

**NHSBT Board Meeting
July 2021**

**A Patient Perspective:
Living donor kidney transplantation - the art of the possible**

Living donation and, in particular, living donor kidney transplantation is one of the organ donation and transplantation success stories of this millennium. For patients with end stage kidney disease, living donor transplantation offers the best chance of a successful transplant. From a threefold increase in activity during the first 10 years of this century to the subsequent development of the UK Living Kidney Sharing Scheme and non-directed altruistic kidney donation, the opportunities for patients to receive a living donor kidney transplant have increased immeasurably.

Despite significant increases in deceased donation, 39% of all donors are living donors, of whom 98% donate a kidney, which accounts for almost a third of all kidney transplants in the UK. Today, within the letter of the law, a living donor can be a close family member, friend or a complete stranger.

As well as excellent recipient, donor and transplant outcomes, one of the benefits of living donor transplantation in comparison with deceased donor transplantation is the opportunity to plan a transplant and, where possible avoid the intrusion of dialysis treatment. The freedom to plan transplantation in advance has become more and more important to patients and their families, when so little about life with a chronic illness is predictable.

Paul's 'career' as a patient started in 1980 when he was 24 years old and first diagnosed with calcium deposits in his kidneys (nephrocalcinosis). By 1984, this, unusually paired with polycystic kidney disease, had progressed into chronic kidney disease. He was in his first job post-university, working at Marconi Radar as a Production Engineer and the prospect of needing dialysis or a transplant within the next 15 years was not part of his life plan.

Over time, 6-monthly monitoring confirmed deteriorating kidney function but mind and body were not aligned - it was difficult for Paul to reconcile the inevitability of end stage kidney disease whilst he continued to feel well and could do the things that he wanted to do. He adopted 'a circle of wagons' approach to protect himself and his young family from reality.

The realisation that something was really wrong came suddenly in October 1999. A keen sailor, Paul capsized his boat during a race and, whilst trying to

free himself, experienced his first feelings of being out of his depth - not in the water, but in what lay ahead.

By this time, I had already met Paul and his wife, Sally, in the advanced kidney care clinic to discuss treatment options. With two small boys (2 and 4 years) in the mix, Sally was committed to living donation and under-going donor assessment. Paul was struggling to come to terms with the idea but recognised that by supporting Sally to donate, he could offer his whole family the best chance of a future. Soon after the sailing incident, a clinic appointment and further blood tests confirmed that Paul's kidney function had deteriorated beyond repair and it was time to 'batten down the hatches'.

Narrowly avoiding dialysis treatment, four months later, in February 2000, Sally donated her kidney to Paul. Paul describes the mental challenges of getting to this point - very much his own person, his 'let's get things done' approach meant that he relied on those he trusted at home and within the clinical team - to support him with the minimum of fuss and the maximum of efficiency. Talking about things and expressing feelings were definitely not his style. He and Sally were very much a team and giving up was not an option.

All these years later, Paul can recall his in-patient experience in vivid detail, his innate sense of humour allowing him to reflect on his own situation, his fellow patients and his appreciation of morphine 'on demand' for the first time in his life.

The next few years did not go as smoothly as he hoped. The life of his transplanted kidney was cut short by BK virus- at the time, little known, hard to identify and difficult to treat. Although Paul kept his kidney at the time and the virus was brought under control, lasting damage meant that he found himself approaching the need for dialysis just 9 years later.

Coping but not thriving on dialysis and with few options for transplant other than a long wait ahead, Paul's mother-in-law, Margaret offered to donate. As Sally's mother, Margaret shared human leukocyte (HLA) antigens to which Paul had developed HLA antibodies from his first transplant. This meant that Margaret was not compatible with Paul.

Before the UK Living Kidney Sharing Scheme was introduced in 2007, Margaret would either have been discounted as a donor or antibody incompatible transplantation, involving more intervention and poorer outcomes for Paul, would have been the only option to pursue.

In 2009, the UK Living Kidney Sharing Scheme looked very different from today - matching runs only included incompatible donors and recipient pairs were predominantly matched in combinations of 2-way (paired) and rarely in 3-way (pooled) exchanges to facilitate blood group and HLA compatible transplants. Non-directed altruistic donor initiated 'chains' of transplants were only introduced later in the scheme.

However, for Paul and Margaret luck was on their side and, in January 2009, they were matched in a 2-way kidney exchange with another couple in the same situation. Both donors donated and, indirectly, each recipient received a kidney transplant. Despite the added complexity of the scheme, being 10 years older and needing more tests to assess his suitability for a transplant, Paul remembers this as a smoother process in comparison with his first transplant experience.

Transplantation is a treatment not a cure. Although it is still the best option available for a dialysis-free life, Paul describes it as 'a difficult life choice' and one that should not be under-estimated. There are consequences associated with having a suppressed immune system - coping with the side effects of the drugs, susceptibility to other health issues such as cancer and viral infections and constant visits to hospital.

You will have an opportunity to hear directly from Paul about what the last 21 years of life with a transplant have meant to him, his family and close friends. It has not all been plain sailing, but would he have done it differently?

A short video will be played during the Public Board Meeting.

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