



Information for people who may need a kidney transplant in the future





REACH Transplant is a Scottish Government initiative to provide information about living donor kidney transplantation to those who may need a kidney transplant in the future.

This booklet has been developed in conjunction with NHS Blood and Transplant's Living Transplant Initiative. We hope that it will be a useful resource for patients who have been diagnosed with chronic kidney disease (CKD) and who may need a kidney transplant in the future.

You may find it helpful to give this booklet to family members or friends. By learning about CKD, they can help to support you - now, and in the future.

A kidney transplant recipient who helped shape the contents of this booklet said:



We have read through the booklet and found it to be like taking a walk back in time with the experience we had going through the process. We felt it covered all the important details. Excellent information pack.



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1. What do healthy kidneys do?

Healthy kidneys are always working hard to:

- Remove waste products and excess fluid from our blood
- Produce urine
- Control our blood pressure
- Make red blood cells
- Keep our bones strong.

When your kidneys are damaged, they can't carry out these functions as well as before.



2. What is chronic kidney disease (CKD)?

Chronic kidney disease (CKD) is when your kidneys are permanently damaged and no longer work normally. CKD is common in the UK, with almost 1 in 10 of the population affected.

CKD has many possible causes, such as diabetes, high blood pressure, autoimmune disorders and some inherited kidney diseases. Sometimes, the cause is unknown.

Many people don't find out that they have CKD until they have a blood test for some other reason. This is because mild to moderate CKD does not usually affect how someone feels in their day to day life.

3. How severe is my chronic kidney disease (CKD)?

When you see your kidney doctor (often called a nephrologist), a blood test is used to check your estimated glomerular filtration rate (eGFR). Your doctor uses this information to tell you how well your kidneys are working now and what is likely to happen to your kidney function in the future.

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
eGFR >90	eGFR 89-60	eGFR 59-30	eGFR 29-15	eGFR <15

For example, an eGFR of 25 means that your kidneys are working at roughly 25% of normal kidneys and that you have CKD Stage 4.

4. What are the symptoms of chronic kidney disease (CKD)?

People with mild to moderate CKD don't usually have any symptoms. Symptoms of CKD usually only start to appear when it is quite advanced.

In some people, CKD may cause tiredness, loss of stamina, shortness of breath, swollen ankles, poor appetite, nausea, itching and difficulty sleeping. Initially, many of these symptoms can be managed with medication and diet/lifestyle changes.

Your kidney doctor will give you advice about this. For example, your doctor may:

- prescribe medication to control your blood pressure, keep your bones strong, prevent anaemia and relieve any itching;
- ask a dietician to give you advice about what to eat and drink; and/or
- advise you to stop smoking, maintain a healthy weight and keep as active as possible.

Depending on the cause of your CKD, there may be specific treatments to help slow the decline in your kidney function – your doctor will tell you about these.

By following your doctor's and dietician's advice, you can give your kidneys the best chance to keep working for as long as possible.

You can usually keep fairly well until your kidney function gets to around eGFR 10-15.

5. What if my kidney function gets worse?

Unfortunately, for some people with CKD, their kidneys gradually get worse over time, until they are doing very little work at all. This can happen even if you have tried your best to follow your doctor's advice about keeping your kidneys healthy.

This is called CKD Stage 5 or end stage kidney disease (ESKD). This is an advanced stage of CKD that will need to be treated with kidney transplantation or dialysis, to relieve your symptoms and to keep you alive.



6. When should I start planning for treatment?

If your kidney doctor thinks that you are likely to develop CKD Stage 5/ End stage kidney disease (ESKD), he/ she may start discussing treatment options with you, such as transplant and dialysis, months or even years before you actually need these. This is to give you plenty of time to learn about your treatment options and to make decisions about your care in the future.



In particular, if your doctor thinks that you are healthy enough to have a kidney transplant, this is a good time to explore whether someone you know might wish to donate a kidney to you, as a living kidney donor.

Living kidney donation has many advantages, including making it more likely that you can have a transplant **before** your kidneys stop working well enough to keep you well. This is called a pre-emptive transplant and avoids you needing to have dialysis while you are waiting to have a transplant.

Dialysis is a treatment that cleans your blood when your kidneys can't, while you are waiting for a transplant. It is an effective and life-sustaining treatment, which can be done in hospital or at home. Unfortunately, dialysis can only replicate about 10% of your kidney function. This means your quality of life is usually better with a kidney transplant, compared to being on dialysis.

7. What is involved in having a kidney transplant?

Having a kidney transplant means having an operation to insert a healthy kidney into your lower abdomen – your own kidneys are usually left where they are. The transplanted kidney takes over the work of your damaged kidneys.

A transplant is not a “cure” for CKD. It involves a major operation and means that you will have to take medication for the rest of your life, as well as regular hospital appointments. However, in terms of your quality of life and how long you will live, a transplant usually offers the best outcomes.



8. How do I know if I can have a transplant?

To make sure that you are well enough to have a transplant, you will need to have a number of tests, such as x-rays and scans. You will also be seen by a transplant surgeon and a transplant coordinator as part of the assessment process.

The clinical team will make sure that you understand the benefits and risks of a kidney transplant, so that you can decide if transplantation is right for you.

9. What if I am overweight?

There are increased risks when having a kidney transplant in people who are overweight or obese.

Body mass index (BMI) is a measure that uses your height and weight to work out whether your weight is healthy:

- BMI of 18.5 and 24.9 – healthy weight range
- BMI of 25 and 29.9 – overweight range
- BMI of 30 and 39.9 – obese range

If your BMI is between 35-40 your clinical team will assess whether you are suitable for transplantation at your current weight. Even if your BMI is below 35 but still in the overweight range, your risks during and shortly after a kidney transplant will be reduced if you are able to lose some weight.

A BMI of over 40 is often a barrier to transplantation. If you need to lose weight for transplant, please ask to be



referred to your local Renal Dietitian or Weight Management Service for advice. If you are unsure of your BMI please ask your health care team to explain this to you or, if you have a smartphone, scan this QR code which will take you to an online calculator.



10. Where do kidneys for transplant come from?

Kidneys for transplant come from:

- living donors (healthy people who donate one of their kidneys) and
- deceased donors (people who donate their organs after death.)

1 in 3 kidney transplants in the UK involve a living donor. Living donor kidney transplants are usually performed twice a week in Scotland.

A kidney transplant from a living donor has some important advantages. A kidney from a living donor tends to work better and longer than a kidney from a deceased donor.

All major religions support living kidney donation.

Although a kidney transplant from a deceased donor can be an excellent treatment, due to the shortage of kidneys from deceased donors, you are likely to wait longer for a kidney from a deceased donor than if you have a suitable living donor.

Both types of transplant are much better than having no transplant at all.

11. How soon can I have a kidney transplant?

If you are well enough to have a transplant, the best time to have this is when your doctor thinks that you are about six months from otherwise needing to start dialysis.

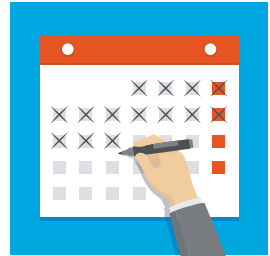
If you have a living kidney donor who has already completed their assessment process, the transplant operation can take place at this point - before starting dialysis. This is why it is useful for potential donors to start their assessment process early, about 1 - 2 years before the transplant is needed..

Having a kidney transplant before you need to start dialysis is called a pre-emptive transplant. This has some benefits compared to waiting longer for a transplant. The less time you spend on dialysis, the better for you.



12. How long will I wait for a transplant?

If you are well enough to have a transplant, you can be registered on the UK Transplant Waiting List when your doctor thinks you are about six months from needing dialysis. Once you are registered, you are eligible to receive offers of kidneys from deceased donors.



The waiting list is not a queueing system (although you do get some credit for the length of time you've been waiting). Rather, when a kidney from a deceased donor becomes available, it is offered to the person on the waiting list who is likely to benefit most from it. This is not usually the person who has been waiting longest, nor the person who is the most unwell.

Since there is no way of knowing which donated kidneys are going to become available, it is very difficult to predict how long you will wait for a kidney from a deceased donor. The average waiting time in Scotland is about 2–3 years. However, this varies widely and means you will likely need to start dialysis before you receive a transplant from a deceased donor.

There is no guarantee that a suitable kidney from a deceased donor will ever become available. Occasionally, people get removed from the waiting list, because they have become too unwell to go through a transplant operation safely.

You can be on the waiting list, and receive offers of deceased donor kidneys, while your living donor is being assessed.

13. Should I go abroad for a kidney transplant?

Some people who need a kidney transplant think that they can have their operation sooner by going overseas to receive a transplant. It is important to know that there may be real risks involved in travelling abroad for a transplant, whether from a living donor or a deceased donor.

Depending on the country, the risks of infection and rejection of the new kidney may be higher than in the UK. It is also harder for your UK clinical team to give you the correct care after an overseas transplant.

For anyone in Scotland, it is an offence to seek, offer or receive payment or reward for donating organs for transplant. It is also an offence to initiate, negotiate, advertise or be involved in buying or selling human organs for transplantation anywhere in the world.

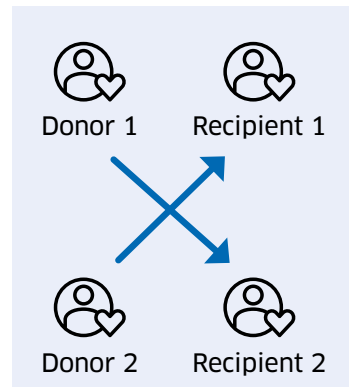
A transplant from a living or deceased donor in another country can be undertaken legally, when it is within approved legal, ethical and healthcare frameworks. For example, some people may travel abroad legitimately to receive an organ from a living donor, for example a sibling.

14. Who can be a living kidney donor?

Many living donors are family members or the spouse/partner of the recipient (person who receives a transplant). However, a kidney donor does not need to be related to the recipient – they could be a friend, colleague, teammate, neighbour or even someone who doesn't know you very well.

A healthy person who becomes a living kidney donor can live a completely normal life with just one kidney. Their remaining kidney increases in size and capacity, to make up for the removal of the donated kidney. Donors are thoroughly assessed to make sure the risks of donating are acceptably low.

A living kidney donor doesn't have to be a "match" (compatible) with the recipient. If your donor's blood group or tissue type is incompatible with yours, they can still donate a kidney to you through the UK Living Kidney Sharing Scheme. This is where an incompatible donor and recipient pair are matched with another incompatible pair in order to "exchange" donated kidneys.



Some compatible donor/recipient pairs also use the UK Living Kidney Sharing Scheme to get an even better match.

If someone would like to be assessed as a living donor, don't discourage them just because they've had some health problems. Potential donors are thoroughly assessed to make sure it would be safe for them to donate a kidney.

There is no upper age limit (although older donors may need to have some extra tests) and every donor is assessed as an individual.

Potential donors who are obese will be advised to lose weight before donating, although initial stages of the assessment process may be carried out while they are doing this.

Starting the living donor assessment process does not commit someone to donating a kidney – there are many reasons why people do not (or cannot) go ahead with donation, and people often have to opt out of the process for a wide range of reasons. This is always managed very sensitively by the clinical team.



15. How can I find a living kidney donor?

Some people find it difficult to talk about living kidney donation with their loved ones. You may feel uncomfortable “asking” someone to be a living donor. This is normal. Try to be as open as you can about your kidney problems and treatment options.

The vast majority of donors say they would not change anything about their decision to donate. They would make the same decision again to help someone. Even if someone has offered to donate, you may feel uncomfortable with the thought of accepting a kidney donated by someone you know. This is also normal. Try to listen carefully to their reasons for wanting to donate.



If you find it difficult to broach the subject of living kidney donation with your family and friends, it can be helpful to discuss this with your clinical team. They can give you some ideas about how to start the conversation.

If your kidney doctor thinks that you will need a transplant in the next year or so, he/she will ask a nurse to visit you at home to discuss this. Many people find a home visit, where family and friends are encouraged to attend, is a valuable opportunity to learn about kidney disease, transplantation, dialysis and living kidney donation in a relaxed setting, with plenty of time to ask any questions you may have.

Your nurse can also help you explore the idea of living kidney donation in a way that you feel comfortable with.

Using social media

Some people who are looking for a living kidney donor use social media to appeal to the public to highlight their need.

For some, this can be effective means of communication, with positive results. However, for others it could result in a negative and disappointing experience. Be aware that some people might well volunteer, but later either decide not to donate or not be able to donate for a range of reasons, so you need to be prepared for that.



Before you think about appealing on social media for a living donor, please speak to your local Living Donor Transplant Coordinator or REACH Transplant Nurse Specialist and tell them of your intention, as they can help and offer some good advice on this.

16. How do potential donors start the assessment process?

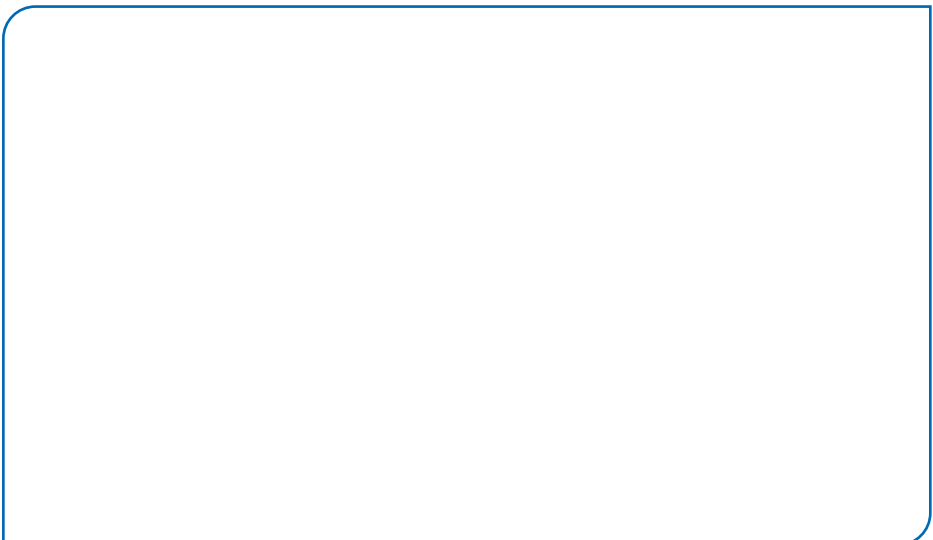
Potential living kidney donors should contact the Living Donor Transplant Coordinator team for the NHS Board where you (the recipient) are cared for.

Contact details and a healthcheck questionnaire are available on the Living Donation Scotland website (www.livingdonation.scot) or from your local REACH Transplant Nurse Specialist.

Contact

www.livingdonation.scot

REACH Transplant Specialist Nurse name and contact details





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