

Tales from Dialysis Nights (Six Thousand Five Hundred and Counting)

By Maddy Warren

As I write this I am sitting in the desert outside Dubai, about to start a busy day of fun, jumping out of aeroplanes and horse riding in the sand dunes. The only reason I am here now, pursuing life with a passion and living very happily and healthily is because of home dialysis.

20 years ago my life was turned upside down by an aggressive onset of FSGS. I spent 18 months in Guy's Hospital undergoing treatment including steroids and chemotherapy plus an array of horrible complications. At 14 years old I had my kidneys removed and immediately opted to dialyse myself at home on overnight APD. The transition from being incredibly unwell with an unpredictable condition, to managing my own treatment at home and regaining my energy, well-being and control over my life was transformational. I went back to school full time and to the sports and hobbies that I loved. I revelled in my newly rediscovered health and freedom – as such I considered my introduction to dialysis to be incredibly positive in contrast to what had gone before.

Within 2 months of starting PD I took my machine to Spain on my own as I wanted to prove that dialysis wouldn't hold me back. I had so many adventures on PD, taking my machine up mountains skiing and all over Europe dialysing in multiple different locations. I had an amusing experience being held up by armed police late at night at the Czech Republic border with a van full of apparently suspicious looking PD fluid. I waited to finish school before going for a transplant because I was determined to get the grades I needed to study Natural Sciences at Cambridge University.

In 2003 when I was 19 my amazing dad donated his kidney to me, but sadly the FSGS recurred within 12 hours so I went to Cambridge as a haemodialysis (HD) patient. Back then home HD wasn't available in the area so I did three nights a week at the hospital, crammed in around studying and a busy student social life. Ultimately I wasn't prepared to sacrifice three years of optimal health in order to stay at Cambridge, so I left university and moved back to London so I could switch to nocturnal home HD, 6-7 hours every night.

I cannot begin to describe how good nocturnal HD is – I have no restrictions and loads of energy and I am convinced I couldn't feel any better even with working kidneys. It has enabled me to be continually employed since leaving education, and for the past 7 years I pursued a very work-hard, play-hard career in investment banking. For a memorable few months in 2015 I was juggling working as an executive director in the day, playing a zombie in a theatre show in the evenings (since I'm very good with blood!) and skydiving all weekend.

Last year I set up my own business as an HR consultant and kidney patient advocate. Working for myself has given me the flexibility to focus more on supporting other kidney patients, championing the cause for patient empowerment and self-care. I find it difficult to believe how relatively few patients do nocturnal home HD in the

UK when it is so transformational. This is why I am a patient advocate for Quanta Dialysis Technologies, as I wholeheartedly support their mission to put patients first with an innovative machine which enables people to fit their dialysis around life and not the other way round. I am very excited to see the SC+ already being successfully used for pilot treatments in patient's homes and look forward to it officially launching soon.

I have been so lucky to have such an amazing experience of dialysis and I am incredibly grateful for the unique perspective, positive energy and deep appreciation for every single day that it has given me. My renal team at Guy's are also absolute legends and I wouldn't be here without them. I try to push myself to extreme challenges, hence my love for mountain hiking, riding racehorses and skydiving. I now have my solo and formation skydive licenses and over 300 jumps in several countries. Travelling on dialysis has become a whole

adventure in itself as I get a kick out of turning up to a new clinic and navigating an unfamiliar healthcare system where I don't speak the local language. I guess dialysis has removed the fear factor for me since nothing will ever be more challenging than finding out at a very young age that I will need a machine to survive for the rest of my life, especially since a transplant is not possible.

As I sit out here in the middle of nowhere, I feel about as far removed from hospitals and the identity of "dialysis patient" as I could possibly get. And as I celebrate my 18 year dialysis anniversary, I'm looking forward to many more years of fun ahead.



Maddy Warren

My top tips for dialysis survival:

Stay positive – keeping a positive and upbeat attitude towards dialysis helps hugely and I believe improves your physical health too. Find the silver linings! You are a dialysis super hero saving your own life every time you set up that machine.

Manage your own treatment as far as possible – taking control leads to empowerment, which in turn can build confidence and also save time. Take small steps to start with like doing your weight, blood pressure and programming the machine and you will quickly feel able to take on more. Don't let those around you tell you what you can and can't do, be confident about your own abilities.

Needling – the majority of patients who I speak to are very nervous about putting in their own needles, which they feel is a major obstacle to starting home dialysis. Rather than focusing on the act of needling, instead visualise the goals you want to achieve when you are able to dialyse independently at home. That could be anything from going back to work or studying, to being able to spend more time with family or take up new hobbies. Focus on the outcomes you want to get to rather than the process of getting there.

Get fit and stay fit – after every surgery or major ill health episode I made a massive effort to rebuild my physical fitness as quickly as I could even when it felt impossible, because it has a huge impact on my energy levels and ability to juggle dialysis, work and life, even on the off days.

Live for the moment - it is tempting to put your whole life on pause until the call comes with a kidney. I hear many people talking about "the wait" and the things they would like to do if they weren't on dialysis. But the reality is nobody knows how long that wait might be or even if a transplant will be successful (and for some like me, a transplant is not a possibility anyway). By living in limbo you are losing the precious time you have right now which you will never get back. Be creative and flexible about finding ways to live your life despite dialysis, and make the most of every moment.

