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Ngari's Story: Addison's disease

Ngari was 65 when she was finally diagnosed with Addison's disease. She is now 73.

For several years she has been invited by Dr Patrick Manning [consultant endocrinologist at Dunedin Hospital] to speak of her symptoms prior to diagnosis to fourth year medical students in Otago – every term for an hour, to four groups of three to four students each time.

This is the story she tells:

I was diagnosed October 1996 at A&E, Dunedin Hospital. But at the end of 1989 my twin sister had died. I was grief stricken to the extent of feeling physically sick. I didn't really recover, this sickness kept recurring, and I just seemed unable to come to grips with it all, although I have faced other crises in my life and got through. But looking back, I feel my illness 'kicked in' (I don't name it at this point in the talk). I visited my GP (rather, two GPs) during this time, explaining the nausea, some vomiting and diarrhoea, feeling very lethargic etc, nasty cramps during the night (I placed magazines beside the bed – the coldness gave relief!).

My increasing desire for salt was so intense that I frequently filled my hand with it and licked it all – feeling guilty for some reason! This made me very thirsty, so I drank lots of water which seemed to go straight through me. It was embarrassing to be invited out for a meal, because I ate so little. My weight was dropping quite dramatically, my blood pressure varied but was lowish. Gradually my skin colour darkened, less so my trunk. All this time I had numerous tests/scans/X-rays etc. The 2-3 years before diagnosis were particularly difficult. The last holiday we were camping. I lived on 3-minute noodles. I don't want to see them again!

A daughter who lived out of town, visited one day, and was horrified at my extreme weakness. That night I couldn't sleep, so I got up with difficulty to make some hot milk, but couldn't lift the jug to pour the milk in. I didn't want to wake my husband, so I just crawled back to bed. Next morning I rang the GP as my daughter had insisted, and she first suggested I come on in. I explained that I wasn't able to. So she called in at 5.30pm, got a blood pressure of 90/40, became very concerned and called an ambulance.

On admittance at A&E I was examined by a young New Zealand-trained doctor, whose name I have never forgotten, who listened to my story, turned my hands over noting black lines on palm creases, and said "You've got [I pause for the

students to give the right answer at this point – some do!] - but it has to be confirmed”.

As soon as they had taken the bloods for a synacthen test, first steps were to rehydrate me, followed by hydrocortisone, and I was sent to Chest X-ray. What a gratifying diagnosis to make. I felt completely better next day, before the blood test results even came back.

I can feel quite angry now, that it took so long for diagnosis, and my quality of life suffered all those years. Also, because the dark pigmentation of my skin was so gradual, my husband did not notice, but he was supportive of my unwellness.

That is the story I give. My second GP told me more than once that she knew nothing about Addison's. Hopefully the students I talk to will file it away in their memories. I appreciate 'life' now – even though I have the odd 'wiped out' days.



There is another twist to Ngari's story, which she sometimes adds.

Her twin sister had some autoimmune conditions - thyrotoxicosis, vitiligo and pernicious anaemia. Ovarian cancer was unfortunately diagnosed late, and that had been the cause of her death.

Eighteen months before Ngari's diagnosis with Addison's, her gynaecologist found an abnormality that raised alarm bells of cancer, and merited a hysterectomy. Fortunately, the problem turned out not to be serious, just a polyp.

After the operation, staff were concerned because her blood pressure was down a bit – but that had happened before, including after the births of her children, so Ngari wasn't worried, and said it wasn't unusual, it would come right. The staff also commented on her tan. She asked her husband to bring in the salt shaker, because she wasn't given enough salt with the hospital food. But the diagnosis of Addison's, "putting two and two together" had to wait a further 18 months.

Ngari doesn't have other diagnosed autoimmune conditions herself, but believes her grandmother had Addison's – "She had vitiligo and low blood pressure, and was given regular injections of what I believe was liver extract. She became very thin and loved salt and pickles and vinegar...!"

Ngari takes 15mg hydrocortisone in the morning, 5mg in the afternoon, and 0.1mg fludrocortisone. Earlier this year, she and her husband moved to Oamaru. She will continue with the talks – it's only an hour and a half's drive, and she enjoys catching up with friends too, she says.