Living kidney donation and raising the subject with family and friends

The best treatment 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.

Why is a living donor transplant the best option?

In most cases a kidney donated by a living donor offers the best long-term outcome for the recipient. 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 options 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 several options to explore with improved anti-rejection treatments and a kidney sharing scheme in the UK. Some people use social media to raise awareness – please discuss this with your transplant coordinator before you involve social media so that you can agree how best to approach it.

My name is on the transplant list – should I just wait?

The earlier you can get a transplant the better it is for you and to live your life – preferably before starting dialysis or so that you are on dialysis for as short a time as possible. If there is an opportunity to discuss potential living kidney donation with friends and family then it may be good to explore this option as early as possible.

How do I raise the subject with friends and family?

We know it is a difficult subject to raise. Probably 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 much-improved life expectancy with a kidney from a living donor. Tell them there are more than 5,000 people in the UK also waiting on a kidney. If they would like to know more they should contact their local unit or better still, the unit or transplant centre where you are being seen – the best person to speak to is a living donor transplant coordinator who knows you or can find out about you and advise people who may be thinking about donation to you. The contact list for living donor coordinators in every centre is available here: www.organdonation.nhs.uk/livingdonation.
I think my potential donor is too old
There is no upper age limit to be a living donor – everyone is assessed as an individual. Every potential donor that comes forward undergoes several standard investigations, and often extra tests, if required. The risks involved are carefully explained to both donor and recipient.

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

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 reaction from parents or anyone being offered a kidney from a younger person – but please discuss and listen to the donor’s views and reasons. A kidney will never be removed unless the person really wants to donate, and the team are satisfied that the short and long-term risks to that person are low. All risks are explained in detail during the donor assessment.

My friend has said she wants to be tested, but I think one of my siblings 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 coordinator or specialist nurse at your unit or transplant centre. He/she will discuss with your family and friends as to who might be best placed to progress with the assessment, depending on circumstances and initial tests.

NOTES