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## **DANIELLE'S STORY**

### **Living in Japan with Addison's disease**

When my second (and last) child was born in February 1992 I was 24. All went well. It was his 3-month check-up when I made the comment to my doctor that my pregnancy mask hadn't disappeared like it had before, and I had big bruise-like marks on my elbows and feet. He looked at my elbows and also my feet and knees, then turned over my hands to look at my palms. He asked me all sorts of questions then, was I tired, any nausea etc etc. He already had the idea that I may have Addison's, sent me for blood tests, and a couple of weeks later I had my diagnosis. Now that I have read some other case studies, I guess I was lucky my doctor spotted this straight off.

The name Addison's disease of course meant nothing to me. I just thought it like my thyroid, take a tablet a day etc, and I would be fine. I'd been doing that for 12 years. I saw a specialist, and then just my GP from then on.

At that stage we were planning to go and live in Japan. My husband was already over there, so it was a relief to learn that I could still go. I asked my GP for literature on the subject, and he copied me a page out of some medical journal that meant as much to me as if it was written in Japanese. I figured Addison's couldn't be too bad.



When we left for Japan, I took a six-month supply of medication with me. Eventually I met my doctor. He was a very young man, who could speak a bit of English, He was very concerned about me, and when giving me any medication or anything, he would say to me "If you catch cold come to me, I put you in hospital." From that day on I decided I would never go and see this man if I was slightly sick – I would go for my prescriptions only when absolutely healthy.

When we lived in Japan, we were entitled to medical insurance through the town council, NZ\$125 per month for the family, not too bad. The council then paid 70% of all our doctors' costs and prescriptions. It was a good system, as you don't have to pay it all and then get reimbursed, you just pay the 30%. But I found out at my first visit that I could only get 2 week's medication at a time.

They have you trapped, as if you get sick you don't have enough to double etc, so you need to see them. I just kept extra of my NZ medicine to compensate for this. One two-week visit would cost me around \$50 for my visit and medication.

I remember I used to get really pissed off with the two weekly thing. One day my lovely doctor said that if I travelled to a city nearby, there was a University Hospital and his professor would like to meet me. I thought I'd try this. What an expedition. I had blood tests, a visit, and then the wait for the medication, all taking over three hours. (Nothing is hurried in Japan!). The professor himself was great. He spoke very good English, and he said to me that although it was illegal, he would prescribe me more medication so I would only have to see him every 3 months. I thought this was wonderful. That little visit cost me nearer to \$500 because of the blood test, but the three month gap would be worth it, I felt. My only thing is, I am not one of those people who lie, or really think about doing it, so when my doctor saw me at a social function a few weeks later, he asked me when I was going back to see his professor. Not thinking, I said "August". Well, that was the end of that! When I visited my professor again, he accused me of telling someone – and I was back to fortnightly visits. I was really devastated for a while – if only he knew I didn't really tell anyone, I just answered a simple question.

While in Japan, I had two incidents that I thought at the time were food poisoning, but looking back, they may have been Addison's crises. I remember vomiting for close to 7 hours, then for 2 days being scared to eat anything. Once I didn't even take my medication as I already knew that it tastes a whole lot worse coming back up again with the water. I did recover from these, although slowly, and the cause of them may have been erratic tablet taking, or even forgetting them altogether. I waited until I returned to NZ and saw my GP, who told me what these could have been, and then I learned that if I missed my medication I could actually get sick and end up in a coma. That information probably would have been good to have had up front, but we live and learn.

Well, I have been back in New Zealand for 3 years. Although at the moment I am going through big changes, I have a lot more control and I know my body better now, when to increase medications, etc. I do feel I am of the lucky ones, having not suffered too much with Addison's disease over the past 6 years. I hope I continue this way! Good luck, everyone.