

New Zealand Addison's Network

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NZAN Newsletter, November 2002 (No 17)

In this issue:

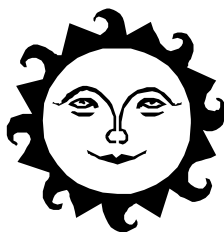
Are you prepared for emergencies?	
• Addisonians their own worst enemies!.....	2
• Letters speak for you.....	2
Are you confident to inject Solu-Cortef?.....	4
Dealing with emergencies, reminder.....	4
Safety tips for travelling.....	5
Membership update, local and international.....	5
NZAN after 6 years, reflections.....	6
Addison's publicity in "Woman's Day".....	7
Bay of Plenty news.....	7
Bouquet for Tauranga hospital A&E!.....	7
Another fan for 7-keto DHEA.....	8
Conference paper: Addison's caused by TB.....	8
White Florinef in NZ late 2003 – problems?.....	8
Distinguishing white pills that look similar.....	9
New UK ADSHG website.....	10
NZAN Website, new features.....	10
Hot Tips from Gary.....	11
Members' news.....	12

From Professor Ian Holdaway, medical advisor:

HRT – risks and benefits for Addisonians?.....	14
Addison's Pills OK on an empty stomach?.....	16

Pamela's story.....	16-18
Other disorders with pigmentation problems.....	18
Ngairé's story.....	19
From Australian Addison's News:	
• Marion's story.....	20

**Wishing you all good health,
Jeanette and the team**



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

Are you prepared for emergencies?

Addisonians can be their own worst enemies!

Addisonians and their friends and family need to understand that a seriously ill or injured Addisonian is in a life threatening situation. Matters don't improve by themselves, and may rapidly deteriorate.

As some NZAN members have shared, the cortisol-depleted Addisonian does not demonstrate a good self preservation instinct!. It's part of the condition. The opposite of "fight and flight" indeed occurs – lethargy and apathy, waiting for things to come right. They linger at home, or sit quietly in a waiting room. The passing wolf would have an easy dinner!

Even NZAN members who "should have known better" have confessed that they waited longer than they should have, to take extra meds, or to get medical help. One recently got a stern telling off by his GP, and his frightened wife!

We need to imprint a simple formula on our brains! – to fight the temptation for apathy, and take action to get more steroid into us as soon as possible, when we recognise the cues.

A serious emergency may never happen, over a lifetime of Addison's. But the challenge is to make sure we automatically carry with us appropriate documentation and back-up medications for the situation. That should help minimise misunderstandings or delays at the reception desk, and with the doctors.

We encourage an accompanying person to follow the advice from Professor Holdaway printed in NZAN newsletter #14 Nov01 – which can be summarised as: be calm and polite, but very firm, repeating as often as

necessary the need for immediate attention, and don't be fobbed off.

Letters speak for you

People with Addison's disease sometimes encounter barriers and delays when they go to a hospital for emergency treatment - whether the reason for going is deterioration in their Addison's, or another serious illness or accident. It's also a scary prospect that a person's Addison's disease might be 'missed' if they are part of an 'ordinary' emergency.

It's a fact of life that the reception staff, the paramedics, or even the doctor on duty may not appreciate the importance for an Addisonian of receiving urgent hydrocortisone and IV fluids.



As you may not have a friend or family member with you in an emergency, it is especially important that the written material you carry speaks clearly for you. Your medic-alert bracelet or pendant (an essential item for an individual with Addison's disease) helps in this regard, but specific written information is also very important and may be life-saving.

The UK Addison's Disease Self Help Group (ADSHG) has recently prepared for its members, and shared with other groups internationally, an emergency letter which could be very helpful in some situations.

The primary purpose of the letter is to alert "first point of contact" para-medical staff to the nature of Addison's disease, and ensure that they give a sick Addisonian appropriate priority for the attention of a doctor. It makes clear that an Addisonian with a serious illness or accident is at risk of sudden life-threatening deterioration.

The letter is available on the ADSHG website www.adshg.org.uk. As not all NZAN members have Internet access, we are including a copy with this newsletter. If you would like a copy with a New Zealand Addison's Network heading, contact Jeanette.

The US NADF also provides an emergency letter for its members, which we have previously published (NZAN newsletter #7, July99). We have it on file, with slight rewording for our New Zealand conditions (see opposite).



Especially if you have other medical conditions as well, emergency letters dealing just with Addison's do not replace a more detailed letter from your doctor (on letterhead and signed, with contact telephone details), which makes clear your needs, and:

- Lists all the medical conditions that you have
- Lists the medications that you take - (drug name as well as brand name, as brand names differ in some countries)
- Highlights your risk of adrenal crisis, and the need to treat any serious illness or accident as a medical emergency. (Details for the management of Addison's disease can be included from one of the emergency letters noted above.)
- Explains how you should be treated in the event of serious accident or illness, for medical conditions other than Addison's, (for example you may also have diabetes, asthma, or other disorders which may also need extra treatment in an emergency.)



We are exploring the feasibility of a National NZAN Conference in Auckland next year, probably May. We'll keep you posted.

(US) NADF emergency letter, slightly modified for local New Zealand conditions:

"Those individuals suffering with Addison's disease, a severe or total deficiency of the hormones made in the adrenal cortex, need specific urgent treatment when entering a doctor's office or A&E centre, having suffered illness or trauma. Addisonians may develop a dramatic change for the worse because of the deficient response from the adrenals to a sudden event like a flu virus, nausea, an accident or other stressful situation. This condition is referred to as an Addisonian crisis and is a medical emergency.

Proper emergency treatment of an Addisonian would include the following:

1. Administer IV or IM hydrocortisone,
2. Administer IV isotonic saline,
3. Continue IM or IV cortisone until oral medication is tolerated,
4. Conditions which must be treated promptly: blood loss, fluid and electrolyte loss, infection, severe diarrhoea, low blood glucose, low blood pressure.

Consultation with an endocrinologist or general physician, preferably the individual's own endocrinologist, is recommended."



Sincere thanks to Annette Church for administrative help and support, including managing our database, and copying and distributing this newsletter,

and to Pharmaceutical supplier Zuellig Pharma, for a further generous supply of stamped envelopes.

Are you are confident to inject Solu-Cortef?

We heard of an unfortunate situation recently, where a teenager needed a hydrocortisone injection, a Solu-Cortef a kit was at hand, but when it came to the crunch, the parent was not confident about giving the injection. Matters didn't flow well with emergency services, and it was many stressful hours before the teenager received the hydrocortisone injection – and the parent got a cup of tea.

Despite what we may fear, giving an intramuscular injection of hydrocortisone is a simple procedure. (See for example, NZAN Newsletter #13, July01) But we need to truly believe that, rather than just hear it!

We plan to cover this topic systematically next time. We have found, for example, that some of the published instructions leave out some practical details.

Also, it can be a source of confusion for New Zealand Addisonians that syringes and needles are often not included with Solu-Cortef obtained on prescription. Some pharmacies do supply syringes, but most people get them from their GP, or hospital clinic. So needles of different length and gauge may be supplied, some of which are easier to use than others, depending on the person's build.

Meanwhile - if you have Solu-Cortef injectible at home, we recommend that you refresh yourself, and the family members most likely to help you, about exactly how you would inject it. If you are unsure, we suggest you talk it through with your GP's practice nurse, or the nurse at your hospital endocrinology clinic – in person or by phone.

When filling a prescription for Solu-Cortef for your emergency kit, we suggest that you ask for a shelf-life of at least 2 years, if possible.

It's interesting context that Addisonians are minority users of injectible hydrocortisone!

We understand that by far its main use is in hospital surgical and medical wards, usually as an anti-inflammatory. Even if every Addisonian in New Zealand used one vial of Solu-Cortef per year, that would be less than about 1% of the total used!

We are happy to email pdf files of our NZAN Newsletters to anyone interested. We are building an e-mailing list of interested GPs and other health professionals. Contact Jeanette.

Reprinted from NZAN newsletter #7, July99:

Reminder: dealing with emergencies

In times of emergency (an Addisonian emergency such as vomiting and dehydration, or a 'general' emergency such as a serious accident):

* INJECT Solu-Cortef BEFORE going to the hospital if possible. The important message is that using the injection can't do harm - but delay may make your situation worse.

* Then pay attention to fluid balance, if possible - drinking plain water is better than nothing, if there has been fluid loss through vomiting.

* Then ensure that follow-through assessment by a doctor takes place as soon as possible, including possible IV therapy for fluid restabilisation.

In other words, just because improvement occurs after the injection (eg the vomiting stops, or you become more mentally alert, and you start to feel a bit human again), don't neglect the importance of getting fluid balance right, or the improvement won't continue!

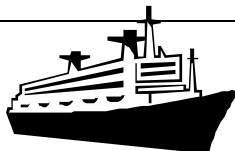
Summarised from NZAN Newsletter #7, July99:

Safety tips for travelling, especially overseas

- Make sure you have enough medications in your hand luggage to last until you can easily get replacements, in case you get separated from your main luggage. Consider taking two full sets – you might lose your hand luggage instead! Keep the medications in containers with the original pharmacy labels. Carry the day's medications on your person, and a bit of extra steroid as well in case of delays or sudden stress.
- One member found that a bonus from carrying with her a signed doctor's letter including her medications and dosages, was that it could have been used to purchase replacement medications no-hassle over the counter (at least in Germany!) - if the baggage had not finally turned up at the end of day three!



- NZAN has on file, emergency treatment information for Addisonians in several languages other than English. (Contact Jeanette) The UK ADSHG is also building up a file of foreign language emergency information on its website.
- The usual emergency injectable for Addisonians is 100mg Solu-Cortef (hydrocortisone). Another option to consider if you really want to head off the beaten track is 4mg dexamethasone, because it will sustain you longer than hydrocortisone - something to discuss with your own doctor.



Membership Update

Membership is now 86. Twelve Addisonians have requested "starter packs" since the July Update (four as a result of the Woman's Day article), and two have become members. Welcome to Murray and Nicole!

Launching International Membership

We've always interacted and exchanged newsletters and information with Addison's support groups internationally.

We send information packs about Addison's and about NZAN to anyone in New Zealand who is interested. The information is now almost all available on our Website too. Our newsletters are posted on our Website, and the information in them from our medical advisors is also consolidated and posted in separate files on the site, accessible to anyone interested. There's a topic index too.

Our website statistics show that a lot of people "come and go" – that's cyberspace! But we've also had some enquiries from people overseas who are interested to join NZAN. So we are offering international membership, for individuals overseas who feel an affinity with New Zealand and NZAN and want to be part of it. We'll be flexible with regard to subscriptions (especially if communications are electronic only). International members won't automatically get the members' contact list, but they're welcome to share their questions and experiences through the newsletters.

Our first international member, Sondra, lives on the island of Kodiak in Alaska. Our second, Allison, lives in Tasmania (and is also a member of the Australian Addison's disease Association). She had a crisis last year at Auckland airport, en route to a holiday in Noumea, and spent four days in Middlemore Hospital - very well cared for, she told us. That story will be in a newsletter soon.

NZAN after six years: Jeanette's reflections

NZAN is six years old this month. It has become a resource of comprehensive and practical information and experience for individuals in New Zealand with Addison's disease.

We draw on international contacts and local experience to provide information about managing the disorder, and tips for minimizing its impact on everyday life. We communicate via our newsletters, our web site, and in response to personal enquiries.

Groups in other countries have also evolved over the six years. We share resources via the Internet, and are all the richer for that.



NZAN keeps members informed about research and new developments. We guide members about navigating the health systems in New Zealand, and communicating effectively with health professionals. We encourage regional meetings. Hopefully, we help people avoid having to reinvent the wheel.

Some individuals with Addison's feel no need of a support network, and we respect this. They're welcome to access our newsletters and practical information on the website, and they know how to find us.

However, the sharing by members of their experiences, questions and ideas, is a vital component of NZAN. Addisonians can become complacent, and settle by default for less than optimal wellness. Several members have told us that they look forward to the newsletters, and the helpful information they provide.

Members have told us in survey responses that they especially value the input from NZAN's medical advisor, and enjoy reading the personal stories. In other people's stories they often recognize part of themselves. Belonging to the Network helps make the Addison's experience less lonely.

We put Nicole, our most recent new member, in touch with Karen, another mum in her 30s with a young family. "So nice to meet Karen when she was in Wellington last week on a course. I was on such a high after our meeting on Monday evening, I managed to 'crash' on Tuesday and couldn't even tidy the breakfast dishes, so my mum came to the rescue and between the two of us we managed to put my house back in order with two boys in tow! Quite an achievement. But really valuable to meet with her. I can't wait until the group has the next meeting. Any idea of when this may be?"

Overseas News and Newsletters A change to our system

Since NZAN began, we've regularly included with our newsletters, some from overseas Addison's disease support groups. That no longer seems realistic. One reason is that we will drown in paper! We've deliberated, canvassed opinions from those members on email, and have come up with this plan:

We're not including overseas newsletters this time. If you'd like to receive printed copies as previously – that's no problem, just contact Jeanette. For some of the overseas newsletters, email is an option too.

Starting with the March 2003 issue, we'll include an International Roundup in our newsletters. We'll also reprint some overseas articles and personal stories. We're including a personal story from Australia in this issue.

We'll welcome your feedback about this plan.

Addison's publicity in "Woman's Day" magazine

Soon after publication of our July newsletter, we found out that the article in the July 29 issue of Woman's Day was part of the material prepared by the Australian Addison's Disease Association, for their Addison's Disease Awareness Week, 6-10 May 2002. We learned that the Australian edition of the magazine had included contact details for the Australian association. After persuasive discussion with Woman's Day in New Zealand, contact details for NZAN were included in the New Zealand edition a few weeks later.

As a result, eight people contacted Jeanette, six with Addison's, one with miscellaneous symptoms unlikely to be Addison's – and one, Nicole, who followed up with her GP and an endocrinologist, soon had a diagnosis of Addison's confirmed, and became our most recent new member.

We will feature Nicole's story in the March Update newsletter.



Bay of Plenty News Colleen's meeting report, 29 July 2002:

"Almost a year after our first meeting, five of the nine local Addison's Network members gathered in our apartment for an informal get-together, with apologies from the absent members.

All said they enjoyed catching up and meeting everyone, including Katrina and Ray who had joined the Network during the year.

Diane and I steered the subjects, generally following the format of our last year's meeting.

Starting at 1.30pm and with an afternoon tea break, we finally wound up at 4.30pm. The time went very quickly and all participated,

with subjects discussed covering DHEA, injectables, hospital experiences, etc.

All are in favour of a meeting at a later date following some publicity through the local media to locate those who are not aware there is a support group in this area.

I have handed over to Diane who will now be the Bay of Plenty co-ordinator, and I know we'll be in good hands."

From Jeanette - thank you, Colleen, for the energy you have put into the Bay of Plenty meetings, and introducing local members to each other.

Diane found out about NZAN just two weeks before the first Bay of Plenty meeting in September 2001, although she'd been diagnosed with Addison's 21 years earlier. Her report of that meeting, including her experience with DHEA, was in the November 2001 newsletter (#14). She said: "I look forward to more contact with NZAN - newsletters and more meetings, as one thing the meeting spelled out to me was, we need to be informed as individuals about our condition so we can make safe decisions for ourselves, and we can do that through sharing experiences."

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



Bouquet for Tauranga hospital A&E

One Saturday in August, Colleen was out shopping with her husband mid-morning in Tauranga. "With no warning I started to feel sick, attempted to make it back to the car, but only managed a few yards before I started to pass out. Graham got me to a table in a nearby café before I passed out, and I believe I didn't seem to "come round" so an ambulance was called – most embarrassing. The people in the shop were really helpful. I had a few tablets in my locket (the one we

described in the July02 newsletter, #16!), and Graham ducked home to get some more – I didn't take any then, because people were concerned I mightn't swallow them properly. I was in A&E for four hours – got A1 treatment. I was improving by the time I got there, so didn't need an injection, but the hospital staff had got my notes, and were in the picture. They were happy for me to have the hydrocortisone tablets as I wanted – I think I took 30mg. They wanted me to stay until I settled down – a very pleasing attitude.” (Colleen is early 60s, and has secondary adrenal insufficiency and some other conditions to contend with.)

* If you have a good or a bad experience at a New Zealand hospital or emergency clinic, please let us know.

Another fan for 7-keto DHEA

In the July 02 newsletter (#16) we mentioned 7-keto DHEA, and one female member's good results with it. It's a patented modified form of DHEA which is claimed to have the benefits of DHEA, but can't convert to the sex hormones estrogen or testosterone.

Another member in Northland is now taking 7-keto. Ian, active, in his mid-seventies, had reluctantly stopped taking DHEA (25mg daily) after a year, because it seemed related to prostate discomfort, and a rise in his PSA blood test. From September 01 until August 02 he didn't take any DHEA, and felt a drop-off in well-being.

Then he decided to try 7-keto DHEA. After a month, his feedback is positive – “I believe it makes a difference, I feel more alive and happier about life, more energy”. There is no downside that he is aware of. Importantly, he doesn't have symptoms of prostate discomfort, as when he was taking DHEA. With just anecdotal information to date, it's not possible to say whether 7-keto DHEA or DHEA has the stronger beneficial effect. But Ian feels the choice is clear for him, and he'll keep taking the 7-keto. [For more information

about 7-keto DHEA, contact Ian on the members' contact list, or Jeanette]

Conference presentation: A case of Addison's caused by TB

Dr Elhan Reda, endocrinology registrar at Waikato hospital, gave a paper about Addison's disease at an endocrinology specialists' conference in Adelaide, Australia, in September. She presented the case history of a Maori man in his late 50s whose Addison's disease was diagnosed this year, caused by tuberculosis.

TB was the cause of most cases of adrenal damage in Thomas Addison's day, but due to the decline of TB in most populations today, autoimmunity is now the most common cause of Addison's disease.

White Florinef in NZ - not before late 2003

We have previously alerted members that the colour of Florinef tablets is being changed from pink to white. (Yet another little round white pill!)

The word from Bristol Myers Squibb Australia is now that white Florinef won't come into New Zealand before late 2003.

White Florinef: Problems in the US?

White Florinef made by BMS Australia has been available in North America, Canada and Malaysia, for about a year.

We understand from our discussions with BMS Australia, that the only difference between the pink and the white tablets is the removal of the dye. There is no intended difference in the way white Florinef works for Addisonians.

Several Addisonians in North America who post on the www.healinglight.com Internet forum, have been changing to white Florinef over the past few months. After making the change, a few have reported becoming unwell, and needing major changes to their dosages of Florinef.

There has been a lot of Internet discussion about this during late October and early November. The situation is being evaluated by the company responsible for marketing Florinef in the US, (King Pharmaceuticals).

Whether the problem is indeed related to the tablets, and whether it may be related to batches, or is inherent in the new formulation and tablet-making procedure, remains to be clarified.

BMS Australia have told NZAN that there doesn't seem to be a common thread to the small number of complaints that have been forwarded to them, by King Pharmaceuticals. At the time of publishing this newsletter, the puzzle has not yet been solved. BMS Australia will let NZAN know the outcome, and we will update members in our next newsletter.

We recommend that Addisonians follow our previous suggestion, to always keep a buffer supply of hydrocortisone (or prednisone, or cortisone acetate, if that's your glucocorticoid) and fludrocortisone – i.e. **don't wait until you have almost run out before filling your next prescription.**

One benefit from this strategy is that, in the event of a brand or formulation change of a medication, when you fill your first "new" prescription, you'll have 2-4 week's supply of the "old" pills on hand. If you suspect the new ones are not performing as expected for you, you'll be able to switch back to the former ones to clarify the situation.

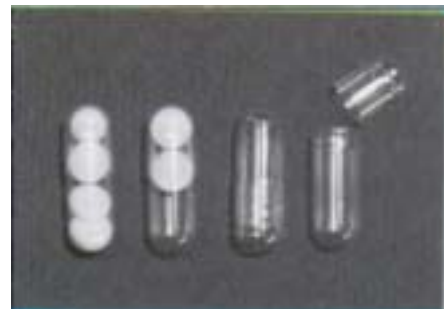
It seems that the white Florinef pills now in the US may be more difficult than the pink ones to cleanly break into halves and quarters – and Lois, our member in Malaysia, agrees. If you need to split pills like Florinef, a pill cutter purchased from your pharmacy may do the trick most easily.

Generic Fludrocortisone now available in the US

A generic fludrocortisone (Fludrocort), is now manufactured by Global Pharmaceuticals. It was approved by the FDA for release in the US in March 2002. Dr Margulies, medical director of the US National Adrenal Diseases Foundation has noted in the most recent NADF News that he has seen no differences in performance of the generic Fludrocort and the brand name Florinef. We've seen no reports of problems with Fludrocort. The generic is not registered in New Zealand – but we will keep our eyes and ears open!

Distinguishing white pills that look similar

With hydrocortisone, prednisone and new Florinef all being white and of similar size, we face a greater challenge for distinguishing between them. We remind members of the ideas in Newsletters November 2001(#14) and March 2002 (#15).



Size 0 capsules – shown actual size.

The capsule on the left contains, top to bottom: 1mg prednisone (P), 5mg P, 0.1mg Florinef, and 5mg hydrocortisone (HC). The second capsule contains, top to bottom, 5mg HC and 0.1mg Florinef

Not many people requested samples of the gelatin capsules Size 0, 20mm long and 7mm diameter. They can be easily opened, the pills put inside, and then reassembled. They can be swallowed intact (they dissolve quickly in the stomach), or can be pulled apart and the contents swallowed. (See Newsletter 15 for details – Jeanette still has some samples for anyone interested to try them.)

Jeanette is a fan for the ‘pull them apart’ strategy when away from home.

NZAN member Graeme is a fan for the “swallow them whole” strategy. His wife Jewel recently shared:

“The capsules have been great and I would appreciate if you could send me some more because I am just about out of them. Since Graeme has been using them he has not suffered the pain and discomfort in the oesophagus area that he used to. That used to be a huge problem for him. Also Graeme finds the capsules are most convenient for taking medication when out. The capsules have taken the hassle out of his 93-year old father's day too. Family members make up his daily medications in advance so he only has to take the capsule, and not put together several different pills.”



Addison's disease websites

New UK ADSHG Website

The UK group has launched its new website, at www.adshg.org.uk (also accessible from the Links page on the NZAN website).

There's a wealth of practical information for Addisonians. We recommend that you explore it, and bookmark it for return visits. It's great that the national support groups can share each other's efforts.

NZAN member Linda, a teacher, found the “What to do in an emergency” information on the UK web site ideal to meet a sudden need in her work situation. She'd explained to the office staff, what to do for her in an emergency. But such instructions were meant to be in writing!

Linda remembered the “emergency instructions” that she'd seen the previous evening on the UK website. She cut and pasted them, standardised the format, printed them, and they were on file in the medical folder when the School ERO team arrived later that day! Other NZAN members may consider pasting and printing this information for lodging at their workplace.



NZAN Website - new features

- ‘Notify me’ when new material is posted
- Google website search trial

Our website remains simple, and seems to effectively meet our intentions. It says why we exist, how to contact us, and is an access point for our information and newsletters. We've received good feedback about its speed and ease of navigation.

We have recently added two features to the Newsletters page of the website:

1. If you would like to be notified by email in future when new material is made available on the newsletters page, send Jeanette an email by clicking on the **Notify Me** button.
2. We are trialling the Google website search facility, on our newsletters page, in a low-key way. It may be helpful, in conjunction with the Index File. Unfortunately it does not pick up all the occasions a key word or phrase occurs in our pdf files. But it does capture quite a

few! We'd like to know whether or not you find it helpful! Sponsored ads, over which we have no control, may appear on the pages of search results - eg selling DHEA, when one uses DHEA as a search term.

On a practical note, a few months ago, a gremlin crept onto the site for a while, making some newsletters unable to be downloaded by some users. If you experience any glitches using the website, please contact Tony, our webmaster (click on the button on the website), or Jeanette.



Found some good websites recently??

Cyberspace is awash with information. Filtering the authoritative from the dubious is always a challenge. Some sites challenge us to think, discuss, and ask more questions.

Please share your "finds" !

Regarding stress management, Jeanette found some useful reminders and practical tips very relevant for people with Addison's disease on the website www.heartcenteronline.com. [Enter the "patients" section, and then, in the bottom left, choose the topic "stress".]



Hot Tips from Gary

Summer is almost with us – so we need to give some thought to keeping injectable Solu-Cortef and spare tablets away from extremes of heat. In the Box below we're reprinting tips from Gary Roselli, our pharmacist member, that were first published in NZAN newsletter #11, November 2000.

As noted then, insulated containers can sometimes be useful. These are marketed particularly for diabetics who need to protect their insulin. One website offering these is www.medport.com.

However, Gary suggests a simple, effective alternative - ask your pharmacist for one of the zinc-lined "disposable" bags in which insulin supplies are delivered. These usually also have little chilly pads inside, which could be useful in some situations to prolong the effectiveness of the insulation. If you can't get one locally, contact Gary (04 565 1783) – or Jeanette.

Don't bake your medications

It is helpful to have spare caches of our meds (e.g. hydrocortisone, prednisone, Florinef, and in some circumstances Solu-cortef). But they are damaged by heat and light, and the manufacturer's original packaging clearly states to store below 30°C.

Baking in hot cars over an extended time can seriously reduce the potency of pharmaceuticals, so should be avoided. The worst areas for heat build up are the glove box, dash, and boot. Insulated containers can help. But it's a better plan to store a few spares in each of the handbags or business bags we are likely to use.

A day's supply, and some extras in case of delays, can be carried in a little bottle in a pocket – preferably a loose pocket, and not one close against the body such as a chest pocket or tight jeans. To minimise the impact of heat damage on these pills, use them up and replace them frequently. "I wouldn't carry pharmaceuticals in my pocket for more than about 4-5 days," says Gary.

TOPIC INDEX: NZAN NEWSLETTERS

We included an index of the main topics from all our newsletters to date, as part of the March 02 issue (#15).

The index is also on the NZAN website, updated with each new issue.

If you'd like a printed up-to-date copy, contact Jeanette.



Members' news

How's your fitness programme?!

There's no doubt that regular exercise and a good general level of fitness benefit the general population – including people with Addison's disease.

Dyan (our member born without adrenal glands) has the Certificate to prove that on the 5th October she joined 400 others for the annual 10km fun walk, starting at the Gleniti Tavern, then through the scenic reserve and the streets of Timaru. She finished in a commendable 1¾ hours. "I'd been meaning to do it for years." Dyan, late-twenties, walks a lot anyway, so didn't need extra training, just careful planning – some extra hydrocortisone and attention to plenty of fluids on the day.

Darren, nudging 30, reports a particularly trying time this year with a few colds and an elbow injury, all occurring around the same time. But he has found that persistence and "determined patience" with his exercise programme has paid off.

The injury necessitated implementing the exercise programme very gradually. "But this can be a good thing for anyone just starting - make small improvements every day or week and you won't even notice the change.



"Running and exercycling have been OK, but I've also started some weight training again, which has been frustrating to start at such low weights for so long. But the patience has paid

off, and now my elbow feels much better and stronger. Now I am doing weights (not so small) every second day and cardio every other day in between. I am a bit "gym averse" so we got a basic weights bench at home, and you can really do a lot with a simple set of weights. Even just some dumbbells are a good place to start.

"I don't always enjoy the exercises themselves but am getting more enjoyment out of each session the more I do - it gives me a positive "buzz" to know that each time I workout I am improving my fitness and strength, and this keeps me motivated (and knowing that my stronger elbows will be less prone to another injury!).

"It often helps to have a specific goal, and it doesn't have to be big. Right now I'm aiming for what I'd consider "normal functional use" of my elbow so I can go kayaking and play tennis again, and being able to comfortably run for 30-40min. It has been a long haul, but moving in the right direction is what counts! PS - finding a good physiotherapist also does wonders!

"It's hard to know whether or not my increased attention to regular exercise helps with my Addison's. Regardless, the benefits of exercise are well known for all people and any positive returns from it certainly lessen the overall "burden" of nasty health surprises (which Addisonians definitely don't need!)."

Joy in Southland (phone 03 206 6806, email: tomjoy@xclear.net.nz) would like some tips or stories from people who have successfully lost weight while still maintaining their appropriate Addison's medication. Please send them to Jeanette too, for sharing with others through the newsletter. [We've heard that some people have found that after stopping HRT, weight is easier to take off, and keep off.]

Jeanette is still going to the gym every other day – almost. Sometimes it’s hard – but she knows it’s important!



Kathryn is another locket fan. In the previous newsletter, Colleen described the locket she wears containing spare pills. Each morning, Kathryn puts her day’s supply of pills into a locket too – which then goes into her shorts pocket. [At the family’s native timbers business, shorts are her year-round dress, so appropriate pockets are a must!] “Filling up fresh each day, I can see if I’ve missed any. If so, I take them later that day – or else the next day. I’ve found that I can’t just go without them.”

Jill (one of NZAN’s co-founders) is back in NZ in early December, after two years in the UK. But she is on the move again – early January her husband takes up a new position in Sydney. Her new contact details will be on the March 2003 members’ contact list.



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

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



The members’ contact list is enclosed with this newsletter.

If you see any details that need changing, please let Jeanette know.



From Professor Ian Holdaway, NZAN's medical advisor:

In response to questions from
members:

1. HRT – what are the risks and benefits for Addisonians?

Question: "A member now in her early 50s with primary Addison's disease asks whether HRT is safe for her situation. She has taken HRT since early menopause in her late 30s. Her mother was diagnosed with breast cancer aged mid-50s."

Answer: Hormone replacement therapy (treating females with estrogen therapy during or following menopause, or after removal of the ovaries) has become a hot topic following announcement of the findings from the Women's Health Initiative study in the USA.

The issue is even more relevant for those with Addison's disease since there is sometimes an interaction between HRT and glucocorticoid treatment.

The WHI study found that there was the expected small increase in risk of developing breast cancer with HRT (this had been found previously in analysis of observational studies), and lowered risk of hip fracture (as also known from previous data).

However, the surprise finding of the study was that the risks of clotting in the veins, as well as heart attack (clotting in the coronary

arteries) and stroke (clotting in the arteries in the brain), were all slightly but significantly increased in the group treated with HRT compared with controls given dummy tablets.

The previous observational studies had suggested there might be protection against stroke and heart attack when taking HRT, but in retrospect this may have been because the women in the earlier observational studies were a healthier group to begin with.

The WHI study used a standard type of HRT comprising a combination of estrogen (0.625mg premarin) and progesterone (2.5mg medroxyprogesterone) combined in a single tablet, taken once daily, compared with placebo tablets.

The results can probably be applied to women of European extraction aged 50-65 in western countries; whether the results apply to all forms of HRT (patches, different types of progestin tablets, those on estrogen alone etc) is also uncertain, but it is probably wise to assume that the findings are generalisable.



The findings of the study indicate that:

1. HRT should not be taken with the sole purpose of protecting women against the risk of heart disease and stroke, or as a general panacea against the effects of aging
2. Use of HRT for a year or two to treat severe hot flushes or other menopausal symptoms is probably safe, and occasional women may need to stay on treatment for a longer time if these problems recur on stopping HRT. Whether some of the "natural" therapies sold over the counter will be effective and safe for this purpose remains uncertain, but they can certainly be tried if the individual wishes.

3. Local estrogen creams are likely to be safe for those with vaginal soreness or other local symptoms.

4. Some individuals at high risk of osteoporosis or fracture may, on balance, be best treated with HRT, but this is a decision to be made with a specialist or GP after bone density assessment and consideration of other treatments for the bones.

5. Some women feel generally better on HRT and are reluctant to stop treatment - again, the decision on the safety of continuing therapy is a balanced one, to be made on discussion with their doctor. The "added" risks of taking HRT are relatively small, and some issues such as the breast cancer risk can be partly addressed by regular mammography and a healthy lifestyle. Although there were more "events" in the HRT-treated women in the WHI study (19 extra events per 10,000 women treated per year) the overall mortality was no different between the HRT and the placebo groups.



Although there has been a suggestion in some studies that women with Addison's disease may have slightly lower bone density than average for age, overall there is no "special" indication for HRT in Addison's females, and their decisions should be as for the general population.

However, the age of menopause may be earlier than average in those with Addison's disease (as with the woman in the question above), and HRT may be considered. One way of looking at this is that nature usually intends most women to have normal estrogen levels up to about age 50, so if periods stop before then HRT should theoretically not increase their risk over and above that due to nature itself. The WHI study was undertaken in women aged 50-65.

Oral estrogen tablets cause approximately a 30% increase in the "half life" of cortisol in the bloodstream (the time taken for the blood concentration to fall by 50% after a dose of hydrocortisone has been absorbed, usually in the order of 90 minutes or so). Thus, when starting HRT, women with Addison's disease may be able to slightly reduce their dose of hydrocortisone, perhaps by 5 mg or more.

Similarly, in those stopping HRT, the dose of hydrocortisone may need to be slightly increased by the same amount. Symptoms of lack of cortisol (increased fatigue, nausea, indigestion, dizziness), or a lowering of blood or urinary cortisol levels, may give an indication of this. Often very little or no adjustment is needed, but occasionally stopping HRT can lead to loss of control of Addison's disease, and adjustment of treatment is needed.

It is a good idea to have some checks with your doctor when stopping HRT, and a gradual reduction is often best, rather than suddenly stopping treatment. How gradual depends on the individual and their tendency to hot flushes etc – in general, reduction by 50% for 1-2 months, then by 50% again for the same time before stopping completely.

If there is a strong family history of breast cancer (2 or more close relatives with the disorder) then an individual's risk of themselves developing breast cancer is increased, and extra care is needed if considering HRT treatment. The individual in the question above has only one first degree relative with breast cancer, and does not require special surveillance over and above routine mammography.



Is it OK to take Addison's pills on an empty stomach?

Question 2: "Is it safe for Addisonians to regularly take their morning dose of hydrocortisone with a glass of water as soon as they awaken, on an empty stomach? I have heard conflicting advice. Would the advice be the same for hydrocortisone and for prednisone for Addisonians? On my prednisone label it says "take with food". When I talked to my pharmacist he said that's automatic from the computer, because most of the prednisone dispensed is large doses for treating chest infections etc, not small doses like Addisonians take, and large doses can irritate the gut lining. He advised me to talk to my doctor about my Addison's situation. I don't notice any difficulties taking the pills on an empty stomach - does that mean it's OK for me?"

**From Professor Ian Holdaway,
NZAN's medical advisor:**

Answer:

It takes time to absorb hydrocortisone and other corticosteroids like prednisone from the small intestine after swallowing tablets. Taking the tablets with food is likely to slow the absorption rate and delay the benefit of getting your blood levels of cortisol into the normal range. The rate of absorption varies from person to person.

Many individuals with Addison's disease feel unwell first thing in the morning until their blood level of cortisol rises after their first tablets of the day. For this reason we always suggest taking your hydrocortisone (or prednisone) and fludrocortisone immediately on awakening, with a glass of water, and wait a little before getting up.

If you are someone who doesn't notice any problems in the morning, then simply take your tablets after getting up. The water is helpful to wash the tablets well down into the stomach so they will start working quicker.

There is no evidence that "replacement" doses of hydrocortisone or prednisone cause stomach irritation or ulcers (unlike large doses, given for conditions like severe asthma, where peptic ulcers can occur). Similarly, there is nothing to suggest that prednisone is more or less irritating to the stomach than hydrocortisone.

Nonetheless, there are occasional patients who may find that they develop indigestion after taking their tablets; this is probably because they have an underlying tendency to gastritis or ulcer trouble independent of Addison's disease. This problem should be discussed with your doctor, and options include using acid blocker tablets, or having a gastroscopy test to examine the lining of the stomach and obtain samples to see if you have a bacterial infection causing gastritis (*Helicobacter pylori*), which can be cured with special antibiotics.



Pamela's story: Addison's disease diagnosed 18 years ago, when in her thirties

Hi, I'm Pamela. I'll be 54 in December 2002. My Addison's disease was diagnosed in July 1984, when I was 35. The usual slow discovery scenario. It didn't help that my Christmas holiday had been at Mapua (a dress optional motor camp) and that I was very suntanned as a result! I experienced a day at the motor camp when I didn't know what was happening to me. I woke up with no energy and sat in my sleeping bag gazing out the caravan window dozing all day. I was fine the next day. Very puzzling. So after the holiday I visited my Doctor because of major migraines I had been experiencing during the previous year, tiredness and leg pains. His diagnosis was "women on their own

sometimes get preoccupied with themselves - you need to get out and find other interests” Huh! (I was divorced in 1980 – some of the problems I experienced then I attribute to the onset of Addison’s - this could be a whole other story).

So I embarked upon a high energy diet which seemed to help, until July when I felt extremely tired, craved salty foods (instant soups were good - requiring no effort) preferring liquorice and fruit to other food. I had to sit down in shops (just like an old lady) because I couldn’t stand too long, glass doors had to be leaned on to open rather than pushed open. Family did not notice anything wrong – probably because I had withdrawn from the world at the weekends to preserve my energy for work.

I forced myself to get up in the mornings, to stand up, and get washed and dressed. I walked up the stairs using my hands to support me on the steps above (like a monkey) - as it was easier. Looking back it’s a wonder how you get to this state, but it is so gradual that you don’t notice that you are making these changes. Another strange thing was that people started commenting on my lovely white teeth. This was the brown face emphasizing the whiteness of my teeth.



Finally after I had suffered bouts of vomiting, continual tiredness and listlessness, I returned to the Doctor but really only because of an excruciatingly bad earache. He was a bit shocked to see me. I was browner in the middle of winter, than I was when I visited him in February, I had lost a lot of weight, including about five kilos that week - I thought I looked good, slim, brown, film starish (poetic license here!!!).

After blood tests my Doctor phoned me Friday lunchtime, advised me to go straight

home, rest and NOT to do anything! He’d made an appointment at the hospital for Monday at 8.00 am. So I stopped shifting my desk and computer to Monday’s new office, and went home – in a little bit of a shocked state of mind.



Well the boy scout in me thought I’d get the place tidy just in case I died. (Someone had told me a girl she knew had died of Addison’s disease and that was the limit of my information). However vacuuming made me vomit so Doctor’s orders were followed and I rested. Family gathered around to support me. On Monday I was immediately admitted with the diagnosis – you guessed - Addison’s disease.

My classic symptoms were: Mid thirties, freckle spots inside my mouth, body and especially on my legs, Brown marks around my waist and pressure areas and brown palm creases. Unable to stand for long or climb stairs easily. A shrunken heart and other muscle shrinkage, and chemical stuff I didn’t understand like a very low level of electrolytes. I was a novelty at the hospital because student doctors were able to study my relatively rare but classic case. I personally learned a lot because of the students.

After a few days in hospital dripped full of cortisone I was up and about, ringing friends, feeling absolutely wonderful. I had a permanent needle in my arm for blood tests which were taken hourly during the day from Monday to Wednesday. I felt full of energy. I suddenly realized how weak I had previously become. On Thursday, however, after an adjustment to the dose, I had a big down. But Friday I was again up and about and released Saturday morning.

I was back at work on Monday (my Doctor didn't think I required any days off). My life since has been great. The Addison's has not appeared to affect my relationships and one of my boy friends taught me yachting, I've cruised 5000 km, mainly Canterbury to the Marlborough Sounds, and in 1992 our women's racing team was ninth in the National Women's Keelboat Championships. I walk to get exercise, roller blade, and have a two story house in which I leap up and down the stairs upright, and generally have good health.

I participated in the Christchurch DHEA study last year, got oily and spotty but felt great – I haven't been to my Doctor to discuss with him continuing with the DHEA, but hope joint and muscle aches I am experiencing this year may be eased with a small dose, without the side effects of oily hair and skin and some aggressive tendencies. I wanted to experience some time without the drug to see what differences I could notice.

My reaction to alcohol changed during the onset of Addison's. Now I can enjoy a glass or three of wine without developing the migraines I got then. [But if I over-indulge (or sometimes this can just be if I haven't eaten before drinking – this has only happened about four times in 15 years), I can't stop being sick in the morning and have to lie still all day until about 5pm, sipping water until I come right again.]

I have never had a crisis needing hospitalization, although I have been flat on my back for a couple of days here or there. In these instances I just keep taking double cortisone until I start feeling normal again. The flu can sometimes knock me down for a week, so I now take the free flu injection. I have a mostly optimistic view of life and feel generally happy. This year I changed jobs, survived a house fire, bought a new house and have held a Board position in my Zonta club of which I have been a member for 15 years.



Addison's disease isn't the only disorder linked with excessive skin pigmentation.

For Ngaire, whose story follows below, a history of "pregnancy mask" ("chloasma"), and a suspected diagnosis of hemochromatosis ("bronze diabetes"), probably diverted the thinking, and delayed the appropriate diagnosis of Addison's disease 40 years ago.

1. The "great sun tan" even without particular sun exposure, that is a frequent symptom of undiagnosed **Addison's disease**, occurs because the adrenals produce insufficient cortisol, and there is excessive secretion of ACTH from the pituitary gland in an attempt to drive the adrenals harder. The excess ACTH acts on skin cells, leading to the increase in pigmentation, which tends to be 'even', rather than blotchy. Once appropriate treatment for Addison's is underway, the tan gradually fades. The Addison's pigmentation occurs not only on skin that is exposed to the sun – but also in body "creases" and hidden places – the roof of Ngaire's mouth was a typical example.

2. **Pregnancy mask (the medical terms are melasma or chloasma)**, is a fairly common skin disorder, usually affecting women who are pregnant, or taking oral contraceptives or HRT – in particular, those with brownish skin. Its symptoms are dark blotchy skin discolouration found on sun-exposed areas of the face. Typically a uniform brown colour is seen over the cheeks, forehead, nose, or upper lip, usually matching on both sides of the face. Melasma usually gradually fades over several months after delivering a child, or after stopping oral contraceptives or HRT. It may return with subsequent pregnancies or use of these medications. Sun exposure is believed to be a strong risk factor for melasma. It is particularly common in tropical climates. Sunscreen helps prevent it.

3. Hemochromatosis (“bronze diabetes”) is an inherited disorder of excessive iron accumulation, also associated with darkening of the skin. Accumulated iron can damage organs such as the liver, and the pancreas (and so cause diabetes, hence the name). Fatigue can be one of the symptoms. Tests of iron status in the blood can usually clarify whether the diagnosis is appropriate. Before Addison’s was diagnosed, Ngaire’s GP suspected hemochromatosis.

Ngaire’s story

My name is Ngaire and I am 75 years old. I was diagnosed with Addison’s when I was about 35 years old, not long after having my fourth baby. I was one of those women who mask badly during pregnancy [see Box]. There were just 18 months between my last two babes, and the mask had remained on my face.

My husband and I owned and ran a motor camp in Paraparaumu where we both worked. I pushed myself to keep up working, running our household plus caring for my husband and four children. The weight fell off me, my body was badly marked where there was any pressure, and I was a very irritable person to those near and dear to me, but pleasant to customers.

My own doctor suspected “bronze diabetes” (hemochromatosis), but I am not aware of the diagnosis being confirmed, and I was not being given any treatment for it.

My parents lived in Shannon. After speaking to a local post girl with Addison’s and discussing her symptoms, my father pleaded that I visit her doctor.

I agreed, and when this doctor asked why I was visiting, I told him that my father thought I had Addison’s. Naturally he was surprised, more so as my father was not a doctor, but a butcher.

After an examination, he asked if I would go into Palmerston North hospital for tests. I

agreed, and it was soon obvious that I did have Addison’s, and I went onto cortisone tablets.

During this stay in hospital, I agreed to attend a medical clinic, where my GP explained my case, and I was then examined by many different doctors. I even removed my teeth and they looked at the pigmentation in the roof of my mouth! I have since participated in several clinics, to help with teaching of doctors about Addison’s.

The improvement in my health after starting the tablets was miraculous, and I became my old self again.

My skin has stayed dark. My father’s sister also had very dark skin. She lived a healthy life, well into her 70s. To my knowledge she had no chronic medical conditions.

About eight years ago, I was diagnosed with diabetes, and after a short time went onto insulin. The diabetes has been hard to control, and I personally think that the Addison’s contributes to this. However, I am still fairly active. For years I played golf regularly. Now I attend exercise classes weekly, play croquet and also work with my husband in our Early New Zealand museum, including giving conducted tours.

I have worn a Medic-Alert bracelet (No 4457 – just four numbers!) since I was first diagnosed with Addison’s, and this has been a good security blanket.

I found my old Medic-Alert card recently. It says I am a patient on steroid treatment, and records that I was taking the same dosage of cortisone acetate then as I do now (25mg, 1½ tablets), but less fludrocortisone (half to one tablet daily, now I take two 0.1mg tablets in the morning). My family and friends are fully aware of the Addison’s and diabetes, and in any “crisis” I am reminded to take extra cortisone, if needed. I am so happy to live in these times, when treatment is available.



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Marion's Story

A tale of two wives.....

This was the phrase my husband used the other morning when discussing the incredible change in my physical and mental state since the insertion of my testosterone implant.

I wonder just how many people really understand the effect of this hormone on our bodies, (other than the obvious in men!). Testosterone is made in the adrenal glands for women. We only require a fraction of the amount that men are producing of course, however this can have a very significant effect on the body. I have also observed that in the presence of the female hormones there can be a great fluctuation in effect.

The problems began for me some time ago. Having been diagnosed with Primary Addison's in September 1985, a year after the birth of my first child. My health had been very poor since during my pregnancy. In and out of hospital with vomiting and such like. Then a number of physical problems, which were all being treated individually. It was at one stage inferred that I was introspective and a hypochondriac. Thankfully an astute GP (in the UK) put two and two together and got a specialist in to see me, whereupon I was hastily admitted to hospital 'just in time', we were told later.

We emigrated here in 1989 and I have been trying to cope with the hot humid summers ever since! It is not easy juggling the pills and salt tablets and extra water, being able to 'read' your body and symptoms without having to be at the surgery every five minutes.

About five years ago I mentioned to my physician that I felt as though my libido was in my boots and also that I never seemed to be bothered in that department. My muscles were not very strong but then I wasn't really that concerned about that. As we have always enjoyed the physical side of marriage this lack of interest, plus my body's lack of response, was a real concern for both of us. The doctor (male) was not that interested and expressed his opinion that it was usual for a woman of my age (then 39) to feel this way.

Not happy with the state of affairs I decided to bring this up with my lady GP. We will be forever grateful to her for her help in this matter. She took blood tests for hormone levels and although the female ones were fine, found that my testosterone levels were way too low.

Following this she inserted an implant under the skin of my tummy with a just a couple of stitches necessary. The difference was truly amazing. Now it was my husband complaining that he hadn't the energy to keep up with me!! In more ways than one.

Before I used to have a lot of trouble with indigestion too, this cleared up, I can only suggest it has something to do with muscle weakness, in the stomach or diaphragm, as the reflux I was getting cleared up and yet, it does reappear when the implant is due for replacement.

Premenstrual problems had virtually disappeared with this implant but reappear when it is running low. There are lots of other little things that generally make life more pleasant, like having an appetite back.

All in all it has radically changed our lives and I thought it might interest some of the readers out there to know of the availability of this.

We have lived in Rockhampton since our arrival nearly 12 years ago. I have worked as a registered nurse, but am at present having a few years at home full-time. My two children aged 16 and 14 are studying at home.