

Bharat and Avril

Bharat

My kidney problem was recognised in year 2001, prior to this for 30/40 years I hadn't visited my GP even once. I used to get headaches and used to take paracetamol.

In 2001, I was driving on the motorway, I started to have dizzy spells and I was taken to A&E in Leicester. They took my BP, it was high that it was off the scale. I was kept in the hospital for a week for 10 days. After carrying out the tests I was told that both my kidneys were failing, and they were working around 24%. I realised that I had been living with the problem and paracetamol was taking the pain away.

I had only studied biology to 'O' level standard and all I knew was that the kidney helps to remove waste from your body, other than that I had no idea about the kidney function.

Initially I wasn't unduly concerned but when I started treatment at General Hospital, I started to understand what it means to have a kidney failure and what would anyone go through as it progresses. The BP was brought under control by the renal team. I used to take 4/5 tablets each day.

In the first instance when you have a renal failure, your condition is managed with medicine and diet, after hearing the diagnosis of kidney failure I was consuming 30 medicines a day, merely to survive, my kidney function was deteriorating and my ability to function as a human being was slowly declining. I got to a point when I found doing small tasks to keep going very difficult. The Renal Team managed my condition from 2001 – 2008. In 2008 my kidney function was 4%. I used to tell the Renal Team, 'You are keeping me alive just for the sake of it, there is no life in my body at all' I could only walk a couple of steps at a time. I could not consume liquids, I was on severely restricted diet, could not sleep at night, legs were swollen, I was really lethargic, I was unable to do anything worthwhile at all, let me give you an example, the postman used to deliver the mail, I couldn't even get up to pick it, after several months someone came to see me and asked 'Why haven't you opened your letters?' I might a cup of tea but to take it back to the kitchen used to take me 2-3 weeks. I was ready to go on dialysis in a couple of days, but Avril came and supported me as a donor for me. Avril had known me for 7/8 years; she was my main carer.

Avril

I looked after him, made his dinner, I helped him with showering, I put his clothes out, I used to go to the temple with him, take him shopping and wherever else he wanted to go.

Bharat

My quality of life was literally zero and Avril was my carer, 24/7, she used to come to a lot of my appointments too. Renal care is slightly different, one has to understand the system of renal failure, especially the diet they follow and the food intake, certain fluid measurements you need to take on a daily basis, take a note of urine output if it's going lower. I had a big dilemma, Avril was my main carer, then the transplant came through, I was asked to take a kidney from a living person. This was the biggest decision that I had to take in my life. Avril was giving me her kidney from her own good will, she wanted to see me better. I didn't want to just take a kidney from Avril and after the transplant we both go our separate ways. So I requested the Renal Team if we could have our wedding ceremony, in the hospital Chapel, a day before the transplant or on the day of the transplant but that could not be arranged. We got married officially a year after the transplant.

Avril

In 2004 I saw Bharat so lethargic and not being able to do anything and he was really depressed, no life for him, I managed to find Bharat's blood group from doctors, and I knew I had the same blood group as Bharat, which was really good. I thought a lot about donating my kidney. I had made up my mind, I am very stubborn if I say I am going to do something, I just do it, nothing can change my mind.

Bharat

A transplant doesn't happen overnight, there is a lot of work involved, there is a long preparation period for 3 to 4 months, a lot of information is given to us. I knew on the day anyone can pull out, so you can change your mind even at the last stage. It is a very free system; you can get help and advice throughout the process. It was very difficult for me, I was taking Avril's kidney, lots of common people would not know what would be the outcome, the medical team supported me to make the decision that I should go ahead with it. A lot of people would not contemplate going through with a living kidney donation. To them you are putting someone in the family at risk. The doctors can never give you the assurance that you fully need. They are going to tell that

this is a procedure, this can happen, that can happen. You have to weigh all the pros and cons as you go along. Normally people say no and I will wait to get a kidney from the register, I was not expecting a kidney from the register. I was on the register. I knew I would need a kidney from someone with similar background, like Asian, same blood group and tissue type, you have to have 5 different types of matches and the blood group. I knew the Asians are pretty poor at donating organs, kidneys are donated rarely. We discussed our options and decided to go for living donor option, subsequently I learnt that it is the right thing to do, before taking a kidney from a donor, the donor's life is mapped out. They will not touch the donor if there was even 0.1% risk. They check your body out thoroughly. They make sure that with one kidney you can live your life as normal for the rest of your life. 15 years later, you can see Avril is a living proof. These days once someone has donated a kidney, they don't even have to come back to the hospital, only the GP's look after them. This shows you the confidence at which this takes place. In Leicester I know for a fact from 1998 onwards not a single donor has suffered, apart from minor coughs and colds. Although its hard to believe but that is the reality.

Avril: I feel fine, the same way as I did before donating my kidney. When I came out of the theatre, I didn't feel

anything. I had taken lots of painkillers, obviously I hadn't had a big operation before and didn't know what to expect. I was fine and was well looked after.

Bharat

When you suffer renal failure, the Renal Team spends most of the time managing your kidneys. They talk about transplant a couple of times but is stored in the back of your mind, because then you are just waiting for that magical phone call for the offer of a kidney. Lots of people on a dialysis ask questions when are they going to be called for a transplant. I can never answer that question, it just depends on when a kidney becomes available. With renal failure, you learn to live with the condition, you have hope for a transplant.

I was a high-flying businessman before I had my kidney problem, I used to handle worldwide projects in the third world countries. I was a contracts manager for educational systems around the world. I was a very successful businessman, my job involved a lot of overseas travelling, it was a high-pressure job, my career just came to an end. In hindsight one can say that if I had my blood pressure checked regularly this may have been avoided. People are so engrossed in their lives they don't take time to see their GP's, so things like

these are not detected early. People don't go to see their doctor for headaches etc. In many cases lots of serious illnesses are discovered by accident. Illness or not being well is the last thing on your mind.

6 months after transplant, I was a perfectly normal human being. My life became completely back to normal. I was once again able to do everything I wanted to do. I could do anything, I could exercise. I asked myself the question, what do I do now? Do I go back to my previous work? As that's all I knew workwise. I am a very religious person, I believe in Lord Jalaram, who has been with me throughout my life. I went to the temple and asked him, 'Bapa, what do I do with this life that you have given me?' to me he has given me this new life, he said to me 'Son, listen, forget what you were doing, I want you to go and work, do the sewa (voluntary work), work in which you expect no rewards.' I have devoted my life to the work of organ donation, helping others who are facing same predicaments as me. I am glad to say since I started in 2008, I have signed up 7000/8000 on the organ donation register. Leicester has the highest number of people from the BAME population signed on the register. The BAME communities are very hard to convince, over the years, things have changed for better. A lot of couples have opted for live kidney donation, they have spoken to us about our

experiences. We have reassured that nothing will happen to them. Because of my generosity, I used to follow the couples offering them psychological support as well. We worked with the Renal Units in the hospital.

Avril

Bapa made it happen for me to be able to donate kidney to Bharat. I used to visit the temple with Bharat. Now we both work together in the temple promoting organ donation.

Bharat

We will continue the work for organ donation, now we have a organ donation centre at the temple, it's a walk in centre with lots of information especially targeted at the BAME communities. A lot of people don't know how it works practically; we support them. There are a lot of myths that exist in the community, we try to dispel these. There is no Hindu religion that I know of that does not support organ donation. Some people think I came to earth in this body so when I die my body needs to be intact, at the time of cremation or burial, that is also wrong. In reality when we perform 'antim sanskar', the last rites, we know that our body turns to ashes, our

organs do not go to the next life, your soul goes to the next life. If you are able to, you should give someone the ultimate or the best gift of life by donating your organs because of your kindness a blind person can get sight back, somebody's liver will start working again, somebody can have your lungs to breathe again, people with kidney problems can get their lives back.

Most people will accept a kidney if they are waiting for one, I haven't come across anyone who has a problem accepting a kidney in all the communities, Hindus, Muslims. When it comes to donating, pluses and minuses come in. In any case when your life is coming to an end, why do you need these organs, 33% of UK's population is waiting for a transplant and this figure is mainly made of the BAME communities, which is mainly from Asian backgrounds. That is a very high number, when it comes to donating the figure from our communities is very small. People need to contribute to that pot so that others can take from it.

You have to die in an ICU and be declared brain dead or circulatory dead to be able to donate an organ, so if you die at home, you will not be able to donate, If people haven't signed up and they die in circumstances where their organs could be utilised. I have noticed 99% of the time people do not sign the register. 33% of the community has diabetes and/or hypertension, these are

the main conditions for causing kidney failure (99% cases). Diabetes is 1 in 4, 4 of ours get diabetes, leaving 1 person from the white communities, same with hypertension. People from our communities are more likely to get heart conditions and kidney failures.

If you stay on dialysis, your life span decreases, if you get transplant within a couple of years that is the best news. But if you've been on a dialysis, say for 30 years, your chances of survival are very low plus the quality of life is not good. It's not just you are suffering; all your family is suffering with you. For example, if you go on holiday, if you need to book dialysis abroad, it used to be free in the EEC some place in the world you have to pay, like America etc, it can be quite costly. I don't like to mention money, but NHS spends something like 60,000 to 70,000 for a dialysis patient each year. You can imagine if we didn't have the NHS in this country and you had to pay for it, most people would not be able to access it as they will not be able to afford it.

Bharat

Just to sum up, Avril has given me her kidney, nothing has happened to her, she is living a normal life. I would like to tell people that living donation is a way forward, people should consider it. To me risks for the donor are

almost zero. Don't believe the myths that they are cutting my body and taking organs out, nothing is disturbed, you can function perfectly well, recipient gets a brand new lease of life, to me I have a baby's life, brand new.

Avril

I would like to encourage everyone to think about live kidney donation, look at me 15 years later, I am able to do everything as before, if you have a family member with a kidney disease, just think about giving them a kidney, I had two kidneys, my kidney function is 80% now, which is very good.