

New Zealand Addison's Network

National Co-ordinator

Jeanette: ph/fax 06 877 4352
email: jeanette.c@paradise.net.nz
PO Box 8562
Havelock North

Karen: Northern Co-Ordinator

ph/fax 09 483 7043
email kcarson@xtra.co.nz

Gary: Central Co-Ordinator

ph 04 565 1783
fax 04 565 3982

Hugh: ph 06 877 6084

email hughd@clear.net.nz

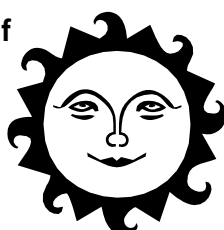
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NZAN Newsletter, November 2003 (No. 20)

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Reminder: Please send back your International Survey Forms promptly, if you haven't already done so



From Professor Ian Holdaway,

Medical Advisor:

(from his address at the Northern Region Meeting May 2003)

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Audio tapes of Professor Holdaway's Keynote Address and the Open Forum at the Northern Region Meeting, and photocopies of the overhead transparencies, are available. See page 6

**Merry Christmas to all
Wishing you good health,
Jeanette and the team**

Disclaimer: The content of NZAN Newsletters is intended as information and sharing of experience, and not as personal medical advice. We advise readers to consult their own doctor before making changes to their Addison's disease management programme.

NZAN Pamphlet in Medi-Boards Nationwide:

In the July newsletter we reported that Neville Osborne, franchise holder for Medi-Board East, is including our NZAN pamphlets at 140 sites throughout the Bay of Plenty, Hawkes Bay and Waikato.

In November, thanks to Ivan Myers the business owner (who is in Auckland) our canary yellow pamphlets have gone nationwide! The sites include GPs, hospitals, health clinics.... It's a great follow-up to the letter and pamphlets sent in July to all GPs, sponsored by a member family.

Karen has jazzed up the front panel a bit, so that in Version 2 our identity stands out more clearly from a distance. [Jeanette finds it a bit ironic that her GP's practice was the first to receive them in the Medi-Board holder. She sees them 'on the wall' whenever she is sitting in the waiting room, and has had plenty of opportunity to think about improvements.]

We hope you'll see our pamphlets soon, in a Perspex wall-holder near you! Please keep an eye out, and give us feedback!

Membership now 107

NZAN's seventh birthday was 23 November. Our 100th member joined in October, and we now have 107 members. Ninety percent have primary Addison's.

We welcome 11 new members since our July newsletter - Bernard, Cheryl, David, Judy, Jackie, Kate, Kathleen, Kevin, Mary, Patsy and Peter. We also welcome back Jan, who was a member in NZAN's early years.

Several heard about NZAN from their GPs, as a result of the mailing to all GPs in July. Information packs were sent to six others.

Thanks David, Dyan, Liz, Marianne, and Patsy for including donations with your subscriptions. Only a few subs are still outstanding.

BOP Meeting Report

Diane Goldsack, NZAN's Bay of Plenty co-ordinator, organised a successful meeting in Mt Maunganui, on Saturday 26 July, 1-4pm. Hopefully her report will motivate others to arrange similar meetings in other parts of the country, north, south, east or west!

"I believe we had a successful meeting. We had good weather and a comfortable venue at the Dominion Salt boardroom - ideal for the 13 that came along. We introduced ourselves - 5 Addison's, 2 secondary, 2 asthma - medication induced, and 4 support people.

"I outlined what Professor Holdaway had talked about at the May meeting in Auckland. Then we listened to the sections from the tapes about medications and how to determine if dosages are appropriate.

"We broke for afternoon tea, then listened to the section on what can initiate an adrenal crisis, and what to do. Ray, Caroline and Chris shared their experiences of crisis situations. We talked briefly about emergency letters and how to give an injection. Most were keen to have a try at giving an injection, so we could use this for a topic next time. All expressed appreciation at getting together, and being able to share.



"The event was not too hard to organize, particularly with the tapes as a topic source. Faxing was easiest for me for contacting radio and the local paper. Next time I will try to have notices to doctors and med labs out earlier. Again, faxing them was easiest. We had three positive replies to radio advertising, and two that were a bit off-beat. I am glad I didn't publicize the address in the public notices, and put it only in Doctors' notices."

Diane's contact details are phone 07 572 1430, email diane.goldsack@actrix.co.nz

Self-Injection of Solu-Cortef Are You Confident?

Karen's "Self-Injection Victory" at the Northern Regional Meeting in May, reported in our July Newsletter, has attracted interest on several fronts.

It has been reprinted overseas. Also after making some nice comments about our newsletters, a US Addisonian surfing onto our website wrote: "Your article about the Solu-Cortef shots was great. I wish we (in the US) were half as organized as you New Zealanders - hats off to you!"



Karen Carson, NZAN's northern regional coordinator, taking the plunge under the watchful eye of Karen Unwin, endocrine nurse specialist.

Allison Crerar, Tasmanian representative for the Australian Addison's Disease Association (and an NZAN member), also reports a very successful self-injection session. "There were 14 at the meeting in September. The community health nurse we had invited and briefed got into the swing. Lots of hilarity as some overcame their squeamishness, one wore a sheet, one dropped their trousers. People were game to inject or be injected with saline. The lemon turned out to be surplus to requirements, and came home unscarred with me!"

As noted on the previous page, self-injection is an action topic in 2004 for the Bay of Plenty members. We encourage other areas to do likewise.

NZAN Guidelines for self-injection with Solu-Cortef were part of the March03 newsletter, with some additional tips in the July03 newsletter. They'll be available in jazzier format early next year.

International Survey Reminder

Along with the Australian, Canadian and UK Addison's groups, NZAN is participating in an International Survey, master-minded by the UK Addison's Disease Self-Help Group (ADSHG).

Gary and Pam Roselli posted out the Survey Booklets early November. We're very pleased with the return rate from NZAN members so far, 63% from Addisonians, 40% from friends. But we hope there are still more to come. A high response rate is needed for best possible accuracy of the results. **If you haven't returned yours, please fill it out and post it back promptly. It's not too late!** Also, please encourage a friend to participate.

If you have misplaced the survey booklet and need another, or if you have any queries about the survey, please contact Jeanette.

Please participate in the survey, whatever the cause of your adrenal insufficiency.



If you have an idea for using NZAN pamphlets to promote greater awareness of Addison's disease, please contact Jeanette! Perhaps there is there a health-related event coming up in your district?



From Professor Ian Holdaway, NZAN's Medical Advisor:

We are including in this newsletter some more excerpts from Professor Holdaway's keynote address at the second Northern Regional Meeting in May. Attendees had the opportunity to influence the topics covered, by submitting questions with their registration. We hope to publish some other excerpts, including from the Open Forum in future newsletters – but, no guarantees! **We encourage you to get a set of the tapes (see page 6).**

ADRENAL "CRISIS"

What is it?

A state where a person becomes very deficient in cortisol (and fludrocortisone) and may collapse with low blood pressure, weakness, dizziness, nausea on some occasions, and, if severe, collapse into a semiconscious or unconscious state.

What changes occur?

The low cortisol and fludrocortisone levels lead to low plasma volume in the bloodstream, and the walls of the blood vessels do not contract normally to maintain blood pressure, so the blood and oxygen supply to tissues becomes dangerously low. Infection or vomiting makes the situation worse. The function of vital organs such as the heart and kidneys may become impaired. These abnormalities reverse with appropriate treatment with hydrocortisone.

Why might a crisis occur?

1. Not enough cortisol due to poor absorption (nausea, vomiting, diarrhoea), or forgetting to take the usual doses.

2. The usual cause is failure to adequately increase the dose of cortisol to cover major illness, particularly severe influenza, viral gastroenteritis, major infections such as appendicitis, gallbladder trouble, etc.

Emergency Treatment?

If you have any doubts, get to a hospital or A&E centre as quickly as possible – don't delay, better to be safe than sorry.

If only mildly unwell and not vomiting, take 2-3 times the usual morning dose of hydrocortisone or prednisone, and repeat 4-6 hours later. If still unwell with the underlying illness after 6 hours it would be best to see your doctor. If you feel back to normal then no further adjustment is needed. If feeling slightly below par it would be sensible to take an extra tablet of 5mg hydrocortisone or 1mg prednisone in the morning for another day.

If feeling quite unwell, and particularly if vomiting occurs, have an intra-muscular injection of hydrocortisone (Solu-Cortef) 100mg, and get to the nearest A&E centre immediately.

On arrival you or your partner/friend should inform the nurse/doctor about the Addison's disease, and whether the injection has been given or not, and say that this is an emergency requiring immediate attention (the Medic-Alert badge and/or a doctor's letter can help.) **Don't accept anything other than immediate attention.**

Immediate fluids by an intravenous drip, and further intravenous hydrocortisone should be given, and blood taken for potassium and sodium levels plus glucose values and haemoglobin and white blood cell count. Any underlying condition such as infection may need treatment. Sometimes no apparent cause is found for the crisis event.

You may only need to stay at the clinic for a few hours if you recover promptly, but

sometimes a brief admission is needed, with extra steroids for a few days.

Question: I take 15mg hydrocortisone in the morning, 5mg in the afternoon. When I double my hydrocortisone for 2-3 days because I am unwell, should I just take double the dose at the usual times? Are there circumstances when it would be better to spread it out more over the 24 hours? If so, please give me guidelines."

Prof. Holdaway answers: When unwell the body needs higher doses of corticosteroids (such as hydrocortisone) around the clock. In those taking hydrocortisone it is important to spread the doses over 3 or 4 intakes per day. Thus, in the above example, the individual could take 25mg in the morning, 10 mg at midday, and 10mg in the evening (2-3 times usual dose, spread over the day). For those taking prednisone the extra dose only needs to be taken once a day (usually in the morning) because prednisone has a long "half-life" (it lasts in the circulation for 24 hours).



Addison's Disease and "Other" Medications - interactions

There are very few medications which have a "direct" interaction with hydrocortisone or other Addison's treatment medications.

Take care with any medication that might induce nausea, vomiting or diarrhoea, such as:

- ## **some antibiotics** (keep a note of your own history with these)
- ## **some painkillers**, such as morphine, occasionally codeine, and tramadol which is a newer painkiller – some people are very sensitive to these.

Diuretics work to make you lose fluid - with most of them you lose potassium as well, and also deplete yourself a little of salt. Monitor weight and serum potassium and sodium

carefully in case some extra potassium (usually as "slow K") is needed.

"NSAID" pain killers such as Voltaren, Brufen, etc can cause fluid retention and act like extra fludrocortisone. Watch blood pressure and weight.

Preferably, try something else as a painkiller – such as paracetamol (Panadol), aspirin, acupuncture.

We tend to underplay the simple remedies, like paracetamol, which is an extremely safe agent, because we don't take enough of it, and too quickly we say it is not effective.

For paracetamol to be effective, you need to take 2 tablets every 4 hours, whether you have the pain or not. People tend to let the pain build up, such as headache or joint pain, saying they don't want to take too much of the painkiller, and by then the pain may have become quite severe. If you take paracetamol regularly, pain or not, when you have a bad migraine, sore joints or a bad back, and take it round the clock for a couple of days (while awake), it suppresses the pain, and you'll likely be able to get off it again.

Paracetamol is useful for keeping the body temperature down when you have flu and the aches.

Oestrogens (in the oral contraceptive pill or in HRT and some "natural" menopausal remedies) slow the rate of clearance of cortisol from the body, so the cortisol replacement dose may reduce by 25-30% when commencing an oestrogen preparation.

A few medications speed up the clearance of cortisol from the body, so the dose of cortisol may need to be increased. However, it is unlikely that the average person with Addison's will ever need these medications:

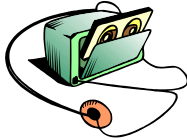
- ## **Phenytoin (dilantin)** – for epilepsy
- ## **Rifampacin** – for TB treatment



REMINDER: AUDIO TAPES FROM MAY 2003 MEETING IN AUCKLAND

Professor Holdaway's talk at the Northern Regional Meeting in May, covered many topics of practical value to Addisonians. Also, in the lively Forum session, in response to questions, he expanded on several topics from his talk, and contributed to the discussion of many other issues.

The tapes will be a great memory jog for participants, and are a mine of information for those who were not able to attend. Prof Holdaway's style is easy to listen to and understand.



Thanks to Andrea and Kathryn's thorough planning and refinements on the day, the quality of the recordings is excellent, and the questions from the audience are picked up clearly too.

Cost: \$15 for the 2 tapes of Prof Holdaway's address, including a photocopy of the overheads. \$5 for the Open Forum tape. [This is the price we paid for copying – no profit is included]

Contact: Jeanette (address on front page)

Medicines Update

NZAN values good communications with the suppliers of Addison's medications in New Zealand.

Florinef :

The distributors have updated us about the timing of the change from pink to white tablets in New Zealand - probably mid to late 2004. We have been assured that the only difference will be the removal of the pink dye. We'll keep you posted.

Solu-Cortef Act-o-vials, for injection

There are plenty in New Zealand! Those of you who surf to Addison's forums on the Internet may have read that Addisonians in some places, especially within the US, have not been able to fill Solu-Cortef Act-o-vial

prescriptions over recent months. Pfizer's takeover of Pharmacia globally led to some hiccups in supply. Pfizer's policy in New Zealand (which was also Pharmacia's policy) is to maintain at least 6 month's supply.

Brain Workouts for better memory and reasoning ability

Said only slightly tongue in cheek, Addisonians sometimes worry whether periods of foggy thinking and poor memory mean we are on a downward slide... The brain is an organ that we do wonder about from time to time.

The September issue of 'Scientific American' magazine had the theme 'Better Brains, how neuroscience will enhance you'. Jeanette found it a fascinating read, with a range of topics covered by experts in the field - ultimate self-improvement, new hope for brain repair, the quest for a smart pill, mind reading machines, brain stimulators, genes of the psyche, taming stress, and neuroethics.

How the brain sustains and regenerates itself is becoming better understood. The brain is turning out to be more "plastic" than used to be thought.

Attention to lifestyle can help 'sharpen' brain function, and even make new brain cells. Yes, some of the research is in mice – but it illustrates important possibilities. If we get medications and lifestyle in better balance, perk up our environments, and apply what seems "common sense", perhaps, the sky is the limit!

In his topic 'Brain, repair yourself', Professor Fred Gage from the Salk Institute for Biological Studies in San Diego, US, said:

"A brain workout:

One of the most striking aspects of neurogenesis [new nervous tissue] in the hippocampus is that experience can regulate the rate of cell division, the survival of

newborn neurons and their ability to integrate into the existing neural circuitry.

“Adult mice that are moved from a rather sterile, simple cage to a large one that has running wheels and toys, for instance, will experience a significant increase in neurogenesis. Henriette van Praag in my laboratory has found that exercising mice in a running wheel is sufficient to nearly double the number of dividing cells in the hippocampus, resulting in a robust increase in new neurons. Intriguingly, regular physical activity such as running can also lift depression in humans, perhaps by activating neurogenesis.”



And in his concluding paragraphs...:

“The best ways to augment brain function might not involve drugs or cell implants but lifestyle changes. Like many other organs, the brain responds positively to exercise, a good diet and adequate sleep, which are already known to enhance normal brain function with fewer side effects and potential problems than most of the other strategies described above.

“I predict that if more people knew that a proper diet, enough sleep and exercise can increase the number of neural connections in specific regions of the brain, thereby improving memory and reasoning ability, they would take better care of themselves.

“A final consideration is the environment in which we live and work. More and more experimental evidence indicates that environment can affect the wiring of the brain. This opens up vistas of possibility for architecture and suggests that future homes and offices might be designed with an eye toward how they might provide an enriched environment for enhancing brain function.”



Skills for Managing Stress

Jeanette found this succinct summary, put together by the University of Washington, Department of Orthopaedics. [www.arthritis.about.com/library/weekly/aa101497.htm]

It is written for people coping with arthritis, but is relevant for people dealing with other chronic health issues. In the one place that word “arthritis” appeared she has substituted “Addison’s”.

Reduce stress

- 1 - Identify the causes of stress in your life.
- 2 - Share your thoughts and feelings.
- 3 - Try not to get depressed.
- 4 - Simplify your life as much as possible.
- 5 - Manage your time, and conserve your energy.
- 6 - Set short-term and life goals for yourself.
- 7 - Do not turn to drugs and alcohol.
- 8 - Utilize Addison’s support and education services.
- 9 - Become as mentally and physically fit as possible.
- 10- Develop a sense of humour and have some fun.
- 11- Get help to cope with hard-to-solve problems.

Accept what you cannot change

- 1 - Realize that you can change only yourself, not others.
- 2 - Allow yourself to be imperfect

Overcome the harmful effects of stress

- 1 - Practice relaxation techniques.
- 2 - Learn to overcome barriers to relaxation.

DHEA Update Muscle Trial and Review Article

During 2003, Addison's volunteers in the US participated in a DHEA research study at the Mayo Clinic, Rochester, led by Dr Ketan Dhatariya. The study was designed to assess the effects of DHEA on mood and muscles.

At the time of recruiting volunteers, Dr Dhatariya said: "Mood has previously been studied and is one of the few things almost consistently shown to improve with DHEA. The unique part of this study is the muscle aspect. We hope to examine muscle tissue to see if muscle metabolism changes on DHEA."

The results of that study have been submitted to medical journals for publication. As part of the project, a comprehensive literature review was done of the available studies on DHEA. This was recently published in Mayo Clinic Proceedings 2003;78(10):1254-1271. The title is "Dehydroepiandrosterone – is there a role for replacement." The authors were Dr KK Dhatariya, and Dr SS Nair.

Co-author Dr Sree Nair is a respected senior endocrinologist who has published many research papers. He has a connection with New Zealand. He was endocrinology registrar at Auckland hospital for a year 'many years ago', and did his medical training and Fellowship in New Zealand, before moving to the US. Our medical advisor Prof Holdaway has some shared publications with him from those days.



The DHEA review clearly and concisely written – but it is 17 pages long! If you'd like a copy in the post, please contact Jeanette.

Most of the points relevant to Addisonians have been covered by Prof Holdaway at the May 2003 meeting, and previously in our newsletters.

"Often, DHEA and DHEAS are referred to as weak androgens; however, there is no evidence that they bind to the androgen receptor. Thus, DHEA and DHEAS have little or no intrinsic androgenic activity. However, they are converted into androstenedione and then further into potent androgens and estrogens in the liver and other target organs. These transformations depend on the tissue activity of [appropriate] converting enzymes..."

The direct mechanism of action of DHEA, if any, is unknown. The effects of DHEA are due to the actions of the sex hormones into which it is converted...

Blood levels of DHEA sulphate (the circulating form of DHEA) peak in one's early 20s, and decline steadily with age. Levels are extremely low in Addison's disease, since it is made only in the adrenal gland. One important point is that although serum levels are low in the elderly, they still have a lot more DHEA than Addisonians do.

DHEA and DHEAS may also act in the brain, but that process is not influenced by factors that control adrenal DHEA secretion. Their role there is unclear.

"Many disorders of aging, such as reduced immunocompetence, obesity, diabetes, and cancers, have been attributed to changes in DHEA based on animal studies and human epidemiological data."

Mood and well being effects? Research results have been variable, at least in part because of research and questionnaire design. In most studies involving hypoadrenal subjects, DHEA replacement seems to lead to an improvement in mood.

What about cognition and memory – including situations such as Alzheimer's? DHEA may have an important role, and the research is ongoing. DHEA may help prevent osteoporosis in elderly or hypoadrenal subjects, but that is still uncertain.

Here is the Summary and Conclusions section, in full:

“DHEA and DHEAS are intriguing hormones. Their metabolites have a variety of effects on several physiological systems, and yet little is known about the role of either DHEA or DHEAS in normal physiology. It is still unclear whether aging should be classified as a DHEA-deficient state. In hypoadrenal subjects, DHEA deficiency is associated with a lower quality of life. However, these hormones are not essential for life because hypoadrenal subjects and those who have undergone adrenalectomy who have little or no circulating DHEA do not have shortened life spans.

“Evidence supports the use of DHEA in individuals with adrenal insufficiency. The lay press has widely promoted the use of DHEA in normal healthy individuals, and body-builders promote its use as a method to increase muscle mass. However, many of the claims made on Internet Web sites (“fountain of youth”, “prevents diabetes”, “prevents aging”, “boosts the immune system”, etc) fail to mention that most of these studies were performed either in vitro or in animals. These reports are further misleading because they fail to state that the results were usually a response to highly supra-physiological doses of DHEA. The degree of quality control of the substances currently marketed is a concern. Finally, there are valid concerns about the use of DHEA in individuals with a history of sex hormone-dependent malignancies. Large-scale human studies are needed to address these intriguing issues.”



Problems with DHEA availability in the US and Canada

The DHEA review mentioned above describes the US situation:.

“The International Olympic Committee banned DHEA use because of its conversion to sex hormones and thus its potential to be

used as a drug of abuse. The Food and Drug Administration also banned the substance until the passage of the Dietary and Supplement Health and Education Act of 1994, when this ruling was overturned.

“DHEA is now freely available in pharmacies and health food stores, where it is classified as a food supplement. This is despite the fact that DHEA is not a food, that DHEA does not naturally appear in the human food chain, and that no foodstuff can perform the physiological role of DHEA. It can be sold directly to the public as long as no claims are made about therapeutic efficacy.

“In an attempt to reduce the potential abuse of DHEA, a bill was recently introduced to the US House of Representatives that aims to restrict over-the-counter sale of DHEA and other androgenic steroid precursors. The manner in which passage of this bill would affect those who may derive benefit from DHEA, such as hypoadrenal and elderly subjects, remains to be determined.

“In the US, food supplements are not required to undergo strict safety and efficacy testing, and thus there are issues of quality control. One study showed that the quantity of DHEA from different manufacturers in several different doses varied from 0% to 150% of what the label claimed was in the product.”

Access to DHEA is under threat in Canada. NZAN understands that the Canadian government is changing its position on approving requested prescriptions and even some Addisonians with prescriptions are apparently are being denied.

Addisonians in New Zealand are fortunate to have access to pharmaceutical quality DHEA, on a doctor's prescription, with no hassle.

As we have printed in previous newsletters, one reliable source of supply is Pharmaceutical Compounding in Birkenhead, Auckland.

For more information contact Jeanette.

News from the UK ADSHG:**New study: effect of DHEA on the Immune System.**

A study is underway in Birmingham, looking at how the immune system of people with primary or secondary adrenal failure responds to DHEA medication. The main researcher involved in the study, Dr Wiebke Arlt, has worked on several of the major DHEA studies published to date. She is also the co-author of a recent review paper titled "Adrenal Insufficiency", published this year in the Lancet. You can read the Lancet article at www.thelancet.com/search/search.isa You have to register with the website before you read it, but do not need to be a subscriber to gain access.

Too much or too little cortisol interferes with sleep

The Canadian Addison Society April03 newsletter contains notes about an endocrinologist's talk at a meeting of the Victoria Island Support Group"

"Questioned on sleep problems in Addison's, Dr. Phillips referred to a study titled "Glucocorticoid Replacement is Permissive for Rapid Eye Movement Sleep and Sleep Consolidation in Patients with Adrenal Insufficiency" published in the Journal of Clinical Endocrinology & Metabolism in 2000. The full study can be viewed and a pdf copy downloaded through the journal's search website:

<http://jcem.endojournals.org/search.dtl>.

Essentially taking cortisol replacement at bedtime may increase and improve REM sleep."

Many Addisonians have found that taking hydrocortisone too late can keep them awake. This paper suggests that not having enough cortisol overnight may interfere with sleep quantity and quality [see also Marianne's story, this issue]. Taking tablets to mimic an endocrine gland is certainly a lot more clumsy than having functioning adrenal glands!

Reminder:**Newsletters from Addison's Support Groups overseas****Subscribe directly with Annette**

Members can receive copies of any they would like, on a one-off or on a regular basis, at no extra cost. These can still be included with the NZAN newsletter. Some are also available on email.

All you need to do is contact Annette Church: Annette@icib.co.nz, ph(09)379 5772; ICIB, PO Box 5734 Auckland.

Away from home without your bottle of pills?**Jeanette's practical test:**

As previously reported, if we don't have the Addison's medications with us that we need, we can get up to 3 days' supply from any pharmacy. We just need to show proof of adrenal insufficiency – eg Medic-Alert ID. The empowering legislation is Section 44m of the Pharmacy Act.

The system still works well. Twice over recent months (before my much-needed Tahiti break!) I found myself separated from my hydrocortisone supply when the lunchtime dose of 5mg was due.

On the first occasion, the omission flashed into my mind as I was driving to an appointment in an adjacent city. The meeting would last a couple of hours, and I wanted to stay "on form". Going home for the meds would make me late for the appointment.

The first pharmacy I passed in a small community didn't have hydrocortisone of any strength on the shelves, but, satisfied by my story and my Medic-Alert ID, gave me 1mg of prednisone instead, for a fee of 50 cents. I decided I'd take that if I couldn't find any hydrocortisone.

There was, however, a pharmacy near my destination. After hearing my story and

seeing my Medic-Alert ID they gave me 5mg hydrocortisone for \$1.

On the other occasion I was at Hawkes Bay Regional Hospital in the morning, with a plan to afterwards head in the opposite direction from home – if I could get 5mg hydrocortisone! The hospital pharmacy heard my story, saw my Medic-Alert ID, and wanted to ring my usual pharmacy to check dosage instructions. I explained the prescription said ‘take as directed’. The hospital pharmacist was very pleasant, and rang my usual pharmacy anyway, which I think was thoroughly sensible. Whereas the two private pharmacies had discretion as to the charge, the hospital computer generated a charge of about \$3.50 for the one 5mg tablet. I gulped, paid, swallowed it, and pretended it was a cappuccino. I had the benefit of the convenience of not having to head home early, or risk flagging as the afternoon progressed.



This is your Network and your Newsletter. Please share your stories, news, and tips for healthy living with Addison’s disease. Please share your ideas and your concerns too.

If you have a topic for discussion, or a question that you’d like passed on to NZAN’s medical advisor, please send it to Jeanette.

On the feedback forms at the Northern Regional Meeting in May, someone proposed a national conference in 2005 – please identify yourself to Jeanette. >

Personal Experience: Jeanette’s salt solution

Feeling really well all the time on a recent two-week holiday in Tahiti, has led to me becoming smarter about my salt (sodium) intake at home. The crunch has been realising that my salt intake has varied quite a lot from day to day, more than I have realised. Sometimes I eat salty foods, but usually my intake has been conservative, and sometimes quite low.

I’ve long treated water as medicine – making sure I have an appropriate intake, staying ahead of dehydration. Now I am also more salt aware. In particular, I’ll try harder to keep my salt (sodium) intake consistent, and remember a bit extra on those days with poor appetite, or when food choices happen to be low in salt, especially in hot weather or when I am more active.



It’s yet another ball into the juggling act, however, with effects for me beyond just Addison’s. I have severe hypertension, for which I take a hefty dose of medications, and which I have found worsens if I have a prolonged period of increased salt. Also, increasing salt intake means more sodium in the urine, and with that goes more calcium, which, because of hypoparathyroidism, I have to try to avoid.

In September, I headed from the cold beginnings of New Zealand spring to tropical Tahiti, not too humid, hot in the full sun, but pleasant in the shade, and wonderful warm water. A pleasant change of ambience to French-Tahitian culture, and a chance to use my school French (indeed I needed it!).

To cope smoothly with the hotter weather and expected increased perspiration, my plan was to ensure a steady fluid intake, and to increase my fludrocortisone by half a tablet (from 0.1 to 0.15mg), and take an extra Slow K in case that turned out a bit potassium depleting. And I was going to follow my specialist's advice to be generous with salt. I took plenty of salt with me, the smallest plastic pack I could buy, in case customs queried repackaged white powder.

But when I was faced with the action, I wondered what exactly would be a generous salt intake be for me, without going 'over the top'?! I started by pouring a bit into the palm of my hand, and licking it (yum!). I continued that 3-4 times per day, and usually also had a drink of water at the same time.



I worked out afterwards that the extra I took daily that way was about 1/3 level teaspoon, about 1.2gm of salt [500mg sodium]. Not a lot, really (see Box, salt intake recommendations). I was also eating every day, higher-salt convenience foods that I didn't eat daily at home – including canned fish and canned veges. Also, during my first swim in the sea most mornings, I had a couple of mouthfuls of seawater, for Margaret (see her story, newsletter number 15, March 02)!!. My first mouthful had been accidental, and I was surprised how nice it tasted. Also, I carried a little vial of salt with me, with my hydrocortisone, so that it was on hand if energy flagged and I needed more.

I was very well the whole two weeks. Probably being away from the usual duties and stresses, and able to relax in a nice place, contributed to that. But, given the climate, I am sure the frequent extra salt played an important part.

Back home, I returned to my usual fludrocortisone dose, and my usual eating pattern, without particularly thinking about it. I soon had inconsistent stamina again, as had been my pattern for a long while. It was again unpredictable which days would be good days and which days I would feel fatigued during the afternoon and need a substantial rest. Was it workload related, or salt related, or both, or neither?

So I tested the effect of returning to the added-salt routine that I had followed in Tahiti, about 1.2gm (1/3 level teaspoon) extra salt per day [500mg sodium], adding a bit to each meal – that was the easiest way to remember. Lightly salting my muesli, yoghurt and banana at breakfast made me smile – it still tasted fine to me. I just 'got on with things', while keeping notes in my health diary. My assessment after a couple of weeks of this extra salt? - my stamina seemed more even, without unexpected severe fatigue. BUT, my blood pressure had risen too high. [Increasing salt and fludrocortisone in Tahiti had increased my blood pressure a bit also - I had taken my BP meter with me.] The 'take a bit more salt every day' method was good insurance on holiday in the hot climate, but not suitable as a long-term plan back home.

Our bodies have a wonderful ways of conserving sodium and potassium in the blood, at the expense of tissue levels. My blood sodium always checks out to be in well inside the normal range (touch wood!). A 24-hour urine test a week or so before I went to Tahiti showed urinary sodium below the normal range, consistent with my own assessment that my daily intake of sodium then was typically low. A repeat 24-hour urine test after the couple of weeks taking about an extra 500mg sodium a day [1.2 gm salt], showed sodium above the normal range.

I'll follow advice to be cautious with salt intake, for best balance of wellness without unduly raising blood pressure. The 24-hour urinary level for me to target is the lowest third of the normal range.

Professor Holdaway comments on salt intakes:

Individuals with Addison's disease lack the hormone aldosterone, which normally acts on the kidneys to retain salt and maintain the blood volume and blood pressure. Untreated Addisonian individuals can thus have low blood pressure and sometimes a low blood sodium level (salt is sodium chloride). Fludrocortisone is a synthetic form of aldosterone and acts to reverse the effects of aldosterone deficiency. The blood renin level is a sensitive marker of whether or not the blood volume and dose of fludrocortisone is OK.

Usually, Addison's individuals should follow normal health guidelines and take moderate or lowish levels of salt. A more liberal intake is needed if the blood pressure is low, often with feelings of faintness, or if the renin is high despite usual doses of fludrocortisone, or if the person is in a hot climate when salt loss is increased.

Jeanette did the right thing by taking some extra salt when in Tahiti, but once the need for this was over the extra salt began to have adverse effects, and in particular it expanded her blood volume too much and drove her blood pressure up. Some individuals with hypertension (high blood pressure) are very sensitive to increased dietary salt, and it is better to keep the intake on the low side.

Salt intake recommendations

from the Statement from the National High Blood Pressure Education Program Coordinating Committee, Revised October 14, 1999

www.nhlbi.nih.gov/health/heart/hbp/salt_upd.pdf

There is a clear causal link between habitual sodium intake and blood pressure. And high blood pressure is linked to a variety of adverse health outcomes. The evidence

taken as a whole is sufficiently strong to warrant a specific recommendation about reducing dietary salt intake.

The consensus from several professional bodies is that that lowering Americans' daily dietary sodium intake to 2,400 mg [6 gm salt] will reduce the U.S. population's mean blood pressure. Current evidence supports that 2,400 mg sodium is a safe upper level of daily sodium intake and is not associated with adverse effects.

From a 1989-91 survey, the daily sodium intake in the US for adults over 20 years, was estimated to be 3400 mg per day – and that didn't include discretionary salt. So the "average" and above average sodium eater, needs to cut down!

Healthy adults living in a temperate climate can maintain a normal sodium balance with as little as 115 mg of dietary sodium per day. In consideration of the wide variation in Americans' physical activity and climatic exposure, a safe minimum of 500 mg of sodium per day has been recommended.

Approximately 75% of dietary sodium is added during processing and manufacture. Only 10% is from foods' natural sodium content. About 15% is discretionary addition to cooking or at table.

A person with a small appetite, avoiding processed meat and fish and added-salt cereal products, and adding no extra sodium as salt could get close to the minimum requirement of about 500mg sodium per day - especially if they don't eat much meat. Or, with different food choices, they could easily exceed the recommendation of 2400mg maximum.

The requirement in New Zealand for nutritional labelling of sodium content makes informed choices a fairly easy exercise – if you can read the small print!

Reminder for Addisonians:

* If you regularly crave salt, or use relatively high salt foods to help deal with fatigue and low stamina – check out with your doctor whether you are taking enough hydrocortisone and especially fludrocortisone, to hold the sodium in your blood..

*If you lack stamina and become fatigued easily and somewhat unpredictably on an occasional basis, especially in hot weather, despite being on current typical doses of hydrocortisone (20-25mg) and fludrocortisone (0.1-0.2mg), check if you are regularly getting enough sodium (salt) in your food.

**Drink enough fluid –
but not too much!!**

Summer is here again. In hot weather especially, it's important for Addisonians to avoid dehydration. But it's important to use common sense too, and not overdo fluid supplements.



The article we have previously printed (Newsletter No 14, Nov01) includes the message from the Australian Institute of Sport, that even when elite athletes training hard know how important fluid replacement is, they tend to swallow less fluid than they have lost in sweat. That is one of the causes of fatigue.

At the other extreme, it seems some recruits in the US Navy go overboard, so to speak. A risk factor for developing dangerously low blood sodium is to consume too much plain water over a relatively short time! Certainly, the navy recruit described below drank far too large a volume – but it wasn't smart that the Navy was allowing just plain water. That has since been corrected, and although the recruits are still calorie-deprived, they are issued with water containing 0.06% salt.

Professor Holdaway comments

about fluid intake: There is a current fashion for individuals in New Zealand to carry extra water and take very liberal amounts which sometimes causes problems with kidney water conservation. In general, it is better to take extra water/fluids only when increased thirst occurs. Addison's individuals should in general keep on the generous side of fluid replacement.

Two MD physicians involved in the training of Navy recruits, Drs SD Flinn and RJ Sherer, describe a case report in the online journal *The Physician and SportsMedicine* Volume 28(9) September 2000 (www.physsportsmed.com/issues/2000/09_00/flinn.htm) - Seizure after exercise in the heat - Recognising life-Threatening hyponatremia. "A 20-year-old military recruit suffered a generalized... seizure following 9 hours of moderate activity in a hot, humid environment. He had drunk at least 5.8 L of plain water before the seizure, and laboratory studies revealed that his serum sodium concentration was 113 mmol/L"

"In our setting, the trainees are calorie restricted, so in order to provide some sodium with the water ingested, a salt-enhanced water (0.06% sodium chloride) was developed with help from researchers at the US Army Research Institute of Environmental Medicine.

This level was the highest concentration of salt palatable in water without adding glucose or flavouring. Additional salt packets are also given. Hydration guidelines now reflect adequate amounts of fluid needed to prevent exertional heat injury without increasing risk of hyponatremia. In non-military training environments, athletes should be encouraged to consume proper amounts of electrolyte-containing beverages during endurance events. Too much fluid can hurt."



Salt Cravings and Salt Tax

by Jeanette

My little "salt project" got me thinking about the term 'salt craving'. Many Addisonians experience salt cravings, especially prior to diagnosis.

If asked whether I crave salt these days, I would answer no. But one thing that supports longstanding relative salt "need" is that I am an intermittent Marmite (or Vegemite) fan – in quite large amounts (eg thick spread on toast), and often daily. I haven't seen it as a salt craving – rather I rationalised it as a good source of B vitamins, which, as they are reported to help with short term memory and mind function, I thought could be a benefit! I took a little container of Marmite to Tahiti – but to my surprise didn't fancy it all the time I was there. I can only attribute that reaction to getting all the salt my body needed from my measured "salt licks", the convenience foods with added salt - and the deliberate daily mouthfuls of seawater.

I found an article by academic historian Roy Moxham, "Salt Starvation in British India – Consequences of High Salt Taxation in the Bengal Presidency, 1765 to 1878".

It is an interesting read on website <http://www.rmoxham.freeserve.co.uk/salt%20starvation.htm>. [He is talking about the general population, not those with Addison's.] He notes that mild salt depletion, resulting from insufficient salt in the diet, produces "extreme lassitude".

"The desire for salt is presumably in-built to ensure survival. Salt, up to a certain limit, is pleasurable to eat. Where it is plentiful, people eat more than they need – and if the body's mechanism for secreting it is impaired, more than is desirable

"Unlike hunger or thirst, however, the desire for salt does not increase when reserves are low (Marriott 1950, 22; Dill 1938, 82). For this reason people receiving too little salt will find food bland, but often not realise why they are

feeling listless, or worse. Similarly, those whose salt reserves have been depleted by illness will experience no added desire to consume salt. Even doctors sometimes fail to recognise that patients are suffering from salt depletion." As Dr Marriott has written in Water and Salt Depletion: "their deaths are ascribed to 'toxaemia' or 'uraemia' or 'circulatory failure' when they have, in fact, died from simple lack of salt and could easily have been saved" (Marriott 1950, 3-5). Since he was writing of the situation in western hospitals in the middle of the twentieth century, it can be appreciated that deaths caused by salt depletion in eighteenth and nineteenth century Bengal would have been even less likely to be correctly attributed."



The members' contact list is enclosed with this newsletter. If you see any details that need changing, please let Jeanette know.

MEMBERS' NEWS:

Bob, in Nelson: In the previous issue, we wished Bob a Happy 82nd Birthday. This is part of his reply:

"Thank you for the birthday wishes. On looking through the members contact list, I notice that I am the oldest listed.

Since my medication was finally sorted out I have felt really well and I shudder at times when I remember the way I felt when I was sick with undiagnosed Addison's.

On my latest visit to my endocrinologist (Nov02), I received a good report. I am managing well on my cortisone dosage.

If you think I am getting old, I find at some of the activities that I attend during the week that I feel rather young, because many that I play indoor bowls with are in their late eighties and some are in their nineties.

Another activity that I go to is called 60+. It is a club for entertaining elderly people. I joined when I was sick with undiagnosed Addison's in 1999, and although I wasn't caring much what happened in those days, I did appreciate the care that I received there, and since my recovery I have continued to attend, and am able to play a small part in helping the others.

Again, I feel rather 'young' there because many of the members are in their late eighties, and some in their nineties. The oldest is 96 and looks really spry, so I always say to myself, 'Bob, you are just a chicken'.

Marjorie in Kawerau was a foundation member of NZAN in 1997. Her Addison's was diagnosed when she was 40. She turned 77 on NZAN's birthday, 23 November.

Marjorie wrote when she got back from a trip to the UK with her 2 daughters, to take back to England the ashes of her late husband Ted, who passed away in 2002.

She and Ted had come to NZ in 1957, and been back for visits in 1977 and 1988.

"We thoroughly enjoyed it all. The first week was very cold, but considering we were staying on the very edge of Ilkley Moors, it's not surprising.

My arthritis got thoroughly tested, with three flights of stairs to our apartment, and a climb up the hill. My health insurance done through Westpac Bank insured me for my Addison's (\$35 extra) but not my osteoarthritic hip. I did plenty of walking about on the plane, while my girls slept!

As we cancelled our overnight stay in Singapore because of the SARS outbreak,

we stayed for 3 nights near Heathrow to catch up on health. Was I pleased to see that bed! We were trundling our cases through the street at 7am to our guest house, and I hit the bed and went out like a light. It took me three days to get back to my usual self. The girls worried about me for a while – but considering in those three days we visited Kew gardens on a bitterly cold day (by bus), walked to the shopping area twice, and walked to the rail station to book our tickets for London and Yorkshire (1.5 hours)... We found people very helpful and friendly, perhaps seeing an old lady in the group made people sympathetic, or was my NZ sticker on my case the attraction!

After I fell at the bottom of an escalator in London, several young people came to my aid, I loved them all! When we came to the next escalator I said 'No'- my daughter said, it's only going up, but I insisted. A young man, in a colourful uniform, was at my elbow, he took me up in the lift, got us a trolley, I tried to hand him a tip, but all he said was "don't be silly, have a nice holiday."

To meet our UK family again was something I had thought would never happen, and to go with my girls was fantastic. They looked after me well."

Beryl is also 77. She was diagnosed with Addison's when she was 70. She's a keen reader of our newsletters, and promptly requested the audio tapes from the Auckland meeting in May.

"I was unable to travel to Auckland to the Northern Regional meeting, but I think that the demonstration on the injection procedure would have been of great value. I recently had a flu virus and needed the Solu-Cortef injection for the very first time. Fortunately my daughter is a nurse, and so there was no problem. I realise now that there have been times when I would have felt much better for having the injection, and in future I will not hesitate if I really think that I need it..."



Darren's story

Darren shares how diagnosis of Addison's was an incentive to make good life choices, sooner rather than later.

I was diagnosed with Addison's disease in 1994 (aged 20), after a short illness and then an Addisonian crisis. It was a very familiar story (in hindsight) of fatigue, nausea, losing weight, dizziness and breathlessness (from low blood pressure), and then (probably precipitated by a viral illness) extremes of the above with vomiting and dehydration.

I was pretty crook on admission to hospital but bounced back pretty quick, and regained my appetite (and a new, temporary craving for salt!) with a vengeance. Since that time I have been well maintained on replacement therapy from a medical perspective, and have not been anywhere near inpatient treatment for it.

The other part of this story however, as is often the case, is the fine-tuning of my Addison's management and the rest of my life so that my health and well-being is optimised.

It took probably a few years to get my replacement steroid doses right, or at least be confident that they were optimised, and I'm pretty happy with them now (Hydrocortisone 15mg morning, 5mg at 2pm; Fludrocortisone 0.1mg twice a day). The hydrocortisone took longer to get right than the fludrocortisone – my dose for the latter has been the same I think since the year I was diagnosed. What was difficult along that time was that my daily environment kept changing, so that it was hard to know whether or not my hydrocortisone replacement regime was at fault, or my work environment. So the lesson I've learned here is that if it is at all possible, it helps to keep as much else constant while

changing medication doses (or vice versa), or else it is very hard to figure out what is going on! This is not always feasible, but the ongoing principle is that I try not to change too much at once if I can avoid it.

I have come to really value the partnerships that I have formed with my Doctors (who have changed) in looking after my Addison's. A good example of this "teamwork" is when we were working out steroid protocols for times of illness that work best for me. It was important for me to have their input as to what were the absolute essential rules that I have to follow, and how to be safe medically (eg. don't underdo it when sick), and adding into that (after some personal experience) I could provide my personal input as to what works best for me regarding the finer points of timing / dosage / type of steroid etc.

So these different roles are both important. My doctors help safeguard my immediate and long-term health so that I don't come to any harm, and I can let them know what affects my day-to-day quality of life so that I can achieve the most positive outcomes.

It is hard to know how much my Addison's has influenced my work and life choices.

I have had many different changes of work and living environments (which is not an unusual part of my career path) and it is difficult to pinpoint one thing or another that made some days, months or years harder or easier than others. So many things are thrown into the mix, including the kind of work I was doing, my personality, what was happening in my personal life, people I was working with, the city I was in, hours of work etc.

I struggled a few times, and an obvious part of that was the long and erratic hours and fluctuating stress levels - this is particularly bad I think when one is trying to get by on an "artificial" steroid regimen. But also part of it was quite possibly that the type of work just wasn't for me – ie. it didn't suit my needs or

personality - and therefore wasn't as enjoyable.

So when people ask me how does Addison's affect my life or work, I can honestly say, "well I'm not really sure, but it certainly is one of many factors in the whole mix". But of course, other people may have obvious and specific things happening in their lives that can clearly be attributed to their Addison's disease. My personal experience is that my quality of life is made up of a number of interrelating factors, so that the sum of it all is probably unique and hard to compare to anyone else's.

Having said that, I'll finish with two points that are probably shared by many other people (with or without Addison's).

Firstly I have found that a workplace environment where you have a certain amount of control over your daily activities, or one that is more pro-active and planned (rather than reactive) is often more enjoyable and manageable, and less stressful.

Secondly, sometimes diagnoses of medical conditions (as with other significant events) are a mixed blessing. They often come with many difficulties, but they can also provide an incentive to make the best choices for oneself sooner rather than later. I am glad that I have thought hard about what I have wanted to do with my life since 1994, and didn't just get swept away with the current and regretted it years down the track.



Marianne's Story: 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 hypopituitarism – 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.

