



# Whose kidney is it now?

and other questions asked by  
potential live kidney donors

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Once upon a time, more than thirty years ago now, I was a young mother and a very junior tutor in political and social sciences at Monash University near Melbourne in Australia. During term time I walked from the car park past a newly planted garden that included a shallow ornamental pond. At the same time, Peter Singer was a Professor of Philosophy at the same university, writing his seminal book, *Practical Ethics* (published by Cambridge University Press in 1979). He wrote:

“ *The path from the library at my university to the Humanities lecture theatre passes a shallow ornamental pond. Suppose that on my way to give a lecture I notice that a small child has fallen in and is in danger of drowning. Would anyone deny that I ought to wade in and pull the child out? This will mean getting my clothes muddy, and either cancelling my lecture or delaying it until I can find something dry to change into; but compared to the avoidable death of a child this is insignificant.* ” (p.169)

Singer concludes that *“A plausible principle that would support the judgment that I ought to pull the child out is this: if it is in our power to prevent something very bad happening, without thereby sacrificing anything of comparable moral significance, we ought to do it.”*

Clear enough, but if you are contemplating donating or providing one of your kidneys to somebody who needs it, the answer may not be so obvious. No major religion or other higher authority makes it obligatory or a duty to agree to a live transplantation of a kidney or any other organ, tissue or body fluid. Such a decision is supererogatory to all the other moral and ethical commitments we may ‘sign up’ to in our religious and spiritual lives. It is not an automatic decision; it’s something that donors and providers come to from the ‘moral space’ which each of us inhabits in the particular cultural, ideological, financial and social contexts of our lives.

This means that we have to make our own decisions about whether to come to the ‘rescue’ of another person. And the ‘imperatives’ that we accept in making our decision will be different for each one of us. As will the circumstances in which we make the decision. Professor Singer remembers the pond as being shallow but it could have had a hole in its centre waiting for the installation of a fountain. The child could have been on the verge of the deep hole. Professor Singer may not be able to swim – unlikely in a coastal Australian, but not impossible. I can swim. Would I have had a greater moral imperative to rescue the child? Professor Singer was already a far, far better philosopher thirty years ago than I will ever be. Was there a greater moral imperative on me to risk my life and less significant brain? But I was a young mother at that time; was Professor Singer a parent then? Did my duties to my own child override those to a stranger child in the pond? But what if it was actually my child who had wandered in to the pond (as my first daughter did at the University of Melbourne when she was about three and thought the lilies on the pond were ‘a carpet’ that could be walked on. She later became an assistant professor at the same American university as Professor Singer... ). What if it was Professor Singer’s child in danger in the pond? What would his family and friends have thought if he had let a stranger undertake a rescue that he could quite easily have done himself? What if neither of us had tried to rescue the child? Perhaps I had a phobia about the leeches I knew to be in the pond. Would it have been more ‘immoral’ of me, a swimmer, to hold back from rescuing the child or for a non-swimmer who also feared blood-sucking leeches? Or what if both us were too drunk or drugged to recognize the child’s predicament? Or to feel a sense of responsibility to him or her?

Professor Singer would describe these dilemmas as exercises in ‘practical ethics’ – situations where we apply our own moral matrices to a particular real-time problem in our lives. One difficulty we have in the first decade of the twenty first century is that many of the moral and ethical ‘doctrines’ or teachings of the previous millennium are not easily and obviously applicable – able to be applied – to dilemmas that even ordinary mortals increasingly face as modern medicine and science give us ever more wonderful ways of extending, improving and even creating life. And it’s not going to get

any simpler with all the incredible possibilities coming into the medical repertoire – cloning, stem cell therapy, xenotransplantation where animal organs are used in humans, in vitro cultivation of ‘customised’ body parts for transplantation, the emergence of face transplants... .

The pace of change is going to be even more rapid than in the twentieth century. In his 1979 book, Professor Singer wrote:

“ A medical technique known as amniocentesis has recently been developed. It enables us to learn a good deal about the fetus during the early months of pregnancy. Using it we can, for instance, discover the sex of the fetus. This is important in the case of sex-linked genetic defects. ” (p.135)

By the time I had my last pregnancy in 1987 I was pushing 40 and living in New York. Amniocentesis was by then routine for what were in those days considered to be late pregnancies. It was being widely used in India and China to enable parents to ‘de-select’ female foetuses in favour of male. For older women such as myself it offered a chance to abort foetuses that were considered to be physically or intellectually ‘defective’. The two or three women I knew who knowingly persevered with such pregnancies, or refused amniocentesis, were considered to be borderline socially irresponsible because of the cost of care such children would incur. Today ultrasound scans offer even young parents the same choices – to abort or not to abort. And abortifacients are sold over the counter as ‘morning after’ forms of contraception. They are even made available in some schools.

When we say ‘attitudes change’ we mean that our socially acceptable responses to ethical and moral dilemmas change, albeit within over-arching religious frameworks which all tend to converge on a few ‘categorical imperatives’ such ‘do no harm’ and ‘do unto others as you would have done unto you.’ The challenge is to ‘cash out’ these general principles into the particulars of the situation given the ever-changing technological and social contexts in which it is happening to real people.

We are all differently placed within our societies and this in itself creates – or absolves us from – different responsibilities. Consider if the child at risk of drowning was at the beach rather than in the Monash pond, and that there is a lifesaver on duty being paid the minimum legal hourly rate (or less if s/he is under eighteen years old). It will take twenty minutes to rescue the child – one or two pounds or dollars of hired labour. It may be the riskiest 20 minutes in the lifesaver’s whole life, especially if there is a shark circling. But having accepted this rate of pay the lifesaver – who will have been selected as a strong swimmer – is generally held to be under a higher duty than the other people on the beach, and may well face legal consequences if s/he fails to try to rescue the child. There are many jobs in our societies that are very poorly paid yet have high risk factors and heightened duties of care attached to them. In the UK, for instance, 17 year olds (formerly known as ‘boy soldiers’) are still recruited into the armed services at a starting pay of £13,500 or half the average annual UK income. For barely the minimum wage, they are expected to engage in combat if required before they can vote. The pay doesn’t get much better for the non-commissioned ranks; the UK government recently made tax-free ‘combat bonuses’ of £2,240 each to 15,000 service personnel who have served in Afghanistan, Iraq and Bosnia. Motivations to join the armed services can be many and varied. Some may be truly interested in the military way of life; some may be looking for training they cannot otherwise afford; some may be passing the recruitment office after being laid off and sign up virtually on impulse in order to pay the mortgage. Some may be looking for a way out of difficult social circumstances. Short of testing for clearly pathological tendencies, we do not question their motivation, or – outside of full scale war – compel people to serve in the armed forces. However, once in uniform, all these individuals, whatever their motivation for joining, are subject to strict duties even unto death – in relation to the defence of the rest of us.

And what if there are two children drowning on the beach, with or without the shark circling? How will the lifesaver decide which to save first? What if there is a wealthy parent imploring him to save her child first and promising five years' income if he does?

As Professor Singer wrote, "*rights is not all there is to ethics*" (p.173). Many elements come in to play when we make such complex decisions as deciding whether or not to share one's spare kidney with another person. And we can't just look to the old 'authorities', religious or otherwise, for the answers – although we may wish to reach answers for ourselves that are compatible with our religious or other beliefs. As two prominent American ethicists, Professors de Grazia & Beauchamp have commented, the history of medical ethics emanating from the practices of 2,000 years ago is disappointing from the perspective of today's concerns in medical ethics about the rights of patients and subjects and the ways in which society should act to promote the health of its members. Most topics and problems in medical ethics that are of major concern today have been ignored or given but passing notice until the second half of the twentieth century. Or hadn't yet arisen.

What we need to do is to review the evidence on which we should make our decision about kidney sharing. "*Good ethics depends on good facts*" say another pair of prominent American medical ethicists, Professors Sulmasy & Sugarman<sup>1</sup>. They remind us that failure to understand the facts of a situation thoroughly will clearly lead to perils in moral decision making. It's been fifty years since the first live kidney transplant (between twin brothers, in 1956). We can find the evidence we need to help us make decisions in the more than 200 studies of kidney donors in the medical research literature. We can listen to the reflections of people such as those in this booklet who have been willing to be interviewed for the record about the experience<sup>2</sup>. I hope my selection and presentation of the information has been enhanced by the more than 200 cases which I reviewed with colleagues during my three years as a non-medical panel member of ULTRA, the UK Unrelated Live Transplants Regulatory Authority which, until it was replaced by the new Human Tissues Acts that came into force in 2006, considered all (legal) applications for non-genetically related kidney transplants. Hopefully these various types of information will add up to a 'descriptive ethics' of the practice of live kidney transplantation from the donor/provider's point of view that will help other people to make their decision about their rights, duties, obligations – or the lack of them – when faced with this powerful ethical dilemma.

No one is 'obliged' by their religion to share their spare kidney. 'Society' does not have a unanimous view on the matter. There can be many personal pressures to share the kidney, especially from those who love the intended recipient. But there can also be pressures not to undergo the operation and unsettle the financial and other relationships that one has. There can be family conflicts and even jealousy if one person is 'chosen' to provide the kidney over other family members. And one has to consider the recipient's point of view – not all sufferers from end-stage renal disease want to undergo the operation for transplantation. Some may have qualms about other people's body materials inside them. Some don't want the emotional pressures of being a recipient; some don't want the obligation to 'take care' of the new kidney.

The humorist Art Buchwald decided to forego even dialysis in mid-2006. "*Dialysis, he declared, was not for him – too boring. At 80, he did not want to spend his remaining time hooked up to a machine cleansing his blood three times a week. He had outlived his wife. He had survived a stroke in 2000, and he had had his right leg amputated below the knee because of complications from diabetes.*" Speaking from the hospice, he said "*I've never been happier. The stress is gone about the decision and the bottom line is everybody is going to die.*" He acknowledged that "*You do hurt people when you refuse dialysis. All of your loved ones don't understand. You have to explain to them that it's your choice, that you didn't want to suffer the pain, and that you can have other diseases when you are on dialysis.*"<sup>3</sup>

And in the new era of 'pre-emptive' transplants where sufferers are given new kidneys earlier in the course of their disease, often before they go on to dialysis (which can be stressful both physically and psychologically as well as highly inconvenient for many patients), more patients will need more than one kidney transplant in their lifetime. One also might want to consider whether the transplant is going to save the recipient's life or merely improve its quality – for ten or fifteen years. These are all legitimate considerations in reaching the decision about whether or not to share one's spare kidney.

As two Oxford researchers<sup>4</sup> put it in 2003: “*Cadaveric donation rates have remained static, whereas transplant waiting lists continue to rise as demand for renal transplants far exceeds supply. One solution to bridge the supply and demand gap is to increase live donation. If live donation is to increase, it is important to offer evidence-based psychologic and social support to ensure that transplant clinical success is not at the cost of psychologic and social harm.*” The following sections seek to answer questions often raised by potential donors. The information provided comes from countries with well-resourced health care systems.

### What are the social patterns of live kidney donation?

Live kidney transplants exceeded cadaveric for the first time in the USA in 2001 and there is a similar trend in Canada; it is estimated that a third of kidneys donors in Europe are now live. In the Middle East it is estimated that more than 85% of the 5000 annual kidney transplants are from living donors, related and unrelated. In the Baltic countries such as Lithuania, Estonia and Latvia it has been suggested that the lack of dialysis equipment under the Soviet regime accounts for high levels of living transplantation.

Access to transplantation can vary widely even within a small country such as Scotland where in the 1990s patients were less likely to be placed on the list if they were female, older, had diabetes, were in a high deprivation category and were treated in a renal unit in a hospital with no transplant unit. Patients living furthest away from the transplant centre were listed more quickly.

Ethnicity can influence both the need for and access to kidney transplants. In the UK the percentage of South Asians on the kidney transplant list is three times their percentage in the general population because of their susceptibility to diabetes. The situation is similar for black African and black Caribbean Britons. However in the early 1990s only 5% of kidney donors in the UK were from an ethnic minority while in 1996 20% of those registered for kidney transplants were. A study done in the late 1990s among the Asian population in Luton found that nearly half the respondents in a survey didn't know what a donor card was used for and only 1 in 8 had heard of the National Donor Register. Only two of 32 Muslims interviewed were aware of the recent *fatwa* by the Muslim Legislative Council of the UK permitting organ donation and 38 out of the 64 people in the study said that they didn't know what their religion's position was on organ donation. There are similar findings from minority communities in the USA, where Afro-Americans are more likely to need kidney transplantations but are less likely to trust the medical system sufficiently to become donors.

### Do people feel pressured into donating?

A Swiss study of emotionally (but not genetically) related donors reported nearly ten years ago that “*In our experience only one case of 46 revealed an unconvincing motivation. As in other centres, we found love and partnership to be the main motivation as well as the hope to have two health partners in the couple instead of one 'healthy' and one 'sick'. Donors are not unconcerned bystanders when their partner has terminal renal failure and when they share a common daily life. Uraemia, the restraints imposed by diet and dialysis, and the reduced professional possibilities all indirectly influence the well-being of the healthy partner. From this point of view, a successful transplantation can reverse a reduced quality of life for both donor and recipient.*” But they also refer to a “*the new psychological equilibrium in the couple*” that can follow such spousal donation. They note that in 55% of cases the consultant nephrologists had made the suggestion about donation and 30% of the donors “*came spontaneously to this idea.*”<sup>5</sup>

German researchers<sup>6</sup> warn against unrecognized coercion of vulnerable donors whose full consent is limited by language barriers or relationship pressures. One important pressure they point to is the possibility of “*an important power imbalance between physician and patient.*” On the other hand, it is standard practice in the UK and elsewhere for doctors to provide ‘medical alibis’ for people who do not really want to donate but are under family or other pressure to do so, in order to provide what has been termed<sup>7,8</sup> a ‘graceful’ means of declining. Every doctor’s first duty is to his or her patient, which may be the donor rather than the recipient. And most transplant centres – certainly in the UK – require a separation of function between the donor’s and the recipient’s medical team. It is interesting to note that a recent Swiss study<sup>9</sup> of 152 donors found that four out of five “*volunteered to donate without pressure from family and/or friends*”, which however leaves us wondering about the types of pressure brought on the other 20% of donors. A Spanish study<sup>10</sup> found that 86% of 22 living donors had themselves informed the recipient about their wish to donate; the other 14% were asked by family members.

A recent Canadian study found that only 40% of potential recipients thought it was ‘appropriate’ to ask a family member to donate a kidney. The researchers point out that this may be a limitation on the availability of kidneys in programmes where it is left to the recipient to find a donor rather than the medical team since “*Those who considered it inappropriate to ask were significantly less likely to have done so.*”<sup>11</sup> One of the first strategies to increase the number of living kidney donations in the UK was to work with dialysis patients to help them recognise the value (both to themselves and to the NHS budgets faced with rapidly expanding demand for dialysis units) of early, ‘pre-emptive’ transplants and to identify potential donors.

A study in the late 1990s in France<sup>12</sup>, which has been slow to accept live kidney donation, found that as part of the evaluation process, potential donors underwent systematic psychological review in a little more than one-half of the [36 out of 46 responding] centres (53%), usually by a psychiatrist (76% of cases). The social situation of potential donors was systematically evaluated by a social worker in 38% of centres, whereas 35% of centres never made use of such an assessment. Only 13% of these 36 centres routinely consulted a nephrologists working independently of the transplant team to assess the potential donor.

Within families, it is increasingly recognized that there can be what Norwegian researchers<sup>13</sup> refer to as “*a kind of unconscious coercion*”, for example “*that other family members expect the oldest sibling to donate, as a result of established family roles.*” German researchers comment: “*it is often extremely difficult to distinguish between truly altruistic reasons for organ donation and psychological factors in an intimate partnership that may eventually lead to some kind of coercion.*”<sup>14</sup> This argument was also made by members of the International Forum for Transplantation Ethics when they called in 2003 for the abolition of the distinction in levels of scrutiny between genetically related and unrelated donors by the Unrelated Live Transplants Regulatory Authority. In the event, the new Human Tissues Acts extended the closer scrutiny to genetically related donors rather than diminishing it for both types. Professor Sheila McLean, the Scottish medico-legal expert, has also raised the possibility that it would be better to widen the use of unrelated but compatible donors while also enquiring more closely into the pressures associated with donation within in families.

AM Homes’ account of being *The Mistress’s Daughter: A Memoir* (Granta 2007) traces the complex emotions aroused by being contacted by her birth mother, who eventually asks her to donate a kidney. Other complications can ensue – it is not unknown for the medical workups to reveal that people in fact are not genetically related. This is usually handled very discreetly by the medical profession but one father and daughter went public (albeit with pseudonyms) about their intention to go ahead with the transplantation despite the new information. The daughter said “*I challenged my mum but she just wouldn’t talk about it. If anything, it made me more determined than ever. I wanted to be part of him; to have a real part of me existing in him.*”

Other families have found that the opportunity to donate has led to reconciliations after long rifts. And one wife who donated to her husband who subsequently left her for her sister-in-law said *"I'm not vindictive at all."*

More American women (56%) than men (44%) donate live kidneys<sup>15</sup> but the female:male ratio in the USA is 51%:49% so it is not clear if this difference is very significant. Some researchers<sup>16</sup> have called for more research in to the 'science' of living kidney donor decision making. In the US one element of this discussion concerns the 'conflicts of interest' of commercial transplant centres that may be trying to maximize profits. But equally there is considerable discussion on how any transplant centre, commercial or not, can reject potential donors on objective rather than purely subjective grounds on the part of the assessors.<sup>17,18</sup>

Terri Apter, *The Sister Knot* (W.W.Norton & Company 2007):

*“In the end Gina's only hope for a normal life was a kidney transplant. Sam was tested and found to be a match. 'When I heard this, I felt two things right at the same time. I thought 'Well, that's good, that's solved,' and I also felt as though chains were being clamped onto me. There was only one choice. I mean there was no choice. But it was still difficult. I mean, boy, was it difficult!... But I couldn't say no. I didn't want to say no. I wanted to do what I could for my sister. I wanted her to live. I sure didn't want to go through life being the sister who refused to give her sister a kidney. But I also thought of my two children, and my husband thought of them, too, and he thought about himself, and his parents thought about him and the kids. But I didn't really understand how deep their feelings were until afterward. It took me so long to recover. I mean, I got better, and she got better, but I was so low for so long, and I feel there's a real difference in me since I have only one kidney, but the doctors tell me there's no physical basis for that, which means that it's all in my mind. But it's there. And we – I mean my husband and me, and not just us, his family too – resent the way I was pushed into it... . What bugs me every day is that my sister and my parents just take it for granted, and I don't think any of them see what it cost me. I don't think my sister is grateful. She's thankful she's well now, but she's not grateful to me.”* (pp159-161)

## What are the health implications for live kidney donors?

There have been nearly forty studies of the 'quality of life' [QOL] as perceived and reported by live kidney donors after the operation, stretching back more than thirty years. Not all donors respond to questionnaires and invitations to discuss their experiences in telephone and other interviews – which may mean that some who are too upset or depressed as a result of the experience are not included in the studies, and this possible 'selection bias' should be borne in mind in reading the results. This caveat holds true too for the interviews reported below, as people who were upset by the experience may not have responded to the invitation to be interviewed which was made through their Transplant Co-ordinator, as required by UK ethical practice.

Another generally acknowledged potential bias in these studies is the fact that donors are medically and psychologically evaluated before being permitted to donate, and most have good physical and mental health – better than that of the general population to which they are often compared in these studies to assess their QOL or Quality of Life. There is a tendency to 'expand' the categories of potential donors to less than fully healthy individuals, and to older people. The two male donors interviewed below are both in their seventies.

One of the most recent studies<sup>19</sup>, with a nearly 90% response rate, took information from 106 of 118 German donors in the period 1983-2001 who were still alive, one having died. Like virtually all studies of donors – whether from Europe, North America or the Middle East – the respondents

reported increased self esteem. This study reported 38 complications in 16 donors (15%) with 9 of them graded as severe. The relationship between donor and recipient remained unchanged in 80% of cases and improved in 20%. More than a third reported anxieties about the future – around health, work and health insurance, and the recipient's health. Two fifths thought psychological follow-up for donors was adequate but a third didn't. More than nine in ten of the donors would donate again.

Another German study<sup>20</sup> at the University of Heidelberg hospital also reported nearly 15% complications but again nearly 100% would donate again and more than 90% remained satisfied with their decision, having had no problem with their recovery. Again, only 80% considered the follow-up to be sufficient. These researchers commented that kidney donors have a better psychological status than the majority of the German population and suffer less from symptoms and complaints, which suggests that their comments on the follow up support should not be lightly dismissed.

It has been noted<sup>21</sup> that *"Donors' QOL [Quality of Life] strongly depends on the QOL of the recipients after kidney transplantation, which is reflected by the close association of donor's QOL and recipient's outcome. In our study the risk of negative effects on the donor was up to 10 times higher in cases in which the recipient demonstrated graft loss or died."* Similarly other researchers<sup>22</sup> comment: *"Living kidney donors describe donation as an intense experience that brought substantial beneficial changes in themselves and their lives, although such benefits tended to be greater among donors whose recipients were still alive."* In their study of nine years follow-up of 628 Mexican living kidney donors, these researchers found no perioperative deaths. Four donors did themselves develop ESRD [End Stage Renal Disease], three of them in turn becoming kidney recipients. None of these four had displayed any risk factor before they operation although Norwegian researchers<sup>23</sup> warn that *"Relatives of recipients with end-stage kidney disease may also be genetically susceptible for kidney diseases, for example diabetes or SLE [Systemic Lupus Erythematosus] or for progression of such disease. We have experienced seven cases of end-stage renal disease among our 1800 donors, suggesting this may be true. Most cases had primary kidney diseases and not sclerosis due to hypertension or hyperfusion."* Nevertheless they concluded *"Although more long-term data are needed, the overall risk of progressive renal failure due to kidney donation appears to be acceptable."* They note that a study<sup>24</sup> that followed 1332 Norwegian kidney donors for an average of 32 years found that donors were more likely to be alive than comparable members of the general public – a function of the selection of particularly healthy individuals as donors.

A Japanese study<sup>25</sup> of 69 of 104 (66%) living kidney donors at Kobe University Hospital found that only 6 (9%) of the respondents reported minor complications and only 3% thought donation had had a negative impact on their health. 97% would donate again.

It is only relatively recently that research has reviewed the types of problems that can occur during the operation. An American group<sup>26</sup> attempted to survey all 893 surgeon-members of the American Society of Transplant Surgeons about problems relating to surgical clips that can lead to severe haemorrhaging. Not quite a quarter (24%) of the surgeons responded, reporting 66 and 39 episodes of arterial and venous haemorrhage respectively. Two incidents resulted in donor death and 2 in donor renal failure; 19 required transfusion. They concluded that *"Significant hemorrhagic complications occur with living kidney donation in both open and laparoscopic approaches. Loss of arterial control jeopardizes donor life and health, especially when it occurs in the postoperative period."* Given that the USA performs as many transplant operations as the whole of Europe, it is difficult to estimate the frequency of such incidents from this report. A survey<sup>27</sup> of 171 of the 234 UNOS [United National Organ Sharing] – listed kidney transplant centres in the USA reported that between January 1999 and July 2001 these centres had carried out 10,828 living donor nephrectomies; two donors died from surgical complications and one is in a persistent vegetative state.

An international group<sup>28</sup> recently conducted a meta-analysis of 48 studies from 28 countries involving 5145 living kidney donors to estimate their risk of hypertension following the operation. They tentatively conclude that kidney donors may have a 5-mm Hg increase in blood pressure within 5 to 10 years after donation over that anticipated with normal ageing. Another similarly-sized study<sup>29</sup> found that *"Kidney donation results in small increases in urinary protein. An initial decrement in GFR (glomerular filtration rate) is not followed by accelerated losses over a subsequent 15 years."* But more long-term studies are required on all these aspects. Equally, the estimated mortality of 1 in 3000 for donors resulting from the operation in affluent societies has remained constant for more than 15 years. Selected donors with moderate, essential hypertension and normal kidney function have been found not to be at risk of adverse effects in the first year after donation in a recent US study. While Toronyi et al<sup>30,31</sup> were probably overly optimistic in concluding that *"after a correct preoperative assessment, unilateral nephrectomy has no long-term consequences for healthy donors"*, the operation is still considered safe enough to be ethical. Surgeons from Minnesota, one of the leading transplant centres, wrote a decade ago that *"Living donation of kidneys appears to be relatively safe, with very few physical and psychological complications. It may even improve the donor's quality of life."*<sup>32</sup>

### How do donors perceive follow-up care after the operation?

A Swedish study of 39 donors<sup>33</sup> reported: *"The postoperative care was unanimously characterized as 'super'. However, seven donors wished for better psychological care in some critical situations such as regressive reactions, pain attacks, and transplant rejection episodes. Eleven donors (eight women and three men) experienced feelings of being abandoned, exploited and ignored by the staff. 'They almost threw me out because they needed my bed for someone else.'"* This is an under-researched area and it is interesting to see several references to it in the interviews below.

### Are 'altruistic'/stranger donors daft?

The new Human Tissues Acts that came into effect in September 2006 in the UK seek to widen the potential source of live kidney donations by permitting people who are neither genetically nor emotionally related to provide a kidney that will be allocated to a complete stranger. On the other hand, the new Acts require closer psychological assessment of genetically related donors to try to inhibit donations that are not really voluntary. At the same time the 'technology' of kidney transplantation has led to so-called exchange or domino operations where incompatible donors/recipients are matched with compatible pairs. This requires considerable administrative agility, especially if the four operations in a swap around' are to be virtually simultaneous given the right of donors to withdraw right until the moment the anaesthetic is administered. The first 'triple swap' kidney transplantation was reported from Johns Hopkins University in Baltimore 2003. The first two-pair swap was reported in the UK in July 2007. At the same time it was reported that the first 'altruistic' donation of a kidney from a complete stranger had taken place in the UK. In 2003 three German writers outlined a 'pooling' system whereby if necessary rather than donating directly to the significant other, the donor would contribute to a pool and the recipient would receive from the pool.

In August 2007 I published a paper<sup>34</sup> in the *Journal of Medical Ethics* reviewing what was known about the motivations and behaviours of 'altruistic/stranger' live kidney donors. There has been an active programme of such transplantations in Minnesota which resulted in 22 transplants from 360 inquiries. Some potential donors were excluded for medical reasons; others dropped out when they heard more about the implications. In all 117 'non-directed donations' from strangers to people they did not know were reported in the USA to May 2003. In the JME article I review the cautious attitude of the medical profession to potential donors of this sort and the small

research literature on the motivations of such donors. I conclude that we need to consider that it is possible that some people are capable of such unselfish acts, and at the same time recognise that there are 'intrinsic' rewards of satisfaction to be gained by such donors that for many people are sufficient to motivate them to undergo an operation that often is likened to a non-elective Caesarean. Indeed, it was pointed out by American transplant doctors in the *American Journal of Transplantation*<sup>35</sup> in 2006 that "Donation by family members, friends and even acquaintances has now become commonplace and considered appropriate so long as there is no coercion and full disclosure of risks given. With application of these same standards, a rational basis exists for support of nondirected donation. Importantly, these candidates are truly not being influenced by anyone to donate and can opt out of the process at any time without incurring feelings of guilt." (p.115)

They sought to redress the assumption that such donors must be psychologically needy to make such a donation.

“ The Temperament and Character Inventory scale scores also provided a consistent view of these [19 American] donor candidates as being self-directed, self-confident and interested in others. Surprisingly, it was not transcendental/religious values or thrill seeking which were driving their behavior... This suggests that the pool of potential candidates for nondirected living donation although remarkable, was not a vulnerable population sample to be summarily excluded from donation. A greater understanding of these donors may provide a foundation for wider acceptance of such donor candidates by the transplant community.”

Steiner & Gert in a discussion of 'Ethical Selection of Kidney Donors' in the *American Journal of Kidney Diseases*<sup>36</sup> in 2000 point out that "The moral legitimacy of altruism means that donation does not have to be perfectly safe to be perfectly acceptable." (p.679) Glannon & Ross<sup>37</sup> in a 2002 article in the *Cambridge Quarterly of Healthcare Ethics* remind us that "if biological histocompatibility generated moral obligations, then it would remove the possibility of altruism from organ donation. Rather, it would justify mandatory participation in national, if not international genotypic registries that would determine to whom one does and does not have moral obligations to serve as an organ donor and vice versa." They conclude that altruistic acts are precisely not obligatory acts, and that they cannot be 'cost free' and still count as acts of altruism: "How laudable or praiseworthy an altruistic act is will be a function of how much cost or risk the agent is willing to assume when acting on behalf of others, in which case it will largely be a matter of degree... an altruistic act is one motivated primarily or solely by respect and concern for the interests and needs of others with whom one has no special relationship, freely chosen rather than done out of duty or obligation, and at some cost or risk to oneself." (p.154)

There has been remarkably little publicity or solicitation of 'altruistic' donation since it became legal in the UK in September 2006. This option should be announced and celebrated far more widely. The social value of such donations should be emphasised in relation to the tolerable costs for many potential donors in terms of recovery and lifestyle interruptions.

# 3

## How do donors feel about it?

### Mrs A was interviewed just over 3 months after she donated her kidney to her father

“I’m feeling really good, really good. It was quite straightforward, really. I’m probably ready to get back now, it’s just that I have to take some holidays before I go back to work, or I may just go back now, really.

I had to have the open operation because my right kidney was suitable and they didn’t feel happy doing the laparoscopic on that kidney because the vein or the artery was shorter on that kidney and it could have damaged it when they took it out, so they had to do the open surgery on that one.

The scar doesn’t bother me, I forget it’s there sometimes... It’s quite a big scar. Because it’s on my right side I don’t really notice it. The only thing it would probably affect was if you wanted to wear a bikini or something, but I was never one to do that anyway. So it’s quite a long scar but it’s not caused any problems.

My dad’s really well, and it’s changed his life completely and he’s got a lot more energy and he feels like he did before he was ill. It was cysts on both of his kidneys and he was probably diagnosed about two or three years ago with it and was on dialysis for about a year and a half and he tried the two types of dialysis that are available and he ended up on the haemodialysis which he was having at home. He’s 65 and I just thought that if we could do something for him now it would be worthwhile, as if he were older it would have been more difficult or we possibly wouldn’t have been able to do it. But he didn’t have a lot of energy and just didn’t feel like doing anything. I would say he was actually depressed with it.

When we found out that we were able to do something like that, because until you actually have a family member you don’t know what you can do and what you can donate and when I asked my mum what were the forms of treatment she looked into it and we looked on the internet and we found out about kidney donation we spoke to the transplant coordinator at the hospital and she said she was more than happy to talk to whoever was interested. And I’ve got a sister who younger than me and we were both interested and both wanted to find out more straight away. My husband and her husband both also wanted to go forward as candidates to see if they were able to do it. They were knocked out straight away because of their blood type and they weren’t going to be able to go forward at the moment because of the restrictions, so it was myself and my sister moving forward. My mum at one point was interested in doing it but we’d managed to talk her out of it because we knew that my dad was going to need caring when he came home, and to have two people in the same house going through that, and because of her age and various health issues we said let us see what we can do. It got down to the final stages of myself and my sister. Everything was exactly the same for all the test results, so we just had to say to the consultant you make the decision and really all that happened was he said my sister’s got a child who’s five years old, I haven’t got any children and don’t plan to have any children and he just said ‘right, I think it should be you.’ That’s really as simple as it was. He’s lucky that there were two of us available to do it, because we looked at the cadaveric option for him it really wasn’t going to be that straightforward because he’s of Asian origin and they looked at his genetic markers and they were unusual markers, they said it was reducing his chances greatly of finding something, so we’re very lucky he had two options with both of us.

My husband was extremely supportive. He’s been supportive all the way through. He was extremely upset by all of it as well because anyone would be a bit with a spousal partner going through it, and he felt that probably people wouldn’t be aware about how partners would feel about it and he has actually expressed an interest in if anyone wants to talk to a partner of someone who’s going through this he’d be happy to talk to them because he said you don’t realise the stress of it all, and I think maybe selfishly I didn’t think about him straight away until the option was that it was myself and realised how upset he was because I was going to be going through a major operation that had risks, you know, a healthy person going through any operation there’s going to be a risk. Yeah, he’s been a real rock, he’s supported me all the way through it.

I think a lot of people are unaware of extended family issues that you have within this when it’s your mum and your dad and you’re doing it, but you forget how it affects everyone around you. I was really fortunate because I had no pressure from any side of it. I did feel that I was worried about my husband being upset, but he was really supportive, so that helped. That would have been the only issue, you know I said to him you’ve got to tell me honestly, are you quite happy for me to do this and even if he’d have said no I would have said well come and talk to some more people about it and I took him up to the hospital to meet my surgeon, he met the coordinator, and I said you can see whoever you want to find out more about it, so you

know, I didn't hide anything from him and he was still happy for me to go ahead with it. No pressure from my family because my mum and my sister had wanted to go forward with it, and, if anything, it was more of an argument of they wanted to go ahead with it, not for me to do it, and no pressure from my father because he actually did feel that we shouldn't be doing it because he's our dad, he's 65 he thought he'd lived his life and that was fine, we had to convince him he's still young enough to have a life. He was young enough that my nephew was going to want him to be around and in the end it was really getting him to be convinced that this was the right thing for him. No proper pressure on him, it was more, I think he went to the hospital and he talked to a couple of people up there and they highlighted the benefits to him and the minimal risk that was involved, so, you know, he was then quite happy to go forward with it, which did shock me at one point because it is quite frightening for a father to have his daughter do this, he said he'd be happier if it was him doing it for us, but he didn't see that we should do it back. He felt like, I think he felt a bit of guilt towards that as well, which he never should have felt that in any way.

I think the guilt went quite quickly. He still thinks I should never have done it, but he can see I'm fit and healthy and after the operation, we went in on the Sunday evening into hospital to be there ready, went down on the Monday morning and I was home by Wednesday, and he can see me as I've gone along, getting so much better, you know, I'm fine and I think he realises it's not a bad thing to do and he'd be an advocate to other people to say it's definitely something you should do and I've seen him get better, which isn't always the case, and that was one thing that did worry me, that what if he doesn't get better and how bad will I feel about that or if something else happens or if something else goes wrong but we've been both really fortunate and seen each other recover really well.

It's just a case, I think, you build up so much hope on this event happening that it's going to be the cure, it's going to make everything better and you feel like it's definitely going to work, you don't have a doubt in your head because otherwise if you did have doubts it might stop you doing it and you don't. My kidney might not have been compatible to my dad when they put it in, maybe it would have rejected or the drugs might have caused my dad some problems because they give you a lot of tablets to take and they have to find the right cocktail of tablets for my dad and he was very fortunate in that everything straight away went well for him, he didn't have to change too much. He's recovered a lot quicker than they thought he would have, he doesn't have to go up to the hospital so much, he doesn't have to switch his tablets around, they've actually reduced him on a lot of it. But, really, you think there are so many things that could go wrong and there can be some side effects of having a kidney transplant and they said that he has to be careful about going out in the sunlight because he could be more susceptible to different types of cancer, one being skin cancer the other being mouth cancer so you do have this sense of you feel like you want to look after that person and that you want everything to work as well as it should do. We met people where it didn't work so well, but for the majority of cases we've talked to it's always worked really well, but there is that percentage chance of things not working right or of him being back in that same situation as he was before the operation.

Having the live donor coordinator there actually helped everything greatly. She was so supportive, she never pushed you in to anything, I would say she never coerced anyone into anything but she would offer you all the information you needed. Over the last two years we went to two events they held in a hotel and lots of people who had been to the process over the last few years came and talked about it. There are, I think, going to be only positive stories that you see on that side of it but in the literature and talking to the consultants and the surgeons they were quite upfront about the things that can go wrong and the times it doesn't work, so I never thought anything was hidden from me and it was great to see the positive side of it. And the last event I went to, which was just a couple of weeks before my operation, they had a lady there who had been in the same situation as myself and she had actually given a kidney to her son and she was seven weeks after the operation and we thought 'Oh good, look how well she looks, this is fine, I'm going to be all right.' The week before I went in for my operation I met somebody who had just given a kidney the day before to her husband and she looked good as well and all of this really made me feel like you'd be up and walking and fine within a few days.

I'm lucky, I work for a big high street bank and I already talked to them over a year before the operation because you go through so many tests and you know it's going to take a while to actually get to the point where you know you can be a donor, so I thought I would forewarn them and my employer was like 'Ok, you've told us, we'll deal with this as you go along.' They're very generous on their sick pay, so I was covered

on that side of it. They have all been very supportive as long as I've kept them informed of everything they've let me go for hospital appointments, there was no issue on me going in for the operation. But on a personal note, I came across friends and family and my actual manager who were going through a lot of problems themselves with family members who had kidney issues and my actual manager, his brother was possibly going to need a donor in the future, so he knew from his personal point of view it could be him doing it. But I don't expect everyone has the same experience because you're asking someone to say 'Can you give me three months off work, possibly,' you know, because they know it is a controlled environment, because they know I am coming back to work and they know I'll be healthy and I think that's what actually helped on that side of it.

The coordinator was really good, she actually checked as I went along, she said 'Are you going to be ok for all of that because we can obviously help you out and the government can actually help you out with any gaps in your salary.' So I felt that anyway, if there was an issue I'd still be able to do that, but there was never an issue that I thought, well if I have to go without some of my money, I'll have to do that because I still want to do this, it's always great to know you've got the support of everybody around you.

I personally didn't have any doubts because for myself I suppose it's a different issue – it's my father and straight way I thought I wanted to do this, but just I would say, you know, you've got to really find out everything about what's involved because I think for myself I could have asked a few more questions earlier on about what's involved in the operation and not been so shocked when I actually had the operation because you forget you're actually going through major surgery, you're going to have a scar on the side of you, you are going to feel terrible for about a week, really, and it's going to take a good few months until you feel fit and healthy and, really, don't go in naively thinking you'll be fit and well within five minutes, it is something that will debilitate you for at least a month. But just, if you need support and help, there are counsellors there and you can ask for help. But I didn't have any doubts at all and I had family members I could talk about to it, so, you know, there was always that help for me. So, use every facility that's there, don't think that you can't back out on it at any time, because there is always that option and they always double checked 'Is it the right thing, are you sure you want to do it?'

The coordinator said there would never have been an issue on the reasons why you couldn't do it, and they would have supported you in whatever way you had to say you couldn't do it, you know, suddenly I come along and I needed to say 'Well, you know, I don't think this the right thing,' there would have been support there for me and I don't think anyone would say 'Well look at her, she's wasted all this time and money and all these tests we've done for her' because there's never a minute where if you turn up on the day of the operation and say it, basically, obviously they wouldn't have done that because there's so many checks along the way you'll never get to that stage. You never feel like there's not a minute where you can not turn around and say 'I can't do this.'

I think, they had told me about it and I had been given the information about it and they said 'This is what's going to happen if we have an open operation' and I had all the literature there, I just think I hadn't let it sink in because maybe I was trying to protect myself from the physical side of it. The emotional side of it, I was quite prepared to feel elated and then a little bit down afterwards because it's all such a high and you've got so many people around you and I'm not that type of person who likes to be the centre of attention. But all of a sudden there were all these people around me, all my friends and family, and I had cards and presents and flowers and that really shocked me and I thought 'Well, I don't really like all this attention' and 'Can you go away and let's get back to normal' and the constant people asking 'How are you' and 'How's your dad' and, you know, it was all the same thing over and over again and that was quite hard and I was very tired at that point and a lot of people probably expected me to look worse than I did and they were all quite shocked how well I looked, but physically I was tired a lot of the time so it was odd trying to deal with it and be happy and show people that this is a great thing to do and also get them to realise I need a bit of time as well.

I think we're a lot closer now in the family. My dad is not a very tactile person, he never used to hug and kiss a lot, that was more my mother, but since he's been ill and since we went through all of this I do hug and give him a kiss a lot more and I think he's realised that when he needed us we were always going to be there and it's made him appreciate the friends and the family around him. I think it's made him realise how much we all care and love him. We are a lot closer, I'd say, all of us, my sister and her husband, all of us.

One issue for my dad was 'What if you're ill in the future?' I said 'Well I think it will be easier for me to find a donor, because I possibly will be younger if anything happens, technology's moving forward all the time and they're now allowing people who aren't related to donate a bit more freely, you don't necessarily have to know the person. They're looking at maybe what they call a cross match thing where somebody else's partner who may not be compatible is looking at someone else across the country who might have the same issue. Over the last couple years I've been more aware that they're talking about kidney problems and kidney donors and I think there have been a lot more donors at the hospital over the past few years, but we've started this process and a lot more people are willing to donate their organs after they've died as well because that seems to have happened a lot. So, I'm not really worried about that issue because I think medical science is moving forward so quickly and there will be different things available for me and my sister said, anyway, I'm a match if there's a problem, so we know there's someone suitable already. ”

### **Mrs B donated to her son five weeks prior to the interview**

“ I'm recovering really well. It will be five weeks this coming Monday. Not too long, but long enough, really, to feel the benefit now. They were very good. At the time I just qualified as a student nurse and I found... I trained at a different hospital... but I found the experience there as a patient really good and a good experience for me, you know. So I hope I'm going to be able to take that forward, you know, and help me with my career, really.

We started having the tests, we started all the procedures probably about February or March of last year. So, six or seven months to get through the process, then. w I was doing my training at the time and it wasn't always... it was sometimes a bit difficult to meet the appointments. Not so much meet them, but, you know, to arrange, like I had to make up my clinical placements on a different day or make up time from university, things like that, you know, that's the only things that I found. But, you know, we did try to come to some mutual agreement but it wasn't always convenient because it wasn't always done within the department, you know, you have to go to different departments and they didn't always have a say in when you could receive an appointment.

To be perfectly honest with you, I didn't tell the university. You know, I mean this was something I didn't feel... probably if I were to undergo the operation at the time I was completing my course then I would have told them, you know, obviously because I'd have had to take time out. But it didn't really affect them in as much as I was able to do everything – besides making up the time and all that – without them being involved, really. So, in hindsight it perhaps might have been a better idea to have told them because it was obviously quite a stressful time and I felt like I was able to complete my studies and everything, you now, without them getting involved, really.

My son's doing very well, actually. There were a few blips to start with initially. I mean, when they did the CT scan on me they took my right kidney because the CT scan showed there was only the one artery going in and whereas there were two on the left hand side. And then apparently when I had the operation there was five, so I think that made it a bit more complex – not just for me but for my son as well. More so for him, really, because they had to plug it in to him. But they proceeded with the operation because they said that, you know, that they felt that the actual arteries were good enough to – all off them – were good enough to actually be fruitful to him, really. So, they continued and, you know, weeks just went ahead like that. But you know it was a bit more complex. I think it took a bit more because there was a lot more involved than just one artery, you know, so it took a bit more time to settle and things like that. But now he's not doing too bad, I mean, he's not – at first he was backwards and forwards to hospital three times a week – but now he's just down to the once a week now at the moment and, you know, things seem to be looking up. Even himself, he's looking fine. He's lost all that fluid retention. Apart from the spots he's got on his face he's doing remarkably well, yeah, we're really pleased and he's trying... well, he's almost back to normal, really, in his lifestyle and things like that.

He's 25, so still quite a youngster, really. But then there's quite a lot of youngsters, as we've discovered as we went through the process, you know.

I didn't know anybody with this problem and throughout my training, actually, you know it's not something I really came across, you know, I'd come across acute kidney failure, but not chronic kidney failure, you know, so I think it's quite a specialized area unless you're in a hospital that actually deals with renal failure – and I didn't... my training hospital didn't have it as a department – so, I didn't really come across anybody who had that problem, so it was quite an insight for me, when I started going up to the clinics and that to have the tests, to see all the youngsters who frequented the clinics, really.

My son went on to dialysis towards the end, but he was only on it for about two months. He went on peritoneal dialysis so he could continue with his job, really. And all credit to him he used to strive to continue with his work, which was quite a physical job as well. So I don't know where he got the energy from, actually, when you used to see him sometimes he'd look pretty dreadful, but he still used to manage to go to work. I think that was what kept him... well not, kept him going, but, you know, he had an incentive there, really, and that was good for him.

Having spoken to the donor coordinator and the consultants as well, you know, I mean no doubt of that I feel to enhance the quality of his life, really, especially at such a young age they found that was the best decision, really, to go to transplantation. Also, in talking to other patients that we've come in contact with, you know, who have also been on peritoneal dialysis, you know, they seem to think that it was a really good decision for them to make purely because, you know, they've been on it a lot longer and their stomach muscles, you know, had really given up, basically, whereas my son – he's absolutely fine, you know. He's quite an active lad anyway, don't get me wrong, and his job involves lifting and all of that anyway, so he was, you know, he's always, you know, his muscles have always been quite toned, but I'm sure some of these other people, their muscles used to be toned as well, but having undergone that for so long they said that it really affected their muscle tone.

I think they were hoping to get it done with him prior to dialysis, actually, but, you know, all the tests and that hadn't been completed and he deteriorated quite rapidly, really, and because of that they felt they couldn't leave it any longer. He would have been on it longer, to be perfectly honest with you, but he had an infection, so he couldn't start it when they wanted him to, so that delayed his dialysis, really, probably by, I don't know, three weeks, possibly a month, you know, so he was fortunate enough, he got away with that.

The operation, I felt, was fine. My coordinator, she was so supportive. I mean, she was with me from the morning, you know, early in the morning she came down to sit with me and she didn't leave until they put me under and I found that really nice. She's such a nice person, you know. She's a lovely, lovely person. I can't speak highly enough of her. So, you know, I had constant support with her there. I had an epidural – I had an open procedure – and I had an epidural, which was quite tricky, really, and that was quite uncomfortable, I wouldn't say painful, it was more uncomfortable because they couldn't find the actual space and, consequently, even though they thought they'd found the space afterwards, they hadn't and the epidural didn't work, so when I came out from the theatre I didn't have any pain relief, basically, and that was uncomfortable. But, they obviously gave me something, you know, I wasn't really with it, all I knew was that I was in a lot of pain, I can still remember that pain now, to be quite honest with you, it's not something that I dwell on, but it's there and I think other people should be aware of that. They told me that, you know that's what they use for pain relief – epidurals. I know myself, as a student nurse, that I had the opportunity to say, you know, that I didn't want that if I didn't want to, but I felt that, even as a student nurse, that I hadn't had much dealings with this type of situation, so I was all guided by them, really. And I know epidurals – when they work are very, very effective, so I didn't argue with them and didn't query their decision, really. I just feel they did explain the risks to me and also told me they 80 percent normally worked well... I think they said it was about 15 percent that worked reasonably well, and then there was the five percent that didn't work at all, so they did explain that to me and it was just unfortunate that I was just one of that five percent, you know. So, my pain relief took a while to be adjusted because they then had to put me on to the morphine, before I got any pain relief at all. So, throughout that day, really, you know, it was quite uncomfortable. Once the morphine took affect it made me feel nauseous. I was quite nauseous with it and I was sick a couple of times. After that first initial day and all that and you came out... And I think they gave me too much fluid, not necessarily before, they gave me fluid cover before just to make sure I would dilate the vessels and make sure I was well hydrated... afterwards they gave me fluid cover then and I think they gave me too much because my eyes and my face and my hands and everything were all very puffy and when the doctors came around,

you now, later that day, they stopped them and said it's too much and they stopped them, so that made me feel a bit uncomfortable. It was something I didn't feel I'd bargained for, to be quite honest with you. And then after that, you know, I think... that was on the Monday... possibly by the Wednesday, it might have been on the late Tuesday, actually, I can't remember now, to be quite honest with you, my blood pressure was quite low and so a decision between me and the nurses, we said that we were going to try, just initially, to come off it just have the Tramadol and the Paracetamol and see how I went with that. So that's what we did in the end and then, you know, things were good then, I didn't have this nauseous feeling, which was a big relief, really.

I left hospital on the Friday but basically I could have left on the Thursday but my bowels weren't opened, and so they said they'd like to keep me there until the Friday so that's what I'd done, I stayed until the Friday.

The scar has healed lovely, actually, I mean really well. I was really impressed that I didn't have any stitch and then the consultant had held it together with strips. I had no dressing over this, at all, just the strips, which was a new experience for me, but my consultant had already told me about this and he said that this is what he preferred because he found that, you know, some of the dressings that they put on cause people to have a reaction and things like that and it delays healing and different consultants had different practices, as you know, and there were other people that I was aware of who got blistering. Well, I had nothing like at all and my wound has healed really well. I was a bit surprised at first because it dipped in quite substantially, you know, and it felt really deep if that makes any sense to you, with the swelling around it and all of the scar tissue it really did feel you know concaved, but that's coming out now. It's almost the same size as the other one now, and this has just been five weeks that the scar itself is just fabulous and really quite small, quite discreet. Well, it's not discreet, but in the position he's actually put it in, like if you were to sit and you had a crease if your waist then that's where he's done this incision for me and, you know I'm very pleased with it, very pleased.

My son doesn't live with me and so, that wasn't so much of an issue. He stayed in hospital longer than me because they couldn't get the drugs to work – well not to work properly – they couldn't get them adjusted properly. So he was in longer than me. So I came home first of all. I mean, we had mobile phones we were able to use those, so I was able to communicate with him by the mobile phone. I didn't feel – it's quite a distance from where I live to where the hospital is – so, I didn't feel that I could make the journey up there, to be quite honest with you. Beforehand I believed that I could, you know, I really felt that after this operation, I don't know what I was thinking to be quite honest with you, but I just thought I was going to be able to come and if he was still in I'd be able to come and visit him, but that just wasn't the case because I just didn't feel up to the journey. When he came home he was looked after by his father, because myself and his father are separated, but he was looked after by his father and his partner and, you know, like everything was fine, really. He was able to come about a lot quicker than I was, so my partner used to go pick him up and fetch him, because neither of us could drive, so he used to go pick him up and bring him around when he wanted to come around, so I knew that my son was in good hands and I knew that I was in good hands and getting a lot of support, so that wasn't a problem at all, really.

I mean, my carers, they weren't there all the time, both of them worked, but we didn't need that sort 24 hour care. My partner could keep up with his job and so forth. Definitely. The only thing that I found, I mean, I was able, when I came out of hospital you don't do heavy things, you don't Hoover, you don't do things like that. But I was quite able to – I wasn't able to fill the kettle all the way up – but I was able to put a little drop of water in the kettle to make myself a cup of tea, make a sandwich for both of us. I didn't want to be sat in a chair feeling invalid. I needed to be up and on my feet and just doing little things. I let my body tell me when I needed to sit down. I did find the stairs – because we have stairs in the house – I did find those quite a chore, you know, they really tired me. I felt quite tired. They don't tire me now, but initially I was really tired, you know. That in itself was probably good because it told me what I could do and what I couldn't do.

I've had two childbirths. I had them both with normal deliveries, I didn't... although with the initial pain of childbirth I didn't ... that was something I forgot instantly, really instantly. This has been something that I haven't forgotten recently. In actual fact I'm going to just touch back to that pain thing because it's something that, if anything, the whole part of the experience that I really feel they should emphasise to others more. The fact that although, when I came out, I didn't feel as if I had pain in my wound as such, which, you know I don't

feel pain now – it's uncomfortable and it aches around the area. But where they'd actually given the incision they cut through a nerve that affects the abdominal area so I had terrible pains and numbness and pins and needles like electrifying. At times it was quite excruciating, it was something that I hadn't been prepared for. Nobody had advised me about this. My own common sense should have told me they're going to interfere with nerves, but it just never occurred to me that it was going to be as intense as it was.

The numbness, actually, I couldn't put anything on my tummy, I couldn't put my clothes on. When I came out of hospital I had a loose skirt on, a summer skirt, but I was still swollen, but my skirt filled me. This is one of those loose skirts, flowy, but it was really tight on me when I came out, which was something else. I mean, I came out of hospital after having my two children back into my normal clothes. And to come out and to feel as if I was much larger when I went it, it was quite a strange experience, really. I mean, I couldn't feel anything that was put on to my stomach. I mean, I had to put the waistband onto my chest because I just couldn't bear anything on that part because it was electrifying, I don't know how to describe it. It was just as if my stomach was electrified. It was like pins and needles and if I put anything on it was a nervous feeling, I know that, but it was such a weird feeling. But that's much, much better now, I actually of rub my hand over it to rub moisturiser in where I just couldn't go near it to start with. It's only been within the last four or five days, really, that that's really eased off.

When I went back for my two week check... I went back to the hospital after two weeks and I explained to them, you know, the problem that I had. Because it was also, it was also I wasn't walking upright. It was making me walk in a really stupid way, you know, so I was holding myself completely different... my posture, I wasn't upright at all. Once this eased substantially I was a different person, you know, I can't explain that. My next door neighbour said 'You can see it in your face' that's how it came across to her, she said 'You look so much better,' but it went instantaneously. One day it was there really bad and the next day it really eased and, you know, was just there intermittently and the difference it made to my quality of life was incredible.

It wasn't difficult to make the decision as to who was to donate. No, not at all. It was maybe easiest, I suppose, because myself, my other son and my ex-husband, we all agreed to go for the tests and we decided that whoever they decided was the best match to actually go ahead with the procedure. So, knowing my son was prepared to go through with this as well I felt better, actually, in myself, knowing it was me and not my other son because to have my two sons on the operating table in one day would have been quite some ordeal, like, you know. Also I felt it should have been me, probably a motherly thing I don't know. I mean I gave birth to my son, I carried him, he was part of me and always will be part of me and this was just a continuing process, really. It seems more natural for me to donate than it did for me my ex or my son to donate. So, you know, I didn't... it was never a problem. As soon as we knew that was one of the options then, for me anyway, I can only speak for myself but I'm sure it applies to my other two as well, that it wasn't a problem. I know now the problem is if ever my other son needs a kidney then, you know, I haven't got an option to donate, so hopefully... and he accepts that as well, it is something we discussed. I said 'You know, there's no more kidneys to donate now' and I mean we did laugh about it and it was said in a joking manner, it was said with an underlying current as well.

My relationship with my son who received the kidney hasn't changed. And I don't mean that in any other way than the fact that I always felt that I had quite close bonds with him – and with both of them really – but I don't feel like my relationship has changed with him at all. Like I just said, to me it was like a continuing process. I don't even feel as if I don't have another kidney, to be honest. It's just you drift in to it. I would have done it for either of them and my relationship with them. Like I said, I can honestly say, thinking about what you just said, I've never considered up until this moment that he's walking around with my kidney inside him. Whether it's because you can't see it? I don't know. Perhaps if it was something that was visual it might be different, but the fact that this isn't. I have looked at his stomach but it's never occurred to me, it's never had an impact on me that what's in there now was my kidney, was once in me as a working kidney. I just tend to think that he's got a life to lead now, and that's just the way I looked on it, really.

My relationship with my partner was quite a new relationship. I'd been with him for probably a year... well under a year actually, when we first started the process. You know, he was supportive. He did say to me 'If it's not you that's chosen I'll be quite grateful for that.' But when it was he was just supportive. I did wonder at one time because I used to go for the tests and whatever else and he'd say 'How was your day?' but he didn't

want to know great details and I used to say to him 'Well, do you want to know how I got on or do you want to leave it?' and he'd go 'Oh no, here, tell me,' but he wouldn't ask for the information voluntarily. I think that's probably him and I'm not sure it's just that situation, that's probably happened in other situations as well, so that's probably his way of coping.

I thought they informed us just right, actually. Apart from this pain issue I felt that I would have liked to have known. I don't think you can ever prepare yourself for pain, but I really wasn't aware what this was. I wasn't aware if something had happened during the operation and even though I knew myself it was nervy I was quite concerned about this and in the end couldn't wait for this two week period to elapse before I went back and got to the bottom of it. Yeah, I found that apart from that everything was just fine. They told me as much as I felt that I needed to know. Anything that I felt I needed to know that I felt they should inform me I asked them. I would do that with anything. The things I perhaps wouldn't have thought to ask I felt they covered anyway. So, for me, it was just the right mix between the parties involved.

I've had good follow up support, definitely, from the coordinator. This has affected me getting a job to a degree. I didn't feel I was in a position once I found out I'd passed my exams and my dissertation and everything. I didn't feel I was in a position to apply for posts with the knowledge I couldn't take them up immediately. Also, because I felt that if I did manage to get an interview I wasn't sure whether or not I could tell them what I was going to do. Otherwise it might have been detrimental to my interviews should I get one. So I was like in quite a quandary there. I felt I had quite a dilemma there. Then after there was a post I knew about that was actually coming up, it was a new unit that actually wasn't opening until after Christmas and it was an area I really wanted to be involved in and so I did put in an application form for it and I've since had an interview after the operation a few weeks ago and I was successful in obtaining the post. So, the coordinator saw my son down at the hospital and she said 'Have you had any news about your mum's job' and he said 'Oh yeah she got it' and straight away she phoned. But that doesn't mean to say... because she's been in touch with me regularly since I've come out of hospital, and I'm really grateful to her for that. Initially, like the day I came home, and the following day... I came home on the Friday and it was the weekend on the Saturday and the Sunday and she rung me, you know, and I know that's taking up her off time and I just thought that was very special.

I saw the doctors when I went back after my two week period. I haven't seen them any more but I just believe it's because there is the coordinator if there's any problems then I would see... I'm under no illusion there that if there was a problem I would be back straight away, that's just the type of care. And seeing how they're dealing with my son, because he's had to have another biopsy since the operation, and seeing how they dealt with him I'm under no illusions that if there was any problems on my behalf I would be back there and wouldn't have to wait around to see them.

I think there is, actually, some financial implication because my colleagues, they've got jobs. I know nursing throughout the UK is not brilliant at the moment. You're hearing lots of reports in England where nurses are qualifying and 80 percent of the course haven't managed to secure a post. It's different like that down here and there are posts out there and the vast majority of my colleagues have managed to obtain posts... well, I've got one now. So that was the only drawback for me. So I went from being a student with a bursary to having no income and then things like... See, my partner's self employed, so he can't really afford to take the time off anyway. Where as a student nurse we were able to get the council tax benefit, a discount... we got discounted for tax benefit... that went, so not only am I not getting a bursary, now we're having to incur costs like that when I'm on even less money than I was before.

I have spoken to the coordinator about that and it's something that's being looked in to and I've spoken to the council, but it's just something that takes time and initially the money just has to come out. So they might be able to refund you at the end, but these procedures aren't in place initially. That's the main drawback.

It's not such a worry, really, I mean my partner, like I said, he's very supportive. But, to me, because we live together and that, we still, up until now, we've had our joint pot where we've both been contributing to and I feel at the moment I've got no contribution and I feel, you know, to me, at my stage in my life, that takes away my independence. It's just something I just struggle with, really, and I know that I don't have to struggle with it, really, because there's no need for me to. It's just my makeup. It's just the way I am.

I'm starting work soon, I've already agreed a date, providing nothing crops up in the mean time. It's the third of December. I'm really looking forward to that.

I do think that actually I have a very positive personality. I was really positive right from the word go and I think my son was as well and I think that's helped him.

My knowledge of people that haven't had a good experience apart from this fact with the muscles in their stomach are not very good is something I've not come across yet. I know everybody experiences pain differently but I don't believe that... I wasn't told that the level of pain could be as bad as it was and the reasons why it was as bad as it was. I'm not sure whether this pain would have been more easily managed with a different type of pain relief which perhaps they don't really want to give out because I only have one kidney now. I don't know about that. I don't feel that I'm experienced enough in that field to comment, really. I'm not sure whether I had the right type of pain relief for the type of pain I was experiencing and I did feel that initially I was relying on the pain relief that I was having and was taking it on a regular basis even though there was a possibility it was still going to keep me constipated. So, like I said, I'm not really sure about that. But I should say, once it eased the quality of life changed immediately. So now I'm able to go for walks and ride in the car, I'm not driving yet and I won't be for another week or so, but I really feel I am mobile now.

I think initially afterwards I felt a bit tearful. I wouldn't say mood swings as such, no, just a little bit tearful afterwards. Not tearful because of losing a kidney or because we were in hospital or my son was in hospital or things like that. I couldn't pinpoint what it was. I just felt a little bit tearful, you know. Everything either seemed wonderful... like, emotional, really, you know, I just felt quite emotional and not ... more so when I was home, you know, like people sent me flowers, you know, things like that. I thought 'Oh my goodness' and things like that because they were lovely flowers, they were beautiful bouquets, and I just thought that people were so kind and just things like that and they did get me really quite emotional, really. It was just nice. I wouldn't say it was so much a mood swing so much as I became angry or anything like that, no.

It is an experience. I just think that the positive thing about it is the fact that you can help somebody enhance their life, really, at a little cost. Really, it is such a little cost. Like I said, I don't even feel that I would know that I'm living on one kidney. It's not noticeable, really. I really don't notice it at all. They said to me 'In three months you will feel much, much better' and the way I'm going at the moment I really don't think it's going to be three months before I'm feeling like I was before. I hope to take up swimming next week and, you know, things like that. I just feel, you know, there are lots of benefits. If people could understand the benefits that people are going to gain from this at really no detriment to themselves.

If it helps others to make the decision then I really hope it does. It's been a very positive experience for me and it's something that... it's the feel-good factor as well. It's not something... I do feel embarrassed sometimes. I was on the phone the other day to the occupational health for this new trust I'm going to work for and she was saying 'Oh I really admire you' and I felt embarrassed then because I don't feel it's a sense of admiration. Perhaps it is to other people, but to myself it's just me being a mum, you know, ... I don't see that and I do tend to get embarrassed if people start saying 'It's a wonderful thing.' I suppose it is a wonderful thing, but if they were in the same situation they would do it, I'm sure, they would do exactly the same, and that's all I can say to them 'If you were in the situation I was in you would have no hesitation, you would have no doubts.' I don't know how else to say that. It's just an immediate response, really, and one that I never thought twice about. ”

### **Mr C was interviewed nine months after he donated his kidney to his son**

“ I had been very good but at the moment I am not very good. When I do anything physical I get very short of breath.

It came to the critical situation where you have to have a kidney and they did ask if there was anybody in the family that could donate, so as it happened I put myself forward. In the beginning there was some trepidation. But I seemed to get on with my life and forget that for a while. But then they did a series on the television of transplantations – all manner of transplant – they did lungs, hearts, and they did kidneys and

liver I believe as well. And I watched all this series and I thought well if they can do that, why should I worry? And I didn't worry about it then.

Normally I don't watch things like that, but once I committed myself then I watched the series each time it was on and I saw what they did and I thought, well, if they can do that, a kidney, which I had been assured anyway would make no difference to me, was acceptable.

Once I made the decision that was it. If I say I'm going to do something, then I'm going to try to do it. I think my surgeon had doubts. I had to see him because of my age. I will be 75 in January. And when I walk through the door of his office down in the university hospital he said how pleased he was to see me because of the way I was looking, I was looking fit. I walk at least twice a week. Half the time I was walking up to about 12 miles, so over a week's period I would be walking about 25 miles.

I believe I am due around this period for a 6 month recheck. I haven't received a letter and I've been expecting a letter for a while and this is what I was hoping, you see, that if I received this letter, whenever I went down, whatever doctor I saw I could explain to him how I am at the moment, because I still believe I am strong, you see. I was operated on on the Tuesday and I was out of hospital on the Friday. When I was home I was able to make myself tea and look after myself in, you know, in both ways.

To be fair, I believe, you know, the coordinator and all the consultants and the all the people in the Hospital, you know, they all do the best for me. And I don't think there was any occasion where – or there may have been one when I did see one clinician, because, you see, prior to the operation of starting the going to the clinics and seeing how fit I was and all that and the various x-rays and the examinations, I had anaemia. And then they were trying to find out what the cause of the anaemia was. And because of my age I think they may have suspected that I may have had cancer or something. And when the gut specialist, when I went to him, he was the only one who made me anxious for a couple of days because as he was leaving he then stated that there was a possibility that I may have had cancer, but he didn't stay for me to question him. I just had to wait for the results, which was several weeks. The only thing that I was concerned about all the time, all the way through, I was concerned in case I didn't stay fit enough to donate the kidney. And the funny thing is that sometimes when you went for a drive in the car you were anxious in case something happened and then you couldn't go forward with it.

Unfortunately what occurred after the operation was that I came out on the Friday and my son had to stay in the hospital a bit longer, but he picked up an infection then. Now, after the operation he had two infections and on each occasion he left the hospital then he was home and he had to have the district nurses call in. Now, this happened twice and the first incident he had the district nurses call in three times a day and on the second instance they came four times a day with intravenous and antibiotic. But after the second occasion and when they got rid of the infection, well then he started to come on and go somewhere. And now he's still got medication, you know, and they're cutting down on it quietly. But he's doing marvellous now. I'll get my checkup done now. ””

### Mr D also donated to his son

“ My son received the kidney. It went very well. He's had a few blips which they said would happen but at the moment he's great, he's back in work and everything. He's 45. I was 70 when I had it done and I'm 71 now. They didn't have any reservations about working with me. I am pretty fit. I had the keyhole, the laparoscopic surgery. Not much in the way of scarring – about three inches, I suppose. No discomfort or pain at all. They had an epidural and if I wanted to I could press the button, but there were no problems at all. I went in on a Sunday, had the operation on the Monday and I was back home on the following Sunday. I couldn't drive a car for six weeks, but even before that I was getting about, basically it took a month.

I didn't have any bad experience, not depression. When I came out of hospital I did have a tear, seeing my son all right and that, you know. But other than that, no.

It was a very easy decision to make. My son went down for a check up and they said he was being put on the transplant list but if anybody in the family could donate then we had the co-ordinator's telephone number and we just rang straight away.

He had this kidney problem for years, but they said it wouldn't attack until his fifties but, of course, it came on a bit earlier. He was due to go on dialysis but he told the doctor I was up for donation and they said when and they said he's just doing the cardiac tests now and they said ok. We wanted to avoid the dialysis. He's got two young children and, you know, it would have impacted his life a lot.

I didn't feel anyone was pressuring me to donate. Actually, we didn't tell anybody, my son didn't want anybody to know, so it was a total secret which was very hard, actually. I don't know, that's just the way he wanted it and we just went along with him, you know.

He was out of work for a couple of months and he went back. He's been back and forward. He'd be in for a few days just getting the tablets right and he went down yesterday for his monthly check up and they don't want to see him for another six weeks, so he's really up.

There was no financial impact whatsoever on me. I had to stop work. I drive coaches part time, I had to stop that for a couple of months but that was my own decision, you know.

There haven't really been any changes in my relationship with my son because of the donation. We've always been pretty close to him. He doesn't live too far away, anyway. It was a very easy, quick decision. We've just got one son.

I'd do it again if I could spare another one, yes, haha. Yes, you know, I wouldn't put anybody off doing it. I don't think there was any danger. They explain everything to you, the surgeon did the week before we went and he said even though you're fit enough to give a kidney doesn't mean that when we get the kidney out we could even use it. So, they prepared you for every eventuality, you know. Me and the wife were never ill and the two of us were up for it in the beginning and then we decided that it should be me because I was a slightly better match, so, no, strangely enough there wasn't any anxiety at all – we just went in and he was done and we were out.

They gave us a booklet to look at and explained more or less what we wanted to know, anyway. We had the video to watch if we wanted to, you know, so that's it. So when it's your son you've got no problems anyway, you know. You want to do it and that's it, you know. ””

## **Ms E had her operation six weeks prior to the interview**

“ I'm feeling well. I'm... it's been a bit of a shock actually because I was told that the donor has the worst end of it and I have found that I've gotten very tired very quickly. Physically I'm fine, I just get these waves of tiredness that comes over me, but that's getting better. All the wounds and scars have all healed nicely.

My brother's doing very well. He was on dialysis for four years and I wasn't actually a particularly good match, but I think he was on the transplant list for about three and a half years and a match was not becoming available for him so they then chose... or the hospital decided that they should take a risk with my kidney so I was then put along this path of testing and everything. Yes, he's doing very well indeed and I'm really quite pleased with him.

What I was told is the donor goes into this operation as a very fit person and I was quite considerably fit. If I may explain, I had to lose three stone to allow them to do this operation. So within a ten month period I made a very conscious effort, very focused, about losing the weight and getting myself fit. So I was the fittest I was I'd say in the last years, to be honest with you, whereas my brother was really quite at the low end. He was really not very well at all. Now it's been roles reversed. He has got all this energy. This new kidney has actually provided a new lease of life for him whereas for me it's... I've gone from being a very fit person to being one that hadn't got that energy I had before the operation. It's coming back slowly, but I didn't anticipate the effect it would have on me as it has.

I was running three miles daily, you know, just to try to ensure that I may... actually, because I had this weight, this goal that I had to meet because I was told quite categorically that I had to be within a certain BMI range and, you know, I was very focused and positive about doing that. I think what I feel, myself personally, was that my brother didn't have very many opportunities left, if you see what I mean. He was on... I think it... is it peritoneal dialysis? He was on that and he had been from the start and they were saying that he was going to not be allowed to be on that for much longer and the haemodialysis, he has a slight heart problem because of this illness, so that would have been a strain on his heart. There wasn't actually a donor available, a cadaveric donor, so, to me, I felt as if I was his only hope and I had to ensure that I was capable of doing this, you know?

I think it was 2001 or 2002 – the January – when he was diagnosed with end-stage kidney failure. We all immediately, all my family – he has a twin brother, you see – we all got tested immediately. I was told then that I wasn't a good match but I... my mum and my other brother had different blood groups, so they were out of the equation straight away... but the, the powers to be decided that he should go on the transplant list initially to see if there was a better match on there. So at that time I discussed it with my family and my children are now 17 and 13, so they were about 13 and 9 so we had a little family discussion, but it was more with my husband, really, and we discussed... because what I didn't want was for my husband to feel as if I went down this road that it would jeopardise our future, you know, health wise or... I know people can survive on one kidney, but you have to discuss this and, you know, there's always risks in having an operation and everything. So we discussed it at that time, but, as I say, it was put to one side for the time being and then when it came about... I think it was October of last year – 2005 he wasn't having, as I say, much success in finding a cadaveric donor, so I was approached again and we had the same conversation but this time I think we both – my husband and I – knew that it was going to go ahead. So really, and the boys were over, we just discussed it as a family and, as I said, whether my husband would have thought that by doing this it would risk our future together. That was what was the main thought on my mind.

To be honest with you, I didn't consider whether my sons might one day need a kidney. That's the truth of it because I hadn't contemplated that. I have a very close bond with my brother and from talking to the transplant coordinator and people who had dealt with him it was just a natural progression that I would volunteer to donate a kidney to... You know, you've voiced that question now and really and truly I was so blinded why what I needed to do for my brother I hadn't even contemplated that.

We were all actually surprised that my brother had this problem. We've all really been quite healthy with regard to that anyway. He was the isolated case. There's never been any history of kidney failure in our family prior to this.

It's been pressure for my husband. I think because I'm the wife... he does a lot around the house but he had to do everything here, especially when I was in hospital he was working. He took two weeks off after the operation for when I was home from hospital. But during the time I was in hospital he was working fulltime, he had to come home, feed the children and then come and visit me, so there was a lot of pressure on him and the pressure of keeping the house going. I do think, although he didn't show it, he felt the pressure of keeping everything going. He did cope admirably, to be honest with you. He didn't moan about it, he just got on. But I think there are pressures if it's the wife or whatever that is donating because, not wanting to be sexist, the wife is the one who tends to run the home.

I wasn't able to drive and our children do lots of activities, so he had the responsibility of taking them to where they needed to go. It's things like that. You think... the pressure's on the ones who have to take over the jobs that you would normally do, you know?

There were no financial implications. I'm a civil servant, so I obviously approached my senior officers and we have a welfare officer and I approached them before I actually made a decision because I needed to know if there would be any problems. Obviously, within civil service there are job cuts and it would have been... how can I say this... it probably wouldn't have been a consideration if they were prepared to – I'm on sick leave at the moment on full pay and there was no question about that at all so that was wonderful – but even if they had said 'Well, you know, we can't pay you but we'll allow you to have the time off' I still would have done it I think. My brother was the one that needed to be helped here.

It would have created another pressure having to go through months without income. And when I went through this process the transplant coordinator did actually mention that in some situations if the employer is not prepared to pay while the donor is unable to work that there are funds that can be called upon. In my case I didn't need to call upon that at all. I was very pleased with the way my employers allowed me to go ahead with this.

I will have had two months off as of the seventeenth of November and then I'm going to see how things go on from there. I finally have met up with my boss and she said to me that she didn't expect me in until after Christmas. Now, whether that will happen... I'm a very active person and I tend to need to be doing a lot of things and this period of holding myself in check I think... I don't know, I genuinely don't know whether I will still feel as tired. What I intend to do is obviously to take on more work in the house, which I have started to do now and this week I'll start driving a little bit as well. I was told I have to wait six weeks before I was able to do any exercise – strenuous exercise – at all, so that will... I have this week to go through now and I'll slowly build up an exercise regime and then I'll see from there whether I'm still getting as exhausted as I am at the moment or whether that dissipates.

To be honest with you, I was so focused on the operation, I was so strong during this whole period that I didn't have any feelings about it whatsoever. Believe it or not, my concerns were for my brother. My concerns were whether he was well enough to actually survive his operation. But, I have to be honest with you, I've had my children by Caesarean section, so I was well used to that operation, if you understand. I had my children by epidural so I made a conscious effort that I was awake when they were born and I took on the fears of this operation in this same manner if you understand.

I felt that perhaps it was worse when I was having the children by Caesarean because obviously then I had to look after them and feed them and then you are actually doing more from a very early stage after having the operation. I was up and about the next day. The day of the operation I was completely... I don't actually as a rule do anaesthetic very well and I was really quite spaced out. So, the Tuesday I didn't really know where I was, but then the Wednesday I was out and going to the toilet and sitting in the chair and I wasn't in quite as much discomfort then as perhaps equates to having the Caesarean sections with the children. But obviously there was discomfort... I felt that I was more mobile then, shall I say, very early on.

I came out of hospital on the Saturday and it was the following Friday I did have this pain on the right side of my abdomen and I just really... you know when you say it took your breath away... it was beyond that, it was beyond that. And I really was really quite scared, I have to be honest with you, because I thought 'Oh my god what is this?' and it didn't subside as quickly as it came because it was quite... I was actually getting dressed, you see, and I wasn't able to get my own trainers on and I wasn't doing that but I was just pulling my trousers up but it was just such an intense pain that it beyond took my breath away and it didn't subside for about five minutes and then it slowly and gradually disappeared. I didn't have it with quite that intensity again, but it did materialise a couple of times. But over the week... over the days and the weeks those – I call the pains that I had drawing, tightening pains where perhaps the wound was knitting together – I had pains like that but that one Friday morning was so intense that I didn't quite know what was happening to me and I've never quite had a pain like that in my life before.

That was after I came home. I went in because I had to go into hospital for a final check on the Wednesday and I did mention that I did have a severe pain to the surgeon but I hadn't had it since that, you see, and really whether it was naivety on my part I did put it down to the knitting and this gelling process where your wound is basically healing within you.

And I have to be honest with you, the day after I had that same twinge in that same area but it wasn't that intense and I just thought 'Oh gosh.' Whether it was something where... I had just had a shower and whether I'd got out of the bath too rigorously and I agitated something, I don't know... but it did dissipate. Within, I'd say, a fortnight those pains not disappeared but the intensity of them subsided, gradually subsided.

I had keyhole surgery. It's all healed. It's really quite a neat scar. I've got about a four inch scar about two inches, three inches below my bellybutton and I've got two incisions on my left side which are about two inches which are healing nicely. I've just got that very fine red line now which I'm sure will go back to its normal skin colour within some time. It doesn't worry me. My bikini days were over along time ago, to be honest with you. I'm not worried about that at all.

It was very emotional. As I explained earlier I had to be focused, I had this goal and what I also found that I was... my brother didn't really want me to do this, even the week before the operation he didn't want me to do this, and I had this attitude that I had to be strong for him, had to be strong for my mum – obviously both of her children were under the knife, – had to be strong for my husband because I didn't him want to be an emotional crutch. As soon as I came out of hospital, it was the week after, I came out on the Saturday and during that week I couldn't stop crying. I don't know whether it was the relief of it being over. I think that possibly, more than anything, it was the relief that my brother had survived his operation and that everything was successful because I think that to go through this – to donate a kidney – and I was made aware that it might not work, my kidney may not functioning in him as well as it should. All of these things I was told about and I think it was the sheer relief that we both came out of it all right, the kidney had worked and what I had gone through hadn't been a waste of time, then. It just poured out. I had a week that I was quite weepy and, you know, my mum had a week as well. We'd see each other and get very weepy. Not hysterical weepy.

Yes, it has changed my relationship with my brother. Well, I think we were always close, we've always been, I would say, out of all my siblings the closest. But yes, I think we have an extra-special bond now, I think, do you know, when we see each other and say hello that hug is a little bit more of an intense hug, if you see what I mean.

His wife obviously on hand to look after him and I really think that obviously within coping with that illness I'm sure she was under pressure herself, you know, they have a young family, they have a six-year-old son who obviously never saw his dad well, so there was the pressure of ... I'd have to say with my brother you don't really know what goes on beyond closed doors and I'm sure it was very stressful living with somebody who is ill and the rigorous timetable that he had to have with his dialysis. I think, eventually, by the end of it they got into a well-worked pattern, a well-worked routine. But from my part it was never visible. When we all had family get-togethers he was always putting on a brave face no matter how ill he was. I'm sure it was a pressure...

No, no I never felt under pressure from anyone. As I say my brother didn't, until the Wednesday even before the operation, he still didn't want me to go through with it. And I said 'I'm here, I'm doing it, you have to accept that I'm doing it.' So he didn't want me to go through this. He wasn't pressuring me at all but I knew that he had his anxieties about me doing this, you see. But no, at no point did I get any pressure, even from my husband, to say 'Look, I really don't want you to do this.' I think he knew how important it was and I think he realised how important it was and that my brother really didn't have many other options, you see.

My mother was devastated that she couldn't do it herself because I can remember her saying 'Well, I've lived the majority of my life and I wanted to do it for him because...' I think she perhaps was upset that it wasn't her and it had to be me and I think that the fact that I was both of her children going under the knife was something that she found hard – I wouldn't say to cope with, because she coped with it very well, but I would say it played on her mind. When we saw her together you could see her welling up. She was quite emotional leading up to the operation and as we got closer to it her emotions over spilled more often than not. You can appreciate how a mother must be feeling when both her children... But again, there's the relief now that everything has gone ok.

On the consultations I had with the various people... because when I first started this journey, so to speak, this path, I spoke to one of the consultants and I was quite happy with the information that I was given then. I have to say that the transplant coordinator was always available if there was anything that I had any concerns about whether they were to be questions or not. I know that I called upon her a couple of times when there were issues that I wasn't quite sure about and she was able to advise me and discuss... they weren't major issues, they weren't major doubts but they were... I regularly give blood and I was called upon to give blood and I wasn't sure if that was something I should be doing, so I felt that the coordinator was there as a support mechanism for such things so I rang her and said 'Can I, while doing this process, is it all right for me to give blood' and she advised me that perhaps not to. So if ever I had any queries I didn't go to the internet, I went directly to her, who was a great support during the whole process where I was tested, even while I was in hospital she came into visit us. We were in on Monday and she missed afternoon and she actually made a special trip on the Monday evening to see how we were. I felt the support I had as a donor

and possibly even my brother as a recipient was absolutely fantastic and I can't appreciate that, I can't say my appreciation of her more because I think she's really quite there for you.

I had regular phone calls from her during the first week that I was off and I then had to go to the clinic and basically I was given, from the surgeon, the 'all clear' just a few guidelines from the surgeon some guidelines about exercise and that's it then. You're free to carry on your life as normal. If I'd be honest, really, you do feel a little bit, initially, 'Oh, well, that's it, then.' You do have this bombardment with contact with these people and then you do feel left with... it's like a guillotine coming down and that's when it stops. Whether you use these people as an emotional crutch a little bit and then that's taken away from you and then you have to learn to get on with your life again. Whether you hear that from people... you know they're busy people and they have to cut the umbilical cord at some point...

I did feel 'Oh right, that's it now, I have to get on with it.' Because it was all so intense that I did feel that and possibly... but then you have to think about it logically because they've got other people that they're doing the same role for and, you know, only one person can cope with so many things at one time, so you have to look at it in a mature way...

I did feel that I had a week of phone calls... I mean don't... she was absolutely fantastic, I don't think it's the person. Perhaps it's the system that needs to be looked at. I had a phone call every day from the coordinator and then a couple... the second week that I was home. As I say, I was fortunate that my husband took two weeks off with me, so I wasn't on my own. I'm sure there are probably some people that are left on their own for some time and perhaps they need that extra bit of support from the donor team. But from my perspective I had my husband and we actually had a wonderful week. I was up an about a little bit and we went... we had a couple of lunches, it was my mum's birthday, so I was fortunate perhaps maybe compared to some people who it is just a cut off and now you have to just get on with it yourself. So maybe I didn't feel it as strongly as maybe others do because, as I say, I did have help in that regards.

But in fact there was a bit of an impact on my relationship. What it was, I think that in his eyes I changed slightly because I was so strong and really wanted to do this that he saw somebody different from who he married and he felt that he wasn't needed any more, if you see what I mean, which is obviously ridiculous, and now we've moved through that. But I don't know if that happens with partners. That is the only negative thing that has come out of this. He will admit that he didn't cope with it very well. I think he saw... he's always been the strong one. He's always been the one...perhaps he saw this strength in me that maybe scared him a bit and he thought perhaps I didn't need him any more and I was capable. Do you see what I mean? I think he felt vulnerable by that. I'd have to say out of all of this, this is the most negative thing that has come out of this that what I have done has affected him in that way... it all comes around as well, with all the pressures of having to run the household as well. But this was in the course of running up to the operation I had lots of people phone me. He felt it was a bit of a circus, you know, and he just couldn't cope with the fact that... he felt he was just on a runaway train and he just couldn't get off this. I don't know if that is something people have experienced. For me, that is the only thing that has concerned me coming out of this. But from my perspective I haven't had any doubts about having to do this. I feel so lucky that I was able to help because I didn't think my brother had many options himself.

For me it was a positive experience and the way I was dealt with by the live transplant team was absolutely... you know, I can't praise them enough. They've actually treated me with the utmost respect and care and sensitivity and they basically allowed my brother to, you know, live again. If I may just say... the difference it's made to his life. He was never able to stand on the touchline and watch his daughter, she plays for the football. His six-year-old son has just started playing rugby. He can now do that; he can watch him play rugby he could never do that before because he just got too exhausted or too cold. It just gave him wonderful lease on life. And I owe a debt to the surgeons and the team who have allowed that to happen. I know that not a lot of people get as far as this. The coordinator says one in five that she sees, there's only one out of the five that actually go on to actually to donate. So I feel very fortunate. Another aspect as well, perhaps, that a donor feels, I am so relieved that I have had a medical MOT out of all of this. To actually come out and say that I am fit and healthy and there's nothing wrong with me is a wonderful thing... 3 stones lighter, yes.

## Mrs F

My son started to have problems with his kidneys 12 years ago, when he was 18 years old. Since then we have been going back and forth to the hospital every 2-3 months. About two years ago, his health deteriorated to the point where he needed to have a kidney transplant. He is blood group O+ which is the universal donor, so there were limited cadaveric kidneys available, so we decided as a family that we all wanted to donate a live kidney. My husband, myself and our two other sons started the tests to see if we were suitable donors, but I was determined that it would be my kidney that he had. I didn't want my twin sons to donate. They have busy lives with families and careers. My son that needed the kidney had developed inside me and as an analogy I compare it a bit like a computer. If you bought a computer and something went wrong, you would take it back to the manufacturer. David would be coming back to me to be repaired. I am a very positive person, I had the utmost faith in the surgeons and the procedure, and I knew in my heart that it would be fine and it would work, with no effect on my life afterwards. And that is exactly how it has been since. Both David and I have bounced back and within six weeks, I was back in the gym and swimming thirty lengths a day. It was exactly as I had anticipated.

My husband wanted to donate as much as I did, I am absolutely certain about that. But I didn't want it to be him either. I knew I could cope better with the discomfort. I have had operations in the past and had an idea what to expect. Also I would have found it so hard worrying about two members of my family at the same time. If anyone was going to donate I wanted it to be me.

We didn't have to consider donating. We didn't come home from the hospital and discuss it. When the consultant in the hospital said David was going to need a transplant and explained about the shortage of cadaveric kidneys, I said immediately, "He shall have one of mine".

I think it helps to have a very positive personality to consider live donation. I think if you've got a negative personality then you are not going to do it because you would be worrying about the consequences to yourself. You need to have confidence in the people who are treating you, and if you've got that confidence and a positive attitude you'll say "I'm going to do it, and I'm going to be ok". It's great to see David now. When I look back over the last few years, I can see that he'd lost his sparkle and bounce. It was something that had happened gradually so we were not really aware of it until afterwards and then we could see the difference. We had David back.

He went on dialysis from the January to the May prior to the transplant. He elected to do the peritoneal dialysis. He was determined not to stop work and it fitted in well with his life. He needed to dialyse four times a day. In the morning, at lunchtime, early evening, and last thing at night. It took about 20 minutes each time. He carried on working right up to a couple of days before the operation.

The only concern I had prior to the operation was that if anything adverse did happen to me, then what effect would it have on David. How would he feel? Would he feel responsible? I actually wrote him a letter and put it in the safe saying that I still would have done it, whatever the outcome. But he never had to read it, and anyway I never thought that anything would go wrong anyway.

I didn't think his twin brothers would ever need a kidney from me. We did all the tests together and we were all O+ and our bloods all matched. None of us genetically matched David perfectly, but we matched enough and in the same ratio. The twins were perfectly matched for each other as they were keen to donate to David then they would obviously donate to each other, should the need ever arise. Also, my husband was a suitable match. We needed to deal with the here and now. You can't keep things about the "what if's".

The operation obviously wasn't pain free. What operation is? I had to have the more invasive operation because they couldn't take my left kidney, as there were extra vessels so they had to take the right one which meant they had to go in from the side rather than the groin. The first 24 hours after the operation were not very comfortable. David and I went in on the Sunday, and the operation was on the Monday morning. I was home by the Thursday. I would say the worse thing was the constipation about two weeks later! I hadn't anticipated that. I was eating loads of fruit and vegetables, and drinking lots of water so I was very surprised. The best part was the day of the operation. After I came round, David's wife came and stood by my bedside and said, "I've just come from David. He's back from the operation and he's had a scan and I've just watched

the transplanted kidney working perfectly". For me that was absolutely amazing. I found it incredible that they could take a kidney out of me and put it in my son within an hour, scan it, and see it working well. It's a miracle.

I would say that five months on and I fit it a bit more thought provoking now than I did before, or immediately afterwards. I'm finding now that it's hitting me a bit more. David's having a bit of a blip this last fortnight, his Creatinin hasn't quite settled down as we'd hoped. I think we weren't really expecting any post-op problems. The doctors were talking about doing a biopsy last week and I find that upsetting. We weren't expecting it. At the time of the operation I wasn't at all stressed. I just took it in my stride. You need to have that type of attitude.

Both my husband and I are retired. It was definitely an advantage. My daughter-in-law and son moved back here, and my husband nursed us after the operation, and my daughter-in-law was able to continue working. Because of the need for post-operative care, I don't think it would have been so easy if either of us had still been working. I would not have liked to have been alone for the first couple of weeks afterwards. I'm sure things wouldn't have gone so well if my husband hadn't been there to nurse us. He was a brilliant carer.

Having the operation had no financial implications for us at all. It didn't really for my son either. His place of work gave him all the time off he needed and paid him. Mind you, he went back to work early. He was back within seven weeks, which was amazing. He works for a big company. I don't know whether a smaller company could have been able to be so obliging.

My donation didn't alter my relationship with my daughter-in-law. We get on extremely well and it didn't draw us any closer together or cause any problems either. Looking back, as a family, we took it all in our stride. It's the same with my son and I. It hasn't altered our relationship to one another. I didn't want him to be overwhelmingly loving and grateful, and feel forever in my debt. We didn't talk about it. It was only when we were recording a television programme about kidney donation that he said to the interviewer, "How can you thank someone for such a gift?" It was a lovely thing to say but I wouldn't have expected it. We just took it as if it was a matter of something to be done, as if we were going to Tesco's to do the shopping!

We took part in a conference six weeks after the operation, giving testaments of our experience. There was another couple doing the same, I think they were husband and wife. Their presentation was so different from ours. They said about wanting to help the other person because they loved them and what a wonderful thing to do. David and I stood up and said this is what we did and how we did it, and how we think about it. So different. Both good. I would do it again, I wouldn't hesitate. Obviously it was uncomfortable for a week or so, but I was soon back in the gym and playing badminton and golf within a few weeks. It doesn't appear to have had any effect on my life at all, and even if it had I would still do it again.

We were given plenty of information prior to the operation. We asked lots of questions because we wanted to know as much as possible and were introduced to patients in the hospital who had recently donated. It actually took 18 months from when we first started the live donor programme to when the transplant actually took place. During that time there was a television programme about kidney transplants. My husband and I watched it and recorded it so that David and his wife could watch it when they were ready. It took them a couple of weeks to feel ready to face it, and we watched it together. I think it was good because it gave us all a much better understanding of what was going to happen. I personally don't think you can have too much information. Most fear comes from lack of knowledge. I learnt that one could function perfectly well with just one kidney. Even if my remaining kidney should fail one day, I can go on dialysis and hopefully cope as well as David did. I have no regrets having donated my kidney.

I would say my husband and family got more anxious about the operation than me. I didn't have to worry about myself, I only had my son to worry about. They had two people to be concerned about. A couple of days before the operation, the surgeon said to me that once my kidney was removed it is no longer mine so it would be best not to refer to it afterwards as my kidney was in David. That was positive advice that I have followed. Once a gift is given then it is no longer yours. From my point of view, it was done and dusted.

I would say to other potential donors, if you are thinking about live donation, then do it. Have faith, because if you have faith in something then it will succeed. Negativity is counter productive.

I am more than willing to help and advise someone thinking about donating or is worried about a forthcoming transplant, but would not like to be involved with a post-operative group who are just interested in self-praise and perpetuating a feel good factor. It would be like someone giving a Christmas gift and then going on and on about how much they spent on it. A gift is a gift.

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