



Living Donor Kidney Transplantation

Donor and recipient perspectives

Photo Diaries

Organ Donation  
**Gift of Life**



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# Introduction

The decision to become a living donor is not easy, but it is one of the most important decisions you are ever likely to make. This booklet gives a first-hand account of what it is like to be involved in a living donor kidney transplant from the people who know best - those who have been directly involved - people like you.

All of the quotes used in this booklet are from people who have either donated or received a kidney. By reading this booklet you will see how other people have coped with the transplantation process from start to finish: from the moment that the decision is made, through to the tests that must be undertaken, what happens before, during and after the operation, both in the short and long term.

It is hoped that this information will help you gain an insight into how you might deal with some of the difficult issues that you may encounter and ensure that you are fully informed to make the right decision.



Thank you to everyone who took the time to write about their experiences, which has given this booklet its valuable insight into the living donor kidney transplantation process.



**Richard received a kidney from his wife, Christine**



**Robert (right) received a kidney from his brother, John (left)**



**Elizabeth (left) gave her sister, Joyce (right), the gift of life**

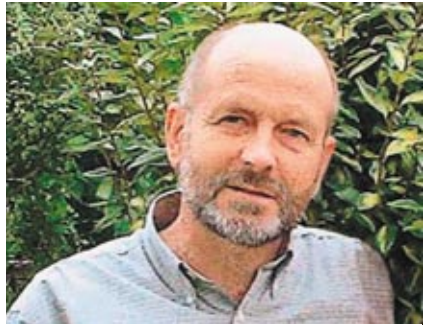


**Paul received a kidney from his father**

## Making the decision

Finding out you need a transplant is a life-changing event and one that can be difficult to come to terms with. Even harder is finding the courage to broach the subject of organ donation with your family or loved ones.

Richard from Bristol had known for 30 years that he might eventually suffer renal failure, as there was a history of polycystic kidney disease in his family. “Early in 1999, my consultant told me that I would probably need dialysis by about mid-2001. He explained about spousal transplants and suggested that I mention the subject to my wife, Christine. I knew that she would offer immediately, but it took me several weeks of mixed emotions before I was able to mention it.”



**Richard was hesitant to talk to his wife about a spousal transplant**

Ken from Kettering describes how he felt when he found out that he needed dialysis, and then later that he would need a transplant. “My initial reaction was one of dread regarding renal dialysis but also the mistaken belief of not being able to work and pay the mortgage. The thought of a transplant of any kind at this stage did not enter my head. It was only later in discussion with my wife that the topic of a transplant came up, and she suggested that maybe we should talk with my family about it. I was reluctant to say anything that might have made my family feel uncomfortable with the suggestion of kidney donation.”

Robert from Leicester received a kidney from his brother, John, in January 2001. This was the second transplant his brother had given him. Previously, John had given Robert his bone marrow to treat acute myeloid leukaemia.

“Realising that I needed a kidney transplant was difficult to accept, but having faced the possibilities of an uncertain outcome following the leukaemia, kidney failure seemed treatable and a transplant would free me from dialysis and give me back a good quality of life,” Robert explains.

However, Robert knew that his need for a kidney transplant was very different to his need for a bone marrow transplant. He would have died without the bone marrow transplant, but he could live for many years on dialysis. This made his decision to accept a second transplant from his brother difficult.

“In a way, this made my feelings towards the transplant even more mixed. I would be asking my brother to undertake, what was for him, an unnecessary operation, with the background fear that if the transplant failed we would both go through a lot for nothing – particularly John, who had already done so much for me.”



**Robert had mixed feelings about his brother giving him a kidney**

Richard felt much the same way at first. He would be putting his wife through a major operation, which would be of no real benefit to her, other than to see him fit and well.

“Christine came with me to see my consultant, where the process was explained - the blood tests showed a good enough match to make a transplant feasible. This was when the emotional side became very difficult for me. Logically, the transplant made a lot of sense - apart from the obvious benefits to me, my wife’s quality of life would be improved with me not being on dialysis, my two sons would see me living a normal life and also, by not taking a cadaveric kidney, I would be giving someone else the chance to use one. Conversely, I felt this was my problem and so up to me to deal with, without inconveniencing anyone else, and that it was very selfish to put my wife through such a major operation. In the end, logic, aided by my wife’s insistence, took precedence.”

Most people who need a transplant find the response of their family to be overwhelmingly positive when they talk to them about it. Indeed, from the donor’s perspective, there is often no question that donation is the right thing to do - even though they may have reservations, or be fearful of what may happen. Ken recalls that the reaction from his family was amazing - with two of his brothers and two of his sisters willing to donate one of their kidneys.

“At that moment I thanked God that I was not born an only child! Knowing my family’s general fear of anything to do with doctors and hospitals, I realised what a brave and loving gesture this was.”

Elizabeth, who donated a kidney to her sister, comments, “When Joyce was told she had kidney failure, I cannot remember actually making the decision about asking to be considered as a donor. I just knew it was what I wanted to do. My husband and children were completely supportive too, which in my opinion is vital to the whole process, because it inevitably involves you all.”

Richard’s wife Christine notes that, “I offered to donate immediately and then began to think about the implications. My first doubts were about our two sons. The kidney disease that my husband suffered from was hereditary - should I therefore be prepared to donate to one of our sons instead? The more I thought about it the more I realised that, at the rate of progression of the disease, our sons would not require a transplant until they were in their late fifties, and by that time I would be in my eighties! Also, with the incredible advances in kidney research, transplants could be a thing of the past.”



**Christine - “I offered to donate straight away and then began to think about the implications”**

# Match-making

Before the practicalities of living kidney donation are discussed fully, a blood sample will be taken from the potential donor and the intended recipient to check that their blood groups are compatible.

If the potential donor's and recipient's blood groups match, then a meeting is usually arranged between the transplant coordinator, transplant surgeon, donor, recipient and partners or close members of their families. This meeting is held to discuss the process of living transplantation and to discuss its potential advantages over cadaveric transplantation. The meeting will also be used to assess the motivation and medical fitness of the donor, and ensure that there is no pressure to donate. The information provided to the donor and recipient will help them both to make an informed decision about whether to proceed.

Joyce from Edinburgh recalls, "Information about the procedure was given honestly, making it clear that the donor underwent a more painful operation than the recipient, and detailed all of the risks involved."

## Matching blood groups

<b>Recipient's blood type</b>	<b>Required blood type of potential donor</b>
O	O
A	O or A
B	O or B
AB	O or A or B or AB

Richard comments that, "Before the tests started, we had a meeting with the transplant coordinator who explained in great detail the various tests that my wife required, and also emphasised the emotional stress that we were both likely to go through. In particular, we were told that there was a possibility that the transplant might not work and that we must prepare ourselves mentally for such an outcome."

Sometimes, the information provided can appear to focus on the possible negative outcomes, rather than concentrating on the positive side. Robert comments, "We already knew after the bone marrow transplant that John and I were an excellent tissue match so we did not worry too much about matching. The doctors explained everything very fully to us all, sometimes we said they told us too much as we knew all about the risks as well as the benefits!"

Elizabeth felt a similar way. "One of my main impressions of this time was that much of the information given seemed to be pointing towards the more negative aspects of what might happen, despite the superb success rates. I found out that this was to ensure that the donor was as clear as possible about what was involved, and that the offer was made without pressure from any quarter."

## What happens next?

If the potential donor and the recipient have compatible blood groups, and both are well informed about the potential risks and benefits of going ahead, the next stage is to carry out a further series of tests.

- Blood tests
- Urine analysis
- Blood pressure monitoring
- Kidney function tests
- Electrocardiogram (ECG)
- X-rays
- Renal ultrasound
- Renal angiogram

The box (left) lists the main tests that will be carried out to ensure that the potential donor is fit and healthy. Your transplant coordinator will discuss these tests in more detail with you. Further information is also available in the booklet **Living Donor Kidney Transplantation: Your questions answered**.

“When it became clear that I was compatible and my general health was good, a two-day hospital admission was arranged for a series of more specific tests. This was my first visit to hospital, excluding the birth of my children, but any apprehension was soon dispelled by the supportive attitude of the staff. The tests consisted of blood tests, blood pressure, a chest X-ray, an ultrasound scan and a renal angiogram. I actually quite enjoyed the experience!” Elizabeth remarks.



**Joyce watches as Elizabeth has a blood test**

The assessment process can take some time (three to six months) to complete. Ken notes his experience. "The matching process took about six months with tests of many kinds (mainly blood). My brother Brian went to hospital in Portsmouth for these tests and I went to Leicester General. In the final stages, we both went to Leicester. Personally, this did not pose any problems as the possible outcome outweighed any minor inconveniences."



**Elizabeth has an ECG**



**Elizabeth has further blood tests**



**Final tests show that Elizabeth is healthy and can be a living donor**

## A testing time

The rigorous testing period is an emotional time for everyone. As Ken notes, recipients often feel more worried about the donor than they do about themselves.

“When I found out that I was a match with Brian, I was absolutely delighted; however, I did have reservations about subjecting him to this ordeal. When the medical procedures were explained in full, I was happy and Brian expressed no concerns even though his was the more difficult operation.”

Richard was also worried about what he might be about to put Christine through. “Part of me hoped that the tests would show that my wife could not donate so the decision would be taken away from me. The initial tests showed that further, more detailed tests were required, and I became very stressed with extremely mixed emotions. One of the tests was very painful and I decided that it should all be called off, but my wife persuaded me otherwise. The extra tests meant that the planned transplant date was not feasible and a new date was set. Needless to say, the delay gave me more time to go through more feelings of selfishness and guilt.”

It was also an emotional time for Christine. “The self-preservation side of my mind kept thinking perhaps I won’t be suitable, whereas the sensible decision side hoped that I would be. I wanted to do it, but I was afraid. Once all the tests were over and everything was found to be OK, my mind was completely adjusted and I was ready to go ahead with it. I had a great deal of support from my consultant and from another consultant required by ULTRA\*.”

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\* The Unrelated Live Transplant Regulatory Authority (ULTRA) is an independent organisation that must assess all offers of kidney donation from individuals genetically unrelated to the recipient. This is to check that there is no coercion to donate, and that the donor’s reasons for donation are genuine.

Richard and Christine were not the only ones to experience mixed feelings. Joyce also found herself riding an emotional roller coaster. "When Elizabeth came up for the pre-transplant tests, I was swaying from being very positive and keen, to being worried and upset. Elizabeth was planning to undergo major surgery for me with no benefit to herself, other than hopefully seeing me enjoy a normal life again. This was brought out into the open and she reassured me that she did not feel pressured or obliged to go ahead."

Joyce's mixed feelings were apparent to Elizabeth, who notes that the recipient probably has a harder time coming to terms with what the donor is put through given all the tests required.

"It was during this time that I realised how complex Joyce's feelings were about what was happening to us all. It was a very emotional time for her. As far as she was concerned, it was because of her that I was in hospital - despite the fact that the tests themselves were straightforward and far from dreadful. It highlights the fact that this is something the recipient cannot repay and how difficult it is for them to accept. Personally, I think it is probably easier to be a donor."

Throughout the extensive assessment period, the transplant coordinator and consultants are always available to talk through any worries that the donor or recipient may have, providing both practical and emotional support.



**Joyce talks with her consultant**

“All the staff seemed to know what was going on and were always friendly and supportive. We felt like we were treated as special people. My consultant, with whom I felt I had a good relationship, was always happy to discuss any aspect of my dialysis or potential transplant and I was able to telephone him for advice at any time,” Richard recalls.

## What if I am not a suitable donor?

The extensive testing period, while stressful at times, is necessary to ensure that both the donor and recipient are fit to give and receive a kidney, and that the benefits far outweigh any risks. Unfortunately, not everyone who wishes to become a living donor can do so. Needless to say, it can be a bitter disappointment for both the donor and the recipient to find out that they are not suitably matched.

Just two weeks before his transplant operation was due to take place, David, from Edinburgh, discovered that his aunt would be unable to donate a kidney to him because a positive 'cross match' was identified. This meant that David had started producing antibodies against his aunt's tissues, despite earlier tests being satisfactory; if he had received the transplant, his body would have quickly rejected it. David would have had to go back on dialysis and his aunt would have been put through a major operation for no benefit to herself or David. "It was more of a disappointment than I thought it would be - not just for myself, but for the whole family," David recounts.

While it can be devastating to find out you cannot be a living donor, the intended recipient can remain on dialysis until a suitably matched living or cadaveric kidney becomes available. In David's case, he received the offer of a cadaveric kidney and was transplanted six months later. "I've had my transplant and things are looking very good for the future," he says.

## Preparing for the operation

Once all the tests are complete and a date for the transplant operation has been confirmed, both the donor and recipient need to check that they have made all the necessary arrangements.



**As Joyce (pictured) and Elizabeth both work as teachers, their transplant operations were set for the summer holiday**

“Much to our delight the results showed that I was in good general health and I had two well-functioning kidneys. Reality strikes! Dates were put into place and arrangements made. Joyce and I are both teachers and we are fortunate enough to have a long break in the summer, so it was arranged that this was when our operations would take place. This was at our request and another example of how well we were looked after,” remembers Elizabeth.

For Christine and Richard, the preparations were equally important. “As both my husband and I would be incapacitated at the same time, there were quite a number of arrangements to make. For example, provision had to be made for the dog, the freezer had to be well stocked and, most importantly, someone had to come and look after us for a few days.”

One of the many benefits of living donation is that the date for the transplant operation can be planned in advance.

“We were able to fix a date for the transplant, which fitted in with family arrangements as John’s partner was expecting a baby. I was most concerned before the operation that it would not be successful - I was bothered by the worry that John would go through all of this for nothing,” explains Robert.

The recipient generally goes into hospital two days before the operation to undergo routine checks and have a final dialysis session. The donor follows the next day, although he or she may choose to go into hospital at the same time as the recipient.

“The day before the transplant was scheduled, I was admitted into the transplant unit. The term ‘unit’ is an excellent description of the place.

Every person, without exception, works as part of the team to provide a service that is second to none. The atmosphere is so positive and caring that it helps to dispel the inevitable apprehensions,” Elizabeth remembers.

Depending on their relationship and the facilities available at the hospital, the donor and recipient may be able to share the same hospital room. For some people this may be the right decision, as Richard confirms: “We had the chance to share a room, which in hindsight was definitely the right decision.” However, Ken notes that he and his brother were on separate wards, “so as to help our recovery without worrying about each other.”

Elizabeth and Joyce opted to stay in the same room together.

Elizabeth describes the night before the operation. “It was most peculiar. Our families visited and it was a time of mixed emotions. Everyone is affected by what is happening. When Joyce and I eventually went to bed it was with hope and expectation.”



**Joyce has one last dialysis session before her operation**



**Elizabeth and Joyce - the morning of their operation**

## What happens during the operation?

On the day of the operation, the transplant surgeon and the transplant coordinator visit the donor and recipient. Richard describes his experience: "The surgeon came to see us on the morning of the operation and explained what he was going to do and how long it would take."

The donor will be prepared for surgery first, followed shortly by the recipient. "On the morning of the operation we were both up early, showered and ready - Elizabeth went to the operating theatre about half an hour before me," Joyce recounts.

In most hospitals, the procedures involved in removing a donor kidney and transplanting it into a recipient occur at the same time, with two teams of surgeons, anaesthetists and nurses working in adjoining theatres. "The operations take place in a specially designed twin theatre and are carefully planned with consultant transplant surgeons leading the two teams. After the kidney is removed, it is transferred to the adjoining theatre to be transplanted," Elizabeth explains.



**The donor's kidney is transferred to the second transplant team**

The wait before the operation can be a worrying time for the recipient, but a member of the transplant team will always be on hand to discuss any concerns. Richard found himself waiting to go into theatre a little longer than he anticipated. "My wife was taken to theatre and I expected to follow about one to one and a half hours later. I had felt fairly relaxed beforehand, but once she had gone I started to feel very stressed, even

more so as the time neared two hours, fearing something had gone wrong. When they came for me, I was relieved to be told that the delay was due to an extra artery on my wife's kidney that had not shown up during the tests, but that everything was OK now."

The transplant team is there to support both the donor and the recipient - they will do their best to ensure that you are not nervous about your surroundings.

"The faces I saw on the ward, on the way to the theatre and in the anaesthetic room were familiar. All had introduced themselves previously, which is so helpful when the surroundings are unfamiliar," says Elizabeth.



**The kidney is transplanted into the recipient**

## The road to recovery

After the operation, the donor and recipient are taken to a recovery room and are then later transferred back to their room or a high-dependency ward.

Elizabeth recalls her first thoughts on coming round after the operation: "When I woke up on the high-dependency ward, Joyce was opposite and seemed to come round about the same time. We both reassured each other that all was well. What a wonderful feeling!" Joyce felt similarly relieved: "Once we were both awake and had reassured each other that we felt 'great', there was amazing relief that the operation was behind us."

"The next few days were filled with a variety of checks, such as blood tests, urine counts and fluid intake. The physiotherapist was on hand to make sure that our mobility returned as quickly as possible," Elizabeth recounts.



**After her operation, a large team of people check on Elizabeth's recovery**

Although relieved, the recipient may initially experience some pain following the operation. "I was taken to the theatre and I remember being pushed along a hospital corridor but nothing else. The next thing I was aware of was coming round after the operation in the recovery room, with this major discomfort in my groin due to the catheter draining urine," says Richard.

Ken notes that he was also in pain when he came round from his operation, but that "with one pain-killing injection the pain disappeared. The following morning I sat up, read my book and felt like a new man.

Over the next couple of days my well-being continued to improve and the doctors confirmed that the operation was a total success."

He admits that he was more worried about his brother. "I was very concerned for Brian's health - when I saw him on the second day I could see why. He was in much pain and using his morphine with relish! I wondered if he would have done this had he known he would feel like this? Brian declared he would not do it again!"

Robert's operation went smoothly and his new kidney functioned immediately. "My wife said that even immediately after the operation I looked a better colour - pinker than I had looked for a few months." He adds that, "After the operation I seemed to have tubes all over my body, but the pain control was good - as long as I didn't sneeze or cough! Within two or three days I was off the pain control drip and some of the tubes were removed by the fourth day. I was soon up and shuffling about."

Robert describes his feelings the first time he saw his brother after the operation. "When I first saw John - which was about the second or third day when he walked round to my bedside - I felt so grateful and relieved that, particularly for him, everything had gone well. John seemed to be in some pain and developed a chest infection which was worrying, but apart from that there were no problems."

Joyce felt a dramatic improvement following her operation, but notes that she was also worried about her sister. "The next day I got up with the help of the physiotherapist and really felt great, but was concerned that Elizabeth was obviously in discomfort and sleeping a lot. The staff were fabulous and assured me that this was the normal pattern, with the donor initially taking longer to recover. It took three days for Elizabeth to return to her usual self and after that there was no stopping her."

“Everyone on the ward helped to make sure that everything was done to make us as comfortable as possible,” adds Elizabeth. “When our families visited later in the day there was so much joy and laughter. My recovery was made so much easier by the signs that the kidney was doing its job. I will never forget Joyce’s euphoria on the second day after the operation when she noticed that the whites of her eyes were no longer yellow, but a clear white colour - a very positive sign.”



© Charlie MacDonald

**Elizabeth (right) is cheered to see Joyce up and walking**

Richard was also up and about before his wife. “I remember talking to my wife and being attended to regularly by nurses. Towards the end of the week my catheter and other connections were removed and I was able to walk around the ward. My wife was obviously in some discomfort, but I was able to help a little by moving pillows, among other things.”

Christine adds, “The one downside of the operation for me was that I suffered a lot more pain than I expected and I didn’t get quite the benefit from the epidural pain relief that I could have had. The situation was made worse because I had a chest infection and in order to relieve it I was supposed to cough, which was not possible due to the pain I was experiencing.”

However, she notes that, “We received the most wonderful treatment while we were in hospital from doctors, nurses and all the staff. The nurses, although rushed off their feet, always had time for us and were so kind and thoughtful - beyond the call of duty.”

The length of time that the donor and recipient will need to stay in hospital varies. "Brian and I stayed in hospital for six days and then spent two days together at my home before Brian returned to Southampton," recalls Ken. "The stay in hospital was very good for me, and with my newfound appetite, I even enjoyed the food! The medical team were extremely efficient but very friendly - I was never in doubt as to a successful outcome."

Robert spent a similar amount of time in hospital. "I was in hospital for one week, moving around and eating and drinking whatever I wanted, which was wonderful. The kidney worked like a dream and still does. The staff and the medical team were all excellent and I was given first-class treatment all along. I have continued to visit the clinic, initially twice a week, now once a month. Whatever help and support I have needed, the staff have always been there for me," he says.

Joyce was also discharged after one week and initially attended the hospital every few days for blood tests.

Sometimes a longer stay in hospital may be necessary and Richard and Christine spent a total of 11 days in hospital. "My husband and I were both released on the same day, which made things a lot easier," she comments.

## No more dialysis!

For many people, the success of the transplant operation is only the beginning and they soon find themselves enjoying their freedom from dialysis.

“Life is so different for me. I have a newfound energy and can eat a much wider variety of foods and drink more fluids than I used to. I have much more time to myself now and I really am a new person. All thanks go to my sister Elizabeth, and the team of people in the transplant unit,” says Joyce.



**Joyce (right) feels like a new person, thanks to her sister Elizabeth**

While the donor often takes longer to recover, it still takes a while for the recipient to get back into his or her normal activities. Ken comments, “I returned to work within three months and was back into my normal routine within six months.”

“My life is now back to relative normality - I can eat and drink whatever I want,” says Robert. “I have energy to do all the things I need to do - although slowly and steadily as I am over 50. I can also now take a holiday for the first time in two or three years - previously I was not happy to undergo dialysis away from the General Hospital. I do take a whole range of medication at the moment, but this is reducing steadily.”

## Life with one kidney

It is well known that a healthy person can lead a completely normal life with only one functioning kidney. In the long term, the donor's remaining kidney will increase in size slightly and be able to carry out the functions that are normally performed by the two kidneys. The overall lifestyle of the donor is not affected and after about six weeks of rest and recuperation, normal daily activities can start to resume. It is important to attend all follow-up visits at the hospital and to keep in touch with the transplant team on a regular basis to prevent any health problems developing in the future.

"After a week in the unit, I was allowed home. A follow-up six weeks after the operation ensures that blood and urine tests have returned to normal. It is also made very clear that if anything crops up at home that causes concern, there is always someone available at the transplant unit to answer questions and provide support," comments Elizabeth.



**Elizabeth is pleased to be back at home with her family**

"It is now about six weeks since the operation and I am feeling a lot more like my old self. I still experience quite a bit of discomfort from the wound site, especially when in bed - turning over still requires some care - and I usually make sure I take some pain relief before going to bed. I also find it difficult to walk very far. I am trying to increase the distance I walk a little each day and there is no doubt that I am improving," notes Christine.

## Looking after your transplant

Kidneys transplanted from living donors have a better chance of long-term survival than those transplanted from cadaveric donors. There are a number of reasons for this, the main one being that the donor is alive and in good health.

Looking after your transplant by taking your immunosuppressive drugs as prescribed and maintaining a healthy lifestyle is important, but will not guarantee that your new kidney will last forever. Dealing with the loss of a donated kidney can be a devastating experience, for both the recipient and the donor.

Paul from Sheffield received a kidney from his father in 1984 when he was only 16 years old. Six years later, the transplant had failed, and Paul and his family had to come to terms with him being back on dialysis and waiting for a cadaveric transplant.

“Rejection is hard. I was in the position where I knew my first transplant was going to fail - not much to look forward to, especially when you can see your blood results rising every week. But you just have to keep going with the support of your friends and family.”

Thankfully, a cadaveric kidney became available two years later in 1992, and Paul is now doing very well. Recently he and his wife celebrated the birth of a baby daughter.



**Paul received a kidney from his father, which later failed. He subsequently had a cadaveric transplant and is doing well**

Describing what it feels like to have received a second transplant, Paul says, "Words are inadequate to describe it, but if I won the lottery tomorrow, I'd double that feeling and then add some! Only then I might come close to experiencing what it feels like - simply great!"

Paul does not discourage others from having a living kidney transplant. "If you have a chance to have a living kidney transplant, you have to go for it, being on dialysis is terrible and what have you got to lose anyway! The potential benefits outweigh any possible costs." He adds, "Although my Dad died before the kidney failed, I am sure he would have been positive about the transplant even though it rejected. It gave me seven fantastic years - I did a lot and took nothing for granted."

Paul still takes nothing for granted. "I am an idealist at heart and I thought my kidney would last forever. Unfortunately transplants do not last forever. However, I am sure that a big part of what happens to your transplant is down to your outlook - be positive, and you never know, your kidney might be the one that lasts forever!"

## You changed my life - thank you!

There is no doubt that being involved in the living donor kidney transplantation process will change your life. Most people find that going through the experience of donating or receiving a kidney, even when things do not go as planned, brings you closer together.

"After nearly 35 years of very happy marriage, I believe that the transplant has brought us even closer together. I will always be grateful to Christine, although deep down I will always feel some level of guilt. For her part she has never once implied that it was not the right decision," says Richard.



**Richard with Christine - "The transplant has brought us even closer together"**

He adds, "My overwhelming memory of the last few months, including the time before dialysis, the dialysis itself and the

transplant, is a very emotional one of how the medical staff - including consultants, outpatients staff, coordinators, doctors, nurses and support staff - worked so hard looking after us, really cared about our well-being and became so personally involved. It is a pleasure to attend the renal unit for my appointments and be greeted by so many friends."

Robert notes that words are not enough to express his feelings towards his brother. "As you can imagine, I will be forever grateful to John for his bone marrow and his kidney. He has never made me feel awkward or embarrassed about our situation and he is a brave person to go through the operation to donate his kidney. It seems insufficient but all I can do is say 'thank you'. Six months from the operation, all is going well."

Ken comments that his life has been totally transformed by his transplant. "I am just living a normal life, going to work, playing golf, eating, drinking and generally enjoying life. Taking numerous drugs to control any rejection does not cause me any problems whatsoever, and has become part of a daily routine."

From the point of view of the donor, there are few regrets, as Christine explains: "My decision to be a donor was totally the right one. Although it has been a more painful experience than I had hoped it would be, it has been so worthwhile seeing my husband looking so well and knowing that, all being well, we can look forward to many happy and healthy years together. I also believe that it has brought us even closer together as it has been a truly shared experience. I would not hesitate to recommend it to anyone thinking of becoming a living donor."

Elizabeth agrees: "Being a donor is a unique experience that not everyone who wishes to has the opportunity to take. I was fortunate to be able to do this and would encourage others to do so as well. Personally, I feel richer as a result of the whole experience and through meeting so many special people."



**Robert with John - "Words are not enough to thank him"**

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Transplant Coordinator, The Royal Infirmary of Edinburgh

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## Where can I get more information?

If you would like more information on what living donor kidney transplantation involves, or wish to talk to someone who has already been through the experience, then please contact your local transplant coordinator.



Alternatively, you may find the following resources to be of value:

### **National Kidney Federation**

6 Stanley Street, Worksop, Nottinghamshire, S81 7HX

**Telephone:** 01909 487 795

**Fax:** 01909 481 723

**E-mail:** [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk)

**Helpline:** 0845 601 0209

**Website:** [www.kidney.org.uk/](http://www.kidney.org.uk/)

### **National Kidney Research Fund**

Kings Chambers, Priestgate, Peterborough, PE1 1FG

**Telephone:** 01733 704 650

**E-mail:** [helpline@nkrf.org.uk](mailto:helpline@nkrf.org.uk)

**Helpline:** 0845 300 1499

**Website:** [www.nkrf.org.uk/](http://www.nkrf.org.uk/)

### **Transplant Support Network**

Room 8, Temple Row Centre

23 Temple Row, Keighley, Yorkshire, BD21 2AH

**Telephone/Fax:** 01535 692 323

**E-mail:** [phatton@tsnet.demon.co.uk](mailto:phatton@tsnet.demon.co.uk)

**Helpline:** 01535 210 101

**Website:** [www.transplantsupportnetwork.org.uk](http://www.transplantsupportnetwork.org.uk)

### **UK Transplant**

Communications Directorate

Fox Den Road, Stoke Gifford, Bristol, BS34 8RR

**E-mail:** [enquiries@uktransplant.nhs.uk](mailto:enquiries@uktransplant.nhs.uk)

**Helpline:** 0117 975 7575

### **Organ Donor Line**

**Telephone:** 0845 6060 400



