

PERSONAL STATEMENT

Submitted in an individual capacity by Ken Tupling –
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Appraisal - Machine Perfusion Systems and Cold Storage of Donated Kidneys.

My family doctor retired from practice in April 1991, having treated me for High Blood Pressure for the previous 25 years. During the last 10 years of this time I had attended a General Consultant's clinic at [REDACTED] Hospital.

After my own family doctor retired, I changed GP practices to that attended by my wife and children. During my initial visit, I was asked if I had been informed that I may have problems with my kidney function or ever been referred for evaluation or had any treatment? My 'new' GP commented that from my records it was apparent that some or all of these things should have been followed through or at least it would have been prudent to have taken these actions "Some years earlier" – Words that were later to prove prophetic.

He immediately 'phoned the 'General' Consultant at [REDACTED] Hospital and made an appointment for the following week. Even at this appointment the Consultant procrastinated, mainly at the thought that a 'mere' GP had questioned his clinical judgement. "I know best" was his riposte. However, I had bloods taken and very significantly within 2 days of this latest visit to [REDACTED] Hospital. I received a 'phone call from my GP asking me to go immediately to his surgery, where I received the news that I had been referred to the Renal Unit in [REDACTED]. It was over a week later that I received the confirmation letter from [REDACTED] Hospital.

With some trepidation I paid my 1st visit to the Renal Outpatients at [REDACTED] Hospital, [REDACTED] on Friday 21 December 1991. The Consultant in Nephrology listened to what I had to say about my symptoms and asking me relevant questions where necessary.

Within about ½hour he was explaining that my kidneys weren't functioning normally and not to put too finer appoint on the matter, I was suffering from something called Polycystic Kidneys and I had reached a stage called End Stage Renal Failure. Of course I had no idea at the time what this was all about. I was on my own, my mind was completely in a haze and then he told me that I would be on Kidney Dialysis within 3 months. It was obviously apparent from my reaction that I hadn't a clue what to do next. As far as I was concerned the Atom Bomb had just been dropped! However the Consultant and staff dealt with the situation marvellously at the time but how I drove my car back to my office and then home, I will never know. What a Christmas present!

It was only on telling my elder brother that I found out that my mother, who died when I was 18 years old, my maternal grandmother and uncle had all died from kidney failure.

My wife and I celebrated our Silver Wedding anniversary in February 1992. The photographs of that occasion tell there own story. By March of that year I had reached the stage where it was decided to put me on to CAPD, which commenced on 26 March. My employer's were extremely supportive, allowing me to go home each lunchtime to do an 'exchange'. They never pressurised me to go back if I wasn't feeling too well after the lunchtime exchange. However we worked on a 'give and take' arrangement where I voluntarily stayed late some nights or went in on the occasional Saturday morning, but it was never suggested or expected by my employer.

My elder son was in [REDACTED] doing his final year at university, the other at Sixth Form College doing 'A' levels. My wife was a full time teacher.

Dialysis has a profound change on a person's lifestyle. I had very little hospital support, apart from being told to watch my diet and clinic visits. Most of the information we had to seek out. My mood changes and general attitude to the illness placed a great strain on our family life initially but I soon came to terms with my situation and from then on was determined not to let the illness rule my life or that of my family.

I spent 13 months on dialysis, doing 'exchanges' in various parts of this country, inside and outside our car and caravan. Eventually it became a way of life. Support from friends increased as they understood more about the illness, everyone relaxed a bit more in my presence and spoke about various aspects of it.

Friday 16 April 1993, a day that will live in my memory forever. I received a 'phone call at work to say that a kidney had been donated which could possibly be suitable for me. My wife was on ½ term holiday and visiting a very close friend, whose birthday it was but also suffering from terminal liver cancer. Should I ring her there knowing our friend's prognosis or wait until I knew she would be at home? Either way I had to get to the hospital PDQ. I took the bull by the horns and 'phoned our 'friend's house. She answered the 'phone and as if by intuition said "I know you're ringing to say they've found you a kidney, aren't you". Tears flowed - from me not her. She continued, " You have just completely made my day".

Following my successful transplant, I made the decision while still in hospital that I would commit my life working to improve every aspect of life for kidney patients. However, my wife and I first had to get over another bombshell, that our youngest son needed heart surgery, which he had in July 1992. My wife deserved the biggest medal possible during her own personal 'Annus Horribilis'

My start on my quest was by getting elected in September 1993 to my local Kidney Patients' Association committee, followed in March 1994 by election to the Executive committee of National Kidney Federation (NKF) where I served a term of just over 3 years. By this time I was self-employed so my time was limited drastically. However in 2002 I again became an NKF Exec. Member serving in various capacities, as Secretary and Co-Chairman. Finally severing my connexion in 2007.

During my time with NKF some of the most contentious and enduring issues, which may come in to, this appraisal's discussions centred on:

- 1 Public Awareness of the Organ Donor Register
- 2 How transplant donor rates might be Improved
- 3 Preservation of organs in its wider sense, those already transplanted and those retrieved awaiting transplantation.
- 4 Decision on how the Transplant allocation system worked.

Through the All Party Parliamentary Kidney Group booklets were produced such as the Transplant Manifesto and Dialysis Manifesto both of which helped to move forward the discussions on these aspects of treatment or lack of it.

As in most things in life, the general public only become aware of the importance of Organ Donation when they have been directly affected by it, a family member, himself or herself, a close friend or even an acquaintance.

THIS APPRAISAL

As a non-medic I am not able to make a judgement on the technical side under discussion but as a recipient, or thinking as someone waiting for a transplant, I can only hope that any lawful medical retention of organs in 'cold storage' will be of benefit for all transplant patients. I know there are other issues with other organs but we should be thinking of the bigger picture not just one organ type in isolation.

Some of the main factors that worry potential recipients are:-

- "Am I ever going to get a transplant"?
- "What state will it be in when it arrives"?
- "How long has it been retrieved from the donor"?
- "Will it be a good match"
- "How will I react know I have a dead person's kidney inside me"? (if this is the case)

Of course many of these questions are outside the recipients control. Can anything be worse than hopes and aspirations being built up after receiving 'THE 'PHONE CALL' only to have them shattered at the last minute because of critical criteria not being met. Every recipient understands the importance of the medical checks and criteria being met but psychologically it is a devastating blow.

If I have understood this appraisal correctly, I can only welcome any advancement in 'cold storage' of donated kidneys. Would it be possible, for example, to retrieve a kidney from a donor with a very rare blood group / tissue type or one that a match cannot be found immediately on the UKT list, to be kept in 'Deep cold storage' so that a future recipient may meet the donor organ characteristics?

The medical experts know more than I how important it is to keep the Ischemic time to a minimum but would a 'cold storage' of kidneys system allow more 'flexibility – if that is the right word?

Whatever method is chosen, a 'cold storage' system must be very closely monitored and assurances given to recipients and their families as to the particular organs suitability for transplantation. Any detrimental publicity could have a serious impact on the general public joining the ODR.

One final point, is there another agenda here? One which if long term 'Deep cold storage' is possible it could mean that larger Renal Units could be built and some of the small and not too small ones closed down?

Cynical? Moi?