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Joy's story

Another slow diagnosis of Addison's disease - her symptoms started during her second pregnancy.

I was diagnosed with Addison's when I was 35. During my mid twenties I often felt dizzy when I stood up quickly, particularly after I had been squatting. As my family had a history of low blood pressure I wasn't overly concerned about this. But I noticed that I was often very lethargic at morning tea time so I added sugar to my coffee in order to boost my energy levels. I retired from fulltime teaching and I had my first baby a month before I turned twenty-eight. I had terrible morning sickness for the first three months but other than that my pregnancy was easy.

Two years later I was pregnant again. This time I had no morning sickness but I craved salted peanuts. I had stopped adding salt to the vegetables that I cooked because my husband had high blood pressure. Little did I know then that it was the salt in the peanuts that I really wanted. Just after my baby was born I got a bout of diarrhea and I remember feeling very weak and faint. Fortunately my mother was staying with me at the time to help with the new baby, and it didn't take me long to recover.

As my baby grew, people began to comment on my lovely suntan, but I thought this was due to my recent interest in gardening. Besides, I thought that I looked great. I had lost weight which pleased me, but I couldn't stand for long periods of time, as I got so tired. I had been troubled with pains in my sides at night for about eight or nine years but nobody was able to tell me what was causing them. I was sure it was my kidneys that were hurting.



The X-rays, CT scan and ultrasound examinations revealed nothing but a cyst on one of my kidneys. The doctors didn't think it would be causing my pain but they offered me no other help.

I decided the pain was probably due to a food allergy so I tried eliminating tomatoes, which I loved, but this didn't solve my problem. Some mornings the pain was so intense that I had to get out of bed early and get my body upright as the side I was lying on always hurt the most. Sleeping on the couch with my body propped up on a 45* angle helped. Some days I was so sore and so tired that I sat around all day, but I found that movement actually helped the pain go away so I was better to start working. Nevertheless I had days when I felt so bad that I did virtually nothing all day.

Most of the time I lived a fairly normal active life as a mother of two young children. I taught part time and was very involved in the local playcentre. But when I got a tummy bug I got so weak and dizzy that once I fainted twice in the middle of the night. The first time I hit the kitchen floor so hard I woke my husband up. The next time I was sitting at the dining room table and I fainted forwards so my husband called the ambulance. On the way into hospital, at about midnight, I could hear the ambulance staff discussing what they should do with me. They took me to A&E where they weighed me and asked if I had been dieting (I was about 55kg). They examined a mole on my back and wondered if it was cancerous. They asked me about my marriage as I was sleeping in the spare room so I wouldn't keep my husband awake. I begged them to let me go to sleep. After nearly an

hour they agreed and I was wheeled down to a ward and put in isolation. I went to the toilet and felt dizzy so I rang the buzzer for a nurse. She didn't come so I convinced myself that I could make it to the bed, which was about four metres away. I walked out of the toilet and fell to the floor. The nurse arrived and I told her that I had fainted. She said I must have slipped because I had socks on! I always had cold feet and therefore wore socks to bed.

The next day the senior medical officer asked me whether I had just come back from the islands, as I was so brown. He then told me that there was nothing wrong with me and they sent me home.



Some months later I began to vomit when I cleaned my teeth in the mornings. If I hadn't had breakfast I would dry retch when I put the toothbrush in my mouth. After weeks of this I decided that I must be pregnant again even though my husband had had a vasectomy. I was also uncomfortable wearing any waisted clothing. I went to my GP and found that the pregnancy test was negative. She decided that I must have been eating too much fruit and this had formed a gas build up in my stomach. I didn't think she was right, as I had always eaten five or six pieces of raw fruit a day, but I took the medication she prescribed because I thought it might help and certainly wouldn't do me any harm. Little did I know!

The next day or two I felt worse, so I stopped taking the medication that she had prescribed, but by this time my condition had deteriorated so much that I was unable to keep down boiled water or flat lemonade. I was also freezing cold during a hot Marlborough summer. I returned to the doctor but still my condition worsened. I began to get violent stomach cramps. I felt like someone was cutting across my stomach with a sharp knife. I couldn't sleep but I didn't want my husband to call another ambulance in the middle of the night and the hospital to tell me there was nothing wrong with me. I prayed to die. I was wracked with pain. I couldn't walk from the bedroom to the bathroom without fainting or sitting down and I carried a bowl with me to throw up into.

In the morning a nurse friend took me back to my GP. She saw me immediately and wrote a referral to the hospital. She thought that I had a blocked bowel. I knew that I didn't as I hadn't been able to keep anything down for days, but it got me into hospital legitimately and that was all I cared about. A male house surgeon examined me and agreed with my GP's diagnosis. The senior medical officer agreed. I think I even signed the papers for an operation! But a young female house surgeon saved my life. Instead of asking me about the last few hours and the last few days she asked me about the last few weeks, months and years. An extremely low salt level in my blood and my beautiful tan made her suspect Addison's disease.

As the lab test results for Addison's take several days and I was already in a crisis the doctors felt that I couldn't wait for a formal diagnosis before treatment so they put me on a saline drip and gave me cortisone intravenously. I woke the next morning like a new person. I walked down the corridor to shower unaided without feeling faint. I was back to normal and I could eat again without throwing up. I rang my husband from the hospital to tell him that I was feeling OK again and he immediately said that my voice had returned to normal. It had deepened quite considerably over the previous year.

I was prescribed 25mg cortisone acetate and 0.1mg fludrocortisone every morning and 12½mg cortisone acetate in the evening, and sent home after only one night in hospital. I have stayed on the same medication ever since (11years) until recently when I first visited an endocrinologist, who

found that my fludrocortisone needed to be increased to 0.15mg then 0.2mg per day. After he increased my fludrocortisone to 0.2mg my periods returned. They had gradually lessened over the years since diagnosis.



When I was diagnosed in 1991 I sought a support group but found there was none. I was given a small information booklet written by Christchurch Hospital endocrinology department and I lived alongside a nurse who had a medical book on endocrinology which although very technical was quite helpful. The senior medical officer also got another Addisonian patient to phone me. She answered most of my questions. I eagerly sought to read everything I could about Addison's but I discovered that most of the material I found was either too basic to be of any use or so medically technical that I couldn't understand it.

In 1998 I found a reference to a New Zealand support group on the world wide web but there were no contact names, addresses or phone numbers listed on the site and it wasn't until 2002 that I found the NZAN website and became a member.

A few years ago I discovered that my uncle died of Addison's disease in Auckland Hospital in 1932. He was only 17 years old. He had been hit in the small of the back by the tray of a coal truck about 9 months earlier. I presume this damaged his adrenals glands. His older brother told me that the whites of his eyes went quite yellow before he died and he was so tired some days he couldn't do up his bootlaces. I think they only discovered the Addison's when they did a post mortem. His death certificate states: "Addison's disease months".

Since being diagnosed with Addison's I have only had one adrenal crisis, which was brought about through having gastroenteritis, as I couldn't keep my medication in my system long enough for it to have any effect. My husband took me to the local hospital and I was seen by my GP who was on duty that evening. He injected me with Solu-Cortef and I went home again straight away.

Every now and then I think about returning to classroom teaching but I have decided to continue teaching part time instead as the pressures and stresses of a classroom teacher's job are not always predictable and are therefore difficult to accurately medicate for. I now work as a reading recovery and special needs teacher at three local schools and I generally keep very good health. During the winter terms I find that I often need more daily cortisone than during the summer months. If I don't increase my cortisone I suffer from a recurrent sore throat, become tearful in stressful situations and I retch in the mornings when I clean my teeth.



Joy speculates...

Is there a link between blood group and Addison's disease? Might her food choices have influenced that she got Addison's disease?

"I have recently read The Eat Right Diet by Dr Peter D'Adamo. He says that people with blood group B (like me) are prone to auto immune diseases.

"He lists beneficial foods for each blood group, which he claims act like tonics to the system, neutral foods and finally foods to avoid which he says can affect us like "toxins". I was astounded to see

that all my favourite foods were in the blood group B avoid list - whereas the traditional country girl's diet that I was raised on and now tried to avoid, because it had a high fat content, was mostly beneficial to my blood group.

"I have wondered for a long time whether my adrenal atrophy could have been caused by my food choices. I had suffered a lot of pain "in my kidneys" for years and this intensified over the Christmas New Year period when I was eating a lot of tomatoes, radishes, fruit and ham etc (on my "avoid" list, according to Dr D'Adamo). Now I wonder if I had stayed on a traditional kiwi diet when I left home whether I would have still developed Addison's disease.

"The year my second child was born (when I was diagnosed with Addison's) was particularly stressful as my husband was unwell and we lost all our investment capital through no fault of our own. After reading that book, I wonder if my body was stressed even further by the foods I loved to eat, eg tomatoes, peanuts, bacon and wholegrain bread, that were the mainstay of my diet.

"I think the possible link between blood groups, food allergies and Addison's disease merits further investigation. It would be good if we could reduce the risk of onset of Addison's disease in our children, by changing their food choices!"

Professor Holdaway comments:

As mentioned above, there are links between autoimmune disorders and tissue type (HLA type), but not strongly with blood groups as far I know. Whether food types can influence autoimmune disorders is not known, and research could certainly be done in this area. However, it seems likely that unravelling the cause and treatments for autoimmunity will come from better knowledge of the complicated factors controlling cell-mediated immunity in general.