

Kidney transplants in ADPKD

Find out when kidney transplants may be needed, how they are performed, what it's like to have this surgery, the risks and benefits, and alternative treatments available. If you're considering having a transplant, please also talk to your kidney specialist and transplant team for advice and information.

When might people with ADPKD need a kidney transplant?

Autosomal dominant polycystic kidney disease (ADPKD) is a genetic condition that causes cysts to grow in the kidneys. As these cysts gradually enlarge, kidney function falls, which results in kidney failure for many people [1]. In the UK, ADPKD affects an estimated 70,000 people [2], but not everyone with ADPKD will experience kidney failure.

If the kidneys are not filtering the blood properly, excess fluid and toxins collect in the body. This has harmful effects on all systems of the body. If you have kidney failure, you'll need dialysis or a kidney transplant to survive. Dialysis or a transplant are known as **renal replacement therapy** and replace some of the work your own kidneys can no longer do.

On average, people with ADPKD start renal replacement therapy aged 55 years, but this differs from person to person [2]. Of all the adults in the UK starting renal replacement therapy, approximately 1 in 14 (7%) have ADPKD [2].

Is kidney transplantation better than dialysis?

Kidney transplantation is the best renal replacement for ADPKD patients with kidney failure [1,3]. It improves quality of life and survival, and is cost-effective for hospitals to provide [4,5,6].

Having a kidney transplant before needing dialysis - known as pre-emptive kidney transplantation - has advantages over having a transplant after starting dialysis. These include: avoiding needing surgery to prepare for dialysis, having a better transplant and a longer survival time. It also reduces costs for the NHS [7].

In the UK, pre-emptive kidney transplantation is offered when your estimated glomerular filtration rate or eGFR (a measure of your kidney function) has fallen below 15 ml/min [7,8].



Martin had a pre-emptive, living kidney donation

“When I dropped below eGFR 20, it was suggested that I start thinking about live transplant. My great niece volunteered and was a really good match. From the time she agreed to donate to transplant was about 2¾ years. I had the transplant at eGFR 9, in October 2016.

“The transplant team told me that mine was a ‘textbook’ pre-emptive live donation. My niece sailed through it - she wanted food as soon as she came back from theatre! The transplant was on the Thursday and she went home on the Monday. I was in the full week. Once out, I was very well looked after by my wife.”



Nicki needed a transplant after having her own diseased kidneys removed

“Dialysis hardly worked for me at all. The doctors had said that my need for a transplant was urgent. Around 3 months after an operation to remove my PKD kidneys, the consultant felt I could risk going on the transplant list.

“Just one week later, I was at home and I received a call to go immediately to the hospital. I had no reservations about having the transplant even though I realised I was vulnerable to infection and still had pain from recent surgery. My creatinine* went from 1,400 to 100 overnight and I woke up feeling like a brand-new woman. I was well cared for and a future felt possible once again.”

**Creatinine is used to measure kidney function. High levels indicate poor function.*

Who can have a kidney transplant?

If your kidneys are failing, a kidney specialist and surgeon will thoroughly assess your health and do tests to check whether you’re suitable for the procedure.

Kidney transplantation involves major surgery. Most ADPKD patients with kidney failure are suitable for the procedure. However, people with severe diseases involving the heart, blood vessels or lungs, those with uncontrolled cancer or an active infection, and those with a predicted survival of only a few years aren't suitable [9,10]. They'll be offered dialysis instead [3].

ADPKD patients are more likely to have an enlarged blood vessel (an aneurysm) in the brain, which can be dangerous, especially during surgery [11]. Before the transplant, ADPKD patients with a family history of aneurysms need investigations for a brain aneurysm with magnetic resonance imaging (MRI) [11]. If an aneurysm is found, it should be treated before the kidney transplant operation [11].

Finding a donor

Kidneys for transplantation can be donated from living or deceased people.

A transplant from a living donor (usually a family member or friend) has several advantages [12]:

- shorter waiting times
- ability to plan the date of the procedure
- more time to check the donor matches you well, which reduces the chance your body will reject the donated kidney
- better chance of the donated kidney surviving
- improved survival for you

If a friend or family member is keen to donate a kidney to you but isn't a match, it might be possible to arrange for a kidney swap with another family or couple in a similar situation [13]. However, finding a living match is not always possible. About two-thirds (67%) of kidneys donated in the UK are from a deceased donor [14].

If you need a kidney transplant and don't have a living donor, you'll be put on the national waiting list. The average waiting time for a deceased donor kidney transplantation is 3 years [14]. Once on the list, you'll need to be able to get to the hospital whenever a donor kidney becomes available - this could happen at any time, day or night.

Matching the donor to you is done by testing your blood group and tissue type (using human leucocyte antigens or HLAs) [15].



Stephen found the wait hard, but coped by keeping fit

“There were some dark periods as one is waiting with a real chance of time running out before a kidney becomes available. Nonetheless I was determined to keep fit and look after myself so that I would be able to take the opportunity should the call ever come.



Rob had some false starts before a suitable kidney was found

“Life is quite normal; until you get the call! My first call was at 1 am. I went to Manchester Royal and had to wait around for about 30 minutes, then was given a bed. I was just in the middle of getting my gown on and a nurse came and said that the kidney wasn't good enough and I could go home. I arrived home at 3.30 am. A very surreal experience! I had a further 3 calls before I was successful.”



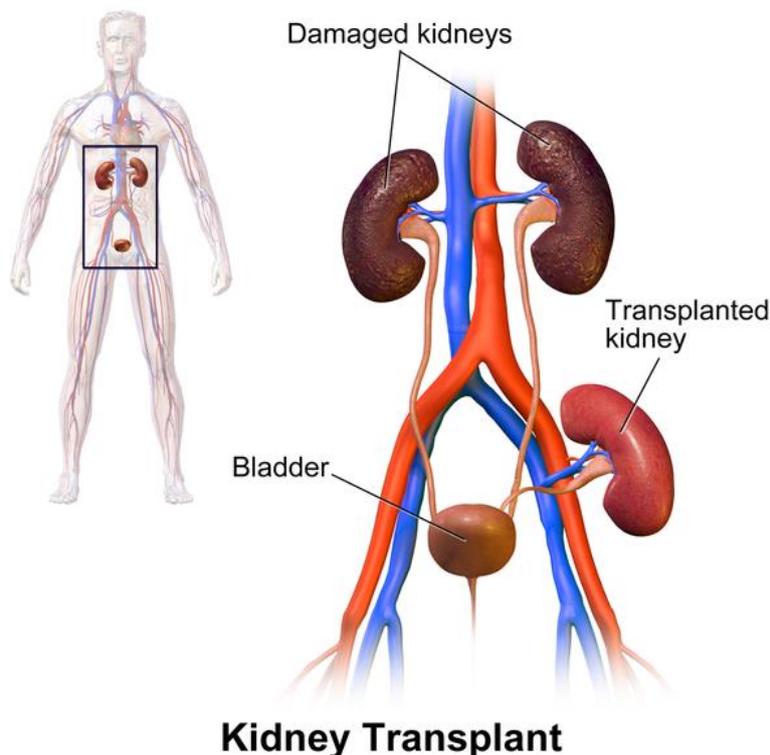
Andy found the wait for a donor kidney and liver a strain

“Being on dialysis was sometimes an emotional strain - and probably on loved ones too. Waiting for a donor with no set date rather than having a live donor planned is just that - a 'waiting game' and can be tortuous. But however hard dialysis could get, I remembered it was keeping me alive.”

How is a kidney transplant performed?

Most ADPKD patients don't need to have their own kidneys removed before their transplant [3]. However, this is sometimes done, for example if the kidneys are causing pain or bleeding, are infected, are taking up too much space in the abdomen, or if kidney cancer is suspected [3].

In the transplant operation, your surgeon will place your new kidney in your groin and connect it to your blood vessels and bladder (see Figure). This takes about 3 hours.



By Bruce Blaus (Own work) [CC BY-SA 4.0 (<http://creativecommons.org/licenses/by-sa/4.0>)], via Wikimedia Commons

After the operation

Most patients recover well after a kidney transplant and can leave hospital after about a week [16]. To prevent your body rejecting your donated kidney, your immune system will need to be dampened down using medication called immunosuppressants. Common immunosuppressants include tacrolimus, mycophenolate mofetil, prednisolone and sirolimus [17]. These should be taken without missing a single dose.

Your transplant team (including surgeon and kidney specialist) will closely monitor the doses of the drugs you're using to check your immune system is not being too strongly or too weakly suppressed. It's important to get the balance right. If your immune system is too strongly suppressed you'll be more likely to get infections (of bacteria, viruses and fungi) and could be at increased risk of developing cancer [17]. However, if you don't take enough immunosuppressant medication your body

will attack your donated kidney (known as rejection) [17]. Rejection of a transplant can be confirmed using a biopsy. Sometimes, rejection can be stopped with stronger immunosuppressants, but if rejection progresses it can lead to early failure and return to dialysis [15].

After your transplant, you'll be followed up in the transplant clinic. Initially this will be 3 times a week for 4-6 weeks. The visits are gradually spaced out to twice weekly, once monthly and so on. When you have had your transplant for 3-4 years, you'll only need to have 3 or 4 follow-up visits a year [15].



Ian had a kidney transplant in 2017

“The operation went smoothly and I woke in recovery as if nothing had happened apart from all the tubes. However, the following day I did feel nauseous, and was sick, then Day 2 started to go into full recovery, and Day 3 the kidney started working and all tubes were removed. On Day 5 I was able to come home.

Initially it went well. I have had a hiccup with a viral infection, but my lifestyle is getting back to normal. I'm feeling healthier, and about to start up physical fitness again. Even with the hurdles I've encountered, my GFR has been up to 65%, and I am looking forward to the future.”



Andy had complications after his joint kidney and liver transplant

“My operation was long and didn't go exactly to plan. I tried to stay pragmatic and positive about the recovery process which was not always easy or straightforward with infections, episodes of rejection and a 'sleeping' donor kidney.

“Everyone's experience is different - I was in hospital for about 10 weeks. I had a few overnight visits over the next 6 months, but things settled down gradually. I celebrate the little victories (like having my first wee in 2 years!). For me, my 12-month anniversary was most significant both physically and emotionally - that was when I felt I had turned a corner in my recovery.”

What are the risks of a kidney transplant?

Some patients experience problems after their kidney transplantation. These can include [8,17]:

- side-effects from immunosuppressant drugs, such as getting an infection, your kidney function falling, tremors in the hands and diabetes
- complications from the surgery which might need further treatment (including bleeding, urine leaking from the transplant, blood clots in the new kidney or narrowing of an artery or the ureter)
- your body rejecting the donor kidney - this happens within 6 months in about 1 in every 6 people (15%)
- long-term risks, including cancer, high blood pressure, weak bones (osteoporosis) and fractures

These problems can mean you need to stay in hospital for longer initially or return to hospital. Depending on the problem, you may need changes to your medications, additional medications and/or further surgery. You'll be very well supported by your kidney and transplant team who will monitor your health closely and immediately address any kidney or other health problems you develop.

Will my donor kidney work?

The survival of your transplanted kidney can be influenced by [12,15,17]:

- whether it was from a living or deceased donor
- the donor's age
- how well the donor's tissue type (HLA) matched your own tissue type
- whether your body tries to reject the kidney
- whether you've had failed transplants in the past
- whether you take your medication as instructed

Chance of your kidney transplant surviving

For people receiving a kidney from a living donor:

Over 9 out of 10 kidney transplants last at least 1 year



About 9 out of 10 last at least 5 years



About 6 out of 10 last at least 15 years



For people receiving a kidney from a deceased donor:

Over 9 out of 10 kidney transplants last at least 1 year



About 8 out of 10 last at least 5 years



About 5 out of 10 last at least 15 years



We show the chance of your kidney transplant surviving for 1, 5 and 10 years in the diagram below [14,15]. This is based on the average person receiving a transplant in the UK.

If your transplanted kidney fails, you'll need to go on dialysis or have another transplant. Your kidney specialist will explain your options if this happens.

How long will I survive after my transplant?

A kidney transplant can allow you to live many years. In the UK, 95 out of 100 people receiving a kidney from living kidney donor and 88 out of 100 people receiving kidney from a deceased donor, survive at least 5 years [14].

The length of time a person survives after their kidney transplant depends on a few factors. Survival tends to be longer in people who [14,18]:

- are younger
- have better overall health
- have a living donor
- receive a kidney transplant within a couple of years of developing kidney failure

On average, overall survival is longer for people with a kidney transplant versus those receiving dialysis [18].

What is life like after transplant surgery?

After having a kidney transplant, most patients find their quality of life significantly improves [2]. The dietary restrictions that you needed to make beforehand (such as the amount of fluid you drank, and amount of potassium, phosphate and protein you ate) are no longer needed after a successful transplantation. The majority of people receiving a kidney transplant return to their normal lifestyles within a year. Patients can enjoy increased energy levels and participate in sports. If their ADPKD was affecting their fertility, this usually returns to normal [19].



Stephen has got more active since his transplant recovery

“I have no dialysis and no dietary restrictions and my fitness is such that I play golf, have been back pedalling on the bike and I competed at this year’s Transplant Games. Life will never entirely return to what it was before, but every day feels like a massive bonus. I am immeasurably grateful to the medics and of course to my donor and his family.”



Nicki’s quality of life improved, but there have been challenges too

“I have been on quite a journey over the last 13 years [since transplant]. Certainly, this donation prolonged my life span and increased my quality of life immensely - I have been able to travel, gain a Master's degree, continue to work for some time and create a home for myself.

“I have also had to deal with the traumatic impact ADPKD has had on my emotional and physical health, and have had some unfortunate experiences of employers and colleagues not understanding what this has been like. Even so I wouldn't have had it any other way. To share life with another person is a great privilege in both directions.”



Rob found freedom from dialysis the biggest change

“Immediately after the transplant, my skin lost its yellow tinge and I gained a normal complexion. I felt normal again, just like I used to.

The biggest change was no longer being tied to dialysis 3 times a week, and once again being able to do all the things that I used to without having to take regular breaks. One thing I will never forget. How lucky I have been.”

Will having a kidney transplant cure my ADPKD?

A kidney transplant will replace much of your lost kidney function, but it won't cure your ADPKD. If your original kidneys aren't removed before your transplant, they might continue to grow, which can cause pain, bleeding and infections [20]. They can later be removed if needed in an operation called a [nephrectomy](#). However, it seems that the original kidneys often shrink after a transplant operation, so you might not need to have them removed [20]. It's safer not to remove them unless they're causing problems.

Having a kidney transplant doesn't stop ADPKD affecting your liver, and liver cysts often continue to grow [20]. If you have liver problems caused by your ADPKD, you'll need to have these treated separately.

What are the alternatives to having a kidney transplant?

Although kidney transplantation is the best type of renal replacement therapy for ADPKD patients with kidney failure, not all patients are suitable and some may choose not to have the operation.

The alternatives to having a kidney transplant are:

- dialysis using a machine to filter your blood (haemodialysis)
- dialysis using fluid placed in your abdomen (peritoneal dialysis)
- changes to diet and lifestyle and supportive medicines only, to ease your symptoms (this won't replace your kidney function).

More from the PKD Charity

- [ADPKD progression](#)
- The [PKD Charity's closed UK Facebook Group](#) - many members have experienced transplantation and provide helpful peer support

More information from others

- NHS Choices has information on [kidney transplantation](#).
- Organ Donation and Transplantation provides information on [UK Kidney Transplant Units, waiting times, and outcomes by unit](#).
- The NHS Blood and Transplant organ donation website provides [information for people considering donating an organ](#), including a [downloadable PDF on becoming a living kidney donor](#).
- The [British Transplant Games](#) is open to people who have received an organ transplant and immunosuppressant therapy. Ask your transplant clinic if you're interested in joining or supporting their team.

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