Emotions of living donation

A photographic portfolio inspired by the thoughts and feelings of living kidney donors and recipients
Transplantation is very special and quite extraordinary. 18 months down the line and I still wake up feeling a surge of life.

Recipient

This portfolio of photographs visually tells the story of the personal emotions of kidney donors and recipients before, during and after living transplantation. The thoughts, compassion, challenges and daily emotions of life during the process are captured through imagery and quotations. Deciding to donate a kidney and undergoing a life-changing transplant operation, carries those involved on a roller-coaster ride of emotions.
Living kidney donation is about giving a kidney to a living relative or close friend who has renal failure. With a shortage of kidneys available for transplantation, the need to think about living donation as an option is increasingly important.

Making the decision to donate a kidney to a close relative or friend is a selfless act, but to some it is a solution to help not only a person they love, but also the whole family.

It is important to discuss living donation as one option to end the need for dialysis or even prevent the start of it. This portfolio will take you on a visual journey through the stages of living donation and encourage debate about the challenges and opportunities. Whilst not an option for everyone, to many it is “the light at the end of a tunnel.”

I don’t worry about whether I might need a spare kidney in future. You’ve got to deal with the problem you’ve got now, not one you might never have. Donor

Until now I didn’t know that I had two kidneys, let alone that one kidney is more than enough for one person! Donor
Living with kidney failure

Whilst dialysis may become an accepted part of life for some, to many people its mental and physical effects, together with the influence it has on the whole family leads them to talk about living donation as an option.

Dialysis makes life difficult for the whole family, not just me.
My most intimate relationship these days seems to be with my dialysis machine.

John is on dialysis at home, all night seven nights a week, and is due to receive a kidney from his sister later this year.
Dialysis changes your life, but it doesn’t have to destroy it.

Nicholas has been on dialysis for 21 years and is awaiting a transplant.
When your life is normal, you want it to be more exciting. When you’re on dialysis, you realise how exciting normal is.
Exploring the option of living donation

Ensuring that donors are both suitable and healthy involves thorough tests and discussions, and includes a physical examination, laboratory and radiological investigations, blood tests and psychological assessments. Donors are able to change their mind at any time during the process.

Some people think I’m brave. I just want a healthy husband back again.

Lynda undergoing tests as a potential donor for her husband
It really helped to talk through donation with people who’d done it.
I had 18 visits to the hospital before donation, including blood tests, scans, meeting psychologists, psychotherapists and counsellors - it was certainly thorough.
I was glad to have all the tests. At least I know I'm really fit!
The morning of the transplant

Mark is donating a kidney to his father, Gordon. On the morning of the operation, they wait side by side on the ward.

When I heard dad needed a kidney I just said - ‘OK mate have one of mine’ and at that stage I didn’t even know that I had two.
Humour helps us get through this. It’s a practical thing really. I’ve got two working kidneys and he’s got none. The solution is obvious.
The transplant operation

Gordon and Mark are photographed at various stages during their transplant operation. One surgeon removes the kidney from Mark. It is then taken to the adjoining theatre, where a second surgeon transplants the kidney.
Life expectancy of donors is actually higher than people of similar age and sex, the testing beforehand ensures that only the really fit and healthy become donors. *Surgeon*

There are risks, but they need to be kept in context. *Surgeon*
Many donors ask me if there's anything they won't be able to do after the operation. My answer is that the only thing they can't do is donate another kidney!

Surgeon

Kidneys from live donors have the greatest chance of working well. Surgeon
I enjoy the moment when the kidney is connected to its new owner and it works straight away. Surgeon
After the transplant

After the operation, the donor and recipient will spend a number of days in hospital to aid recovery - the time varies for everyone. Both the donor and recipient will return to the hospital for checks. Many donors and recipients feel able to return to work after three months.
It was all about getting back to normal. That’s all we wanted. Recipient
After 3 months, I’m back running my pub. Regulars say I’m less short-tempered and more jovial now – they’re right, that’s how I feel. **Gordon, Recipient**

**It’s not a pain-free process but it’s manageable.** **Recipient**
Donors and recipients

Donors can be close family members, but can also be family without a genetic link e.g. a husband or wife, and there are also occasions where friends are donors.

I could see my sister's suffering and she was crying so much. All I could think was how quickly can I give my kidney.
Maggie donated a kidney to her 16-year-old son Sam. The operation was the light at the end of the tunnel.

Susan donated a kidney to her partner Richard. We had to do it for the kids. We had no family life.

I really hope he can have a normal life again. I'd like John to have what I have in life.

Ours is a good story — a great story. There were no problems.

Holly is donating her kidney to her brother John.

When best friends Terry and Sue find that Mark needs a kidney, they both offer, but Terry is the best match.

Maggie donated a kidney to her 16-year-old son, Sam.

Susanne donated a kidney to her partner Richard.

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Fulfilling the dream

The freedom allowed by transplantation is what matters to many - the ability to go on holiday, spend a day out with the family, socialise, eat without worrying about the content, drink fluids freely, and enjoy the feeling of more energy.
After the operation, all the lights were switched on.

I can drink, I can eat what I want and go where I want and I have a social life again.
The joy of going on a normal family holiday is something I can't put into words.
If you would like to talk about living donation as an option, please ask to speak to the transplant co-ordinator, the living donor surgeon or kidney specialist at the hospital, where you, your relative or friend are being treated.

For medical information on the process of living donation and details of steps involved in the process there are a number of new leaflets available.

This portfolio has been put together with the help of many donors and recipients who have given so generously of their time. We would like to thank:

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Novartis works in partnership with the transplant community throughout the world to support a broad range of initiatives and pioneering research into new treatments for transplant patients.

For more information you may also find these organisations useful:

National Kidney Federation
www.kidney.org.uk
Helpline 0845 601 0209

Kidney Research UK
www.kidneyresearchuk.org
Helpline 01733 704661

Transplant Support Network
www.transplantsupportnetwork.org.uk
Helpline 01535 210 101

UK Transplant
www.uktransplant.org.uk
Helpline 0117 975 7575

I know he doesn’t want me to keep thanking him, so I can’t. Words fail me anyway.
The portfolio has been inspired by the thoughts and feelings of people who have been through living kidney donation. Dr Jennie Jewitt-Harris and Victoria Lush have spent time talking to donors and recipients about their emotions before and after donation.

Photography and interviews
Dr Jennie Jewitt-Harris and Victoria Lush

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