

Stories from patients who have received a Kidney Transplant at the Queen Elizabeth Hospital Birmingham  
These were sent to mark World Kidney Day and  
50 years of Kidney Transplants the the Hospital

All names were supplied but withheld

*If you would like to add your own story please send it to the  
Queen Elizabeth Hospital Kidney Patients' Association*

I had renal problems  
since I was born.

They recognised it  
back when I was little  
at Heartlands. Was in  
hospital most of my  
child life. As I got  
older I had go on  
dialysis. Did it at  
home and work four  
times a day I did it at  
work first one in rest



room at 5.30 am. Then badly needed a transplant. My sister Sharon and my mom Lyn were both good matches but my sister decided to do it because of my lovely moms age. It's now been 18 years on March 3rd and my life changed so much. I now work and also have a little boy Charlie who's nearly 7 in May. Also my sister is well and has boy Alfie who's nearly 9. I still go every 4 months for check-ups at the Q.E.

Thank you for reading this.

*Message from a daughter. 'David' is a nick name for my Dad's Kidney.*

Forgot to say Happy Birthday 'David'  
Thanks for looking after my Daddio so well.  
xxx

When I was receiving chemotherapy and was warned of the potential damage it would cause to my kidneys which would mean needing dialysis, the time scale mentioned seemed so far ahead that I did not feel the need to be concerned.

About a decade later, as my kidney function decreased steadily, the need to assess the various options for care became much more pressing.

Stamina increasingly was an issue. Playing sport was a struggle as was trying to run. My main exercise became walking which, in itself, became difficult because of breathlessness.



When the time came, I received peritoneal dialysis and the 8 hours per night of treatment became the new norm. Time away from home overnight certainly was not impossible but did take a little planning as you don't travel lightly! I missed the spontaneity of life.

As I started the dialysis regime I also went onto the transplant list but was not lucky enough to secure a donor at this time. However, my wife of 45 years, volunteered to be a donor, was tested and, to my great good fortune was found to be an appropriate match for me.

We went into the QE in August 2016 and I received my wife's kidney in an operation performed by Mr Andrew Ready MBE.

Now, a year and a half later, I feel fitter than I have for years. I walk about 7 miles a day, can run around with our grandchildren and breathlessness is a thing of the past.

I have since taken part in 2 medical trials in the hope that these will benefit kidney patients in the future as I myself have benefitted from those who have done so in the past.

I must say that the care and treatment we received in the QE could not be faulted and we will forever be in your debt.

Hi K.P.A.

My husband I wish to submit our picture and story for the upcoming celebration of 50 years of kidney transplants at the Queen Elizabeth Hospital.

It was back in 2008 after having my 15 week pregnancy scan that I was diagnosed with polycystic Kidney disease. From then on the Queen Elizabeth Hospital monitored my condition throughout the pregnancy and when the time came that my kidneys deteriorated enough for a transplant my husband volunteered to become a live donor.



It's been two years now since the transplant and I am enjoying good health and have a lot more energy thanks to my husband and all the transplant team at the QE.

Regards



Hi Nick

I recently received a copy of Kidney Matters and thought I would send you in my story of my transplant which took place on 12/06/2017.

I was diagnosed with Lupus in 1997 and have had problems with my kidneys as a result but my medication controlled the symptoms really well, however in October 2015 I suffered a flare up after my medication had been significantly reduced. As a result I was rushed to the QE from Hereford and underwent another biopsy which showed my kidneys were rapidly failing. I struggled to come to terms with the prospect of starting dialysis, I have always worked full time and dreaded the prospect of being what I saw as an invalid who had to rely on a machine to keep me alive! I refused initially but was told if I wanted to live then I had no choice, my world fell apart.

I have been happily married for over 20 years with a daughter who was 18 at the time, we also foster a young boy so I was worried who was going to provide and take care of them? I had always prided myself on looking after my family and felt helpless that my wife would have to cope with everyday tasks as well as coping with the changes that dialysis would bring. I lost both my parents 10 years ago but have a good support network with other family and friends, I knew I could rely on their support which was reassuring. I began dialysis and was lucky to get a space at the Hereford dialysis centre, I only live a 10 minute drive away so it made life easier. I can honestly say that all the care at the QE and at the dialysis centre was outstanding, everyone works so hard and their care goes above and beyond their daily duties. I felt incredibly low at times which scared me because I have never experienced any kind of depression as I am an incredibly optimistic person, I think the lack of control I had over my life and being hooked up to a machine 3 times a week was steadily taking its toll on me. It was the other patients, my family and friends and also all the people involved in my care who helped me to stop getting deeper into this black hole I sometimes found myself in. I decided to return to work and because I had changed jobs I had to go back full time, this meant dialysing on the twilight shift which was tough but I felt a bit more like my old self and I could get lost in my work. I chose to try PD which would fit in with my lifestyle better but soon after completing all the training I developed peritonitis, this was another setback but I knew I couldn't stay on Haemo dialysis at the centre so I began preparing myself for the thought of a transplant.

My brother and wife were a donor match which was incredible, it was decided that my brother would be the best chance of a successful transplant so after numerous tests we were given the date of 12th June 2017. I will be honest and say that I felt very apprehensive and I couldn't stop myself from thinking what if it doesn't work? I can't go back on dialysis. Thankfully it was successful and I am eternally grateful to my brother for everything he went through to allow me to return to my life before kidney failure. I met other people who had transplants at the same time as me and they haven't been so lucky. It's a massive decision to proceed with a transplant but the chance of being able to experience a life free of dialysis is well worth the risk and I feel privileged that we have the best health service to take care of us. Everybody plays a huge part in our care and we can only thank them on behalf of ourselves and family members, as it makes a difference to all of our lives.

This photo was taken when we went to Bournemouth for a short break, I dialysed at the local centre which allowed me a few days freedom to enjoy the summer! I am visiting the QE for an outpatients appointment on Thursday so I will pop by and say hi.

Kind Regards



## My Kidney Transplant

I received my new kidney in August 2016. It was the most amazing gift that anyone could receive. I have to thank my wonderful husband for donating it to me. I also have to thank everyone in the renal team at Birmingham Queen Elizabeth Hospital. Their knowledge skill and dedication has transformed my life.

I have polycystic kidney disease which slowly over time gets worse. Finally, I found myself on dialysis with a kidney function of 6 to 10. Having a new kidney has completely changed my life. I can go out and do more generally. I can spend time with my grandchildren. I am currently giving my granddaughter some extra help with her school work. I can have a normal diet without taking all sorts of tablets.

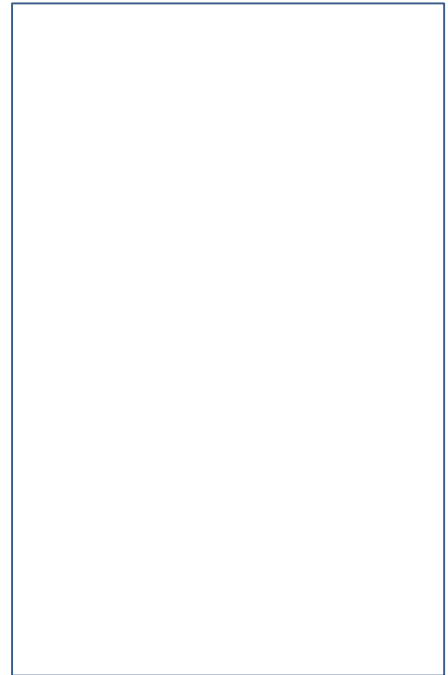
My transplant was ABO incompatible and it is amazing how research has allowed Dr Ball and his team provide treatment to overcome this. My new life bears no resemblance to my old one. I feel well and I take an interest in things that previously I found I was just too tired to be bothered with.

Thank you everyone for my new life and a special mention to Mr Nick Inston who performed the operation.

Having a transplant meant freedom from dialysis and to look forward to days out and holidays.

Most of all I felt very fortunate as my Gran, Mom, and Uncle were unable to have the same.

Very grateful to both the Renal teams at the Q.E and Heartlands.



I was just 19-years-old and one of the first kidney transplant patients at the Queen Elizabeth Hospital Birmingham (QEHB) when I underwent my operation in May 1976 - and 42 YEARS later my donor organ is still going strong.

I'm living proof that transplant patients can go on to live long and very full lives I'm eager to make sure that others get the same chance – by backing awareness campaigns on World Kidney Day.



After my transplant, I remember asking how long the kidney would last. They told me to ask again in three months. Then they said they thought it might last three years and after three years they admitted they didn't really know and just told me to get on with living my life – and here we are 40 years later.

My kidneys had first failed when I was six and I spent six months in hospital followed by many years of ill health as a child until my kidneys failed again in my early teens.

I was really ill at the time and eventually had to go on haemodialysis'.

This meant trips from home in Wolverhampton to what was then the North Staffordshire Royal Infirmary in Stoke for 10-hour dialysis sessions three times a week while at the same time my diet was also severely restricted – with little protein allowed and only one pint of fluid per day.

Ten hours of dialysis three times a week takes over your whole life, On the other days you recover. It was no life for a teenager.”

After one false alarm I got the call from the Q.E. to say that a compatible donor organ had become available and I headed to Birmingham for my transplant. But there was an anxious wait after the operation.

The kidney didn't start working for two weeks. At the time doctors told me that if it took longer to start working it might last a long time. So the fact that mine took those two weeks to start working probably says something – given that it is still working now.

I know nothing about my donor and regret never having had the chance to pass on my gratitude for a gift which gave me my life back.

Without my transplant, I would never have been able to do what I've done and countless other things I never dreamed I would be able to do.

I've got two sons, who are now in their twenties. I've done lots of travelling, and lived a fantastic life.

QEHB consultant nephrologist Dr Adnan Sharif said: "What Peter has achieved with his donor kidney is an inspiration to all transplant patients".

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Hi Nick,

Just received my copy of 'Kidney Matters', which I think is very good, well presented, interesting and informative. Plus, the fact I won £10, in the raffle, also helps me feel positive about it!.

You mention 'World Kidney Day', and ask for transplant people to send you their stories, about how their transplant transformed their life, so this is mine.

'In my early twenties, a virus which attacked my kidneys. This meant that I had to leave the Police Force, my chosen career, which was devastating. I then had six years of home dialysis, 30 hours a week, and as many kidney patients know, endured a very restrictive lifestyle, in terms of breaks away from home, and diet.



In September 1978, I received a phone call from the Q.E., whilst dialysing, "can you get yourself up here we have a kidney for you".

In 1981, I ran three marathons. I ran 7 in all, and represented Great Britain in six World Transplant Games. A real change in my life style, from pretty much total inactivity to being able to run 26 miles.

My life was completely transformed by the Queen Elizabeth

Hospital and by a family's generosity at a time of great sadness for themselves'.

I am now in my fortieth year of my transplant, and hoping to play golf in this year's British Transplant Games, in Birmingham.

The photo is of myself in the Mall, near the end of the 1982 London Marathon (looking better than I felt!).

Best wishes to everyone

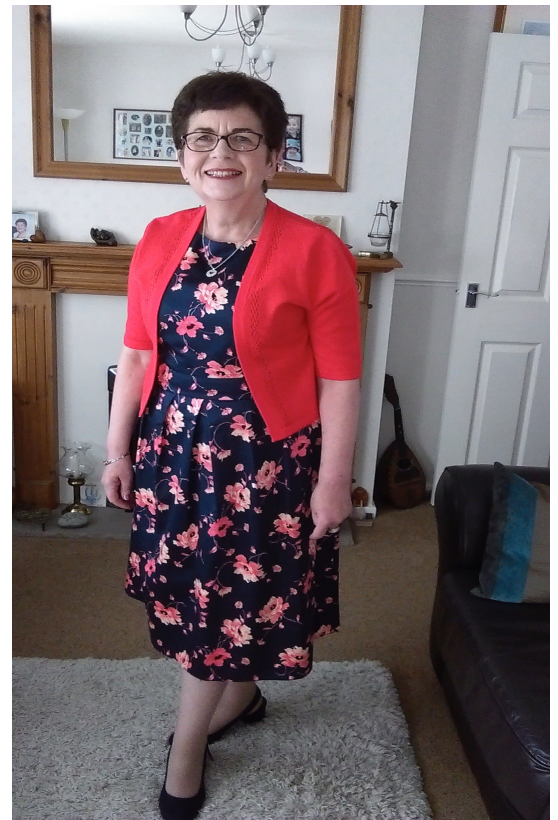
Kind regards

Hello.

I was very fortunate to receive a kidney from a donor on 30th March 1998 after nearly 7 years on C.A.P.D., so I will be celebrating 20 wonderful years as a transplant patient. I am so grateful for all my care from QEH from all who have been involved in my care particularly Miss Buist who was the surgeon that performed my operation.

I have been able to see my three children grow up and marry and now with my husband Jon have 5 wonderful Grandchildren. I also started my own Childminding business which I was able to care for many children over the past twenty years. We have also been able to visit many places like Italy, Croatia, Switzerland and more.

I will always be so grateful to my donor and his family for such a precious gift of life.



## The Gift of Life

I shall never forget the time when I had my Kidney Transplant 20 years ago.

I had been OK on PD for 3 years but the change I felt in the days following my transplant was amazing.

A new life, a fresh start, getting my energy back. I felt so pleased and grateful to everyone at the Queen Elizabeth Hospital.

But with all the joy and feeling great, I felt a sadness and a feeling of sorrow, for the person who had made this possible. A man out there who had been prepared to be a donor, who did not want to be one, had passed away suddenly and a very generous family had agreed to say yes at the most difficult time in their lives.

A day never goes by without a thought about them and how wonderful their gift of life was and what a difference it made.

## **How I Benefited from the Renal Transplant Service at QEH**

As a longstanding patient and a successful beneficiary of the Renal transplant service, I am extremely pleased to be celebrating the momentous occasion of 50<sup>th</sup> anniversary of the service at Queen Elizabeth Hospital.

My story started in 1986, when I was diagnosed with chronic kidney failure. It was initially quite a shock to find out that I was suffering from this condition and I realised there was likely to be a long road ahead. Back then, the renal team advised a very restricted diet and I was advised about a lot of changes that would be required by the renal dietician. This meant the end of a lot of my favourite fried goods, and thankfully my wife set to work carefully planning and balancing our meals to fit the strict guidance. There were further alterations that were needed when I suffered from gout and anaemia, but we were able to manage these issues with the support of the renal team.

In January 2001 I discovered that I was going to need dialysis, which would involve going through peritoneal dialysis 4 times a day. At the time I was working full time as an eye surgeon and had a very busy schedule balancing clinics and operating. It was a very tough time for me, as I tried to continue with my duties as before, but often struggled to find time and a suitable location to but dialyse in between my work commitments and was left exhausted at the end of the day. My children were very young at the time, and I was often too tired to spend time with them or help my wife in taking them to their school and music activities. It was really difficult for me to watch my wife struggle to juggle her own work responsibilities in a hospital lab as well as managing the household and looking after the children. I then switched to a night time dialysis machine that was much less disruptive to my days, but also had its frustrations. This meant an unsettled night of sleep and being attached to a machine for 8 hours a night.

In January 2003, I was finishing my lunch and getting ready to go back to work when I received a call from the transplant service asking me to attend the hospital as a suitable donor has



been identified. I can't quite describe the joy I had when I heard this news and was immediately overcome with emotion. Once I had regained my composure,

I contacted work to find cover for me and my family and went straight to QEH. It all happened very quickly, and I had the transplant surgery done by Miss Laura Buist that night.

Thankfully the surgery was successful and when I awoke the following morning I could immediately feel the vast difference in myself. It was a difficult time on the ward as there is always the chance of rejection and there were some other patients who were not quite as lucky. I have to say that the surgeon and the rest of the team were remarkable in the dedication they showed after the surgery and the care and attention I received from the nursing staff.

After my transplant, my life completely changed. I was able to enjoy my family and social life again and we were able to go abroad as a family. I can't explain how much better I felt in myself and I had a new lease of life. Now 15 years later, I am still unbelievably lucky to say my donor kidney is still working well and apart from a few infections along the way, I am in still in good health. I have to say that this is almost entirely down to the dedication of the Renal Transplant team, my kidney donor and my wife. They have supported us over the years and have gone above and beyond the call of duty, and for this I am eternally grateful.

I had the unique opportunity to meet with the parents of my kidney donor which was a very special moment. I was overjoyed to meet them and it was difficult to put into words my gratitude, but they took solace in the fact their son had given me this gift. We have kept in touch and will be visiting them again soon.

I cannot thank the Medical and Nursing team of the renal unit at QEH enough for their exceptional service and my special



thanks to Dr Graham Lipkin for all the care & support given to me over the years.