

New Zealand Addison's Network

www.addisons.org.nz

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March 2002 Survey results

SUMMARY:

ADDISON'S MANAGEMENT

- 48 questionnaires were returned, from 62% of NZAN members. 43 have primary adrenal insufficiency (primary Addison's)
- Of those with primary Addison's, 79% were taking hydrocortisone (HC), 12% prednisone (P), 7% cortisone acetate, and 2% a mix of HC and P. In 1999, 65% of the respondents were taking hydrocortisone.
- The average **hydrocortisone dose** was 23mg. The range was 15-30mg.
- The average **fludrocortisone dose** was 0.11mg, essentially the same as in 1999 (0.12mg.) The range was 0-0.25mg. The most common dosage both years was 0.1mg.
- 18 (42%) had made **changes to their medications** in the past 1-2 years, most driven by less than optimal wellness. Of these 13 (72%) reported the changes were for the better.
- **Hypothyroidism** – the prevalence among the primary Addison's respondents was 20%, essentially the same as in 1999, 19%.
- **DHEA** – 40% had talked to their doctors about it, and six (14%) were taking it. A man stopped taking it when his prostate test (PSA) was reported elevated – the PSA level then returned to normal for age.
- **Solu-Cortef hydrocortisone for injection:** 35/48 (73%) said they were confident about the circumstances in which they would need Solu-Cortef, but only just over half (26/48, 54%) had it at home. Only 20/48 (42%) always took it with them, when away from home overnight or longer. A further 6/48 (12%) said they took it with them sometimes. That left 22/48 (46%) saying they never took it with them. Nine members reported a situation where they'd have been better off to get a Solu-Cortef injection sooner – all nine now keep Solu-Cortef at home!
- **Medication delays in a hospital ward** were reported by only six respondents - although 31 (65%) reported admission to a hospital since diagnosis with Addison's, for diverse reasons.

ABOUT NZAN

- **Meetings:** 33/48 (69%) are keen to participate in a regional meeting in 2002; 27/48 (56%) are in principle able to participate in Auckland, Wellington or Christchurch; 17 would like to attend a smaller meeting in their own area; 16 from throughout the country, volunteered to help organise meetings. Roll on the action!
- **The members contact list** has been used by 29% of respondents.
- **Newsletters:** 58% have read information of direct benefit to them; 92% keep their copies for future reference; 64% loan their copies to someone else (mostly partners and GPs).

Survey Return Rate

Questionnaires were returned by 48 members – that's 62%, a good rate. For the 1999 survey the return rate was a bit higher, 74%. However Jeanette didn't do a comprehensive reminder this time!

Quoting from NZAN's March 2000 Update: "We compared notes with Consumer's Institute. For them, a 40-60% response rate (depending on topic) is typical, with a further 10-20% coming after a reminder. They are quite happy with that. We've been told that most market research companies sigh with relief when they get a 30% response rate."

THE DETAILS:

SECTION 1: ADDISON'S MANAGEMENT

Question 1:

What medications do you currently take for managing Addison's disease? Please write the medications, the doses, and the time of day that you take them.

- hydrocortisone/ prednisone/ cortisone acetate**
- fludrocortisone**

The responses are tabulated in Tables 1-5, together with some of the same information from the 1999 survey.

Note: The summary data in Tables 1-5 are for the respondents with primary adrenal insufficiency - Addison's disease, and one member born without adrenals; also one member with Cushings treated by adrenalectomy. Five with secondary adrenal insufficiency are excluded from the summary tables unless separately identified as 'Secondary AI' One has pharmacological steroid-induced adrenal insufficiency; one has Cushings treated by pituitary surgery; two have secondary adrenal insufficiency due to pituitary malfunction; and for one the diagnosis of adrenal insufficiency was being queried by her specialist. All these were taking hydrocortisone, but no fludrocortisone.

TABLE 1: Comparison of glucocorticoid taken by Addisonians, November 1999 and March 2002

	<u>1999</u>	<u>2002</u>
Survey response rate:	74%	62%
Total number of responses from Addisonians:	37	43
Hydrocortisone (HC)	24 (65%)	34 (79%)
Prednisone (P)	8 (22%)	5 (12%)
HC + P mix	1 (3%)	1 (2%)
Cortisone acetate	4 (11%)	3 (7%)

In the 2002 survey, hydrocortisone was taken twice-daily by 19/34 (56%), three times daily by 14/34 (41%) and once daily by just one person (3%).

TABLE 2: Hydrocortisone dosages March 2002

Hydrocortisone dose (mg)	Addisonians	Secondary AI*
15	4	1
17.5	1	1
20	11	
22.5	2	
25	8	1
27.5	2	1
30	7	1

For those with Addison's, the average dose was 23 mg. (Note: one person taking 20mg was also taking 1mg prednisone. Except in table 1, this response has been included with the hydrocortisone set, as the prednisone was just 1mg.) * see note above

TABLE 3: Comparison of hydrocortisone doses for respondents with primary Addison's, November 1999 and March 2002.

	1999	2002
Total number of responses from Addisonians:	37	43
Percentage of Addisonians taking hydrocortisone:	65%	81%
Hydrocortisone dose:		
less than or equal to 20mg:	44%	46%
More than 20mg, less than or equal to 25mg:	16%	29%
More than 25mg, less than or equal to 30mg:	20%	26%
More than 30mg, less than or equal to 35mg:	12%	0
More than 35 mg	8%	0

Comment about Table 3:

There is evidence of some reduction in hydrocortisone dosage, but further scrutiny shows it is not as dramatic as the table suggests.

Because survey responses are identified, we know which members participated in both surveys, and whether their personal dose changed, and so can do paired comparison. Both respondents taking more than 35mg in 1999, and one in the 30-35mg category were not participants in 2002.

Both respondents taking 30-35mg in 1999 who were also respondents in 2002, had reduced their dosage by 5mg to 30mg.

21 participants with primary Addison's in the 1999 survey also participated in the 2002 survey. Of these 16 were taking hydrocortisone, three prednisone, and two cortisone acetate in 1999. In 2002, the two on cortisone acetate and one on prednisone had made no dosage change; one on prednisone had reduced by 2mg; and one had changed to hydrocortisone. Of the 16 taking hydrocortisone in 1999, nine were on the same dose in 2002. Of the other seven, some had increased their dose, and some decreased it - one had increased by 5mg, one had increased by 10mg on alternate days, one had added 1mg prednisone, and four had reduced by 5mg (included in this four are two who were on 35mg and reduced to 30mg, already mentioned above.)

TABLE 4: For respondents with primary Addison's, March 2002:

Fludrocortisone dose: (mg)	Number	
0	2	(5%)
0.05	7	(17%)
0.075	2	(5%)
0.10	16	(39%)
0.15	8	(20%)
0.2	5	(12%)
0.25	1	(2%)

Average = 0.11mg

(Total = 41, because two dosages were not recorded. The two not taking fludrocortisone have primary Addison's disease.)

TABLE 5: Comparison of fludrocortisone doses for respondents with primary Addison's, November 1999 and March 2002.

	1999	2002
Responses from Addisonians:	37	43*
Fludrocortisone daily dose:		
zero	3%	5%
above zero but less than 0.05mg	13%	15%
above 0.05mg but less than or equal to 0.1mg	51%	44%
above 0.1mg but less than or equal to 0.15mg	8%	19.5%
above 0.15mg but less than or equal to 0.2mg	22%	12%
above 0.2mg but less than or equal to 0.25mg	3%	2.5%

The distribution of doses is similar in each survey.

(*because two questionnaires did not have the dose recorded, the percentages are of 41).

Question 1, continued:

- c) **Does your medications regimen differ now from what it was 1-2 years ago?**

Yes: 18 (42%) of the Addison's respondents.

- d) **If yes, how has it changed?**

The changes involved doses of hydrocortisone and/or fludrocortisone, and/or changes between cortisone acetate, prednisone and hydrocortisone.

- e) **What were the reasons for the change?**

For 14 (78%), the changes were driven by less than optimal wellness. For the other 4, their specialists were proactive with the change.

- f) **Have you noticed an improvement?**

Thirteen (72% of those who made changes) reported the change was for the better. Two said "maybe slightly", and one said no. Two were quite well, but followed their specialist's advice to make the changes, and continued well.

The respondent with steroid-induced adrenal insufficiency, and the two with secondary adrenal insufficiency had increased their hydrocortisone over the past 1-2 years, and felt better for it. (Dosages at time of survey, respectively 30mg, 17.5mg, 27.5mg)

- g) **What other medications do you take on a regular basis for other disorders?**

Nine were hypothyroid, taking thyroxine - 20% of the Addisonians. This was similar to the prevalence in the 1999 survey - 19%. Two reported overactive thyroid, for which they were taking carbimazole.

Some reported taking a large number of medications for other conditions. Marjorie again topped the list with a total of 13 prescription medications daily.

In contrast, 12 of the respondents (28%) were taking no prescription medications other than their adrenal replacement. Six taking just female HRT and/or calcium and/or DHEA made up another 14%. So just over half (58%) of the respondents were taking prescription medications for conditions other than Addison's.

Question 2:

DHEA

a) Have you discussed DHEA with your doctor?

Yes: 17 (40%) of the 43 Addisonians.

b) Do you take it now?

Yes: 6 (14%).

All believed it was a benefit for them. Doses were 5, 10, 10, 20, 25, 25 mg. Another Addison's respondent reported taking 50mg doses occasionally.

One of the respondents with secondary adrenal insufficiency had talked to the doctor about it, but none of the six were taking it. (As production of DHEA is mainly controlled through the pituitary, levels tend to be low in those with underactive pituitary glands, or in those taking high doses of corticosteroids eg for asthma.)

Ian, an NZAN member in his mid-seventies, shared his experience:

"I had been taking 25mg DHEA daily since May 2000. A PSA test in May 2001 was just over the upper limit for my age (6.6 instead of 6.5). [The prostate specific antigen (PSA) test is used to screen for the possibility of prostate cancer.] The resulting physical examination caused considerable continuing discomfort which hadn't occurred with previous exams. Information in the [NZAN] newsletters suggested DHEA may be having an effect, so I stopped DHEA in September 01. No discomfort! PSA dropped to 5.6! My regular test in April showed 5.2, which is what it was before I started DHEA. My prostate is still enlarged, and I still need to get up in the night. But I am not taking DHEA any more. I'd rather be taking it, though – I believe I had more energy."

[Note: DHEA can be converted to the sex hormones estrogen and testosterone. Specialists are aware high levels of DHEA might be a problem for people with a personal or family history of breast or prostate cancer. There is a modified form of DHEA, 7-keto DHEA (patented), which is claimed to have the benefits of DHEA, but it can't convert to estrogen or testosterone. We are not aware of any formal studies of "7-keto" with Addisonians. However, it is available in New Zealand, and at least one NZAN member is a fan for it. She says it helps her energy, stamina, and memory; she copes better with late nights, and has fewer mood swings. For more information about 7-keto DHEA contact Jeanette.]

Kathryn, in her early 60s, takes 25mg. "DHEA has helped with my heat problem and general well-being, and enabled me to reduce my daily hydrocortisone by 5mg."
[See also NZAN Update #15 March 02]

Jeanette continues to take 10mg DHEA, because she believes it has helped her heat tolerance in summer. (That dosage gives her a normal-for-age blood level of DHEA.)

Question 3:

Solu-Cortef hydrocortisone injection:

a) **Are you confident about the circumstances in which you would need Solu-Cortef hydrocortisone injection?**

yes: 35/48 (73%).

b) **Do you have at least one package of Solu-Cortef injectable hydrocortisone (plus appropriate syringes) in your home now?**

Yes: 26/48 (54%).

20/48 (42%) always took Solu-Cortef with them, when away from home (overnight or longer); 6/48 (12%) said they took it with them sometimes. That left 22/48 (46%), saying they never took it with them.

Jeanette prefers the "no-brainer" habit of having Solu-Cortef in the meds bag she takes whenever she is away from home, overnight or longer. She has only once had an injection of hydrocortisone in 28 years of Addison's, except as part of a planned medical procedure – but admits there was an occasion 15 years ago when travelling when good luck was on her side, rather than good management.

c) **Have you ever been in a situation where it would have been safer for you to have received an injection of hydrocortisone, but there was a significant delay in getting some into you?**

Yes, said 9 members. They now keep a supply of Solu-Cortef at hand!

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- Caroline's experience was reported in our previous survey (Update #12 March 01) She didn't realise that the stress of moving house had precipitated an Addison's crisis. The doctor was finally called and he gave her own injection, then into hospital by ambulance for two days. "Being aware now, I think I would be more on to it, and not wait if in doubt."
 - Catherine's experience also was mentioned in our previous survey report. Admitted to hospital in 1998, with vomiting and diarrhoea due to food poisoning, she was distressed by the delay before she received hydrocortisone injection, despite her Medic-Alert bracelet.
 - Ngari's first experience (Update #12 March 01), was a 7-hour delay when admitted to hospital because of vomiting and diarrhoea – she couldn't keep down oral meds, and didn't have Solu-Cortef at home. Medic-Alert ID wasn't

enough to get speedy action, so she resolved to carry a letter from her specialist. In this survey she reports vomiting and diarrhoea again, and delays again at hospital, despite her specialist's letter. She now has Solu-Cortef at home - "in future I think will try to get the injection **before** admittance, but still go to A&E or the medical centre to get checked for dehydration etc."

- Beverley: "I got sick on a flight from Egypt to London coming in to land. Got the injection at my son's home in London and recovered quickly."
- Dyan suffers from migraines too, which can make her vomit or feel very nauseous. "If I am not able to see my own GP, there can be delays while trying to explain what and why I need it. Sometimes they (the GP) even tries to tell me that I really don't need it at all. I've gotten good at insisting and have trained my family and friends to do the same. One major migraine I went to the hospital and the A&E doctor gave me every painkiller in the book but wouldn't give me hydrocortisone. I left without it, and called out my GP."
- Vicki: "I had vomiting and diarrhoea, arrived at hospital about 5.30pm telling them I really needed some, and finally I got it about 8.30pm, by which time I felt pretty sick."
- One member was a hospital emergency for heart problems. "They were aware of Addison's but failed to grasp this should be dealt with first. I went into crisis, which initiated the correct response immediately. Thereafter surgery was dealt with appropriately with extra cover."
- Karel: "gastro problem, doctor was called at 3am. Treated my diabetes but did not give Solu-Cortef despite being informed about Addison's. I was admitted to hospital in a serious condition. It was acknowledged that the Solu-cortef should have been administered, and/or admission to hospital should have been made earlier." [See also Ngaire's experience in the March02 Update.]
- Karen's experience is reported earlier in this issue.

So your excuse might be you are needle-shy?! Rosemaree writes: "I have lived in remote rural areas (Asia), where I injected my own hydrocortisone, and inserted my own IV fluids replacement while friends drove me to a hospital (twice!)."

Question 4

Have you experienced delays receiving Addison's medications when hospitalised?

- a) **Have you been admitted to a hospital since your diagnosis with Addison's?**
Yes, said 31 (65%).
- b). **If yes, have you had any difficulties getting appropriate Addison's medication reasonably on time? If yes, please explain.**
Only 6 reported difficulties. That's reassuring!

Karen's story is earlier in this Update, with comment and advice on a strategy from Professor Holdaway – pages 6-8.

Colleen: When trying to explain to hospital staff that I needed a higher dose of hydrocortisone than stated on the bottle, the bottle was thrown on the bed and I was told to medicate myself. I've done that when in hospital since then."

Gary's slight difficulty getting meds on time, was perhaps compounded by being on prednisone. Prednisone is more familiar to hospital staff as an anti-inflammatory or immunosuppressive, and more commonly used for those purposes than hydrocortisone. "I was asked if I was on a diminishing dose. My dose was scheduled for 9am, and it was difficult to get it altered to earlier."

Jeanette and Marjorie reported problems getting their meds too.

Margaret has had several hospital admissions, but no trouble getting the right meds, she reports. Her story (Update #15 March 02) revealed her love of teaching. Her survey response included this note with "Thought you might like to read a positive experience. About 4 years ago I was in National Woman's Hospital for an operation. While recovering I had a 'low' one morning. I tried to explain to the nurse – a kindly Island lady – the cortisone had been cut down too much. I couldn't face breakfast, I felt nauseated. She was concerned and felt that with my "experience" I probably knew best. She went away and came back to say "yes" you can increase our dosage. I did and after a while when she returned, she was quite amazed at the difference. Next day she came and told me that she had gone home and read up about Addison's. I still admire that nurse. I met her again 2 years later – she still remembered the occasion."

SECTION 2: ABOUT NZAN

Question 5: Meetings with other Addisonians:

- a) **Would you like to participate in a regional meeting for members and their family and friends during 2002?**
Yes, 33/48 (69%)
- b) **If the meetings are held in Auckland, Wellington and Christchurch, would you (in principle) be able to attend one of them?**
Yes 27/48 (56%)
- c) **If you live outside these centres, would you like to attend a smaller meeting in your own area?**
17 members said yes.

d) Are you willing to help organise a meeting?

16 members said yes.

Northland (Robyn, Beryl)

Auckland region (Marianne, Andrea, Karen, Caroline)

Waiuku Karel

BOP (Diane, Colleen, Katrina),

New Plymouth (Vicki)

Wanganui (Hayley)

Wellington (Ngaire, Gary)

Christchurch (Pamela)

Timaru (Dyan)

Dunedin and Southland (Ngari)

Jeanette is happy to offer help, resource materials, and encouragement, where it is needed. We think the format of the Wellington meeting would easily adapt to other centres – see earlier in this Update. Who is going to catch the ball next!?

Question 6: NZAN members' contact list:**Have you ever used this list to initiate contact with another Addisonian?**

Yes: 14/48 (29%)

Some of the comments:

Marianne: "I rang and spoke to four different people shortly after joining NZAN and I have found these contacts very valuable. It was good to hear someone else talk about "my" symptoms that until then had often been met with blank stares."

Pamela: "I met with one person. It was interesting, but I haven't seen them since – not a deliberate decision, just happened."

Bob: "I found that the person I phoned attends the same church as me, and we often compare notes."

Ngaire: "It worked well with another Addisonian from my home town."

Caroline: "Awesome to have this list. Made and kept contact with a girl of similar age – the only one on the list of same age."

Robyn: "I received a lot of reassuring advice and information. Once you've contacted someone, you feel able to contact them again, if necessary."

Question 7: NZAN "Update" Newsletters**a) Have you read information in the newsletters that has been of direct benefit to you?**

Yes: 28/48 (58%)

b) Do you keep your newsletters for future reference?:

44 (92%) said yes, one said sometimes, and the rest didn't fill that in.

c). Do you loan your copy to anyone else to read (eg your partner, your GP)?

Yes: 31/48 (64%)

To whom? 11 to GPs, 18 to partners, some to parents, children, pharmacist, nurses, other care-givers.

d) If your GP or other health professional would like to receive copies of NZAN Updates by email, please write the email address here:

Three addresses have been added to the list.

e) What topics would you like to read about in future newsletters?

Thanks for your feedback. If we can't cover them all, we'll try and provide references. Several respondents singled out the personal stories, and the medical advisor's material. We will do our best to keep these flowing. But for that we need your offer of stories, and your questions for our medical advisor.

Question 8: Ideas?

Do you have suggestions for anything NZAN could initiate, or could do differently, for the benefit of individuals with Addison's disease? (And would you be willing and able to help?)

Food for thought from some of you – thanks!

If you'd like more information about the survey responses, contact Jeanette.

All possible care has been taken with this analysis –
but we recognise that transcription errors are possible.
if anything looks odd to you, you are welcome to follow up with Jeanette.