



Kidney Myth Busters

Patient Information



Working together for better patient information

This leaflet addresses some of the more common 'myths' about your kidneys and transplantation. For more information about the topics covered please visit www.kidneycareuk.org



General facts about your kidneys

Kidney disease is very rare

- Chronic kidney disease (CKD) is a common problem, affecting around 10% of the adult population.
- CKD becomes more common with age, affecting between 20-25% of people aged 65 to 74.

You need two kidneys to survive

- Most people with one kidney lead normal healthy lives.
- **There are several reasons why you may have only one working kidney:**
 - You may be born with only one kidney (renal agenesis) – and may not even know it!
 - You may have two kidneys at birth but only one that works (renal dysplasia)
 - You may have donated a kidney to someone else
 - You may have had one of your kidneys removed to treat a disease such as cancer
- There is an increased risk of higher blood pressure if you have just the one kidney but in most cases one healthy kidney can do the job of two.

If you have kidney disease you will definitely need dialysis

- You may never need to go on dialysis or have any treatment to improve your kidney function.
- Your need for dialysis is determined by the level of kidney function and the rate at which this is changing. This is estimated by the glomerular filtration rate (eGFR) which is the rate at which your kidney filter your blood.
- You will usually need to see a specialist kidney doctor if your eGFR falls to less than 30ml/min i.e. less than 30% function
- Discussions with you, your family, nurses and doctors will help you to make a choice about whether you would like and are suitable for treatment to improve your kidney function (dialysis or a transplant)
- You can choose not to have dialysis and just have treatment for your symptoms or any complications of your kidney disease. This is called conservative care.
- This ensures you will have a clear treatment plan, which can always be changed if your situation alters.

Kidney disease is curable

- Kidney disease is not curable. However there are treatments and lifestyle changes that can help to preserve your remaining kidney function. This includes stopping smoking and ensuring good blood pressure control.
- If your kidneys are working less than 10-20%, a plan will need to be made whether to replace the function of the kidneys with dialysis or transplantation or to choose conservative treatment.
- Replacing kidney function can be done via haemodialysis (filtering the blood outside the body using a machine), peritoneal dialysis (using your abdomen as a filter to remove fluid and toxins) or by a kidney transplant.
- A kidney transplant is usually the best treatment but unfortunately these are not suitable for everyone.
- Even following a kidney transplant you will still need to see your kidney team regularly to monitor your kidney function and manage your medications.

You can live the rest of your life on dialysis

- The average life expectancy on dialysis is 5-10 years but many people live much longer. Someone who starts dialysis in their late 20s can expect to live for up to 20 years or longer, but adults over 75 may only survive for 2 to 3 years. These are only estimates and as treatment improves, so does life expectancy.
- There will inevitably be a time when dialysis will need to stop. Reasons include your own choice, if it is no longer helping your quality of life, you are becoming more frail or have another illness or are having technical issues with carrying out the dialysis.

Diet and Lifestyle

Everyone can eat and drink on the haemodialysis machine

- Most people are able to eat and drink while having haemodialysis. High protein, light meals are recommended.
- However some people get cramps, low blood pressure, nausea and vomiting if they eat or drink during haemodialysis. If this happens to you, try eating a light meal a couple of hours before dialysis and bring a snack to eat soon afterwards.
- Your Dietitian will be able to provide you with suggestions.
- Some people eat crisps or other high potassium foods during their haemodialysis treatment as they think the machine will “clear” the potassium out. This is not true. It takes at least 3-4 hours for food to be digested and absorbed so the potassium will reach the blood long after you have finished your dialysis session.
- If you are on a low potassium diet at the recommendation of your kidney doctor or Dietitian, it is important that you stick with this and don't ‘slip’ while having haemodialysis



Everyone with kidney problems needs to follow a special kidney diet and you're not allowed to have bananas or chocolate anymore

- Not everyone with CKD needs to follow the same diet
- As your kidneys work less well you may need to change what you eat since your kidneys cannot get rid of harmful substances (e.g. potassium or phosphate) from your blood.
- By attending a specialist kidney clinic your blood potassium and phosphate levels will be checked regularly with a small blood test and you will receive personalised advice if it is necessary to change your diet.
- You may need to see a dietitian who will provide specialist advice to help you identify any foods you may need to cut down on and advise about suitable alternatives.
- It is unlikely that you will need to completely exclude any foods from your diet
- Further information may also be found in our leaflet on A healthy diet and lifestyle for your kidneys

Drinking alcohol will damage your kidneys, so you shouldn't drink alcohol

- Alcohol is not specifically harmful to the kidneys as it is cleared from the body by your liver.
- However you should aim to only drink alcohol in moderation and stick to the recommended limits for your overall well-being
- Check out www.drinkaware.co.uk for more information.

You need to drink eight full glasses of water (and only water) a day to flush out the toxins in your kidneys/body

- There is no medical guidance to support this for people with CKD.
- In fact as your kidneys function less well, they will be less effective in removing excess water and salt.
- You may be advised by your doctor to limit how much fluid (water, juice, tea, coffee, milk, soup) and salt you eat.
- Signs that you are retaining too much fluid include shortness of breath while lying flat or the need to sleep upright in bed, swollen ankles or weight gain.

Transplantation

A kidney from a deceased donor is no good/second best

- Kidney transplants can come from one of three sources:
 1. A deceased donor whose heart has been kept beating artificially on a ventilating machine after their death. The machine keeps the oxygen supply circulating in the organs so the kidney has a blood supply for longer. This is donation after brain death (DBD).
 2. A deceased donor whose heart has stopped beating. It is sometimes possible to use their organs if they have died in hospital and the operation can take place quickly. This is donation after circulatory death (DCD).
 3. A living donor – related, unrelated or altruistic (from someone you don't know).



All three sources have similar outcomes in the long term but there are some differences:

Donations from a deceased donor

About half of kidney transplants from deceased donors start to work within a few hours of surgery. If this doesn't happen ('delayed graft function' or a 'sleepy kidney'), you will need dialysis until the new kidney starts working. This may be a few days or sometimes a few weeks. You will need regular ultrasound scans of the kidney and a weekly kidney biopsy (where a tiny piece of tissue is removed from your kidney with a needle and examined under a microscope) to make sure that there are no other problems.

Donations from a living donor

Kidneys from live donors are functioning very well before removal. The process for removal and transplantation is much shorter. Any damage caused by the removal process is therefore minimised, and usually the kidney starts working immediately.

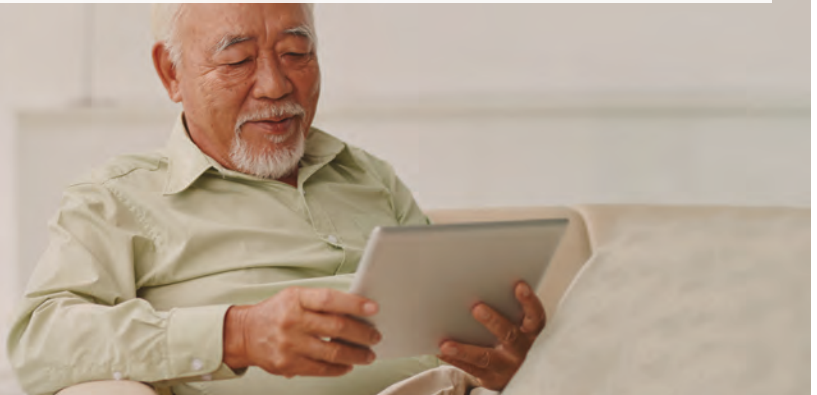
The table below shows the average survival rates for kidneys from deceased and live donors.

	Kidney survival rates Deceased donor	Kidney survival rates Live donor
At 1 year	85-90%	90-95%
At 5 years	70%	80%
At 15 years	50%	60%

I will definitely get a transplant if I'm on the list

- Unfortunately the demand for organs outweighs supply, even with more than 1,800 deceased donor transplants taking place annually.
- The transplant waiting list is not a normal list. It is not a case of first come, first served. There is no top or bottom of the list, and the time that people wait for a transplant varies.
- **Your chance of receiving a kidney will depend on a number of factors including:**
 - how well matched you are to the donor
 - immune system factors like blood group and tissue type
 - age similarity between donor and recipient.
- The average waiting time is around 2 – 2.5 years. Some people can be called with an offer within a few days of listing and others have to wait many years.
- People from South Asian, Black African and African-Caribbean communities may need to wait longer since donation rates are relatively low among these communities, therefore reducing the chance of a successful match being found.
- Sadly hundreds of people still die each year while waiting for a kidney transplant.

You must let the unit know if you're going abroad or are unwell so you can be temporarily suspended on the list. Your suitability to be listed will be continually assessed at transplant appointments



I've had one transplant so I won't get another

- Most people can have further transplants if a transplanted kidney fails. However you may have to wait longer as it can be harder to get a good match.
- The success rate for second or third transplants is generally as good as for the first.
- You will also need to go through the same tests again to make sure you are healthy enough to have another kidney.

You need to live within 2 hours of the transplant unit and race to the unit as quickly as possible when called

- It is not a race to get to the unit but ideally your operation should take place within 24 hours to give the transplant the best chance of working.
- You should get to the hospital as soon as you can while still staying safe.
- Kidneys may come from across the UK so the doctor will tell you how long you have got when they call.
- Usually there is enough time to pack a bag and notify your family.
- **Before you leave home:**
 - 1.** Arrange for someone to bring you or get a taxi. Driving yourself will mean you will have to pay parking fees. Transport cannot usually be arranged for you.
 - 2.** Stop eating and drinking. This is crucial since your stomach needs to be empty when the operation begins.
 - 3.** Bring in your current medications – including insulin, EPO and any over the counter drugs - night clothes, belongings, small amount of money, any reading/music materials.

Please note you may be called at any time day or night with an offer of a kidney. Therefore you need to be contactable and give your unit details of family/friends to get hold of you. You must let the unit know if you're going abroad or unwell so you can be temporarily suspended on the list



I can't get pregnant with kidney failure /after donating/receiving a kidney

Pregnancy in CKD

- It is possible to get pregnant at all stages of CKD. However, the better your kidney function, the greater the chance of a successful and uncomplicated pregnancy.
- If your creatinine level is above 125 or 250 amol/litre you have a much greater risk of problems during pregnancy
- With late-stage CKD, we recommend women have a transplant before trying to conceive .
- You may be advised to wait a year after your transplant before trying to get pregnant, to make sure that the transplant is stable.
- For individual advice please discuss with your kidney doctor.
- Further information can be found in our leaflet on **Pregnancy and Chronic Kidney Disease**

If you are not intending to get pregnant you must use effective contraception with condoms or progesterone only (e.g. the Pill, implant or Mirena coil)



Pregnancy post-transplant

- After a successful transplant most women's fertility will improve and you will usually be able to get pregnant.
- The general advice is to wait one year following your transplant when your kidney function is stable.
- Some medications, including some anti-rejection drugs, have harmful effects on a developing baby. So before trying to conceive, it is important that you talk to your doctor about changing you to safe and effective medications for you, your baby, and your transplant.

Donors

- Most women have uncomplicated pregnancies after donation.
- There is a slightly increased risk of having complications such as high blood pressure or pre-eclampsia - a serious illness causing high blood pressure and protein in the urine, which can happen in the second half of pregnancy.
- You should tell your GP if you are intending to get pregnant since you will require more frequent health checks





Where can I find out more information?

- Think Kidneys:
www.thinkkidneys.nhs.uk/aki/information-for-the-public/think-kidneys-almost-everything-you-need-to-know-about-your-kidneys
- Patient View: www.patientview.org - Online access to your health records. Ask your renal unit for details about how to join



 www.kidneycareuk.org

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