

'Second Shot At Life' - 7 years on... by Dom

This year's Organ Donation Week, planned by NHS Blood & Transplant, flies under the campaign banner 'Leave Them Certain', to encourage people to talk to their loved ones about organ donation and their wishes and highlighting that loved ones are always involved before organ donation goes ahead.

21st July 2014 is a date etched in my mind when my 13 month wait on the transplant list, merely existing with badly deteriorated lungs came to a happy end, thanks to the kind-hearted gift of a stranger who had presumably 'had the talk' with her family of her organ donation wishes and crucially her family had stood by her wishes. My transplant took place that day, late morning, during a period of sweltering weather, typical of those days in summer that even those without CF struggle to get around in.

I'm the second in my family to go through transplant, my late brother also having a double lung transplant to replace his CF lungs back in the mid-nineties. I suppose I had the benefit of knowing, to an extent, what to expect, although you can never really know what it'll all entail, I feel, until it happens. However, with great clinical support from the CF team on ward 26 and counselling/guidance from my fantastic transplant team at the Q.E. and our own ward 26 clinical psychologist, I felt as well-prepared as possible and knew transplant was better than the unimaginable though becoming increasingly imaginable alternative, so long as the call came.

Thanks to a successful transplant, my life had changed from constant headaches and 'fuzzy head', severe tiredness and discomfort, of course severe breathlessness, managed by ambulatory oxygen and a struggle to maintain sufficient appetite or energy to eat, so my PEG feed and dietitians' nutritional support became crucial, the PEG feed my mainstay, night after night. The physiotherapy team on ward 26 are to be applauded for great commitment in finding ways to help clear my lungs - NIV and acapella, well-learnt autogenic drainage, and getting me exercising on that treadmill in the ward's gym with NIV and O2 right up to transplant point. The arsenal of IVs was reducing due to my allergies to some and no longer responding effectively to other IV antibiotics, even with the very best efforts and creative thinking of the committed CF consultants. Actually, on the day my transplant took place, I was supposed to be attending Heartlands for desensitising to one of the IV antibiotics to increase my choice antibiotics.

The transplant call was my seventh call, following six 'false alarms' when I was offered potential donor lungs when, on a couple of occasions, in hospital, too unwell for them to risk transplant. On one occasion we were eating chips on the seafront at Aberystwyth and heading home to the Midlands when a call came through. On another occasion I was painting at night when I got a call and had to put my paints, brushes and picture to one side to 'rush', bag packed and waiting by front door, to the transplant centre. Other calls did not result in a transplant due to issue with the donor lungs, even on a couple of occasions after they'd gone through the ex vivo lung perfusion process, which washes 'marginal' donor lungs and passes a solution of nutrients through them to improve their

condition for potential transplanting. This was an important opportunity for the transplant team to get a better assessment too of the donor lungs though.

Fast forward 7 years from transplant and I've been able to continue working part-time, get back to walking, cycling, some wildlife photography and painting (art, not DIY) in my spare time and 'do my bit' around the house and spend quality time with my wife. As the transplant team mentioned, the transplant is not a cure, but another 'treatment' and it still requires a lot of effort to keep on top of medications and hospital appointment, though not quite so many appointments and far less nebulising time in the mornings and evenings (i.e. just to nebulise Colymycin). It hasn't always been a smooth journey since transplant, but I'm mindful that I've been more fortunate than some (sadly) and strive to make the best use of time ahead.

I have strength back in my legs, built up over the years since transplant and more energy with far better lungs and with this 'gift', I knew during 5 weeks recovery on the surgical ward at QE that I wanted to put the new lungs and new-found energy to good use. I signed up for the 100 mile Birmingham Velo cycle sportive which took place in May 2019. I trained all winter from starting with 6 mile rides and managed the Velo in 9hr 24 mins. The last 20 miles were at times extremely uncomfortable and the hills around Northfield/Kings Norton were a 'killer' at 80 miles distance. It was thoughts of my sponsors, CF and transplant teams and other people with CF still facing the challenges of CF which made me dig deep on the steep hills. I cycled with the sole aim of fundraising for equipment for both the transplant centre and CF ward 26/Heartlands. I wrote a book in 2015 - admittedly not in any way a high-quality literary piece but an odd mix of CF musings and in coffee-table book style with wildlife and natural world images, subjects which had given me strength as my life looked to be expiring, before transplant materialised. It was both a cathartic exercise - I'm no writer - but also an enjoyable way to fundraise for the two hospital teams.

Apart from writing to my donor family, if there is such a family out there, I felt it hard to know how to really show my full appreciation for my good fortune and hence the fundraising as an enjoyable way of giving back to two great teams, at Heartlands ward 26 and QE Hospital Birmingham Heart & Lung Transplant Centre. I also had the opportunity to join QE Hospital's Organ Donor Awareness Week on a couple of occasions in recent years; a nice opportunity to meet some heart transplant recipients and learn about their experiences and importantly for us all to raise awareness to the wider public of the real value of signing up to the organ donation register or at least letting loved ones know their wishes, to give people, like us with CF, hope for extended, improve quality of life.

Key to fundraising for me has been to tie it in with a hobby, interest, or if well enough, exercise. It's given me a focus at times and helped me find a way to support the CF service and transplant service in return for their commitment and help over the years.