

# Visualising the Emotions of Living Kidney Donation

It's one thing knowing that your father's chances of survival rest on having a new kidney but it's quite another deciding to give one of your own. Mark had no doubts about giving his father, Gordon, the kidney he needed and even joked that he could have a kidney, at a stage when he was unsure that everyone has two!

Mark and Gordon have been interviewed and photographed for a new thought-provoking exhibition and portfolio, produced with an educational grant from Novartis Pharmaceuticals. The aim of the materials, which are freely available to renal and dialysis centres throughout the UK, is to raise awareness of the option of living donation and encourage discussion about living donation amongst family and friends.

Whilst more than 5,000 patients are waiting for a kidney transplant, there is an increasingly severe shortage of donor organs. And, although living donor kidney transplantation results in better clinical outcomes than deceased kidney transplantation, the rate of living kidney donation in the UK is only 28 per cent, compared to 50 per cent in the US and 90 per cent in Japan.

After spending time interviewing and photographing donors and recipients before, during and after the transplant, Dr Jennie Jewitt-Harris and Victoria Lush have produced this revealing portfolio of images which link with powerful personal quotations to offer a visual journey through the process of living donation. The thoughts, compassion and challenges of life are captured as those going through this life-changing process experience a roller-coaster ride of emotions.

The exhibition and patient portfolio have been put together with input and support from renal experts.



*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.*



*Kidneys from live donors have the greatest chance of working well.*

Involvement and encouragement have come from Mr Chris Rudge, Managing Director of UK Transplant, Lisa Burnapp, Consultant Nurse, Living Donor Renal Transplantation at Guy's and St Thomas' NHS Foundation Trust and Mr Andrew Ready, Transplant Surgeon at Queen Elizabeth Hospital, Birmingham.

Mr Chris Rudge of UK Transplant says, "These new materials are an important step in raising awareness of living donor transplantation as an option for patients with kidney failure. They cut through the medical jargon that sometimes faces patients, relatives and friends and tells them what it's really like to go through it. It's an inspiring insight for everyone involved."

Many of the quotes used in the portfolio also address the underlying concerns and misconceptions that people may have about living donation. The aim of using the quotes is to reassure possible donors and recipients that these are normal feelings and to put the emotions during the various stages of donation into context and perspective.

As one donor said, "You can't worry about whether you might need a spare kidney in the future. You've got to deal with the problem you've got now, not the one you might never have."

Another donor stressed that, "Some people think I'm brave – I just want a healthy husband back again."

And as a recipient said, "After the operation, all the lights were switched on." Many patients find the mental and physical effects of life on dialysis difficult to cope with

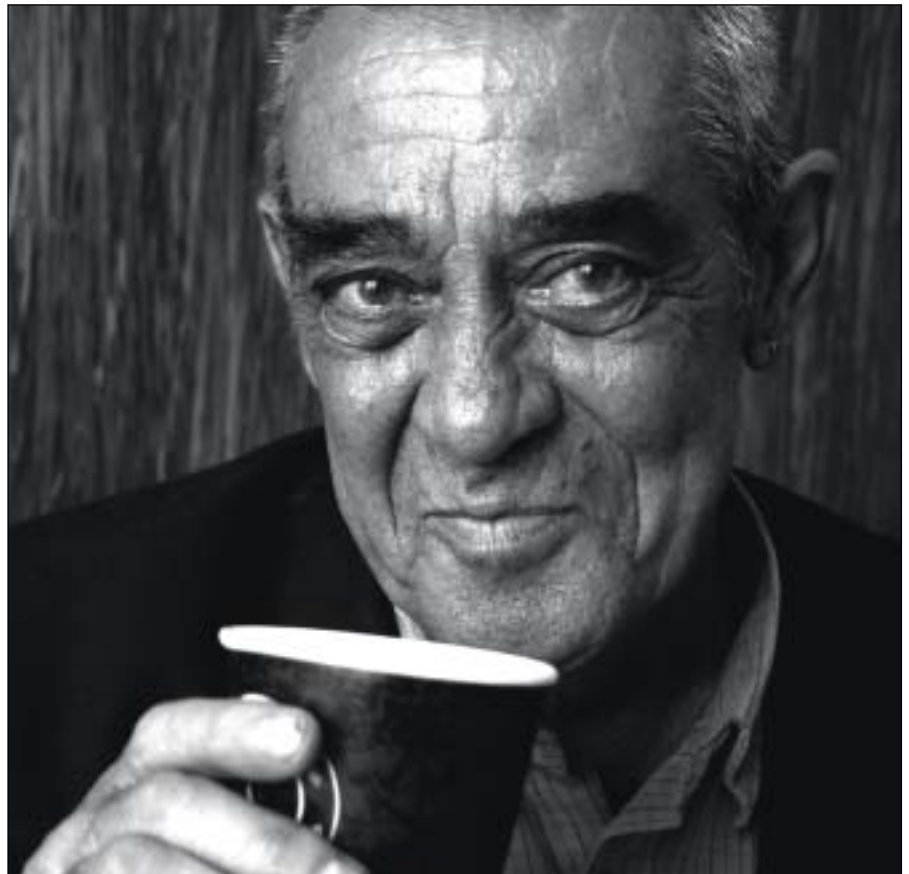
personally and find "dialysis makes life difficult for the whole family, not just me."

Others continually stressed the beneficial effects after transplantation of being able to lead a life without the ties of dialysis and as one recipient said, "The joy of going on a normal family holiday is something I can't put into words."

"Transplantation is very special and quite extraordinary. 18 months down the line and I still wake up feeling a surge of life."

Whilst not an option for everyone, to many, living kidney donation is "the light at the end of the tunnel."

Research shows that patients would like more information and this exhibition and portfolio are an important step in that direction. The "emotions of living donation" materials have been produced to give an honest and open visual account of the process of transplantation, that will encourage patients, their relatives and friends to talk about it.



*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.*

**If you would like a copy of the portfolio, or you would like information sending to hospitals within your constituency, please contact Nikki Bryant on telephone number 01276 692255 or via email [nikki.bryant@novartis.com](mailto:nikki.bryant@novartis.com).**

# EMOTIONS OF LIVING DONATION

Photographs and personal quotations from kidney donors and recipients have been used to develop new materials for renal and dialysis units throughout the UK.

Holly is donating her kidney to her brother John.

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



Tapati travelled from India to donate a kidney to her sister.

*"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."*