

## LYN'S STORY

Not sure how long I actually had Addison's before diagnosis but could conceivably have been quite some time. I spent the whole of 1994 unwell. Felt exhausted all the time and had chest infection after chest infection during the winter of '94. Many visits to the doctor complaining of fatigue during the year when I was told I was overdoing it, needed a good holiday all of which was probably true.

Despite the exhaustion pushed myself off to work each morning and tried to get some exercise in but in hindsight the exercise became less and less as the year progressed. Even a walk to the shops had me labouring up the hills to get home again – where had the gym queen and cyclist disappeared to?? Had my morning routine down to a fine art so I could stay in bed until the last possible moment and in 20 minutes could shower, dress, breakfast and get out the door.

The beginning of December really tested all my remaining reserves. We had flown to Melbourne to partake of a nine-day bike ride from Swan Hill to Melbourne – some 700km. This despite the fact I couldn't even manage a long walk, somehow I thought everything would come right once I was on the bike.

Right from Day One the temperatures soared from the low- thirties to the mid- forties day after day, and with us camping out there was no respite from the heat In air-conditioned hotel rooms. I woke in the tent each morning at 5.30am and wondered how I could drag myself out of the sleeping bag, let alone how I might bike up to 100km to our next campsite. And of course as each day in the searing sun passed my tan got darker and darker and darker until I resembled an aborigine. Despite what was by now total exhaustion I managed to bike most of each day. I would set off biking each morning and when unable to continue grab a ride in a support vehicle. There was only one day I didn't ride at all and most days I rode the full distance. Amazing what a good strong dose of determination can achieve.



The medical people who supported the ride checked me out but could find nothing specific wrong except for a very slow heartbeat, so I was instructed to drink 2 litres of electrolyte drink and back out into the heat. Biking into Melbourne on the final day saw me collapse on the hotel bed craving for Chicken Noodle soup (my salt fix).

My grandfather was always very determined and stubborn, and I think I have inherited double doses of these traits which make me push myself along despite the adversities. I like getting the job done and done well.

Back home and it was now even more difficult to drag myself off to work, so back to the doctor complaining once more of exhaustion. The week before Christmas I was back in the surgery, the blood tests had shown I had hypothyroidism and I was put on 100 micrograms thyroxine. However the first working day after Christmas had me phoning the surgery as I was now significantly sicker. The doctor "minding" the practice between Christmas and New Year checked my file and advised me over the phone to immediately increase my thyroxine dosage to 200 mcg. This from a doctor I had never met. A few days later I met my Waterloo.

The only day I suffered from nausea was the day I was admitted to hospital. The day unfolded with my husband heading out early to golf with me still in bed. When he returned at midday I was still in bed, feeling sick and dizzy. He called the doctor and my Mum. Before either arrived I had drifted into a coma and was delivered to Middlemore Hospital by ambulance. I remained in the coma until 8.00pm when a "drug cocktail" was administered in an effort to bring me round. A brain scan was done immediately I came round but it showed no problems

The morning after admission I was back to my best after the shots of hydrocortisone they had given me which brought me round. Rushing around helping deliver the breakfast, making the beds – you name it. And feeling better than I had in months, I could see how skinny I looked as I wolfed down all the food the kitchen could provide. Put nice little messages on my daily meal sheet to get extra portions of jelly and ice cream.

Over the next few days so many blood tests were requested that I was the first bed visited in the ward each morning, and the little instruction book was pulled out for some of the weird and wonderful tests requested. Six days after admission a test showed problems with the adrenal gland that was confirmed with an ACTH test where the pre-test cortisol output was 20 rather than 270, and which was raised to 21 rather than around 540 after an injection of ACTH (Synacthen)..

Once diagnosed the Auckland Hospital Endocrinology Department were consulted for medication and I was released one week after admission and went straight back to work.

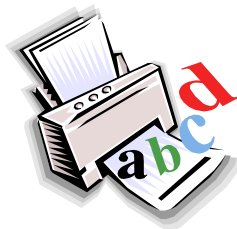
Took a few months to get my medication correct and have tweaked it slightly since. I currently take 20mg hydrocortisone, 200mcg fludrocortisone, 100mcgs thyroxine early morning with an additional 10mg hydrocortisone early afternoon. When biking long distances I up my hydrocortisone and fludrocortisone dosage subtly. An additional 5mg hydrocortisone per 50km travelled after the first 50km and on a very hot day when we have a long and difficult ride planned I add an additional 100mcg fludrocortisone before leaving home to counter mineral depletion from sweating. These changes in medication are always made after consulting with my endocrinologist

I listen very carefully to my body and find that when I am biking and need more hydrocortisone the muscles of my thighs and upper arms ache as though they are

badly bruised. The aching disappears within half an hour of taking an additional dose. Paying close attention to how I am feeling gives me confidence in knowing when things are going wrong and finding out why.

I refuse to feel sorry for myself having this condition. I get the most possible into every day. I never have problems sleeping always falling asleep the minute my head hits the pillow. I was forty when diagnosed and have probably achieved more since diagnosis than before. It's like I have been given a second chance and I don't intend to waste it. I do start my day early and rarely stay up late on working days except for special occasions. I don't bother much with alcohol, don't smoke and try to eat good healthy food – I am a salad nut!! Drink a couple of litres of water a day but must admit I don't drink as much as you might think biking, rarely getting through two 500ml bottles in 100km unless of course it's hot or really hilly.

I work in the IT industry, which can be stressful, and have most recently worked as part of team on a very large computer system implementation spanning some four years. I do find my memory is not as good as prior to getting sick, and I make lists to ensure I have a finger on the pulse.



And working in the normal air-conditioned office environment I get my fair share of coughs, colds and tummy bugs. I have never needed to take additional medication for the coughs or colds but always pay close attention when I get an upset tummy and medicate according to how I feel. I have had one crisis that saw me admitted to Middlemore with severe abdominal pain for an overnight stay with a Cortisol injection prior to admission. An Ultrasound suggested the problem was an ovarian cyst and I have had no problems since.

I have had one bike crash which saw me picked up off the road by ambulance and taken to local A&E but managed on an additional 10mg dose of hydrocortisone rather than an injection. (I do carry an injection kit and two doses of Solu-Cortef with me on the bike at all times in case of accident or crisis miles from nowhere and my husband is dying for "the opportunity" to put that needle in my backside.)

I have travelled overseas extensively since being diagnosed, carrying all my drugs and injections without difficulty. I always carry a letter from Auckland Hospital with my injection kit and wear a medic alert bracelet at all times.

Prior to getting sick I couldn't say NO, I was superwoman getting up 5.00am to get a gym session in before working long hours at a full time job. After work I hurtled home and into interior design or paint finishing (like rag rolling, stencilling, marbling) jobs I had on the go. I hardly got a minute to myself from 5.00am through to 10.00pm then flopped into bed ready to do it again the next day. I tried to be everything for everyone and simply forgot to look after myself.

Things have changed since being diagnosed. I now put more time aside for me and mine, have stepped back from the interior design and paint finishing but still work full time. Biking is my recreation of choice though hiking and adventure travel rank right up there as well. We have plans to bike across America, mountain bike from Lhasa to Kathmandu, walk across France, so still heaps to achieve.

I am lucky to share my love of the outdoors, biking, hiking and adventure travel with my husband Clive and we do most things together. We decided 25 years ago that children might not fit our busy lifestyles but are kept busy with godchildren, nieces and nephews.

I am not sure I can tell you why I manage to fit a lot in but it's probably a combination of factors. I keep fit with my biking and hiking and am lucky that I enjoy pushing myself a bit physically. I have a very positive frame of mind – always whether at work or at home. I am willing to try new things although must admit in this area I have a little less confidence than pre-Addison's.

I also think the earlier comment that I have been given a second chance is certainly key to how I feel about life in general. I am not going to miss out on anything I have in my long list of To Do's and my grandfather's determination and stubborn genes keep me pushing on even if I am having a less energetic day than normal. I can say that when I have a morning bike ride that really sets me up for a good day.

