the appetite is one of the reasons why doctors start (or restart) dialysis. When a patient is on dialysis, a change – hopefully an improvement – in their appetite is often a more reliable guide to the effectiveness of the dialysis than are any of the blood tests (including the ‘key’ test, the blood creatinine, see Chapter 2).

Dialysis usually restores a kidney patient’s appetite to near normal, although few dialysis patients ever really have a ‘good’ appetite. Dialysis is just not good enough at getting rid of the toxins that suppress appetite. (Doctors do not even know which these toxins are.)

If there is under-dialysis (i.e. a patient is not receiving enough dialysis), loss of appetite is one of the first symptoms of kidney failure to return. An increase in the dialysis dose will then probably help to improve the patient’s appetite. However, only a transplant will fully return a patient to a ‘normal’ appetite.

A build-up of toxins in the blood may not be the only reason for appetite problems in a kidney patient. Severe anaemia (see Chapter 5) may also suppress appetite.

Also, PD patients may have a poor appetite because of the dialysis fluid in their abdomen, which can make them feel bloated.

**Other causes of weight loss**

In addition to appetite problems, a number of other factors may contribute to the increased risk of weight loss in kidney patients on dialysis.

PD patients lose protein and amino acids (substances from which proteins are built up) into their bags of dialysis fluid. Haemodialysis patients also lose amino acids into their dialysis fluid. So kidney patients on both types of dialysis need extra protein in their diet to make up for these losses.

Poor control of blood acidity level (blood tends to be acidic in kidney failure) is another important factor. This is shown by low bicarbonate levels (see page 42). A study carried out by Dr Stein showed that dialysis patients with higher bicarbonate levels (less acidic blood) were more likely to be alive and better nourished after the first year of dialysis.

Infections also increase a person’s requirements for high-protein and high-energy foods, and infections tend to be more common in dialysis patients.
A further possible cause of malnutrition in kidney patients may be that some patients are not eating enough because of dietary restrictions imposed by their doctor or dietitian. Fortunately, such over-zealous dietary restrictions are now going out of fashion.

Loss of weight tends to be more common in haemodialysis than PD patients. PD patients have an extra source of calories – the sugar contained in PD fluid. Some of this is absorbed by the patient, providing the equivalent of approximately 300–500 calories a day – similar to eating between one and two Mars Bars. Haemodialysis patients don’t have this extra energy source and may need additional dietary advice and supplements.

**Protein/energy supplements**

Protein and/or energy supplements can be very helpful if a kidney patient is not eating enough. These supplements are really very good and supply varying amounts of protein and energy depending on what is needed. The supplements are available on prescription, and hospital dietitians can ask their patients’ GPs to prescribe them.

**Phosphate and calcium**

Phosphate and calcium are two minerals that affect the health of the bones. When a person has kidney failure, the calcium level in their body tends to be too low, and their phosphate level too high. This puts them at risk of bone problems, due to a condition called renal bone disease (see Chapter 6).

Treatment for kidney patients therefore aims to raise blood calcium levels and also to lower blood phosphate levels. Both these aims can often be achieved by moderating the phosphate content of your diet, by adequate dialysis if this has been started, and with the use of a phosphate binder (calcium carbonate, e.g. Calcichew) taken as tablets with meals.

A low-phosphate diet is not as straightforward as it sounds. It is very difficult to cut down phosphate intake without also lowering protein intake.

Patients who need to adjust their diet to reduce their blood phosphate level will be given specific advice by their dietitian. This will probably include asking them to be careful about eating dairy produce, offal and shellfish – as these all contain particularly high amounts of phosphate. The dietitian may also give advice about the distribution and timing of phosphate-binding tablets.

In general, patients only need to worry about the amount of phosphate in their diet if their doctor or dietitian specifically tells them they have a problem.

**Potassium**

Potassium is another very important mineral in the human body. The kidneys normally regulate potassium level without any difficulty, but in kidney failure this control is lost. Potassium levels may then be either too high or too low (see Chapter 7, page 36).

The main problem with potassium is that if it rises to a very high (or falls to a very low) level in the blood, it becomes dangerous to the heart, which can stop beating.

Potassium is one of the substances that is measured when dialysis patients have blood tests. Any patient who regularly has high blood potassium levels will get to know their dietitian very well. The dietitian will try to find out if the patient is eating anything that might be causing a high level of potassium in the blood.

Many foods contain potassium, but some have more than others. Kidney patients whose blood potassium levels are high or rising will normally be asked to restrict their intake of high-potassium foods. This will involve avoiding some (rather nice) foods, such as chocolate and crisps, and moderating their intake of other potassium-containing foods, such as bananas, oranges and mushrooms.

PD patients rarely need to restrict their potassium intake, and in fact may sometimes need to increase it.
This is because PD is a continuous process that generally clears potassium from the blood very effectively. Haemodialysis, on the other hand, is an intermittent process. So, in the intervals between dialysis, the blood potassium may begin to rise. These patients may therefore need dietary advice on potassium intake.

Unless their doctor or dietitian tells them otherwise, kidney patients can assume that they do not have a problem with their blood potassium.

**What about salt and fluid?**

Salt and fluid advice are often given together. A salty diet may make patients thirsty, and make life very uncomfortable if a fluid restriction is necessary. Salt restriction usually involves:

- using little or no salt in cooking and at the table;
- and
- decreasing the intake of high-salt foods, which are mainly convenience and processed foods.

Haemodialysis patients often have greater restrictions on fluid intake than PD patients, and therefore need to be extra careful about salt.

Fluid advice for individual kidney patients is based on a combination of their urine output (if they still pass urine) and the amount of water removed by dialysis. Generally speaking, the more urine patients pass, the more fluid they can drink. A common generalisation is that dialysis patients can drink 500 ml of fluid every day plus the equivalent of their urine output on the previous day. For many patients, this works out to be about 1 litre for haemodialysis patients and 1.5 litres for PD patients.

**Vitamin Supplements**

There are different opinions about the value of vitamin supplements when someone has kidney failure.

Most doctors and dietitians agree that the so-called fat-soluble vitamins (i.e. vitamins A, D, E and K) are rarely a problem and don’t need supplementing. Supplements of fat-soluble vitamins may even cause problems, as excessive amounts accumulate in the body. One fat-soluble vitamin – vitamin A (found in large amounts in cod and halibut liver oil capsules) – is known to be toxic and can cause problems if taken to excess.

It is known that the so-called water-soluble vitamins (i.e. vitamins B and C) are lost in both types of dialysis. It is therefore possible that there may be deficiencies if patients reduce their intake of certain foods, either voluntarily or because of potassium restrictions. A case can therefore be made for supplementing these vitamins. But should everyone take supplements, just to make sure, bearing in mind the large number of tablets most kidney patients are taking anyway? Different units adopt different policies.

**Individual Dietary Recommendations**

All people with kidney failure are advised, as far as possible, to follow ‘healthy eating guidelines’ (in brief, to eat a high-fibre, moderate-fat and low-salt diet). In some cases, however, specific individual priorities will over-ride these guidelines.

The most common example of going against the usual guidelines is if someone is losing a lot of weight and needs to boost their intake of calories with fat. In this situation, malnutrition is a more serious and immediate danger than any possible future increased risk of heart disease from a high-fat diet. Hence the reason for the ‘unhealthy’ compromise on fat intake.
Diet after a transplant

A common question after someone has had a kidney transplant is, ‘Do I still need to follow a special diet?’ The simple answer is, ‘No’. If a kidney is functioning well, then there is no need to be on a special diet. If the transplant starts to fail, the situation may be different.

Transplant patients, being immuno-suppressed and at greater risk than other people of picking up infections, should be given information about food hygiene. In addition, they will be advised to follow normal healthy eating guidelines. This is particularly important because of two problems associated with a transplant. Both these problems—excessive weight gain (usually a side effect of taking steroid drugs, such as prednisolone) and high cholesterol levels—increase the risk of heart disease. Healthy eating habits may help reduce the risk.

Key facts

1. Dietary advice differs according to the stage of kidney failure, and the type of treatment a patient is receiving.
2. ‘Healthy eating guidelines’—for a high-fibre, moderate-fat and low-salt diet—are generally recommended whether a patient is pre-dialysis, is on dialysis or has a transplant.
3. It is difficult to measure a patient’s nutritional state. The blood albumin level is often used, but is not very reliable. A low level may be a sign of malnutrition in some cases.
4. Kidney patients should only alter their diet when advised to do so by their doctor or dietitian.
5. Weight gain (obesity) can lead to practical problems for patients wanting haemodialysis or PD. It may also make a patient so unfit that a transplant operation becomes too dangerous.
6. Weight loss and malnutrition are the major problems for many patients on dialysis—both PD and haemodialysis. So high protein intakes are recommended.
7. Potassium restriction is generally not needed on PD but may be needed on haemodialysis.
8. Excessive salt makes people thirsty. Salt intake may need to be restricted, particularly if fluid is restricted.
9. Most transplant patients will not have any dietary restrictions. They should follow healthy eating guidelines.
This chapter looks at the reasons why people with kidney failure may feel different from healthy people. It also suggests how to identify and cope with the various psychological problems that patients may experience.

**Introduction**
Kidney failure has a massive impact on the whole of a person’s life – not just on their physical condition. People with kidney failure have to alter the way they live, to learn new skills and coping strategies. They are also likely to find the illness affects the way they feel about themselves, and their priorities in life. All these factors give the psychological aspects of kidney failure considerable importance.

**Body and mind**
A kidney patient’s psychological and emotional well-being has a major impact on their physical well-being. The way someone feels influences the way they behave. If a person feels low, they may eat or drink to cheer themselves up. If they are anxious, they may row with their partner. If they don’t feel able to manage, they may decide their whole treatment is not worth bothering with.

The way kidney patients behave has a direct effect on their physical condition. They may become less careful about their diet, forget to take their tablets, or abandon fluid restrictions – all of which put additional strain on an already poorly body.

**Psychological needs**
Psychology is about behaviour: why people behave the way they do, and how they can change the way they behave. It is about how people feel about themselves, their situation, the people who are part of their lives. Everybody has psychological needs – not just kidney patients. However old or ill we might be, we all need to be heard, understood and valued. Illness can make this more difficult. People who are unwell may find it hard to express their fears and anxieties, or feel in control of the situation.

**Stresses on kidney patients**
Any long-term or life-threatening illness, can be extremely stressful. Any change – even a pleasant change like getting married – is stressful. When changes are ‘negative’, however, stress will be greatly increased.

The treatment of kidney failure enforces major changes in lifestyle. Patients have to adapt their usual routine. They may have to make changes to their eating and drinking habits. They may not have sufficient energy to continue working or to pursue hobbies or interests.

Some of the stresses that commonly affect kidney patients are:
• having to make decisions about things they have never even thought about before;
• taking in strange information, to enable them to understand a complex medical subject;
• learning about themselves and the ways they cope with things;
• needing to ask for support to manage their treatment;
• seeing themselves as a complete person, not just as a disease or condition;
• learning to live differently for the rest of their life; and
• worrying about the future.

Changes to the expected progression of life may also cause stress. For example, it may be difficult for a young person to leave home, either because they have kidney failure, or because they feel they should look after a parent with kidney failure. Sometimes a kidney patient will have to cope with unpleasant reactions from their employers and work colleagues. Later in life, retirement may come early and be totally unwelcome.

Other members of the family also have to make adjustments. Kidney failure has an impact on their lives too. The normal pattern of life is disrupted and relationships have to be redefined.

**THE DIAGNOSIS**
For some people, the diagnosis of kidney failure comes completely out of the blue. This can be extremely difficult to cope with. Even when kidney failure was already suspected, confirmation of the diagnosis can cause difficulties. The way that the diagnosis is given, and the quality of support offered immediately afterwards, can make a big difference to a kidney patient’s future well-being.

**INITIAL REACTIONS**
Following a diagnosis of kidney failure (or any other serious long-term illness), people typically go through the following stages:

1. **Shock.** At first, patients (and sometimes also family members and friends) go into a state of shock, feeling stunned, bewildered or strangely detached – as though they are observing life rather than being part of it. This shock can last a short while or may continue for weeks.

2. **Grief.** Then people begin to react to the news, often with feelings of loss, grief, helplessness and despair. They may feel overwhelmed by reality, and find it difficult to think clearly or plan effectively.

3. **Denial.** One very common reaction to serious illness is to deny the existence of the disease or its implications. But the problem does not go away, the symptoms get worse, and there are reminders from other people that the illness exists.

4. **Acceptance.** Gradually, people come to accept reality a little at a time, and begin to make progress towards adapting successfully to their condition.

**LONGER-TERM PROBLEMS**
Patients with kidney failure also often experience longer-term psychological problems. Some of these are described below:

1. **Non-compliance.** This is a term used by doctors for ‘not doing as you are told’. Common reasons why patients may find it difficult to do as they are told are:
   - they believe that the treatment is not effective, and there is no obvious benefit from it;
   - they do not know what effect the treatment is supposed to have, or why it is important to continue with it; and
the side effects of the treatment are unpleasant.

Problems with non-compliance can often be solved by better communication between doctors or nurses and their patients.

2. Anxiety. As well as the anxieties felt by most people at some time in their lives, kidney patients have additional anxieties relating to their condition and its treatment. Some possible problem areas include:

- relationships (e.g. ‘We can’t share the same interests any more’; ‘We’ve both changed so much’);
- quality of life (e.g. ‘I miss walking the dog’; ‘I’d planned to go abroad’);
- employment (e.g. ‘I’ve taken too much time off work’);
- practical management (e.g. ‘How can I do my CAPD exchanges when I feel so ill?’); and
- understanding (e.g. ‘I can’t understand all the medical words’).

3. Body image. Not all kidney patients have problems with their changed body image, but some do. They may see their fistula or PD catheter as a mutilation of their body. They feel horribly scarred and find it really hard to look at themselves.

   The perceptions of patients and medical staff can differ widely here. When doctors and nurses talk about a ‘really good fistula’, they are talking about the ease of access, the rate of blood flow, and the strength of the blood vessels. What the patient experiences is a forearm with a continuous buzzing sensation, and a disfiguring swelling where it used to be smooth and flat. Some patients cannot see their fistula as a ‘good’ thing at all.

4. Awareness of early death. People with kidney failure know that without treatment they would die. Having to live with this sort of knowledge puts a very different perspective on life’s priorities.

5. Dependency and self-confidence. Kidney patients are very dependent – on hospital doctors and nurses, and on their partners, relatives and friends. People with kidney failure have to deal with the fact that their life depends on a machine, on PD bags, or on someone else’s kidney. This necessary dependency can undermine a person’s confidence in coping with both kidney and non-kidney issues. They may wonder if they are ‘doing it right’, for example, or worry about becoming dependent on someone they are used to ‘taking care of’.

   If issues relating to dependency and self-confidence are not dealt with, they may cause conflict between kidney patients and hospital staff or carers.

6. Sense of loss. A person’s kidneys have been a part of them since birth. A healthy person will take their kidneys (and every other organ) for granted, never having to think about them. So the failure of this essential body part is likely to give rise to a kind of grieving.

7. Depression. Most people get depressed at some stage in their lives. Periods of depression may be useful, in that they enable people to withdraw from the world for a while, and resolve certain issues. People with kidney failure are no exception. There are times when they feel low, and to do anything at all requires a huge effort; times when they should allow themselves to feel sorry for themselves; and times to cry.

8. Changes to treatment. One of the many difficult things about kidney failure is that the treatment changes over time. For example, patients may change from PD to haemodialysis, or vice versa, or they may receive a transplant, or resume dialysis after a transplant fails.

9. Ageing. It is not only a patient’s treatment that
changes. Everyone changes to some extent as they get older. Tasks that seem easy when someone is young may become more troublesome as the years go by. Coping with kidney failure may become more difficult.

10. Sexual activity. Sexual problems are very common among people with kidney failure and can put strain on a relationship. Concerns about sexual ability vary from person to person. There may be a loss of sex drive, especially in men. For many young men, the most distressing aspect of kidney failure is their inability to get or maintain a normal erection. Women may worry about whether they can get pregnant, or have a healthy baby. (See Chapter 16 for more information about sexual problems and fertility.)

11. Conflicting advice. People with kidney failure receive information from lots of different people. The people who pass on this information have themselves already interpreted it according to their own backgrounds and beliefs. So, what a patient hears may not always be totally true. The advice from one source may conflict directly with advice from another. It is not surprising that kidney patients are sometimes confused by what they are told.

Also, what a doctor or nurse tells one patient may not be the same as what they tell another. Every case is individual.

12. Poor concentration. Patients sometimes worry that kidney failure may be affecting their brain. They may find that they sometimes cannot concentrate as well, or think as clearly, as they used to before their kidneys failed. These problems may last from a few minutes to several days at a time. However, for most people with kidney failure, most of the time, the ability to concentrate and think clearly is as good as it ever was. When there are problems, efficient dialysis will often help a patient to think straight.

Factors affecting the ability to cope

Some people cope more easily than others with the psychological and emotional aspects of kidney failure. Research indicates that an individual's ability to cope with illness is influenced by a range of factors.

1. Illness-related factors. The first group of factors relates to the illness itself:

- Some patients are more afraid than others of the possible consequences of kidney failure. Fears of disability, disfigurement, pain or early death may need to be addressed. The more a patient feels threatened by their illness, the harder they will find it to cope.

- Kidney failure often occurs together with other conditions, such as diabetes, anaemia (see Chapter 5) and renal bone disease (see Chapter 6). These conditions cause their own symptoms, giving kidney patients even more things to worry about.

- Some kidney patients have to cope with unpleasant side effects from the tablets they must take (particularly if they have had a transplant, see Chapter 13).

- The treatment of kidney failure involves major time commitments, which can make it difficult for patients to find or hold down a job. Lack of secure employment can be an additional strain.

- Kidney failure requires patients and their families to make changes in their lifestyle. These changes may put pressure on relationships and increase stress.

- Many people with a chronic illness, such as kidney failure, feel self-conscious about their disease and want to hide it from others. This can cause stress and make it harder to cope.

2. Age. The age at which a person develops kidney failure is likely to influence the way they will cope:
Children may not understand the long-term implications of the condition.

Adolescents need to be liked and accepted by their peers. Because of this, some may neglect their medical care to avoid appearing different from their friends.

Young adults with kidney failure may feel they no longer have the chance to develop their lives in the direction they planned – to get married, to have children, or to enter a particular career. Such feelings may cause anger and resentment.

Middle-aged patients may have problems adjusting to the disruption of an established lifestyle. They may find themselves unable to finish tasks they have started, such as building up a business.

Older patients may resent not being able to enjoy their retirement.

3. Personality. Aspects of a patient’s personality can affect their ability to cope with kidney failure:

People who cope well with long-term health problems tend to have hardy or resilient personalities which allow them to see good in difficult situations. They are able to balance hope against despair and to find purpose in life whatever happens. They maintain their self-esteem and resist feeling helpless and hopeless.

Kidney failure often means that patients must take on a dependent and passive role, for a while at least. Some people find this especially difficult since it is so different from the independent role they have developed over the years.

4. Social and cultural factors. A person’s ability to cope with illness is also affected by their background:

People from different social, cultural and religious backgrounds will have different ways of dealing with situations. Problems may arise if doctors and nurses fail to take this into account.

People’s beliefs about health come from a number of sources, including the media, advertising, other patients’ experiences and their friends. These beliefs may be incorrect or only half true. Sometimes, misconceptions can add to the difficulties of adjusting to kidney failure. For instance, people who believe that nothing is seriously wrong unless they are in pain are not likely to seek help for a condition that has no obvious symptoms, such as high blood pressure.

5. Support. The amount and quality of support available to patients are further influences on how well they cope with kidney failure:

People who live alone, away from their family and with few friends, tend to adjust poorly to long-term diseases. Other forms of support are particularly important for these people.

For many kidney patients, the immediate family is the main source of psychological support. For others, this role is taken by one or more close friends. Such support is usually a big help to the patient. However, it is also true that relatives and friends sometimes undermine effective coping by providing bad examples or poor advice.

Hospitals do not always provide kidney patients with the support they need. Hospitals can be dull places for patients, and further depress their mood. Unfortunately, at present, very few renal units have a clinical psychologist. However, there is a general recognition of the need to provide patients with psychological support, and some nurses have had special training in counselling.
For some people, lack of practical support at home may be a problem. Patients may have difficulty getting round the house or doing everyday tasks. Many lack equipment that could help them become more self-sufficient.

Many support groups have been set up by and for people with kidney failure. These groups can provide emotional and sometimes financial support, as well as information. (See the ‘Useful Addresses’ section on page 141.)

**Coping Strategies**

People with kidney failure use different strategies to help them cope with this long-term illness. Many kidney patients find the following strategies helpful:

1. **Denial.** In the early stages, it can be very useful to deny the situation or not to take it seriously. This helps people escape from the feeling of being overwhelmed by the disease. It also allows time to organise other, better ways of dealing with the situation. The belief that a person with kidney failure is still the same as everyone else is a very important element in psychological well-being.

2. **Information seeking.** People often find it helpful to seek information about their disease and its treatment. Becoming expert in a subject gives people a sense of control over it.

3. **Disease management.** Many patients gain a sense of control over their disease by becoming involved in its management – including being responsible for tablet taking and perhaps doing their own dialysis.

4. **Prioritising different activities.** For some people with kidney failure, it can be helpful in the long term to reduce the importance of some of their current activities, such as social drinking or playing contact sports.

5. **Goal setting.** A very useful coping strategy for many people is to set themselves appropriate goals. These might include, for example, exercising or going out, and trying to maintain regular routines.

**Key Facts**

1. Kidney failure has a major impact on the whole of a patient’s life.
2. Psychology is about behaviour and beliefs.
3. People with kidney failure have to cope with extra stresses.
4. Kidney failure and its treatment affect the lives of people who are close to the patient.
5. People diagnosed with kidney failure usually go through shock, grief and denial before acceptance.
6. Longer-term problems may involve non-compliance, anxiety, problems with body image, loss of self-confidence, depression, adapting to changes, and a loss of interest in sex.
7. Kidney failure can sometimes affect a person’s ability to concentrate and think clearly. Efficient dialysis helps most people.
8. Many factors affect a person’s ability to cope with kidney failure.
9. Various coping strategies can help people deal with the psychological problems that often occur with kidney failure.
16 Sexual Problems

This chapter describes the problems commonly experienced by men and women with kidney failure. It examines the causes of these problems, and makes some suggestions as to what can be done about them.

Introduction
Although some kidney patients never have sexual problems, many others do. Sometimes, sexual problems start quite early in kidney failure, before dialysis is needed. Patients may then experience an improvement in their sex lives when they start dialysis, although some notice no difference. Other patients with kidney failure develop sexual problems only after they start dialysis (either PD or haemodialysis). A kidney transplant often improves a person’s sex life, but problems may continue.

Investigating Sexual Problems
In the past, many health professionals working with kidney patients have tended to avoid getting involved with their patients’ sexual problems. Patients, doctors and nurses have often been embarrassed to discuss the subject. Even now, despite the more general interest in and openness about sexual matters, kidney patients may still find that they have to raise the subject first.

As with other aspects of kidney failure, it is not usually a case of just one straightforward problem that can be easily corrected. Often there are several issues to look at, and patience is required. Nevertheless, treatment is usually successful, provided both partners are keen to have a sex life and are willing to accept help.

Impotence: The Male Sexual Problem
Men with kidney failure have a variety of sexual problems. These include having sex less often, loss of interest in sex (sometimes called loss of libido), and being unable to ejaculate (‘come’). However, the most common sexual problem – and often the most worrying one for a man – is difficulty in getting or keeping a hard penis. This is usually called impotence. Erectile dysfunction (ED) is an alternative name.

What normally happens first in men with kidney failure is that they become less able to keep an erection for as long as usual, although they are still able to ejaculate. Eventually, many kidney patients lose the ability to get a hard penis at all. Obviously, this can lead to frustration, particularly if the sex drive is unchanged. The situation can be even more upsetting if the man’s partner interprets the problem as a loss of interest in her personally.

What Causes Impotence?
Impotence has many possible causes. In most men with kidney failure, sexual problems do not have just one cause, but are usually due to a combination of:

1. Poor blood supply. In order to make the penis hard, extra blood enters the penis and is then prevented
from leaving it. Many kidney patients have narrowed blood vessels all over their body, including those vessels that supply the penis. This reduces the blood supply to the penis, and makes it difficult to get an erection. It is not just kidney patients who have this problem. It also occurs as part of the natural ageing process and is more common in older men as well as in men with diabetes.

2. **Leaky blood vessels.** To keep the penis hard, the extra blood that has entered the penis must stay inside it. In men with kidney failure, the extra blood sometimes leaks back out of the penis, and so the erection is lost.

3. **Hormonal disturbances.** Hormones are chemical messengers that control many body functions. They are carried around the body in the blood. Some hormones are specifically designed to control sexual urges. The levels of these sex hormones can be either higher or lower than normal in people with kidney failure. In particular, the testicles may produce less of the male sex hormone, testosterone.

4. **Nerve damage.** The nerves that supply the penis are also involved in getting an erection. When someone has kidney failure, nerve damage may prevent the nerves from working properly.

5. **Tablets.** Most tablets do not cause impotence on their own. However, a few drugs can contribute to sexual problems. The biggest culprits are the blood pressure tablets called beta-blockers, such as atenolol, propanolol, metoprolol and bisoprolol.

6. **Tiredness.** Tiredness can affect sexual performance. Tiredness in a kidney patient may be caused by anaemia (see Chapter 5), by under-dialysis (see page 14), or by other medical problems, such as heart problems.

7. **Psychological problems.** When a kidney patient starts dialysis, there are many stresses to deal with (see Chapter 15). Not surprisingly, some patients feel quite depressed. If so, they may not feel like having sex.

8. **Relationship difficulties.** The illness of one partner naturally causes stresses in a relationship. For instance, household jobs such as decorating or mowing the lawn, which used to be done by the patient, may now have to be done by the partner. This can lead to arguments or resentment on either side of the relationship.

**How is impotence investigated?**
The first and most important step is for the subject to be raised. There is often a lot of unnecessary suffering due either to denial of the problem or to fear of embarrassment. Some kidney doctors and nurses have no experience of treating sexual problems in people with kidney failure, or are embarrassed themselves. If this is
the case, patients should ask to see an expert in sexual problems. Sadly, few kidney units have access to such an expert at present.

Once the problem of impotence has been recognised, the following should take place:

1. **A general health check.** This will include an assessment of the distance a person can walk on level ground without having to stop, which is a useful guide to general health.

2. **Physical examination.** This will include an examination of the genitals. The doctor will also feel for a pulse at various points in the legs. If the pulses are weak, this means that the blood vessels in the legs have narrowed, reducing the blood supply. There will then usually also be narrowing of the blood vessels supplying the penis, reducing its blood supply.

3. **Blood tests.** In addition to the usual blood tests, there will be tests to measure the blood levels of various hormones. These include testosterone, and also luteinising hormone (LH), follicle-stimulating hormone (FSH) and prolactin. LH and FSH are hormones that regulate the testicles. Prolactin’s usual role is to produce milk in females, but it is often present in larger than normal amounts in male dialysis patients with impotence.

4. **Review of medication.** The doctor should review the various tablets that the patient is taking. Some types of tablet may contribute to a patient’s sexual difficulties. Alternative medication is sometimes available.

5. **Investigation of psycho-sexual problems.** The patient will be asked to consider whether psychological or relationship difficulties may be contributing to the physical problem of impotence.

**How is impotence treated?**

The doctor will begin by looking at any more general problems that may be contributing to a patient’s impotence. These may include:

- treating anaemia (see Chapter 5);
- increasing the amount of dialysis; and
- changing the patient’s tablets.

More specific physical treatments for impotence will then be considered. These may include:

- tablets (Viagra and Uprima);
- hormone treatment;
- use of a vacuum device;
- penile injection therapy;
- penile insertion therapy (putting a drug down the penis); and
- penile implants.

In addition to the various physical treatment options (see below for more details), patients may be recommended to seek help for emotional problems relating to impotence (see page 111).

Men who are on dialysis or have a kidney transplant can have treatment for impotence free of charge on the NHS. People who are not getting treatment for kidney failure (i.e. dialysis or a transplant) may not be able to get free treatment for erection difficulties. However, if the doctor thinks the problems caused by impotence are causing a lot of distress, treatment might be free.

**Tablets (Viagra and Uprima)**

Viagra (sildenafil) is the best known tablet for treating impotence. It has had a lot of publicity since it first became available in America in April 1998. It works by opening up the blood vessels in the penis. This causes the man to have an erection.

An early trials of Viagra in kidney patients with impotence who also had diabetes showed that the drug
worked well in about half of them. However, they did get some side effects from the drug. These were occasional headaches, indigestion and muscle aches. People who have a condition called angina and use GTN (a spray which relieves the pain), and people who have very low blood pressure, should not take Viagra.

During the past few years, Viagra has become the first choice of treatment for kidney patients with erection problems. It works well in around 75% of the dialysis and transplant patients (diabetic or not) who take it. Many patients even say it lasts longer than usual – it can still be effective ‘the morning after’!

There is a new drug called Uprima (apomorphine) on the market, but – as far as we are aware – it has not been used with kidney patients yet. In fact, the manufacturers recommend that it is not used for patients with kidney failure. The tablet dissolves under the tongue, and should be taken about 20 minutes before sex. Tests show that it is not as effective as Viagra in people without kidney failure. However, if a kidney patient cannot take Viagra (perhaps because they use a GTN spray), then it may be worth a try.

**Hormones**

Most male dialysis patients with sexual problems have lowish testosterone levels. This deficiency can be treated by an injection of testosterone every 3–4 weeks, or by using testosterone replacement patches (such as the Andropatch). Although testosterone therapies replace the hormone that is lacking, they are not always very effective in treating impotence. This is probably because impotence in men with kidney failure is not usually due only to low testosterone levels.

Many other hormones are also often found to be at the wrong level, but correcting them rarely makes much difference to sexual difficulties. If the prolactin level is too high, a tablet such as cabergoline or bromocriptine may be given. However, these tablets are not always very successful at making erection problems better.

**Vacuum Devices**

Many kidney patients with impotence require therapies which act directly on the penis, helping them to get and keep an erection. One of these is called vacuum tumescence therapy, which uses a mechanical device (such as the ErecAid) to produce a hard penis. Nearly three quarters of the male dialysis patients who use a vacuum device are able to have full penile erections.

To use the vacuum device, the man first inserts his penis into the clear plastic cylinder. He then holds the device against his body so that the chamber is closed with an air-tight seal. Using either a hand- or battery-operated pump, the man then withdraws air from the cylinder to form a vacuum. This causes the penis to enlarge in a way that mimics a natural erection.

1. **The man’s penis is inserted into the plastic cylinder of the ErecAid. The ErecAid is then held against the body to form an airtight seal.**

2. **The man uses the pump to withdraw air from the cylinder forming a vacuum. The penis enlarges in a similar way to a natural erection.**

3. **The tension ring is slipped off the ErecAid onto the base of the penis to help maintain the erection, and the ErecAid is then removed.**
Penile injections have the advantage of not involving surgery. They are also effective in many dialysis patients. The main problems with this technique are pain in the penis, and a condition called priapism, which is an unwanted erection that goes on too long. There may also be bleeding, bruising or scarring (fibrosis) at the injection site. Because of the risk of bleeding, patients on haemodialysis are advised not to have the injection on a dialysis day because of the heparin used during dialysis (see page 61). Another problem is that the penis may become mis-shaped. After a while, some patients get fed up with this treatment, but it is usually possible for them to change to a different therapy option.

Penile insertion (transurethral) therapy
Patients who use this treatment have to pass urine beforehand. This makes insertion of the pellet easier (because of the lubrication), and it also helps to dissolve the pellet. Some patients who don’t pass much urine may therefore have difficulty using this treatment.

Penile insertion therapy, such as MUSE (Medicated Urethral System for Erection), involves the patient slowly inserting an applicator into the end of his penis. A button on the applicator is then pressed to release a tiny pellet of medication (alprostadil). Once the pellet has been released, the applicator is removed and an erection develops over the next 10–30 minutes.

The erections may be longer lasting than natural ones, and do not usually disappear after an orgasm. The most common complaints are mild discomfort and ‘timing difficulties’ (such as pumping too rapidly with the hand-pump) when the device is first used. Occasionally, harmless, tiny reddish spots (called petechiae) may appear on the penis.

The main advantages of vacuum therapy are that it is safe and non-surgical, can be used as often as desired, and works well for most male dialysis patients. Its suppliers also claim that it may improve blood flow to the penis and result in occasional natural erections.

The disadvantages of vacuum therapy are that it involves a loss of spontaneity in lovemaking, it requires some skill to use, and it can cause mild bruising. The treatment is available on the NHS, and is a cheaper long-term option as the only cost is the equipment. There is no need to buy regular medication.

Penile injection therapy
Penile injection therapy is another non-surgical technique used to treat impotence. The man injects medication (usually alprostadil) into the base of his penis. This causes the penis to become hard almost immediately. The erection then lasts for 1–2 hours.

The use of the injection is limited to not more than once a day and three times a week. Several clinic visits are usually needed to establish the dose of medication required. The treatment is available on the NHS. (The cost in 2002 was £6.50–£18 per injection – i.e. typically £300–£900 per year.)
**Penile implants**

The decision to have a penile implant should be made only after very careful consideration. This surgical treatment for impotence is usually effective, but it does have disadvantages (see below). Penile implants are available on the NHS, but cost significantly more than other treatments. The implant is inserted during an operation performed under a general anaesthetic. There are various different types available. It is usual to have a cylinder implanted in the penis, and connected by a tube to a pump in the scrotum. This pump is connected by another tube to a fluid-containing reservoir in the abdomen (tummy). Squeezing the pump with the fingers causes fluid to pass from the reservoir into the cylinder, so simulating an erection.

The main disadvantage is that the operation to insert the implant alters the penis permanently, ending all hope of natural erections. There is also a risk of infection, and a possibility that the implant will be rejected by the immune system (the body’s defence system). Another problem is that an implant can be difficult to conceal.

**Emotional problems**

Even though the treatments described above usually help to correct erection difficulties, they cannot by themselves restore a sexual relationship.

Sexual problems involve two people, and both partners need to work hard to sort them out. It is very common for people to experience changes in loving relationships after the development of kidney failure. Often, early in kidney disease, one partner becomes the ‘carer’ and the other adopts the ‘sick role’. Later, the improved health of a patient on dialysis, and the desire to restore a sexual relationship, can create new stresses which may take time and patience from both partners to resolve.

Other hidden fears may also be present. For instance, some people may believe that kidney disease could be transferred during sex. This is not true.

Many kidney patients and their partners may want to have counselling, from either a psychologist or a sexual counsellor. This can be very effective.

**Sexual problems for women**

Many women who have kidney failure do not have problems with having sex and have happy and fulfilled sex lives. However, there are some specific problems that female patients may experience:

1. **Discomfort during sex.** Some women do find that sex is sometimes painful. This may be due to a problem with a lack of lubrication (producing juices in the vagina). If this is the case, having more foreplay can help, although using a water-based lubricant (like KY jelly), which is available over the counter from chemists, may be the answer. Another cause of painful sex in women is an infection of the vagina (for example, thrush) or of the womb. If an infection is present, it can easily be treated with antibiotic or antifungal medication.

2. **Reduced sex drive.** People who need regular dialysis often feel very tired, especially following a session on the haemodialysis machine. However, there are many other reasons that sex drive may be lower than usual, and these include depression, anaemia or a change in roles between partners.

   One of the most important things a woman with kidney failure can do is to make sure her partner knows her feelings for him haven’t changed. She can make a point of letting him know he is still valued. Planning something romantic on the days when the tiredness isn’t so bad can work wonders.

   It is also a good idea to discuss the problems of tiredness and reduced sex drive with the doctor when visiting the kidney unit. The various medications prescribed may make the situation worse for some patients.
3. **Body image.** Some kidney patients have problems and worries with the way they look, especially those on dialysis, because of either the catheter or fistula. This often leads to feeling self-conscious, unattractive and no longer desirable. This in turn can lead to avoiding sex with their partner. However, it is often only the patient (and not the partner) who feels this way. The truth is that a woman with kidney failure is still the same person with the same lovable characteristics she had before her kidneys failed.

It is very common for patients to lose confidence in themselves and not feel like making love any more. But this can lead either partner to blame themselves, and think that they are no longer attractive. The easiest and often most effective remedy in these situations is to talk to each other. If both partners can reassure each other, and express affection for each other, they will each be well on the way to regaining their confidence.

Many kidney units now have a counsellor who is specially trained to deal with problems such as this. If you are worried and would like professional help, ask your nurse or doctor if you can see a counsellor.

### **Menstrual periods and fertility**

It is common for the menstrual periods to become irregular when women develop kidney failure. If a woman with kidney failure does not yet need dialysis, she will probably be less fertile (less likely to become pregnant, even if she is having regular sex) than normal. However, she should use contraception, as pregnancy is still possible.

In dialysis patients, the periods often stop completely. This means that women on dialysis are not very likely to become pregnant. However, again, women should not rely on this as a form of contraception. It is still possible to get pregnant even if the periods are absent.

Treatment with erythropoietin (EPO) has been shown to restore menstrual periods in about 50% of women on dialysis. This is thought to be due to two effects of EPO. It improves disturbed hormone levels, and it treats anaemia (see Chapter 5). Treatment with EPO increases a woman’s chance of becoming pregnant, so contraception should always be used to avoid an unwanted pregnancy.

#### **Risk of problems during pregnancy for kidney patients**

<table>
<thead>
<tr>
<th>Creatinine</th>
<th>Creatinine</th>
<th>Creatinine</th>
</tr>
</thead>
<tbody>
<tr>
<td>less than 125 µmol/l</td>
<td>of between 125 and 250 µmol/l</td>
<td>of more than 250 µmol/l</td>
</tr>
<tr>
<td>Chance of problems occurring during pregnancy</td>
<td>25%</td>
<td>50%</td>
</tr>
<tr>
<td>Chance of the baby being born small</td>
<td>30%</td>
<td>60%</td>
</tr>
<tr>
<td>Chance of the baby being born prematurely</td>
<td>55%</td>
<td>70%</td>
</tr>
<tr>
<td>Chance of a successful pregnancy</td>
<td>85–95%</td>
<td>60–90%</td>
</tr>
</tbody>
</table>
Pregnancy

Many women of child-bearing age who are on dialysis have irregular periods or no periods at all, yet it is still possible for them to become pregnant. However, the success of pregnancy varies widely, depending on the degree of kidney failure. The easiest and most reliable way to calculate the risk to both mother and baby is by estimating the level of kidney function, and this is most easily done by measuring the level of creatinine in the blood. The table on page 112 shows the percentage chance of problems occurring, depending on the level of creatinine in the patient’s blood when she becomes pregnant. As you can see, women who have a creatinine level of less than 125 µmol/l (micromoles per litre of blood) have a much better chance of a trouble-free pregnancy and having a healthy baby.

If a woman does become pregnant when she already has even mild kidney failure, there is a risk, despite the success of the pregnancy, that her kidney failure will worsen. If you do have kidney failure, but are not yet getting treatment (dialysis or a transplant), it is worth taking this into consideration before getting pregnant.

The table below shows the likelihood of kidney damage during pregnancy, depending on the level of creatinine in the patient’s blood.

Following a transplant, most women find their periods start again as their hormone levels return to normal, and there is better clearance of the toxins from the body. Oestradiol is one of the hormones controlling a woman’s periods, and this is usually restored to normal after a transplant, resulting in a return of normal ovulation (egg production in the ovaries) and periods. Generally speaking, the risks during pregnancy, for the health of the mother and baby, are less for women who have a well-functioning transplant. The table on page 114 shows the percentage chance of problems occurring for mothers who have a transplant, depending on the level of creatinine in the blood.

There is also a risk that the patient’s transplant kidney may be damaged during the pregnancy; however, this too depends upon the patient’s blood creatinine level when she gets pregnant. If the patient’s blood creatinine is less than 100 µmol/l, the risk of damaging the transplant kidney is almost nil. However, if the patient’s blood

## Risks to Kidney Function during Pregnancy

<table>
<thead>
<tr>
<th></th>
<th>Creatinine less than 125 µmol/l</th>
<th>Creatinine of between 170 and 220 µmol/l</th>
<th>Creatinine of more than 220 µmol/l</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chance of losing kidney function</td>
<td>2%</td>
<td>40–65%</td>
<td>75%</td>
</tr>
<tr>
<td>Chance of kidney function deteriorating after the birth</td>
<td>20–50%</td>
<td>60%</td>
<td></td>
</tr>
<tr>
<td>Chance of severe kidney damage requiring dialysis or transplant</td>
<td>2–33%</td>
<td>40%</td>
<td></td>
</tr>
</tbody>
</table>
creatinine is between 100 and 130 µmol/l during the pregnancy, there is a 15% chance that the transplant will have failed after 8 years. For women whose creatinine is more than 130 µmol/l when they become pregnant, there is a 35% chance that the transplant kidney will have failed after 3 years.

Kidney transplant patients who do get pregnant will be under the care of both the kidney and maternity teams. They will work together with the patient’s GP and midwife throughout the pregnancy. It is important to monitor the kidney function and blood pressure during pregnancy. The drugs that transplant patients take to prevent rejection are unlikely to cause any problems during the pregnancy. Even so, it is best to tell your kidney doctor if you are planning to become pregnant, or as soon as you find out.

Once the baby is born, some of the drugs can be passed through breast milk, but many doctors feel that the benefits of breastfeeding the baby outweigh the risks.

Overall, if a woman with kidney failure wants to get pregnant, it is best for her to do so either in the early stages of kidney failure or after she has had a transplant (as long as it is working well). It should be pointed out that the baby is likely to be normal and not inherit the mother’s condition. Nonetheless, any woman with kidney failure who is thinking about having a family should consider all the potential problems and risks, both for herself and for the baby, before going ahead. If she is in any doubt at all about whether to go ahead and try for a baby, she should speak to the doctors and nurses in the kidney unit. They are there to help people make decisions like this.

If the risks are considered too great, some form of contraception is recommended. The Pill is best avoided in women who have high blood pressure or clotting problems. Other methods of contraception, such as the coil (intra-uterine device) or condoms, can be discussed with the doctor.

It is also a good idea to practise ‘safe sex’ to reduce the likelihood of getting AIDS and other sexually transmitted diseases, by using condoms.

### Risk of Problems During Pregnancy for Kidney Transplant Patients

<table>
<thead>
<tr>
<th></th>
<th>Creatinine less than 125 µmol/l</th>
<th>Creatinine of more than 125 µmol/l</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chance of problems during pregnancy</td>
<td>30%</td>
<td>82%</td>
<td>89%</td>
</tr>
<tr>
<td>Chance of a successful pregnancy</td>
<td>97%</td>
<td>75%</td>
<td>95%</td>
</tr>
<tr>
<td>Chance of the mother having long-term health problems</td>
<td>7%</td>
<td>27%</td>
<td>12%</td>
</tr>
</tbody>
</table>
# Key Facts

1. Sexual difficulties affect the majority of male and female dialysis patients.

2. Patients may find that doctors and nurses are reluctant to talk about sexual problems.

3. Impotence (difficulty in getting or keeping a hard penis) is the most common and worrying problem for male patients.

4. Treatment of impotence is usually successful, although patience may be required.

5. Treating anaemia, adjusting the amount of dialysis and changing tablets can all help.

6. Viagra tablets have been shown to be effective in many dialysis patients, as have vacuum devices.

7. Penile injection therapy may be successful, although there are disadvantages.

8. Penile insertion (transurethral) therapy is slightly less effective than some other treatments. Men must also be able to pass urine before using it.

9. Sex counselling can be helpful.

10. Kidney failure affects women’s periods. Pregnancy is less likely, but contraception is still needed.

11. If a woman with kidney failure gets pregnant, there are considerable risks to both mother and baby.

12. A successful pregnancy is sometimes possible.

13. If a woman with kidney failure wants to get pregnant, it is best for her to do so either in the early stages of kidney failure or after a transplant, as long as the transplant is working well.
INTRODUCTION

Death is a subject seldom discussed openly with patients in a dialysis unit. Dialysis represents, after all, the success of our knowledge and skill in conquering a previously fatal illness. Dialysis is all about life. Yet nobody can attend a kidney unit without the realisation that death is always close at hand. In a large dialysis centre, a week rarely passes without the death of a patient. Units are close communities, where patients know many of those attending as friends. Patients are therefore aware of a succession of losses, reminding them of the fragility of their own lives.

Kidney patients live with the knowledge that they have a shorter life expectancy than the rest of the population (as can be seen from the tables in Chapter 18). The cause of death is not usually kidney failure, with the exception of one important group – those who choose not to receive dialysis. It is therefore fitting to include a chapter acknowledging the fact that what doctors can provide is far from perfect.

There is no doubt that life on dialysis can be full, rewarding and worthwhile for many people. However, there are some who feel either that they would not wish to live with the limitations imposed by treatment, or that they have done so long enough. When the need for dialysis approaches, those who are already elderly, or whose lives are seriously restricted by other illnesses, may decide that they would rather allow nature to take its course – even though this means they will die. Some, therefore, choose not to start dialysis treatment. There are others, who may have dialysed for many years, becoming more frail or disabled as time goes on, who decide that the time has come to stop treatment and die with dignity.

It is important for patients and their families to understand that dialysis is not compulsory. If you do not wish to receive treatment, or decide that you wish to stop dialysis, you should discuss this with the staff at your renal unit. Remember that only you can judge whether your quality of life is acceptable. You may be frail or elderly, severely disabled or restricted, yet satisfied that life is still worthwhile. If this is the case, starting or continuing dialysis is ‘right for you’. You may, on the other hand, appear to be doing quite well in the opinion of others – yet, in your eyes, life is intolerable. It is your point of view that counts.

Most units have a sympathetic attitude and will offer you all the information and support you need in taking this decision.

DEATH FROM KIDNEY FAILURE

Patients are often afraid to ask renal unit staff, whose lives are devoted to maintaining life against the odds,
what it is like to die from kidney failure. While every death is different (just as every life is different), it can be said with some confidence that it is, in general, ‘not a bad way to go’. The problems that occur in the final days of death from kidney failure vary from patient to patient. The symptoms that may need to be controlled include nausea, muscle twitching and breathlessness. Sometimes there is some agitation and confusion. Pain is not usually a serious problem.

Nausea can be caused by the waste products, removed by normal kidneys, building up in the blood. There are several drugs available that can be used to reduce or prevent nausea. Breathlessness may be due to heart failure, or to excess fluid building up in the body. Both drugs and suction treatment can be used to keep the lungs clear to reduce breathlessness, while carefully administered drug treatment can keep the patient comfortable and free from distress. Most of the drugs used for nausea, breathlessness or agitation (e.g. morphine and similar drugs) cause some degree of sedation, leading to drowsiness.

Patients and families usually want to know how long a person can survive with untreated end-stage kidney failure. This too is variable, depending on the extent to which their old kidneys are working – and therefore the amount of urine that they pass. The kidneys may be able to get rid of some excess fluid, but unable to process waste products such as creatinine and urea, or salts such as potassium. It is the build-up of these substances in the blood (especially the potassium) that usually leads to death.

On average, patients who are passing reasonable amounts of urine (say over 1 litre per day) can survive for about 2–6 weeks. If little or no urine is passed, they may survive for 10–14 days. During this period, they generally become increasingly weak and drowsy, sleep more and more, and finally become unconscious. Then they will pass away peacefully.

**Where should this period be spent?**

This is very much up to the patient and family. If a patient wishes to be at home, specialist nursing can be arranged through the GP. It is very important for some patients to feel they are in familiar surroundings, with family members and pets around them. Whenever this is the case, patients should receive every support to spend their last days at home.

Some hospices (which mainly deal with patients dying from cancer) will admit kidney patients who have decided not to dialyse, or to stop dialysis. Hospice care and support of the dying is particularly sympathetic, taking into account the needs and feelings of both patient and family.

Most kidney units are experienced in the care of dying patients, who are usually nursed in a side ward, offering quiet and privacy. It is usual for relatives to be allowed to stay with the patient all the time. Some kidney units offer accommodation in a ‘relatives’ room’. One of the benefits of remaining in hospital is that, if the person has a change of heart and decides to go for dialysis after all, the facilities are close at hand.

**The decision not to start dialysis treatment**

If a patient attending a pre-dialysis clinic tells the kidney consultant that, when the need arises, he or she does not want dialysis treatment, that it is important that this decision is made with full knowledge – it is an ‘informed’ choice.

In the first place, the patient needs to ask the doctor, quite directly, about the likely outcome – i.e. how long they might expect to live both with and without dialysis, and also what can be done to make their last days comfortable if they choose not to dialyse. This information is essential for making a rational decision. It may be that, with dietary care and medication, a person would live for some months, free of frequent hospital
visits or preparations for treatment such as access surgery. This is particularly true in the case of very elderly people, leading an inactive life.

We do not know that dialysis necessarily prolongs the life of all very frail elderly people (especially those over, say, 80 years of age). This does not mean they will not be offered the treatment. It is possible that dialysis in this group will shorten their lives. Or, if it prolongs it a little, then the quality of that life could be poorer than it would have been had dialysis not been started. Little research has been carried out into an active decision not to have dialysis.

It is important to be aware too that it is impossible to know exactly what life on dialysis is like unless one has experienced it. Even talking to others receiving treatment does not give the full picture, as everyone is different. Sometimes, patients agree to treatment reluctantly, only to find that it is not nearly as bad as they had imagined it would be. Others tell us that, on the contrary, they had expected it to be much easier to cope with, or that they had hoped to feel far better on treatment than they actually do.

**TRIALS OF DIALYSIS**
To discover what life on dialysis is like, some patients opt for a ‘trial of dialysis’, lasting a few weeks or months. This allows them to discover both the good and bad sides of life on dialysis, and to decide whether the benefits outweigh the drawbacks.

In some cases, a short period of treatment may be undertaken in order to give patients time to settle their affairs, or resolve conflicting feelings in the family. These are not uncommon during the heightened emotional tension surrounding such a decision. Others need time to allow visits from family members living abroad, and to say goodbye. Everything should be done that will allow the patient peace of mind. Relatives, too, need a sense of resolution, free from unnecessary guilt and regret.

**CHOOSING THE LESSER OF TWO EVILS**
There may be good medical reasons to decide not to dialyse, without even considering a trial of treatment. If a patient with kidney failure is already suffering from another terminal illness, for example an inoperable cancer, a progressive neurological or vascular disease (such as recurrent strokes) or severe heart failure, it can be a blessing in disguise to be offered the opportunity of refusing dialysis. This can allow a dignified death, in less distressing circumstances than might otherwise apply. Those who need dialysis to stay alive have a control over the time and manner of their death that is denied to most other people.

**THOSE WHO CANNOT MAKE AN INFORMED CHOICE**
So far, we have only considered those people who are in a position to make an informed choice. Sadly, some patients may have a condition or illness that makes it impossible for them to choose what they wish to do. Those with advanced dementia (with Alzheimer’s disease, for example) or severe learning disability may not be able to understand the implications of the decision. They might, in addition, be unable to understand the necessity of attending for dialysis, or of observing diet and fluid restriction – and would, in all probability, find the treatment very hard to tolerate. Each case needs to be considered on its merits, with the patient’s best interests always in mind.

People who have had a stroke causing irreversible brain damage, or an illness or injury that makes them drowsy or semi-conscious all the time, cannot express an opinion about their wishes. In these cases, it is very much more difficult for the doctors to know how to act for the best – i.e. in the patient’s best interests. It can be helpful, especially for the relatives, if patients make their wishes known at a time when they are able to decide for themselves.
If you feel that there are circumstances in which you would not wish to be kept alive by dialysis, you can confirm this in writing, and ask for the document to be kept in your medical notes. While this document, sometimes called a ‘Living Will’ or an ‘Advanced Directive’, has no legal status, it is valuable in giving a guide to your doctor and next of kin, and in reducing any feelings of guilt your family may experience after your death.

Most kidney consultants will discuss all the options with the family, the patient’s GP, the multidisciplinary team in the unit, and any others close to the patient. The consultant has the final responsibility for deciding what is in the best interests of the patient, having taken everyone’s views into consideration.

**The Decision to Stop Dialysis**
Withdrawal from dialysis is not an uncommon cause of death in long-standing dialysis patients, particularly those who are elderly. In fact, up to 20% of patients die in this way.

For some people, dialysis can become like a treadmill, or a conveyor belt, on which they feel as if they are trapped. The truth is that nobody can force a patient to attend for dialysis. To dialyse somebody against his or her will is legally an ‘assault’.

Sometimes, the very knowledge that they are able to stop when they wish is enough to give individuals the will to carry on for the present.

Patients sometimes fear that they are ‘letting down’ the staff of the kidney unit by wanting to stop treatment. It can seem like ingratitude, or a rejection of the care they have been given. While staff will be sad, they may also be relieved, having been aware of the person’s distress. They should, in any case, respect the patient’s decision. Nobody can know fully what life is like for another person.

There are many reasons why this decision may be taken. Probably the most common is that the patient suffers a medical setback, often unrelated to the kidneys, such as a stroke. In patients with diabetes, needing to have a limb amputated would be such a setback. It would inevitably result in further disability and limitation, which the patient might regard as just too much to cope with. Life on dialysis may have been tolerable, but the additional problem may remove what quality remained in the patient’s life. Loss of independence is often the deciding factor.

The second most common reason for withdrawal is the gradual deterioration caused by ageing and the complications of many years of dialysis. The patient may have considerable pain and restriction from renal bone disease, or problems with blood circulation from narrowing of the arteries. Dialysis access may have become difficult over the years, leading to frequent hospital admissions. Older patients may also have been bereaved due to the death of their spouse, resulting in less motivation to carry on for the sake of others. Whatever the reasons, the person may feel that it is no longer worth the struggle to continue.

If a patient asks renal unit staff to discontinue dialysis, the subject should be gently explored, to see whether there is anything that can be done to improve the situation. In some people, the request to withdraw is a cry for help, or an expression of a state of depression that could be helped either by sympathetic counselling or by medication. In some cases, patients may be asked to talk things over with a counsellor, psychologist or psychiatrist, to discover whether this is the case.

Stopping dialysis is a decision that should not be rushed, but properly considered. Some patients wish to stop, but find their families become distressed by the suggestion. It is important that the feelings of the others who are involved are considered and explored, but the final decision should be the patient’s alone.
WITHDRAWING FROM TREATMENT AFTER TRANSPLANT

While successful transplantation offers the best possible quality of life for a patient with kidney failure, it is not without risks. The powerful drugs used to prevent rejection can lead to infections, skin cancers and, in a minority of cases, more serious cancers, especially lymphoma. There is growing concern that newer, ‘stronger’ drugs which are ‘better’ at preventing rejection may also be ‘better’ at stopping the immune system from preventing cancer. It is possible, therefore, that cancer is becoming more common in patients on these drugs. Patients need to be aware of the risks as well as the benefits of transplantation and to discuss their concerns with their consultant. (More information about the risks of transplantation can be found in Chapter 13.)

One of the treatments for some serious types of cancer (including lymphoma) is to stop (or reduce the doses of) the immuno-suppressant drugs. In this case, the kidney will be rejected and the patient will need to go back onto dialysis. If the cancer is so advanced that no measures will prevent it, the patient is left with a bleak decision. Life might be prolonged for a short time by stopping the immuno-suppressant drugs and returning to dialysis. But this involves more time spent in hospital when time is short in any case. The advantage of being on dialysis is that the patient can choose when they’ve had enough, and decide to withdraw. Some patients, however, feel it is preferable to continue the immuno-suppressant drugs and maintain the kidney, but allow the cancer to take a quicker course. Should you be unlucky enough to find yourself in this situation, your doctors should be able to guide you as to the best decision in your particular case.

Other patients, who have had a long period of successful transplantation, develop an incurable condition not related to the drugs they are taking. These patients have a range of options which their doctor should discuss with them. One option might be to stop taking their immuno-suppressant medicine and allow the kidney to reject (and fail). Then they could die from kidney failure without dialysis, if the death from kidney failure is ‘better’ than it would have been from their new incurable disease. Or, if the incurable disease is killing them slowly, they might decide not to have dialysis when their transplant ‘naturally’ fails at a later date.

There is another group of patients, often elderly ones, who are not dying of an incurable disease. But the build-up of serious although non-fatal complications of kidney failure (such as bone pain or ‘access’ problems) is becoming too much for them. So they can ‘take the opportunity’ of their transplant’s ‘natural failure’ to allow themselves to die, rather than suffer a new period of dialysis – especially when they know they are now unfit to have another transplant and would otherwise have to have dialysis until they die anyway.

SPIRITUAL CONCERNS

Those who do not wish to receive dialysis or stop treatment after receiving it sometimes express concerns that this is the equivalent of suicide, and therefore against the teachings of most major religions. The same views might also be expressed by patients who allow their transplants to fail then refuse dialysis. However, priests from a number of different faiths have considered the case of the kidney patient who wishes to withdraw from treatment, and none has concluded that such withdrawal is either suicidal or sinful. The basis for this is that, but for an artificial and highly technological treatment, the patient would have died naturally in the first place. One could see this as the original decree of fate, nature or the Deity. As a result of human intervention, the patient has lived beyond his or her natural term. To give up dialysis or stop taking immunosuppressant drugs is simply to cease prolonging life unnaturally in someone whose body is not capable of sustaining itself.
Any patient, or relative of a patient, who has any concerns, or needs spiritual support, should talk to his or her priest or religious leader. Many hospitals now have a chaplaincy service, with leaders from all the major faiths available to give support and advice.

**Key facts**

1. Dialysis is not compulsory.
2. A trial of treatment may be a sensible option.
3. Withdrawal from dialysis is not uncommon, especially in older patients.
4. The reason for withdrawal is usually a medical event unrelated to the kidneys – such as a stroke or cancer.
5. The decision should not be rushed, allowing time for others to come to terms with the situation.
6. Death from renal failure need not be distressing, if well managed. It should take place where the patient feels most comfortable.
7. The wish to stop dialysis may be due to depression, or a cry for help, needing action to improve some intolerable situation.
8. Kidney patients have greater control in ensuring a dignified death than most other people.
9. Where a patient is not capable of an informed choice, the consultant has the final responsibility, after discussion with everybody concerned.
10. Transplant patients can decide to stop their immuno-suppressant drugs, to make them reject and lose the kidney, and then not have dialysis. In this way, they can allow themselves to die of kidney failure.
11. Refusing dialysis, or deliberately allowing a transplant to fail, is not suicide. A patient who wishes to take this route should not be made to feel guilty.
12. If religion is important to a patient, it is a good idea for them to discuss these issues with a priest or other religious leader – either from their own community or from the hospital.
INTRODUCTION
The number of patients being treated for kidney failure in the UK has increased in recent years. Without dialysis or a transplant, anyone with end-stage kidney failure (ESRF) will die within a few weeks. With successful treatment, some people with ESRF can expect to live for many years. However, it is still true that not enough patients in the UK are getting the treatment they need. This is the case for both dialysis and transplantation, and the later part of the chapter considers some of the reasons why this might be.

SURVIVAL WITH KIDNEY FAILURE
Kidney function is essential for life. Once a person’s own kidneys fail, some form of treatment is necessary if they are to go on living. Currently, there are two forms of treatment – dialysis (in which the kidney function is taken over by artificial means) and transplantation (in which another person’s kidney is used instead). Successful treatment – by dialysis or a transplant – now gives people with kidney failure a new lease of life, sometimes for many years.

The ‘Survival on Dialysis (by Age)’ table on the right shows the percentage chances of still being alive 1, 2, 5 and 10 years after the start of dialysis. People who start dialysis when they are young clearly have a better chance of surviving for longer than people who start dialysis later in life. Another factor affecting the likelihood of dying from kidney failure is the person’s sex – once patients are over the age of 35, women are likely to survive for longer than men, unless the cause of their kidney failure is diabetes.

Neither of these points is surprising, given that older people are more likely to die than younger people when they do not have kidney failure, and women in the general population can expect to live for 5–6 years longer than men. However, people on dialysis have less chance of surviving for 5 years than healthy people in the same age group.

Another way of looking at survival is to look at the average number of years a person is likely to live after

<table>
<thead>
<tr>
<th>Survival on Dialysis (by Age)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age at start of dialysis</strong></td>
</tr>
<tr>
<td>(in years)</td>
</tr>
<tr>
<td>Under 20</td>
</tr>
<tr>
<td>20–44</td>
</tr>
<tr>
<td>45–64</td>
</tr>
<tr>
<td>65–74</td>
</tr>
<tr>
<td>Over 74</td>
</tr>
</tbody>
</table>
the start of dialysis. According to North American researchers, a 45-year-old kidney patient has a life expectancy of 7 years, compared with 35 years for someone from the general population (most people live to about 80 these days). More recent UK data is even less optimistic, particularly for the older age groups, suggesting that people over 75 years live for 19 months on average after starting dialysis, while those in the age range 65–75 live for 30 months, and people aged between 50 and 64 for 52 months. Obviously, these figures include all patients, whatever the cause of their kidney failure, and the number will be higher in patients with a ‘good-outlook’ cause of ESRF, and lower in a ‘bad-outlook’ cause. For example, it is 3 years for patients with diabetes, 18 months for myeloma and 1 year for amyloidosis. So you can see that kidney failure, of whatever cause, is likely to reduce the patient’s natural lifespan dramatically. The latest figures suggest that 25% die during the first year they are on dialysis, and 10–15% within the first 3 months of dialysis.

The percentage chance of surviving 5 years after the start of dialysis is also affected by the cause of kidney failure. The table on this page shows the percentage chance of being alive 1, 2, 5 and 10 years after the start of dialysis, depending on what has caused the person’s kidney failure. As shown, people with high blood pressure or diabetes are not as likely to live for 10 years on dialysis as those with either polycystic kidney disease or glomerulonephritis.

The general health of the patient has also been shown to affect the chance of survival for people on dialysis or with a kidney transplant. People have a higher risk of dying if they have had a heart attack or stroke, peripheral vascular disease (narrowing of the arteries to the legs), serious cancers (including myeloma and amyloidosis) and diabetes. If someone with kidney failure has none of these conditions, they have a good chance of long-term survival, either on dialysis or with a transplant.

### Why do people with kidney failure die?

Although people with kidney failure have a lower than average life expectancy, once they start treatment (by either dialysis or a transplant), they are more likely to die from something other than kidney disease. The most common reason that people with kidney failure die is because they have heart disease as well (42% for patients on dialysis, see the table overleaf). This is also one of the most common causes of death in the general population of the UK (23%). However, if you have kidney failure, you are more likely to die of heart disease than if you have healthy kidneys.

In most developed countries, most people die of cancer (25%), then heart disease (23%), then strokes (11%). So, although a lot of kidney patients do die from these common causes, there are other causes of death. For example, many people with kidney failure die of infections. Dialysis patients may be prone to peritonitis or other infections (see pages 57–8, 68–9). In transplant patients, infections are common because the patient is taking immuno-suppressant drugs (see page 92) to prevent rejection of the kidney.

### Survival on Dialysis (by Cause)

<table>
<thead>
<tr>
<th>Percentage chance of surviving for:</th>
<th>1 year</th>
<th>2 years</th>
<th>5 years</th>
<th>10 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Polycystic kidneys</td>
<td>94%</td>
<td>85%</td>
<td>70%</td>
<td>42%</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>88%</td>
<td>79%</td>
<td>58%</td>
<td>37%</td>
</tr>
<tr>
<td>Obstructive nephropathy</td>
<td>82%</td>
<td>69%</td>
<td>46%</td>
<td>21%</td>
</tr>
<tr>
<td>Unknown cause</td>
<td>76%</td>
<td>65%</td>
<td>41%</td>
<td>19%</td>
</tr>
<tr>
<td>High blood pressure</td>
<td>77%</td>
<td>63%</td>
<td>33%</td>
<td>14%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>79%</td>
<td>63%</td>
<td>29%</td>
<td>11%</td>
</tr>
</tbody>
</table>
People are more likely to die from the complications of kidney failure, especially those affecting the heart, than from the kidney failure itself. It seems that permanent damage to the heart often occurs early in kidney failure, before dialysis or a transplant is needed. This damage is probably due to several factors, including high blood pressure, anaemia and fluid overload. It is also possible that the wastes that build up in the blood in people with kidney failure have a directly toxic effect on the heart. Neither dialysis nor a transplant can do anything to repair an already damaged heart.

Patients with advanced kidney failure may die because they choose to stop dialysis. This and the surrounding issues are discussed fully in Chapter 17.

**INDIVIDUALS NOT STATISTICS**
Although statistics can give an indication of the average survival chances of different groups of patients treated for kidney failure, they cannot predict what will happen to any one person. People with kidney failure are individuals not statistics. Even if you belong to a group of patients whose overall chance of survival is poor, you as an individual may still survive for many years. Your survival odds are obviously better though if you belong to one of the groups with the best chances of survival.

**HOW GOOD ARE THE SERVICES?**
Survival is affected by two things – the severity of a person’s disease and the treatment services that are available. While dialysis and transplantation can make an enormous difference to a person’s life expectancy, the availability of these treatments does vary from one country to another.

One way of assessing how good the services for kidney patients are is to make comparisons with the services available in other countries. The table below

<table>
<thead>
<tr>
<th>Country</th>
<th>Unit HD</th>
<th>PD</th>
<th>Home HD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>60</td>
<td>28</td>
<td>12</td>
</tr>
<tr>
<td>Austria</td>
<td>91.8</td>
<td>8</td>
<td>0.2</td>
</tr>
<tr>
<td>Canada</td>
<td>66</td>
<td>30</td>
<td>4</td>
</tr>
<tr>
<td>Germany</td>
<td>93</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Italy</td>
<td>86</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Netherlands</td>
<td>68</td>
<td>30</td>
<td>2</td>
</tr>
<tr>
<td>New Zealand</td>
<td>26</td>
<td>56</td>
<td>18</td>
</tr>
<tr>
<td>Norway</td>
<td>81</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>Sweden</td>
<td>87</td>
<td>12</td>
<td>1</td>
</tr>
<tr>
<td>UK</td>
<td>60</td>
<td>36</td>
<td>4</td>
</tr>
<tr>
<td>USA</td>
<td>88.5</td>
<td>10.2</td>
<td>1.3</td>
</tr>
</tbody>
</table>

(Adapted from the Renal Registry Report 2000)
A COMPARISON OF THE NUMBER OF PEOPLE WITH KIDNEY FAILURE AND RECEIVING TREATMENT IN SEVERAL COUNTRIES

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of people currently being treated for ESRF p.m.p</th>
<th>Number of people with transplants p.m.p</th>
<th>Number of people on dialysis p.m.p</th>
<th>Number of new cases of ESRF each year</th>
<th>ESRF patients with diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>USA</td>
<td>1,177</td>
<td>267.2</td>
<td>909.8</td>
<td>320</td>
<td>40%</td>
</tr>
<tr>
<td>Italy</td>
<td>757</td>
<td>168</td>
<td>589</td>
<td>119</td>
<td>15%</td>
</tr>
<tr>
<td>Germany</td>
<td>764</td>
<td>179</td>
<td>585</td>
<td>148</td>
<td>35%</td>
</tr>
<tr>
<td>Canada</td>
<td>609</td>
<td>238</td>
<td>371</td>
<td>152</td>
<td>29%</td>
</tr>
<tr>
<td>Austria</td>
<td>668</td>
<td>319</td>
<td>349</td>
<td>125</td>
<td>31%</td>
</tr>
<tr>
<td>Sweden</td>
<td>668</td>
<td>364</td>
<td>304</td>
<td>119</td>
<td>23%</td>
</tr>
<tr>
<td>New Zealand</td>
<td>541</td>
<td>246</td>
<td>295</td>
<td>96</td>
<td>44%</td>
</tr>
<tr>
<td>Australia</td>
<td>555</td>
<td>260</td>
<td>295</td>
<td>85</td>
<td>22%</td>
</tr>
<tr>
<td>Netherlands</td>
<td>583</td>
<td>293</td>
<td>290</td>
<td>93</td>
<td>16%</td>
</tr>
<tr>
<td>UK</td>
<td>534</td>
<td>261</td>
<td>273</td>
<td>97</td>
<td>19%</td>
</tr>
<tr>
<td>Norway</td>
<td>526</td>
<td>403</td>
<td>123</td>
<td>91</td>
<td>10%</td>
</tr>
</tbody>
</table>

(Adapted from the Renal Registry Report 2000)

gives you some idea of the different forms of dialysis offered by different countries.

The table shows that, like New Zealand, the UK puts many more patients on PD than on haemodialysis. The reason for this is not clear. The authors do not feel that PD is necessarily a better treatment, rather that both types of dialysis have advantages and disadvantages for different people at different times in their lives.

In order to make useful comparisons about what treatment is available to kidney patients in different countries, it is necessary to take population size into account. This is done by dividing yearly totals from a particular country by the number of millions of people in that country’s population. This provides us with tables of comparable figures expressed as numbers per million population (p.m.p.).

The table above shows the numbers of people currently being treated for ESRF (by either dialysis or transplant) in various different countries, together with the number who also have diabetes.
In health care, as in football, some countries are clearly better than others. If all football teams were equally good, all teams would gain the same number of points each year – and all would come ‘equal top’. Every world cup match would end in a draw. However, not everyone can be top all or even some of the time, and there may be a number of reasons why any country holds the position it does.

One possible explanation is that people from different countries are not similar – that Norwegians and people who live in the UK are not genetically predisposed to developing kidney failure, while North Americans are. The table shows the USA to have almost twice as many people per million population with ESRF than the rest of the world. This seems unlikely, although the North American population does include a greater ethnic mix than is currently the case in European countries, which may make some difference. In addition, there is one group of people who are considerably more likely to develop kidney failure than others. This is people with diabetes. To account for this, there is a separate column showing the numbers of diabetic people in the table.

Another reason for the variation in number of people being treated is that some countries are better than others at identifying and providing treatment for people who develop kidney failure.

The fact that countries such as Germany, Italy and the USA have much higher numbers of patients on dialysis than the UK clearly shows that the UK is failing to treat large numbers of people who develop kidney failure. This is all the more worrying when it is remembered that people with ESRF die within a few weeks unless they are treated by dialysis or a transplant.

Fortunately for kidney patients in the UK, the rate at which patients are starting dialysis is improving, but the rate of improvement is still too slow.

THE ‘POSTCODE LOTTERY’
The lack of new patients starting dialysis in the UK is a concern. But probably a more major concern is that there are massive differences within the UK. In 2000, there was a wide variation in the numbers of new patients starting dialysis around the country – from 52 per million per year to 157 per million per year. While the unit with the highest acceptance has a relatively high ethnic minority population, and the very lowest areas have relatively small ethnic minority populations, there is no clear relationship between acceptance rates and the proportion of population from ethnic minorities. In other words, it is not just that busiest units have the greatest numbers of Blacks and Asians in the local population. Some areas of the UK treat more patients than others – it’s as simple as that.

RATE OF TRANSPLANTATION
Another way of assessing how well different countries are meeting the need for treatment for kidney failure is to compare the number of kidney transplants performed per million population in any one year. Like the rate for dialysis (see page 124), the rate of kidney transplantation should be the same in all countries. Again, it is easy to see from the table opposite that this is far from being the case. Some countries perform many more kidney transplants than others.

As can be seen from the table, the UK’s performance in terms of transplantation among developed countries is mediocre, at best. Spain is the ‘transplant king’ of this group of countries. They achieve good results by emphasising cadaveric transplantation. One way they do this is to have transplant co-ordinators in every main hospital in the land, so that all potential donors are assessed. Norway, Sweden and the USA achieve very good results, but in a different way. They make sure that all potential living donors are informed about the possibility of helping their loved one. And indeed, they
## New Transplants Performed in Various Countries

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Spain</td>
<td>49.8</td>
<td>0.5</td>
<td>1%</td>
<td>15. Germany</td>
<td>25</td>
<td>4.3</td>
<td>17%</td>
</tr>
<tr>
<td>2. Ireland</td>
<td>42.3</td>
<td>0.3</td>
<td>1</td>
<td>16. UK</td>
<td>23.2</td>
<td>4.1</td>
<td>18</td>
</tr>
<tr>
<td>3. Austria</td>
<td>40.6</td>
<td>6</td>
<td>15</td>
<td>17. Slovenia</td>
<td>23</td>
<td>0.5</td>
<td>2</td>
</tr>
<tr>
<td>4. Belgium</td>
<td>36.1</td>
<td>2.6</td>
<td>7</td>
<td>18. Hungary</td>
<td>22.6</td>
<td>0.8</td>
<td>4</td>
</tr>
<tr>
<td>5. Finland</td>
<td>35.1</td>
<td>1.2</td>
<td>3</td>
<td>19. Estonia</td>
<td>22.6</td>
<td>3.3</td>
<td>15</td>
</tr>
<tr>
<td>6. Czech Rep</td>
<td>34.9</td>
<td>0.7</td>
<td>2</td>
<td>20. Italy</td>
<td>20.9</td>
<td>1.4</td>
<td>7</td>
</tr>
<tr>
<td>7. USA</td>
<td>33.4</td>
<td>15</td>
<td>45</td>
<td>21. Latvia</td>
<td>20.9</td>
<td>0.4</td>
<td>2</td>
</tr>
<tr>
<td>8. France</td>
<td>30.8</td>
<td>1.2</td>
<td>4</td>
<td>22. Denmark</td>
<td>20.3</td>
<td>7.2</td>
<td>35</td>
</tr>
<tr>
<td>9. Portugal</td>
<td>30.6</td>
<td>0.5</td>
<td>2</td>
<td>23. Australia</td>
<td>19.1</td>
<td>7.7</td>
<td>40</td>
</tr>
<tr>
<td>10. Switzerland</td>
<td>28.7</td>
<td>9.7</td>
<td>34</td>
<td>24. Luxembourg</td>
<td>15</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11. Norway</td>
<td>28.3</td>
<td>17.6</td>
<td>62</td>
<td>25. Poland</td>
<td>13.8</td>
<td>0.2</td>
<td>1</td>
</tr>
<tr>
<td>12. Slovak Rep</td>
<td>27.1</td>
<td>0.6</td>
<td>2</td>
<td>26. Croatia</td>
<td>8.7</td>
<td>2.8</td>
<td>32</td>
</tr>
<tr>
<td>13. Sweden</td>
<td>26.7</td>
<td>13.5</td>
<td>51</td>
<td>27. Greece</td>
<td>8.7</td>
<td>8.2</td>
<td>94</td>
</tr>
<tr>
<td>14. Netherlands</td>
<td>25.3</td>
<td>7</td>
<td>28</td>
<td>28. Lithuania</td>
<td>5.8</td>
<td>5.8</td>
<td>100</td>
</tr>
</tbody>
</table>

(Source UK Transplant 1999. Reproduced with permission)

find if they do this, many more do come forward to donate. The UK is not particularly good at either cadaveric or living transplantation.

The number of transplants done in the UK is increasing, but very slowly. In 1999 it was 1,737 (i.e. a transplant rate of 29.4 per million per year), and 1,821 (30.8 per million) in 2000, compared with 23.2 per million in 1998. Even though any increase is ‘good news’, this rate of rise is not keeping up with the demand for transplantation. This is because the number of people put on the transplant waiting list is also increasing, with 4,633 people waiting in 1998, 4,737 in 1999 and 4,891 in 2000.

Unfortunately the percentage of living transplants performed is also not improving dramatically (18%, in 1998, 15% in 1999, and 18% in 2000).
THE SHORTFALL IN UK RENAL SERVICES

The figures given earlier in this chapter show UK services for kidney patients as ranking well behind those of many other countries in the developed world. There are a number of reasons why this could be the case.

We suggest three that might be particularly important:

1. **Provision of renal units.** One reason why the provision of dialysis in the UK is so low is because this country has relatively few renal units (and therefore relatively few specialist renal doctors, renal nurses and dialysis machines).

   The table below shows the number of kidney doctors (nephrologists) per million population in some European countries in 2000.

   The UK also has far fewer renal units than many other countries in Europe. However, it is very difficult to make direct comparisons with other countries as many renal units in other parts of the world are small and privately run. Nonetheless, in 1995 we think there were 83 units in the UK compared with 776 in Germany and 654 in Italy.

   Most UK renal units are based in large cities, which means that many patients have to travel 1–2 hours two or three times a week for haemodialysis. This means that each of their ‘4 hour’ dialysis sessions actually takes up to 8 hours. Fortunately, an increasing number of units now have smaller ‘satellite’ units – by March 1999, the number of these had reached 82. This is a welcome development.

   Why does the UK have so few kidney doctors and renal units? Not surprisingly, the answer is money. The NHS is inadequately funded. The UK needs to put more money into healthcare in general, and into kidney medicine in particular (at present only 1.5% of the healthcare budget is spent on treating kidney failure). If current government pledges are fulfilled, there would be more renal units, more specialist doctors and nurses, more patients on dialysis and more transplants performed.

2. **Cadaveric transplants in the UK.** One reason why the UK does not do more transplant operations is that this country has a relatively low death rate from road traffic and industrial accidents. This obviously has an effect on the availability of cadaveric kidneys for transplantation. The situation would be improved if more people registered their willingness to donate their organs for transplantation, and discussed their wishes with their next of kin.

   Even more important is the lack of beds in intensive care units (ICUs) in the UK. If a patient becomes brain dead, and therefore a potential kidney donor, that person needs to be kept on a life support machine to preserve their organs (including their kidneys) until an operation can be performed to remove them. When ICU beds are in short supply, patients who have a chance of recovery must be given priority over patients who are

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**Comparison of Numbers of Specialist Kidney Doctors in Different Countries**

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of nephrologists p.m.p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Italy</td>
<td>65.8</td>
</tr>
<tr>
<td>Germany</td>
<td>32</td>
</tr>
<tr>
<td>Spain</td>
<td>30</td>
</tr>
<tr>
<td>France</td>
<td>14.2</td>
</tr>
<tr>
<td>Sweden</td>
<td>11.8</td>
</tr>
<tr>
<td>UK</td>
<td>5.2</td>
</tr>
</tbody>
</table>

(Adapted from the Renal Registry Report 2001)
already brain dead. Inevitably, many potential cadaveric organs are lost in this way. Again, a lack of investment in the NHS is an important factor.

3. Living donor transplants in the UK. It is well worth looking at why the UK carries out so few living related (and unrelated) transplants, especially as this is the best and cheapest treatment for ESRF.

One possible reason why a patient may not be given a living related transplant is that they have no medically suitable donors among their family members. In fact, medical unsuitability among family members is quite uncommon.

Carrying out a living related or unrelated transplant requires a lot of preparation work by renal doctors, nurses and transplant co-ordinators. Not all renal units in the UK put much time and effort into such work, finding it generally ‘easier’ (less work) to put patients on the ‘normal’ (cadaveric) transplant waiting list. Also, carrying out transplants from living people means that doctors and nurses are more likely to have to confront ‘difficult’ issues with patients and their relatives. Perhaps some prefer to avoid this.

The low rate of transplantation from living donors in the UK is partly the fault of the doctors and nurses who do not always tell patients and their relatives, partners and friends about the full range of possibilities. If potential donors are not told that kidney donation is a possibility, and are not gently encouraged to come forward, they are unlikely to do so. Members of the UK public must also share some of the blame. More relatives, partners and friends need to come forward to donate their kidneys.

The Renal National Service Framework

In April 1998, the UK government launched a programme of National Service Frameworks (NSFs). This was part of a number of measures that were introduced in the NHS Plan to raise quality and decrease variations in service in the NHS. These NSFs cover a range of conditions including mental health, cancer and diabetes.

A number of commitments were made in the NHS Plan which related specifically to services for kidney patients. It stated that, by 2004, there would be:

- 450 new and replacement haemodialysis machines to treat another 1,850 kidney patients;
- better treatment for a further 1,200 existing patients.

Funding to help healthcare commissioners meet this target includes a capital investment of £9m in 2001/2 and £9m in 2002/3.

The Renal NSF was announced at the Secretary of State for Health’s Summit on Organ Donation on 27 February 2001 as ‘the blueprint for national standards and services that will improve treatment and care for the 30,000 patients on dialysis or living with a kidney transplant’. Publication of the Renal NSF is expected in 2003.

The document aims to:

- raise standards of care for kidney patients;
- reduce variations in the service to kidney patients across the country;
- put in place strategies so that these standards can be reached and maintained; and
- design ways to measure progress and performance.

Each NSF is written and developed by a team of external reference groups (ERGs), which brings together health professionals, patients and carers, health service managers, partner agencies and other advocates. The Department of Health supports the ERGs and manages the overall process.

The development process for the Renal NSF will take about 3 years. There will be four sections of the NSF produced at various times during these 3 years. The
sections (or modules are they are officially called) will contain standards for:

- dialysis;
- transplantation;
- prevention, primary care and pre-dialysis; and
- end of life care.

These modules will each have a number of sections called ‘Topic areas’ which concentrate on specific issues. The topic areas for each module are listed below:

1. Dialysis
   - Preparation for dialysis. The main areas to be included in this topic area are the selection of patients, patient information and advice, informed choice of treatment type, vascular and peritoneal access, and the planned initiation of dialysis including testing and immunising against viruses such as hepatitis B and C.
   - Peritoneal dialysis. The main areas here are all forms of peritoneal dialysis including APD, CAPD, anaemia management and peritonitis.
   - Haemodialysis. This section will include service planning including capacity issues – making sure that there are enough haemodialysis units available for the number of patients who need treatment, home haemodialysis, anaemia management and the treatment of acute and potentially reversible kidney failure.
   - Patient issues. This section will cover patient transport services, holiday dialysis, social care and support.

2. Transplantation
   - The selection of patients.
   - Patient information.

- Organ donation.
- Organ retrieval.
- Allocation of organs.

3. Prevention, primary care and pre-dialysis
   - Acute kidney failure. This section will cover the management of acute renal failure, working with intensive care units, cardiac units and others, and protocols about the training needed by intensive care unit specialists.
   - The causes of ESRF.
   - The diagnosis of kidney failure.
   - Primary care for kidney patients (GP services).

This section will also cover overlap with other NSFs.

4. End of life care
   - The conservative or supportive management of ESRF.
   - Palliative care (looking after someone who is not having any active treatment for the disease).
   - Withdrawal from dialysis.

Some more general NSF themes, such as children’s renal services, research, finance and workforce issues, will be present throughout all the modules and topic areas because they relate to all aspects of the NSF.

Patients’ voices, patients’ rights
Where there is a shortfall in available treatment, or where patients feel they are not getting the choices they deserve, there are some things they can do about it. If you, or someone you care about, is in this position here are some suggestions:
If you feel that local services are substandard, why not write to your local paper? Publicity is a powerful tool.

Contact the British Kidney Patient Association (see page 141), and join your local Kidney Patients’ Association if there is one. If there is not one, consider whether you might be the person to start one.

It is also a good idea to join the National Kidney Federation (NKF) who speak for all kidney patients and have links with the Renal All-Party Group – a group of MPs who fight for resources for kidney patients.

Write to your MP or, even better, visit his or her local surgery. Not all politicians are aware of the major problems in British kidney medicine.

Whether you do one or all of these, keep at it!

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**Key facts**

1. Without dialysis or a transplant, people die within a few weeks of developing ESRF. Successful treatment (by dialysis or a transplant) can prolong life for many years.

2. Average survival chances for people on dialysis (or after a transplant) are affected by age, sex, the underlying cause of kidney failure and various other medical factors.

3. People with kidney failure are individuals not statistics. Doctors cannot predict what will happen to any one person.

4. Some countries treat a far higher proportion of their people who develop kidney failure than do others.

5. The number of people per million population in the UK who are having treatment for kidney failure is much lower than it should be.

6. There is a serious shortfall in the provision of treatment for kidney failure in the UK.

7. Inadequate funding of the NHS means that the UK has fewer kidney doctors and renal units per million population than many other developed countries.

8. More ‘living transplants’ are needed, and relatives, partners and friends should be actively encouraged to consider donating a kidney to a loved one.

9. A National Service Framework for the care of renal patients is in the process of being developed. This will give guidelines for ensuring that services for kidney patients are of an appropriate standard everywhere in the UK.

10. Patients have a right to be heard. Joining relevant organisations and writing to the local paper or your MP is a good place to start.
This glossary provides brief explanations of the various technical words and abbreviations used in this book. Words printed in italic type have their own glossary entry.

**Abdomen** The lower part of the trunk, below the chest. Commonly called the tummy or belly.

**Access** A method of gaining entry to the bloodstream to allow dialysis. Access methods used for haemodialysis include a catheter, fistula or graft.

**Acid** A chemical that builds up in the blood in kidney failure.

**Acute** A word meaning short term and of rapid onset, usually requiring a rapid response.

**Adequacy** This term is used to describe the tests that are used to see how much dialysis a patient is getting. Samples of the dialysis fluid, blood and samples of urine are used to measure the dialysis adequacy.

**Albumin** A type of protein that occurs in the blood. Low blood levels may be linked to malnutrition.

**Aldosterone II (AII) antagonist** A type of blood pressure tablet that can make kidney function worse, although it is useful in certain situations.

**Alfacalcidol** A vitamin D supplement.

**ALG** Abbreviation for anti-lymphocyte globulin, a strong treatment against the rejection of a transplant kidney.

**Alkali** A substance that is the chemical opposite of an acid.

**Alpha-blocker** A type of blood pressure tablet – examples include doxazosin and terazosin.

**Aluminium hydroxide** A commonly-used type of phosphate binder, used to help prevent and treat renal bone disease. An example of aluminium hydroxide is Alu-Cap.

**Amino acids** Substances from which proteins are built up.

**Anaemia** A shortage of red blood cells in the body, causing tiredness, shortness of breath and pale skin. One of the functions of the kidneys is to make erythropoietin, which stimulates the bone marrow to make blood cells. In kidney failure, EPO is not made, and anaemia results.

**Angiogram** A type of X-ray that uses a special dye to show the blood vessels. The dye is put into the blood vessels via a tube that is inserted into the groin and passed up to the kidneys.

**Angiotensin-converting enzyme (ACE) inhibitor** A type of blood pressure tablet that can make kidney function worse, although it is useful in certain situations.

**Ankle oedema** An abnormal build-up of fluid in the skin around the ankles. It is an early sign of fluid overload.

**Antibiotic drugs** A group of drugs used to treat infections caused by bacteria.

**Antibodies** Substances that normally help the body to fight infection. They are made by white blood cells. After a transplant, antibodies can attack the new kidney and cause rejection.

**Antigen** A type of protein that occurs on the outer surface of all the cells in a person’s body. Antigens act as a ‘friendly face’ for the cells. The immune system normally recognises the friendly face of the body’s own cells, and does not attack or reject them.

**APD** Abbreviation for automated peritoneal dialysis. A form of peritoneal dialysis that uses a machine to drain the dialysis fluid out of the patient and replace it with fresh solution. APD is usually carried out overnight while the patient sleeps.

**Arteries** Blood vessels that carry blood from the heart to the rest of the body.

**Artificial kidney** Another name for the dialyser or filtering unit of a dialysis machine.

**ATG** Abbreviation for anti-thymocyte globulin, a strong treatment against the rejection of a transplant kidney.

**Atheroma** Deposits of cholesterol and other fats that cause furring and narrowing of the arteries (also called atherosclerosis).

**Azathioprine** An immuno-suppressant drug used to prevent the rejection of a transplant kidney.

**Bacteria** A type of germ. Bacteria are microscopically tiny, single-celled organisms capable of independent life. Most are harmless, but some cause disease.

**Beta-blockers** Tablets that slow down the heart rate and lower blood pressure. Examples are atenolol, bisoprolol, metoprolol and propranolol.

**Bicarbonate** A substance that is normally present in the blood which is measured in the biochemistry blood test. A low blood level of bicarbonate shows there is too much acid in the blood.

**Biochemistry blood test** A test that measures the blood levels of
various different substances. Substances measured in people with kidney failure usually include sodium, potassium, glucose, urea, creatinine, bicarbonate, calcium, phosphate and albumin.

**Biopsy** A test involving the removal of a small piece of an organ or other body tissue and its examination under a microscope. A kidney biopsy is sometimes used to try and establish the cause of kidney failure. Biopsies are also used to check whether a transplanted kidney is being rejected.

**Bladder** The organ in which urine is stored before being passed from the body.

**Blood cells** The microscopically tiny units that form the solid part of the blood. There are three main types: red blood cells, white blood cells and platelets.

**Blood group** An inherited characteristic of red blood cells. The common classification is based on whether or not a person has certain antigens (called A and B) on their cells. People belong to one of four blood groups, called A, B, AB and O.

**Blood level** A measurement of the amount of a particular substance in the blood, sometimes expressed in mmol/l (millimoles per litre) or µmol/l (micromoles per litre) of blood.

**Blood pressure** The pressure that the blood exerts against the walls of the arteries as it flows through them. Blood pressure measurements consist of two numbers. The first shows the systolic blood pressure, the second, the diastolic blood pressure. One of the functions of the kidneys is to help control the blood pressure. In kidney failure, the blood pressure tends to be high.

**Blood vessels** The tubes that carry blood around the body. The main blood vessels are the arteries and veins.

**Bone marrow** The ‘runny’ part in the middle of some bones, where blood cells are made.

**BP** Abbreviation for blood pressure.

**Brain death** A term indicating that the entire brain has permanently stopped working, and that further life is possible only on a life support machine. A person must be diagnosed brain dead before their organs can be removed for a cadaveric transplant.

**Cadaveric transplant** A transplant kidney removed from someone who has died.

**Calcium** A mineral that strengthens the bones. It is contained in some foods, including dairy products. It is stored in the bones and is present in the blood. The kidneys normally help to keep calcium in the bones. In kidney failure, calcium drains out of the bones, and the level of calcium in the blood also falls.

**Calcium antagonist** A type of blood pressure tablet that can cause ‘ankle swelling’. Examples include amlodipine and nifedipine.

**Calcium carbonate** A commonly used type of phosphate binder, used to help prevent and treat renal bone disease. An example of calcium carbonate is Calcichew.

**Candida albicans** A fungus that sometimes causes peritonitis in patients on peritoneal dialysis.

**CAPD** Abbreviation for continuous ambulatory peritoneal dialysis. A continuous form of peritoneal dialysis in which patients perform the exchanges of dialysis fluid by hand. The fluid is usually exchanged four times during the day, and is left inside the patient overnight.

**Catheter** A flexible plastic tube used to enter the interior of the body. A catheter is one of the access options for patients on haemodialysis. For patients on peritoneal dialysis, a catheter allows dialysis fluid to be put into and removed from the peritoneal cavity. A catheter may also be used to drain urine from the bladder.

**Cells** The tiny units from which all living things are built up. Most cells have some common features (including a nucleus that is the cell’s control centre, and an outer membrane or skin that gives the cell its shape). Cells in different parts of the body look different from each other and perform different functions (for example, skin cells are very different from blood cells).

**Cholesterol** A lipid (fat) that is a major contributor to atheroma.

**Chronic** A word meaning long term and of slow onset, not usually requiring immediate action.

**Clearance** The removal of the toxic waste products of food from the body. Clearance is one of the two main functions of the kidneys. In kidney failure, clearance is inadequate, and toxins from food build up in the blood.

**CMV** Abbreviation for cytomegalovirus.

**Creatinine** A waste substance produced by the muscles when they are used.

**Creatinine clearance test** A blood test that measures the blood level of creatinine. The higher the blood creatinine level, the worse the kidneys (or dialysis or kidney transplant) are working.

**Cross-match** The final blood test before a transplant operation is performed. It checks whether the patient has any antibodies to the donor kidney. The operation can proceed only if the cross-match is negative (i.e. no antibodies are found).

**CT scan** Abbreviation for a computed tomography scan. An investigation that uses a computer to build up a picture from a series of low-intensity X-rays.

**Cyclosporin** An immuno-suppressant drug used to prevent the rejection of a transplant kidney.
**Kidney Failure Explained**

**Cytomegalovirus (CMV)** A virus that normally causes only a mild ‘flu-like illness. In people with a kidney transplant (and in other people whose immune system is suppressed), CMV can cause a more serious illness, affecting the lungs, liver and blood.

**Dehydration** A condition in which the body does not contain enough water to function properly. Dehydration often occurs with low blood pressure, which causes weakness and dizziness.

**Diabetes mellitus** A condition (also known as ‘sugar diabetes’ or simply as diabetes) in which there is too much sugar in the blood. Whether this type of diabetes is controlled by insulin, tablets or diet, it can cause kidney failure. This happens most often to people who have had diabetes for longer than 10 years.

**Dialyser** The filtering unit of a dialysis machine. It provides the dialysis membrane for patients on haemodialysis. The dialyser removes body wastes and excess water from the blood in a similar way to a normal kidney.

**Dialysis** An artificial process by which the toxic waste products of food and excess water are removed from the body. Dialysis therefore takes over some of the work normally performed by healthy kidneys. The name dialysis comes from a Greek word meaning ‘to separate’ – i.e. to separate out the ‘bad things’ in the blood from the ‘good things’.

**Dialysis fluid** The liquid that provides the ‘container’ into which toxic waste products and excess water pass during dialysis for removal from the body.

**Dialysis machine** The machine used to perform haemodialysis. It includes a dialyser, which filters the patient’s blood. The machine helps to pump the patient’s blood through the dialyser, and monitors the dialysis process as it takes place.

**Dialysis membrane** A thin layer of tissue or plastic with many tiny holes in it, through which the process of dialysis takes place. In peritoneal dialysis, the patient’s peritoneum provides the dialysis membrane. For haemodialysis, the dialysis membrane is made of plastic. In each case, the membrane keeps the dialysis fluid separate from the blood (essential because dialysis fluid is toxic if it flows directly into the blood). However, the tiny holes in the membrane make it semi-permeable, allowing water and various substances to pass through it.

**Diastolic blood pressure** A blood pressure reading taken when the heart is relaxed. It is taken after the systolic blood pressure, and is the second figure in a blood pressure measurement.

**Diffusion** A process by which substances pass from a stronger to a weaker solution. Diffusion is one of the key processes in dialysis (the other is ultrafiltration). During dialysis, body wastes such as creatinine pass from the blood into the dialysis fluid. At the same time, useful substances such as bicarbonate and calcium pass from the dialysis fluid into the blood.

**Diuretic drugs** The medical name for water tablets. These drugs increase the amount of urine that is passed. Two commonly used diuretics are frusemide and bumetanide.

**Donor** A person who donates (gives) an organ to another person (the recipient).

**Donor kidney** A kidney that has been donated.

**Doppler scan** A type of ultrasound scan (sound-wave picture) that provides information about blood flow through the arteries.

**ECG** Abbreviation for electrocardiogram.

**ECHO** Abbreviation for echocardiogram.

**Echocardiogram (ECHO)** A type of ultrasound scan (sound-wave picture) that shows how well the heart is working.

**Electrocardiogram (ECG)** A test that shows the electrical activity within the heart.

**End-stage renal failure (ESRF)** A term for advanced chronic kidney failure. People who develop ESRF will die within a few weeks unless treated by dialysis or transplantation. These treatments control ESRF but cannot cure it. Once a patient has developed ESRF, they will always have it, even after a transplant.

**End-stage renal disease (ESRD)** An alternative name for end-stage renal failure.

**EPO** Abbreviation for erythropoietin.

**Erythropoietin (EPO)** A hormone, made by the kidneys, which stimulates the bone marrow to produce red blood cells.

**ESRF** Abbreviation for end-stage renal failure.

**ESRD** Abbreviation for end-stage renal disease.

**Exit site** The point where a catheter comes out through the skin. Exit site infections can be a problem for peritoneal dialysis patients.

**Ferritin** A substance in the blood that indicates how much iron is present. The more iron there is in the body, the higher the level of ferritin in the blood.

**Fistula** An enlarged vein, usually at the wrist or elbow, that gives access to the bloodstream for haemodialysis. The fistula is created by a surgeon in a small operation. It is done by joining a vein to an artery. This increases the flow of blood through the vein and causes it to enlarge, making it suitable for haemodialysis needles.

**FK506** Another name for tacrolimus.

**Flucloxacillin** An antibiotic used to treat exit site infections of peritoneal dialysis and haemodialysis catheters.

**Fluid overload** A condition in which the body contains too much...
water. It is caused by drinking too much fluid, or not losing enough. Fluid overload occurs in kidney failure because one of the main functions of the kidneys is to remove excess water. Fluid overload often occurs with high blood pressure. Excess fluid first gathers around the ankles (ankle oedema) and may later settle in the lungs (pulmonary oedema).

**Gentamicin** An antibiotic used to treat peritonitis.

**Glomerulus** One of the tiny filtering units inside the kidney.

**Glomerulonephritis** Inflammation of the glomeruli, which is one of the causes of kidney failure.

**Glucose** A type of sugar. There is normally a small amount of glucose in the blood. This amount is not usually increased in people with kidney failure unless they also have diabetes mellitus. Glucose is the main substance in peritoneal dialysis fluid, drawing excess water into the dialysis fluid from the blood by osmosis.

**Graft** A type of access for haemodialysis. The graft is a small plastic tube that connects an artery to a vein. It is inserted into the arm or leg by a surgeon. Haemodialysis needles are inserted into the graft, which can be used many hundreds of times.

**Haemodialysis** A form of dialysis in which the blood is cleaned outside the body, in a machine called a dialysis machine or kidney machine. The machine contains a filter called the dialyser or artificial kidney. Each dialysis session lasts for 3–5 hours, and sessions are usually needed two or three times a week.

**Haemodialysis catheter** A plastic tube used to gain access to the bloodstream for haemodialysis.

**Haemodialysis unit** The part of a hospital where patients go for haemodialysis.

**Haemoglobin (Hb)** A substance in red blood cells that carries oxygen around the body. Blood levels of haemoglobin are measured to look for anaemia. A low Hb level indicates anaemia.

**Hb** Abbreviation for haemoglobin.

**Heart-beating donor** A term used to describe a donor whose heart is still beating after brain death has occurred. Most, but not all, cadaveric transplants come from heart-beating donors.

**Hepatitis** An infection of the liver, usually caused by a virus. Two main types, called hepatitis B and hepatitis C, can be passed on by blood contact. This means that dialysis patients, especially those on haemodialysis, have an increased risk of getting these infections. Care is taken to reduce this risk, and regular virus checks are made on all kidney patients.

**HIV** Human immunodeficiency virus, the virus that causes AIDS. Tests for this virus are carried out before a patient can have a transplant. This is because HIV may be present and inactive in the patient’s body but can be activated by the transplant and immuno-suppressant drugs, and cause illness.

**Home haemodialysis** Treatment on a dialysis machine installed in a patient’s own home. For home haemodialysis to be considered, the patient must have a partner or friend who is able to supervise every dialysis session.

**Hormones** Substances that act as chemical messengers in the body. They are produced in parts of the body called endocrine glands. Hormones travel around the body in the blood, and control how other parts of the body work. For example, parathyroid hormone from the parathyroid glands in the neck affects kidney function.

**Hyperparathyroidism** A disorder in which the parathyroid glands make too much parathyroid hormone.

**Immune system** The body’s natural defence system. It includes organs (such as the spleen and appendix), lymph nodes (including the ‘glands’ in the neck) and specialist white blood cells called lymphocytes. The immune system protects the body from infections, foreign bodies and cancer. To prevent rejection of a transplant kidney, it is necessary for patients to take immuno-suppressant drugs.

**Immuno-suppressant drugs** A group of drugs used to dampen down the immune system to prevent rejection of a transplant kidney. Commonly used examples are cyclosporin, azathioprine and prednisolone. Tacrolimus (FK506) and mycophenolate are newer examples.

**Intravenous pyelogram (IVP)** A special X-ray of the kidneys. A dye that shows up on X-rays is used to show the drainage system of the kidneys. The dye is injected into the patient’s arm, travels in the blood to the kidneys, and is passed from the body in the urine.

**Iron** A substance that is necessary to prevent anaemia. A low blood ferritin indicates low levels of iron in the body.

**IVP** Abbreviation for intravenous pyelogram.

**Kidneys** The two bean-shaped body organs where urine is made.

They are located at the back of the body, below the ribs. The two main functions of the kidneys are to remove toxic wastes and to remove excess water from the body. The kidneys also help to control blood pressure, help to control the manufacture of red blood cells, and help to keep the bones strong and healthy.

**Kidney biopsy** Removal of a small piece of kidney through a hollow needle for examination under a microscope. It is needed to diagnose some causes of kidney failure, including nephritis. It is also used to check whether a transplanted kidney is being rejected.

**Kidney donor** A person who gives a kidney for transplantation.
Kidney failure A condition in which the kidneys are less able than normal to perform their functions of removing toxic wastes, removing excess water, helping to control blood pressure, helping to control red blood cell manufacture and helping to keep the bones strong and healthy. Kidney failure can be acute or chronic. Advanced chronic kidney failure is called end-stage renal failure.

Kidney machine Another name for a dialysis machine.

Kidney transplant An alternative name for a transplant kidney, or for the transplant operation during which a new kidney is given to the recipient.

LFTs Abbreviation for liver function tests.

Line infection A term for an infection of a haemodialysis catheter (or line).

Lipids Another name for fats. People with kidney failure tend to have raised lipid levels in the blood.

Liver function tests (LFTs) Blood tests that show how well the liver is working. They often appear at the bottom of the biochemistry blood test results. Some people with kidney failure also have liver problems.

Living related transplant (LRT) A transplant kidney donated (given) by a living relative of the recipient. A well-matched living related transplant is likely to last longer than either a living unrelated transplant or a cadaveric transplant.

Living unrelated transplant (LURT) A kidney transplant from a living person who is biologically unrelated to the recipient (such as a husband or wife).

LRT Abbreviation for a living related transplant.

LURT Abbreviation for a living unrelated transplant.

Lymphocytes Specialist white blood cells that form part of the immune system.

Malnutrition Loss of body weight, usually due to not eating enough (especially foods providing protein and energy). Malnutrition is the major nutritional problem of dialysis patients.

Marker A substance that is known to occur in the presence of another substance. Both creatinine and urea are markers for many less easily measurable substances in the blood. The higher the blood levels of these marker substances, the higher also are the levels of harmful toxins in the blood.

Membrane A thin, skin-like layer, resembling a piece of ‘cling film’. The peritoneum is a natural membrane used as the dialysis membrane in peritoneal dialysis. In haemodialysis, the dialysis membrane is a plastic membrane inside the dialyser.

Methylprednisolone A strong version of prednisolone, a drug used to prevent or treat the rejection of a transplant kidney.

mmol/l Abbreviation for millimoles per litre. A unit used to measure the blood levels of many substances. Creatinine is measured in smaller units called micromoles per litre (µmol/l).

Molecule The smallest unit that a substance can be divided into without causing a change in the chemical nature of the substance.

MRI scan Abbreviation for magnetic resonance imaging scan, a scanning technique that uses magnetism, radiowaves and a computer to produce high-quality pictures of the body’s interior.

Mycophenolate A new immuno-suppressant drug. Sometimes used as an alternative to azathioprine.

Neph- Prefix meaning relating to the kidneys.

Nephrectomy An operation to remove a kidney from the body. A bilateral nephrectomy is an operation to remove both kidneys.

Nephritis A general term for inflammation of the kidneys. Also used as an abbreviation for glomerulonephritis. A kidney biopsy is needed to diagnose nephritis.

Nephrologist Another name for a kidney doctor.

Nephrology The study of the kidneys.

Non-heart-beating donor A donor whose heart is not beating after death, for example after having had a heart attack in casualty when resuscitation has failed. A few cadaveric kidneys come from this source.

Nuclear medicine scan Another name for a radio-isotope scan.

Obstructive nephropathy Blockage to the drainage system of the kidney, through which the urine passes.

Oedema An abnormal build-up of fluid, mainly water, in the body. People with kidney failure are prone to fluid overload, leading to oedema. The two most common places for water to collect in the body are around the ankles (ankle oedema) and in the lungs (pulmonary oedema).

OKT3 Abbreviation for orthoclone K T-cell receptor 3 antibody, a strong treatment for the rejection of a transplant.

Organ A part of the body that consists of different types of tissue, and that performs a particular function. Examples include the kidneys, heart and brain.

Osmosis The process by which water moves from a weaker to a stronger solution through tiny holes in a semi-permeable membrane. In peritoneal dialysis, it is osmosis that causes excess water to pass from the blood into the dialysis fluid.

Parathyroidectomy An operation to remove the parathyroid glands.

Parathyroid glands Four pea-sized glands near the thyroid gland at the front of the neck. They produce parathyroid hormone.

Parathyroid hormone (PTH) A hormone produced by the...
peritoneum, a natural membrane that lines the inside of the wall of the abdomen. The peritoneum provides the dialysis membrane for peritoneal dialysis. It has a large surface area, contains many tiny holes and has a good blood supply.

Peritoneal cavity Inflammation of the peritoneum, caused by an infection. People on peritoneal dialysis risk getting peritonitis if they touch the connection between their peritoneal dialysis catheter and the bags of dialysis fluid. Most attacks are easily treated with antibiotic drugs.

PET In this context, an abbreviation for the peritoneal equilibration test. (The abbreviation PET in PET scan is short for positron emission tomography.)

Phosphatase A measurement of the rate at which toxins pass out of the blood into the dialysis fluid during peritoneal dialysis (PD). Patients are described as ‘high transporters’ (if the toxins move quickly) and ‘low transporters’ (if the toxins move more slowly). The test is used to assess a patient’s suitability for different types of PD.

Phosphate A mineral that helps calcium to strengthen the bones. Phosphate is obtained from foods such as dairy products, nuts and meat. The kidneys normally help to keep the right amount of phosphate in the blood. In kidney failure, phosphate tends to build up in the blood. High phosphate levels occur with low calcium levels in people with renal bone disease.

Phosphate binders Tablets that help prevent a build-up of phosphate in the body. Phosphate binders combine with phosphate in food so that it passes it out of the body in the faeces. The most commonly used phosphate binders are calcium carbonate and aluminium hydroxide.

Plasma The liquid part of the blood in which the blood cells float.

Platelets A type of blood cell that helps the blood to clot.

Polycystic kidney disease (PCKD) An inherited disease (a disease that runs in families) in which both kidneys are full (‘poly-’ means ‘many’) of cysts (abnormal fluid-filled lumps). PCKD is one of the causes of kidney failure. It is diagnosed by an ultrasound scan.

Potassium A mineral that is normally present in the blood, and which is measured in the biochemistry blood test. Either too much or too little potassium can be dangerous, causing the heart to stop. People with kidney failure may need to restrict the amount of potassium in their diet.

Prednisolone A drug used to prevent the rejection of a transplant kidney.

Proteins Chemical components of the body, formed from amino acids. The body needs supplies of protein in the diet to build muscles and to repair itself.

PTH Abbreviation for parathyroid hormone.

Pulmonary oedema A serious condition in which fluid builds up in the lungs, causing breathlessness. People with kidney failure develop pulmonary oedema if fluid overload is not treated promptly.

Pyelonephritis Inflammation of the drainage system of the kidneys, one of the causes of kidney failure. It can be diagnosed by an ultrasound scan or by an intravenous pyelogram.

Radio-isotope scan A method of obtaining pictures of the body’s interior, also called a radio-nuclide scan or nuclear medicine scan. A small amount of a mildly radioactive substance is either swallowed or injected into the bloodstream. The substance gathers in certain parts of the body, which then show up on pictures taken by a special machine.

Radio-nuclide scan Another name for a radio-isotope scan.

Recipient In the context of transplantation, a person who receives an organ from another person (the donor).

Red blood cells Cells in the blood which carry oxygen from the lungs around the body.

Reflux The movement of a liquid, such as urine, in the opposite direction to normal. The word ‘reflux’ is sometimes used to mean reflux nephropathy.
Reflux nephropathy  A condition in which urine passes back up from the bladder, through the ureters, to the kidneys, where it can cause infections. It occurs because a valve that normally prevents the backflow of urine from the bladder is faulty. Reflux nephropathy is one of the causes of kidney failure.

Rejection  The process by which a patient’s immune system recognises a transplant kidney (or other transplanted organ) as not its own, and then tries to destroy it and remove it from the body. Rejection can be acute or chronic.

Renal  Adjective meaning relating to the kidneys.

Renal bone disease  A complication of kidney failure, in which bone health is affected by abnormally low blood levels of calcium and vitamin D, and high levels of phosphate. Without treatment, renal bone disease can result in bone pain and fractures.

Renal unit  A hospital department that treats disorders of the kidneys.

Renovascular disease  Atheroma affecting the blood vessels that supply the kidneys (‘reno-’ means relating to the kidney, and ‘-vascular’ means relating to the blood vessels). Renovascular disease is a common cause of kidney failure in older patients.

Residual renal function (RRF)  The amount of kidney function that a patient with kidney failure has. This varies from patient to patient. It is likely the RRF will reduce over a period of time, and in many patients, it eventually disappears altogether. A creatinine clearance test is used to assess RRF.

Rifampicin  An antibiotic drug used to treat long-term exit site infections of peritoneal dialysis catheters.

Rigors  Cold shivers that sometimes occur with a fever. They can be a symptom of an infected haemodialysis catheter.

RRF  Abbreviation for residual renal function.

Satellite haemodialysis unit  A place where some patients go for haemodialysis away from the main hospital renal unit. Satellite units have relatively few nurses, and are suitable only for healthy patients, who do some of the haemodialysis preparation themselves. These units tend to be more easily accessible to patients than most main hospital buildings.

Scan  One of several techniques for obtaining pictures of the body’s interior without using conventional X-rays. Examples include CT scans, MRI scans, radio-isotope scans and ultrasound scans.

Semi-permeable  An adjective, often used to describe a membrane, meaning that it will allow some but not all substances to pass through it. Substances with smaller molecules will pass through the holes in the membrane, whereas substances with larger molecules will not.

Sodium  A mineral that is normally present in the blood, and which is measured in the biochemistry blood test. Sodium levels are not usually a problem for people with kidney failure and are quite easily controlled by dialysis.

Sphygmomanometer  The instrument used to measure blood pressure.

Staphylococcus  One of a group of bacteria responsible for various infections (often called ‘staph’ infections). A common cause of peritonitis in patients on peritoneal dialysis, and of line infections in haemodialysis patients.

Systolic blood pressure  A blood pressure reading taken when the heart squeezes as it beats. The systolic blood pressure is measured before the diastolic blood pressure and is the first figure in a blood pressure measurement.

Tacrolimus  A new immuno-suppressant drug, also known as FK506, which is an alternative to cyclosporin.

Tissue  A collection of similar cells that share a similar function, such as skin cells or kidney cells.

Tissue type  A set of inherited characteristics on the surface of cells. Each person’s tissue type has six components (three from each parent). Although there are only three main sorts of tissue type characteristic (called A, B and DR), each of these comes in 20 or more different versions. Given the large number of possibilities, it is unusual for there to be an exact tissue type match between a transplant kidney and its recipient. However, the more characteristics that match, the more likely a transplant is to succeed.

Tissue typing  A blood test that identifies a person’s tissue type.

Toxins  Poisons. One of the main functions of the kidneys is to remove toxins from the blood (a process known as clearance).

Transplant  A term used to mean either a transplant kidney (or other transplant organ) or a transplant operation.

Transplantation  The replacement of an organ in the body by another person’s organ. Many different organs can now be successfully transplanted, including the kidneys, liver, bowel, heart, lungs, pancreas, skin and bones.

Transplant kidney  A kidney removed from one person (the donor) and given to another person (the recipient). Transplant kidneys may be either cadaveric transplants, living related transplants or living unrelated transplants.

Transplant operation  The surgical operation by which a patient is given a donated organ. The operation to insert a transplant kidney takes about 2–3 hours. The new kidney is placed lower in the abdomen than the patient’s own kidneys, which are...
usually left in place. **Blood vessels** attached to the transplant kidney are connected to the patient’s blood supply, and the new kidney’s **ureter** is connected to the patient’s **bladder**.

**Transplant waiting list** A system that seeks to find the ‘right’ transplant organ for the ‘right’ patient. It is co-ordinated nationally by **UKT**, whose computer compares patients’ details (including **blood group** and **tissue type**) with those of cadaveric organs that become available. The average waiting time for a **transplant kidney** is about 2 years.

**Tunnel infection** A possible problem for patients on **peritoneal dialysis** (PD). It occurs when an infection spreads from the exit site into the ‘tunnel’ (i.e. the route of the PD catheter through the abdominal wall).

**UKT** Abbreviation for United Kingdom Transplant, based in Bristol. This is the national co-ordinator for **cadaveric transplants** in the UK.

**ULTRA** Abbreviation for Unrelated Living Transplantation Regulatory Authority. This government body must give approval to all **living unrelated transplants**.

**Ultrafiltration** The removal of excess water from the body. Ultrafiltration is one of the two main functions of the **kidneys**. In **kidney failure**, problems with ultrafiltration result in **fluid overload**. **Dialysis** provides an alternative means of ultrafiltration.

**Ultrasound scan** A method of obtaining pictures of internal organs, such as the **kidneys**, or of an unborn baby, using sound waves. A device that sends out sound waves is held against the body. The sound waves produce echoes, which the scanner detects and builds up into pictures.

**Under-dialysis** Not having enough **dialysis**. If a dialysis patient does not achieve target blood levels for **creatinine**, the symptoms of **kidney failure** are likely to return. The amount of dialysis will then have to be increased.

**Urea** A substance made by the liver. It is one of the waste products from food that builds up in the blood when someone has **kidney failure**. Like **creatinine**, urea is a marker for other more harmful substances. The higher the urea level, the worse is the kidney failure.

**Ureters** The tubes that take **urine** from the **kidneys** to the **bladder**.

**Urethra** The body’s tube that takes **urine** from the **bladder** to the outside of the body.

**Urinary catheter** A plastic tube inserted into the **bladder** for the removal of **urine**.

**Urine** The liquid produced by the **kidneys**, consisting of the toxic waste products of food and the excess water from the blood.

**Vancomycin** An **antibiotic drug**, commonly used to treat **peritonitis**, long-term **exit site** infections (of **peritoneal dialysis** catheters) and line (**haemodialysis catheter**) infections.

**Vasodilator drugs** Tablets that lower the **blood pressure** by making the **blood vessels** wider, so that the blood can flow through them more easily.

**Veins** **Blood vessels** which carry blood from the body back to the heart.

**Virus** A type of germ responsible for a range of mild and serious illnesses. Viruses are much smaller than **bacteria** and usually reproduce inside the cells of other living organisms.

**Vitamin D** A chemical that helps the body to absorb **calcium** from the diet. Blood levels of vitamin D are usually low in people with **kidney failure**.

**Water tablets** The common name for **diuretic drugs**.

**White blood cells** **Cells** in the blood that normally help to fight infection. They are part of the **immune system**. After a **kidney** transplant, they can be a ‘bad thing’, as they may attack (reject) the new kidney.

**Xenotransplantation** The transplanting of tissues or organs from one type of animal into a human or other type of animal.
Stewart Cameron, *History of the Treatment of Kidney Failure by Dialysis*. Oxford University Press.
Lawrence Keogh and Rashmi Soni, *Food for Life*. Class Publishing.
Hannah McGee and Clare Bradley, *Quality of Life Following Renal Failure*. Harwood Academic.

Peter Sonksen, Charles Fox and Sue Judd, *Diabetes—the ‘at your fingertips’ guide*. Class Publishing.
Please note that addresses change from time to time.

Access to Communication and Technology
Oak Tree Lane Centre
Oak Tree Lane
Selly Oak
Birmingham B29 6JA
Tel: 0121 627 8235
Fax: 0121 627 8210
NHS centre offering a wide range of services throughout the UK to assist people of any age with disabilities, including assessment and rehabilitation, home equipment loan service, artificial limbs, electrical appliances and training by professionals.

Action on Smoking and Health (ASH)
102 Clifton Street
London EC2A 4HW
Tel: 020 7739 5902
Fax: 020 7613 0531
Helpline: 0800 169 0169
Website: www.ash.org.uk
Information on how smoking affects medical conditions.

Age Concern England
Astral House
1268 London Road
London SW16 4ER
Tel: 020 8679 8000
Fax: 020 8766 7211
Helpline: 0800 009 966
Website: www.ace.org.uk
Researches into the needs of older people, and is involved in policy making. Publishes many books, has useful fact sheets on a wide range of issues from benefits to care, and provides services via local branches.

British Association for Counselling
1 Regent Place
Rugby
Warwickshire CV21 2PJ
Tel: 08788 550 899
Fax: 0870 443 5161
Website: www.counselling.co.uk
Send s.a.e. for information about counselling services in your area, and publications list.

British Kidney Patient Association
Bordon
Hampshire GU35 9JZ
Tel: 01420 472 021
Fax: 01420 475 831
Website: www.bkpa.org.uk
Provides information and advice to people with kidney illnesses throughout the UK. Grants available.

Cancerlink
Macmillan Cancer Relief
89 Albert Embankment
London SE1 7UQ
Tel: 020 7840 7840
Fax: 020 7840 7841
Helpline: 0808 808 0000
Website: www.cancerlink.org
Helps cancer patients, families and carers with practical and emotional support.

Carers’ National Association
20–25 Glasshouse Yard
London EC1A 4JT
Tel: 020 7490 8818
Fax: 020 7490 8824
Helpline: 0808 808 7777
Website: www.carers.demon.co.uk
Offers information and support to all people who have to care for others due to medical or other problems.

Carers Scotland
91 Mitchell Street
Glasgow G1 3LN
Tel: 0141 221 9141
Fax: 0141 221 9140
Helpline: 0808 808 7777
Offers information and support to all people in Scotland who have to care for others due to medical or other problems.
Crossroads Association
10 Regent Place
Rugby
Warwickshire CV21 2PN
Tel: 01788 573 653
Fax: 01788 565 498
Website: www.crossroads.org.uk
Supports and delivers high-quality services for carers and people with care needs via its local branches.

Crossroads Scotland Care
Attendant Schemes
24 George Square
Glasgow G2 1EG
Tel: 0141 226 3793
Fax: 0141 221 7130
Website: www.crossroadsscot.fsnet.co.uk
Information leaflets and support for carers within their own homes; for patients of any age, whatever their disability or illness.

Cruse
126 Sheen Road
Richmond
Surrey TW9 1UR
Tel: 020 8940 4818
Fax: 020 8940 7638
Helpline: 0870 167 1677
Website: www.crusebereavementcare.org.uk
Offers information on bereavement, sells literature and has local branches which can provide one-to-one counselling.

Department of Health
Richmond House
79 Whitehall
London SW1A 2NS
Tel: 020 7210 4850
Website: www.open.gov.uk/doh/dhhome.htm
Government department involved with policy making and health service issues.

Department of Work and Pensions
Disability Benefit Centre
Olympic House
Olympic Way
Wembley
Middlesex HA9 0DL
Tel: 020 8795 8400
Helpline: 0800 88 22 00
Government information service offering advice on benefits for people with disabilities, and their carers.

Depression Alliance
35 Westminster Bridge Road
London SE1 7JB
Tel: 020 7633 9929
Fax: 020 7633 0559
Website: www.depressionalliance.org
Offers support and understanding to anyone affected by depression, and relatives who want help. Has a network of self-help groups, correspondence schemes and a range of literature. Send s.a.e. for information.

Diabetes UK
10 Queen Anne Street
London W1G 9LH
Tel: 020 7323 1531
Fax: 020 7637 3644
Helpline: 020 7636 6112
Website: www.diabetes.org.uk
Provides advice and information on diabetes; has local support groups.

Disability Scotland
Princes House
5 Shandwick Place
Edinburgh EH2 4RG
Tel: 0131 339 8632
Fax: 0131 339 5168
Website: www.dis-scot.gcal.ac.uk

Disability Wales/Anabledd Cymru
Llys Ilfor
Crescent Road
Caerphilly
Mid Glamorgan CF83 1XL
Tel: 029 2088 7325
Fax: 029 2088 8702
e-mail: info@dwac.demon.co.uk

Disabled Living Foundation
380–384 Harrow Road
London W9 2HU
Tel: 020 7289 6111
Fax: 020 7266 2922
Helpline: 0845 130 9177
Website: dlf.org.uk
Provides information on all kinds of equipment for people with special needs.
**DVLA (Drivers and Vehicles Licensing Authority)**  
Medical Branch  
Longview Road  
Morrison  
Swansea SA99 1TU  
Tel: 01792 772151  
Fax: 01792 783779  
Helpline: 0870 6000 301  
Website: www.dvla.gov.uk  
*Government office providing advice for drivers with special needs.*

**Employment Opportunities for People with Disabilities**  
123 Minories  
London EC3N 1NT  
Tel: 020 7481 2727  
Fax: 020 7481 9797  
Website: www.opportunities.org.uk

**Eurodial**  
Website: www.eurodial.org  
*The international dialysis organisation dedicated to the care and mobility of dialysis patients in Europe.*

**Free Prescriptions Advice Line**  
Tel: 0800 9177 711  
(Mon–Fri 8am–6pm;  
Sat & Sun 10am–4pm)  
*Advice on entitlement to free prescriptions, dental and optical care.*

**Globaldialysis**  
Website: www.globaldialysis.com  
*Gives details of holidays and travel information for dialysis patients.*

**Holiday Care**  
Imperial Buildings, 2nd Floor  
Victoria Road  
Horley  
Surrey RH6 7PZ  
Tel: 01293 774 535  
Fax: 01293 784 647  
*Information and advice about holidays, travel or respite care for older or disabled people, and their carers.*

**Impotence Association**  
P O Box 10296  
London SW17 9WH  
Website: www.impotence.org.uk  
*Offers help and advice on sexual problems.*

**Kidney Cancer UK**  
11 Hathaway Road  
Tile Hill Village  
Coventry CV4 9HW  
Tel: 02476 470 584  
Fax: 02476 470 584  
Website: kcuk.org  
*Information and support for people with kidney cancer and their carers. Chat room available via the website.*

**Kidney Patient Information Websites**  
Website: www.kidneydirections.com  
*Information for kidney patients and suggestions for ways to plan treatment.*  
www.kidneypatientguide.org.uk  
*Information for patients with kidney failure, and those who care for them.*  
http://www.kidnelywise.com  
*Advice and support for those affected by kidney failure.*

**Medic-Alert Foundation**  
1 Bridge Wharf  
156 Caledonian Road  
London N1 9UU  
Tel: 020 7833 3034  
Fax: 020 2213 5653  
e-mail: info@medicalert.co.uk  
*Offers selection of jewellery with internationally recognised medical symbol: 24-hour emergency phoneline.*

**MIND (National Association for Mental Health)**  
Granta House  
15–19 Broadway  
Stratford  
London E15 4BQ  
Tel: 020 8519 2122  
Fax: 020 8522 1725  
Helpline: 0845 766 0163  
Website: www.mind.org.uk  
*Mental health organisation working for a better life for everyone experiencing mental distress. Has information and offers support via local branches.*

**National Kidney Federation**  
6 Stanley Street  
Worksop  
Nottinghamshire S81 7HX  
Tel: 01909 487 795  
Fax: 01909 481 723  
Helpline: 0845 601 0209  
e-mail: nkf@kidney.org.uk  
*Aims to promote, throughout the UK, the welfare of people suffering from kidney disease or renal failure, and those relatives and friends who care for them.*
National Kidney Research Fund
King’s Chambers
Priestgate
Peterborough PE1 1FG
Tel: 01733 704 650
Fax: 01733 704 692
Helpline: 0845 300 1499
Website: www.nkrf.org.uk
e-mail: enquiries@nkrf.org.uk
Funds research into kidney disease, its causes and treatment. Works to raise awareness of kidney disease.

NHS Direct
Helpline: 0845 4647
Website: www.nhsdirect.nhs.uk
The gateway to health information.

NHS Organ Donor Information Service
Helpline: 0845 6060 400
Website: www.nhsorgandonor.net
Provides information about donating organs, and how patients can benefit from organ donation.

Patients Association
PO Box 935
Harrow
Middlesex HA1 3YJ
Tel: 020 8423 9111
Fax: 020 8423 9119
Helpline: 0845 608 4455
Website: www.patients-association.com
Provides advice on patients’ rights.

Registered Nursing Homes Association
Calthorpe House
Hagley Road
Edgbaston
Birmingham B16 8QY
Tel: 0121 454 2511
Fax: 0121 454 9032
Website: www.mha.co.uk
Information about registered nursing homes in your area.

Relate
Herbert Gray College
Little Church Street
Rugby
Warwickshire CV21 3AP
Tel: 01788 573 241
Fax: 01788 535 007
Helpline: 09069 123 715
Website: www.relate.org.uk

Renal Registry of the United Kingdom
Southmead Hospital
Southmead Road
Bristol BS10 5NB
Tel: 0117 959 5665
Fax: 0117 959 5664
Website: www.renalreg.com
Collects, analyses and presents data about the incidence, clinical management and outcome of renal disease.

SPOD
286 Camden Road
London N7 0BJ
Tel: 020 7607 8851
Fax: 020 7700 0236
Association to aid the sexual and personal relationships of disabled people.

UK Transplant
Communications Directorate
Fox Den Road
Stoke Gifford
Bristol BS34 8RR
Tel: 0117 975 7575
Fax: 0117 975 7577
Website: www.uktransplant.org.uk

United Kingdom Register of Counsellors
P O Box 1050
Rugby
Warwickshire CV21 2HZ
Tel: 0870 443 5232
Fax: 0870 443 5161
Part of British Association of Counselling and Psychotherapy Regulatory body which provides details of registered counsellors who offer safe and accountable practice.

Winged Fellowship Trust
Angel House
20/32 Pentonville Road
London N1 9XD
Tel: 020 7833 2594
Fax: 020 7278 0370
Website: wft.org.uk
Provides holidays and respite care for disabled people and their carers.
bilirubin 39, 42
calculator 38, 42
cholesterol 40, 42
creatinine 13, 36, 42
dialysable substances 35
ferritin 40, 42
and liver function 39–40, 42
parathyroid hormone 40–1, 42
phosphate 37, 42
potassium 36, 42
results, summary of normal and target 42
sodium 38, 42
and treating kidney failure 35
urea 13, 36–7
blood transfusions and anaemia 28
blood vessels 21, 133
bone
cross sections of 26
health 4, 42
marrow 26, 27, 133
pain
and renal bone disease 30
and dialysis amyloidosis 33
body image, problems with 56, 66–7, 102
BP see blood pressure
brain death 73, 133
breath, shortness of 5, 19, 26
British Kidney Patient Association 131, 141
bromocriptine 109
bruit 64
bumetanide 19

C

cabergoline 109
cadaveric transplants 73–4, 133
life of 78
Calcichew 32, 37, 70
calcium 133
blood test 33, 38, 42
and bone health 4
in the diet 30, 95
and renal bone disease 30–32
calcium antagonists 24
calcium carbonate tablets
after parathyroidectomy 33
and phosphate levels 32, 37, 97
cancer
and immuno-suppressant drugs 92
and survival with kidney failure 123, 124
and transplant suitability 79
candesartan 24
Candida albicans 57, 58, 133
CAPD (continuous ambulatory peritoneal
dialysis) 53, 54, 133
captopril 24
catheter 133
see also haemodialysis catheter;
PD catheter
children
survival chances of 122
cholesterol 133
and renovascular disease 6
blood tests 40, 42
chronic 133
clearance, toxin 2, 133
how it is measured 11–12
before dialysis 15
during dialysis 15–16
and peritoneal dialysis 49
types of test 12
blood 13–14, 42

clearance 14–16
why it is measured 11
CMV see cytomegalovirus (CMV)
concentration, poor 103
confidence, loss of 102
constipation and peritoneal dialysis 57
continuous ambulatory peritoneal
dialysis (CAPD) 53, 54, 133
coping with kidney failure
and diagnosis 101
factors affecting 103–5
strategies for 105
contraception 112, 115
creatinine 133
how and why it is measured 11–12, 36
production, normal 11–12
creatinine blood tests
before dialysis 13
during dialysis 14
normal and target levels 36, 42
and starting dialysis 7, 8, 13
after a transplant 14
creatinine clearance tests 14–15
normal level 15
target level 16
cross-match 75–6, 133
CT (computed tomography) scan 43, 133
cyclosporin 89, 90, 133
side effects 91
cysts, kidney see polycystic kidney disease
cytomegalovirus (CMV) 73, 92, 134

d
death
awareness of early 102
causes of 123–4
dehydration 19–20, 134
denial, after diagnosis 101
dependency 102
depression 102
diabetes mellitus (sugar diabetes)
and access 62
and blood glucose levels 38
causing kidney failure 6
and survival chances 123, 125
and haemodialysis problems 68
and prednisolone 91
and transplant suitability 79
and Viagra trials 108–9
diagnosis of kidney failure 5
reactions to 101
dialysate see dialysis fluid
dialyser (artificial kidney) 61, 134
and dialysis membrane 45–6
types of 60, 61
dialysis 45, 134
basic principle of 45, 46
cannot ‘cure’ kidney failure 1, 9
delaying 8, 24
how it works 45
fluid removal 47
waste removal 46–7
monitoring of see clearance, toxin;
   blood tests
starting 8
survival on 122–3
types 45, 48
see also haemodialysis; peritoneal
dialysis (PD)
dialysis amyloidosis 33
dialysis bags
delivery and storage 56
size and strength 38–9, 54
dialysis catheter see haemodialysis
catheter; PD catheter
dialysis fluid (dialysate) 134
cloudy 58
role of 45, 46–8
special types of 55
substances in 46–7
   alkali 37
   calcium 38
   glucose 38–9
   sodium 38
dialysis fluid exchange
   in APD 53
   in CAPD 53
   training patients to do 51–2
dialysis (kidney) machine 61, 134
   how it works 47, 61–2
dialysis membrane 45–6, 134
   see also peritoneum
diastolic blood pressure 22, 23, 134
diet
   and changing needs 94
   before and during dialysis 95
   healthy eating guidelines 94, 99
   individual requirements 98
   malnutrition 96
   ‘nutritional status’ 94–5
   after a transplant 99
   vitamin supplements 98
   see also calcium; fluid intake;
      phosphate; potassium; protein; salt
diffusion 134
   process of 46–7
   waste removal by 46
   and haemodialysis 61
   and peritoneal dialysis 50
diltiazem 24
diuretic drugs 19, 20, 134
dizziness
   during haemodialysis 67
   and dehydration 20
   and low blood pressure 23
donor 134
   dead see cadaveric transplants
   heart-beating 73–4, 135
   living see living related transplants; living
      unrelated transplants
Doppler scan 134
double J stent tube 85, 86
doxazosin 24
drainage problems in PD 55–6
drink see fluid intake
drugs
   immuno-suppressant 90
   iron tablets 29
   phosphate binders 32, 137
   vitamin supplements 98
   see also antibiotic drugs; beta-blocker
      drugs; steroid drugs; vasodilator drugs;
      individual drug names
E
ECG (electrocardiogram) 73, 80, 134
ECHO (echocardiogram) 73, 134
emotional problems see psychological
   aspects of kidney failure
enalapril 24
end-stage renal disease (ESRD) see
   end-stage renal failure (ESRF)
end-stage renal failure (ESRF) 134
   survival chances 122–4
   treatment 7–9
   unknown causes of 6
what is it? 4, 7
see also kidney failure (chronic)
EPO see erythropoietin (EPO)
ErecAid 109–10
erectile dysfunction (ED) 106
   see impotence
errection
   normal 106–7
   problems see impotence
erythropoietin (EPO) 27, 28, 134
erythropoietin (EPO) injections
   and anaemia 28–9
   poor response to 29
   side effects 29
   who needs? 28–9
ESRD see end-stage renal failure
ESRF see end-stage renal failure
exercise and peritoneal dialysis 55
exit site 134
infections
   in haemodialysis 68–9
   in peritoneal dialysis 57–8
F
facial swelling and steroids 91
facilities, renal 124–6, 128
fat
   blood levels, high 24
   in diet 94, 95
femoral line 62, 63
ferritin
   and EPO treatment 29
   blood test 40, 42
ferrous sulphate tablets 29
fertility, female 112
fever
   and acute rejection 89
   and haemodialysis 69
   and line infections 69
   and peritonitis 57
fibrin, blocking PD catheter 57
‘figures’ 35–42
fistula 134
   operation to create 63–4
   problems with 63–4, 68
fits 29
FK506 (tacrolimus) 89, 91, 134
flesh
and body fluid 17
and malnutrition 96
fluid balance
control of 18
and dehydration 19–20
\textit{treatment} for 20
and sodium 18, 38
and ‘target weight’ 18
what is it? 17
\textit{see also} fluid, body; fluid overload
fluid, body
and blood pressure 24
excess
and starting dialysis 8
build-up of see fluid overload
and flesh 17
measuring changes in 17
removal of excess
by dialysis 47
by kidneys (ultrafiltration) 3, 17, 18, 139
\textit{see also} fluid balance
fluid, dialysis see dialysis fluid (dialysate)
fluid exchange see dialysis fluid exchange
fluid intake
and dehydration 19–20
for haemodialysis patients 67, 98
for PD patients 98
restricting 98
fluid overload 18–9, 134
and blood pressure 24
and blood transfusions 28
and haemodialysis 67
and peritoneal dialysis 56
treatment 19
focal and segmental glomerulosclerosis (FSGS) 71, 83
follicle-stimulating hormone (FSH) 108
food see diet
fractures 4, 30
frusemide 19
\textbf{G}
gamma-glutamyltransferase (gammaGT)
blood test 40, 42
ganciclovir 92
glomerulonephritis (GN) 5, 135
and survival chances 123
glomerulus 3, 135
glucose (sugar) 135
blood test 38–9, 42
in dialysis fluid 47
glucose polymer, in Icodextrin 55
GN see glomerulonephritis
Goodpasture’s disease 71
grafts 64, 135
limited life of 68
gum hypertrophy 91
\textbf{H}
haemodialysis 135
access see access, haemodialysis
amount of 65
at home 66
effect on lifestyle 66–7
how it is done 60–62
how it works 45, 60–62
in hospital 65–6
problems with 67–9
satellite 66
single-needle 64–5
target blood creatinine levels in 14
urea and creatinine clearance targets 16
who is suitable for 48, 60
\textit{see also} dialysis (kidney) machine
haemodialysis catheter 135
and body image 66–7
and heparin 62, 68
lines, entry positions for 62, 64
operation 62–3
problems with 67–9
single-barrelled 64
haemodialysis unit 135
\textit{see} renal units
haemoglobin (Hb) 135
blood test
to diagnose anaemia 27, 29, 40

normal and target blood levels 28, 40
and EPO treatment 28–9
role of 26–7
haemolytic uraemic syndrome 71
healthy eating guidelines 94
heart
and blood circulation 21–2
and blood pressure 22
damaged
and survival chances 123
and transplant 92
heart attack, increased risk of 24, 123
Henoch-Schönlein purpura 71
heparin
and haemodialysis 62
and bleeding 68
and diabetics 68
and peritoneal dialysis 57
hepatitis 28, 79, 135
hernias and peritoneal dialysis 57
home haemodialysis 66, 135
hormones 135
and impotence 107
\textit{see also} parathyroid hormone
HIV 28, 79
hydralazine 24
hygiene, importance of 58, 63, 69
hyperkalaemia (excess potassium) 67–8
hyperparathyroidism 135
\textbf{I}
Icodextrin 55
IgA nephropathy 71
immune system 88, 135
suppression see immuno-suppressant
\textit{drugs}; steroid drugs
immuno-suppressant drugs 135
and cancer 92
and delaying dialysis 8
and infection 58, 92
peritonitis 57–8
and liver function 39
and rejection 88–9
impotence 106
causes 106–7
emotional problems 111
how it is investigated 107–8
treatment
  hormone injections 109
  penile implants 111
  penile injection therapy 110
  penile insertion therapy 110
  transurethral therapy 110
  vacuum devices 109–10
  Vi (sildenafil) 108–9
independence
  and EPO injections 28
  and haemodialysis 66
  importance of 105
  loss of, and sexual problems 107
  and peritoneal dialysis 48, 49, 51–2, 54, 55
infection
  and diet 96
  and EPO treatment 29
  and haemodialysis 68–9
  peritonitis 57–8
  after transplantation 92
  tunnel 58
  see also exit site infections; line infection
intravenous pyelogram (IVP) 41, 135
intravenous urogram (IVU) 41
irbesartan 24
iron
  blood test see ferritin
deficiency, and EPO treatment 28
tablets and injections 29, 40
itching 5, 31
IVP see intravenous pyelogram
IVU see intravenous urogram

J
jaundice 39
joints, problems with 33, 91
jugular line 62, 63

K
kidney 1, 3, 135
functions
  controlling blood pressure 4, 21
  keeping bones healthy 4, 30
  red blood cell manufacture 4, 26
  removing toxic wastes 2
  removing water 3, 17
  urine production 1, 2
location 2
  ‘small’ 6
structure 3
kidney, artificial see dialyser
kidney biopsy 41, 135
  and nephritis 5
  and rejection 89
kidney donor 135
  matching 72–3, 74–5, 80–1
kidney failure
  acute 4
  causes of 5–6
    and survival chances 122–3
  chronic 1, 4, 135
  diagnosis 5
  number of UK patients with 1
  progression of 7
  survival chances 122–3
  symptoms 5
  see also treatments for kidney failure
kidney filtering unit (nephron) 3
kidney machine see dialysis (kidney)
machine
kidney transplant 136
  see also transplantation; transplant
  kidney; transplant operation
kidney units see renal units

L
labetolol 24
leg cramps 5
legs, restless 5
LFTs see liver function tests
lifestyle changes 101, 103, 105
  and haemodialysis 66–7
  and peritoneal dialysis 55
line infection 68–9, 136
lisinopril 24
  liver
    and urea production 11, 36
problems 39, 91
liver function tests (LFTs) 39–40, 42, 136
living related transplants (LRTs) 78–80, 136
  national comparisons 127
living unrelated transplants (LURTs) 81, 136
  national comparisons 127
losartan 24
LRTs see living related transplants
lungs, excess fluid in see pulmonary oedema
lupus nephritis 71
LURTs see living unrelated transplants
luteinising hormone (LH) 108
lymphocytes 88, 136
lymphoma 93

M
malnutrition 94, 96, 136
marker 12, 136
mefruside 19
membrane, dialysis 45–6, 136
  see also peritoneum
membraneous nephropathy 71
menstrual periods 113
methyldopa 24
methylprednisolone 89, 136
metolazone 19
metoprolol 24, 107
micturating cystourethrogram 41
minoxidil 24
molecule 136
moxonidine 24
MRI (magnetic resonance imaging) scan 136
muscles and creatinine 11–12
MUSE (Medicated Urethral System for Erection) 110
mycophenolate 90
  side effects 91

N
National Service Framework 129–30
nephrectomy 136
nephritis 5, 136
  and delaying dialysis 8
  see also glomerulonephritis
nephrology 136
nephron 3
neutropenia and azathioprine 91
NHS funding 128–9
NHS Plan 129
nifedipine 24
non-compliance 101–2
NSF see National Service Framework
‘nutritional status’ 94–5
  and albumin blood test 39
obesity 95–6
oedema 136
  see also ankle oedema; fluid overload;
  pulmonary oedema
OKT3 (orthoclone K T-cell receptor 3)
  antibody 89, 136
osmosis 47, 136
osteodystrophy see renal bone disease
pancreas 38–9
parathyroid glands 136
  location of 31
  over-active 31
  removal of see parathyroidectomy
parathyroid hormone (PTH) 136
  blood test 31, 33, 40–1, 42
  and renal bone disease 31–2
parathyroidectomy 33, 34, 136
PCKD see polycystic kidney disease
PD see peritoneal dialysis
PD catheter 137
  blocked 56–7
  and body image 56, 102
  displaced 57
  and infections 57–8
  leaking 57
  operation to insert 51
  position inside body 51
  protecting in sports 55
  removing in peritonitis 58
penile implants 108, 111
penile injection therapy 108, 110
penile insertion therapy 108, 110
perindopril 24
periods and fertility 113
peripheral vascular disease 123
peritoneal cavity 50, 137
  and dialysis 50–51, 52
  position of 50
peritoneal dialysis (PD) 137
  effect on lifestyle 55
  how it is done 51
  how it works 50
  learning how to do 51–2
  problems with 56
  toxin clearance goals 14, 16
  types of 52–3
  CAPD or APD? 54
  who is suitable for? 49
peritoneal dialysis catheter see PD catheter
peritoneal dialysis fluid exchanges
  see dialysis bags; dialysis fluid (dialysate);
  dialysis fluid exchange
peritoneal equilibration test (PET) 43, 137
peritoneal function test (PFT) 43
peritoneum 50, 137
  as a dialysis membrane 46, 50
  infection of see peritonitis
  ‘wearing out’ 56
peritonitis 57–8, 137
  and EPO treatment 29
  and suitability for a transplant 58
PET see peritoneal equilibration test
PFT see peritoneal function test
phosphate 137
  blood levels
    normal 32, 37, 42
    target 32, 37, 42
  blood test 37, 42
  and diet 97
  sources 30
  and renal bone disease 30–1, 32
phosphate binders 32, 137
plasma 27, 137
platelets 27, 91, 137
poisons see toxins
polycystic kidney disease (PCKD) 5–6, 137
  and anaemia 28–9
  and survival chances 123
potassium 137
  blood test 36, 42
  and diet 97–8
  excess (hyperkalaemia) 67–8
prazosin 24
prednisolone
  and delaying dialysis 8
  and rejection 89, 90
  side effects 91–2, 99
pregnancy 113–14
prolactin 108
propranolol 24, 107
protein 137
  and creatinine 12
  in the diet 95
  loss and ACE inhibitors 8
  supplements 97
  and urea 11
psychological aspects of kidney failure
  how people cope 101–5
  coping strategies 105
  diagnosis, initial reactions to 101
  long-term problems 101–3
  stresses 100–1
  and sexual problems 107, 111
PTH see parathyroid hormone
pulmonary oedema 19, 20, 137
pyelonephritis 6, 137
radio-isotope scan 137
radio-nuclide scan 137
ramipril 24
red blood cells 27
  lack of see anaemia
  reduced lifespan of 27–8
  role of 4, 26–7
  see also haemoglobin (Hb)
reflux 6, 137
reflux nephropathy 6, 138
diet after 99
monitoring after
   and blood creatinine levels 14
   and measuring clearance 14–15
possible problems after
cancer 92
drug side effects 91–92
high cholesterol levels 99
infection 92
rejection see rejection, transplant
post-operative tubes 85–6
pregnancy after 113–14
procedures before
   ‘call-up’ for 75
cross-match 75
dialysis 71
physical examination 75
sex after 86
transplant waiting list 74–5, 138
transporters, high and low 54
  and peritoneal equilibration test 43
transurethral therapy 110
treatments for kidney failure
  changes in 102
cannot ‘cure’ 1, 9
  shortfall in UK renal services 128–9
  and survival chances 122–3
see also haemodialysis; peritoneal
dialysis; transplantation; transplant
kidney; transplant operation
tunnel infection 58, 139

U
UKM (urea kinetic modelling) 15
UKT 74, 139
ULTRA 81, 82, 139
ultrafiltration 139
   in dialysis 39, 47, 61
   in healthy kidneys 3
ultrasound scan 43, 139
   and kidney donation 80

and polycystic disease (PCKD) 5
and pyelonephritis 6
after transplantation 89
and unknown causes of kidney failure 6
under-dialysis 14, 139
and appetite loss 96
and EPO treatment 29
unit haemodialysis 65–6
urea 11, 95, 139
   blood tests 13, 36–7
   normal and target levels 42
   clearance tests 15–16
   reasons for measuring 12, 36–7
urea kinetic modelling 15
urea reduction ratio 65
ureters 1, 2, 139
   blocked 89
urethra 1, 2, 139
urinary catheter 139
urinary system 1, 2
   location 2
urine 139
   and fluid loss 18
functions 2–3
production
   and fluid intake in dialysis patients 98
   in kidney failure 2, 3, 18
   normal 1, 3, 18
   after transplantation 86

V
vacuum devices 108, 109–10
vancomycin 58, 139
vasodilator drugs 24, 139
veins 21, 22, 139
   and fistulas see fistula
and haemodialysis catheter lines 62–3
Viagra (sildenafil) 108–9
virus 139
   infection and blood transfusions 28
tests before transplantation 73

vision problems and haemodialysis 67, 68
vitamin D 139
   and renal bone disease 30, 31, 33
dietary sources 31
see also alfacalcidol
vitamin supplements 98

W
waste removal
   by healthy kidneys 2–3
   in dialysis 46–7
see also clearance, toxin
water (body fluid) see fluid, body
water loss 18
water tablets see diuretic drugs
weak, feeling
   and anaemia 26, 29
   and dehydration 19–20
   symptom of kidney failure 5
weight
   and amount of haemodialysis 65
   and amount of peritoneal dialysis 54
   and monitoring dialysis 16
   and ‘nutritional status’ 94
   ‘target’ 18
weight gain
   and glucose 39
   and steroid drugs 99
weight loss and malnutrition 96, 99
white blood cells 27, 88, 139
   and azathioprine 91
work
   difficulties with 101, 103, 104
   and haemodialysis 66
   and peritoneal dialysis 55
   and transplantation 86

X
xenotransplantation 74, 139
X-rays 41, 43, 80
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