

Darren's story

Darren shares how diagnosis of Addison's disease was an incentive to make good life choices, sooner rather than later.

I was diagnosed with Addison's disease in 1994 (aged 20), after a short illness and then an Addisonian crisis. It was a very familiar story (in hindsight) of fatigue, nausea, losing weight, dizziness and breathlessness (from low blood pressure), and then (probably precipitated by a viral illness) extremes of the above with vomiting and dehydration.

I was pretty crook on admission to hospital but bounced back pretty quick, and regained my appetite (and a new, temporary craving for salt!) with a vengeance. Since that time I have been well maintained on replacement therapy from a medical perspective, and have not been anywhere near inpatient treatment for it.

The other part of this story however, as is often the case, is the fine-tuning of my Addison's management and the rest of my life so that my health and well-being is optimised.

It took probably a few years to get my replacement steroid doses right, or at least be confident that they were optimised, and I'm pretty happy with them now (Hydrocortisone 15mg morning, 5mg at 2pm; Fludrocortisone 0.1mg twice a day). The hydrocortisone took longer to get right than the fludrocortisone – my dose for the latter has been the same I think since the year I was diagnosed. What was difficult along that time was that my daily environment kept changing, so that it was hard to know whether or not my hydrocortisone replacement regime was at fault, or my work environment. So the lesson I've learned here is that if it is at all possible, it helps to keep as much else constant while changing medication doses (or vice versa), or else it is very hard to figure out what is going on! This is not always feasible, but the ongoing principle is that I try not to change too much at once if I can avoid it.

I have come to really value the partnerships that I have formed with my Doctors (who have changed) in looking after my Addison's. A good example of this "teamwork" is when we were working out steroid protocols for times of illness that work best for me. It was important for me to have their input as to what were the absolute essential rules that I have to follow, and how to be safe medically (eg. don't underdo it when sick), and adding into that (after some personal experience) I could provide my personal input as to what works best for me regarding the finer points of timing / dosage / type of steroid etc.

So these different roles are both important. My doctors help safeguard my immediate and long-term health so that I don't come to any harm, and I can

let them know what affects my day-to-day quality of life so that I can achieve the most positive outcomes.

It is hard to know how much my Addison's has influenced my work and life choices.

I have had many different changes of work and living environments (which is not an unusual part of my career path) and it is difficult to pinpoint one thing or another that made some days, months or years harder or easier than others. So many things are thrown into the mix, including the kind of work I was doing, my personality, what was happening in my personal life, people I was working with, the city I was in, hours of work etc.

I struggled a few times, and an obvious part of that was the long and erratic hours and fluctuating stress levels - this is particularly bad I think when one is trying to get by on an "artificial" steroid regimen. But also part of it was quite possibly that the type of work just wasn't for me - ie. it didn't suit my needs or personality - and therefore wasn't as enjoyable.

So when people ask me how does Addison's affect my life or work, I can honestly say, "well I'm not really sure, but it certainly is one of many factors in the whole mix". But of course, other people may have obvious and specific things happening in their lives that can clearly be attributed to their Addison's disease. My personal experience is that my quality of life is made up of a number of interrelating factors, so that the sum of it all is probably unique and hard to compare to anyone else's.

Having said that, I'll finish with two points that are probably shared by many other people (with or without Addison's).

Firstly I have found that a workplace environment where you have a certain amount of control over your daily activities, or one that is more pro-active and planned (rather than reactive) is often more enjoyable and manageable, and less stressful.

Secondly, sometimes diagnoses of medical conditions (as with other significant events) are a mixed blessing. They often come with many difficulties, but they can also provide an incentive to make the best choices for oneself sooner rather than later. I am glad that I have thought hard about what I have wanted to do with my life since 1994, and didn't just get swept away with the current and regretted it years down the track.