



A Catch 22 kidney

In June 2012, an Austrian, Volker Tulipan, read an account in the German magazine *Der Spiegel* of an Englishman who had donated one of his kidneys to a stranger at the age of 82. Here he recounts his own effort to donate one of his kidneys.



Photo: Katharina Lassnig

At the time I was 68 and I remember telling myself: "If I should remain in reasonable health into my eighties, I might just do the same as he has done."

Some months later I felt unwell and being a bit of a hypochondriac, I went to see my doctor, who recommended a CT scan of my abdomen. Subsequently I was pleased to find that nothing was seriously wrong with me and that it seemed that I had a perfect pair of kidneys. I thought: "maybe I should consider giving a kidney now, and not wait until I am eighty plus".

After trying various hospitals, I found the only one in Austria that was carrying out living kidney transplants. It was about 80 miles from home and after several attempts I made an appointment to see the chief surgeon of the transplantation team. He regarded me with a mixture of curiosity and aversion and told me that I would be the first altruistic living donor in Austria. Also that a kidney transplant costs a lot of money. Proudly I handed him the CD of my CT scan, which would, at least in my eyes, prove that I was a kidney donor to be reckoned with. I was then given an appointment with a psychologist.

After several weeks I contacted the head surgeon again and reluctantly he granted me a further consultation. Together with the psychologist he told me that it would be necessary to carry out a number of psychological tests. The medical view seemed that I must be mad to wish to give a kidney,

continued on Page 2...

Why do they do it?

The puzzle of altruistic kidney donation, by Nicholas Crace

Since it became legal in 2006, more than 300 UK citizens have decided to undergo major surgery to donate one of their kidneys to a stranger whom they do not know and will probably never meet. These people are known as altruistic donors. Who are they, and what impels them to risk their health and well-being to help others?

Most people find the act of altruistic organ donation worthy of admiration but inexplicable. Why do they do it? Altruism has been defined as the unselfish concern for other people, involving doing things simply out of a wish to help, not because of an obligation of duty or loyalty, or for religious reasons, and has intrigued scientists over the years as to why it occurs.

Psychologists used to think that altruistic behaviour reflected egotistic motives, but are now coming round to the view that real altruism – sacrificing something for someone other than self, with no expectation of any compensation or benefits – does exist and forms part of human nature. This view conflicts with Darwin's theory that we are selfish creatures, engaged in a battle for survival. Why do we act philanthropically, even at a cost to ourselves?

People look upon altruistic donation either as madness or bravery, with no intermediate position. Donors are either saints or mentally ill, and they face the problem of how others, both their friends and relations as well as medics, view the act. For why would anyone want randomly to give away a vital organ?

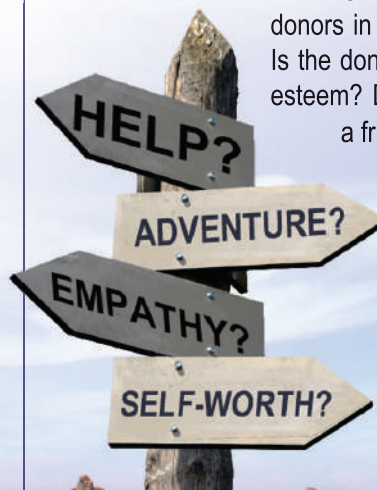
A number of reasons for altruism have been propounded by psychologists and they are still searching for causes. Some believe that it stimulates 'reward centres' in the brain, and that an altruistic act in consequence activates the brain's pleasure centres. Others think that there are less obvious inducements, such as helping others in order to relieve their own unhappiness, or to sustain their self-belief as good-natured and sympathetic people.

The altruism that prompts an individual to make a possibly risky sacrifice for someone he does not know needs careful examination. There are similarities between psychopaths and altruists. These include impulsiveness, the need for excitement and adventure, and reluctance to conform.

On the other hand altruists have the capacity to react to others' feelings and put themselves in their shoes, while psychopaths are unable to feel remorse or share the feelings of others.

This means that before giving a kidney, most potential donors in the UK have to have a psychological assessment. Is the donor trying to counteract depression or boost his self esteem? Does he seek publicity for himself, or hope to become a friend of the recipient? Hospitals have the responsibility to examine all these and other motives, and to refuse any donations that are suspect.

Whatever their motives, there is no doubt that donors derive great benefit from the experience. As John Fletcher, a Scottish vet put it: "The whole thing has been life-enriching beyond anything that I could ever describe. Of all the things I have done in my life, this one has been the happiest. I cannot recommend it strongly enough."



...continued from Page 1

and that if I was mad I was unsuitable to be a kidney donor. When I told them that this looked like a Catch 22 situation, the doctor nodded and explained to his young colleague that I was referring to a story 'about some crazy guys'.

To save myself the round trip of about 300 miles, I was given the address of a psychologist in my home town. After I told this lady of my situation, she told me that it would take her up to ten sessions, costing me £75 each, to find out if I was a suitable donor.

To undergo major surgery for the benefit of a stranger, and have to pay for the preliminary process as well, convinced me that I would indeed have to be crazy to be a living kidney donor, so with great reluctance I abandoned the idea.

On the bright side, though, I struck up a friendship with the man whose story had inspired me, which culminated in our meeting for a lunch of Schweinebraten mit Bier during his visit to the city of Passau in September 2013.

Volker Tulipan

NHS Blood and Transplant: A Strategic Perspective

The end of March saw the first UK Strategy for living Donor Kidney Transplantation (2010-14) come to fruition and it is worth taking a moment to reflect upon some of the key achievements of the past four years. In all, 4,199 patients with end stage kidney disease were transplanted from a living donor during this time and more than 500 patients received a kidney through the national living donor kidney sharing schemes, half of which were donated by altruistic donors to unknown recipients - and for the readership of this newsletter, that is perhaps the most striking statistic of all. More altruistic donors came forward last year than ever before - a total of 118 (1st April 2013 to 31st March 2014). 34 of these achieved 68 transplants by donating into an altruistic donor chain, whereby a recipient in the paired/pooled scheme received the altruistic kidney and his/her incompatible donor, in turn, donated to a recipient on the national transplant

list. Altruistic donation now contributes 10% of all organs to the living donor pool and just under 50% of altruistic kidney donors are currently opting to donate into a 'chain'; which we hope will continue to increase. As of the end of May this year, the total number of altruistic donations that have taken place since April 2007 was a phenomenal 306.

So what next? The new strategy, 'Living Donor Kidney Transplantation 2020' (LDKT 2020) was approved by the NHS Blood and Transplant Board in May and will soon be published on the website. LDKT 2020 builds on the strengths of the previous strategy and aims to match world class performance in living donor kidney transplantation by 2020. It complements the deceased donation strategy: 'Taking Organ Transplantation to 2020' (TOT 2020). The strategy has been coordinated by NHSBT but successful implementation will rely upon active engagement from all members of the wider transplant community who have been involved in its development. 'Give a Kidney' members have already had input into this work but your enthusiasm and commitment will be much needed in the years ahead. So a huge 'thank you' to all of you for your fantastic achievements and continued efforts on behalf of all those patients and their families who benefit so enormously from the precious gift of a transplant.

Lisa Burnapp

*Lead Nurse – Living Donation
NHS Blood and Transplant*

SPREADING THE WORD IN THE HEALTH SERVICE AND EDUCATING YOUR GP

While the co-ordinators, nephrologists and surgeons directly involved in living donor transplantation know about non-directed donation, there are many in the health service who do not. The ground has shifted so fast that even those involved in other areas of renal care such



as those working in dialysis units, are not fully aware of its potential to make a difference and the extent to which it is already doing so. This is even more true for GPs. It is forgivable seeing that there is so much more on their agenda, but also important that they have some awareness of the issue so that they can be helpful to people making enquiries. In particular they need to have some reliable information to give anxious relatives and friends of potential donors.

Some of this information can be provided in professional journals but the most powerful messages come from donors themselves and we all have a role here. No GP wants patients to come in and give her or him a long lecture at the end of a consultation but we can get a concise message across in less than 30 seconds. Make sure you don't go beyond this as GPs have a limited attention span. The message might be that the risks are smaller than is often supposed, we remain well and healthy, it did not seem unduly difficult or painful and that we would do it again if we had another kidney to spare. Ask them to share this information with their colleagues and have the details of the website written down to hand over.

Dr Paul van den Bosch, GP

Fundraising success

In the last edition we covered the story of Paul Dooley's fundraising extravaganza in Glasgow. "It was a huge success - a fantastic night!" said Jan Shorrocks, Give a Kidney PR Officer, who attended the event. "He sold 400 tickets and secured some great raffle prizes, raising over £5,000 for Give a Kidney. The Edrington Group more than matched what he raised with a wonderful donation of £10,000, so all in all an incredible boost to Give a Kidney's funds thanks to this very successful event."

Added to this, Paul is planning another fundraiser in November!

Spotlight: Paul Gibbs FRCS (Eng), Renal Transplant Surgeon

Chat to Paul Gibbs at one of the *Give a Kidney* conferences and you could mistake him for any of the donors or recipients in the room, with his casual gear and easy conversation. He has absolutely no airs and graces. But this is a man who has performed 200 to 250 transplant operations, and has transformed and saved many lives.

His first involvement with kidney transplantation was in Cardiff in 1994. But this hadn't been part of his career plan. His family came from a long line of teachers, except for an uncle who was a consultant anaesthetist and whose flamboyant personality and interesting tales inspired Paul to be a surgeon from the age of 10.

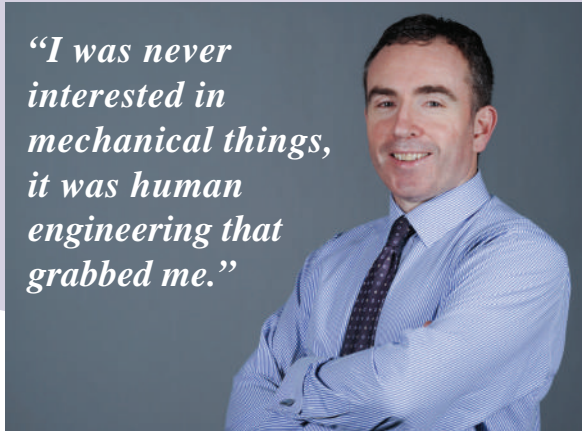
"I loved the buzz of a hospital, and had a fascination with how the body works" he explains. "I was never interested in mechanical things, it was human engineering that grabbed me."

Early on, his goal was to be a cardio-thoracic surgeon and securing his very first job at Harefield Hospital, becoming Senior House Officer at such a prestigious centre for heart and lung transplants was a bit of an accomplishment. But somehow this didn't cut it for him. The turning point came after he'd moved away from London and was offered a six month post in the renal transplant unit at Cardiff - he hadn't come across transplants at all at Med School - and that was the start of a whole new direction.

"I realized that this was what I wanted to do" Paul enthuses, "I had a great team around me. The senior registrar at the time was doing vascular and renal transplantation and was a supportive mentor... I'm still in touch with him."

Paul Gibbs has been at the Queen Alexandra Hospital in Portsmouth for the past 10 years. He performed the first operation in Portsmouth on an altruistic kidney donor but now concentrates on the implanting of kidneys from deceased and live donors and other areas of vascular surgery such as fistula formation, aortic aneurysm repairs, lower limb bypasses and amputations. In common with the trend in the rest of the country, the hospital has seen a sharp rise in renal transplants over the last few years: QA, which covers a population of 2.2 million, carries out 400 to 500 renal-related operations each year and did 85 transplant operations between April 2013 and April 2014, a 30% increase over the last three years. Altruistic donation

"I was never interested in mechanical things, it was human engineering that grabbed me."



is also growing fast. Portsmouth now leads the country and is about to do their 38th donation. The growth means that a third surgeon is being trained in laparoscopic techniques to help meet demand.

I'm curious to hear a bit about the operation itself. Paul outlines what will be happening the next day, a surgery day, with a directed live donor transplant on the list.

"I'll arrive at the hospital at about 7.30 am and see the kidney donor and their recipient; the donor will be operated on by my colleague. Both will be asked to sign a consent form agreeing to the planned operation. Then I meet with the anaesthetist and the donor surgeon and check the blood tests again, followed by a team brief in the operating theatre to ensure everybody knows their duties and that all the equipment is ready."

"By 9.30am the donor op is usually under way and about one to two hours later it's my turn to step in: I receive the disconnected kidney and whilst the surgeon is closing the donor up, I take the kidney to the back table to clean up the arteries and veins and flush the kidney out so it's in good shape for implanting in the recipient, which is my role in this procedure."

"Whilst the donor is in recovery, there is a brief chance for him/her to see the recipient (in the case of directed donors) so they can see all has gone well. At this time I grab a bite to eat! Then I start the transplant, which will take about two and a half hours. The transplantation process is slightly easier on females because of their anatomy, though we actually perform slightly more operations on males."

Of course not all oper-

ations on sick people can be a success. Occasionally it's not until a patient is actually opened up that it's discovered that the arteries are badly diseased and there's no hope of a transplant, ever. What a huge disappointment that must be, to have those aspirations dashed in the final hour. There are potential complications with every operation and Paul has had his share of casualties, which affects him every time.

"Someone once said to me: 'every time a patient dies they take a little bit of you with them' - and it's true" he says. "But that's partly because as a species we always tend to remember the negatives more than the things that go smoothly. You don't want to become too thick skinned anyway, as you won't learn from the experience" he adds.

On non-surgery days there is a constant stream of emails to keep up with, plus the organization of rotas, outpatients clinic, departmental meetings and general issues concerned with the running of the Unit - plus his teaching commitments with medical students.

Paul Gibbs comes across as an enthusiastic, articulate man with a sense of humour and a big heart, who puts the 'e' into energy in his work and life in general. He believes strongly in the concept of altruistic donation, which is why he has been on the Give a Kidney Steering Committee since its inception - although time constraints now mean he will have to take a less active role in future.

And will his children be following in his footsteps? "No", he laughs - "my 10 year old isn't interested and my 14 year old daughter thinks it's quite grotesque that I'm putting my hands in people's insides!"

We are rather glad that he does.

Viv Calderbank

Types of donor for kidney transplants

Deceased donor:

from a deceased donor who was on the NHS Organ Donor Register

Living Donor:

Directed ie. to a known person - usually between family members or close friends

Altruistic or Non-Directed ie anonymously to a stranger

DIABETES:

Its impact on kidney donations

Diabetes mellitus is the leading cause of end-stage kidney disease and the most common reason for people to start dialysis in the UK. While type 1 diabetes is caused by a complete lack of insulin, the more common type 2 diabetes is caused by not enough insulin being produced (usually in the context of obesity). There are currently over 3 million people in the UK diagnosed with diabetes, but many people also have diabetes yet are not aware of it.

Diabetes can cause many other medical problems, one of which is kidney disease. Kidney problems are common with diabetes and develop slowly over many years. Although one in three patients with diabetes will develop kidney problems, not all get severe kidney disease that makes their kidneys fail. This is partly because of better understanding within the medical profession on how to screen, treat and delay kidney disease getting worse. This therefore means there are increasing numbers of people with diabetes and milder forms of kidney disease who may wish to become organ donors.

Kidney donation after death for patients with diabetes is often possible, as long as there is no significant evidence of kidney disease. This is often based on a review of kidney function tests and urine analysis. There is no clear evidence that such

kidneys fare badly long-term in comparison to other kidneys. Further research is required to determine the long-term outcome of these kidneys after transplantation, compared to similar kidneys taken from people without diabetes. However, chances are that outcomes after kidney transplantation would still be better for those patients receiving these kidneys from diabetes patients versus staying on dialysis.

Living donation for patients with diabetes or borderline diabetes is more complicated and careful counselling is required. While national guidelines do not absolutely prohibit live kidney donation from people with diabetes, they do suggest a very careful evaluation must take place to assess the risks and benefits. In the context of other risk factors, many transplant centres would be very reluctant to take such kidneys due to a perception of unacceptable long-term risk of developing kidney disease. However, this is very much dependent on each individual case and a thorough assessment by the clinical team. People with borderline diabetes can be considered as living donors but also require careful counselling regarding long term risks and advice at trying to reduce their personal risk of developing type 2 diabetes and possible kidney disease.

*Adnan Sharif
Consultant Nephrologist*

Letters to the Editor

Dear Editor,

Am I the only kidney donor uneasy at having the description 'altruistic' applied to me? It implies an element of saintliness which I certainly do not possess. People become donors for all sorts of reasons, and altruism may not be one of them.

In the eyes of the NHS the word has become a definition rather than an adjective. Can any of your clever readers think of an alternative?

Misanthrope

Dear Editor,

As a tentative and anxious prospective donor I am worried about the level of pain that I am likely to experience.

Can any former donors say how much pain they suffered, on a scale of 1 to 10, and for how long? I know that levels of pain vary, but it would be helpful to know what I can expect.

Apprehensive



National Transplant Week 2014 will take place from 7 – 13 July. So get ready to get involved and help raise even more awareness of organ donation.

www.transplant.co.uk/

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