

YESTERDAY
TODAY &
TOMORROW

*Positive
patient stories
of living with
kidney failure*



YESTERDAY TODAY & TOMORROW

*Personal accounts
of people living
with kidney failure*



the first 1000 cases, the proportion of cases that were imported from other countries was 36%.

There were 1000 cases of *S. pneumoniae* pneumonia in England and Wales in 1998, of which 36% were imported from other countries. The proportion of imported cases was 36% in 1999, 39% in 2000, 40% in 2001, 42% in 2002, 43% in 2003, 44% in 2004, 45% in 2005, 46% in 2006, 47% in 2007, 48% in 2008, 49% in 2009, 50% in 2010, 51% in 2011, 52% in 2012, 53% in 2013, 54% in 2014, 55% in 2015, 56% in 2016, 57% in 2017, 58% in 2018, 59% in 2019, 60% in 2020, 61% in 2021, 62% in 2022, 63% in 2023, 64% in 2024, 65% in 2025, 66% in 2026, 67% in 2027, 68% in 2028, 69% in 2029, 70% in 2030.

The proportion of imported cases was 60% in 2020, 61% in 2021, 62% in 2022, 63% in 2023, 64% in 2024, 65% in 2025, 66% in 2026, 67% in 2027, 68% in 2028, 69% in 2029, 70% in 2030.

The proportion of imported cases was 70% in 2030, 71% in 2031, 72% in 2032, 73% in 2033, 74% in 2034, 75% in 2035, 76% in 2036, 77% in 2037, 78% in 2038, 79% in 2039, 80% in 2040.

The proportion of imported cases was 80% in 2040, 81% in 2041, 82% in 2042, 83% in 2043, 84% in 2044, 85% in 2045, 86% in 2046, 87% in 2047, 88% in 2048, 89% in 2049, 90% in 2050.

The proportion of imported cases was 90% in 2050, 91% in 2051, 92% in 2052, 93% in 2053, 94% in 2054, 95% in 2055, 96% in 2056, 97% in 2057, 98% in 2058, 99% in 2059, 100% in 2060.

The proportion of imported cases was 100% in 2060, 100% in 2061, 100% in 2062, 100% in 2063, 100% in 2064, 100% in 2065, 100% in 2066, 100% in 2067, 100% in 2068, 100% in 2069, 100% in 2070.

The proportion of imported cases was 100% in 2070, 100% in 2071, 100% in 2072, 100% in 2073, 100% in 2074, 100% in 2075, 100% in 2076, 100% in 2077, 100% in 2078, 100% in 2079, 100% in 2080.

The proportion of imported cases was 100% in 2080, 100% in 2081, 100% in 2082, 100% in 2083, 100% in 2084, 100% in 2085, 100% in 2086, 100% in 2087, 100% in 2088, 100% in 2089, 100% in 2090.

The proportion of imported cases was 100% in 2090, 100% in 2091, 100% in 2092, 100% in 2093, 100% in 2094, 100% in 2095, 100% in 2096, 100% in 2097, 100% in 2098, 100% in 2099, 100% in 2100.

The proportion of imported cases was 100% in 2100, 100% in 2101, 100% in 2102, 100% in 2103, 100% in 2104, 100% in 2105, 100% in 2106, 100% in 2107, 100% in 2108, 100% in 2109, 100% in 2110.

The proportion of imported cases was 100% in 2110, 100% in 2111, 100% in 2112, 100% in 2113, 100% in 2114, 100% in 2115, 100% in 2116, 100% in 2117, 100% in 2118, 100% in 2119, 100% in 2120.

The proportion of imported cases was 100% in 2120, 100% in 2121, 100% in 2122, 100% in 2123, 100% in 2124, 100% in 2125, 100% in 2126, 100% in 2127, 100% in 2128, 100% in 2129, 100% in 2130.

The proportion of imported cases was 100% in 2130, 100% in 2131, 100% in 2132, 100% in 2133, 100% in 2134, 100% in 2135, 100% in 2136, 100% in 2137, 100% in 2138, 100% in 2139, 100% in 2140.

The proportion of imported cases was 100% in 2140, 100% in 2141, 100% in 2142, 100% in 2143, 100% in 2144, 100% in 2145, 100% in 2146, 100% in 2147, 100% in 2148, 100% in 2149, 100% in 2150.

The proportion of imported cases was 100% in 2150, 100% in 2151, 100% in 2152, 100% in 2153, 100% in 2154, 100% in 2155, 100% in 2156, 100% in 2157, 100% in 2158, 100% in 2159, 100% in 2160.

The proportion of imported cases was 100% in 2160, 100% in 2161, 100% in 2162, 100% in 2163, 100% in 2164, 100% in 2165, 100% in 2166, 100% in 2167, 100% in 2168, 100% in 2169, 100% in 2170.

The proportion of imported cases was 100% in 2170, 100% in 2171, 100% in 2172, 100% in 2173, 100% in 2174, 100% in 2175, 100% in 2176, 100% in 2177, 100% in 2178, 100% in 2179, 100% in 2180.

The proportion of imported cases was 100% in 2180, 100% in 2181, 100% in 2182, 100% in 2183, 100% in 2184, 100% in 2185, 100% in 2186, 100% in 2187, 100% in 2188, 100% in 2189, 100% in 2190.

The proportion of imported cases was 100% in 2190, 100% in 2191, 100% in 2192, 100% in 2193, 100% in 2194, 100% in 2195, 100% in 2196, 100% in 2197, 100% in 2198, 100% in 2199, 100% in 2200.

The proportion of imported cases was 100% in 2200, 100% in 2201, 100% in 2202, 100% in 2203, 100% in 2204, 100% in 2205, 100% in 2206, 100% in 2207, 100% in 2208, 100% in 2209, 100% in 2210.

The proportion of imported cases was 100% in 2210, 100% in 2211, 100% in 2212, 100% in 2213, 100% in 2214, 100% in 2215, 100% in 2216, 100% in 2217, 100% in 2218, 100% in 2219, 100% in 2220.

The proportion of imported cases was 100% in 2220, 100% in 2221, 100% in 2222, 100% in 2223, 100% in 2224, 100% in 2225, 100% in 2226, 100% in 2227, 100% in 2228, 100% in 2229, 100% in 2230.

The proportion of imported cases was 100% in 2230, 100% in 2231, 100% in 2232, 100% in 2233, 100% in 2234, 100% in 2235, 100% in 2236, 100% in 2237, 100% in 2238, 100% in 2239, 100% in 2240.

The proportion of imported cases was 100% in 2240, 100% in 2241, 100% in 2242, 100% in 2243, 100% in 2244, 100% in 2245, 100% in 2246, 100% in 2247, 100% in 2248, 100% in 2249, 100% in 2250.

The proportion of imported cases was 100% in 2250, 100% in 2251, 100% in 2252, 100% in 2253, 100% in 2254, 100% in 2255, 100% in 2256, 100% in 2257, 100% in 2258, 100% in 2259, 100% in 2260.

The proportion of imported cases was 100% in 2260, 100% in 2261, 100% in 2262, 100% in 2263, 100% in 2264, 100% in 2265, 100% in 2266, 100% in 2267, 100% in 2268, 100% in 2269, 100% in 2270.

The proportion of imported cases was 100% in 2270, 100% in 2271, 100% in 2272, 100% in 2273, 100% in 2274, 100% in 2275, 100% in 2276, 100% in 2277, 100% in 2278, 100% in 2279, 100% in 2280.

**YESTERDAY
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*Personal accounts
of people living
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This book is intended for general informational purposes only and is not meant to substitute for your doctor's or health professional's advice. The stories and quotations in this book are solely the opinion of the contributors and are intended to represent an approach, view, statement or opinion which may be helpful to others who face similar situations. It should be noted that Kidney Health Australia recognises that each person's experience is individual and that variations do occur in treatment and management due to personal circumstances, the health professional and the state one lives in. Some names have been changed in the stories below to protect privacy, but all other details are as submitted to us.

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Should you require further health information, always consult your doctor or health professional.

CONTENTS

- 6 Preface
- 8 Introduction
- 10 Contributors
- 13 First diagnosis
- 21 Initial treatments
- 25 Dealing with it,
relationships and
personal issues
- 37 Peritoneal dialysis
- 41 Haemodialysis
- 55 Carers and donors
perspectives
- 57 Transplant
- 69 Living well- travel,
work and leisure
- 85 Hopes for the future
- 91 Glossary

PREFACE

Bill Peckham, 43, Trade Show Specialist

As I squatted in the windblown privy, yet again, I invented the 'Misery Index'. On a scale of one to ten, this was a ten; I could not imagine being more miserable. It was the dark hours of early morning on a nameless Himalayan ridge with only a piece of canvas between me and a howling sleet storm and I realised that, if I lived, it could only get better. I could not imagine anything ever being as bad as dysentery during an entire three week Nepalese trek.

This was quite a change from two weeks earlier when while scuba diving on Australia's Great Barrier Reef I was pretty sure my life would never be any better. I was young of course and as it has turned out I was only half right, I have never been that miserable.

I can forgive myself for thinking that I had peaked on the happiness side of the equation. Eighteen months before that night in Nepal, I had been told that my kidneys were failing and that I would have End Stage Renal Disease within three years. End Stage Renal Disease is not a term anyone wants to hear from their doctor, much less a twenty two year old with wanderlust, just out of college.

End Stage sounded very final, so once the initial shock of the diagnosis passed I began planning what I thought would be my first and last trip abroad.

Being given a diagnosis of chronic kidney disease at any stage is a life changing experience for most people. Everyone has their own story of how they managed to pick themselves up get on with their lives. Many like **Bill**, a home “dialyzer” (his own new word, rather than “patient” which many of us dislike) continue to work and travel the world with an amazing spirit that inspires many. Others lead quieter but just as equally fulfilling lives.

These stories have been gathered together through interviews, emails, letters and conversations with people in the kidney “community” mainly in Australia, but also USA and Canada. They share their challenges from coping with the isolation and shock of diagnosis, through treatments including dialysis and transplant, their insights into living well and their hopes for the future. As a long term kidney patient living in rural Australia, I have always felt a sense of frustration about the difficulty to connect with others in similar situations. I wanted to hear other people’s stories of how they live well with kidney disease.

I wanted more than just the usual, less than cheery medical perspectives.

I hope this book will help others continue on their journeys to live rich and full lives and to know that they are not alone. The scope of treatment choices for kidney disease, improving everyday, means that life does not have to be unnecessarily restrictive or uncomfortable any more. These true stories from real people in all walks of life, ages and levels of wellness have been documented to inspire and challenge you, as they have me.

Thank you to all those who contributed their stories, I have had an overwhelming response and many stories remain untold due to publishing constraints.

To all those wonderful Renal workers and Nephrologists who treat those they look after with empathy and compassion every day, please know that your efforts are appreciated and that without you all our journeys would not have been so positive. You do make a difference.

**Melissa Darnley
Collator**

INTRODUCTION

This is a wonderful collection of stories from people with kidney problems and their families gathered with love and care by Melissa Darnley. The book has been many months in gestation but the stories and the messages contained in them are timeless.

My own career in nephrology began in 1964 and I have seen many changes come and go in the treatment of kidney failure in that time. Yet the impact on those on the receiving end has changed little – kidney failure (or “end stage” - surely a term we should abandon!) has always been a life-stopping diagnosis for the individual affected and a life-changing condition for the whole family. The physical demands and intrusion into free time created by dialysis, and the medications and anxieties engendered by transplantation have changed little in 40 years.

The constant theme in the stories woven together here is that of how ordinary humans adapt to extraordinary stresses and strains. My overwhelming conclusion is to marvel at how great is our individual capacity to positively adapt to situations that were previously thought unmanageable. Time and again I have heard “I can’t do that” or “I really don’t think I want to go down that pathway” only to see individuals a few months later happily doing home dialysis or enjoying the benefits of successful transplantation. The instinct to survive is indeed a strong one.

This book captures all that and much more. There are no punches pulled and there has been little editing. The truth is that the kidney pathway is full of difficulties and pain, imposes huge burdens on those affected and impinges in a major way on their families. Flexibility in planning life is lost, job opportunities become more limited and financially everyone is worse off – even in our well supported and subsidised public health system. These messages all come through in the stories but so does the fact that life goes on and often with a better quality and more optimism than seemed possible at times of earlier despair.

I hope that this book will be read widely by those with kidney disease and that as a consequence the immediate pressures and problems being experienced will seem a little easier to cope with. Remember there are few absolute truths – but the real truth at the personal level is what we feel and experience and that is what this book is all about.

Dr Timothy Mathew
National Medical Director
Kidney Health Australia
Dec 12, 2007

CONTRIBUTORS

Alexandra

57, Retired clerical worker

TYPE OF ILLNESS

Bilateral urethral reflux and congenically deformed kidneys

TREATMENT

In centre haemodialysis, Transplant
pgs 21, 27, 28, 41, 67, 88

Aloys

67, Retired accountant, organic farmer

TYPE OF ILLNESS

Polycystic kidney disease

TREATMENT

Peritoneal dialysis, home haemodialysis
pgs 17, 27, 34, 45

Amber

27, Nurse

TYPE OF ILLNESS

Focal segmental glomerulosclerosis (FSGS)

TREATMENT

Peritoneal dialysis, transplant, nocturnal home dialysis
pgs 25, 29, 36, 39, 52, 59, 78, 87

Andy

51, Carer to Melissa
page 56

Anne

68, Retired teacher

TYPE OF ILLNESS

Polycystic Kidney Disease

TREATMENT

In centre Haemodialysis
pgs 20, 45, 75, 80

Bill

43, Trade show specialist

TYPE OF ILLNESS

FSGS

TREATMENT

Transplant, in centre & daily home haemodialysis
pgs 25, 28, 42, 48, 70, 85

Bob

69, Retired builder

TYPE OF ILLNESS

Nephritis

TREATMENT

Home haemodialysis
pgs 18, 59, 79

David

57, I.T. operations

TYPE OF ILLNESS

IgA Nephropathy

TREATMENT

Nocturnal home haemodialysis
pgs 14, 23, 38, 52, 76, 85

Debbie

34, Customer service Officer

TYPE OF ILLNESS

Mixed Connective Tissue Disease

TREATMENT

Haemodialysis
Transplanted 2 years
pgs 17, 42, 76

Diane

48, Sister and donor to Jenny
pgs 56, 66, 88

Gary

46, Landscape photographer & web administrator

TYPE OF ILLNESS

Reflex nephropathy

TREATMENT

Peritoneal dialysis, transplanted 29 years
pgs 29, 40, 66, 77, 83, 88

Gavin

47, Medical sales rep

TYPE OF ILLNESS

Uncontrolled hypertension

TREATMENT

Peritoneal dialysis

pgs 16, 19, 30, 39, 78, 88

Glenda

69, Carer to Les

pgs 28, 41, 55

Graham

72, Retired

TYPE OF ILLNESS

Nephritis

TREATMENT

Nocturnal home haemodialysis

pgs 33, 53, 83, 86

Jenny

48, Home duties

TYPE OF ILLNESS

Polycystic kidney disease

TREATMENT

Transplanted 1 year

pgs 19, 22, 60, 65, 72

Jo

34, Direct marketing coordinator

TYPE OF ILLNESS

Reflux nephropathy

TREATMENT

Home haemodialysis,

Recently transplanted

pgs 15, 16, 21, 26, 30, 34, 46, 58, 63, 74, 79, 80, 87

John

59, Retired school teacher

TYPE OF ILLNESS

Polycystic kidney disease

TREATMENT

Home haemodialysis

Transplanted 5 years

pgs 18, 24, 36, 49, 58, 61, 69

Julie

57, Retired sales manager

TYPE OF ILLNESS

Polycystic kidney disease

TREATMENT

Automated peritoneal dialysis

pgs 14, 21, 31, 34, 37, 73, 81, 86

Kate

49, Human resource officer

TYPE OF ILLNESS

Goodpasture's syndrome

TREATMENT

Home haemodialysis

Transplanted 7 years

pgs 17, 23, 27, 32, 42, 44, 46, 48, 50, 67, 82

Lenore

64, Retired nurse and accountant

TYPE OF ILLNESS

Analgesic nephropathy

TREATMENT

In centre and home haemodialysis

pgs 47, 80, 85

Les

69, Retired heavy machinery operator

TYPE OF ILLNESS

Unspecified

TREATMENT

In centre and home haemodialysis

pgs 16, 34, 45, 50, 51, 89

Margaret

67, Retired public servant

TYPE OF ILLNESS

Glomerulonephritis

TREATMENT

Peritoneal dialysis

pgs 20, 40

Marj

69, Carer to Bob

pgs 33, 55, 59, 74

Melissa

51, Teacher librarian

TYPE OF ILLNESS

FSGS

TREATMENT

Nocturnal home
haemodialysis
pgs 15, 22, 26, 33, 35, 51, 57,
73, 77, 84, 86

Nancy

36, President Dialysis
Escape Line,
Medical surgery worker

TYPE OF ILLNESS

FSGS

TREATMENT

In centre dialysis,
peritoneal dialysis
Recent third transplant
pgs 19, 24, 29, 32, 38, 41, 66,
69, 75, 76, 88

Pierre

53, Retired technical
translator
Lexicographer and
military officer

TYPE OF ILLNESS

IgA nephropathy

TREATMENT

In centre and
nocturnal home
haemodialysis
pgs 13, 29, 35, 43, 53, 57, 80,
90

Rex

83, Retired school principal

TYPE OF ILLNESS

Unspecified renal failure

TREATMENT

In centre haemodialysis
pgs 26, 45, 83

Sarina

45, Home duties

TYPE OF ILLNESS

Unspecified

TREATMENT

In centre haemodialysis
pgs 15, 28, 35, 44, 87

Shane

48, Software developer/
consultant

TYPE OF ILLNESS

IgA nephropathy

TREATMENT

Daily home haemodialysis
pgs 17, 23, 34, 47, 78, 81, 85

Sylvie

67, Retired

TYPE OF ILLNESS

Stage 3 kidney disease
pgs 17, 27, 83

Thelma

86, Retired

TYPE OF ILLNESS

Unspecified

TREATMENT

Peritoneal dialysis
pgs 27, 39, 42

Theresa

58, Retired nurse

TYPE OF ILLNESS

Glomerulonephritis

TREATMENT

Transplanted 13 years,
In centre and home
haemodialysis
pgs 15, 49, 66, 88

William

78, Retired

TYPE OF ILLNESS

Polycystic kidney disease

TREATMENT

In centre haemodialysis
pgs 22, 44, 81, 87

FIRST DIAGNOSIS

Sometimes kidney failure can happen quickly, caused for example by a sudden loss of large amounts of blood or an accident. A sudden drop in kidney function is called Acute Kidney Failure and is often short-lived but can occasionally lead to lasting kidney damage.

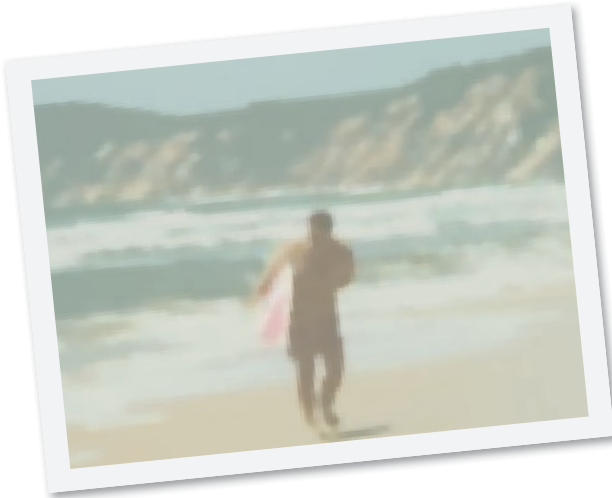
More often kidney function worsens over a number of years. This is good news because if kidney disease is found early, medication, dietary and lifestyle changes can increase the life of your kidneys and keep you feeling your best for as long as possible. If you have lost over one-third of your kidney function and the loss persists for over three months, it is called Chronic Kidney Disease (CKD). Sometimes kidney disease leads to kidney failure, which requires dialysis or a kidney transplant to keep you alive.

Pierre, Retired technical translator, lexicographer and military officer

I never really went through stages of acceptance in the classic sense because development of chronic renal failure due to IgA nephropathy was a very gradual process over a period of 25 years. Kidney function declined so gradually that at any given time, it seemed to be stable rather than in any significant decline. Even though I knew that dialysis was likely after the first 15 years with this disease, even up to the last month, it seemed like something that might happen sometime in the future rather than as an immediate reality. But on the other hand, when it did happen, it was not a surprise. During the last year before dialysis, I felt sick enough that I actually welcomed dialysis as offering the possibility of making me feel better. So I wasn't distraught when my nephrologist told me it was time to start dialysis.

David, IT operations

I was in a pretty desperate state, when I first staggered into the renal unit, early in 2004. I had actually been admitted to another hospital the previous weekend and I thought I was going to die. So finding I had ESKF (end stage kidney failure) caused by IgA nephropathy, despite all the complications and “crap” that go with it, I was actually a little relieved.



David after a surf

Julie, Retired sales manager

I had been feeling really tired, looking pale and had pains on my waistline, thinking I was anaemic I decided to be brave and have a blood test two days after Christmas, 2003. Yes, very brave as I used to be horrified at the sight or the very idea of blood!

The results came back showing I had polycystic kidney disease and I thought my life was over. I was terrified of the idea of having dialysis as the blood thing was too confronting I thought I could never do that.

Having lost over 30 kilos through a weight loss program we had moved to retire. Life is full of surprises and I was offered a job as a weight loss program leader which I thoroughly enjoyed for four years. It was a demanding role, especially physically. So after the shock of diagnosis and taking five weeks off from leading meetings while I tried to come to grips with the devastating news, I went back to my meetings and stayed until I could train a replacement leader.

Jo, Direct marketing coordinator

I was 11 when I was first diagnosed with kidney disease (reflex nephropathy) but the impact of that didn't hit home until I turned 30 and was told by my doctor that within a year I would be doing dialysis. I had been to see him for my usual check up and had asked the question about having children and was told that it would not be an option at that time because of the decline in my kidney function.

Of course finding out I would start dialysis was initially harrowing and I remember the train trip home that day, it was awful and I couldn't stop the tears. I cried a lot over this period but I was so upset that my plans to start a family had also fallen through for the time being.

Sarina, Home duties

Denial was my first feeling. I thought, "okay, yeah, give me a tablet and I will be fine." I told all my family that I was alright and there was nothing to worry about. From when I was diagnosed with renal failure it took six months to start dialysis.

Theresa, Retired nurse

I was first diagnosed with Brights disease (Glomerulonephritis) when I was seven years old after chicken pox, so I can't remember much. Everything seemed alright until I was about 40 years old when I went on dialysis at home for four months after which I had a transplant.

Melissa, Teacher librarian

At the age of 36, when life felt like it couldn't get much better for my husband and myself, it all came crashing down in a heap. A back injury meant my husband spent the next year or so in incredible pain and two weeks after this happened to him, I woke to find I was totally swollen up with fluid overload. I was eventually diagnosed with focal segmental glomerulosclerosis and remember wondering where my kidneys were and being amazed that I actually knew nothing about them and how they really worked. I do recall cringing with horror at the thought of dialysis and assumed that was equivalent to a death sentence.

I left the doctor's rooms that day wondering how I was going to keep all this from friends and family. I was at the stage of life where I thought I should be thinking about having children, but really wasn't all that keen. My thoughts after diagnosis were "well that solves that problem" and "at least it isn't as bad as being diagnosed with cancer!"

I was given a pile of pills to try, told to go on a low protein diet, go home and enjoy life and see how long I could stay off dialysis.

I went through the shock of diagnosis with my head reeling, thinking "why me" and spent many fruitless hours trying to find different cures. I cried buckets, mainly in the shower or in the dead of night, which only made my eyes swell up and look puffy! This was the pre-internet days and information available was scant, very patient unfriendly and pretty depressing.

Then I stopped reading all the dreadful things that may happen and found it easier in those first years not to talk about it because it only upset me and everyone else. At first I had to force myself to keep up appearances and not creep into a shell, never to reappear.

Les, Retired heavy machinery operator

I was devastated when I was told but my faith and a loving wife sustained me. I felt it would tie my wife down and restrict her life also. I thought my life would change drastically and it did, but I have accepted the changes and am getting on with life at a changed level.

Graham, Retired

When I first found I had kidney disease I was only 20 years old and about to be married. The doctor back then advised me to stay away from crowds to avoid any infection and to be very aware of my diet, which I did for about 40 years.

Jo, Direct marketing coordinator

I told my husband straight away and we were both devastated but it took me a couple of days to tell the rest of my family because I just felt I needed those days to come to terms with it in my own head. Then I could talk fairly calmly about it.

Debbie, Customer service officer

In late August my whole life took a turn that I thought would forever change my life, my kidneys failed. While I was told years earlier that would probably happen in the years to come, I was completely unprepared for the day when it actually happened.

Aloys, Retired accountant, organic farmer

Polycystic kidney disease has been running in the family for at least three generations. I was told dialysis was soon to be a reality on my 60th birthday whilst in hospital. The greatest help were the flowers from family and friends. They seemed to be able to dry the tears in the hours of loneliness.

Sylvie, Retired

I was knocked for a sixer, when first told. I also got depression. I think my faith has helped me to accept this illness.

Shane, Software developer/consultant

I was first diagnosed with IgA nephropathy eight years ago. At the time I was working as a manager for a software development company in Denver, Colorado USA. Three years ago, I moved back to Australia and set myself up as a consultant. The plan was to find a place in the country, close to a major regional hospital, an airport, and close to the beach. I found a place up the top of the hill with a good view that met all my requirements.

I guess I went straight to acceptance. Before diagnosis I just knew something was up, so it was relief to discover the cause. Once the diagnosis was confirmed, I had a good long discussion with my doctor to determine what the future might be and what my options were. Then I hit the internet to find out as much as I could. I knew that it would affect my life, so I started planning for the best possible outcome.

Kate, Human resource officer

I was 37, happily married with two small children, working part-time and studying part-time. Life was great until I

started to feel as if I was coming down with the flu. Within days I had gone into acute renal failure. I was told I had Goodpastures Syndrome and it had caused my renal failure - my immune system had mistaken my kidneys for the virus and shut them down. There was no notice, no time to get used to the idea and it was very, very scary.

John, Retired school teacher

When I was 18, nearly 42 years ago. I started to notice I was passing blood from time to time. I was at university at the time and had to go to Sydney for an X-ray. This doctor opened me up and told me I had polycystic kidney disease and said "...from what we know you will die around 50". I thought I would just wait for medical improvements and science and just ride along with it apart from occasional bleeds.

I used to do a lot of skin diving and spear fishing. I remember I did something so stupid I realised that I could have been bitten by a shark! You wouldn't put that down to kidney disease, but it would have been. You have your wet suit on and the spear gun and you are paddling along. What you do is that the water is cold and you have a pee in your wetsuit, which is actually nice and warm. I swam out to this island, there were grey nurse sharks and whalers and I was spearing fish. When you are reasonably young you think that nothing can happen but I knew that I was a swimming, floating, leaking burley bag!

My kidneys did grow big and I was tempted to have one of mine out. They become uncomfortable. They put pressure on everything else in the stomach and there are many lumps.

Bob, Retired builder

When I was forty years old and working as a builder, I went down the street for a blood test. A week later, I got a letter from the doctors. I went in and they took my blood pressure and said, "Why are you still walking around? You should be dead."

My kidneys were 75% and they said that in twelve months I would be on dialysis but I reckon that I had had kidney disease for years. I used to get very baggy

under the eyes and my hands and feet used to swell up. But on the job, I still felt as good as gold.

Jenny, Home duties

At the age of 27 I found out I had polycystic kidney disease. While I was not impressed about it I knew that I had four children to look after and had to keep on with normal life.

My mother had the same disease so I knew what to expect but hoped that continuing improvements in technology would lead to a better result as time went on.

Nancy, Medical surgery worker

I was in end stage kidney failure when I was 18 years old. I had just returned from an overseas holiday and returned to work in Sydney as a Nanny. Looking back now I realise how sick I was getting while travelling in the USA. When I arrived back in Sydney apparently I was retaining a lot of fluid and looked very puffy, but I thought I was just getting fat. I was starting to feel unwell, and had severe stomach pain and severe headaches. I went to the local GP and had a routine blood test. The results were bad and I was sent straight to see a Professor in Nephrology. I had not told my mother any of this, as I did not want to worry her as she had only just got over having cancer. I finally got caught out when my mother rang me at work and my boss told her I was at the doctor, so then I had to tell her.

Gavin, Medical sales representative

My problem was picked up only when I had a road accident and my GP sent me for a full check up since I had a general feeling of being unwell, nausea etc. My kidney specialist did not feel that there was a link between this and the disease but sometimes I wonder whether the shock of the accident hastened the process. Anyway the doctors verdict is the cause of the "end stage kidney failure" could be due to uncontrolled hypertension and there could be a hereditary element as well.

Margaret, Retired public servant

I was working in a mailroom when I got the news from the nephrologist that I would have kidney failure within five years. I was angry, it was not fair as I didn't smoke, drink or go out with bad men! It was a real shock.

I was still reeling from the news when I got back to the mailroom where my supervisor saw my face. When I told her, "I've only got five years" she immediately said "Well Margaret, he's not God! So sit down and have a piece of chocolate cake." I've adopted that attitude and five years turned to nine years.

Anne, Retired teacher

My first diagnosis of polycystic kidney disease (PKD) was at the age of 33. As my mother died of kidney failure at 49, I immediately thought that I would too and remember being glad I had married young so my kids would be fairly well grown when I died. Having another baby three years later mucked that theory up! I hardly thought about it for the next few years, as my health remained excellent and I was very busy teaching and tending seven little (and big) Australians. My sister began dialysis years ahead of me so she became my mentor and educator for all renal issues.

The main thing that worried me was whether I had passed PKD on to any of my kids. Sure enough, four of the seven have it and two grandchildren.

INITIAL TREATMENTS

Dialysis or a kidney transplant is needed when the kidneys have stopped working.

Dialysis removes waste products from the blood when the kidneys fail.

There are two forms of dialysis -

haemodialysis and peritoneal dialysis.

During haemodialysis, a machine acting as an artificial kidney cleans the blood.

Peritoneal dialysis (PD) allows the blood to be cleaned inside the body.

A transplant is a treatment for kidney failure but is not a cure.

Jo, Direct marketing coordinator

I spent the first few months doing a lot of research about dialysis and treatment methods and that helped me accept what was going to happen and having strong family and friends made all the difference.

Julie, Retired sales manager

Sixteen months after diagnosis my kidney function was down to about 15% and I was feeling quite nauseous. My doctor said it was time to “get me going” on peritoneal dialysis and feeling better. In preparation I first had a prolapse repair so I could hold the fluid in my abdomen.

Alexandra, Retired clerical worker

I was born with congenitally deformed kidneys and bilateral urethral reflux; hence my life has been a maze of hospital stays, medical treatments and untold numbers of pills and potions.

I have always accepted my limitations as a natural part of life, but my sense of humour and a positive nature have been a godsend. I face each day with the attitude that life is not a rehearsal so I’d better make the most of today and live it to the fullest within my levels of energy and health.

Melissa, 51 Teacher librarian

I found being told I needed to take cortisone quite a scary prospect at first and although I know it has probably done some harm to my body in the long term, it has helped keep my kidney disease under control for a long time. I lost count of the number of blood pressure tablets I had to try, and rising blood pressure was probably the thing that plagued me the most about my treatment. Toilets became a bit of a consuming passion: where they were, how long before the next one, how could I nick out of the classroom whilst teaching for a quick wee! Travelling and cycling in Europe and trying to find any toilets, now that was a challenge!

Later on I was prescribed an immunosuppressant which kept me off dialysis for a couple more years. In one respect it was actually almost a "relief" to start dialysis and watch that blood pressure drop dramatically. I never suffered from nausea as my nephrologists made sure I started dialysis before I felt serious symptoms. Now I am on nocturnal dialysis, blood pressure is always near perfect and all those other medications I was on are no longer necessary!

William, Retired

I had known for nearly 40 years that I had polycystic kidneys but continued life the same way until I was informed that dialysis was imminent.

Jenny, Home duties

Over the twenty years as the disease [polycystic kidney disease] progressed, I had two separate operations to have cysts removed from first the left and then the right kidneys.

Early in 2005, I was told by my doctor that it was a big possibility that later that year I would be on dialysis. I told my family what was happening and my doctor had suggested that it would be best if I had a living related transplant.

David, IT operations

My catheter operations (I needed a second to adjust it) were fairly straightforward and I was totally out, of course, so I didn't feel a thing. Not too much post-op. discomfort either. Anyway, to cut a long story short, peritoneal dialysis did not work for me (they did warn me I was probably too big for peritoneal dialysis) so in 2005 I had another two operations for a fistula (again, it had to be adjusted) and was in the home haemodialysis training unit by late July.

Kate, Human resource officer

My renal failure was very sudden so it was a huge shock for all of my family. I was admitted to hospital on a Tuesday and flown to a metropolitan hospital the next day after having a renal biopsy. They had hired a four seater plane to fly me there accompanied by a nurse. The nurse had a learner pilot's license and asked if we minded if she flew for a while! My children (7 and 10 years old) were at school and I didn't get to see them before I left with my husband. The children were picked up after school by my brother and he and his wife looked after them for the three weeks I was in hospital. It was very, very traumatic for everyone.

I was given plasmapheresis in an attempt to restore my kidney function but my kidneys were producing less and less urine each day. As an inpatient, I was given dialysis on the night shift. Seeing the other patients on dialysis in the middle of the night was scary - I was tired and they all seemed so sick and I remember thinking 'Oh my God, is this what my future holds!'

Shane, Software developer/consultant

As my kidney function continued to deteriorate I reduced my workload to compensate. At the time I started dialysis I was only managing a couple of days' productivity a week. My cognitive abilities were severely limited and it took me much longer to get projects completed. I found this very frustrating and hard to cope with, especially when combined with the constant nausea.

John, Retired school teacher

Every five or six years I would see a nephrologist. In my forties, I started finding out about dialysis and what it might mean.

The Regional Hospital had just got their first nephrologist and he took over my case. I was monitored all the time. Eventually I took erythropoietin because my energy levels were so low and then about five months before dialysis I booked in to see a vascular surgeon to create a fistula. (However, since I have had the transplant I have had my fistula removed because it can be dangerous if you go under a barbed wire fence! I like to fish and you have to be careful of hooks and fish knives. You just have to take precautions. Once you know you have a weakness you just do something about it).

One day I got a phone call telling me that my kidney function was down to 10% and they said that when there was a vacant chair I should start dialysis. I wasn't sick before I started dialysis, but was weak, with dark rings under the eyes from trying too hard, just battling along with reduced energy.

Nancy, Medical surgery worker

I now know where all the toilets are in all the shops and places in my hometown I think!

DEALING WITH IT, RELATIONSHIPS & PERSONAL ISSUES

Kidney failure brings with it many changes. Adjusting to kidney failure is more difficult for some people than others, even with time to prepare for it. When there is no time to prepare, the sudden impact makes dealing with kidney failure much harder.

RELATIONSHIPS

Bill, Trade show specialist

Kidney failure brings with it many changes. Adjusting to kidney failure is more difficult for some people than others, even with time to prepare for it. When there is no time to prepare, the sudden impact makes dealing with kidney failure much harder.

My kidneys were failing. I had a year, maybe two, before I would need a transplant or dialysis, so I decided to go big and plan a six-month trip around the world. I tried to experience a lifetime of travel in one trip – hiking the Milford Track in New Zealand, attending an opera in Sydney, diving the Great Barrier Reef, climbing Ayers Rock, shopping in Hong Kong and trekking in Nepal.

Amber, Nurse

I remember Mum almost in tears and I was thinking, “What the hell is wrong, don’t cry Mum it’s alright, it’s no big deal.” Mum just went into auto nurse-mum mode and did everything for me to keep me from having to worry about it. She sat with me all day and all night until I went to sleep. She lost weight from doing so much walking around, as Dad had the car at home while Mum stayed at Ronald McDonald House. My sister started high school that year, and on her first day Mum and Dad weren’t home. She still reminds us of that.

Jo, Direct marketing coordinator

I think having to deal that year with my emotions made all the difference to how I felt starting dialysis.

My family were devastated for me and we all had to educate ourselves so we could get through it but I think it made our family stronger, we had to come together to deal with this. I know my family felt that they had no control over what was happening and every time something would go wrong and I would end up in hospital it made them feel even less in control.

A lot of emphasis is put on the patient and how they feel when in fact it is a bigger problem than one person and it really does affect your family and friends as they all feel helpless to a degree. It also means you need to remain positive so they don't feel sorry for you which can be a good and bad thing.

Rex, Retired school principal

It came as a surprise to find that I had a kidney problem, as there were no previous indications of a malfunction in this area. Family members were alarmed and, not being fully conversant with the disease and its implications, imagined dire results. However, being of a fatalistic nature I resigned myself to the remedial treatment necessary.

Melissa, Teacher librarian

I used to take the phone off the hook at first because I just didn't want to talk to people. Then I realised that I actually needed to talk, but found most of my friends didn't want to delve too deep. They just wanted to know that I was fine, so I found it easier to just tell them what they wanted to hear. But as the saying goes "You sure find out who your real friends are!" I treasure the friends that have stuck by me when I started dialysis and showed empathy and compassion rather than just sympathy.

Because my husband was suffering with chronic back pain, I often shielded him from what I was really feeling. I knew this was wrong but it was my way of coping.

Life and what is important to you does take on new clarity when you have a serious illness. I see people around me fussing over the smallest things and getting themselves wound up over what I perceive as "nothing

much". I'm afraid I don't tolerate shallowness in people very well anymore.

I also found that I now treasure precious days or moments more. It is like I am storing them up to retrieve them at some time in the future.

Thelma, Retired

My family were naturally worried because of my age but they are very helpful and caring to my needs. They visit me regularly and I am truly blessed.

Alexandra, Retired clerical worker

My family have always been a tremendous support. It was difficult during my school years but I was fortunate to have understanding teachers. Having lived with my illness all my life, my sister takes any hiccups/hurdles in my progress as a mere interruption to normal routine. My parents both regarded me as a strong character and no matter what happened knew I would give it my "best shot."

Sylvie, Retired

My family and friends have helped me accept this illness. They were all shocked but have been very keen to help me.

Kate, Human resource officer

We didn't know what impact it would have on our family - I was just anxious to get home and let everything settle down so we could all adjust to the changes dialysis meant for us. I had about two and a half months at home having dialysis at a local hospital before I went back to a metropolitan hospital to train for home dialysis - another five weeks away from family and friends.

Aloys' partner

Diagnosis was in South Australia. It meant big changes, moving 2,500 kilometres, away from friends and my part time job. But I am used to changes and new homes, so I make the best of diversity.

Bill, Trade show specialist

Being one with an irresistible impulse to travel, it was hard to take the news that I would need dialysis. Even as my new kidney succumbed, I travelled the Cayman Islands and the Inside Passage because I was sure that, once I started dialysis, I could put my passport away because my travelling days would be over.



Bill and best mate, Cairny

Alexandra, Retired clerical worker

No matter at what stage of kidney disease one is at, it is important to remain positive and focus on the “big picture of life.”

My advice to other renal patients...life is not a rehearsal, so enjoy each day/hour for what it can offer you.

Glenda, Carer to Les

We are both retired with no family at home. Dialysis has certainly restricted our lifestyle as far as travelling, sport, and evenings out as Les doesn't always come off 100% well and I wouldn't leave him alone after dialysis.

We now concentrate on day trips to refresh us.

Sarina, Home duties

I have not made it all out to be a big deal. Perhaps I have trivialised it a bit but I don't feel it is necessary to dwell on the negatives. Maybe I'm still in denial

myself, I don't know, but that's how I'm coping and it's working for me. If I want to cry about it all, I usually do that when I'm home alone.

I think my family and I thought that life would change for us but it didn't, we all continue to do our own things. I still drive everyone to where they want to go and we go out to functions with family and friends. I try to appear normal in front of the family because I don't want anyone to feel sorry for me.

Sometimes when I am at family functions I feel normal and eat and drink like everyone else and get carried away but then I will pay for it on Monday when we all get weighed. At least it was worth it for a while.

Nancy, Medical surgery worker

Having my experience with kidney disease, dialysis and transplantation means I don't have much sympathy for patients coming into my place of work complaining of having a cold or flu. I have also learnt that in a lot of ways I am a very lucky person as I have seen so many people who are worse off than myself.

Amber, Nurse

Having kidney problems has definitely made me more aware of my health and that of others. I also have learnt not to take things for granted.

Gary, Landscape photographer and web administrator

The emotional toll on other family members was severe, particularly in the period between 1973 and 1976 as chronic renal failure took hold. Bouts of major surgery meant that I became emotionally very frail and the emotional 'flashback' scars remain today whenever I am subjected to procedures. I can react aggressively to pain, so considered pain management is important.

Pierre, Retired technical translator, lexicographer and military officer

My family had the same reaction I had, relief that it was finally time to start dialysis and that it would help me feel better. I had already been on disability for a year

at that point due to uncontrollable high blood pressure, and so it really didn't represent that much change. It was even an improvement diet wise compared to the pre dialysis low protein diet I had been on for some time. I drove myself to and from dialysis, and so my having to go for dialysis three times per week didn't really have an impact on anyone's schedule. Other relatives outside of my immediate household were most surprised to learn I had started dialysis. When you have kidney disease for 25 years, people get a little complacent about it.

Jo, Direct marketing coordinator

Being told you have to go on dialysis or die certainly puts things in perspective for you, how can it not! Also only being 34, it makes you realise that you need to make the most of your life right now and not wait for something around the corner. I don't worry or stress about work as much as I used to and I try to see the positives in life as much as possible. It has also made me more accepting of other people and I try to make more time for family and friends when I can. On another side it has also made me more aware of making time for myself and thinking of my needs more.

I guess the main thing that changed with my family and friends was I didn't have as much time as I had before to be there for them and had to be a little selfish with what I did. Sometimes I would come off the machine and feel fairly tired or flat so that would impact on any social event I may have had that day. I had to think twice before I committed to things and it was hard to be out in a social setting for too long if I couldn't drink much, so I would tend to shorten the length of my stay.

Gavin, Medical sales representative

My family consists of my wife (we have been married for 24 years) and three kids who live at home and at this stage are doing pretty well for themselves. We migrated from India in 2000 and we are very appreciative of the Australian medical system here which keeps me alive and running. I do wonder how things could have been different had we been overseas where affordability of dialysis is out of the reach of the average person and sadly many patients pass on because of this.

Julie, Retired sales manager

My husband is strong, intelligent and very practical. He went to the internet and found all the info he could about polycystic kidney disease and downloaded me the Kidney Health Australia book which taught us both all about what to expect and types of treatment, how they work. We were able to discuss which would be best and he has always been encouraging and supportive. He was very keen to be trained with me on the automatic peritoneal dialysis (PD) cyclor and does all the heavy lifting, carrying boxes, sorting supplies in the wardrobe, carrying the 12 litre boxes up to the bedroom and spoils me too by opening the bags, drying and checking for leaks and lifting them onto the machine. It is amazing how that helped us emotionally to feel we are in this together.

My daughter was totally devastated and terrified of losing me. She drove nearly three hours on the night I was diagnosed and she drove me home and stayed with me. She is so afraid I will give up and think it's all too hard. Initially I was horrified in case I needed haemodialysis as I used to have an aversion to the sight of blood. However I had at first been told I was at least five years away from end stage kidney failure (that expression seems so final, I wish they'd change it!). In the event I needed to start dialysis 16 months after diagnosis but am coping really well on bloodless PD. I am proud to say I feel in control when I inject with erythropoietin (EPO) and can also watch the needle being inserted during a blood test and watch the blood being drawn, practically with no emotion. Sometimes I lose the plot and cry or should I say 'howl' but not much nowadays.

My son is a big, strong body builder and is inwardly afraid of this ever happening to him so I believe he may either be in denial or not allow himself to think about it much. After all PKD does not skip a generation. Having said that he is a very loving son, very tender with his old Mum, helps me to get up from a chair, and likes to help with my drains setup when he visits. The three grandchildren have a very close relationship with me and help with the machine and seem to take it in their stride. It is very pleasing to me that they still enjoy spending time with me although I don't do the fun things I used

to do with them e.g. rollercoaster rides and rides in the speed-boat, but we do other things they like such as drawing and painting.

Nancy, Medical surgery worker

I never considered how this was going to change my life, I never thought about dialysis. My family were very supportive from the beginning. My mother was there for me every minute of the day over the time I spent on dialysis. I spent a lot of time in hospital when I first started dialysis with various issues but she was always there, all day and everyday in the hospital with me. My mother has always been a part of my positive attitude. Don't think I never had bad days but I think my mum was the only one who saw it.

Kate, Human resource officer

My husband Kev was a tower of strength. His first priority was always my welfare; he never hesitated to support me with the home dialysis option even though it must have been very daunting. Our two children were very scared by my illness and dialysis. The first time they saw me on dialysis, the nurse explained it all to them, but my poor daughter had tears running down her cheeks and my son went really pale and almost fainted. It was a huge adjustment.

I was always trying to keep the family life as normal as possible. Dialysis really fitted around what they were doing. I was very conscious of the fact that Kev was working full time, had two young kids and a wife on dialysis. He was carrying a fairly hefty load. I tried to spare him some of the pressure of being around the machine.

My children seemed to not want to invite their friends around when I was on dialysis but they knew I was a 'captive audience' if they wanted my attention or some one-on-one time with me.

It must have been difficult for my husband to work full-time and come home to a wife on dialysis, two young children to organise and the evening meal to serve. He did it without complaint. I tried to ensure his load was as light as possible and that he had outside interests to escape to when needed. Whenever I asked about how he was feeling he never indicated that dialysis was a

problem at all and was always more concerned about what I was going through.

Marj, Carer to Bob

Our youngest daughter wouldn't come home from school at first; she was so petrified of the dialysis machine. We have had a couple of people faint! One of Bob's mates was in the area and he said he would come over and see Bob. When he came in, Bob was on the machine. I took one look at him, he was breaking out in a sweat and I said, "I think you had better go outside!"

One day, I was having real trouble putting Bob's needles in while a friend and her husband were visiting. I said, "God, let this needle go in" and next thing... bang, my friend was on the floor!

It makes you wonder about people that have all these things cast upon them. I have also had bowel cancer. I don't know how we have managed. I have often thought, "Is there a Lord up there? What did I do to deserve this?" Other people Bob and I know have done it really tough though. We have always thought we are battlers and are still together.

Graham, Retired

Living with kidney disease has kept our family close together and aware of organ donation.

Melissa, Teacher librarian

Living in a country area one can feel very isolated. I knew no-one else with kidney disease for years, except for a lady I met once on peritoneal dialysis, who died after a transplant, so that wasn't very cheery! I was desperate to meet others, but there was no support network when I was diagnosed and there was no way I was ready to go near a dialysis unit to meet others.

I often suspect that those living in cities have access to 'better' care with more funding in the large hospitals with greater support and the latest medical advancements more readily available.

I have since met some 'kidney people' that I can call close friends, some even through the internet kidney discussion forums. One friend has helped me come to terms with facing dialysis. I think of her often when I

have moments where I don't think I can do the needling or am having a bad night. Knowing she has been through all of that herself and come out the other side with a successful transplant definitely helps. Another friend and I talk often and have developed a lifelong bond as we ended up on dialysis at around the same time. She however chose PD whereas I chose haemodialysis. Now I realise there is a whole renal 'family' out there on the internet as well as in the real world and that has helped me overcome the isolation of living in a country area, but you do have to do a lot of the leg work yourself out here.

Shane, Software developer/consultant

We currently live in a rural area. Isolation has not been a problem for me as I have many friends that communicate with me over the internet from around the world. My extended family lives within five hours' drive so I get many visits.

Aloys, Retired accountant, organic farmer

I live in a country area and do home dialysis. There are only two people from my family here in Australia. The rest of my brothers and sisters live in Holland.

PERSONAL ISSUES

Les, Retired heavy machinery operator and Glenda, carer to Les

Dialysis has, strange to say, brought us closer together.

Julie, Retired sales manager

I am used to having the catheter in my tummy... but haven't felt like an alluring, sexy or attractive woman since dialysis started nearly two years ago. My body image is extremely bad mainly due to the sudden weight gain after spending 5 years losing close on 50 kilos. I had had so many compliments; people do treat you differently when you are trim, taut and terrific. Sex life? That would be nice!

Jo, Direct marketing coordinator

As far as body image, I look back now after the transplant and can see that I looked fairly gaunt but I didn't feel like it at the time, which was probably a good thing. I felt quite

well most of the time and the scars on my arm from the needles never bothered me. My husband told me I looked like a very neat junkie! I did lose some sex drive and probably didn't care if I got it or not but I certainly didn't lose the need to be intimate with my husband or have the closeness of being with someone you love.

Sarina, Home duties

I do have body image issues related to my excess weight and am battling obesity. I've been overweight since childhood. I am trying to lose weight in order to get a transplant.

Melissa, Teacher librarian

I really haven't noticed much difference in our sex life which is still good. The mornings I come off nocturnal dialysis I can definitely do without it though!

As for body image, I am enjoying eating more protein than before dialysis, going to the gym and getting muscle tone back. I feel like I am getting stronger every day. Have to watch I don't overeat though. Sometimes I feel I could eat a horse when I come off the machine.

My fistula is still fairly small after a year on dialysis probably because I use the 'buttonhole technique', which is a godsend. I also use low blood pump speeds on nocturnal. So all you can really see on my arm is two 'vampire bite' marks and the look of it doesn't worry me and wouldn't even if I had a large fistula as I know it is my lifeline.

Pierre, Retired technical translator, lexicographer and military officer

Having kidney failure definitely affects sex life if you're a man (reduced desire and ability). Daily nocturnal does improve things on that front, but I wouldn't say it's completely normal.

My biggest challenge every day is simply finding ways to ensure I eat enough protein foods. I have asthma, and I do find that being on dialysis aggravates it somewhat, but daily nocturnal does so less than the three times per week variety. In terms of body image, everyone I see now says I have 'more colour' and that my face has filled out. I've gained weight since starting daily haemodialysis at home because (a) my appetite is better and (b) I can eat almost anything without the limits I had when I was dialysing

three times per week. In fact, now, instead of being too thin, I have to watch how much I eat because I'm gaining too much weight.

John, Retired school teacher

For a guy who was used to having a healthy sexual life to someone who experienced an almost 'non erectile situation' there were difficulties talking about this at home. It took me a while to realise that I was actually feeling sick and down. The nephrologists said you lose a lot of red blood cells when you dialyse. I went to my local GP and said "Listen I've got a red blood cell, testosterone related, loss of sexual performance situation happening here, do whatever medical science can do to address the situation!" I had fortnightly injections of testosterone, which worked a little bit. It's a blokey thing. It's been a part of you for so many years; you don't want to lose that erection.

One of the initial responses within a week of a transplant was to lie back and watch the physiological changes within myself.

Amber, Nurse

I am surprised my partner is still around! It must be a hard thing for him to deal with too. I just manage changes as they come, and try not to fret about it. Take things one day at a time. I try to eat a healthy diet as best I can but it is very hard when your fluid is restricted, and the diet is somewhat restricted for nocturnal. I'm finding it difficult to exercise at the moment, as I am pretty tired. Since I lost a lot of weight on PD my body has changed and I really don't like it. I don't like the look of the fistula either. But there's not much you can do about it. I really would like to get a transplant so I can start working if all goes well. I would probably consider having a few things 'fixed up' on my body. Dialysis, in general, has had a huge impact on my family and relationship with my fiancé. I rarely get to visit my family as they are interstate and I cannot take the machine with me. It does interfere with my relationship as doing nocturnal every second night I sleep in a different room and just the stress of everything adds stress to the relationship. Plus, on my nights off the machine, I look forward to a good night's sleep and I don't always feel up to doing 'you know what!'

PERITONEAL DIALYSIS

Peritoneal dialysis replaces some lost kidney function. It occurs inside the body using the peritoneal membrane as a filter. This membrane is a fine layer of tissue with a rich blood supply. It lines the peritoneal cavity, covering organs such as the stomach, liver, spleen and intestines. During peritoneal dialysis it can be used to filter waste and extra fluid from the blood.

A catheter or tube is used to fill your peritoneal cavity with a special fluid called dialysate. The fluid contains glucose (a type of sugar) but also contains substances that are similar to those in the blood. Waste and extra fluid are drawn out of the blood vessels and through the membrane into the dialysate.

After a time the dialysate, carrying the waste and extra fluid, is drained out and replaced with fresh dialysate. Each time the cycle is repeated, it is called 'an exchange'.

Julie, Retired sales manager

Once my catheter was inserted it went very well and healed nicely. Now 14 months after dialysis has started I am bonded physically and emotionally with my 'tube'.

I do 12 hours automated peritoneal dialysis every night. It is flexible as I may go from 8pm to 8am or 6pm to 6am if I am rushing to catch a plane. I have a 'dry day' and feel pretty good. My blood pressure is now perfect, whereas it used to be sky high. The biggest change has been my weight gain from being slim and energetic. I am back to 'enormous' size clothes and feeling like 'the fat lady' I used to be called in the street sometimes. That is really hard to deal with. I have asked for help from the hospital nutritionist and am starting a new weight loss plan next visit. I will do what it takes IF I know what will work.

Managing the 12 hours a night was hard at first but I am a very organised person and always did love lying around in bed. It is mainly an attitude thing - I don't say to myself, "oh no, I am attached to a machine half my life" instead I say "well, I'll get an early night, watch television while hooking up and be up and around by 8am tomorrow." When folk say "Isn't it cruel?" which many do, I say I don't look at it like that; I regard it as a slight inconvenience.



Julie about to take off on one of her many trips with her PD machine

David, IT operations

PD's biggest impact for me was that it didn't do the job! It would be okay to be on PD if it works for you, as it can be a lot more convenient than haemodialysis - particularly for travel.

Nancy, Medical surgery worker

I refused to even look at peritoneal dialysis, thinking I wasn't going to have some 'god awful' tube sticking out my

stomach. Two years later I was doing peritoneal dialysis and five bag exchanges a day. PD was mainly a good experience for me. Nocturnal was not around when I was on PD. I hated people asking me if I was pregnant, obviously the extra fluid in the peritoneal cavity didn't give me the best look. I could not cope with the fluid restriction. Being 19 I wanted to go out to all the parties my friends were going to. I wasn't going to let dialysis change my life and be different to everyone else. These thoughts continued always throughout my career on dialysis. I was going to do everything my friends were doing and be like everyone else. I think I put in a pretty good effort and achieved everything my friends have.

Gavin, Medical sales representative

I have been on PD since July 2001 and I have both a Tenckhoff catheter fixed, as well as a fistula, so that in the event of any problem with PD I can do haemodialysis. This decision has already proved to be useful a few times.

Thelma, Retired

I trained for three weeks, going home on weekends. I had a room with all the 'mod. cons' and the renal nurses were very helpful. I prefer PD so that I can spend the days doing what I want. At 4pm I prepare the machine for the night, if I have a day out I prepare it before I leave as I feel too tired when I come home because of my age.

The nurses are very kind and caring and they keep in touch with me regularly and even travel to visit my home as well. My specialist travels to my hospital where I see him regularly also.

I have been on PD now for nearly four years. I am used to it now and it is a part of my life. I am happy with PD and don't want to change it.

Amber, Nurse

I was only 14 when first diagnosed so the reality of it all didn't sink in. I was in total denial when they told me I would need a tube put into my stomach. Before going for the surgery I was thinking some miracle would happen and I wouldn't need this horrible tube. Well I was wrong! When I awoke after the surgery I immediately looked down at my

stomach, and there was a massive dressing. So I assumed they put the tube in and I would have to deal with it. That was what made me realise this thing is real and I would have to accept it. I don't know how I coped, I just did. I think being young helped me, as mum did most of the talking to the doctors, so I didn't have to worry about it. I didn't really think it would change my life, I just saw it as something added to it. It was so long ago it is hard to remember. Mum did everything for me, I only had to do the one manual bag when I got home from school, then she would hook me up to the 'train' later. I had a massive PD cyclor, which my sister said sounded like a train. I can't remember the name of it now, but it was as tall as me. Not a lot changed, as I was still at school, so school was my life pretty much. I did have a fair few days off though, as I just couldn't get out of bed in the morning. I still managed to finish high school and go on to university to get a degree in nursing. I was only on PD for nine months and then I got a transplant.

Gary, Landscape photographer & web administrator

Peritoneal dialysis was a novel, pioneering treatment in the mid 1970s. I had a general anaesthetic for it, to put me at ease. In use, PD was satisfactory and enabled me to travel home on weekend leave.

Margaret, Retired public servant

I was very undecided about hospital or PD although I attended all educational meetings. The one thing in my mind was that I wanted to stay as active as possible as I'm used to being active.

The whole experience of training to do PD was all to do with the excellent way the staff prepared me for doing it myself. They helped me to feel confident.

HAEMODIALYSIS

During haemodialysis blood travels to a dialysis machine where it passes through a special filter called a dialyser before being returned. The dialyser removes waste and helps to balance water, minerals and chemicals in the blood. Only a small amount of blood is out of the body at any time.

IN-CENTRE HAEMODIALYSIS

Glenda, Carer to Les

There is a certain sense of community in the dialysis unit. A 'oneness' or empathy between patients and their problems, especially with their problem fistulas and progress on dialysis. Because of the distance travelled there was lots of time for me (the carer) to get to know other patients. The empathy between some patients was almost palpable. I have developed an appreciation of the nursing staff.

Nancy, Medical surgery worker

For me the worst part of dialysis was not the time involved, or going to dialysis but the fluid restriction! I was also sick and tired of feeling sick and tired a lot of the time.

Alexandra, Retired clerical worker

I dialysed for 18 months before my transplant. The routine of five and a half hours three times a week and the dietary and fluid restrictions were tough at first then became part of my life. I refused to allow dialysis to rule my life entirely. The social aspects of my dialysis 'shift' has continued post transplant. Life as a dialysis patients can be tough when family and friends don't understand the ups and downs of 'making love' to a machine.

Bill, Trade show specialist

Usually people need dialysis after years of diabetes or high blood pressure but my particular kidney disease, focal segmental glomerular sclerosis (FSGS), is a bit of a mystery. A blood test revealed that the FSGS would reoccur in my new kidney so another transplant would have to wait for a medical advancement; I would need to use dialysis to replace the functions of my dysfunctional kidneys.

Dialysis can replace some of the work done by healthy kidneys but dialysis takes time. During dialysis, blood is circulated through an artificial kidney that removes waste and water, things that are normally eliminated by urination. Right from the start, I had to dialyse three times a week for four hours per treatment. Dialysis felt like a lousy, exhausting part time job. A job that seemed to mean that I would never get to live my many travel dreams.

Debbie, Customer service officer

I was hooked up via a vascular access catheter located in the upper right hand side of my chest. This took anywhere from 10 – 20 minutes as everything has to be sterile, then I started my 4 to 5 hours of dialysis. Once my time was finished it took another 10 – 20 minutes to ‘unhook’ me. Fun! But it was getting rid of all the waste products building up in my system and I was able to start doing things that I had to let go of because of shortness of breath and lack of energy.

Theresa, Retired nurse

I don't think I would enjoy dialysis at home now. We have a lot of fun at the unit with the other patients. There are ten in all and we get on very well together. We have question time in the morning; jokes with the staff and patient dress-up days for anything!

Kate, Human resource officer

I can remember a time when I was in centre and they said, “Kate, we have a problem scheduling everybody so would you mind coming in tomorrow instead of the next day?” I understood my diet and fluid restrictions and was compliant on dialysis but also knew this request offered me a window of opportunity to enjoy a bit more freedom with both my diet and fluid intake. “I am walking out the door heading for the supermarket and for the orange juice right now!” I said.

**Pierre, Retired technical translator,
lexicographer and military officer**

I chose in-centre haemodialysis over peritoneal dialysis based on my nephrologist's recommendation, but I did complete treatment options education a year before in order to make an informed choice. Based on the horror stories I had heard of or read about from other people, my initial reaction to dialysis was, "Is that all there is?" Thanks to my nephrologist referring me for fistula surgery well in advance, I was able to start haemodialysis with a well-developed fistula and, because it was a planned start rather than an emergency, I started the first few treatments with a more gentle new fistula protocol and shorter treatments. I still had good residual kidney function, and my blood work never presented any problems. The worst thing about dialysis is that it's boring, and three and a half hours can seem like an eternity to a person who doesn't like to sit still. I do eight-hour nocturnal treatments now, but it seems shorter because I sleep through most of it. I can remember spending so much time watching the clock when I was dialysing in-centre.

Cartoon by David Pritchard



Kate, Human resource officer

I was on in-centre dialysis for some months before I trained for home dialysis and made regular use of respite and holiday dialysis during the years I was on home haemodialysis.

I liked having someone else put my needles in and accept responsibility when things went wrong. I liked the air-conditioning; spare machines and back-up power supply that hospital dialysis offered. I particularly appreciated respite dialysis - I took advantage of regular respite to give my family a break. I didn't wait until there was a crisis or they were feeling stressed - it was something I organised so they were never put in the position of feeling like they were letting me down if they said they needed a break.

The experience I enjoyed the most during my periods of in-centre dialysis - each Saturday night a small shift of patients about my age used to order in a pizza as a treat and we would pull our dialysis machines and chairs close together and play cards, trivial pursuit and other games. It was great fun and we laughed a lot. I'm not sure whether our nephrologist ever knew about the pizza but our creatinine levels were okay and we weren't going to tell him!

William, Retired

Because we live in a small unit in a retirement village, there is no room for a dialysis machine at home. When first in-centre, they seriously miscalculated my dry weight and took off far too much liquid far too quickly. I crashed within an hour with excruciatingly painful cramps. They got it right the third time and the following morning I woke up and there was a different man in the bed! He got up and did one and a half hours bike riding and swimming, for the first time in six months.

Sarina, Home duties

The day I commenced treatment was the day it all sank in. I sobbed uncontrollably while sitting in the chair. I cannot needle myself; in fact when I get needled I still have to look away after five years.

My initial response was "Okay, I'll look at it as if I was going to work part-time." All the patients were/are my co-workers. It is certainly difficult when a co-worker passes away. Some of us patients and nurses go out for breakfast

or lunch together. We definitely develop a close relationship like work colleagues.

Anne, Retired teacher

I chose to dialyse at a hospital because:

- 1) We lived on a farm so water was scarce
- 2) I was 62 years old and my husband was 65
- 3) I did not want to tie my husband down to my regime

My first dialysis was at a major Melbourne hospital and went well until just before the end. My leg cramped excruciatingly and they stood me up and I saw stars! Then the nurse took off the pad too soon and blood sprayed everywhere. It frightened me silly and I really didn't want to go back the next day.

Les, Retired heavy machinery operator

We live in a small country town, 50 kilometres from a major centre where the renal unit is situated. Before home dialysis the distance travelled to in-centre dialysis was a major and exhausting problem for both of us. There was no community transport available as it was already full and there was no possibility of accessing any other form of transport.

I had to have dialysis at the hospital for six months. I was in a state of shock, despair and depression. These feelings diminished and I began to feel a little better in myself and about things in general.

Aloys, Retired accountant, organic farmer

I was without a choice (of dialysing in-centre), not having a permanently working fistula or graft for one whole year. In hospital I preferred 'isolation' in a separate room so as not to be distracted by TV, videos etc. Looking into the garden or the landscape with sunshine and a good book is more to my liking.

Rex, Retired school principal

Because of my location, hospitalisation was the logical choice. My initial visit to the dialysis ward was startling as I saw rows of bodies wrapped in shroud-like blankets but was assured that this was a living, breathing reality. Patients should not be overly concerned as the old 'washing machine' will work wonders for you in a painless fashion. Sit still and think of England!

HOME HAEMODIALYSIS

Kate, Human resource officer

I didn't like the time spent waiting at hospital, the inflexible timetable of dialysis and the infection risks and ultimately the freedom of home dialysis made it a much better option for us.

Jo, Direct marketing coordinator

My first dialysis session was also my first training session so I had to come to terms with being on the machine and also start learning how to use it all at the same time. I found the training fairly comforting. I was in a room initially with two guys who were further along with their training than me and they gave me confidence plus they were really lovely people who both had positive outlooks on life. The nurses were all very positive and I think the attitude of everyone there made it a lot easier. Having done dialysis a number of times in hospital now I am really glad I went straight to the dialysis centre as hospitals can be fairly depressing places and I think it would have made it harder for me to deal with.

The first few months at home were a little daunting because you expect things to go wrong and you don't have the back up of the nurses with you but I adapted fairly well. I was luckily a good learner and really didn't have any major concerns with the machine. I blew a couple of needles at home but nothing I couldn't fix but once I got used to where to cannulate it was a lot easier to deal with.

I chose haemodialysis because I thought it would be the most successful form of dialysis for me and even though it limited where you could go at times I believe I felt so good throughout because of this decision.

My husband adapted fairly well with the machine at home and was very good at making me lunch and getting me drinks on a Sunday when he was home to help. A couple of times I didn't stop the bleeding properly when I was coming off and once I managed to nearly get him with a healthy shot of blood which in the end landed on the sofa! I also had a couple of problems with the machine and the alarms are pretty loud so I got him out of bed a few times thinking I had blown a needle or worse passed out from low blood

pressure!! He isn't a morning person so it was quite funny from my perspective but he didn't see it that way!

I did have a number of issues with my fistula and had to have an angioplasty quite regularly to fix blockages. The worst time was when my husband had organised a seaplane flight for our second wedding anniversary and a night out at a five star hotel. He didn't give me enough warning about the plane trip to take some seasickness tablets so I got sick on the plane. We landed in this remote spot for lunch and I had to tell him halfway through that my fistula had stopped. The flight back was just as bad but we made it back, cancelled the hotel and went straight to the hospital where I spent the next five days!! It is definitely an anniversary I will remember.

Shane, Software developer/consultant

My training was very good. The first few weeks of haemodialysis were in-centre and all the staff were very helpful. By the time I started the home training sessions I was comfortable with the process and doing most of the preparation. I found the actual home training very straight forward and was cannulating myself after three days. It was just a matter of repeating the process enough times 'til it became automatic. During this time I did make a few minor mistakes that the staff helped me through. This turned out to be very positive, as it gave me experience at troubleshooting problems that can occur, and as a result I am a very confident operator now.

Lenore, Retired nurse and accountant

When attending the hospital for a dialysis session I was always very pleased when 'Matilda' the dialysis machine was assigned to me. To me, she had that little something extra, and I felt an immediate affinity with her. Unlike some of the other 'girls', we got on very well together, sailing through the treatment without a single problem.

At home, the water unit had been delivered and installed, the stock arrived, and then three days later Matilda rolled through the door. I was overjoyed, as I had no idea that she would be living with me, and welcomed her into my home like a long lost friend. Since starting home dialysis we have had a lot of one-sided conversations, she

buzzes and I react, by asking, in a very curt manner to tell me the problem. Usually it's something I've done wrong or overlooked, and together we manage to sort out the problem quite amicably.

Bill, Trade show specialist

People shouldn't live to dialyse but to have a life and do the things they were meant to do. Short daily haemodialysis makes that possible, and more people should do it. After 16 years I have an earned confidence in my ability to feel how my treatment is proceeding, to monitor the process and respond to the unexpected. I think I am not taking undue risks, and as always risks have to have a context. I do not see self-dialysis as a game of Russian roulette with an inevitable morbid conclusion. I see self-dialysis as life affirming activity very much like scuba diving or parachuting (something else I've done).

Self-dialysis is something with true but manageable risks; it takes a level head and attention to detail to do safely. I would prefer to have a partner - if you know any single nephrologists who enjoy dogs and travel, let me know - but I don't have a partner and I am not going to wait for one to show up for me to start living my life. I know everyone involved in my care wishes I had a partner but it is not something I can make happen or if I could make it happen I don't know how. Until I figure it out I am very grateful that I have been given the opportunity to use high dose dialysis and make the sort of risk decisions other 43-year-old people are allowed to make.

My number one point is that I do not believe kidney failure should call one's judgement into question. Self-dialysis is and should be my call.

Kate, Human resource officer

My husband joined me for the last week of my home haemodialysis training. I did not want him to feel like my carer - he was my husband. I was adamant that this was my condition and my responsibility. I would set up the machine, do the needling and control my dialysis. Kev would only step in if there was a problem I couldn't fix and would sterilise the machine when I finished dialysis.

I dialysed at home for five and a half years. Most of the time it went smoothly but on occasions there were problems. One time I needed to dialyse on the same day that I had broken my ankle. Of course, I ended up with a cramp in that foot and the pain was incredible. I'm sure they could hear me yell all over town that night. The kids were crying. The Renal Community Nurse came out the next day and said to me "It's a good thing you don't want to have dialysis in the unit because it is full." We got through it without their help.

John, Retired school teacher

I was dialysing in-centre for five or six weeks when they said they had a vacancy at the home training centre. So the very next day I arranged to drive down, organised my infra-structures and just went. I spent four and a half weeks training, my wife came down for a week and a half to learn how to handle the machine. My wife was prepared to do it but it eventually stressed her out. I learnt how to master inserting needles, I wasn't going to let it beat me! I always used local anaesthetic. I did three times a week at home over three and a half years.

You had to adjust to home haemodialysis, learning to do it properly and efficiently, talking and thinking down the stress of it and coping positively with doing it, planning your drinks, reading blood results, trying to be normal and hoping for and not getting visits from friends (with few and very valuable exceptions).

It was best not to hope for a transplant as it would add additional 'wish for' pressure you had no control over. You eventually become proud of doing haemodialysis and so-called coping very well, but I was weaker, had dazed-headaches and noticed that I was not totally well, but OK, anyway.

Theresa, Retired nurse

My training for home haemodialysis was extensive with my husband as my carer. We made a good team and worked that way for four months after which I had a transplant.

Les, Retired heavy machinery operator and Glenda, carer to Les

Because of the distance to the home training from home, we travelled down several times a week and stayed in a motel subsidised by the hospital. The lessons were hands on doing the dialysis ourselves with our instructor (nurse) with us. She was a very easy person to relate to, friendly and not at all intimidating. The whole learning process was a very sharp learning curve for both of us, quite a challenge to work the machine and to actually give the needles. Never once did we feel we weren't given enough help or support. Our confidence grew slowly, and it was six and a half weeks before we felt ready for home.

The first few weeks were fairly nerve wracking, but we muddled through. If the needles didn't go in properly, the alarms would often frighten the life out of us. But we managed somehow and now six months later the machine doesn't bother us.

The whole process, still quite dominating, no longer fills us with trepidation.

Kate, Human resource officer

My home training was intense. I didn't know anyone and I had been put in an old hotel with no cooking facilities. Each morning I would walk up to the Hospital at around 7am and pass people sleeping in the streets - it was scary. The first people I met at training were quite old and when I asked how long they had been there the response was six months. I went back to the hotel that afternoon and cried - it was like being in jail and I wasn't going to be released until they said so!

Thankfully training went well - I was very focused and my only goal was to learn as quickly as possible so I could get home. Each night I would ring home to speak to my family and reassure them that I was OK.

I had had abdominal surgery so peritoneal dialysis was not an option for me. Home haemodialysis was definitely the best option. The flexibility it offered was definitely the most important advantage for us. I was able to work around my family, work and social commitments and get the most out of life.

Home dialysis had unexpected positives for us. I would

start dialysis late in the afternoon before my husband Kev got home from work so the kids (7 and 10 years) were actively involved in my treatment. At different times they would take on a support role, washing their hands, passing me lines to connect, saline bags and making cups of tea etc. At times dialysis just had to take priority over their wants and needs. I believe this experience has helped them grow into compassionate young adults.

Les, Retired heavy machinery operator

The benefits of home haemodialysis for us are great.

- 1) No travelling to dialysis.
- 2) We can choose when to "go on".
- 3) Friends and neighbours can pop in to help pass the time.
- 4) Allows my wife (carer) to have a life.

Melissa, Teacher librarian

My nephrologist fortunately put me on dialysis before I felt too many symptoms and I went straight into home training for nocturnal haemodialysis as I wanted to bypass dialysing in centre as it initially scared me! So began nearly seven weeks of learning the many steps involved in setting up the machine, self-cannulating and dealing with emergencies. To say it was mind-boggling would be an understatement but the training staff were extremely compassionate and knowledgeable. I was determined to try and adjust to nocturnal dialysis as soon as we got home. Nocturnal haemodialysis means doing around eight hours at least every second night with a slow pump speed. Then the days are ours. The blood results are outstanding, meaning much less medication and the slow pump speed hopefully is better for the heart. I feel really good most days and exercise by swimming, walking and going to the gym. Life can be good! I can't thank Professor John Agar enough for his wonderful website on nocturnal dialysis. As soon as I read it I knew it was the way to go for me.

Learning to sleep to the sounds of the machine and the reverse osmosis unit has been very difficult along with the stress of making sure the needles weren't going to go anywhere in the middle of the night! The 'buttonhole technique' of putting the cannulas in the same two 'holes' each time has helped alleviate the stress of needling 100%. Boy,

what an enormous relief that is! It took us a good six to eight months to feel relaxed around 'Freni' but we have it fairly well sorted now. She gets pushed into a wardrobe when not being used and we have our life back again until the following night. You cannot let it rule your life, you have to treat it with the respect it deserves but don't let it take over what really matters in life.

David, IT operations

Haemodialysis chose me, rather than the other way around. I was still so sick, from a wasted year on PD that they really did not try hard to train me for the first few weeks.

Dialysing at home allows you to do it on the days and times that suit you, plus you can do longer hours. Most of us 'nocturnals', in particular, seem to get about 30-40 hours per week. I have to dialyse in an armchair in a separate room to my wife who is a light sleeper and works as a teacher. I have enough trouble getting sleep myself on nocturnal.

Amber, Nurse

My personal opinion is that the more dialysis you can get, the better. After about three months on the six hours x 4 day regime, I was asked if I wanted to do nocturnal. I jumped at the chance. I have been on it now for 10 months and I must say it really is the best way to go. I do feel much better in myself. I still get very tired, which I think is due to a number of things.

There are quite a few benefits of home dialysis. I am on nocturnal so I will list the benefits of that.

- I can do it overnight while I sleep
- My days are virtually free
- I am in control of my own treatment
- My clearances become normal or very close to normal
- It is much more gentle on my body, no rebounding blood levels
- My diet is reasonably free
- I feel a lot better in myself – more energy, increased libido, appetite returned

Some cons of nocturnal:

- It can interfere with my sleep and those around me
- It can affect intimacy
- It can interfere with night time activities.

Cartoon by David Pritchard



Graham, Retired

I did not realise how slow I had become until I started nocturnal haemodialysis. I could not have had the enjoyment of playing bowls as I have now.

My home training was a bit of a worry at first as I dreaded the thought of needling myself, but with the excellent tuition and care from the staff it was so easy I could not believe it! The benefits I achieved were as if almost leading a normal life.

Pierre, Retired technical translator, lexicographer and military officer

I enquired about switching to peritoneal dialysis two years after starting haemodialysis. When I found out during the home dialysis intake presentation that I might be able to do haemodialysis at home, I decided it was better to stick with the devil I knew than to experiment with the unknown of peritoneal dialysis. By that I mean that I already knew that haemodialysis was working for me. Before that, I knew some people were on home haemodialysis, but I didn't know it

was generally available. I started training four months later. My training consisted of doing short daily haemodialysis treatments on weekdays at the home dialysis unit for six weeks. I showed up at the dialysis unit every morning between 8 and 9am, and I generally headed for home sometime after noon. Short daily in this context meant two hour treatments. It is supposed to add to the same number of weekly hours as conventional in-centre haemodialysis (12 hours). Once home, I did two hour short daily treatments for about two months, until I could be scheduled for a three night sleepover at the hospital. This coincided with reconstruction of the dialysis unit at the hospital, and so it took longer than usual. Those three nights are required in order to convert to daily nocturnal from short daily. I finally did that, and I started daily nocturnal at home uneventfully.

The greatest benefit of doing daily nocturnal haemodialysis at home for me was not the fact of not having to travel to a dialysis centre, since I did not live far from the dialysis unit anyway. The greatest impact was how much better I felt because I was able to stop taking blood pressure medication entirely for the first time in years, and I was able to eat and drink without limit (within reason). I felt much better, had better appetite, gained weight, and I was able to start exercising more. It's a much better life than going to the dialysis centre for half a day three times per week. All my daytimes are free now, once I take myself off the machine in the morning.

CARERS & DONORS PERSPECTIVES

Carers can also be deeply affected by kidney disease. Carers don't have to go it alone. As well as friends and family there are also many organisations that can help carers looking after a loved one with kidney disease or other chronic conditions.

Glenda, Carer to Les

I am the carer for Les. I put him on dialysis, take him off and manage the machine. I'm quite happy to do this and I do feel I am valued. It's hard to believe but the whole situation has brought us closer together as a couple, although we have always been close. I can see that it could also drive couples apart, but we have been lucky. I do sometimes get headaches and I also resort to sleeping tablets occasionally. Talking to my daughters also relieves my stress.

Marj, Carer to Bob

I couldn't explain to you what Bob and I have been through over the years. I would hate anyone to have to go through all that. We have done it hard. We do have our moments, one time I was having a bad day and I could have kicked that 'bloody' machine all the way to the floor. I just treat it as a non-paying job. I invited the local doctor, whom we knew very well, to come around when we first got home to dialyse, as I was very nervous. He stood there and watched, came and gave me a hug at the end and said, "Well I couldn't have put those needles in!"

I am a very determined and strong willed person and still work part time. I do his needles as he has a very big fistula in his dominant arm making it difficult to do it himself. When Bob first got crook I said, "I want to do the needling for that man. He is my husband. I love him. We have an agreement. I am going to do it for him." The nurses said "No way!"

One day a nurse said to me "I will teach him if it's the last thing I do!" I went outside and after a while, out he

comes, so upset with five puncture marks in his arm! Then we had to go back in again the next day.

I said, "Right, this is it. Just forget it, from this day on I am going to do those needles." They told me if I wanted to take that on my shoulders, there is nothing they could do about it.

Andy, Carer to Melissa

I found the fact that Melissa needed to start training for home dialysis very overwhelming at first. However when I saw she was in very good hands with the renal home training staff my anxieties eased somewhat. We usually take it in turns to set up the machine at night. She does her needling and I make sure everything is taped, set and in the right place for us to sleep on nocturnal dialysis. This is sometimes difficult because of the noises the machine makes but we are over the worst, particularly those initial few months where we were always having to attend to alarms in the night and were fairly stressed by it all. I help Melissa off the machine in the morning and remove the lines from the machine.

I do feel I am being useful and I know she appreciates the fact that I am always there for her. We have been together for 30 years so we are a pretty good team but people out there really have no idea of the difficulties dialysis patients and their loved ones face.

Diane, Donor to sister, Jenny

It's funny the feelings you go through. I knew how much mum had wanted a successful transplant and I thought, "What if I say I'll do it and then it all falls apart?" I would have liked to do the testing before I told her. Playing with someone's emotions like that is not to be taken lightly. Once you have made the commitment you need to be sure you can go through with it.

Telling my kids was the hardest thing because they had been around mum on dialysis, but they coped fine as did my husband. I thought everyone would say, "Are you nuts!" but they didn't.

There was no pressure from anyone. Your family has to be happy. All the way along it is about your health and your feelings.

TRANSPLANT

A kidney transplant is a treatment for kidney failure. A transplant offers a more active life, free from dialysis as well as dietary restrictions. However, the new kidney needs a lifetime of care.

Kidney transplants come from living or deceased donors. The person getting the kidney is the recipient and the person giving the kidney is the donor. Living donors can be relatives as well as partners and close friends. Deceased donors are people who have decided to donate their organs after death.

Pierre, Retired technical translator, lexicographer and military officer

I hope that I won't have to wait too much longer for a kidney transplant, and that when I do get one, I will be able to gradually build up my fitness level so that I can ride in a bicycle tour. However, I do recognise that a kidney transplant is just another treatment, like dialysis, and that it's not necessarily a panacea and not necessarily permanent. I don't expect that I will start a new career at this point, but at least I won't have to be tied to a machine every night while the transplant lasts.

Melissa, Teacher librarian

I have mixed emotions about being on the transplant list. Initially, I was sort of hoping a family member or a friend might want to donate, but as I know my disease (focal segmental glomerulosclerosis) may reoccur in the donated kidney, I don't think the emotional turmoil of possibly losing a donated kidney would be all that good for anyone. I decided that it would be better to get the home dialysis under control and be feeling fit and well again, before pushing the issue of getting on 'the list'. Now that I am finally on the list and better prepared mentally and physically, I have to try not to become too frustrated with how long it may be before my name comes up. In NSW it can be a very long wait!

I am also concerned about the effects of the transplant medications as I have already been on several for a few years pre dialysis. Also the many blood tests and doctors visits that come with a transplant are something that needs to be considered. However I figure having the gift of another functioning kidney is something that is too good a chance not to take. The freedom to travel and do things spontaneously I miss terribly but who knows what tomorrow may bring!

Jo, Direct marketing coordinator

The whole prospect of one of your family members going through the donor testing is very daunting. It dredges up feelings of guilt and selfishness and it is something I took a long time coming to terms with. My mother and sister both wanted to donate and came to me with the suggestion. I would never have asked and think it is something the individual should initiate if they wish to do so. The first thing I did was say to hold off for a year while I got used to dialysis and I started a new job so it gave me some time to get used to everything as well as giving them some time to really consider if they still wanted to go ahead with it. A year or so later my mother did the testing but was unable to donate. This in itself was traumatic, partly because although I didn't want to take a kidney from my mother I did want a transplant and it was fairly confusing for me when she couldn't do it. I felt bad for myself, bad for mum because she wanted to do this for me and even worse for mum because she couldn't do it for medical reasons which is always hard to hear. My sister then started the testing and she had her own ups and downs with the testing but eventually after a long time we got the all clear for the transplant. I have to say there was a lot of anxiety for all of us going into the surgery and a lot of pressure for a positive result.

John, Retired school teacher

During my three years on dialysis, there was often talk of a kidney transplant, how it would free up the dialysis patient, return them to proper health, allow freedom to travel around, take the stress from partners with their partner either dependent on them for assistance with home dialysis or to balance their lives around hospital in-centre dialysis. These are

all valid thoughts. Everyone expressed them. The renal physician and renal nurses were enthusiastic when another patient had a transplant. The home dialysis renal liaison co-ordinator spoke positively about it.

The problem was, everyone knew there was a low rate of donated cadaver kidneys in Australia and the average waiting time averaged four to seven or eight years, and for some it never came.

Amber, Nurse

I had a transplant in 1994 and it completely stopped working mid-2003. I prayed for a kidney, although I'm not religious, and I got one nine months after starting dialysis. It is a lot to deal with. You don't just have the surgery and go home, there is a lot of follow up appointments and blood tests involved in the first three or more months. That is the hard part. You also have to remember to take the medications and drink lots of water. I don't think I went through a great deal of emotions, I was mainly just happy to feel well again. I did have some body issues though, as I gained over 10 kilograms post transplant.

Mum is planning on giving me a kidney as soon as I can get some weight off. It's just not that simple.

Bob, Retired builder

They rang up one night and said they had a kidney for me. It lasted twelve months. I spent more time in hospital than out. Three years later we were up from Victoria visiting Expo in Brisbane and having holiday dialysis. I received a phone call to get home as quickly as possible to get a kidney. I was smelly under the arms and thought I would have to get a wash somewhere. We grabbed a new shirt at K-Mart.

There was a bloke from the transplant unit I had never seen before waiting at the airport for me when I got home. I bounded up to him and he said, "I saw you, but thought you looked too fit!"

The kidney ended up lasting around ten years.

Marj, Carer to Bob

I was so flabbergasted. The sister said I had twenty minutes to get him to Coolangatta Airport. I was standing there

bawling and thinking, "Oh my God, I have to drive all the way home to Victoria from Queensland by myself!"

Jenny, Home duties

I never went on dialysis. I wasn't looking forward to that as our mother was on dialysis and had two unsuccessful transplants. Fortunately, technology has improved since then.

One day I was shopping with my sister and my daughter, who also has polycystic kidney disease. We were having lunch and talking about different things when the subject of my kidney disease came up. I explained to them that there were two ways, live related transplant or going on dialysis and then put on the transplant waiting list. After discussing it for a while we went on with our shopping. The next day my sister rang me and we talked about our day out, and how we both felt tired and had aching feet. After chatting for a while Diane asked me for the doctor's name and number as she wanted to enquire about donating a kidney to me. She had discussed it with her family and wanted to go ahead with the transplant if possible. I was so stunned I couldn't talk for a few minutes and then gave her the information.



Jenny, eight months after her transplant

John, Retired school teacher

I have two brothers: one has his own cardiovascular problems and because of love and fatalism, offered me a kidney early in my home haemodialysis. But his vascular system was very inappropriate. I still salute him for his unprompted offer.

After about a year of dialysis, my other brother spoke to me of maybe seeing if he was suitable. I told him he had two sons and he should check to see if he or they had polycystic kidney disease. I don't think he did, but I told him that for the time being he might have responsibilities regarding them. Perhaps if I was still dialysing years into the future he would have offered again. I never suggested anything to anyone, as I thought it was morally incorrect, plus I had been instructed that it was not to be done as such an approach would surface later in psychological screening.

My partner's brother-in-law and I were very good friends as well as nearly in-laws. After a couple of years, he offered his kidney to me as a live donor. This was a tremendous and gratefully accepted offer, as we are of the same age and I knew his offer was based on compassion and wishing to help.

For several months we travelled back and forth for tests and related testing protocols. This was never easy as a travelling day was then followed by dialysis for half a day at some point in the hospital dialysis unit. Everyone at this unit did all they could to help me and accommodate my strange time needs, even night dialysis treatments.

I had an angiogram, doppler scans, blood tests etc. It was the angiogram that ended the offer as my intended donor had noticeable elevated blood pressure and a good but not perfect cardiovascular flow. The health of the donor comes first, so that was it. The matching and suitability program came to an end. I wasn't sad...I was very grateful to him for wanting to do this and as always, reality was just tomorrow's dialysis away. I was not let down. My hopes had been partly up, but I was a realist about unrelated live donor problems.

The next stage came months later. My partner's sister, rang up and said could she volunteer a kidney, if suitable. She was always like this, generous and giving. I said, yes and accepted her offer. She thought about it, we all have strong love feelings for each other and her offer was based on 'want and love' as much as any compassion, as I reminded those people I was dealing very well with life on dialysis.

As it got so close to a 'yes' my excitement grew quickly. It was going to happen. There would be a transplant operation. What would it be like, not dialysing, putting needles in, having a wide world restored, going up to the Great Barrier Reef, fishing once again, travelling again, lots of thoughts. There was not much talk by professionals about the dangerous side effects of the anti-rejection drugs, only a vague comment back then.

Operation day, my partner is with me. My donor and I are in adjoining rooms at the transplant centre, we talk, I thank her quietly one last time, person to person, we kiss, shake hands, wish each other luck and we are wheeled away. My partner is very close to me, we have talked about this day for a long while. Fear and hopes. My donor's son arrived the day before and I overheard him say, "I am very proud of you mum." As it should be, she was what this was all about; it was her wish, her gift; all you can do is say thanks and love her for it.

After the usual or common settling in procedures, including a mild rejection on the fifth day, things moved quickly. Notably, I was 'piddling' again, and very well too. Everyone likes piddling transplant patients. Also, suddenly, no more dialysis treatments. These two things, piddling and no dialysis, drive home what you already know...I have a new, functioning kidney.

Because of the fear of infection, and the hazards of a high school site, reluctantly I resigned from teaching. I might only have one chance of a transplant and I couldn't wish an infection to it, which is a grave danger with a suppressed immune system.

The downside, and it's deadly serious, is the emergence of skin cancers from Bowen's disease to basal cell carcinomas, to squamous cell cancers. This means every five weeks a visit to the skin specialist for freeze-burns, curette and

cauterization or excisions. This has been ongoing for five years.

The major threat is of life threatening cancer. In my case, two years ago, an annual chest x-ray revealed a large tumour on the right lung. CT scans and other scans confirmed it, and within a week a surgeon in Brisbane removed two-thirds of my right lung. This was serious. Surgery was the best option. There was no indicated need for radiation or chemotherapy but I have had CT scans every six months since and the lungs have been clear. The great fear is that cancer cells may travel and develop as secondary cancers elsewhere but so far all is clear. It is a constant thought that pervades your everyday thinking. You do what you can, I take 1000 mg vitamin C each day, try to eat fruit and vegetables and I also have a miso soup nearly daily but who knows? Medical people do not really tell you everything. I know other renal transplant recipients and friends who have suffered from a serious cancer since their transplant.

Transplantation has enabled me to live a normal life in almost every respect and this is worth a lot. Naturally you have to expect constant and ongoing medical and physician supervision.

Jo, Direct marketing coordinator

Both of our surgeries went like clockwork but my new kidney wouldn't start straight away due to dye given to my sister in a CT Scan the day before surgery. This caused a multitude of anxiety for the whole family: what if the kidney failed? How will I feel? How will my sister feel? For two weeks we waited for the kidney to start up and in the interim I was back on the blasted machine I thought I had said goodbye to. A biopsy showed I had acute tubular necrosis, which basically meant the tubes had died off during the transplant and needed to regenerate. My renal physician told me it would take up to two weeks to recover and my surgeon made things difficult by continually telling me it was rejection. My renal physician, thank God, was right and within two weeks I was peeing again and could give the dialysis machine the flick!!

The biggest impact obviously for me is no more dialysis and although they only give you an average of 8 – 10 years life expectancy of a kidney I am going to do my utmost to make it last longer than that. My sister didn't lose a vital organ for nothing. I know that having kids may impact on this so I'll only be going ahead with this option if it is feasible. You get used to the drugs and a fat face and some extra weight is nothing to being on the machine for 18 hours a week. The steroids can alter your moods and when I get a happy mood swing it is a great feeling and definitely a plus! Also my waxing hurts less as well so you have to look at the bright side of all of this!

I go to clinic currently twice a week, which will reduce soon to one day a week and keep reducing as I remain stable. All of the medical staff have been tremendous and are very proactive with treating any issues that come up at the earliest opportunity.



Jo's sister and donor, Toni, friend Fiona and Jo enjoying life four months after transplant

I think one of the best things for me is being able to go out to a pub with some friends and just sit there with them all day and drink water and soda and not once think how thirsty I am as I would have on dialysis, and not having to worry about getting home to get on the machine. It is just fantastic. I also feel so much better; I have so much more concentration and am basically ready to take on the world. My husband has voiced his concern about all this extra energy I have!

Jenny, Home duties

After all the tests that were required we went ahead with the transplant from my sister. Everything went well and we both now have good health. When I started I was on seventeen tablets morning and night, now I am on about six. It took me a long time to relax and know what I was doing with the medications.

While it has been a long road with many doctors' visits and ongoing tests, all is good. We could not have faulted the treatment we received. I will never be able to put into words the gratitude I feel towards Diane, her husband Wayne and her children for giving me this chance of good health and by-passing dialysis.

Diane, who donated a kidney to sister, Jenny



Diane, sister and donor to Jenny

I didn't need painkillers when I came home after a week. The surgery to remove one of my kidneys for donation to Jenny had gone well. It wasn't really a big deal, the needles and all the tests were the worst and so time consuming when you are working full time. But you know it will all come to an end. I feel very lucky that I was able to do it successfully. However it does take a lot out of you and I feel I needed about eight to ten months to feel totally well again.

Theresa, Retired nurse

I was more emotional after the transplant and wished I could have let the donor family know how I was going from time to time, as I was very grateful to them. I am very thankful to the donor of my transplant and for the 13 years I had with it, as I couldn't remember what it was like to be so well.

Nancy, Medical surgery worker

My brother's wife donated to me. I never had to ask. I was always told from the beginning we were not allowed to ask family members, they had to offer.

Gary, Landscape photographer and web administrator

After surgery dialysis continued as the transplant was anxiously watched. Years later as I recovered, I made a personal decision not to participate in donor-patient contact and have thus been very happy with what I see as an anonymous altruistic gift. My transplant was done in 1977. It is one of Australia's most stable. Any problems are usually related to the long-term immunosuppressant regime: things like fungal infections, urinary tract infections and osteoporosis are common. The transplant's blood picture has not wavered in thirty years of testing. A well-functioning transplant is an amazing thing to live with.

Alexandra, Retired clerical worker

I felt an immense sense of humility and appreciation when my living unrelated donor offered his kidney.

My family were somewhat overwhelmed with the implications of transplantation and drug side effects. Life off dialysis for me has meant freedom of movement but continuing limitations due to post transplant complications.

Kate, Human resource manager

During my rough patches on dialysis, I thought that a transplant was the light at the end of the tunnel. I was relatively young, had been compliant on dialysis and had done what was asked of me. If given the chance, I was sure a transplant would go well for me. I intended to finish my degree, return to full-time work and with some extra income, my family would be able to make the most of the freedom a transplant would offer all of us.

Initially, it didn't quite turn out like that. I experienced my fair share of problems and side effects from the anti-rejection medication and the reality that transplantation was a treatment option for renal failure, not a cure, hit home very hard. I went into acute rejection soon after my transplant, contracted both cytomegalovirus (CMV) and glandular fever from my new kidney and faced bowel cancer. There were times when I struggled with both the physical and emotional challenges I faced.

It's now seven years since my transplant. I have learnt a lot, especially about what is important to me, what I want to achieve during my life and I continue to learn about adapting to life's challenges. My kidney and I are going well, my medication levels have been reduced and my family and I enjoy the freedom having a transplant offers. I have a happy life and am very grateful to my donor's family for the opportunity they have given me.

Despite the challenges I have faced since my transplant, I feel privileged to be the recipient of such a special gift. About three years ago, I was able to express my gratitude in person to some local donor families at the opening of a special 'garden of remembrance' created to recognise the generosity of organ donors and their families. It was

a special day and I was given a plant to remember the occasion. The plant was called 'Reflection Rose' - a rose developed and dedicated to organ and tissue donors and their families for making transplantation possible. My rose is very special - I care for it with love and every year, on the anniversary of my transplant, I am presented with a beautiful red rosebud to honour my donor and remind me how very lucky I am.

LIVING WELL

TRAVEL, WORK AND LEISURE

Kidney failure can make travelling difficult but not impossible. You may be able to attend work and social events or enjoy a great holiday with careful planning.

It's important to maintain your contacts (both formal and informal) at work when you are off sick. Don't let your employer forget your valuable contribution. Keep up-to-date with changes at your workplace. Whether or not you can still do the same job will depend on the work involved and the state of your health.

TRAVEL

Nancy, Medical surgery worker

I travelled overseas and around Australia. Dialysis never stopped me from doing a lot of things. I might have been exhausted and had to make myself do things but I did them.

John, Retired school teacher

As we did the year before dialysis, we travelled overseas, to Turkey, Scandinavia and Russia: we had a great time.

This is the freedom that transplantation offers. To be able to visit people far away, to travel, to feel stronger, to feel fully well, to go with my brother and our friends fishing to the Great Barrier Reef once a year, to be normal, to see the haemoglobin levels rise, to feel strong sexual desire again (to be able to perform!), to have days stretch out, to fish in our local angling club's outings, all normal things. Also, no food or drink restrictions!

Bill, Trade show specialist

I worked, I travelled and I volunteered but the news was I did this while dialysing at home, by myself, five to seven nights a week. Most people did not realise that someone on dialysis could work, so they were surprised that I worked full-time as a tradeshow specialist. Travel is not something you think someone on dialysis could enjoy.

As I got used to dialysis, I also got use to travelling as a 'dialyzer'. From New York to Florida, Hawaii to the north woods of Wisconsin, I took many trips around the US. Adjusting to the news that dialysis would now be a part of my life was difficult but travel helped me make the adjustment. When I travelled I felt normal.

In 1994 I took a big, ambitious road trip. My dog and I travelled through 22 states and Mexico over 40 days and 14,000 miles. I dialysed 15 times in 11 different units and the trip's success proved to me that extended travel was an option. As I travelled, I learned to appreciate the differences between dialysis units. The atmosphere in some of the other units was more like a noisy video arcade than the library like atmosphere at my kidney centre, USA. The kidney centre helped me minimise the differences among units. They encouraged me to take responsibility for my own care so that I could bring their high standards with me.

I started working in January 1995 fitting in shifts around my dialysis schedule. With work came insurance and the opportunity to travel abroad. That same year I spent three wonderful weeks in Costa Rica. I dialysed at the main hospital in San Jose Monday, Wednesday and Friday. Between treatments I was able to walk the beaches, fish the sea, raft the rivers and explore the country's natural beauty. It was great to be travelling, exploring; I had a lot of living left to do.

After Costa Rica my attention turned to Europe. In April of 1996 I started a two-month European tour. I used travel guides to decide where to go, what to see and how to do it. My goal was to just be a normal travel guide devotee touring the best of Europe. I found that with a little planning, dialysis will not interfere with taking the sort of trip described in these books and on TV. In fact dialysis enhanced the travel experience. Instead of thinking of dialysis as an

inconvenience, I came to see dialysis as a 'backdoor'. Through this backdoor I saw a side of Europe not open to most travellers.

I discovered that American dialysis standards are not universal. In fact the basic elements of my treatment – the blood pump speed, size of the artificial kidney – were not standard at all. I had to laugh when I realised that in each country treatment choices seemed to mirror the national character. In the US, my big artificial kidney and fast pump speed are just what Europeans would expect from an American – big and fast dialysis.

The French prefer a smaller artificial kidney, longer treatment and slower pump speeds – they seem to finesse the blood clean. The Dutch expect people to be responsible for their own choices: how long I dialysed and at what setting was up to me. At home I had been dialysing for four hours and forty-five minutes but while travelling I preferred to run for four hours and thirty minutes. That was not a problem in Amsterdam but the Germans took a dim view of shortening the treatment, preferring a strict adherence to my medical orders. And the Swiss? The Swiss dialysed people in the middle of the extremes – a neutral stance.

Dialysis was my private 'European Backdoor', a great opportunity to get to know another culture. What all the units had in common was their excellent quality of care. If the measure of a trip is that at the end you are not ready to leave, then this had been a great trip. After sixty-two days of travel I could have kept going. I returned to Seattle and began planning my next trip.

From 1996 to 2004 I made yearly trips to Europe and beyond. In 1997 I took a four-week trip from Lisbon to Rome through Spain, France and Monte Carlo. In 1998 I went from Amsterdam to London through Paris by train and then Dover to Copenhagen by sea. For twelve days I experienced dialysis at sea, travelling via cruise ship to the Scandinavian capitals and St. Petersburg. Between port calls a company that had contracted with the cruise line would provide dialysis in the ship's infirmary.

In October 1999 I set off on a three-month trip all the way around the World, joining up at various places with friends and family. The trip began with two weeks in Europe. From Europe I flew to Capetown where my mother and I spent

two weeks touring South Africa. The highlight was spending two nights at the beautiful Sabi Sabi River Lodge, which provided two-a-day big game photo safaris. After Africa, I spent two great months in Australia and New Zealand. However, nothing beats those two weeks in South Africa. If there had been any doubt before, I was now sure that with a little planning I could go just about anywhere.



Bill on holidays in Turkey

Jenny, Home duties

Before my transplant we travelled a fair bit. We went with five other couples 19,000 kilometres up north when I was first diagnosed. The doctor said he didn't know whether it was such a good idea but I said, "well I'm going, just watch me!" He gave me a supporting letter and it was a great trip.

Melissa, Teacher librarian

When I was first diagnosed a good friend and I travelled to Europe and did a cycling trip through Central France. I thought it would probably be my first and only time abroad. Taking all the medication was a pain but it was sure worth it! I thought that once I started dialysis all thoughts of travel would cease.

Then when I first read about Bill on the “Global Dialysis” website I was blown away! He is a total inspiration to many the world over and gave me courage to think about being able to continue to travel whilst on dialysis. I booked my first trip away to Noosaville in Queensland six months after starting dialysis and all went well. It was nice to have a break from setting up the machine, although I still did my own needles. I want to continue to go to a new place every few months although finding dialysis centres within Australia that will take travellers is VERY difficult and it shouldn't be! But knowing what Bill has managed around the world means I won't or can't ever give up trying to travel.

I also make sure my husband and I get away for short breaks of even just one night regularly to keep our sanity as living with a dialysis machine and all the supplies at home can wear you down.

Julie, Retired sales manager

PD also allows us to enjoy family holidays. My husband and I bought a quiet Honda generator which we take onboard houseboats on the Broadwater and we can spend several days on the water which we love. In a few weeks our family arrives from Scotland and all seven of us including three toddlers are hiring a big houseboat for fun and frivolity. I can't complain can I? Life is good.

I also fly with my PD cyclor and travel with my travel case asking folk to lift or carry it every step of the way. This has been hard as I am very independent and hate to feel like a 'crock' but I get about. I used to belly dance till recently and will return to it. I can still climb into a light aircraft and fly it, which is my passion. I coordinate a Fear of Flying Clinic so PD doesn't hold me back. It actually allows me to live a fairly normal life.

Jo, Direct marketing coordinator

I had one week where I did dialysis at the local hospital. My one mistake was allowing the nurse to do my needles as she blew one of them, so I learnt from then on to do my own if I was away although I didn't actually do another long trip. I did do a lot of weekend trips whenever I got the chance.

Marj, Carer to Bob and Bob, Retired builder

We travel from our home in Victoria up to Queensland in a caravan with the dialysis machine set up inside, for three and a half months in winter. We stay with our daughter on the Gold Coast for a month, have a week in Newcastle with my sister, and usually stay in a caravan park at North Haven for a month where we have friends. On the way home, we may stay in Iluka for a week and then back to North Haven for a couple of weeks. We stick to the same route up the coast and if anything fouls up we know where to go for help. We know of two other couples that dialyse in caravans.

Bob has been on dialysis for nearly thirty years and we used to take a screwdriver to our previous machine but this latest one is computerised and we can't do that! We could



Mary and Bob on holidays up North with dialysis machine in their van

see that two pieces of tubing had come apart so we managed to push them back together. Bob likes to dialyse with the sun coming into the caravan and the machine was giving us low temperature alarms. We worked out that if we closed the curtains the alarms stopped!

Anne, Retired teacher

Probably the worst thing in some ways is that travel is so restricted. Some of my family live interstate and it is very difficult to arrange dialysis to visit them.

Nancy, Medical surgery worker

I always used the time while on dialysis (when on a holiday) to catch up on sleep from being out and enjoying myself while on holiday. I also used the time to write numerous postcards.

I love, through Dialysis Escape Line Australia, that we can help people to dialyse in places where there is no dialysis available. Offering respite for that persons family too. Any person who has been on any of our getaways is always very appreciative of having this opportunity.

Nancy cruising with dialysis



WORK

Nancy, Medical surgery worker

I worked everyday and went to dialysis in the afternoons. I started Dialysis Escape Line with a friend of mine. What helped me through dialysis was I always had something to look forward to. I found this very important as well as keeping busy. It was important to me to be as normal as possible, to be like everyone else. There were always people worse off than me. I at least had a life support system to keep me alive, a lot of people don't.

David, IT operations

I work Monday, Wednesday and Friday and do nocturnal dialysis on those same nights, plus Sunday evenings. I have a fair bit more energy than I've had for a few years, so I want to get back into surfing. I'm hoping to get a special wetsuit sleeve made soon, to protect my fistula from any knocks.

The guys at work used to be more than okay with me being on PD before. I had two big S hooks, used for hanging pot plants, one stuck in the ceiling, one on a screw hook on a partition, so I could hook one onto the other to get the right height for the bags. I put the output bag under the desk and continued to work on the computer. I did two exchanges at work, usually, and three at home.

Debbie, Customer service officer

Over a few months my health improved greatly. Doctor's visits have been cut back and days at work have gradually increased to three days per week. Apart from the occasional hiccups, most of which involved biopsies of the transplanted kidney and an iron infusion, that is all medically that has happened in the last sixteen months.

The only other major exciting thing that has happened to me during this time was that my boyfriend finally asked me to marry him and we had 22 weeks to get everything booked and prepared. I only had two major problems. The first getting my fiancé and the groomsmen into the hire shop to try on their suits. Eventually they went in but one by one, how painful. The second problem was that toward the big day I kept on losing weight. Both the doctor and I could not

work it out, as I was still eating lots and lots, but it annoyed the hell out of my dressmaker who had to keep altering my skirt every time I went back!

Melissa, Teacher librarian

I returned to work as a primary school teacher just after a week of starting nocturnal haemodialysis at home. I dragged myself to work feeling very tired and washed out due to little or no sleep and eventually realised I had lost my “edge” for teaching. Being in front of a class of children you really do need to have your full complement of wits about you! I thought I was becoming unreliable and letting the staff down so I have since taken unpaid leave. I am sure there are many jobs that I could do that didn’t require me to be so on top of things while on dialysis but I find I now have time to get myself fit and well and do some of the things I have wanted to do for a long while without the pressure of work.

Gary, Landscape photographer and web administrator

I enjoy working with, and know the transplant is tolerant of physical stress, as it motivates me to work through scenarios to find solutions or alternatives. Being a landscape photographer where logistics, equipment, safety, routing and photography all come together means a lot of stress, both physically and mentally.

Gary on photographic expedition



Amber, Nurse

Dialysis pretty much robbed me of the entire Year 9 of school but because my work improved so much after the transplant, I didn't have to repeat the year.

Gavin, Medical sales representative

I work for a pharmaceutical company as a sales rep and have been doing a similar job both here and overseas. My job requires me to travel extensively both in country Victoria, interstate and even overseas, and at present things are going pretty well. In 2005, I got an award as the "General Practitioner Rep of the Year" for my company which is a prestigious annual award for best performing GP sales rep in the company.

Shane, Software developer/consultant

I work as an IT Consultant with a few very good customers that know of my situation, and allow me to work remotely. This has worked out very well as I can dialyse while working, which passes the dialysis time away quickly.



Shane ready for work in his home office

Bob, Retired builder

I thought I could go back to work full time after I started dialysis but as a builder they couldn't rely on me as some days I was no good. Well, I thought, I have to face it. Four kids, paying off the house and not a lot of money in the bank and then all of a sudden to have to give up work. It was tough. Eventually I got to the stage where I could do jobs for people in my own time and then I went on the pension.

Jo, Direct marketing coordinator

I wouldn't say that dialysis stopped me from doing most of the things that I wanted to do. I still managed to work although I decided part time was a better option for me as I wasn't able to do nocturnal dialysis which meant a chunk of time was taken out of my week to do dialysis. I did a lot of exercise, sometimes probably too much, but it enabled me to drink a little bit more and gave me a lot more energy than I think I would have previously had. I went to the gym and ran a couple of times a week and would walk to and from work. I did the City to Surf each year and managed just under 84 minutes in my last run.

LEISURE

Anne, Retired teacher

I feel the main focus has to be on your attitude to your condition. Accept it and get on with your life. I do most of the things I've always done and try to do some exercise. You don't ever have to look very far to find someone who is worse off.

I am a volunteer at St Vincent de Paul every week and play table tennis with an over 50's group. I ride a bike and walk the dog. I try and eat healthily but this is my biggest problem, as often I don't have much appetite (I need a personal chef!).

Jo, Direct marketing coordinator

Family and friends would come and visit me sometimes and have lunch with me while I was on the machine and I would try and get out and visit friends as often as possible. I definitely didn't have a bad life and dialysis also gave me the opportunity to call friends while I was tied up. I also managed to read a lot of books!

Lenore, Retired nurse and accountant

'Matilda' (home haemodialysis machine) and I have been together now for almost five months and are waltzing-whoops-dialysing along merrily with only the occasional hiccup. Thanks to her, I am free of the restraints and limitations of attending hospital for dialysis. She is my lifesaver – a marvellous machine that earns and deserves all the care and attention I can give her.

Pierre, Retired technical translator, lexicographer and military officer

Daily nocturnal dialysis does impact on late evening activities. For example, my wife sleeps in the living room until after I'm on and I've turned the lights out. I tend to be a night person, and so I never like to put myself on too early. It did take a while to get used to the idea of not being able to get up during the night. But the

benefits are outstanding. I have a lot more ability to exercise now, and so I try to combine a little cycling and walking every day. I have various interests that keep me occupied. The major one is the IgA internet support group run to help people who have the same kidney disease that put me on dialysis. I read quite a bit of non-fiction, tinker with bicycles, make meals for the family, and walk the dog. My primary activity each day is ensuring I get at least an hour's worth of exercise (which I consider essential as I am on the waiting list for a kidney transplant). Thinking positive and keeping as active as possible are extremely important.

Shane, Software developer/consultant

Now that I am on dialysis I exercise twice a day, usually a 30 minute walk to the Post Office or on the beach. This summer I hope to learn to surf.

William, Retired

Within two weeks of starting dialysis I was back to where I had been before, exercising and working. I am convinced that is what dialysis does for one. If you were somewhere before kidney failure you go back to it. If you were nowhere before kidney failure, you go back to that too. Dialysis doesn't give you what you never had. It does give you the opportunity to make somewhere to be.

Julie, Retired sales manger

My nutrition training has stood me in good stead. I eat my vegies and fruit every day, don't drink alcohol very often and never much, generally have a low fat and always low sugar diet. I don't exercise much, never did, but I do miss swimming laps every day as I did while losing my weight initially. I do short walks several times a week, strolls actually, best around shopping centres as where I live it is very hilly and I am exhausted by the time I reach my post box! I did learn "incidental activity" is effective so I hang out the washing, do some housework and try to include some activity where I can.

There is good in everything if you look for it. Having never had any illness or hospital visits in my life except for two easy childbirths, I now have much more empathy for folk with disabilities, challenges in their lives and the clients on our phobia clinics.

I have enjoyed a life long love affair with aviation. I adore aeroplanes of all types, love flying - it is my favourite thing and earned my pilot wings in 1986. I still fly occasionally in a light plane over North Stradbroke Island for example... such a buzz and great to know I can fly and fly darned well if I do say so myself. For 17 years I have been a volunteer with a phobia clinic and I coordinate the two courses in different states. Thanks to PD, the dialysis supply company and my trusty machine I can travel interstate and feel very at home living in hotel rooms. The concierge helps with the luggage and lifting of the machine to wherever I set up in the room. PD has allowed me to continue doing what has a great deal of meaning for me, that is, helping others set themselves free from their phobias. I have used the techniques we teach to try to desensitise to blood and that is the main reason I can now cope well with blood tests.

Kate, Human resource officer

Like everyone on dialysis, I had some low points but always made sure we had something to look forward to such as a weekend away, a holiday or a night out to help me through those moments and remind me of all the good times we have. I reassessed my life and filled it with things I liked to do. I worked part-time, studied part-time and concentrated on giving my children as normal a life as possible. We went on family holidays and enjoyed lots of good times. I got rid of things I didn't like doing such as housework - (I paid a cleaner to lighten the load). I had chosen to go on dialysis so I could live and I was going to do my best to enjoy the life that dialysis had given me.

Transplant recipients John and Kate
enjoying catching up for a chat



Gary, Landscape photographer and web administrator

I started cycling in 1979, and set a benchmark in riding 320km over 2 days in the 1980s to alleviate boredom. I still ride long distances, but the emphasis now is more often on physically challenging walks that are part of the landscape photography process.

Sylvie, Retired

My life has not really changed; I clean the brass at my church each month, and have two grandchildren over each day before and after school.

Rex, Retired school principal

Because of my age, there has been little change to our lifestyle although I do have visual, hearing and vascular problems with which I cope quite satisfactorily.

Graham, Retired

I walk and play bowls three or four times a week without any worries.

Melissa, Teacher librarian

I exercise daily by walking, swimming or going to the gym, which keeps me fit and well on dialysis and ready for a transplant. I drum in a hot sweaty Samba dance band every week and we regularly dress up and perform at festivals. I love the energy it creates and the pleasure it gives our audiences. All this exercise keeps me emotionally well and puts dialysis in perspective in a little 'box' so it doesn't rule the rest of my life.



Melissa and the Samba Blisstas in a Parade

HOPES FOR THE FUTURE

Bill, Trade show specialist

I have now visited twenty-nine countries since starting my dialysis career, dialysing in nineteen countries on five continents. Last year I spent three weeks in Cancun over Christmas; this year I hope to be in Peru in November. It should take eleven more years to reach my goal of visiting fifty countries.

And perhaps that is travel's greatest gift – I'm looking forward to the future.

David, IT operations

I'm hoping portable machines and easier setups for haemodialysis will come about fairly soon, to enable travel without having to book in at strange renal units and only being able to get three times five hours a week or whatever when you do.

It would also be good to be able to take a relatively easily moved machine and supplies (or have supplies delivered in advance if going overseas or long distances) away on holiday and do your normal dialysis regime.

It might be a long way off, but getting your own cloned kidney would be the real deal!

Lenore, Retired nurse and accountant

I truly appreciate the opportunity to have a machine at home and hope 'Matilda' and I will enjoy a long association together.

Shane, Software developer/consultant

Having kidney disease and the associated ramifications has definitely changed my perspective on how I live my life. The changes I have made to my lifestyle have resulted in me enjoying life more than ever before.

Graham, Retired

I look forward to celebrating our 50th wedding anniversary this year and am looking to play bowls for a long time yet!

Rex, Retired school principal

Patients in my age bracket (83-150) will note very few changes in life as the majority of leisure time is of a sedentary nature, reading, viewing, listening etc, which can be carried out in the ward. Dietary changes I have found are minimal and present no problems.

Melissa, Teacher librarian

I try to remain positive about the future and enjoy every day as it comes. I really miss the freedom to travel and I hope for very small, portable dialysis machines that are already making a big impression in the US to soon be available here. I wish the people that hold the purse strings were more supportive of dialysis patients in general. The possibilities are endless in improving the quality of kidney people's lives and so much more needs to be done.

I would love to have a successful transplant with no major side effects but I am not holding my breath waiting as Australia has a long way to go to overcome the donor shortage. Life is too short and precious to waste on wondering if my number will ever come up.

Julie, Retired sales manager

I have tapped strengths I didn't know I had. I am a Christian and have been since I was 18 but can honestly say my faith and belief is now stronger and I am not afraid of death when it comes or what is on 'the other side of the door'. I have not asked, "Why me Lord" but have asked "for what purpose" - how I can use what has happened to me to lighten the load others carry. It has been a wonderful experience having been asked to do several presentations at seminars or nursing homes. I like to be useful and feel I can still contribute. My life has been enriched by new friendships I have made. Melissa, who is the collator of this book attended a pre dialysis seminar and we 'hit it off' and have developed a firm friendship helping and supporting each other through the beginning of our journeys, our first

tentative steps on home dialysis and now both hoping for a successful transplant. I also have a PD penpal in USA who is going through early stages of using the cyclor and we encourage each other and swap cyclor tips.

The dream I dare not dream is to one day, after a good transplant, have my big polycystic kidneys removed, return to normal weight, buy another "skinny wardrobe" and travel to Paris with my daughter.

Jo, Direct marketing coordinator

Well, nearly three months into my transplant I have a number of big plans for my future. On the dull side I have huge plans to renovate my home and spend some time doing that up. I would love to do some travel and have plans to go to Western Australia and New Zealand and hopefully in the not too distant future Ireland and parts of Western and Eastern Europe. Eventually I would love to have a family and my sister, by donating a kidney, has given me the best chance possible to make that happen at some point all going well, although that is in the lap of the Gods. I would love to get a dog at some point, which will be good training for me and if that is as far as I go with growing the family then I will be just as happy.

William, Retired

I am already in my future and I intend to enjoy it as much as possible. I do appreciate the genius of the people who developed the dialysis system.

Amber, Nurse

Ideally I would love to have a successful transplant, and go on to working as a nurse. I would love to eventually work in haemodialysis.

Sarina, Home duties

I hope to lose more weight and get on the transplant list and then to travel with my partner. We haven't had a good holiday since our honeymoon 24 years ago, so we are looking forward to that without being tied to dialysis every second day, and kids.

Theresa, Retired nurse

I tend to take things in my stride. I am very grateful to be alive and to all the dialysis staff for helping me stay alive. I hope to be alive for a long time to come as I have a lot of living to do yet!

Diane, Sister and donor to Jenny

I went back to work one month after donating my kidney to Jenny, but I had a very stressful job which I have now given up. I have realised that there is more to life than work and money. I have a little granddaughter and can now smell the roses.

Gavin, Medical sales representative

I am a strong believer in the 'power of positive thinking' and it helps me move forward day by day. Also definitely my disease state has made me re-think my approach to life and I feel it has made me a better person and taught me to appreciate what I have. I have a case of wanderlust and love travelling in Australia. I personally feel that it is important to always have something to look forward to do and this takes the mind off the disease state.

Alexandra, Retired clerical worker

I appreciate every day for what it holds and try to accomplish something of importance each day as my level of energy allows. I would hope the future holds more travel and I want to be available to help other renal patients, live life to the fullest and write my autobiography!

Gary, Landscape photographer and web administrator

I would like to do more international travel but will never put my transplant at risk by going to Third World or developing countries.

Nancy, Medical surgery worker

I will continue to be involved with people on dialysis and continue to be involved with Dialysis Escape Line Australia. A transplant is never a guarantee so I will try and enjoy it

as much as possible. I will visit dodgy places overseas that I would not want to dialyse in. I am now faced with a future and I never thought I would live past about the age of 40 something.

One of the biggest changes I think, is that I can do what I want, when I want, however I want. Spontaneity is now available. A burden has been lifted off my shoulders and my family's shoulders. And I can have a damn big glass of water whenever I want.

Les, Retired heavy machine operator

I live day-by-day, week-by-week. I plan to make each day as good and happy as I can. I now have a greater appreciation of good health.



Debbie and Darrin on their wedding day

The final words should go to Pierre, who encapsulates the courage, spirit and empathy of “kidney people” so well.

**Pierre, Retired technical translator ,
lexicographer and military officer**

Having Kidney Disease has made me much poorer monetarily, but much richer as a human being. I think I’ve learned more about myself and my ability to stay positive and optimistic. Being on dialysis has opened up opportunities to meet many fine people I would never have come into contact with otherwise, and to develop lasting friendships.

Postscript: Shortly after contributing to this book Pierre received a cadaveric kidney donation which started working almost immediately. Pierre is doing well, enjoying “weeing” and freedom from the dialysis machine.

GLOSSARY

Analgesic Nephropathy: kidney damage caused from over use of analgesic (pain-relieving) medications

Automated Peritoneal Dialysis: see Continuous Cycling Peritoneal Dialysis

Bag exchanges: refers to one complete treatment cycle of peritoneal dialysis. See Peritoneal Dialysis

Basal Cell Carcinoma (BCC): a type of skin cancer

Bilateral Urethral Reflux: see 'reflux'

Buttonhole technique: a technique that is sometimes used to insert needles into a fistula

Cardiovascular: refers to the heart and blood vessels, such as arteries and veins

Catheter: hollow tube used to transport fluids to and from the body

Cramp: many people with kidney failure get muscle cramps. Imbalances in fluid and electrolytes, nerve damage or blood flow problems are thought to be some of the causes. Some people experience cramps during or after haemodialysis and this may be due to a drop in blood pressure or a rapid loss of fluid or sodium.

Creatinine: waste that is made by the muscles. It is usually removed from the kidneys and passes out in the urine (wee). When the kidneys aren't working very well, creatinine stays in the blood

Continuous Cycling Peritoneal Dialysis: a form of peritoneal dialysis where the fluid is moved in and out of the body continuously for a few hours by a machine called a cycler, usually at night. Also called Automated Peritoneal Dialysis (APD)

Cysts: are sacs filled with clear fluid. Cysts can develop with age, kidney disease or be inherited. There can be one or many cysts, which can be simple or complicated

Cytomegalovirus: is a virus that is a member of the herpes family. In healthy people, CMV can lead to a flu-like illness

that lasts a few days. People with transplants are more at risk of serious complications of this virus

Dialysis: a treatment for kidney failure that removes waste products and extra water from the blood by filtering the blood through a special membrane to remove waste products. There are two types of dialysis; haemodialysis and peritoneal dialysis

Dialysis machine: A machine used to perform dialysis

Dialysis session: Length of time spent on dialysis according to specialists prescription

Dialyzer: new term coined by dialysis users who resist the term "patient"!

End Stage Kidney Failure: (ESKF) total kidney failure that cannot be reversed. Sometimes also called End Stage Renal Failure

Erythropoietin (EPO): a hormone mainly made by the kidneys that stimulates the bone marrow to produce red blood cells

Fistula: produced when a vein and an artery in the arm or leg are joined together to provide adequate access to the blood for the haemodialysis process

Fluid restrictions: some people may need to limit their fluid intake when they are in end stage kidney failure. The healthcare team will decide if fluids need to be limited and how much can be consumed each day

Focal Segmental Glomerulosclerosis: (FSGS) scarring of glomeruli (units within kidney where blood is cleaned)

Glomerulonephritis: a type of kidney disease in which the tiny filters in the kidneys are damaged; often referred to as nephritis

Goodpasture's Syndrome: an uncommon disease that affects both the kidneys and lungs

Home Haemodialysis: people are trained to perform haemodialysis in their own homes. People on home haemodialysis often report feeling more independent

Hypertension: Another word for high blood pressure. May be either the cause of, or the result of, kidney disease

IgA Nephropathy: IgA nephropathy is a chronic kidney disease that may slowly worsen over 10 to 20 years. IgA refers to the antibody IgA (Immunoglobulin A), which helps to fight infection and is made in your throat, air passages, intestine and bone marrow. Nephropathy simply means kidney disease

Immunosuppressant: medications taken following a transplant to prevent rejection

In centre Haemodialysis: usually performed in hospital, satellite unit or private clinic three times a week for around 5 hours

Kidney function: blood tests are taken regularly from kidney patients to monitor how well the kidneys are cleaning the blood

Live related donor transplant: a transplanted kidney that has been donated by a compatible living relative

Mixed Connective Tissue Disease: A chronic inflammatory autoimmune disease that may affect the kidneys

Nephritis: see Glomerulonephritis

Nephrologist: A doctor that specialises in kidney function

Nocturnal Home Haemodialysis: A form of haemodialysis available in some regions. Dialysis occurs whilst you are asleep. Dialysis usually takes place at home for around eight hours, six nights a week

PD cyclers: see 'Continuous Cycling Peritoneal Dialysis'

Peritoneal dialysis: home based treatment using the body's own natural peritoneal cavity as a filter. The cavity is filled with dialysis solution through a catheter. Waste and extra fluid are drawn out of the blood vessels by osmosis and diffusion and transferred to the dialysis solution

Permacath: An access device for haemodialysis. It is a catheter that is usually placed in the neck or groin so that blood can flow to the artificial kidney or dialyser

Polycystic Kidney Disease: (PKD) an inherited disease that produces fluid-filled cysts in the kidneys

Reflux Nephropathy: a form of kidney failure associated with the backflow of urine from the bladder up the ureters into the kidney that affects children

Renal biopsy: a needle is passed through your skin to the kidney. A small piece of kidney tissue is removed for examination under a microscope

Tenckhoff Catheter: tube (catheter) surgically placed through the wall of the abdomen to provide a point for dialysis solution to enter and leave peritoneal cavity during peritoneal dialysis



