

Mary's Story

(1) Overview:

A dairy farmer and horse breeder, Mary lives in Hari Hari, South Westland, population including all children, 300. The nearest hospital is in Greymouth, 1.5 hours away. The nearest town is Hokitika, an hour away in the same direction. When Mary [originally from Christchurch] and her Coaster husband went to Harihari in 1976, the population was twice as large as it is now. A forestry settlement, a Ministry of Works settlement, and three timber mills are all now closed.

It's a lovely part of the world, Mary says. But it wasn't the easiest place to get a diagnosis of Addison's disease. She remembers the date she finally started hydrocortisone 13 March 2002, when she was 52. She'd been admitted to hospital on 4 occasions over the previous 10 years, severely dehydrated, with vomiting and diarrhoea and with the classic Addison's symptoms of pronounced tanning and salt craving. IV fluids had perked her up somewhat, and she'd be discharged. Then, at last, a diagnosis. She says she is very grateful that the new clinical physician from Iraq (who has since moved to Australia) was such a thorough and well educated doctor.

At the time of her diagnosis, there was a resident GP in South Westland, but that isn't the case now. A GP contracted by the base hospital is flown over for a week per month, and spends one of those days in Harihari, the others between there and Haast. "We do have a good district nursing system and I think all I have to watch is getting scripts filled often enough - health willing. The base hospital in Greymouth has improved markedly over the past few years. Also, the endocrine clinic in Christchurch has been very good and both of these places have offered me support at any time which is good."

Mary had hoped to attend the NZAN meeting in Christchurch in July 04. But early calving and issues with builders of their new house prevented that at the last minute. So her first meeting with other Addisonians was the Nelson meeting in February 2005, a 5.5 hour drive each way. She is keen to attend other meetings.

(2) Diagnosis at last

I was diagnosed at Greymouth Hospital, after being kept at home by my local Doctor for about 10 days only able to drink water and having intermittent vomiting and diarrhoea. I couldn't stand or walk much at all and was mostly sitting like a zombie or lying in bed. Someone came to the door once and I managed to open

it and then spoke to him from a kneeling position. My blood pressure was very low.

Our District Nurse phoned the doctor a few times and recommended a hospital visit but the doctor said he didn't think it was necessary and I should take more fluids - what an effort that was. My husband was very concerned but I was really away with the pixies a good deal of the time. I lost 5kg over that period.

I'd had many episodes that had started similarly in the past, but they usually resolved after just a few days.

Eventually we decided that I was getting a bit terminal and insisted on hospital. The nurse came and set up a drip. When the ambulance came I was bundled into it and taken the hour and a half to hospital. The nurse followed the ambulance for the first hour and the ambulance stopped a few times for the nurse to check me.

I was on a drip in hospital for five days and the recovery to normal was much slower than it had been on my four previous hospital admissions. The good thing was that the hospital physician was very thorough, quite stern with the staff and he had a fair idea what was wrong. He didn't think I was an alcoholic - this had been written on my notes on one of my previous admissions!. [My husband later arranged for it to be removed from the records.] I was discharged as soon as I came off the drip, but without being told what might be wrong, even though copious testing had been done and samples of everything had been sent to Christchurch and Wellington.

I was told at my 6 week follow-up with the hospital physician that he wanted me on tablets straight away. I was still nauseous, and had great difficulty swallowing them, and they hurtled back straight away. So I went back to hospital and was given IV hydrocortisone, then took a tablet the next day and felt stronger almost immediately.

I waited a week until I felt stronger, before talking seriously with my own doctor about his preventing me from going to hospital earlier when the nurse thought it would be a good idea, and we reached an understanding.

(3) The decades before diagnosis

I was prone to bilious attacks all my life - either during times of stress or more often just after the pressure came off. I always liked savoury things and not sweets - Mum used to hide the Snax packets or I would eat them all. Most of my life also, I have eaten a great deal of seafood.

I had pneumonia twice (when I was 11 and 23), and broke my ribs twice (during the 90s). I always took longer than the rest of the family to recover even from a cold.

About a dozen years before Addison's diagnosis, my then GP had sent me off to see various specialists and the best they could come up with then was that I was prone to migraines, and was having silent ones. I would wake up in the night vomiting, often with no other symptoms of migraine. [I did also have many migraines with headaches and wavy lines in my vision.] The general consensus was to make sure that I kept well hydrated and if I felt dull or seedy to take Aspro Clear before anything developed. I was careful not to overdo anything and get plenty of sleep - and I could sleep the clock round without trying.

For years I just toughed it out. I remember when my youngest were still going to school in the late 80's and early 90's, I didn't always get up and get them off to school - just yelled until someone got up and when they left I staggered out and drank a pot of tea before heading for the cowshed to do only essential duties. I felt really bad about it at the time, but it really was the only way I could get the basics done, and it gave me an extra hour in bed, one of my favourite places then.

I went to Rarotonga in 1994, as our youngest son is a Cook Islander. I was there for a week on the way to the UK, and ended up in hospital for three days with supposed food poisoning - but I know better now, I am sure it was an Addison's collapse. After several bags of saline I was able to stagger onto the plane and sleep until Los Angeles. I had salty crackers and water for the flight and arrived in the UK feeling pretty good although my sister thought I looked terrible. I had several light headed times in the UK but just used to stop somewhere and have soup - nice and salty and easy to get down. I had been hospitalised in NZ about 3 months before this trip - one of the four occasions in the 1990s when I was just rehydrated, checked for bugs (which were never found) and sent home.

I know I had been very brown for the whole of the 1990s. Looking back at the notes for my hospital admissions, the endocrine clinic in Christchurch said that I should have been picked up on my earliest admission over 10 years ago. I'd been admitted very dehydrated after a bout of vomiting and almost but not quite unconscious. Doctors commented then on my good suntan but never told me what my blood chemistry was doing. It's clear in hindsight that they should have tested me for Addison's.

My Grandmother, an Englishwoman, had very brown, wrinkled skin in her later life and I thought I was just being like her. Maybe I was, as she had an overactive thyroid in her early 50's and maybe had Addison's too as she wasn't very active for her last 30-odd years, and was very thin. My family has a pattern of glandular weakness that I wasn't really aware of until my own diagnosis - pernicious anaemia, diabetes, Reynaud's syndrome, thyroid problems, six family members each with one of these disorders.

(4) Mary's Reflections on her life before and after diagnosis

I can do anything I want today and most days. I don't have to think of having a fall back position, for example if I am driving to town (1 hour away), I don't have to engineer company in case I feel too tired to drive home.

I can do a good day's work, longer in the spring, 10-11 hours. Some evenings I am quite tired, but now there is a good reason.

I only need a normal amount of sleep and not bed at 8pm and up at 8am. I can stay up until after 10pm and still get up at 6.30am.

I can cook an evening meal without several stops and a short horizontal rest. I have taken up swimming every day in the summer using the local school's very cold pool – I hadn't been swimming since I was a teenager. I have bought and use a 10-speed cycle and really enjoy that, plus I walk a great deal again.

I have pink gums and lips, hair on my arms, a reduced tan on my arms. legs and face. and a white body where the sun doesn't shine - it was beige with dark smudges on the wrinkles and folded bits.

I don't have aching and stiff legs for days after digging the garden - I can dig the garden in one hit instead of over several days.

I don't have blinding headaches, dry retching on cleaning teeth, a hacking and very repetitive cough often leading on to the odd vomit. I don't feel like I have continuous morning sickness. I can eat anything I want at pretty much normal speed - for as long as I can remember I had been notable for still eating when everyone else has well finished.

I do have a good appetite and don't feel the need to have lots of soups, crisps, savoury and salty foods. If I felt not right I would often eat a whole tin of asparagus and even drink some of the salty juice it was in. I do take a bit of extra salt when I feel the need, but nowhere near like I used to.

I used to think my husband's breathing was really fast - now mine is the same speed.

I don't have cramps every day and don't have regular bouts of hiccups. I don't have continuous hay fever.

I used to take forever to shake off colds and flu. Now I don't get them.

I coped really well with the spring calving (by myself most of the time) about six months after being diagnosed. My husband was diagnosed with active,

aggressive prostate cancer and had the operation just before our busiest time. We were both lucky in 2002 as I couldn't have coped without my Addison's pills and my husband would most likely have died if he hadn't had that blood test as he had no symptoms and we are told he would have been too advanced for treatment by the time he did.

Any drawbacks?

I have put on a bit much weight, although I have managed to lose a bit over the last few months. [I was on 30mg hydrocortisone for the first year]. I am still 66kgs and would rather be 60 Kg. But before diagnosis I was only 56kg on a good day. [I'm 5ft 2 and half tall.]

I have to take a few pills, and be aware if my health is not up to scratch.

I had only one child (our youngest two are adopted). My pregnancy was five months of all day morning sickness and migraines from the time of conception. Then it settled to just a bit of nausea, and after a normal labour our healthy son was born. We have never used birth control and I had fallen pregnant on my honeymoon in 1970. Maybe I had Addison's coming on for years, and it affected my fertility before it became an obvious nuisance.

(5) Mary's update, December 05:

We have had such a busy year, and I haven't done half the things I wanted to. My Mum was diagnosed with lung cancer in March, and I had nearly a month in Christchurch mostly at the hospital visiting her and just generally being there as were my four sisters. In a perverse way we had a lot of very good times with Mum then, but although the hospital thought they could ease her symptoms and give her several months at home, she took quite a sudden turn for the worse and died.

It was pretty shattering for all of us and I upped my pills for a few days to good effect. Our father died in 1967 so Mum had been the everlasting one there for everything and everyone. Now I am the oldest woman in the family, an honour not sought.

We have recently sold off our run-off block at Whataroa and that has eased the pressure here a bit and allowed Lindsay to go hunting more. I am accumulating time off for an overseas trip with my youngest sister - hopefully Autumn/Winter. We have booked tickets to Rome for a rail trip of Italy and France and then on to England - six weeks in all and we will do a cruise if possible in the Adriatic. This is travel on a shoestring and I am really looking forward to it.

I have managed a trip to Tokoroa to visit our youngest grandson just before he turned one. It was the first time since being diagnosed and, of course, no problems. In fact it was better as I used to be forced to stop driving from time to

time being too tired and needing vast quantities of soup, water and peanuts or similar to nibble on.

Sometimes it still feels quite strange that I am now nearly normal! I have had a couple of times when the world has gone wonky this year, but fortunately with Lindsay telling me to swallow more pills or he would get the doctor in, that has sorted things.

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No problem explaining my email address!

Chaos is my husband Lindsay's nickname from a long time ago - the late 1970's really. The friend who gave it to him was killed in a helicopter crash in 1980, so the nickname has lasted in his memory. We also have a car and a ute with plates Chaos 1 & 2.