

## From NZAN Newsletter No 10 July00

### Gary's story:

My name is Gary. I am 66 years of age, and have been diagnosed with Addison's for about 36 years.

Probably 4-5 years earlier, I developed the typical unwell symptoms – upset stomach, nausea, loss of appetite and general tiredness. I had always played a lot of sport, and gradually gave it all up as I got worse. For example, I played in a regular four at golf, and it became a standing joke that it didn't matter if I was ahead after 12 or 14 holes, because the opponents would pick up the last ones as I wilted!

I saw one GP as soon as I was aware of the symptoms, and then two others. They failed to pinpoint my health problems, and a full examination by a specialist (who wasn't an endocrinologist) resulted in a diagnosis of functional dyspepsia, or "nervous tummy". I was put on Stelazine, a tranquilliser, with anti-nausea properties, and this helped a little. I kept taking it right up until I was diagnosed with Addison's.

In the last year before diagnosis, I got progressively worse. I am a pharmacist, and had great difficulty lasting the whole day on my feet, often working from a chair. I was sleeping 12 hours a day, lost a lot of weight, my blood pressure was low, and people commented on my tan. My memory was jogged when I saw part of "Dr Findlay's Casebook" on TV – the patient was tanned. I recalled something from a textbook, and that set me thinking. My GP laughed – he had seen the programme too. He sent me for tests, and told me everything was clear. One year later, I demanded to see an endocrinologist, he admitted me to hospital immediately, and the diagnosis was made.

I was born and bred in Westport. I had regular X-rays there, because TB was quite prevalent, but mine were reported normal. I came to Wellington when I was 22. When I was 27, an X-ray at a mobile clinic showed scarring of my lungs caused by TB - I don't know how I got it. The endocrinologist attributed my Addison's to TB. There's no evidence that I have any autoimmune problems.

I was put on cortisone acetate, 37.5mg in the morning, 12.5mg in the afternoon (perhaps higher than average because of my lifestyle), and fludrocortisone 0.1mg daily. I took those dosages for about 30 years. About 4 years ago I was switched from the cortisone acetate to prednisone 7.5mg daily (5mg in the morning, 2.5mg in the afternoon), because of its longer duration of action, plus the 0.1mg fludrocortisone. I am 5ft 9 inches, and 80 kilos. My health generally has been very good, with the occasional episode where Solu-cortef was needed – usually after vomiting and diarrhoea in South-East Asia, etc (but I did not inject myself!). I always carry a vial of Solu-cortef when I travel, together with spare

prednisone. I had a bone density test done about 5 years ago – everything great.

Heat has been a problem, especially playing tennis in Australia, with temperatures up to 45°C. All the loading with carbohydrates, electrolytes, fluids and extra fludrocortisone has little effect. After a few hours I get dizzy, and I have been carried off the court. I don't get tired generally, but after a weekend of tennis, it takes me about 3 days to "recover". I don't take extra prednisone, but did take a little extra cortisone acetate during a competition. I don't take sleeping tablets.

Travel poses a different set of difficulties, as far as medication is concerned, and I tend to 'split the difference', ie take an extra lesser amount of prednisone to see out the day. I find a 30 hour day easier to handle than a 20 hour day. Eating and drinking alcohol just in moderation is vital for me, and water intake must be stepped up. It is wise for me to limit flying time to 8-10 hours, with a stopover for a day or two.

I am fortunate that I tend not to get sick – perhaps I have built up immunity at work! I don't get stressed. I still work 45+ hours per week. Friends and family all know that I have Addison's – most of them have seen me struggling at times, eg in the heat, on the tennis court, etc.

I think that probably more than any other illness, Addison's Disease must be managed by the patients themselves - only you know if you are well or not. We are fortunate to live in an age where the condition can be managed – after all, treatment was not available until the late 1950s. I count myself lucky to be still in business doing what I enjoy, taking part in competitive sport, and travelling extensively. We all must just be aware of our limitations.

*Editor's note: Gary was reluctant when asked to share some achievements in his life, but we encouraged him!*

Highlights in my life? Professionally, probably helping set up a medical centre with doctors, pharmacy etc. Sporting? I have won several NZ titles and teams events in NZ and Australia, and have captained NZ teams at the World Championships – over 60 and over 65. But I have never won a world title – yet!