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Pamela's story: Addison's disease diagnosed 18 years ago, when in her thirties

Hi, I'm Pamela. I'll be 54 in December 2002. My Addison's disease was diagnosed in July 1984, when I was 35. The usual slow discovery scenario. It didn't help that my Christmas holiday had been at Mapua (a dress optional motor camp) and that I was very suntanned as a result! I experienced a day at the motor camp when I didn't know what was happening to me. I woke up with no energy and sat in my sleeping bag gazing out the caravan window dozing all day. I was fine the next day. Very puzzling. So after the holiday I visited my Doctor because of major migraines I had been experiencing during the previous year, tiredness and leg pains. His diagnosis was "women on their own sometimes get preoccupied with themselves - you need to get out and find other interests" Huh! (I was divorced in 1980 – some of the problems I experienced then I attribute to the onset of Addison's - this could be a whole other story).

So I embarked upon a high energy diet which seemed to help, until July when I felt extremely tired, craved salty foods (instant soups were good - requiring no effort) preferring liquorice and fruit to other food. I had to sit down in shops (just like an old lady) because I couldn't stand too long, glass doors had to be leaned on to open rather than pushed open. Family did not notice anything wrong – probably because I had withdrawn from the world at the weekends to preserve my energy for work.

I forced myself to get up in the mornings, to stand up, and get washed and dressed. I walked up the stairs using my hands to support me on the steps above (like a monkey) - as it was easier. Looking back it's a wonder how you get to this state, but it is so gradual that you don't notice that you are making these changes. Another strange thing was that people started commenting on my lovely white teeth. This was the brown face emphasizing the whiteness of my teeth.



Finally after I had suffered bouts of vomiting, continual tiredness and listlessness, I returned to the Doctor but really only because of an excruciatingly bad earache. He was a bit shocked to see me. I was browner in the middle of winter, than I

was when I visited him in February, I had lost a lot of weight, including about five kilos that week - I thought I looked good, slim, brown, film starish (poetic license here!!!).

After blood tests my Doctor phoned me Friday lunchtime, advised me to go straight home, rest and NOT to do anything! He'd made an appointment at the hospital for Monday at 8.00 am. So I stopped shifting my desk and computer to Monday's new office, and went home – in a little bit of a shocked state of mind.



Well the boy scout in me thought I'd get the place tidy just in case I died. (Someone had told me a girl she knew had died of Addison's disease and that was the limit of my information). However vacuuming made me vomit so Doctor's orders were followed and I rested. Family gathered around to support me. On Monday I was immediately admitted with the diagnosis – you guessed - Addison's disease.

My classic symptoms were: Mid thirties, freckle spots inside my mouth, body and especially on my legs, Brown marks around my waist and pressure areas and brown palm creases. Unable to stand for long or climb stairs easily. A shrunken heart and other muscle shrinkage, and chemical stuff I didn't understand like a very low level of electrolytes. I was a novelty at the hospital because student doctors were able to study my relatively rare but classic case. I personally learned a lot because of the students.

After a few days in hospital dripped full of cortisone I was up and about, ringing friends, feeling absolutely wonderful. I had a permanent needle in my arm for blood tests which were taken hourly during the day from Monday to Wednesday. I felt full of energy. I suddenly realized how weak I had previously become. On Thursday, however, after an adjustment to the dose, I had a big down. But Friday I was again up and about and released Saturday morning.

I was back at work on Monday (my Doctor didn't think I required any days off). My life since has been great. The Addison's has not appeared to affect my relationships and one of my boy friends taught me yachting, I've cruised 5000 km, mainly Canterbury to the Marlborough Sounds, and in 1992 our women's racing team was ninth in the National Women's Keelboat Championships. I walk to get exercise, roller blade, and have a two story house in which I leap up and down the stairs upright, and generally have good health.

I participated in the Christchurch DHEA study last year, got oily and spotty but felt great – I haven't been to my Doctor to discuss with him continuing with the DHEA, but hope joint and muscle aches I am experiencing this year may be eased with a small dose, without the side effects of oily hair and skin and some

aggressive tendencies. I wanted to experience some time without the drug to see what differences I could notice.

My reaction to alcohol changed during the onset of Addison's. Now I can enjoy a glass or three of wine without developing the migraines I got then. [But if I over-indulge (or sometimes this can just be if I haven't eaten before drinking – this has only happened about four times in 15 years), I can't stop being sick in the morning and have to lie still all day until about 5pm, sipping water until I come right again.]

I have never had a crisis needing hospitalization, although I have been flat on my back for a couple of days here or there. In these instances I just keep taking double cortisone until I start feeling normal again. The flu can sometimes knock me down for a week, so I now take the free flu injection. I have a mostly optimistic view of life and feel generally happy. This year I changed jobs, survived a house fire, bought a new house and have held a Board position in my Zonta club of which I have been a member for 15 years.

