Let’s Talk About Transplant

I didn’t want to take his kidney, but once I knew they would check him over and over and if he wasn’t fit, it wouldn’t go ahead, I agreed. I want to be there for him, my other kids and my grandkids into the future.”

Brian received a kidney from his son Scott.

I have two potential donors, but I know that I am not blood group compatible with either of them. Should they still contact you?

Yes – there are a number of options that can be explored in this situation and the transplant team will advise both potential donors.

The UK living kidney sharing scheme makes it possible for you to be matched with other donor/recipient pairs in the same situation and the donor kidney ‘exchanged’ or ‘swapped’.

Where can I find out more information and advice on living kidney donation?

Visit:
livingdonationscotland.org

Email:
livingdonationscotland@nhs.net

Call:
Contact the Living Donor Transplant
Co-ordinator at your nearest Transplant
Unit on:
Edinburgh 0131 242 1703
Glasgow 0141 451 6199

Thank you will never be enough. I have a family and a future and will be forever grateful.

Julie, Kidney Recipient
Discussing living kidney donation if you need a kidney transplant

The best option for most people who need a transplant is a kidney from a living donor. There have been many changes and advances in living kidney donation over the past 10 years, but we know it can be a difficult subject to raise with family and friends. This leaflet aims to help you start that conversation and answer some of the questions you and they may have.

Why is a living donor transplant the best option?
In most cases a kidney donated by a living donor offers you the best long term outcome. Studies have shown that the average patient survival at 10 years is 90% with a living donor transplant compared to 75% after a deceased donor transplant. These are both much better than having no transplant at all.

Do I need to be related to my living donor?
No – nowadays anyone can donate. It is very common for partners or friends to donate. Even if you are not a match there are a number of options to explore with improved anti-rejection treatments and a kidney sharing scheme in the UK.

My name is on the transplant list – should I just wait?
The earlier you can get a transplant the better – preferably before starting dialysis or at least minimising the time on dialysis. If there is an opportunity to discuss potential living kidney donation with friends and family it would be good to explore this option as early as possible.

My potential donor is willing to be tested, but we can’t afford for them to be off work.
There is a scheme for reimbursement of reasonable expenses relating to living donation, so if the donor does not receive sick pay from work they may be eligible for reimbursement of loss of earnings and other expenses. Ask your local living donor transplant co-ordinator or specialist nurse at an early stage in their assessment.

I think my potential donor is too old
There is no upper age limit to being a living donor – everyone is assessed as an individual. Every potential donor that comes forward undergoes a number of standard investigations, and often extra tests, if required. The risks involved are carefully explained to both donor and recipient.

My son and daughter are both keen to donate to me, but I don’t want them to take the risk.
This is a common concern from parents or anyone being offered a kidney from a younger person – but please discuss and listen to their views and reasons. A kidney will never be removed from a living donor until the team are satisfied that the short and long term risks to the donor are low. All risks are explained in detail during the donor assessment.

It’s humbling to know what a loved one is willing to go through for your health. Thanks to all those involved we came through it even stronger and closer than before." John

Being part of the kidney sharing scheme meant that it wasn’t just us, but other people too that benefited at the same time – amazing!" Eleisha

John & Eleisha, husband and wife.

I think my brother or sister would be a better match – what should we do?
If any of your family or friends have expressed a wish to be tested, ask them to contact the living donor transplant co-ordinator or specialist nurse at your unit. They will discuss with your family and friends the most suitable person to progress with the assessment, depending on circumstances and initial tests. Visit www.livingdonationscotland.org for contact details.

How do I raise the subject with friends and family?
We know it can be a difficult subject to raise. The best way is to give everyone the facts: you need a transplant and a kidney from a living donor is your best option. Explain what you know about life on dialysis and the improved life expectancy with a kidney from a living donor. Tell them there are more than 6,000 people in the UK waiting on a kidney. If they would like to know more they can visit livingdonationscotland.org, which will give them more information on the process and exactly what is involved. Or they may wish to speak to someone, in which case they can find the number for their local specialist unit via the website.

Some people use social media to share their story – we would advise discussing with your transplant co-ordinator or specialist nurse how best to manage this.