

The **About:** Documents

Spreading the word about kidney disease!

Our **About: documents have been developed to help you spread the important message about kidney disease in Australia.**

Kidney disease is currently the 10th cause of death amongst Australians, but very few people understand the consequences of it, or how important it is to detect it early.

Please use these documents to educate key people or influencers in your community. These people may include but shouldn't be limited to:

- Local Mayor
- Federal or state member for Parliament
- Rotary, Lions Club or Probus executives
- Chamber of commerce
- School principal

We recommend you make a quarter or half hour appointment and explain that as someone living with kidney disease, you would like to give them an overview of kidney disease in Australia to ensure they're aware of the important facts regarding this chronic disease.

As all our Consumer Committee members spread the message, we're going to map out who has been briefed and where to create a picture of knowledge across the nation! Please ensure you send a quick email to consumer@kidney.org.au each time you talk about kidney disease with details of:

- Who you met with
- Their position and who they represent or which organisation they belong to
- Their contact details (preferably email)
- Any feedback on their response or the visit

Let's make sure Australians know **About:** kidney disease.

About: Kidney Health Australia

Originally established in 1968, Kidney Health Australia, formerly known as the Australian Kidney Foundation, is a national not for profit organisation with offices throughout Australia.

Our Vision:

To save and improve the lives of Australians affected by kidney disease.

Our Mission:

To promote good kidney health through education, advocacy, research and support.

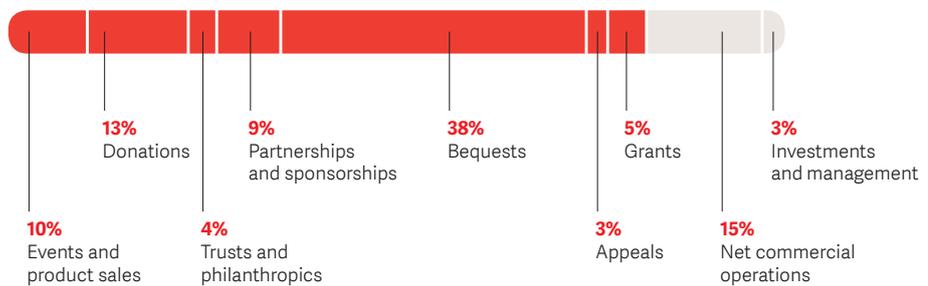
Programs & Services

Kidney Health Australia provides a range of services and programs for consumers, health professionals and the community including:

- A wide range of health information and publications
- An informative, detailed and widely-accessed web-site
- Kidney Health Information Service—a free-call 1800 number for health information, advice and referrals
- Kidney Community—our national newsletter
- Support programs including Kidney Club meeting groups
- Kids Programs—National Kidney Kids Camps and state-based programs for children effected by kidney disease
- Adult Holiday Dialysis programs
- Transplant Housing
- Consumer advocacy opportunities
- Education initiatives for consumers, carers and health professionals
- Primary Care Education Programs (accredited health professional education program)
- Priscilla Kincaid Smith Kidney Research Foundation

Did you know?

Kidney Health Australia is funded almost entirely by donations, fundraising and other charitable income.



About: Kidney Disease

What do kidneys do?

Kidneys have a number of vital roles to play in the daily functions of our body, your kidneys:

- act as filters for your body to clean blood of wastes, yet retain essential elements needed by the body
- control blood pressure
- help to keep your internal fluid levels balanced
- make red blood cells and help maintain your blood composition and pH levels
- maintain strong and healthy bones and help to keep mineral balance

What is chronic kidney disease?

- Chronic Kidney Disease (CKD) refers to all conditions of the kidney, lasting three months or more, where a person has had evidence of kidney damage and/or reduced kidney function, regardless of the specific diagnosis of the disease or condition causing the disease
- Many people do not know they have kidney disease, because up to 90% of kidney function can be lost before symptoms are evident
- 70% of kidney failure in Australia¹ is caused by:
 - Diabetes (37% of new cases)
 - Nephritis or inflammation of the kidney (20% of new cases)
 - Hypertension, high blood pressure (13% of new cases)
- One in ten² or approximately 1.7 million Australians over age 18 years have at least one clinical sign of existing CKD, such as reduced kidney function and the presence of proteinuria (protein in the urine)

What are the risk factors?

Adult Australians are at increased risk of CKD if they:

- Have high blood pressure (hypertension)
- Have diabetes
- Smoke
- Are obese
- Have a family history of kidney failure
- Are over 60 years of age
- Are of Aboriginal and Torres Strait Islander origin
- Have established cardiovascular disease
- Have a history of acute kidney injury

People with one or more risk factors for kidney disease should see their GP about a kidney health check.

¹ ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2016.

² Australian Bureau of Statistics. Australian Health Survey: Biomedical Results for Chronic Diseases, 2011-12. ABS, Canberra; 2013.

³ Australian Bureau of Statistics. Causes of Death, Australia, 2014. 2016.

Did you know?

In 2014, disease of the kidney and urinary tract were the 10th leading cause of death in Australia.³

Around 60 people a day die with kidney related disease.³



About: Treatment Options

Dialysis or a kidney transplant are needed to continue to survive when kidneys have stopped functioning effectively.

Dialysis

Dialysis is a treatment which removes waste products and extra water from the blood by filtering the blood through a special membrane to remove waste products.

Peritoneal dialysis:

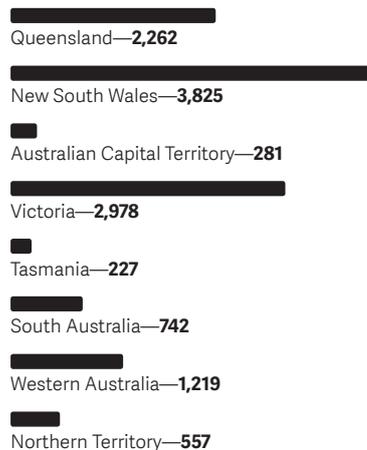
A tube is permanently inserted in the abdomen. Special fluids are then introduced regularly to draw impurities from the body.

Haemodialysis:

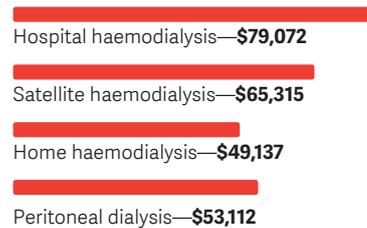
This involves connecting to a haemodialysis machine either at home or in hospital at least 3 times a week for around 5 to 8 hours at a time to cleanse your blood.

Numbers & Costs

A total of **12,091¹** people were receiving dialysis treatment at the end of 2014:



The cost of dialysis for one person on average is **\$61,659²** per annum:



Dialysis must be undertaken for the remainder of a person's life unless a transplant is received i.e. the treatment for a single adult patient on 20 years of dialysis could be \$1.6 million.

1 ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2016.

2 Cass A, Chadban S, Gallagher M et al. The economic impact of end-stage kidney disease in Australia: Projections to 2020. Kidney Health Australia, Melbourne, Australia; 2010.

3 <http://www.anzdata.org.au/anzod/v1/waitinglist2016.html>

4 Wright J, Narayan S. Analysis of kidney allocation during 2012. National Organ Matching System

Transplantation

914¹ kidney transplant operations were performed in Australia in 2014.

- As at 1 May 2016, **1034 were waiting for a kidney transplant in Australia³**
- The average waiting time for a transplant is about 3.5 years but waits of up to 7 years are not uncommon⁴
- Kidney transplant requires an ongoing regime of medication to avoid rejection
- The average unit cost of a kidney transplant in the first year is \$81,549 and \$11,770 in subsequent years,² i.e. over 20 years about \$310,000

About: Live Donors

Live Donation

'Live donation', 'living-related transplantation' or 'donor nephrectomy' are terms used to describe the process where a living person donates one of their kidneys for transplantation to another person.

Many people have a live kidney donation because it reduces or removes the need for dialysis. In Australia the waiting time for a kidney transplant from a deceased donor can be from 3.5 to 7 years, so a live kidney transplant can reduce this wait.

Live donation can also be planned. This reduces the time between a kidney's removal and transplantation so the success rate improves. Hospital admission and surgery can also be organised ahead of time, allowing the donor and the recipient plenty of time to prepare for both surgery and recovery.

- Living donor transplants accounted for 29% (267) of all kidney transplants in 2014.¹
- The kidney transplant success rate in Australia is very high. Results from live kidney donation are better for recipients than kidney transplants undertaken with kidneys from deceased donors.
- At 5 years after receiving a kidney transplant from a live donor 96% of recipients are still alive, and in 91% of cases, the transplanted kidney is still functioning.¹

1 ANZDATA Registry. The 38th Annual ANZDATA Report. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2016.

Live Donors

To be a live donor, you must have normal kidney function and overall good health. The blood and tissue type of the potential donor must also match with the recipients.

- Live donors are often **relatives such as parents, brothers, sisters or adult children**. Living donation can also come from someone who is emotionally related to the recipient, such as a husband or wife, an in-law, or a good friend.
- People who are considering being live donors need to contemplate many aspects of the process, i.e. there will be a period of recuperation when they will be unable to work or may find it difficult to manage usual daily tasks.
- Live donors **must not be forced** into donation or receive any benefit for doing so.

• Live donor support

Many people who become living organ donors are required to take leave from work, which is often unpaid, adding further financial strain to an already stressful situation.

Kidney Health Australia continues to advocate for living organ donors and people with kidney disease, their families and carers. One outcome of that advocacy is the "Supporting Leave for Living Organ Donors Programme", which supports live organ donors by providing paid leave for up to nine weeks (based on a 38 hour week), up to the National Minimum Wage. It works by reimbursing the employer, so as to enable the employer to provide the employee with paid leave, without being out of pocket.²

2 <http://health.gov.au/internet/main/publishing.nsf/Content/Leave-for-living-organ-donors>

About: Kidney Myths

I don't feel sick so I can't have kidney disease

False!

You can lose up to 90% of your kidney function before you notice any symptoms.

Only old people get kidney disease

False!

While kidney disease can be more common in older people, young people and children can also have kidney disease.

Kidney disease can be cured

False!

There is no cure for kidney disease. Early detection, well controlled blood pressure and diabetes, and a healthy lifestyle however can slow the progression of kidney disease. Once the kidneys fail completely, ongoing dialysis or transplantation is required to survive.

Kidney disease is caused by drinking too much alcohol

False!

While heavy drinking imposes a strain on kidney function, it is not a 'cause' of chronic kidney disease.

Kidney disease is caused by not having a healthy lifestyle

False!

While a good diet and healthy lifestyle can reduce the progression for some kidney disease, kidney disease can be hereditary or simply caused by kidney malfunction.

Kidney patients always need dialysis

False!

Deterioration of kidney function can take many years after first detection. Early detection and management including changes in lifestyle, can reduce the progression from reaching the stage that requires dialysis.

I must travel to a hospital if I need dialysis

False!

Both peritoneal dialysis and haemodialysis can be undertaken at home, assisting in a more 'normal' lifestyle. A health professional will discuss if home dialysis is an option that could be suitable.

Transplantation cures kidney disease

False!

Transplantation is a treatment for kidney disease, but does not cure it. On average, a kidney transplant can remain effective for around 14 years, before kidney function again declines.

About: What Is Needed

For People Living With Kidney Disease

The National Consumer Council call on Government to help kidney patients by ensuring people in all State 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, out-of-pocket expenses and preservation of leave entitlements.

For All Australians

The National Consumer Council call 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 in 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 for chronic kidney disease, patient support programs and the training and promotion of these services in the community.

About: Kidney Disease in the Aboriginal & Torres Strait Islander Community

Aboriginal & Torres Strait Islander people on dialysis

RPM=Rate per million population

QLD	NSW & ACT	VIC & TAS	SA	NT	WA	Total	RPM	Total Dialysis Patients (Aus)	RPM (Aus)
320	162	51	78	419	272	1,302	1,844	11,446	505

Aboriginal & Torres Strait Islander people with a functioning transplant

RPM=Rate per million population

QLD	NSW & ACT	VIC & TAS	SA	NT	WA	Total	RPM	Total Transplant Patients (Aus)	RPM (Aus)
32	29	12	36	32	50	190	330	9,320	411

- Although Aboriginal & Torres Strait Islander peoples represent less than 2.5% of the national population, they account for approximately 9% of people commencing dialysis or receiving a transplant each year.¹
- The greater prevalence of CKD in some Aboriginal & Torres Strait Islander communities is due to the high incidence of additional risk factors including diabetes, high blood pressure and smoking, in addition to increased levels of inadequate nutrition, streptococcal throat and skin infection, and poor living conditions.²
- The incidence of kidney failure is considerably greater in Aboriginal & Torres Strait Islander people compared with non-Aboriginal peoples.³
- Aboriginal & Torres Strait Islander peoples are almost 4 times as likely to die with CKD as a cause of death than non-Aboriginal peoples.⁴
- A significant issue for Aboriginal & Torres Strait Islander patients comes from when they are forced to move to regional centres or major cities to undertake their dialysis.⁵
- A study of Aboriginal & Torres Strait Islander patients who have had to relocate to Alice Springs from remote central Australian communities to undertake dialysis, reported the socio-cultural alienation as extreme, debilitating and ultimately life threatening and similar findings have been reported in recent WA research.⁵
- Findings indicate that the loneliness resulting from removal from family and land and the following sense of loss and disempowerment were considered worse than the illness itself. Added to the stress of not being able to attend significant events and obligations considered culturally essential, this geographical isolation often discourages Aboriginal & Torres Strait Islander people from undertaking treatment.⁵

1 Australian Institute of Health and Welfare (AIHW). The health and welfare of Australia's Aboriginal and Torres Strait Islander people: an overview 2011. 2011.

2 Cass A, Cunningham J, Hoy W. The relationship between the incidence of end-stage renal disease and markers of socioeconomic disadvantage. New South Wales Public Health Bulletin 2002 July;13(7):147-51.

3 ANZDATA. The 34th ANZDATA Registry Report. Australia and New Zealand Dialysis and Transplant Registry, South Australia, Adelaide; 2011.

4 Australian Institute of Health and Welfare. Chronic Kidney Disease in Aboriginal and Torres Strait Islander people 2011. Canberra Australia: AIHW; 2011. Report No.: Cat. No. PHE 151.

5 Stumpers S, Thomson N (2013) Review of kidney disease among Indigenous people. Australian Indigenous Health Bulletin 13(2).

About: Our Stories



"I need my children to be used to hospitals and understand the concept of dying because the reality for me is that even though my transplant's healthy at the moment, this is going to be part of my future."

Amber, Queensland

"Many people wouldn't appreciate how the impact is shared—you change your diet to suit theirs, you change your life to suit their dialysis and although you love them dearly, it can strain even a strong relationship."

Barbara, Western Australia



"Alex lives with Kidney Disease and a vision impairment. The support we have received from Kidney Health Australia has been amazing. Alex feels so special within this community! Our shy little girl who has suffered through many traumatic experiences, has grown in confidence and is treated like a superstar, I feel grateful and blessed!"

Rachel, Queensland

