

Could I be a living kidney donor?



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NHS Organ Donor Register

0300 123 23 23

www.organdonation.nhs.uk



Barbara Ryder gave a kidney to a stranger, Andy Loudon who was suffering from polycystic kidneys.

"The kidney was literally a spare part which you can do without. I thought 'Good. At last I can do something physically useful.'"

Chris Kemp, who gave a kidney to his son, Oliver.



"Having only one kidney certainly doesn't stop me doing things. Oliver and I joke about the transplant sometimes. I tell him he's had my money – he might as well have my body!"



Tom Bortey (right), who received a kidney from his brother George.

"If my brother hadn't donated his kidney there would have been no hope for me. I owe it to other black people to tell them our story, so they can think about making a donation."

Paulette Cain, who donated a kidney to her husband, David.



"People say it was a generous thing to do. However, in reality, I wanted it for myself and Jade, our young daughter, as much as for David because the strain on our lives was so great."

Donating a kidney is a major decision and it takes courage to be a kidney donor. There are many things that you should know before considering kidney donation and this leaflet hopes to answer some of your questions.

Kidneys may be donated by people who have died or by living donors who either wish to help a loved one, or a stranger, with kidney failure by giving a kidney.

It is important that anyone who wants to be considered as a living kidney donor thinks seriously about the possibility.

Points to consider are:

- the survival of transplants from living donors is significantly better, allowing more people to receive and benefit from a kidney transplant
- living donors who are close relatives can be an excellent tissue-type match for the recipient and this can be an added bonus for the recipient
- unrelated donors, such as spouses, are unlikely to be well matched to the recipient. However, in all but the perfectly matched situation, the success rates of these transplants are equal to those of related donors
- living kidney donation allows the transplant operation to be planned at a time that is convenient for the recipient and the donor and for some people this can be planned before the need for dialysis
- recipients who are transplanted prior to dialysis have better long-term transplant survival.

Living kidney donation in the UK is increasing. This is against the following background:

- the number of people needing kidney transplants continues to increase
- there are not enough kidneys from donors who have died available for transplant
- the average waiting time for a kidney transplant is two and a half to three years and for some minority ethnic groups and individuals with rare tissue types, it may be more than five years.

Frequently asked questions

Who can donate?

Donors are often a close relative such as a parent, brother or sister, son or daughter but may also be individuals who are not related but have an established emotional relationship with the recipient such as a partner or close friend.

Sometimes a donor and a recipient may be incompatible with each other because of blood group or antibody incompatibility and in this case it may be possible for them to be paired with another donor and recipient in the same situation. This means that each recipient will benefit from a transplant that they would otherwise not have had (this is called paired donation). Where more than two pairs are involved in the swap it is called pooled donation.

Increasingly people are putting themselves forward as non directed altruistic donors. These are individuals who are unknown to the recipient.

What is the minimum age for being a donor?

In England, Wales and Northern Ireland, there is no minimum age limit specified within the Human Tissue Act 2004 for a person to be considered as a living kidney donor. However, the majority of donors will be over the age of 18 years and children would only be considered in very exceptional circumstances, and this would require court approval. In Scotland, only people over 16 years of age can be legally considered as living kidney donors.

How will I know if I am suitable to donate?

You will have a thorough medical, surgical and psychological assessment to establish that you are fit and healthy to donate. A number of people who wish to donate find that they are not able to do so because health problems are discovered through the assessment process. Members of the healthcare team involved in your assessment include doctors, nurse co-ordinators, counsellors, psychologists and social workers.

Are there any risks to me?

All operations carry some risk and this is no different for living donation. Donors are at risk of infections (eg chest, wound or urine) and, more rarely, bleeding or

blood clots. There is a very small risk of death for the donor: this is estimated at 1 in 3,000 for this operation.

Are there any long-term risks?

There is a small possibility of a slight rise in blood pressure and excess protein in your urine. However studies have shown that there is no long-term effect on the health of the donor or your remaining kidney.

Am I at greater risk of developing kidney failure?

You are at no greater risk of developing kidney failure after donating than anyone in the general population.

Will it shorten my lifespan?

Studies have shown that donors live longer than the average population. This is because donors are selected on the basis of good health and are thoroughly screened prior to donation.

Will I have to change my lifestyle after donating?

No. You should lead a normal healthy life as before.

Will donating my kidney affect a future pregnancy or fathering a child?

The small amount of data available shows that, having donated one kidney, there is no evidence to suggest an increased risk of complications during pregnancy. A man's fertility will not be affected.

Will I be covered by my health insurance?

You should check with your insurance company.

What if I live in a different part of the UK from the person I am donating to?

You can still donate. The transplant team can arrange for your donor assessment to take place at a hospital near you if that is more convenient for you. Usually the donation will take place in the hospital where the person you are donating to is cared for. However, different arrangements can be made depending upon individual circumstances for both the donor and recipient.

What if I live overseas?

You can still donate. Some preliminary tests can be arranged in your own country to see if you will be a suitable donor.

What are the religious views on living donation?

Most religions support living donation as they view it as a gift to a loved one. If you have any doubt, you should contact your religious leader.

How long does the donor assessment process take?

In general, this will take at least three months. There is variation depending upon where you live and what tests you may require. Wherever possible, the assessment is tailored to your needs and commitments.

How much time will I need to take off work?

Most transplant centres will try to arrange the tests and investigations before the operation around your work schedule to minimise disruption to your job. It is sometimes possible to arrange for some of this to be done locally if the donor lives a long way from the transplant centre. The operation and recovery period varies from 2 - 12 weeks depending on surgery, your individual recovery and the type of work you will be resuming.

How will I be able to afford time off work?

You should discuss this with your employer and find out what is available under your (their) terms of employment around Statutory Sick Pay. You may be eligible for reimbursement of loss of earnings and costs. However, reimbursement is at the discretion of the recipient's health care providers. You will need to discuss this with your transplant team.

What if I am in receipt of a benefit such as job seeker's allowance?

You should take advice about this by contacting your local Citizens Advice Bureau.

How is the kidney removed?

You will be given a general anaesthetic which means that you will be asleep during the operation. Traditionally, the kidney has been removed by making an incision in the side or abdomen (tummy) which is known as the "open" technique. This procedure is still used but now keyhole surgery has become more common and is offered in many centres around the UK. Increasingly, keyhole surgery is used to remove the kidney and this is also available in a number of transplant centres in the UK.

How long will the operation take?

The operation takes approximately two hours and you will have a urinary catheter and a drip when you return from theatre.

How long will I be in hospital?

This varies depending on your individual recovery. The average stay is three to seven days.

Will I experience a lot of pain?

Strong pain relief will be provided to help alleviate pain and discomfort after the operation.

Will I need to take any medication after donating?

You will need to take some painkillers immediately after the operation and during the recovery period. You may also be prescribed antibiotics for a short period if you need them. However, you will not need any long-term medication as a result of kidney donation.

What about follow-up?

You would usually be seen by the transplant team between two and six weeks after donation. We recommend that you attend an annual follow-up appointment, if you wanted this, for the rest of your life.

Do some donors have trouble making the decision?

Some people make the decision easily. Others go through some soul searching before deciding. Being afraid of donating a kidney or feeling guilty about not wanting to

donate is quite normal. The only “right” decision is the one that makes you, the potential donor, feel comfortable. Finding out more information about living donation and what it involves may help you with this decision.

Can I speak to somebody who has donated?

Your co-ordinator at your local transplant centre should be able to arrange this for you.

Suppose I decide against being a donor?

You have the right to withdraw your offer at any time and you would be supported in your decision by the transplant team.

Who makes the final decision?

Once all the tests have been completed and found satisfactory by the transplant team, a date is set for the operation. The transplant will only take place if both the donor and recipient are willing to proceed.

Will the transplant be successful?

There is no guarantee that any kidney transplant will work. However, living kidney transplantation is overwhelmingly successful with 96% of live donated kidneys working well at one year. This compares with a success rate of 93% for kidneys from deceased donors.

What is the first thing I should do if I am thinking about being a donor?

If you know the person who you are considering donating to, you will need to contact the hospital/transplant centre where the intended recipient is cared for. The first piece of information we would need to know is your blood group to see if it is compatible with your recipient. After this an appointment will be arranged for more detailed discussion and initial blood tests. If you do not know who the intended recipient might be, the best thing to do is to contact your local transplant centre for further advice.

What governs living organ donation in the UK?

In England, Wales and Northern Ireland the Human Tissue Act 2004, and in Scotland the Human Tissue (Scotland) Act 2006, provide the legal framework for

organ and tissue donation in the UK. The Human Tissue Authority (HTA) regulates the donation by living people of solid organs and part organs. The HTA must have given approval before any living donation can proceed. All donors will be assessed by an Independent Assessor, who is trained and accredited by the HTA, as a routine part of the evaluation process to ensure that all the legal requirements have been met. The law requires that the donor must fully understand the nature and risks of the procedure and there must not have been any coercion, pressure or payment involved in the donation of the organ or part organ, which is illegal in the UK.

Donating a **kidney to a child**

The average waiting time for a kidney transplant (from a non-living donor) for children is between six to twelve months and for some children the wait can take up to five years.

Where a child is involved, donors are normally a close relative with parents being the most usual donors. Grandparents or siblings can also be considered depending upon their age and aunts, uncles and other family members or close friends can donate if tissue matching is suitable.

Frequently asked **questions**

Will I be operated on in the same hospital as my child?

This depends upon where your surgery takes place. Some hospitals look after both adults and children whilst others are exclusively for children. Wherever you are, there will be a team of people caring for each of you. The donor assessment and operation will always be performed in an adult transplant centre. This will be nearby if you and your child are cared for in separate hospitals.

If I am in a different hospital how long will I be separated from my child?

As a kidney donor you will need time to recover from the immediate effects of the surgery. This is dependent

upon the type of operation you have and your individual recovery. You should be able to leave hospital after three to seven days. You will be anxious to see your child but it is also important that you rest as much as possible in the first few days to help your recovery. The staff in the transplant centres will help you stay in touch by telephone and will keep you fully informed of your child's progress. Family members and friends will be able to visit both of you. If you are in separate hospitals, you will be able to see your child once you have been discharged home.

If I am the parent and the donor, who will care for my child whilst I am in hospital?

You will need to plan for the care of your child whilst you are in hospital well in advance and staff can help you to do this. In some families the non-donating parent stays with the child but a grandparent, aunt, uncle, or close family friend may be nominated instead. Whoever it is, it needs to be someone both you and your child feel comfortable with and who understands what is involved in being with your child in hospital. You can speak to your child's doctor or nurse about this and they will be able to give you more information to help you decide. It is important to make childcare arrangements for any other children you may have and for some help at home immediately after you leave hospital. There are people who may be able to help you with this and any other practical concerns you may have.

If we are in the same hospital will I be able to see my child?

The staff caring for both you and your child realise how important it is that contact is maintained. They will do their best to keep you and your child informed of each other's progress.

If I am donating, how long will it take me to recover?

Recovery can take between two to twelve weeks, depending upon the donor operation and your individual progress. You will need to rest following discharge from hospital. You will need help caring for your child and with day-to-day domestic tasks.

Sources

UK Living Donor Kidney Transplantation, BTS & Renal Association, 2nd Edition, April 2005

Living Donor Kidney Transplantation: Your Questions Answered, Gift of Life, 2005

Information about living donor transplants, Human Tissue Authority, 2006

Organ donation and religious perspectives, NHSBT, 2009

Waiting Time on Dialysis as the Strongest Modifiable Risk Factor for Renal Transplant Outcomes, Meier-Kreische, H-U, Kaplan, B. Transplantation, vol. 74, 1377-1381, no.10, November 27, 2002

Useful contacts

National Kidney Federation

Charity run by kidney patients for kidney patients

Email helpline@kidney.org.uk

Helpline 0845 601 02 09
Monday - Friday, 9am - 5pm

Web www.kidney.org.uk

Kidney Research UK

Charity funding research and raising awareness of kidney disease

Email kidneyhealth@kidneyresearchuk.org

Helpline 0845 300 1499
Monday – Friday, 9am – 5.30pm

Web www.nkrf.org.uk

Transplant Support Network

Network of transplant patients and their carers

Email tsnetwork@tiscali.co.uk

Helpline 0800 027 4490/4491

Web www.transplantsupportnetwork.org.uk

Human Tissue Authority

Finlaison House, 15-17 Furnival Street, London, EC4A 1AB

Email enquiries@hta.gov.uk

Tel 020 7211 3400

Web www.hta.gov.uk

The decision to become a donor must be entirely voluntary. After learning more about the process and discussing your concerns you can decide whether donation is right for you.

You can change your mind at any time during the evaluation process and your reasons for withdrawal will always remain confidential.

For more information on living kidney donation you should contact the transplant co-ordinator or transplant liaison nurse at your nearest Renal Unit.

For more general information about organ donation and transplantation or to register on the NHS Organ Donor Register:

Visit www.organdonation.nhs.uk

Phone 0300 123 23 23 (open 24 hours)

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