



National Consumer Council  
**Kidney Health Australia**

# The impact of kidney disease

and what Government should be doing about it



[www.kidney.org.au](http://www.kidney.org.au)

Free Call: 1800 4 543 639



**National Consumer Council  
Kidney Health Australia**

## Position Statement

**From the National Consumer Council of Kidney Health Australia\* on behalf of all Australians with kidney disease**

There are over 18,000 Australians currently being treated for end stage kidney disease (dialysis or transplantation). Each week an additional 50 people commence dialysis. With only 5% of the 10,000 people on dialysis lucky enough to receive a kidney transplant each year, most will never have that opportunity. In fact, the number of people on dialysis is projected to double to 20,000 by the year 2020. Every day 50 people die with kidney failure.

Living with advanced kidney disease has a serious negative impact on people's quality of life.

We want you to understand the world of kidney patients with advanced disease, particularly those on dialysis, and their families.

Kidney patients often feel:

- **Fatigue** which is overwhelming and limits their ability to work, participate in family and social activities, exercise and enjoy hobbies.
- **Unwell** and complain of poor concentration, memory lapses, physical pain, nausea and vomiting.
- **Surprised and confused** about the complexity and cause of the disease.
- **Scared** about the treatment and their future.
- **Uncertain** about how quickly their health will deteriorate.
- **Anxious** about the impact on their work, financial implications and social life. Many need to reduce work hours, change to lower level jobs, or give up work and interests totally in order to cope.
- **Guilty** about the financial and emotional pressures on their family and loved ones.
- **Isolated and alone** when dialysing.
- **Powerless** about their lack of control of the path ahead especially with the treatment choices they face.
- **Worried** about the lack of support for their loved ones and carers.
- **Trapped** by the lack of dialysis places locally and interstate limiting contact with friends and family.
- **Frustrated** at the lack of respite services available for patients and carers.
- **Depressed.**

**Kidney disease is an under-recognised and growing problem.** Those on dialysis form the small tip of a huge "iceberg" of people with advancing chronic kidney disease who will die prematurely.

**Kidney disease is a life sentence.** People with kidney failure frequently feel powerless to fight on, so much so that many dialysis patients simply decide to stop treatment.

Patients face equity and access problems because of limited choice about their dialysis treatment and barriers to live donation.

There is a wide difference in the treatment of patients in different parts of Australia.

**There is increasing anger that the health system is failing to provide much needed services and support.**

**The National Consumer Council of Kidney Health Australia\* is calling for Governments to act now to fix the current shortfalls in services and stem the tide of future patients.**

*\*The National Consumer Council of Kidney Health Australia advocates for the interests of kidney patients and carers throughout Australia. The National Consumer Council comprises kidney patients and carers working together to improve the quality of life for people affected by kidney disease.*

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## Interventions needed for kidney patients NOW!

The National Consumer Council calls on Government to help kidney patients by ensuring people in all States and Territories have access to:

- 1. Adequate dialysis capacity** that enables patients to:
  - Access and choose from a full range of treatment options in their own region.
  - Access respite and holiday dialysis in other regions and interstate to facilitate contact with family and friends.
- 2. A patient transport and accommodation scheme** to ensure patients who need to recurrently travel to receive dialysis treatment are adequately reimbursed.
- 3. A scheme which meets out-of-pocket expenses** incurred by patients choosing to undertake dialysis treatments in their own homes.
- 4. A reimbursement scheme for people donating a kidney** to a loved one. This scheme should reimburse all reasonable and verifiable expenses incurred by the donor, including loss of income and out-of-pocket expenses, and preserve leave entitlements.

## Interventions needed for all Australians NOW!

The National Consumer Council calls on Government to reduce the future burden of kidney disease in the community and on individuals by:

- 1. Recognising** chronic kidney disease as a major chronic disease of the 21st century and one that multiplies the morbidity and cost of cardiovascular disease and diabetes.
- 2. Developing** a national program to increase awareness and early detection of chronic kidney disease through increased professional education and the introduction of specific programs in primary care aimed at monitoring, improved management and better outcomes in early chronic kidney disease.
- 3. Funding** and resourcing the development and delivery of high quality information and education services in chronic kidney disease, patient support programs and the training in and promotion of these services in the community.



**Madilyn, Age: 7 years**

**Years on dialysis: 1½**

"I really miss Sunday morning cuddles in Mummy and Daddy's bed because I have to be on my dialysis machine for 12 hours in my own room."



**Maxine, Age: 66 years**

**Years on dialysis: 1½**

"My husband's life has virtually stopped since having to look after me."



**Bev, Age: 50 years**

**Years on dialysis: 6½**

"The worst thing about being on dialysis is that you never get to go away on holiday. When my father died I was unable to go and stay with my mother as she lives too far away and I wouldn't have been able to have dialysis."



**Julie, Age: 45 years**

**Years on dialysis: 4½ (1<sup>st</sup> time),  
13 (2<sup>nd</sup> time)**

"I've discovered that some people don't even know what 'kidney failure' is."



**Brian, Age: 76 years**

**Years on dialysis: 10½**

"One of the worst things about dialysis is that you have a set program. Six hours of my day, including travel time, is gone with my dialysis."

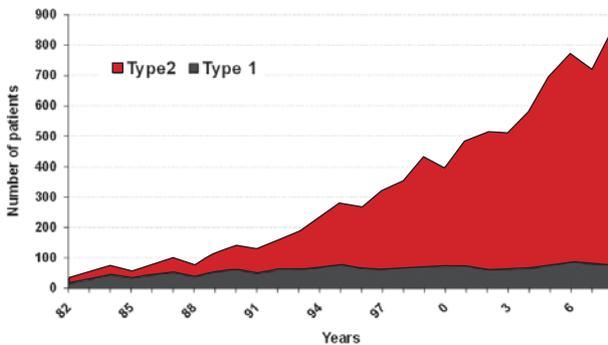


## Important facts about kidney disease

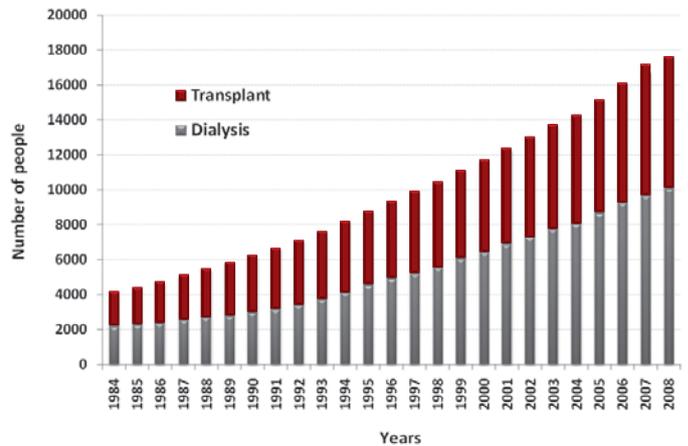
- The growth in kidney disease is being fuelled by the rise of obesity and diabetes in the community.
- Surveys show that about 1.7 million adult Australians have evidence of mild to moderate kidney disease and are at increased risk of kidney failure or cardiovascular disease.
- People with diabetes and hypertension now account for almost one half of all new diagnosed cases of treated end-stage kidney failure.
- 7 people each and every day are accepted onto dialysis programs <sup>1</sup>. New data shows that an equal number of Australians are dying of kidney failure without being accepted onto or considered for treatment programs
- Chronic kidney disease has a high rate of premature death. It has been identified as the seventh most common cause (underlying or associated) of death in Australia.<sup>2</sup> 50 people die every day with kidney failure.
- In 2008, 217 deaths in dialysis patients occurred due to withdrawal from dialysis for “psycho-social reasons”. This represents 25% of all non-cardiovascular deaths in people dependent on dialysis.
- If the current rate of growth of kidney treatment programs continues there will be about 29,000 people on dialysis or with a transplant by 2020.
- Treating end stage kidney disease is expensive.
  - The average cost of receiving dialysis in hospital is \$82,764 per person.
  - To dialyse at home is also costly for the patient. Once off set up costs in NSW are \$1591 with ongoing annual out of pocket expenses of \$2800.
  - On current figures the cumulative cost of dialysis from 2004 – 2010 is expected to be \$4.5 billion dollars.<sup>3</sup>
- The equity and access problems faced by patients include:
  - The forcing of people onto their non-preferred type of dialysis in many Australian dialysis units
  - A 4-fold variation in the number of people established on home dialysis by large dialysis units
  - A 3-fold difference between States in the acceptance rate onto dialysis of people over the age of 75 years
  - An 8-fold difference in the access to live kidney transplantation amongst patients in large dialysis units.

### The epidemic of type 2 diabetes Australia 1981 - 2008 (ANZDATA)

The number of people with type 2 diabetes starting on dialysis has doubled in the last 8 years



### Number on dialysis and transplant Australia 1984-2008 (ANZDATA)



<sup>1</sup> McDonald SP, Excell L. ANZDATA registry report 2008. Australia and New Zealand Dialysis and Transplant Registry 2008.

<sup>2</sup> Australian Bureau of Statistics. Causes of Death. document 3303.0; p 43 : 2007

<sup>3</sup> Cass, A., Chadban, S., Craig, J., Howard, K., McDonald, S., Salked, G., and White, S. Economic Impact of End Stage Kidney Disease in Australia. 2006. KHA