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Dyan's story:

Dyan is 24. She works in the fruit and vegetable section of a Timaru supermarket, 7am to 4pm, and every second Sunday too. She walks an hour to and from work each day – and is intending to join a hockey team again next season. Self-reliant and independent, she lives alone – or rather with a big black Labrador, with whom she plays daily “tennis” after work in the park across the road.

Dyan is almost as rare as hen's teeth, because she was born without adrenals - a CT scan when she was 12 years old confirmed their absence. Quoting her specialist's letter: “Dyan's presentation in early infancy with classic features of adrenal insufficiency, yet no obvious enzyme defect, has led us to label this disorder as congenital adrenal hypoplasia”.

This is the history Dyan shared in the letter she sent when joining NZAN recently: “It all started when I was 5 months old. It was not long after I stopped being breast-fed that I developed an ear infection. Treatment with antibiotics had little to no effect, and I continued to go ‘downhill’. Lethargy and vomiting led to convulsions and unconsciousness. I was rushed to Timaru Hospital, where, according to my Plunket book, I had more convulsions, a couple of cardiac arrests, nearly dying on more than one occasion. I was fed IV through my ankle for two weeks.

At the time, my parents and I were living 5-10 minutes south of Timaru. After my stay in Timaru Hospital, I was sent home. One or two weeks later I had another cardiac arrest, and was transferred through to Christchurch Hospital. Many tests followed.

The diagnosis finally arrived: “non functioning adrenals”. Initial treatment was liquid hydrocortisone, 5mls 3 times daily, and fludrocortisone tablets 0.1mg twice daily. The hydrocortisone worked fine, as long as it was fresh. After a while the medicine would go “off”, and result in another rush trip to hospital for an injection.

As you can imagine, first off, my mother panicked a fair bit. She still does when I get sick – not that she'd admit it! There was worry when my brother was born (18 months after me), so he was tested at birth, and cleared. And the worry over me was settled slightly when I was changed to hydrocortisone tablets. Teething caused problems, but increasing the dose seemed to control it.

Over the years the amount of pills has increased with age and weight. When I was 12, I was put on another pill as well for 6-12 months, to cover the lack of another adrenal hormone produced during puberty. A bone mineral density scan when I was 18 was fine.

Puberty also brought migraines, which seem to be related to lack of sleep and too much stress. Sandomigran tablets seem to control them. Asthma has also been another player in the game, hitting when I was 7 or 8 years old. Touch wood, it's nearly gone!

I last saw my endocrinologist in April of this year, and was extremely surprised to be told of the existence of NZAN. Any information I had ever found on the adrenal glands was either the wrong sort or thirty years out of date. The information pack sent is currently doing the rounds in my family. It has helped to explain a lot on a variety of topics.

People ask me what it's like to always be swallowing pills. I tell them I've never known any different. Now I'm glad to have information to back up why. “

In a phone conversation, Dyan rounded out her story. It had been a typical day. Pills at 4.45am, then out the door at 6am. She had walked to and from work, and then played with her dog in the park. “I can't stand not walking for at least an hour a day!”

She takes 15mg hydrocortisone (10 in the morning and 5 in the evening) and 0.15mg Florinef daily. She's 5ft tall, but a bit overweight for her frame. “Increased appetite and weight gain is a side effect of the migraine pills I have to take.” She remembers being sent to a dietician when she was just six. “My brother always told me I was overweight. I put it on at puberty too.”

“If I get very tired I might take an extra 5mg, or some paracetamol. But that doesn't happen often, only about once a month.” She doesn't get sick more than other people – and if she does, she follows the doctor's instructions to increase her hydrocortisone dose until she is on the mend. The flu injection for the past couple of years has kept the flu away.

During childhood she wasn't as active as her younger brother. “I wasn't given the encouragement to go out and do things.” I slowed down at intermediate school, and did what I could to get out of sport. But at high school she got more active, helped by the fact that she had to walk to and from school. “I'd previously been told that I wouldn't be able to manage sport. I tried hockey, and found that I enjoyed it. I enjoy the physical work at the supermarket too, but it is a bit tough on my knees and hips.” She certainly doesn't view herself as restricted.

Dyan laughs as she explains that she has always been interested in biology. It was compulsory until 5th form. “Then in the sixth form I chose it as a subject – but the adrenal glands got just three lines on a page. I said, is that it! Is that all you are going to give me!”

Stress management? Not really, she says. “I avoid people that annoy me. I recognise my own short temper.”

Dyan remembers an asthma attack, and a hernia, when she was a child. But for at least the past 10 years, migraines have been her only ‘emergencies’, 2-3 times a year. The letter she carries documents the cocktail to give for her migraines, and also IM or IV hydrocortisone. She also wears a Medic Alert bracelet. Because her father and grandmother also get migraines, she is able to be clear on the symptoms – “fuzzy eyes, and I can’t see, like looking through water... My head splits, my temples throb, and pins and needles move around my body.”

On her days off, Dyan goes into town, and walks the dog. She couldn’t say ‘walk’ on the phone, but had to spell it, as the dog was nearby, and would be straight to the door with tail wagging, she said. She used to be member of the drama league, but had to give it up because of her working hours.

So is she a ‘party animal’? “I’d like to be”, she says with a laugh, “but working every second Sunday with a 7am start would cramp my style”. She chooses not to drink alcohol. “My girlfriend and I were saying just the other day that we haven’t been out for ages. At 24, we must be getting old!”