



MORE
THAN
A
MATCH

One family's thoughtful and uplifting experience of living kidney donation

by Dela Idowu



“This book gives a compelling personal account of one family’s struggle to come to terms with kidney failure, dialysis and transplantation. It is heartfelt, honest and inspiring. I wholeheartedly recommend this book to anyone facing the challenge of a loved one with kidney failure”.

Rachel Hilton MA PhD FRCP,
Consultant Nephrologist,
Guy’s Hospital, London

More Than a Match tells the story
of living kidney donation from the
point of view of a potential donor.
It explains not only the processes
involved but also the emotions
experienced along the way.
As a kidney patient I would
recommend this book to anyone
considering donating a kidney to a
family member or friend.

Trevor Cook
Chair,
Guys & St. Thomas'
Kidney Patients Association

Dela Idowu

MORE

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One family's uplifting experience
of living kidney donation

GOLD
lift of living donation



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Dedication

This book is dedicated to my family

*“Life is an opportunity,
benefit from it.*

Life is beauty, admire it.

Life is a dream, realize it.

Life is a challenge, meet it.

Life is a duty, complete it.

Life is a game, play it.

Life is a promise, fulfil it.

Life is sorrow, overcome it.

Life is a song, sing it.

Life is a struggle, accept it.

Life is a tragedy, confront it.

Life is an adventure, dare it.

Life is luck, make it.

*Life is too precious,
do not destroy it.*

Life is life, fight for it.

Mother Teresa

“Imagine your life with all its
amazing possibilities. Decide
today to give someone that same
chance to live an amazing life.”

Dela Idowu





Acknowledgments

As with any good story, this one would never have come about without the help and support of a few people. I want to thank my brother, Tayo and his family, for their consistent encouragement and support whilst writing this book.

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CONTENTS

Introduction	1
A Bit of Background History	4
My Decision to Become My Brother's Donor	7
My Journey Begins	9
Evaluation to Assessment	12
Next Stages in the Donor Evaluation Process	14
The Emotional Impact	21
More Tests	23
Religious and Cultural Beliefs on Organ Donation	26
Sad News!	28
Looking Forward	30
Bimmi's Journey	32
The Transplant Operation	36
A Recipient's Perspective of a Kidney Transplant	40
Final Word	43
Further Information	45







INTRODUCTION

When I started writing, I was planning to just keep notes describing my living donation experience for me to look back on. Living donation is where a living person donates a single kidney, a segment of the liver, or part of a lung in order for a person to receive a life-saving transplant. As I read, researched, and offered to become a living donor, I was convinced that it was an amazing thing to do. But I also realised the biggest obstacle that stopped most people from coming forward as donors was fear. People were afraid the operation could go terribly wrong; they were scared that in future their remaining kidney could be damaged through illness or an accident, thus putting their own lives at risk, and for many, the stakes were just too high.

My personal experiences as a potential donor lead me to write this book for various reasons. First it was to give people an insight into the practicalities of being a living kidney donor from a donor's perspective; this could make things easier for a person looking for a donor for their life-saving transplant. I believe if you provide people with the relevant information and real life situations, it would give them a better understanding of the living donor process.

Second it was for people who have the desire to become a living donor for a loved one but struggle with the potential risks involved





More Than a Match

with having such a major operation. The risks and fears of being a donor are real and many will find it difficult to see beyond that; they will often say, “But what if...?” But if we allow ourselves to focus on the “what if,” some of us would not be married, have started a business, or even followed our dreams today. When we see the people we love struggling with a life-threatening illness, the truth is we can turn our “what if something goes wrong?” into “I want to help change their life.” The third reason was to raise the profile of organ donation within the Black and Asian communities as there is a desperate need for more Black and Asian donors to come forward. The final reason for writing the book was to show people the real value of saving a human life. The majority of us are born with two kidneys, and we can live healthily with one, which allows us to be living donors. Some of us have loved ones for whom life is a daily struggle of hospital appointments and dialysis. To be willing to help them takes tremendous courage, and hopefully my story will testify what can happen when we take a different approach to living organ donation.

The book narrates my family’s story as potential kidney donors. It’s a factual account of a personal journey that began when I offered to donate a kidney to my brother who needed a life-saving transplant, but ended with my brother’s need for a kidney practically saving my daughter’s life. Our emotional journey captures the love of a family in a personal and heartfelt way. It takes you through our tests, trials and tears, but also portrays our joy at being potential donors.

Living kidney donation is our loved one’s fast track to a transplant; it is very successful in the UK, representing 38% of the total number of kidney transplants. The book details the procedure to remove a kidney (otherwise known as laparoscopic donor nephrectomy), the





Introduction

medical tests, and the stages of the living donor assessment process, the potential risks, the emotional impact, recovery after the operation, getting back to normal and living with one kidney. When a person needs a transplant, it can be very difficult approaching the family for potential donors, our story could make that process easier. The decision I made to become my brother's donor was one of the most rewarding decisions I had ever made, and as the story unfolds, it will become clear that although our donor assessment process had many twists and turns, it is a story about bringing hope to others. May our experience as potential donors be a starting point for taking you on your own personal journey in giving someone the gift of life.





A BIT OF BACKGROUND HISTORY

In December 2010, my father passed away in Lagos, Nigeria. It was whilst the family were grieving and making arrangements for the funeral that my brother told me he would not be able to travel to Lagos, as he had end-stage kidney failure and needed a transplant. I listened, stunned and speechless as he told me what had caused his kidney failure and why he had not told me sooner. With tears streaming down my face and hugging him so tight that he could hardly breathe, I chastised him for not telling me sooner. I was also upset with myself for not noticing something was wrong. I asked him how he was coping, and he said he was on the organ donor register waiting for a compatible kidney to become available, but because his kidney function was deteriorating, he would need dialysis. Dialysis is the treatment that replicates many of our kidney's functions, and without it, many people with kidney failure would not survive. During our conversation, my brother told me although most people have two kidneys, we could live a healthy and active life with just one, which was something I was not aware of. As we sat in my kitchen talking about dialysis over coffee, I knew I wanted to give Tayo one of my kidneys; it made sense to me that if my brother desperately needed a kidney and I could live well with





A Bit of Background History

just one, why not give the other one to him so he could live? To me, it was a no-brainer, especially as I am his only sibling.

We did some internet research on living kidney donation. There are risks involved in donating a kidney, as with any major operation. However, potential living donors are put through a vigorous health check to ensure their health is not compromised. After donating a kidney, a person can live exactly the way they lived before with just a few changes to their lifestyle. Other benefits of having a kidney from a living donor are that there is a better chance of a successful transplant with a living kidney, as the donor and recipient are in the same hospital, allowing for the kidney to be transplanted immediately. Living donor transplants done between family members are genetically similar and a better genetic match lessens the risk of rejection. A kidney from a living donor usually functions immediately, making it easier to monitor. Some deceased donor kidneys do not function immediately, and as a result, the patient may require dialysis until the kidney starts to function. Potential donors like myself can be tested ahead of time to find the donor who is most compatible with the recipient. A kidney from a live donor has a life expectancy of about 18- 20 years, whilst one from a deceased person has a life expectancy of approximately 13 years. All in all our loved ones transplant would have a higher success rate if a family member was to be their living donor.

Although desperate for a kidney, my brother wanted me to know the potential risks and be absolutely sure it was something I wanted to do. I researched the risks and found that, as with most surgeries, there were the potential risks of infection, blood clots, hypertension, pain, bleeding, hernia, and an allergic reaction to the anaesthesia.





More Than a Match

These risks sound quite daunting and I don't want to make light of them, but if we pause for a moment, we will realise our life is full of risks, no matter what choices we make. We can't control the bad drivers on the road or the pilots who fly our planes, and these days, you don't have to be in the wrong place at the wrong time to be at risk of being harmed or killed. I know people who take all kinds of risks. I have a friend who chain-smokes—they know it's a big risk to their health but they still continue—and another friend of mine climbed Kilimanjaro to raise money for charity, which, to me, is a bigger risk than donating a kidney!

With my mind made up, my brother now had the difficult task of telling our mum about his kidney failure. This was a tough one, as she was grieving over the loss of our dad. She broke down when she heard, and I knew telling her about the donation was going to be even more difficult. When I did, she was worried that both of us would undergo major surgery as the same time. When I told my children, they were more agreeable to the idea. We discussed the donor assessment process as a family and agreed it was the best chance we had of giving Tayo a better quality of life. The day ended on a high, with my brother overwhelmed at my decision to donate one of my kidneys to him; there were no words adequate to match the moment. He came that day for a family meeting and left with the possibility of a healthier and fuller life. The donor process started us on a journey we never could have imagined.





MY DECISION TO BE MY BROTHER'S DONOR

Donating an organ may be one of the most important decisions you make in your life, and it takes sacrifice and a lot of courage. Offering to become my brother's donor was a natural thing for me to do, and the decision to donate came from my heart. I, like thousands of other people, have seen the campaigns, watched television documentaries, and heard commercials appealing for people to register as organ donors in order to save lives. However, sometimes hearing about such matters is not enough to spur us into action.

I decided to become a donor because it was for my brother, whom I dearly love. I wanted him to live longer and regain his full health and, as his sister, it was important for me to give him that chance. During a transplant, doctors need to match a donor and recipient's blood group and tissue type, and siblings are more likely to be a closer match. The closer the match, the greater the likelihood of a successful transplant. There is also a shortage of kidneys from black donors, and if I did not offer to donate; my brother could have to wait three times as long for a transplant than the national average waiting time of just over three years. This would be stressful for him and the whole family, and the longer he was on dialysis, the more his health would deteriorate. If I went ahead with the transplant operation and there





More Than a Match

were no complications, maintaining my remaining kidney would be my responsibility. While it is possible to live a normal and active life with only one kidney, it's important for me to make healthy lifestyle choices. I would need to maintain a healthy diet, avoid salt, drink lots of water and exercise regularly. I would also need to have an annual check-up. Having a major operation, a permanent scar, upheaval to my life for ten months, and maintaining a healthy lifestyle was a worthwhile sacrifice for my brother's life.





MY JOURNEY BEGINS

Today was the start of my donor assessment process. My brother had contacted the living donor transplant team at Guy's Hospital, where he was receiving treatment, about me being his donor. This was important because if I was found to be compatible, he might not have to start dialysis. Prior to my appointment, I was sent a DVD and booklet about living kidney donation. My first consultation at the hospital was to see the clinical nurse specialist. As I live quite far away, I spent the night at my brother's house, which was convenient for my morning appointment. We spent the evening reminiscing about our childhood; I reminded him that he was not such a nice brother when we were kids, and that he was lucky I did not hold a forty-year grudge!

I had arrived early for my appointment. This gave me the opportunity to observe what was going on in the kidney unit, as it was all very new to me. I was surprised by the number of people with kidney problems. There were people of all ages and nationalities, ordinary people like myself who were struggling with major health problems. It made me realise how fortunate I was to be healthy even though at the time, I thought having a broken ankle and hobbling around on crutches was my worst nightmare. The appointment put





More Than a Match

a quick end to my pity party! Whilst waiting to be seen, I had the chance to talk to a few people. I got talking with Carol, who asked how I broke my ankle. She had a transplant last year and was at the clinic for her routine check-up. She mentioned her father had donated one of his kidneys to her and it had completely changed her life. I asked about his donor transplant. She said it went very well and he was doing fine. She gave me her mobile number in case I wanted to talk or had any questions, and she wished me luck before she was called to see her doctor. When she left, a woman who had overheard our conversation mentioned that having a transplant was the best thing. She came to the hospital three times a week for the most commonly known type of dialysis called haemodialysis. Each session takes four hours; blood is transferred from her body into a machine that filters out waste products and excess fluids. The filtered blood is then passed back into her body. She mentioned she was usually exhausted after each session and needed half a day to recover before the next round. Dialysis for her was crucial, as it was her life support. She was among the 7,000 people in the UK currently waiting for a kidney donor.

I met Miri, who was my clinical nurse specialist; she explained her role as a clinical nurse was to take me through the different stages of the donor process and medical assessments to assure the transplant team I was a compatible donor. If I passed all the medical tests, the details would be sent to the Human Tissue Authority (HTA), which controls the use of organs of people in the UK. If approved as a donor, arrangements would be made for the transplant. The assessment process could take between three to seven months.

I was asked general questions about my health. My weight, height





My Journey Begins

and blood pressure were checked. I asked Miri what the risks of living with one kidney were. She said there were no serious risks from donating. Sometimes there could be a slight rise in blood pressure or an increase of protein loss in the donor's urine, but these would not have an adverse effect on my health. She said I would not be on any long-term medication and as a donor, I was at no greater risk of developing kidney failure or ill health than anyone in the general population. My remaining kidney would increase slightly in size and capacity for greater functionality, but I would not notice the difference and would continue to live a normal life. It would be important for me to maintain a healthy balanced diet and exercise regularly. This explanation put any fears and doubts I had about donating to rest.





EVALUATION TO ASSESSMENT

Before you can become a kidney donor, you need to undergo a series of blood tests, the first which is to check that you and your recipient have compatible blood groups. This reduces the chance of rejection, although in some cases and in some transplant centres transplantation can take place between people who are not the same blood group.

Blood Tests

I assumed Tayo and I would be the same blood group because we are brother and sister, but this is not always the case, as family members can have different blood groups.

Other blood tests are taken to see whether you are anaemic or have previously been infected with certain viruses. These checks are important to make sure you are in good enough health to be a kidney donor and that your kidneys are working normally. Other blood tests check your tissue type. The tissue type of a person is determined by marker proteins on the surface of white blood cells. Everyone's tissue type is different (except for identical twins) but if you have a close tissue type match with your recipient there is a higher chance that the transplant will be successful in the long term. Close tissue





Evaluation to Assessment

type matching is more likely when people are closely related.

Blood Pressure Monitoring

Blood pressure is monitored at several stages during the donor assessment process as high blood pressure can cause kidney damage and this might make you unsuitable to be a kidney donor.

Urine Sample

Urine samples are tested for the presence of bacteria, glucose, protein and blood to see if there is any infection or signs in the urine of an underlying kidney problem.

My nurse also explained that during the thorough testing, the kidney unit might discover that I was not a suitable donor, and I would need to prepare myself for the disappointment of not being able to help my brother. Whilst in Lagos with my mum for my dad's burial, I received an email saying my preliminary blood tests results were back. I had a compatible blood group and was an excellent tissue match for my brother (6 out of 6). Hooray! This meant I could proceed with the donor assessment.





NEXT STAGES OF THE EVALUATION PROCESS

There are different stages in the donor assessment process. The hospital usually lets you know well in advance your appointment times, including how long they may take. This makes it easier to plan and book time off work. My brother came with me to the initial discussion, as he wanted to have an idea of what I would be going through. The five different stages of the process may vary depending on the hospital. Usually they are as follows.

- 1. Initial Discussion**
- 2. Medical Tests**
- 3. Consultant Kidney Specialist Review**
- 4. Consultant Transplant Surgeon Review**
- 5. Independent Assessor Appointment**

1: Initial Discussion

This included giving a brief summary of my medical history of vaccinations, smear tests, the number of children I have, mammograms (as I was 50), allergies and recent medical problems. I had to sign a consent form allowing the hospital to contact my doctor for other relevant medical information. As I am of African ancestry I needed a





Next Stages of the Evaluation Process

further blood test to check for sickle cell disease (I am a carrier)

2: Medical Tests

These are the major tests to determine if one is medically suitable to donate a kidney. Just having a compatible blood group and tissue match are not enough. These medical tests were what I called the make or break it tests. The four tests are: Glomerular Filtration Rate (GFR), Electrocardiogram (ECG), CT Angiogram, and x-rays of the chest and abdomen.

3: Consultant Kidney Specialist Review

A doctor who specializes in kidney disease is called a nephrologist. During this appointment, the consultant will review the results of your Stage 2 medical tests. It is at this stage you will find out if you are able to donate, need to go for further tests, or are not a suitable donor.

4: Consultant Surgeon Meeting

At this stage, you will meet the consultant who will perform your operation. It is the final stage where your suitability to donate would be confirmed. The consultant specialist provides you information about the operation, the transplant, recovery and the treatment you would receive until you are discharged from the hospital.

5: Independent Assessment

The blood tests carried out at the hospital already showed that Tayo and I are related. However, it is a legal requirement that we can also prove that we are. We would need to provide documents such as birth certificates, passports and photographs of us together.





More Than a Match

THE MEDICAL TESTS

Glomerular Filtration Rate (GFR):

This was the first test of the day; it took place at the hospital's Nuclear Medicine Department. This test measures how well the kidneys filter your blood. During my initial discussion, I was told I needed a GFR rating of 77mls per minute to be able to donate. The doctors were precise about this figure and I knew the transplant could not go ahead even at a rating of 75mls per minute. The reason for this was firstly, the kidney I was donating to my brother had to be in pristine condition, and secondly, my remaining kidney had to last me for the rest of my life. The extent of my brother's kidney failure was such that he only had a GFR of 5mls per minute. Knowing his kidney function was so poor made me cry. The radiologist explained the procedure for the test and asked if I had any questions. I asked why it was called Nuclear Medicine. He explained it was because they use a radioactive tracer to obtain pictures of the kidneys, but there were no risks as it was a very small amount of radiation and not harmful. He began the test by placing a butterfly cannula into my left arm (a cannula is a small, flexible tube which is inserted into a vein) for my blood samples to be taken. Having this tube in my vein meant I did not need to have a needle inserted into my arm each time they took blood (this is great for those who don't like needles!). A small amount of heparin was injected to stop blood clotting in the tube, as this would interfere with the samples. He then injected a very small amount of the special radioactive tracer. I needed to give three blood samples, one every hour. When the last blood sample was taken, the tube was left in my arm for the kidney scan I had to have later.





Next Stages of the Evaluation Process

Electrocardiogram (ECG):

An ECG traces the electrical rhythm of your heart; it is carried out for anyone who will be going to have a general anaesthetic. I went to the Cardiology Department in between my blood samples. The test was to find out whether there were any weaknesses in my heart and if it was functioning properly. I had several small electro-sensitive pads (which did not cause any pain or electric shocks) placed at different points on my chest, arms and legs. The test lasted around 15 minutes.

CT Renal Angiogram:

The CT scan takes pictures of your insides to check the number of kidneys you have, their size and structure and the number of blood vessels attached to each one. Each kidney should have two blood vessels, the kidney vein and the kidney artery, and also a draining tube which is called the ureter. The kidney artery brings blood from the heart to the kidney and the kidney vein drains blood from the kidney back to the heart. The ureter drains urine, containing toxins and waste products which the kidney has removed from the blood, from the kidney to the bladder. Normally each kidney has only one artery, one vein and one ureter, but some healthy people can have more than one of each. This may make the operation more complicated for the surgeon.

The CT scan also takes pictures of other parts of your insides such as the liver, stomach, bowel and pancreas, so if there are any abnormalities in these organs it could be picked up during this test. I had to lie on a motorised bed which moved slowly through the scanner just above my abdomen (it all looked a bit scary but it was





More Than a Match

not). Iodine-containing dye was injected into my vein through the tube which was still in place in my arm and the CT scanner took lots of pictures of my kidneys. The whole procedure took around 30 minutes and was painless, although I felt a bit sick afterwards.

Chest X-Ray:

This was done to see whether my heart was healthy, on the correct (left) side of my chest and was of normal size. It also checked for any signs of lung disease such as emphysema, tuberculosis or any other abnormalities.

Abdominal X-Ray:

The x-ray took a picture of my ureters and bladder to look for any abnormalities such as kidney or bladder stones.

I had no side effects or pain from the tests but I was shattered by the end of the day; this was a combination of the tests and traipsing around the different departments (Guy's Hospital is huge).

MEETING WITH THE CONSULTANT KIDNEY SPECIALIST

Two weeks after the medical tests I met with the consultant kidney specialist for a review of the results. During the meeting I was asked general questions about my health and fitness, and my weight and blood pressure were checked. I felt quite anxious as it had been a nerve-racking experience waiting for the results. Good news! I have two kidneys connected to the correct number of veins and arteries, which is a priority for the transplant.

My consultant explained that the tests revealed I had high cholesterol (the cause of which was genetic). This would not stop





Next Stages of the Evaluation Process

me from donating, but I would need to see my own doctor for treatment. One of the benefits of being assessed as a potential kidney donor is that you have a thorough health check which may flag up health issues you were not previously aware of.

My consultant did have two concerns which could prevent me from being a donor. Firstly, she explained my GFR had been measured at 72mls per minute and I needed a minimum GFR of 77mls per minute in order to safely donate. Secondly, microscopic traces of blood were consistently appearing in my urine on dipstick testing, and the cause of this would need to be identified before I could donate. She wanted me to repeat the GFR test as there was a possibility that a second measurement might be higher. The other two tests I would need to undergo even if my repeated GFR measurement was 77mls per minute or higher would be to see where the blood in my urine was coming from. The first of these would be a simple procedure called a cystoscopy which means that a small camera would take a look inside my bladder to see whether the blood in my urine was coming from there. This might be caused for example by a stone, by bladder inflammation or even bladder cancer. She explained that if the inside of my bladder looked normal, I would then need to have a biopsy of one of my kidneys to see whether the bleeding was from coming from there. This might mean that I had a problem with the health of my own kidneys. She told me that there was a 40% chance that this could be the case, and, if so, I might not be able to donate.

I saw my nurse to rebook my GFR measurement. She explained that the assessment tests are very thorough as the hospital wanted to minimize any risk to my health. She knew I was upset about the





More Than a Match

results, but encouraged me to stay positive. I asked if there was anything I could do to increase my GFR like drink more water, change my diet or take more rest. She said no, these would not change it, but there could have been a number of factors which might have influenced the results on that day. I called my brother to give him an update. I felt a bit down, but he was upbeat and told me not to worry, but that was easier said than done. That evening, I went to bed physically and mentally drained.





THE EMOTIONAL IMPACT

Being a potential donor is quite an emotional experience. I am quite an emotional person by nature and cry at the drop of a hat, so my journey was a tearful one. I had a roller coaster of emotions: some days I was excited, positive, and full of hope about my intentions, and other days I would be consumed with fear that I would not be a suitable donor or Tayo's body might reject my kidney. I felt the enormous pressure of wanting to help and it was absolutely frustrating waiting for the test results to come back! Whenever I saw Tayo, it was worrying to see how his kidney failure was affecting his health; he was very tired and had lost a lot of weight and was suffering very badly from gout and constant itchiness (some of the side effects of kidney failure). He was waiting patiently for the outcome of the assessment process, but I knew his kidney function was deteriorating rapidly. Whenever he left my home I would be in tears. It's estimated that three people die each day whilst waiting for a kidney; I had already lost one brother and could not bear to lose Tayo as well.

The emotional impact was hard on my mum as she was still in mourning in Lagos. She would call me almost every day for news on my brother's health. I knew if anything happened to Tayo, she would be totally heartbroken and, in her eighties, I don't think she would have recovered





The Emotional Impact

from it. Waiting and praying became her daily routine. My brother was tremendous, he was concerned about my well-being during the tests and very appreciative of the sacrifices I was making for him. Many times he would express his love without words, and would have followed me to every appointment if I had allowed him. It's very important to have friends, family, or members of your faith group who you can turn to for support, as you will definitely need it.

After two weeks, I went back at the hospital to repeat my GFR test. It was a very different experience this time around and I was slightly nervous, but the radiologist told me not to worry as many people repeated the test. The test results would be back in five days. The wait consumed my every waking moment because I knew the importance of repeating it; my measurement needed to go up to 77mls per minute for me to help my brother. As a Christian, my faith played an important part in my decision to donate; I prayed, searching for answers, but knew ultimately that God had the final say.

When the call finally came, my nurse was pleased to tell me the results had come back and my GFR measurement was above 77mls per minute, so I was free to continue with my assessment. She said she would go ahead and book the cystoscopy procedure. I called my brother immediately to give him the good news. He was pleased and I was relieved. I realised there were many hurdles to face as a donor, and at each hurdle I was challenged either by further tests or feeling emotionally low. On other occasions, my faith was tested or I felt the anticipation of waiting for the test results to come back. Whatever the hurdle I faced, I did not mind as I knew it was taking me closer to the end of the assessment process and hopefully a transplant for Tayo.





MORE TESTS

I needed to have a cystoscopy to see whether the blood in my urine was coming from my bladder. This might be caused for example by a stone, by bladder inflammation or even bladder cancer. The procedure was slightly intrusive and uncomfortable and lasted about fifteen minutes. The only after-effect was a burning sensation when I went to the toilet. After the procedure, I was told the bleeding was not from the bladder and everything was normal which meant I would need to have a biopsy to investigate if the bleeding was from my kidneys.

I spoke with my nurse, who immediately booked me in for the biopsy. Miri was not part of my brother's medical team, but was aware of the urgency for me to complete the assessment process. I felt that we were not just hospital numbers to her, but people she had developed a good relationship with, this made the assessment process much easier. I know the media likes to portray the NHS Trust in a negative light sometimes, but I beg to differ and have nothing but praise for the staff at Guy's Hospital. I often witnessed their professionalism and dedication to patient care as they carry out their daily jobs.

I was booked in for a kidney biopsy, which was my last medical test





More Than a Match

in the assessment process and would determine if I would continue. As it was a day surgery, my eldest daughter, Bimmi, came with me. I was admitted into the kidney day ward, where I immediately had a blood test as the results were needed for the biopsy. Whilst I waited for the results, Bimmi and I wandered around the ward. We were deeply moved by the number of people on dialysis. I don't believe what we read or hear paints a true picture of the daily challenges and struggles people on dialysis have to face. The dialysis machine, when connected up to a patient, can look quite intimidating while it filters and cleans the blood. Some of the patients I met looked tired but still managed to give me a smile as I walked past their bed. Whilst listening to Guy's lunchtime concert, I reflected on what I had seen. The walk brought home to my daughter and me why being a donor is so vital to our loved ones' health. It showed us that our act of kindness can play a big part in adding quality to their life.

The Kidney Biopsy:

The doctor to perform the biopsy explained the procedure and the risks involved. The main risk was bleeding; and about 1 in every 10 people had signs of visible blood in their urine after a biopsy, however the doctor said it would eventually stop on its own. The biopsy involved taking small samples of kidney tissue to be analysed. I was given a local anaesthetic and remained fully awake during the procedure. The doctor inserted a special needle into a tiny incision he made on my back and, with the aid of a camera and TV monitor, was able to navigate the needle to obtain the sample. The doctor talked me through each stage of the procedure which lasted about 30 minutes.





More Tests

Once back in the ward, I had to lie flat on my back for six hours as this position added pressure to the incision and helped stem any bleeding. My blood pressure and temperature were monitored throughout. Whilst resting, I had time to think about what living with one kidney would really mean for me. I also thought of my brother and what this transplant would mean for him. Just the thought of having my brother back to his old self brought silent tears of joy. After six hours, the doctor told me I had no blood in my urine. He gave me some painkillers and discharged me. Apart from the tiredness and slight pain, I had no side effects; however, I needed to take things very easy over the next few days. The results would be ready in eight weeks, which meant another anxious wait.





RELIGIOUS AND CULTURAL BELIEFS ON ORGAN DONATION

As an African, I knew my ethnic group were reluctant donors, but it was not until I came forward as a donor that I realised the magnitude of the problem. The demand for donor kidneys for transplants far outstrips the current national supply, but it is a bigger problem for Black and Asian people living in the UK, as they are three times more likely to develop diabetes and high blood pressure than white people, which can lead to the need for a transplant. I conducted my own research using friends and family who were African, Asian, Caribbean, religious and non-religious, with the aim of finding out what influenced their attitude towards organ donation. There are a variety of reasons why Black and Asian people were reluctant donors; fear and the thought of dying during such a major operation stopped a lot of people. For some, it was not a subject they even considered, and others felt the risks were too high. But religion and culture seemed to be the two major obstacles that prevented people from donating. Some questioned whether it was acceptable for their religion to donate; others felt it was acceptable, but that there were still some grey areas. My Muslim friends said living kidney donation was permissible in their religion. A friend said he would be willing to donate but





Religious and Cultural Beliefs on Organ Donation

knew his family would fiercely oppose it. Healing for many of my Christian friends was a hot topic. Many would not even consider telling others they were facing a life-threatening illness; they believed their faith would heal them, as this was a fundamental part of their Christian values. There were friends who mentioned organ donation was a taboo in their culture. These cultural beliefs had been passed down through the generations and were now an integral part of their mindset. But many of them had not taken the time to find out the basis for these beliefs or question if they were still relevant in the 21st century. In summing up my research, I am not dismissing the strong beliefs and opinions Black and Asian people have towards donating, but I do feel we radically need to change our mindset and look beyond these beliefs so that we can give our loved ones the quality of life they rightly deserve. The UK is seeing a rapid rise in the number of overweight and obese people, those that have unhealthy diets and do little or no physical exercise; as a result, we will see an increase in the number of young people with diabetics, high blood pressure and illnesses that lead to kidney failure. We need to send out a positive message about organ donation especially as the up and coming generation will be the living donors of the future. Black radio and TV channels are doing a tremendous job in promoting organ donation, but black majority churches also need to take a more proactive role in talking about such a sensitive issue, as this platform can tackle some of the issues black Christians have towards donating.





SAD NEWS!

After waiting nine long, nerve-racking weeks, my nurse called to say she had very sad news. The results of the biopsy were back, and unfortunately the blood in my urine was the result of a minor inflammation in my kidneys. My health was not at risk whilst I had two kidneys, but if I donated one my doctor could not be sure whether the inflammation would cause a strain on my remaining kidney affecting my health in future. For that reason, she could not give the go ahead and allow me to be a donor. I was stunned, I had always been confident that I would donate to my brother, and never imagined that anything could stand in the way of that. I was so upset and the thought of him on years of dialysis or even dying was too heart-breaking for me to even think about at the time. It didn't make sense to have come this far and now face such disappointment. Our lives had been on hold for the past eight months as we waited for the assessment process to finish and for Tayo to hopefully have his transplant, but now it had all come to an abrupt end. I struggled as I told him the sad news. I could hear the disappointment in his voice, and I can't describe how I felt for him at that moment. I cried for days and felt such an aching emptiness at not being able to help my brother. It took weeks to





Sad News!

come to terms with the whole outcome, and I did not realise it would affect me so much because there was never a doubt in my mind that my brother would not have his transplant.





LOOKING FORWARD

A couple of months later it was my birthday, and my daughters, Mo and Bimmi, had a special birthday surprise. They had decided to put themselves forward as potential donors and try the donor process to see if they were compatible. They were also concerned about their uncle's health. It was heart-breaking for them to see how much weight he had lost and how dull his complexion looked; he had been a very active and fit person, so it was sad to see his poor health set him back. They had seen me go through part of the assessment process, so they had a fair idea of what was involved and wanted to do it. My brother could not believe how fortunate he was to have not just one potential donor but three! and as for me, it was the best birthday gift, especially after my disappointment of not being able to donate. Mo and Bimmi contacted the living donation team at Guy's Hospital to put themselves forward as potential donors. They went through the same preliminary medical tests as the ones I had gone through. Once the tests were complete, the results showed that Mo, my youngest daughter's blood pressure was slightly high and she had traces of blood in her urine, Bimmi also had high blood pressure, but with no signs of blood in her urine she was considered a better





Looking Forward

match. Our mood had lifted once again and the family was happy that at least one of them was through to the next stage. There was finally light at the end of the tunnel as Bimmi continued the journey I started as my brother's potential donor.





BIMMI'S JOURNEY MY DAUGHTER

I was secretly quite pleased that I was more of a match than my sister, as I really wanted to help my uncle. As a child, I can remember him constantly around giving my mum (who was then a single parent) the support she needed to raise me and my siblings. When she was ruled out as a donor, I needed no convincing; seeing her courage and love for my uncle challenged me to step in and offer to donate. I was not afraid of being a donor, but I was anxious about the transplant, as there was still the possibility that my uncle's body might reject my kidney.

During my appointment with the consultant kidney specialist my tests showed that my blood pressure was high and the doctor told me that I would need to go on medication immediately to lower it. Once it was lowered to the right level I could probably go ahead and donate. My next appointment in the process was to meet the transplant surgeon who would perform my operation, and, although I was a suitable match, he confirmed my blood pressure was too high and would need to come down before he could operate. He also told me that if I was able to lose a stone in weight it would help reduce my risk of a hernia after surgery. Doing physical exercise would help me lose weight and lower my





Bimmi's Journey

blood pressure at the same time. The procedure for the operation would be keyhole surgery: this is where two or three small holes are made at one side of my abdomen and a larger hole close to my navel where the kidney is taken out. The operation can take up to three hours. Depending on my recovery, I might be up and about the next day and out of the hospital in three days.

Handy Tip: : If you are offering to donate, check your Body Mass Index (BMI) as soon as possible in case you need to lose weight. Don't wait until you see the surgeon before you head down to your local gym, as it may delay the assessment process and transplant.

One weekend when I was at my cousin's house, my uncle was having his dialysis exchange. Seeing him hooked up to the machine made me cry, I was anxious now for my blood pressure to come down so as to continue with the assessment. When I returned to the hospital a few weeks later, I had lost weight, but my blood pressure had not dropped despite the fact I had started taking the tablets. My doctor increased my dosage and I was advised to monitor my blood pressure over the next four weeks at home. My blood pressure was going down but it also kept fluctuating during that period. A month later, I went back to the hospital and my blood pressure had come down, but it was still too high to go ahead with the donation. By now, my nurse specialist was concerned as to why, even with the tablets, the weight loss, and exercise, my blood pressure was still high. I was still relatively young (26), and such levels would put me at a high risk if I were to





More Than a Match

donate. Another appointment was booked for eight weeks' time; hopefully, by then there would be a significant change. During this time, I completely avoided salt as it is linked to high blood pressure, I drank fresh beetroot juice with ginger as it has been known to reduce it, I was still losing weight and exercising, and, in fact, I had a complete lifestyle change. Up until the donor assessment I was not aware my blood pressure was so high and it was quite scary to think what might have happened if I had not offered to donate.

After eight weeks, I returned to the hospital, but this time I was told by my consultant because my blood pressure had not come down to the recommended level for donating and was constantly fluctuating around the 139/92 level it was advisable for me not to be a donor as it would put my health at serious risk. I cried when I was told this; I could not believe it was happening again. My sister had been ruled out because of her blood pressure and the traces of blood in her urine. My family was very upset as this was another blow for my uncle. My consultant's explanation for mine and my sister's high blood pressure was that it could be genetic; and is very common in African, Asian and Caribbean families. Unfortunately, I would have to be on tablets long term to stabilize it. But she also said that my uncle could have inadvertently saved my life. High blood pressure is known as a silent killer and if I had not come forward, it might have gone undetected until it became life-threatening or even caused death. Naturally, we were upset that my uncle would not have his transplant yet, but to know that if I had not come forward I might not have reached 30 made us all very grateful for the donor process.





Bimmi's Journey

WHAT I KNOW FOR SURE!

I am not a fearless person, you can't get me to bungee jump or even go on the Oblivion ride at Alton Towers, but I do have the heart and courage to be a living donor. Offering to become a living donor for your sister, brother, someone else in your family or even a friend is the best gift you can give, as it could mean the difference between life and death for them. Coming forward as a donor in my twenties has made me appreciate the value of having good health and looking after my body for the long haul. My high blood pressure was a frightening wakeup call and now I tell all my friends to get their blood pressure checked. The experience also taught me the importance of standing up for what you believe in; I had plenty of critics, but I ignored their comments because my uncle's health was very important to me. I would highly recommend being a living donor; it's a life changing experience!





THE TRANSPLANT OPERATION

After the sad outcome of my family's donor assessment process, I asked myself if my book was still worth publishing, as I wanted to give readers as much information as possible if they choose to donate. I spoke with my family; they urged me to continue as the book might encourage other families to come forward. I had a talk with my doctor who provided me with information about the transplant operation, recovery and living with one kidney which readers will find useful. I have paraphrased the information in my own words.

THE DAY OF THE TRANSPLANT OPERATION

On the morning of the operation, both the donor and recipient are up early, ready to spend the last few minutes saying goodbye to their family before going to the operating theatre. The donor will be asked to sign a consent form saying they have agreed to the operation and that they are aware of the risks. The donor is prepared for surgery first, followed shortly by the recipient. In most hospitals, the procedure occurs at the same time with two teams of surgeons, anaesthetists and nurses working in adjoining theatres. After the kidney is removed, it is transferred to the adjoining





The Transplant Operation

theatre to be transplanted. The operation usually takes up to three hours. Most recipients say they feel the new kidney working after a couple of hours after the transplant; that is amazing!

AFTER THE OPERATION

After the operation, the donor wakes up in the recovery room where they will be for a couple of hours before going to the ward. Once settled, your family is allowed to visit you. Be prepared for the pain and the number of different tubes attached to your body. As well as dressings over your wound, there will be a small plastic drain tube attached to a wound drainage bag, which will collect bloodstained fluid from your wound. This will be removed when there is little or no drainage from it, which is usually the next day. You will also have a urinary catheter, which makes it easier to pass urine. Getting in and out of bed can be painful and will hurt a lot around the lower abdomen where the kidney was removed; however, you will be on pain-killing medication. These strong pain-killers are often based on morphine, which may make you constipated, so it's recommended that you eat plenty of fruit, vegetables and fibre.

The next day, you will be encouraged to sit out of bed for short periods. Throughout the day, there will be various checks, such as blood pressure, blood tests, and measurements of how much urine you have passed and how much fluid you are taking. A physiotherapist will be on hand to make sure you can get up and about and to help you to cough and breathe after surgery. The wound itself is quite small and usually closed with dissolvable stitches. The wound dressings will be removed after 48 hours or





More Than a Match

sooner if required. The length of time a donor stays in the hospital varies, but it's usually about three days.

RECOVERY AT HOME

When you arrive home, do not be tempted to do anything! It's very important to rest and allow yourself time to heal. You will definitely need someone around to help you for the first week, as even simple tasks such as making a drink can bring on pain. Find a comfortable position, i.e. laying in bed or sitting upright in a chair with lots of cushions. Be very careful of the wound as it is healing. Don't reach and pick things up too soon, and try to be careful not to get the wound wet as doing so may lead to an infection. You will experience pain in the first week at home, but you will be given a supply of pain-killers from the hospital.

GETTING BACK TO NORMAL

Recovery time after the operation varies, but generally, you should start to feel better two weeks after your operation. Going back to work depends on the type of job you do; but, one is advised to take about six weeks off. The donor should allow three months for a complete recovery; however, keep in mind that a lot of patience is required, as there is a temptation to get back to normal life too soon. Listen to your body and do not push yourself. You will have an appointment to visit the hospital about six weeks after the operation.

LIVING WITH ONE KIDNEY

Having one kidney can in fact make you healthier. A healthy diet is important for looking after your remaining kidney and preparing





The Transplant Operation

meals from scratch is a good way of controlling the amount of salt, sugar and unsaturated fat needed in your diet. Regular exercise and drinking plenty of water is essential. The donor team recommend a yearly check-up to monitor your kidney function and to detect early signs of kidney problems.





A RECIPIENT'S PERSPECTIVE OF A KIDNEY TRANSPLANT

Much has been written about living donation from a donor's perspective, but I also want to give readers a recipient's perspective on how having a life-saving transplant can transform a life. I called Carol, whom I met at my first appointment, and asked if I could include her story for the book. She gladly gave her permission.

CAROL'S STORY

I had been diagnosed as having kidney failure in 2000. For eight years, I experienced a slow but steady decline in my kidney function. During this time, I was working as a head of year teacher in a girls' secondary school. In 2008, I went on dialysis. Up until then, I generally felt well and functioned normally except for being constantly tired. I was on a low-protein, no salt diet for the last two years and I think that helped delay my kidney failure for perhaps up to a year. I was on haemodialysis for two years prior to my transplant. I struggled at first and was very, tearful, depressed and irritable and I actually hated it. The worst part of dialysis was realizing that my life had completely changed. I had dialysis three days a week for about four hours each time, usually after teaching; this meant most evenings I was shattered. I missed days off work.





A Recipient's Perspective of a Kidney Transplant

Although I generally felt lousy most of the time, several things made it bearable: the support from my family, my partner and my job. I found it better to stay busy and not dwell on my condition.

Originally I was meant to get a kidney from my sister, but it turned out my father was a better match. The staff at the hospital were great and I really don't remember having any apprehensions prior to the surgery. If anything, I was excited about a new dialysis-free life. It was also very reassuring to have your father giving you a kidney. It is hard to describe the feeling of having my father give a part of himself to me. It certainly is the most wonderful gift I can ever imagine!

I remember being taken into the operating room and meeting the anaesthetist. I was given a general anaesthetic and was then out for the count. My next recollection was waking up totally disoriented and heavily sedated. Although I was in a lot of pain, I remember the smiling faces of my family. I recovered quite quickly and I was up walking around the next day. Although I was supposed to be discharged after a week, my body tried to reject the kidney (a common occurrence) and I spent an extra week in the hospital. I was given a higher dose of steroids to knock down my immune system. I recovered very well at home with my family looking after me. I was able to go back to work part time about a month after my transplant, and full time after two months.

Since then, I have been quite healthy and feel great. I have had no further rejection incidents and my kidney function has been stable. I live a completely normal life, and in September 2011, my daughter was born, so it is possible to conceive a baby after a transplant. The immunosuppressant drugs do have a slight side





More Than a Match

effect on me, I've noticed I sometimes find it hard to concentrate, but that's minor compared to being on dialysis. In summary, my transplant experience was a very positive one and having my dad as my living donor made all the difference in the world to me: it's keeping me alive, I am free from dialysis, and it has made a big difference to my health and family life. Having a donated kidney from a family member gives people like me a chance to really be happy and enjoy life again!





FINAL WORD

As a family, we wanted to give Tayo a healthier and possibly a longer life, but sadly, none of us were successful in our quest to be his living donor. But I know our journey was not in vain. I hope *More Than a Match* has answered some of your questions, addressed some of your fears, and enlightened you on the benefits of becoming a living donor and the living donor process. I also hope it has been informative, and conveyed the emotions, challenges, disappointments as well as the joy and triumph you will encounter if you decide to become a living donor. I am optimistic that the book will help families look at the different ways they can support their loved ones in having a transplant. Living donation is a topic that many people know little or nothing about, however I have simplified it in a way that makes it easy for people to understand. Nothing could have prepared me for the experience. It showed me the struggles and challenges people with kidney failure face on a daily basis, it brought to light the number of people that maybe dying needlessly every day whilst waiting for donor kidney, and the thousands on the waiting list. I realized a lack of information and knowledge on a topic stops us from making wise decisions. I met people with courage and compassion who donated a kidney





More Than a Match

to a loved one or friend, and it brought home to me that health is truly wealth! It may take a personal situation like mine to come forward as a potential donor, but if the opportunity presents itself, I hope by reading my story you will believe that you too can give someone in your family or a friend the chance to be around for their children, a partner or just the opportunity for them to live out their dreams.





FURTHER INFORMATION

More Than a Match is part of Gift of Living Donation (GOLD) an organization set up by the author in 2011, to increase the number of living kidney donors in the UK. One way they hope to achieve this is by a step-by-step workshop to the practicalities of being a living kidney donor for the family and friends of a loved one with kidney failure. This workshop is a unique and innovative way to bring their closest friends and family together so that they will learn all there is to know about living kidney donation in the hope one of them will come forward as their living donor.

The relaxed atmosphere allows a great deal of time for the group to talk openly about their fears, concerns and ask questions. It's also a chance for them to understand how their loved one or friend deals with the daily challenges of living with the illness, as well as how a transplant would change their life.

We believe the workshop offers a solution to the growing need for more living donors in the UK as it opens up lines of communication for living donation to be discussed with a group of people who otherwise never would have considered being donors. We know being a living donor is not an easy task and is an unlikely position many would have found themselves in before, for this reason Dela Idowu draws on





More Than a Match

her experience as a potential kidney donor to educate other potential donors. Her goal is to ensure that the group has all of the information needed if they wish to donate a kidney.

Go to www.giftoflivingdonation.co.uk where you can:

- Book a workshop
- Buy the book
- Arrange a one-on-one appointment for support and advice
- Leave your comments about the book





About the author

Dela Idowu, is the Director of Gift of Living Donation (GOLD) a project set up in 2011 to increase the number of living kidney donors in the UK, especially among family and friends of a loved one with kidney failure. Her background in community and charity work coupled with her experience as a potential kidney donor, has enabled her to write her story with empathy and honesty.









LIVING ORGAN DONATION, THE AMAZING GIFT OF LIFE!

Dela Idowu and her family bring humour, honesty, laughter and tears all together in this unique and important story of living kidney donation. They believe organ donation is one of the greatest gifts that can ever be given, and want to share their own experience to help others overcome their fears and anxieties about becoming an organ donor. The book offers valuable information on:

- **WHAT IS INVOLVED IN LIVING KIDNEY DONATION**
- **DIFFERENT STAGES OF THE LIVING DONOR PROCESS**
 - **DEALING WITH EMOTIONS**
 - **THE TRANSPLANT OPERATION**
 - **LIVING WITH ONE KIDNEY**
- **RELIGIOUS AND CULTURAL BARRIERS**
- **THE RISKS OF BEING A DONOR**

They have shared their experience as potential living donors, so all that's left is for you to read the book and find out how you can give someone freedom from dialysis, a life-saving transplant and a new lease of life!



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