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Rosemaree's Story

Rosemaree didn't let diagnosis of Addison's disease and Graves' disease stop her from going to live in Thailand the following year, and work there as a teacher and paramedic for four years.

She weathered several adrenal crises, sometimes administering her own IV fluids. She's keen to go back, but she says she wouldn't live there alone again, and would make sure she had a means of transport and a phone.

These days, she has a busy life in Hamilton, with her husband and two stepsons. What drives her? To quote the final paragraph of her story: "My parents both died with significant unfulfilled goals, when I was in my mid-twenties. I decided then that if anything was really important to me I would do my best to do it now, rather than wait for some time in the future. I regularly reassess my lifestyle & adjust it where necessary to help achieve the things that are the most important to me"

Her story...

DIAGNOSIS:

I first became sick while living in Perth as a student in Bible College for two years. I was working part-time and studying full time. Towards the end of my first year away (1994), my mother died after a long battle with leukaemia. During the second half of the following year I started losing weight & was constantly tired. Despite comments from my workmates, I brushed their concerns off, putting these symptoms down to stress from Mum's death & my long working hours.

After graduating from Bible College at the beginning of December, I followed it immediately with an intensive 12-week block missions training course in Sydney. I planned to return to New Zealand for one year to work in my church to gain ministry experience then to move to Thailand long term as a missionary. Two weeks before I was due to return home, my father died suddenly & unexpectedly. I returned to New Zealand for his funeral, & completed the last two weeks of my course the following year.

After my return to Auckland in January 96, many friends commented on my wonderful "tan". Since I had always had a naturally dark skin which tanned easily, & had just returned from 2 years in Aussie where my main mode of transport was a bicycle - again I thought nothing of it. I continued to feel very lethargic, forcing myself to work each day. I lost weight steadily (about 15kg over 7-8 months) despite eating huge meals & starting to "snack" as well to try to maintain my weight.

By about March, I was often nauseous, getting heart palpitations daily & often getting dizzy while walking up stairs or hanging out the washing etc. I was also getting a lot of cramp, often waking at night with my back muscles arched in cramp. After Easter I went to see my GP who ordered a range of blood tests. She rang a few days later to say that I had hyperthyroidism (Graves' disease, an overactive thyroid gland), & that she had spoken with a specialist at the hospital for an urgent appointment in about a month. The specialist told her to order further blood tests, those results pointed to my having Addison's disease as well, so my GP arranged for me to see the specialist in a few days. He confirmed the diagnosis of Addison's disease & Graves' disease after my first visit (at age 27). Then began the process of juggling medications to find the right balance.

STABILISATION:

Initially I took 25mg of hydrocortisone daily, 15mg in the morning, and 10mg with dinner at 6pm. I also took 0.1 mg of fludrocortisone and 15 mg of Carbimazole (to slow my thyroid metabolism). I had regular specialist appointments while we fiddled with drug dosages & I gradually began to feel like a new person. I also had a persistent cough, which caused the specialist to wonder about TB as I had worked in a TB lab previously. He soon realised it was asthma & put me on to Flixonase & Ventolin, which resolved the cough – which I still take. I slowly regained the weight I had lost, to about 65kg (my height is 172cm). But it has continued to fluctuate up and down, depending on my state of health.

My specialist encouraged me to have radiation or surgery to reduce the size of my thyroid gland as he felt that would help stabilize my Addison's. But for various reasons I chose not to do that. I was told that most people with Graves' disease take carbimazole for only about two years, then, if they haven't improved, have other treatment. My dose of carbimazole has been gradually decreased, and I am now (6 years later) taking 5mg daily.

LIVING WITH ADDISONS;

When I spoke to my specialist about my plans to move to Thailand the following year, he was gently encouraging. He had done some of his medical training in Thailand & was confident in the level of healthcare I could be provided there, as long as I was carefully monitored.

I had been an Ambulance Officer. I had also done a short tropical medicine course at the School of Medicine, University of Sydney, before my Addison's diagnosis.

I moved to Thailand as a missionary in March 1997, and was to live there for a total of four years, with a few months home after my third year. I took with me a 3-month supply of tablets, 10 bottles of Solu-Cortef and some needles, and two



one-litre bags of fluid replacement with the needles, tubes etc. Getting more medicines in Thailand was easy –I went to the chemist, and bought whatever I needed (hydrocortisone, carbimazole, etc), no prescription was necessary. When I later switched to prednisone I had to buy that from the hospital pharmacy, however. I got replacement needles from a mission hospital, because I knew they were not re-used.

My New Zealand specialist put me in touch with a specialist in Bangkok whom I saw a few times at an outpatient clinic in my first year or so there. The system is that people turn up, and are seen in order of arrival. No appointment is necessary.

I began working for a Thai organisation as a teacher/paramedic. I was supposed to have one day a week off, but in practice that rarely happened. I was "on call" for medical emergencies 24 hours a day, & 7 days a week so often had broken sleep. There were three other westerners working in the same place, but we had very different responsibilities and hours so really only saw each other for a meal once a day. At that stage I spoke no Thai, but with an urgent need to be able to communicate I gradually picked up a few words. After 6 months, there was an opening for me in a language school where I spent 6 months full-time in intensive language study, learning as much as most do part-time in 2 years.

One day during my stay there I developed a fever, and was too weak to get out of bed. I had no telephone & no means to contact anyone for help. I upped my oral hydrocortisone, and by chance a friend who was a nurse dropped in to visit, and stayed to help. She was a great morale boost, got me fluid etc, & I rapidly improved.

On my return to the campus where I worked, I began to teach my classes & prepare class notes in Thai. The cultural, language, climate changes & work conditions all increased the stress on my body. However my doctor was about 12 hours away by public transport so I learned mostly by trial and error how to alter my medication doses as needed. I knew the principles, but was still on a learning curve with regard to applying them. For example, I wasn't really sure how sick I would need to be before having an injection.



At one stage I had an acute Addison's crisis (minor) with nausea, vomiting, fever & diarrhoea. I was too ill to travel to Bangkok by public transport to see my doctor, & the staff at the hospital would not allow me to talk to him by phone. I decided that was no help to me, so once I had improved (after increasing my hydrocortisone orally) I rang friends who worked in a mission hospital in central Thailand (Manorom Christian Hospital) who said they were happy for me to

phone them in future. That hospital was harder to get to, but going there worked better for me.

A few months later I contracted a tummy bug with copious diarrhoea, & vomiting. I inserted my own IV & gave 100mg Solu-cortef & 1L of fluid replacement. This was tricky as it was night-time (we had no electricity where I was living), I was too unwell even to sit up & had to insert the IV one-handed. Some friends kindly drove me to the Manorom Christian Hospital (about 6 hours drive) where I was admitted for a week & received excellent treatment. They also changed me from hydrocortisone to prednisone as it has a longer half life & the doctors felt it would suit my erratic working hours better. Initially I was taking about 20 mg prednisone daily, but this was gradually decreased. They also increased my fludrocortisone to 0.2mg daily. They allowed me to stay with a friend on the hospital compound for a few extra days than I really needed to, to ensure I was strong enough for both the return overnight journey by public transport & a return to full workload as soon as I arrived back on campus.

After about a year in Thailand, I found some breast lumps which were growing steadily. I'd had friends die of breast cancer so was understandably nervous. Due to my isolated living conditions & limited access to medical care I asked the surgeon I saw to remove the lumps prior to a biopsy, which he agreed to. The school where I was teaching was about to go into recess as our Thai director was overseas on sabbatical leave, the temporary acting director had to leave Thailand & no-one else was available to fill the role.

Once this was arranged, I travelled to central Thailand to have the surgery - removal of three breast lumps under general anaesthetic. The doctors followed the Addison's protocol my specialist in New Zealand had given me, for increasing my steroid dose prior to & following surgery. There were no complications (the lumps were benign) and about a week later the acting director drove up to collect me from hospital.

On the return journey he told me he was leaving the following week, but our director had forbidden us to put the school in recess – so I would be the acting director! My scheduled leave was cancelled - I had not yet been allowed to take any since my arrival in Thailand. I had limited language ability & cultural knowledge & was required to oversee a mixture of Thai & western staff who were at the time in conflict with each other.

At this point I had another Addison's crisis, with vomiting, diarrhoea & fever. I again inserted my own IV therapy by torchlight, & decided not to travel to hospital as I was too unwell for the journey. A close friend who I thought of as my foster mother had come to visit me in Thailand for my recuperation from the surgery. She went to see the acting director before he left, demanding that I be allowed two weeks leave or insisting that she would return me to New Zealand on a one-

way ticket. After two-weeks of sitting on a deck chair at a beach I was much improved & returned north to begin my new role.

A few months later our director returned, & I prepared to return to New Zealand after 3 years in Thailand. I was in New Zealand for about 5 months, working part-time and my health slowly improved. I wanted to go back to Thailand, but wanted to work elsewhere, where I could have a more realistic workload & be closer to medical help when I needed it. During that time I was introduced to a Bible school where I could teach in Chiangmai, which is a large city in northern Thailand (so a cooler climate) and has excellent hospitals. So I went there and worked for a year, teaching.



By this stage my Thai was almost fluent so preparation for classes was much easier. I also had electricity, a telephone and Internet access (a life-line to home for me). During the year I had one minor Addison's crisis, again with vomiting, diarrhoea and fever. This time however I was able to phone friends, who drove me 5 minutes down the road to a hospital where I stayed for only 1 night. Being a westerner, I was treated like a VIP (this was the case at any hospital I went to). My New Zealand specialist's letter made it clear that I had Addison's and what I needed. All the doctors speak English, (but the nurses don't). It was a luxury not having to deal with the injection myself. At the end of this year the school where I was teaching was restructured. Rather than stay on in a different role, I chose to return home to New Zealand, in March 2001.

Back again in Auckland, I had two part-time jobs, one in administration & one doing evening shifts in a medical laboratory. My health was good & I continued periodically to see the specialist who had initially diagnosed me.

A friendship gradually developed between myself and a man I had met in Thailand who was there short-term at the same place I was working. We decided to marry, so in November 2002 I left my work and moved to Hamilton in time for our wedding. I found part-time work in a medical laboratory (3 days a week) and also began to work one day a week as a volunteer ambulance officer. I was also a new step-mother to 2 boys (then aged 6 and 8), adjusting to family life, so my life was again very full.

During the first few months of 2003, my Addison's again became unstable. I was waking most mornings with nausea &/or vomiting. I was on a waiting list to see a specialist at Waikato hospital for the first time, which I was told would be a wait of several months. My GP did pregnancy tests (negative) & wrote to the specialist asking for an urgent appointment. Nothing changed, so I sent an SOS email to my previous specialist in Auckland saying that I was sick, but unable to get a doctor's appointment. He advised me to double my Prednisone & the following week I was given a specialist appointment in Hamilton. This new specialist is very good, and rapidly rearranged my medications until they were again controlling things well. This included splitting my daily prednisone into three

doses, 2-3mg am, 2mg (6pm) & 1mg before bed. This seems to be working well & has eradicated my morning nausea.



CURRENT:

My current medications are prednisone as above, Florinef 0.2mg, Carbimazole 5mg, Flixotide/Ventolin, & Flixonase as needed for hayfever.

I keep busy & active, also playing sport with my family, including swimming, running, tennis & mountain-biking. During active exercise or hot weather I increase my salt intake (usually by adding a little salt to a fruit juice drink) to prevent severe cramp which wakes me up at night when uncontrolled. Having Addison's hasn't affected my choice of sports, but I do take care to watch my energy levels & not push myself too hard on "low" days. If needed I also increase my Fludrocortisone (especially during hot seasons in the tropics). I wear a medic-alert bracelet & keep Solu-Cortef injections & prednisone tablets with me for emergencies.

Since being back in New Zealand I have only had one Addison's crisis (Christmas 2001), again with vomiting, diarrhoea & fever. Friends took me to an A&E clinic where I was given Solu-Cortef IM, observed, then sent home to recuperate. My family, some workmates & some close friends know about my Addison's, and my husband is confident to inject Solu-cortef if needed.

Addison's hasn't affected my choice of work, however at the moment I have chosen not to attempt shift work (eg a return to full-time ambulance work) as lack of sleep is an aggravating factor for me. I have chosen to work part-time (20 hours a week) rather than full-time in my lab job. My work performance is only affected if I "crash", otherwise I am well able to do whatever is required.

However Addison's has been a factor in our decision not to have more children at this time, due to concerns about my health during a pregnancy & with the broken sleep required with babies & young children.

When hearing about my health issues, many people are surprised at my active lifestyle, and that I chose to live and work in Thailand, despite Addison's. My parents both died with significant unfulfilled goals, when I was in my mid-twenties. I decided then that if anything was really important to me I would do my best to do it now, rather than wait for some time in the future. I regularly reassess my lifestyle & adjust it where necessary to help achieve the things that are the most important to me.