

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!!).



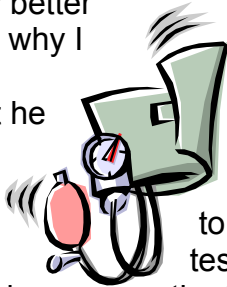
I remember commenting to a friend that I was worried that I might have cancer as I had lost weight (a miracle for me) without trying and that I was tired all the time and had lost my appetite (unheard of also!). I only wanted to eat packets of soup, chips and salt. I put it down to stress (as our house 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 that 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. 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 an 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 vomited up my medication I was to take it couldn't keep that down then I was to get get it intravenously. Fortunately it never



was told that if I again and if I myself to hospital to 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 crèche 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!