

Marianne's Story

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Reminders and context

For some people, Addison's disease (primary adrenal insufficiency) is the only chronic disorder they have to cope with. Some have other endocrine conditions to manage as well, such as hypothyroidism, diabetes, premature ovarian failure, pernicious anaemia, etc

For some people the adrenal insufficiency is secondary rather than primary – their pituitary doesn't send enough of the right message (ACTH) to the adrenals, and so the adrenals don't release enough cortisol into the blood. For some people in this category, the pituitary fails to send several different hormone messages, so not only are cortisol levels low, but some other pituitary-driven hormones as well, including growth hormone, thyroid hormone, and some sex hormones.

People with secondary adrenal insufficiency mostly still produce aldosterone. When they become deficient in cortisol they usually don't progress as rapidly into adrenal crisis as an Addisonian does. Which is just as well, because without appropriate replacement doses of cortisol, they can feel unwell for years, without the alerting symptoms of tanning or salt craving that are common for primary adrenal insufficiency, before the penny finally drops, and diagnosis is made.

One occasional cause of secondary adrenal insufficiency is failure of the pituitary to produce ACTH normally after tapering back from treatment with high-dose corticosteroids given to control some serious disorder such as asthma. In this situation other pituitary hormones are usually produced normally. Some of our NZAN members are in this group, and Anne's story was published in Newsletter Number 12 (March 2001).

Marianne shares her story below. She did take a course of high dose prednisone to control severe eczema. But the symptoms which finally led to diagnosis of adrenal insufficiency had started and become severe several years before that. So her situation doesn't fit easily into a "classical" category.

Not only does she have to deal with adrenal insufficiency, but Marianne also has another chronic disorder, a progressive neurological condition, CMT II, which is a form of muscular dystrophy, that includes muscle weakness and wasting. That clouded the situation when the new symptoms came along. It continues to be a challenge for Marianne to live with them both.

Marianne shares her story below:

Marianne's Story

In early 2000, when I was 47, after nine years of severe physical symptoms, I was finally diagnosed by my GP with secondary adrenal cortex insufficiency, and commenced on replacement hydrocortisone. Within hours I felt "a new person", the much eased "haziness behind the eyes" clearly indicating that I was on the right track. Since then I celebrate that date as my birthday!

To there had been a very bumpy and rocky journey. In 1990 I had early menopause, at age 37.



Starting in the early 1990s, I gradually became aware of several problems. I had sleeping problems. I was often falling asleep “on the spot”, ie regularly having to pull off the road or motorway to sleep for minutes or half an hour. Even waiting at traffic lights I would have to recline and shut my eyes (oh what relief!). I found it difficult to get to sleep in the evening. Often waking up shortly after falling asleep, I'd be awake from midnight to about 5am, then I'd fall into a deep sleep, but wake up extremely exhausted and nauseous.

Going someplace, I always had to allow extra time to recover. Reaching my destination I was mostly unable to leave the car immediately and “get on with it”. Instead on arrival I had to recline and rest, feeling dizzy, hazy, buzzy, shaky, exhausted, and weak.

I had lowered immunity, with ongoing respiratory infections to a varying degree, coughs, colds, runny nose. For years I woke with a sore throat daily. I had digestive problems, constipation and bloating, pain under the rib cage, and a white coated tongue.

Most of the time I felt shaky, as though each cell in my body was buzzing. That in itself was exhausting. My blood pressure was low, 80/50 on average.

I regularly experienced haziness, fogginess, a feeling of “veil behind the eyes”. Especially in the six months prior to diagnosis of adrenal insufficiency, I saw black “dancing” spots which I found unnerving, and I had impaired night vision.

I had increasing gum problems which led to loss of most of my teeth in 1998. I had general exhaustion, facial swellings, and was susceptible to cold weather, etc. I'd had eczema occasionally, mainly as a baby, but by the mid 1990s it had become very severe.

Thus I continued to struggle on for years, repeatedly refusing specialist referrals. As limiting and debilitating as these symptoms were most of the time, they also came in “waves”, with a few days in between with noticeably more energy. Based on those better days holding up hope for improvement (“How can something be really wrong when I am feeling so good at other times?") I continued to keep up appearances and pull myself together more than I can put into words.

My hope was also supported by the fact that the myriad blood tests done during those years showed no abnormalities except for low iron and raised CRP (inflammatory marker). Cortisol levels were not being considered at the time.

I was working part-time as an Occupational Therapist. On home visits, before going in, increasingly I also had to nod off in the car, only to be greeted with “oh, you look so exhausted!”. I was also, with my husband Bernhard, developing the large life-style block that we had acquired in 1992. And from 1991-95 I was studying Herbal Medicine.

From my herbal studies I gained ample inspiration and knowledge for dealing with and relieving those symptoms to a considerable degree. Although my overall health continued to decline, I felt and still feel that herbs and herbal remedies helped me keep going.

Establishing the underlying cause remained **the** question. The determination of wanting to find my own answers seemed to increase at the same rate as the symptoms worsened.

I have a neurological condition (CMT Type II), a muscular dystrophy, which has so far led to my right leg being amputated in 1993 below the knee, because of severe deformity. My left foot also has a

deformity which makes walking difficult. So I was attributing my tiredness and muscle soreness mainly to the neurological condition.

In 1998, giving in for the first time, I agreed to see a dermatologist who to my disgust put me onto Prednisone for the horrendous skin condition. But then, feeling so much better all round, I couldn't wait to get off these chemicals once the treatment programme was being tapered down, thinking that the body had now "been shown the way" and would be able to pursue its own healing journey. Well – it didn't!

My stubbornness and determination got in the way again, until finally, more than a year after I had stopped the high-dose prednisone, my GP had the enlightening idea to have the cortisol levels measured – a date that, as I have already said, I since celebrate as my birthday!



The learning curve continues – fine tuning the replacement steroids is on-going, and has involved four endocrinologists. Some of the old symptoms still resurface from time to time, but they are not as frequent and severe as they used to be. Because of the overall improvement early signs are much easier to spot, and pacing myself has become priority.

No cause has been established for the hypo-pituitarism – in my case low production of ACTH, while the other pituitary hormones (GH, TSH, FSH, LH, PRL and ADH) appear within normal range.

Because of low ACTH and cortisol production (rather than none), the idea was to "kick-start" the pituitary by slowly lowering the hydrocortisone dose. I have now tried this several times, but each time was sent into a downward spiral.

Since May this year I have been on 20/10/5 mg hydrocortisone daily, a dose that is considered 30% surplus to my average requirements, but I have a life! I upped the dose from the previous 15/5/5 mg.

I cope, and can reasonably plan and foresee my day without having to allow for "crashes" and recovery. I can visit two shops consecutively without slumping back into my car for a reclining rest in between. Sleep and digestion have slowly normalised, and generally I wake refreshed. I am seldom nauseous or shaky, and only had two bouts of flu in 3.5 years! Not to mention the pleasant lack of exhaustion!

It continues to fascinate me that between waking and eating breakfast, I don't have to rest or sleep! Food choices, such as cheese, nuts or pickles, seem to play a part in aggravating or bringing on symptoms, but not reliably, so I am still exploring that.

One symptom I have gained since being on steroid replacement is intolerance to direct sun and heat causing nausea, lethargy and general weakness, a considerable nuisance when wanting to be and work in my so very large herb garden. I grow herbs and would like to sell them fresh or dried and make herbal medicines. Because of the physical limitations I can't do it as I envisioned, but I continue to try.

I attend yoga class once a week, doing easy stretches. Since May, for the first time in my life, I have been able to go to the gym. The trainer there has made a programme for me. I started off just with 5 minutes, and was encouraged at how well I coped. CMT Type II is a progressive disorder, but I am doing my best to maintain mobility and flexibility as much as I can.