

New Zealand Addison's Network

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Greetings, fellow Addisonians

Another bumper issue! This month's topics include membership progress and geographical distribution, general snippets, two members' stories, our second annual Members' Survey, and some team changes.

MEMBERSHIP

Since the July Update we welcome nine new members: Margie, Hayley, Jessie, Jeff, Marianne, Anne, Marie, Kathryn and Jennifer. Three found us through last December's Woman's Day mention on the 'Your Help' page. The tally from that source is now 15 people requesting starter packs: 12 of whom have joined NZAN. Margie and Jennifer heard of us from a pharmacist friend. Thanks to Chris (on behalf of Stephen and Michael), Margie, Pamela, Jim and Kathryn for your generous donations. Three other starter packs have also been sent out since the July Update.

We have 64 financial members – only three didn't respond to the 'overdue' reminder. As the number is small, and this is our Annual Survey Issue, we are

keeping them on the mailing list just once more.

DISCRIMINATION AGAINST AUCKLANDERS?? No way!

One member issued the challenge – why are there so few Aucklanders on the phone contact list? Good question! Nearly 100 Addisonians have requested starter packs from NZAN since its launch in November 1996. That's likely to be about one third of the Addisonian population in New Zealand, a reasonably sized data-set.

We've looked at the membership data. Some request to be left off the phone list, so that distorts the overall impression of membership distribution. And what about the geographical location of those who request starter packs, but don't subsequently join?

Using the populations in regions as reported in the 1996 Census, we found that NZAN membership follows regional population densities reasonably closely!

- ❁ Auckland has 30% of the population, 24% of current membership, and has received 20% of all starter packs.
- ❁ Taking Northland and Auckland together: 33% of the population, 32% of the members, 25% of the starter packs.
- ❁ Wellington has 11% of the population, 17% of the membership, and has received 13% of the starter packs.
- ❁ The South Island has 25% of New Zealand's population – and 14% of NZAN's members, and has received 23 % of the starter packs. Specifically, Canterbury has 13% of NZ's population, 8% of NZAN's members, and has received 11% of the starter packs.
- ❁ Two relatively small regions show the sort of clustering that can occur – by chance, and by the operation of an effective local network, where Addisonians tell each other about NZAN.
The Manawatu and Wanganui region has 6% of the population, but has 8% of NZAN's current membership, and received 10% of the total starter packs.
- ❁ Taranaki region has 3% of the population, 3% of NZAN's members, but has received 8% of the starter packs.

Which brings us back to the phone list that triggered this exploration. We wonder how many members have used it, and whether it will be more useful if it includes date of birth (or year of birth), plus age when diagnosed. Members already supply this information on the database forms – if we receive your permission (see enclosed survey!) we will include it in future phone lists.

NZAN at ICE

The International Society of Endocrinology holds a world congress every four years. The most recent was just a few weeks ago, 29 October to 2 November, in Sydney, and was expected to attract between 4000 and 6000 delegates from around the world.

Under the banner of “Australian Endocrine Support Groups”, the Australian Pituitary Foundation, the Australian Thyroid Foundation, and the Australian Addison's Disease Association shared one of the booths. Support groups in other countries were invited to provide sample publications for display. So we sent ICE packs containing copies of our NZAN flyer (updated with the latest membership numbers!), starter packs and our three most recent NZAN Updates. We hope to give you some feedback in the next issue.

DON'T BAKE YOUR MEDICATIONS

Tips from Gary Roselli, our pharmacist member:



Summer is coming – at least that's what we want to believe! It is helpful to have spare caches of our meds (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.

WEB ADDRESSES

With the previous Update, we included a list of web addresses compiled by the Canadian Addison Association.

Despite best intentions Jeanette and Jill have not had a chance to log on to all the sites. We do know that there are a few errors in the addresses. Here are some corrections:

NADF: www.medhelp.org/www/nadf

NIDDK: www.nidk.nih.gov

Australian Addison’s Disease Association:
www.addisons.org.au

If you find any other errors, or any interesting new websites, please let us know.

NZAN SURVEY 2000

The high response rate to the November 1999 NZAN Survey has encouraged us to include surveys as a regular Update feature.

Although we are all at risk of an Addison’s crisis, many Addisonians never experience one.

Overall, Addison’s crises are not frequent and can often be “nipped in the bud” – but if they do occur, they can be a serious emergency.

The purpose of the first section of the Survey is to benchmark how many NZAN members have experienced an Addison’s crisis, and why.

If members are willing, we will share some of the stories in future Updates.

The second section of the Survey contains some questions seeking feedback about NZAN, and its current and potential activities.

NZAN will be 5 years old in November 2001. Would a national conference in 2001 be appreciated and well attended by members? If so, where and when? Rather than a national conference, would it be better to have get-togethers during 2001, in a few regions where willing organisers live, and with an appropriate programme? Or does the current system of three Update newsletters a year, and phone contacts available when needed, work just fine for the majority of members?

Because of Jill’s departure overseas (see below, alas!), we are seeking more helpers to share the NZAN load. Are you willing to contribute your energy, skills and experience? There’s a section on the Survey form that we hope everyone will consider carefully.

Please answer all the questions in the enclosed Survey, and return it **promptly** to:

NZAN,
PO Box 8562
HAVELOCK NORTH

We will publish a summary of responses in the March 2001 Update.

** NZAN’s Surveys provide a “reality check” for members. If there are issues you would like addressed in future surveys, please let us know.

Reminder:

The usual symptoms of an Addison’s Crisis are:

Extreme fatigue, low blood pressure and dizziness on standing, salt craving, and sometimes vomiting and abdominal pain. Symptoms can worsen quite quickly.

The cause is essentially insufficient glucocorticoid (hydrocortisone or prednisone) in the body, often because of increased need, due to e.g. illness or accident, or because the swallowed medication couldn't "stay down". Enough mineralocorticoid in the body (Florinef or natural aldosterone) is important too.

An Addisonian in a crisis, needs prompt IV or IM hydrocortisone, and fluid replacement (usually IV saline).

LIBRARY NEWS

Returning fulltime to the workforce is gobbling Shirley's time and energy, and she is unable to continue as NZAN Librarian. Thank you, Shirley, for being part of the team since NZAN's very early days, and for your systematic cataloguing that leaves a good base to build on.

Meanwhile, for library enquiries, please contact Jeanette.

CUSHING'S SYNDROME BOOK

Cushing's Syndrome is caused by an excess of cortisol production, or by excessive use of cortisol or other similar steroid (glucocorticoid) hormones. (For more information, see, for example, 'what you need to know' on the NADF website – or ask us for a photocopy).

Last year, the Dutch Addison and Cushing Society sent NZAN a copy of their publication "Cushing Patients in the Netherlands". To quote from the foreword, it is "a report of a large scale patient survey, a social-medical analysis of the treatment and the consequences of Cushing's Syndrome as experienced by the patient and the ex-patient. In most studies of Cushing's Syndrome only a limited number of patients are involved and the medical aspect is by far the most important. This survey not only considers the purely medical side of the treatment, but also gives attention to the experiences and findings of the patient. The book

contains information that is highly relevant to patients with [Cushing's Syndrome], and no less so for other chronic users of corticosteroids."

A relatively small proportion of NZAN's members have adrenal insufficiency because they have treated Cushing's Syndrome. Hayley, for example, was diagnosed with Cushing's Syndrome earlier this year, and thorough investigation in July indicated that surgical removal of her adrenals was appropriate.

Hayley read our library copy of "Cushing Patients in the Netherlands" before her hospital admission, and told us afterwards that it prepared her a bit more for what she might encounter. "It was interesting to note, according to the book, that there are 80 symptoms for Cushing's – I counted how many symptoms I had had and arrived at 71. I would recommend this book to anyone with Cushing's as I believe it is helpful in giving an overview of the situation we are in. If I can help anyone with the experiences I have had with Cushing's please don't hesitate to contact me."

**** If you would like to borrow the Dutch book from the NZAN Library, please contact Jeanette.**

WELLINGTON DINNER:

NZAN member Mike is keen to organise a "low key" dinner in a Wellington restaurant for fellow Addisonians, and their partners and friends, to meet each other. The proposed date is Saturday 17 February 2001. Mike will be contacting members in the broader Wellington area nearer the time. If you'd like to attend, we encourage you to contact Mike directly, phone 04 934 7759, email: woods@policyanalyst.com

THIS IS YOUR NEWSLETTER

We have it on good authority that the Updates are welcomed by many of you, so we warmly encourage you to submit snippets, stories, or comments.

Your questions about Addison's will be passed on to our medical advisor for reply through the newsletter. There were no questions submitted for the current issue!

FAREWELL FROM JILL

This newsletter is my last active involvement with NZAN. I'm off to the UK with my husband, Rodger, for 12-24 months. I have thoroughly enjoyed getting to know you all and meeting some of you. I have particularly appreciated my liaison with Jeanette which has blossomed into a genuine friendship. Thank you, Jeanette, for all your support.

Jeanette's Response:

Jill first contacted me in August 1996, with some questions about her newly diagnosed Addison's. We began a burgeoning email exchange. Jill was an enthusiastic participant in the inaugural meeting to form NZAN in November that year.

An action person and an effective communicator, Jill has juggled her NZAN activities around her fulltime career and busy social life, and has always come up trumps. What she agrees to, happens.

As well as helping with the content of all the newsletters, Jill has formatted them, arranged their photocopying, posted them locally and emailed them internationally. She has maintained and sent out the 'starter packs', set up spreadsheets to track the starter packs and subsequent members, and dealt with many phone enquiries from Addisonians.

Thank you Jill, I value your friendship, and I'll miss your NZAN support.

This is our last by-line together!

Wishing all NZAN members the best of health for the Christmas season, and the year ahead.

Jeanette and Jill

ALISTAIR'S STORY:

Alistair's diagnosis with Addison's Disease at the age of 12 was rather sudden. The only warning sign was reducing energy levels over a few weeks, perhaps months. One day he collapsed at school, became unconscious, and was put straight into hospital. "Addison's was diagnosed, and I stayed in hospital some time, while a workable regime was established."

Now Alistair is mid-fifties. Over the past year, some new symptoms have been confusing –involuntary muscular jerking in bed; out walking, suddenly his right leg especially 'gives way' and he falls over. Until last year he umpired senior cricket for 10 years – but he was finding that he just couldn't move quickly enough, his legs had slowed down. Looking back, there had been a slow decline in mobility and stability over 10-15 years.

When Alistair read the adrenoleucodystrophy (ADL) story from the Australian Addison's News, that we sent NZAN members with the March Update, it rang a bell. It arrived just a week before his review with his endocrinologist, and he took the article with him. Blood samples were promptly taken, and sent to Adelaide, and the diagnosis was confirmed. Then numerous tests were organised. The huge uncertainty of ADL is the most frustrating health situation he has faced. His freedom of walking is somewhat restricted now, and he has put on some weight as a result. At about the time NZAN members receive this newsletter, Alistair will be getting clarification from a senior neurologist about his condition.

Just a few months after Alistair's own ADL diagnosis, his 3 year old grandson Sam was admitted to hospital with severe dehydration. Alistair made the paediatrician aware of his own Addison's and recently diagnosed ADL, and also told his own endocrinologist about his grandson's situation.

Bloods were promptly sent to Adelaide, and the dual diagnosis was confirmed for young Sam. ADL is very rare, and can be very difficult and slow to diagnose, if not suspected. The extent to which Addison's itself is inherited is usually not at all clear-cut. But ADL is a more clearly inherited disorder, expressed in males only; females being carriers. So Alistair's only sibling, his sister, and her three daughters are being tested too.

Sam is believed to be the only ADL sufferer in his age group in New Zealand. He is currently being closely monitored with 3-monthly MRI scans. The best treatment to stop disease progression is a bone marrow transplant, and Sam's 14 month old brother is a compatible donor. "We've been told that a bone marrow transplant is likely to be needed for Sam, and it'll be a first in New Zealand," says Alistair. "The specialists are linking with expertise in Adelaide and New York. We've been told that Sam's early diagnosis gives a high probability of successful outcome - if all goes well, he will start school on target at age 5 with his peers. It's made us more like soul-mates. We both bring our bottles of pills out, and take them together."

But back to Alistair's life with Addison's. "When I was diagnosed, I was told it would be necessary for me to adopt a sedentary lifestyle, with little or no manual activity. I followed this advice, and chose to join the accounting profession. During my University days I worked part time for a chartered accountant. Then I worked for

26 years in the banking profession. For the last 10 years I have expanded my accounting client base, and have established a couple of business interests."

"For the first 3 years after diagnosis, I played little sport. But I soon became bored with being the odd one out. The doctors at the 'cortisone clinic' that I attended 6-monthly agreed for me to try swimming first, then cricket, then rugby. I found that I coped well, and developed a very active interest in sport, and for a number of years played senior cricket, rugby and water polo. When my cricket playing days ended, I umpired at senior level for 10 years. I was also interested in squash and swimming, but not competitively."

Since diagnosis, Alistair has experienced only one Addison's crisis. "A couple of years after diagnosis I was at an international Boy Scout Jamboree in Auckland. A 'flu epidemic' hit, I joined the band of sufferers, and was admitted to Greelane Hospital. This was before Medic-Alert, or at least before I became associated with them. As a result I could not get my prescribed medication in time, and went into an Addison's crisis."

Alistair regularly attended the Addison's clinic in Christchurch until he was 23. Then he went to Auckland, for the next 10 years. His Addison's gave no particular problems, he'd get prescriptions when he saw his GP, and he didn't have a review with an endocrinologist until he went back to Christchurch - and that was triggered by something else.

A sports injury in Auckland had required a cartilage operation, and a consequence was deep vein thrombosis. Certainly not the outcome he wanted, but it's not particularly uncommon, he says. He needs to take blood thinning medication permanently. However, Alistair has been in the relatively unusual and "unlucky"

situation of having clots break away on several occasions – always, so far, going to his lung and stopping there, causing pain, easily identified. When having a clot fixed in Christchurch hospital, he mentioned his Addison's, and was promptly put back in the system for 2-yearly reviews. At his first review, his prednisone dosage was adjusted downwards. He was changed to hydrocortisone a few years ago, and now takes 20mg hydrocortisone, and 0.2mg Florinef daily.

In 1991, he had both hips replaced. The surgeon attributed the situation to his relatively high prednisone dosage in earlier years, says Alistair. Looking back, he never needed to adjust his medications despite being active in many sports - that confirms that his dosage was probably on the high side. But the real answer may not be simple, he says. "Subsequent bone density scans have showed no problems in other bones, and I've never broken any bones, before or after that."

For getting through all this surgery, his clot history was far more of an issue than his Addison's! Before the hip replacement could be done, his blood had to be thickened again, that took about 3 months. After the first hip replacement, there was a 3 month wait before the second one. Then his blood had to be thinned again before he could be sent home. But on the date he was due for discharge, the new right hip dislocated. It popped out twice more, and there was no choice but re-do the operation. So he had Vitamin K therapy to thicken the blood for that, and then he had problem with a dislodged clot, but all came right.

After the hip replacements, his work situation changed. He'd been general manager of a bank that was taken over, and he was suddenly displaced. That was an opportunity for enjoyable extensive

overseas travel, all of which happened without any Addison's related problems.

"I consider Addison's as something readily controlled by drugs. My family and work and social colleagues are all aware that I have it, and that I require medication at regular times of the day. They are also aware of my more recently diagnosed problem. I am extremely fortunate to have the degree of caring and support of all of these people. I have led a full and happy life."

KAREN'S STORY

Karen's story was written for the previous Update – but for space reasons we held it over. In the intervening months, Matthew has continued to thrive, and Karen has weathered a hysterectomy, without any extra hassles due to her Addison's. She has also established a 'phone friendship' with another on our members' list. "It was really good to hear first hand how someone else copes, and we've decided to phone each other every now and again for a catch up, and perhaps to meet – she lives just out of Auckland."

When I was asked to write my pregnancy and birth experience for NZAN, I thought that it was really a non-story as it all was very uneventful. Then I realised that perhaps that is what Addisonian women of child-bearing age needed to hear. So here goes...

In the beginning...

As a mother of two young children – then 3 and 19 months – and being heavily involved in a Parents Centre (a voluntary organisation) as well as running a very small secretarial business from home, life for me was very busy (and still is!!).

I remember commenting to a friend that I was worried that I might have cancer as I had lost weight (a miracle for me) without trying and that I was tired all the time and

had lost my appetite (unheard of also!). I only wanted to eat packets of soup, chips and salt. I put it down to stress (as our house had been on the market for six months!) but went to the doctor as I did feel quite low and thought I might have a (very) delayed Postnatal Depression. The doctor tried Prozac for the depression and a blood test revealed a slightly underactive thyroid so he put me on thyroxine.

The diagnosis...

I had a flu which didn't get any better and one day I couldn't get out of bed. I phoned Steve at work and said I needed him to come home as I was vomiting and had a really bad headache, lifting my head was excruciating. When Steve got home I couldn't keep my eyes open and he took one look at me and insisted we go to the doctor. The doctor couldn't register a blood pressure and by this stage I could only stand supported. He told us to get to hospital right away. We dropped our two toddlers off at friends on the way to the hospital and called my parents. By the time we got to emergency I was only semi-conscious and couldn't stand at all. Things are pretty unclear to me from then on for a while as I was not too coherent. I was given lots of tests including a lumbar puncture which revealed that I had viral meningitis. The symptoms are the same as bacterial meningitis but not life threatening. I was in hospital for six days and was seriously ill. I couldn't have any light in the room at all and I spent the whole time vomiting. My headache was still excruciating and every muscle in my body ached. All in all I was not a happy girl. My parents and Steve came to visit – I was too ill for the children to come and we decided that it would be too traumatic for them to see me so sick. The doctors took me off the Prozac and treated me with antibiotics.

They sent me home on the sixth day. I still couldn't stand up and my head hurt so much that when I stood up I practically

collapsed and had to hold it still. After a week I was still no better and still vomiting so I went back to the doctor. He still couldn't get a blood pressure reading and said I was dehydrated and needed to go back to hospital for rehydration. I was in for another few days – still vomiting but my headache was gone. I still didn't want to eat. They sent me home but I didn't get any better and went back again overnight. They were puzzled as to why I was no better. That night a new doctor came on duty and he asked me if I had been overseas recently. When I said I hadn't he commented that for a person who was so gravely ill I looked incredibly tanned and healthy! He then said it was a very outside chance but there was one more test that he wanted to do first thing in the morning before I went home again. This test was a ACTH test but would probably show up nothing. I had the test and then went home loaded down with painkillers, stuff to stop the vomiting and my thyroxine – still pretty wobbly and not feeling too well.

Next was a call from the hospital to come in the next morning at 7am. Once again we headed up to the hospital. They did an ECG and some more blood tests and then the doctors arrived. We were then told that in all probability I had something called Addison's Disease. I had never heard of it. They explained about the adrenal failure and listed the symptoms. It was like a huge "AHA" to me. All those little things that I was always complaining about – individually were nothing but together added up to Addison's. I was not a hypochondriac after all!

I went home again with a prescription for thyroxine, prednisone and Florinef., and was told the hospital endocrinologist would contact me in due course – which turned out to be a couple of months later. In the meantime I was still very weak and not too well and when I returned to my GP he recommended a private endocrinologist. I got an appointment and saw him several

times before being conclusively diagnosed with Addison's. When we look at photos taken before I was ill, we couldn't believe that we didn't notice how my skin had changed – I was practically black. I still do have “quite a tan” and pigmentation all over my body but have been told that will go eventually.

It was a very long recovery and very difficult on my family. I am so lucky that I have such a wonderful husband and parents. My 19-month-old son found it very hard and was very quiet and unhappy for a long time after. I didn't recover fully until December – so it was difficult. My business completely ground to a halt during this time. Steve was able to reduce his hours (he normally works very long hours) and work in with my parents to look after the kids and me. My friends, family and even some people we barely knew came to the rescue with babysitting, kindergarten runs, meals etc. As I was sick from a disease not a surgery, my insurance wouldn't cover for home help and as I had a spouse, neither would the government. Financially and emotionally it was a real strain on my family.

More children?

We were worried that we wouldn't be able to have more children. We had always wanted three or four and I had already battled endometriosis successfully to have the other two. As I was 32 early menopause was a threat, but we needed to wait until I was strong enough and had stabilised on my medication.

I was lucky that once medicated I became stable fairly quickly, but it took me a long time to gain my strength back. From the outset we consulted my endocrinologist and my obstetrician about becoming pregnant. With their support we planned and worked towards being well for our third child. I had fallen pregnant the first time we tried with Rebecca and Samuel, but this pregnancy took us a few months to

achieve. I was very worried that the steroids would harm the baby or that I would have another crisis during the pregnancy. Previously I had gestational diabetes and was concerned about that also.

My third pregnancy

We discovered in June that I was pregnant – due on Valentine's Day 2000. We were over the moon, but I was very ill with morning sickness. Fortunately I always managed to keep my medication down and not become dehydrated. I was very careful with my diet and joined a gym in my fourth month of pregnancy. Fortunately I didn't get diabetes and had a very healthy pregnancy although I was extremely tired the whole time and had lots of fun with my varicose vein!

My obstetrician, a midwife and my endocrinologist oversaw my pregnancy. I saw my endocrinologist on becoming pregnant. He increased my prednisone from 5mg to 6mg daily (4 in the morning and 2 in the afternoon), my thyroxine was doubled from 50mcg to 100mcg daily and my Florinef was doubled too. If I had no energy at lunchtime I could take an extra prednisone at that point. I saw him again at six months and then three months after I had Matthew.

The morning sickness was a real concern. I was told that if I vomited up my medication I was to take it again and if I couldn't keep that down then I was to get myself to hospital to get it intravenously. Fortunately it never came to this.

I took folic acid until the fourth month. I also had monthly blood tests and glucose tolerance tests at approximately 16 and 24 weeks. At 12 weeks I had a scan which showed a very healthy little baby!

During the pregnancy I tried not to focus on what could go wrong but on keeping myself healthy. I made sure that I kept my

fluid intake up so I didn't get dehydrated during the summer months and wound down my activities as much as possible so that I could rest. I needed to lie down for an hour every afternoon, as I seemed to get a real "dip" in my energy levels. My skin also went very dark.

Matthew's birth

As I approached my due date my main concern was that I would go into labour at home alone with the kids and not have time to get to hospital. From 36 weeks I was having lots of contractions and they were getting so intense that several times I thought I might be in labour, but they would stop about 1 or 2 in the morning.

Six days before my due date I dropped the children off at kindy and creche and then went for my weekly check. I was three centimeters dilated and we decided to go to North Shore Hospital that afternoon and break my waters so that the pregnancy could be managed in a controlled environment.

After some running around organising things Steve and I arrived at the hospital at 1.15pm.

The delivery room was a full house. We were assisted by - my midwife (who was newly qualified - Matthew was her first independent delivery!), her supervising midwife, my obstetrician, and three of my friends (one who is a trainee nurse and was observing the pregnancy and birth as part of her studies).

My waters were broken and then they went over my notes and set up a drip and got everything ready in case I dehydrated or hemorrhaged (as I had previously). The only difference I noticed from my other deliveries was that my temperature and blood pressure were taken more frequently and I was ordered to drink water every few minutes.

I went into full labour at about 4pm and delivered Matthew at 5.26pm. No drugs, no tears or stitches. The labour was well managed - I was fine, I didn't hemorrhage and the baby was beautiful and healthy weighing 8lb 12oz. He was in fact my smallest baby; the other two were over 9lb.

The "team" had foreseen any complications and put measures into place to deal with them. One interesting thing was that I requested Voltarin for the after pains but they would only give me Panadol as if you take steroids you can't have Voltarin. I later found out that you can have Voltarin if you are taking REPLACEMENT steroids. So this is worth remembering should the occasion arise!

Afterwards I took three days out in a private birthing unit to "recover" and spend some time with Matthew before real life sucked us back in! I did find this time that the recovery for me was longer. I was very tired but didn't sleep very well.

A pediatrician saw Matthew, as he was born with a natal cleft (a dimple above his bum) which can be an indicator for spina bifida. We weren't too concerned as until that point he had been reaching his milestones and was a healthy happy bubby. He had an ultrasound and it was clear.

When I returned home and to this day things are going well - much better than I expected in fact. The little things (irritability, tiredness etc) could be due to Addison's or my age or the fact that I have three children under five - who knows!

Matthew is a very contented baby - exactly like my other two were. Breastfeeding has been a breeze. I have been reassured that the steroids do not pass into his milk. However I do find it very tiring and need to rest each day (which as

you can imagine is not easy). We are feeding five months down the track and I will continue until Matthew wants to stop. He sleeps through the night and is gaining weight, so we are doing something right.

When I saw my endocrinologist a month after Matthew's birth he reduced my medication (4mg prednisone, 50mcg Florinef and 50mcg thyroxine). This has been fine but I still have to slip an extra 1mg prednisone in the middle of the day sometimes as I just run out of energy. I noticed a huge drop in my appetite when my medication was reduced and lost another couple of kilos. Prior to the reduction I was eating four or five bowls of cereal a day – the last one usually at 11pm. Once the medication went down I was back to normal eating! I started back at the gym when Matthew was 7 weeks old, but the weight has been very slow to come off. Once again it could be Addison's or my age or the fact that he's a third baby!

I do find that I get very irritable and have bad days. To deal with this I have cut down on my commitments and have been very clear to people about what I can and can't do. On bad days I do the minimum and we have lots of reading stories in my bed and watching videos and singing songs. My children are well versed in what Addison's does to mummy and understand if I say that I'm not feeling well today and need to stay in bed or on the couch resting. On a bad day I will try and go to bed as soon as Steve gets home. I do have a very good support network of friends and if I am feeling really terrible I know that I can ask one of them to pick up the kids so I can rest.

I try to do as much as I can when I am feeling energetic – I do one housework thing a day rather than a whole heap. I realise that I am not a superwoman and try not to put pressure on myself to run around all the time. That way my kids are happy

and I am happy. If I get run down and ill then it affects my children and I don't want to do that.

Having Matthew has brought much joy into our lives and we did it with the minimum of risk to him and me. The pregnancy was well planned and very managed. Home birth was out of the question and an obstetrician was part of the equation – ruling out solitary midwife care (which would be my preferred option). The biggest thing is what other (well-meaning) people say - especially when it comes to steroids and pregnancy! Everybody else was far more worried than we were. We felt confident – we had specialised care right from the word go with the specialists and midwives communicating between themselves and with us.

My tips to new Addison's mums would be:

- Be well informed and talk to your endocrinologist and doctors when you are unsure. Feel confident in your choices.
 - Don't be a martyr – make sure you look after you. If you're ok everybody's ok. If you're not ok no one else is. Get enough rest. Eat properly. Take time out.
 - Don't feel guilty. If you need to rest you need to rest. Don't feel guilty about what you aren't doing. Feel good about what you are doing – looking after yourself and your baby.
 - Set up a really good support network – friends, coffee group etc. Parents Centres have a huge parenting support network throughout New Zealand. Hook into help where you can.
 - Enjoy your pregnancy and your baby – it's worth it!
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