

Reader reports from the Food Intolerance Network

www.fedup.com.au

("reflux" keyword only)

[1304] More reports of self harm from food intolerance (February 2015)

My 2 year old daughter has silent reflux and can be in a considerable amount of pain. When this happens she can't/won't sleep at home and throws inconsolable tantrums lasting hours, including self harming behaviour. Getting her medication and food intolerances sorted have pretty much fixed all the issues - Raechel

[1294] Amines make me awful (cranky, reflux, lethargy, tiredness) (December 2014)

No more chocolate or bananas (or chicken skin) for me, ever. Makes me awful (cranky, reflux, lethargy, tiredness). Luckily I don't react to salicylates so there is always coffee to fall back on!!

I have suffered for over 30 years with reasonably mild but persistent issues ranging from reflux, tiredness, foggy brain, itchy skin etc. Doctors have at various times looked at me strangely, given me dozens of blood tests (then ignored me when the tests have come back negative to everything), and tried to prescribe me anti-depressants. No doctor at any time EVER suggested food could be the problem. So far I am intolerant to wheat, amines. Not sure about dairy or soy (will re-test). I feel better than I have ever done (except during the failed challenges!!) and will be forever grateful to your website and the RPAH research.

[1137] "almost no help from the medical profession" with Sandifer syndrome (September 2012)

I have started on the diet, currently supported by the book and recipe book. So far it is quite delicious despite the lack of our usual foods.

I have been forced to be free of preservative 220+ and flavours 621+ for over 8 yrs now because of debilitating migraines. My children exhibit various learning and attention difficulties which are inconsistent in nature (think Dr Jekyll and Mr Hyde). We suspected the little one to have Sandifers (Sandifer syndrome is a paediatric medical disorder, characterised by gastrointestinal symptoms and associated neurological features) as a baby so I went Gluten and Dairy free to help with that and it worked a charm. However I could not figure out if it was the much cleaner diet or the Gluten or Dairy that were a problem. He reacts to flavour enhancers with rashes and difficult behaviour.

Through all our various issues I have had almost no help from the medical profession and when they were trying to help it was usually with reluctance and a lot of talk about how stressed I must be. My hormones, migraines, restless legs and anxiety were always put down to some psychological problem that I knew did not exist. I even had a workers compensation neck and shoulder problem that my then doctor decided was due to stress and not the work desk that I was at. So I have had a gutful of the medical profession and am wary of shelling out more money to specialists.

When I read your book (referred by a friend) I was amazed. It was as though all my symptoms and the boys symptoms were also problems shared by many other people and not a result of my over active imagination. I had suspected our diet for a long time but could not pin it down. I am so grateful just to know that I am not alone in this.

(One week later) On rereading what I have told you it is crazy to think of the issues that I have not even touched on.

This is our second week Failsafe and the seriously awful headaches from the withdrawal seem to have stopped and I am feeling energetic again. I have had a nice comment from the teacher about my middle child - he is being looked at for Asperger's (seriously difficult behaviour) and I thought it would be better to try him on the diet before the \$1000 psychologist visit in November.

The Sandifers is hardly ever diagnosed I think. Many of my friends had babies that had similar symptoms but were all told they had either reflux or torticollis. I watched one friend's baby who seemed normal on waking but as soon as she fed him the neck would twist to the side just like my baby had. She asked her health professionals about it and they either had not heard of it or discounted it completely. I think that is so terribly sad.

I will get on to a dietician to start the supervised reintroduction of foods. However the amount of support you have provided is so good we hardly need it.

Keep up the great work – you are making a difference! - Shannon by email.

[1073] Some feedback from the Fedup Roadshow 2011 (September 2011)

'I failed Tresillian', said one mother, and we heard the same about other baby management centres. Typically, there were extreme sleeping patterns – e.g. sleeping for 30 minutes at a time - with reflux, breastfeeding difficulty or other problems. Yet none of the mothers who spoke to us were warned about salicylate intolerance. This breastfeeding mother was eating a diet exceptionally high in salicylates through foods and supplements.

[993] Low salicylate versus low fructose diet (March 2011)

My 4 year old son' behaviour has always been challenging, but has been particularly bad in recent weeks. After complaining of bloating, diarrhoea etc a breath test revealed that he was fructose intolerant (Note: about 50% of people have a positive breath test, so it is not very useful - [Fructose malabsorption factsheet](#)). So we started on the strict fructose elimination diet. My GP asked me a couple of weeks later how the diet was going. I responded that it was going well and that my son had not complained of bloating, stomach pains, etc since. However the thing I had noticed the most was his improved behaviour. I'm sure my GP thought I was a little odd, and commented that it wasn't something he'd heard of before but perhaps my son's behaviour is better because he doesn't have tummy pains. I wasn't convinced.

After a few weeks, we started a challenge by reintroducing the high fructose foods. He seemed to tolerate them well as long as he doesn't eat too much fruit each day. However, his behaviour has been foul! He seems more angry than ever, and last week I was wondering if he may be ODD. The Magic 123 which worked well for so long, now has no impact as he is just so defiant.

So, I started FAILSAFE eating 6 days ago. We haven't done it perfectly as his diet is very restricted due to food allergies and the fructose intolerance. But I've removed the high salicylate items, particularly tomatoes, strawberries and cantelope; and we're really just having the good old meat and 3 veg for tea every night. I've cut his fruit intake to 1 serve every 2-3 days.

Day 1 perfect behaviour although it was still like walking on egg shells.

Day 2 bad morning, good afternoon.

Day 3 good behaviour a little less eggshells!

Day 4, 5, 6 great behaviour.

When things are good he is the perfect gentleman, well-mannered a real angel. But when things aren't going his way he still gets grumpy but most of the time he can now control the anger. A week or more ago, he just couldn't.

Update 3 months later after doing the elimination diet with a dietitian: Things went really well for some time. However, my son was desperate for some of the non-failsafe foods, particularly tomato sauce and jam. So I gradually caved in, and allowed him to have some. Initially it was a little bit every few days, then a little each daily. Although I'm still careful with his diet, he mustn't be able to tolerate even these quantities as we've started to notice some of the same old behaviour. The salicylates seem to have a cumulative effect on him. Whilst his behaviour hasn't been as aggressive or defiant, I'm certainly noticing that he is loud and unsettled. He can't concentrate on playing with his toys, but instead races around the house and jumps on the furniture! So this week were back on failsafe - strictly! – Carly, by email.

What the researchers say: (See page 14 of the RPAH Elimination Diet Handbook 2009 available from www.allergy.net.au): 'Having excessive amounts of fruit especially fruit juice and dried fruit can cause symptoms such as bloating, reflux, abdominal discomfort, wind and diarrhoea. Although incomplete fructose absorption can cause stomach and bowel symptoms, it does not cause other symptoms such as headaches, fatigue or skin rashes ... improvement of symptoms after going onto a low fructose diet is most likely to be due to the simultaneous reduction of intake of natural chemicals in fruits and vegetables'.

[981] Reflux and GI issues: dairy free probiotic made a huge difference (October 2010)

I was just reading in your newsletter a reference to probiotics and thought I would share my daughter's story briefly. In short, she was diagnosed with dairy allergy at 8 weeks, and was finally skin prick tested at 12 months (after Dr's said it would never show up). She had a huge reaction to the skin prick and was promptly issued with an epipen etc. She is also allergic to soy. Her very understanding and experienced gastroenterologist (she has reflux and GI issues as well) suggested that Lactobacillus GG (available in Aust in Vaalia Yoghurt only) had been shown to assist resolution to food allergy. We imported some from the US (called Culturelle there) and she tolerated it very poorly. Her Dr found out that there was a tiny trace of dairy and this reacted with my daughter.

At the end of last year, in desperation because my daughter's quality of life was so poor, we thought we would give Inner Health Plus dairy free a go. It made an enormous difference to her- she started eating again and was not in constant pain. Today she was skin prick tested again with no reaction to dairy. We are about to do patch tests to look for non Ig-E allergies- but this is at least a step in the right direction. As dairy allergy is largely outgrown by the age of four, it could just be a natural resolution, but I wonder if the probiotics helped, because it certainly made a huge difference to her life in many other ways. – Sara, by email

[901] Has his sights on the Olympic games (February 2010) COURAGE AWARD

We began our Failsafe journey 3 years ago. My now 9 year old was 18 months when the doctors first made the suggestion that he should be medicated. I flat out refused to medicate a little baby, and advised the doctors that food was triggering his extreme behaviour. On almost every occasion I was either laughed at or made to feel a fool and told that 'food doesn't alter behaviour' - this was despite the fact that he already been diagnosed with anaphylaxis to eggs and a severe dairy allergy and

suffered chronic reflux as a baby, and I myself had suffered food intolerance for many years - this went on for nearly 6 years ...

As I wasn't particularly well versed in the ways of the internet and had no idea where to turn, I took things on myself, taking a common sense approach to removing things from my son's diet - if he went 'crazy', the food was removed and replaced with something else that didn't make him 'crazy'... We discovered that wheat was a major player in triggering offensive, violent and extremely hyperactive behaviour and insomnia ... so that was removed, and my son has been wheat free for nearly 9 years now. Whilst the wheat free diet took the edge off his severe behaviors, he was still an unpleasant, uncontrollable child and we tried many disciplinary techniques, play techniques, putting him in sports, we had his eyes and hearing checked and still had no answers.

His severe reflux started again at 6 years old, and once again doctors wanted to treat the symptoms and not determine the cause ... I went along with what the doctors wanted, but the reflux medication appeared to exacerbate the behavioural symptoms. We dealt with the behaviours as they reared their ugly heads, but in addition to the reflux, my son then continued to get more and more physiological symptoms, such as rashes, vomiting, and severe hayfever - I knew this certainly wasn't normal - and he was beginning to have random and bizarre allergic reactions and I had absolutely no idea what he was reacting to. The culmination of these allergic reactions ended up with an anaphylactic reaction, to what has since been determined as an allergy to red meat.

Unfortunately it took an anaphylactic reaction to have to doctors send me in the right direction. We saw a paed who prescribed adrenalin and promptly sent us on to an immunologist ... who explained to us that allergies and food intolerance often go hand in hand. Following all the usual tests and discussing at length my son's behavioural issues we were sent to an accredited dietitian for help and to be placed on an elimination diet.

We found the most amazing dietitian, who was very supportive and was very eager to help. Once I knew what the problem might be, I began my research as well ... and that is where I discovered the fed up website. On the elimination diet and the subsequent food challenges, we have since discovered that my son is completely intolerant to wheat, completely intolerant to amines, completely intolerant to glutamates, colours and preservatives and we have discovered that certain brands of shampoos, toothpaste and hair products trigger negative behaviour, he also has a milder intolerance to salicylates, but we are very strict with what he does have. Luckily, he has grown out of his dairy and egg allergies, which makes the preparation of food that little bit easier.

My son went from a child who slept no more than 3-4 hours a night, couldn't sit still, was compulsive, aggressive, insolent, destructive, hyperactive, would make constant noises, had severe reflux, had eczema, has issues at school with book work and reading, etc, to a child who is pleasant, well mannered, focused and actually sleeps. And it was with the advent of the new diet/lifestyle that we also discovered that my son has quite a talent for sport.

Before the diet, my son didn't have the attention span to stay between the white lines on a running track or didn't think he had to wait for the starter's gun in a running or swimming race. Within the first 6 months of the lifestyle change he went on to represent his school in swimming and athletics, in the next year he went onto represent at regional level and last year competed at state level in swimming, cross country and athletics, for both the school and at club level. And this year, as a 9 year old, my son has already broken records on the athletics track and is on his way to breaking more records in the pool ... he has his sights firmly on the Olympic games in 2020, he just isn't sure which sport he wants to compete in!!

I find that his discipline in his chosen sport helps to keep him disciplined in his diet, and I am very honest and blunt in explaining to him what is in the foods that he wants to eat and why he can't eat other stuff. We are about to begin meeting with our dietitian again to ensure that he is receiving adequate nutrition to sustain the endurance that he requires for his sports and to ensure that he is receiving adequate protein for proper muscle development.

People are often perplexed as to how a child who 'misses out' on so much food can be quite so athletic ... I explain to them that the food he doesn't eat actually enables his sporting and academic ability, but sadly, most people can't understand that concept. They can't understand why my son simply drinks water and eats an apple and some rice cakes or a chicken sandwich after a race when every other kid at a swim meet is eating a chocolate bar or drinking a powerade or the newest fad - pouring honey all over a banana to 'restore their energy'.

We still have bad days, and find peer pressure a constant issue, but as a family we are positive towards all facets of my son's limited diet and I am constantly inventing new and interesting things to eat! - Belinda, NSW

[808] From multiple daily tantrums to none in two weeks of failsafe eating (June 2009)

I have five children aged 1, 7, 8, 10 and 11. It was the behaviour of my 8 year old daughter which prompted me to try FAILSAFE. Since about the age of 2 this daughter has had what seemed like multiple daily tantrums – consistently over 10 per day. Prior to this she was an extremely easy going toddler, but a reflux baby (as were all my children). She was so easy in fact that I used to call her my calming factor in the family and her daycare carer once described her as a little pot plant that you just placed in the corner, fed and watered her and watched her grow.

Earlier this year I reached a rather scary place where, even though I love my daughter to death, I often didn't like being with her because the tantrums would start the moment she got up and seemed to go on until she finally went to sleep at night. I dreaded picking her up from school as it inevitably meant her storming out to me at the car and immediately complaining about something which soon resulted in constant sibling rivalry with my 7 year old daughter increasingly becoming the victim of my 8 year old's assault. The entire household was on edge and her behaviour was extremely disruptive to all of us.

Over the years I have read several parenting books and tried many approaches: reward charts, time outs, consequences, firm approach, soft approach and nothing seemed to work. The bigger she grew the worse her tantrums became, reaching a climax earlier this year when she started to throw any item she could find at any of us. I should also add that over the years my daughter has developed several food aversions.

The turning point for me was when I saw her behaviour change before my eyes after eating food at a party. It suddenly dawned on me that perhaps the food she was eating was affecting her behaviour. That's when I conducted some internet research and stumbled across your website. Despite my family eating what I would call a well balanced healthy diet, I was surprised to learn that there were still several healthy foods which could affect behaviour. The most fantastic thing about your website for people in my position was that I could download The Failsafe Booklet which provided me sufficient information to try the diet out without having to spend money on purchasing books upfront when I didn't know if it would work or not. I started the whole family on Failsafe following this booklet to the best of my ability.

To my absolute surprise, within 24 hours I had a totally different daughter. After 2 weeks of no tantrums my husband was forced to agree that the diet made a huge difference also. I reclaimed my

calm, happy and pleasant daughter which was very emotional for me because I had forgotten how sweet she could be. The entire household was calmer (mainly down to my 8 year old's improvement but I did notice a slight improvement in behaviour in my other children in terms of them being less irritable and more cooperative) and I not only looked forward to picking up my daughter from school again but she would actually skip out to the car and greet me nicely - what a transformation. Her teacher reported her concentration in class was better and the sibling rivalry was what I would call normal. At this point I purchased the books and DVD. The recipe book is fantastic and gave me a larger variety of meals and baking options to choose from, plus a much more detailed shopping list.

I have struggled to keep my family Failsafe, mainly due to time constraints, but there are a few dietary changes which have stuck. For example, I bake my own bread now, my 8 year old daughter drinks magic cordial instead of commercial cordial and uses 100% maple syrup on her toast instead of honey, peanut butter or vegemite/promite, and I purchase Failsafe grocery products whenever I can. She doesn't consume much fruit as this is an area where she has developed several aversions over the years. Overall, we seem to have reached a happy balance whereby we are no longer 100% Failsafe but my daughter's behaviour has improved immensely.

Thank you for your wonderful website and all the incredible insight into the world of additives. I truly had no idea. – Nikki, by email

[682] I was pushed to control cry my son (September 2008) [COURAGE AWARD]

I just wanted to tell you about the startling difference we have seen in my son since removing salicylates. He is now 18 months old and the difference is profound - removing apple alone reduced nearly all of his night wakings, and removing avocado and corn as well has stopped his moodiness, screaming and irritability. His reflux is more under control and he no longer screams during the day and most especially at night. If he does we know it means either he or I have eaten something we shouldn't by accident. I've also determined that he reacts to a lot of additives as well. 160b produces aggressiveness, defiance and screaming within 24 hours. I now have a really happy well behaved little boy. I was pushed to control cry my son due to his poor sleeping, but I knew something deeper was wrong. I'm SO glad I went with my gut instinct that it was food related. – *Taryn, Vic*

[634] Silent reflux, gastro, extreme nappy rash – months of needless medication (February 2008) WINNER OF THE COURAGE AWARD

The writer of the following letter wins our award for persisting despite all the paid 'experts' being against her:

My 13 month-old son has had silent reflux (just weaned him off losec now), and yet still has bad gastro problems - excessive burping, difficulty swallowing/coordination with swallow and breathing, tummy aches (frequent back arching, screaming and night waking all the time). My paed has recommended an immunologist but reading your website it seems we need to do a diet approach for intolerances.

I have always been careful with my diet as I breastfed him avoiding foods that were known to cause wind. I even saw a dietitian out of desperation when he was a little babe - who took my money and told me breastmilk is not affected by what Mum eats. My instincts told me otherwise. I know that strawberries, tomatoes, stock, gravy (to some extent), sausages (two nights in a row), citrus, onion and ham produces bad painful gastro reactions in him. Yet despite avoiding these, our problems still continue. If we eat out, guaranteed he will have a bad night in the next 24 hrs and bad poos for days after. My son has never had a normal poo - even on breastmilk. Acid smell is very common, and it

produces the worst nappy rash I've ever seen with skin completely gone and large patches of exposed sores.

Two weeks later ...

In the two weeks since I first emailed you from sheer desperation, I almost cry every time I think about how my little son's severe gastro problems have so simply and easily disappeared. He slept through the night 48 hrs from our first meal of chicken fried in golden syrup with pasta (the only quick makeshift meal I could make the first night after I emailed you!). His reactions of reflux, pain in tummy, badly burnt bottoms (v. extreme), excessive night waking and festy burps have all disappeared!!!! I have spent the past 13 months in a sleep deprived land (lasting on about 4 random hours a night on average), with my daughter not getting much quality mum attention and my husband declaring 'no more, this is it re: kids'.

Now I have a son who in two weeks has spoken five extra words, gained 600g weight, sleeps hard, eats hard, plays hard (every mum's dream), plus two new teeth - and generally very alert, smart, and most of all, wakes from his sleep playing in his cot – no screaming. Two days after I started with that first crude meal I woke in the morning to hear his toy whizzing around, and not him – a dark cloud just physically lifted from my body and I just knew this was the last piece of the puzzle of our long journey. I continued the diet from the info on your internet site and saw the dietitian you mentioned. The other amazing thing is that my husband is a completely different man (see story [630] 'No need for Beyond Blue due to diet').

I have now seen three dietitians, three paed's and a whole swank of GPs. I could have saved my son months and months of pain and high levels of losec medication. The medical profession has a lot to answer for, not listening to Mum's intuition. We had attended a feeding clinic where they have sessions with a dietitian, speech pathologist, and child health nurse (3 with you and bub) to work out reflux issues. My son had all three problems - still has swallow/coordination problems, and is very very cautious with food textures. So I spent most my time in these clinics (been 3 times already) talking diet - and you know I remembered this morning out of nowhere that the dietitian in these clinics did say something like: 'tomatoes, strawberries, stock - yes they contain salicylates, ahh but you don't need to worry about that. That's too much detail.' I did question her again on it, but I forgot what the 'salicylate' word was at our next visit and ended up sounding stupid. I was nearly there with my list of existing reacting foods but did not have the expertise to link them together. I thought it was acids affecting my son and sugar affecting my husband. Oh well. Move forward. At least I have my husband back again and a gorgeous boy we can all enjoy. :) – Fiona, ACT

[630] 'Depression - no need for Beyond Blue due to diet' (February 2008)

We did the elimination diet for my 13 month-old son (see story [634] Silent reflux, gastro, extreme nappy rash – months of needless medication). The other amazing thing is that after two weeks, my husband is a completely different man. He is no longer depressed, low, moody, disengaged, angry at everyone, abusive to himself (putting himself down). I had been on the verge of asking him to see a GP who is a specialist in beyond blue stuff but now there is no need. Since the diet, he is helpful as anything, has positive comments, is physically touching the kids so much more, is enthusiastic, has initiative and is just an all round changed man!!!! He can feel the difference himself as well. My mum has been blown away with his changed attitude to everyone. – Fiona, ACT

[472] 'Years of difficult days, tears of frustration and questioning myself as a mother' (November 2006)

Two years ago I made the link between certain breads and my then two-year-old's out-of-control behaviour. He had been born with reflux, and at 8 months we found he was allergic to wheat, which later became an intolerance. I have endured countless judgements from people regarding my "theories" that even preservative free breads from the supermarket still affected his behaviour considerably. Making my own bread has had a major impact on improving his behaviour, he is like a different child, but I have been struggling to find compassionate people to help me take the next step in assessing his diet further. He is a great child, but is "more excitable", "over active", "emotional". Many words have been used to describe him but I've always been told that I lack parenting skills and I am hiding behind excuses to explain his behaviour. In your website I have found people that understand me and him. In other people's stories I read my own, countless times. After years of difficult days, tears of frustration and questioning myself as a mother, I feel I've finally found people who are "on my side". I feel validated. – by email, Tasmania

[414] Gastroscopy results and the failsafe approach (May 2006)

Some years ago now, I remember reading a message from a failsafer who'd had a gastroscopy before he went failsafe, which showed scarring and evidence of reflux, and he was put on strong antacids and told he might eventually need an operation (presumably to repair the gastric sphincter).

Exactly the same happened to me. I get the neurological symptoms (depression, paranoia, neurosis, ADD, and visual discomfort dyslexia - which improves but hasn't been resolved), but I also had years of gastric symptoms and had had two gastroscopies before I discovered failsafe eating. The first one showed no ulcer but that the lining was inflamed. After the second I had exactly the same diagnosis as in the story above. I remember the gastroenterologist telling me that although the symptoms weren't typical, the problem was definitely reflux, and suggesting the operation.

After I had been on the diet for some years, I had another gastroscopy to investigate the possibility of coeliac sprue. This wasn't found (thank heavens) but it did demonstrate that the scarring and inflammation that had previously been there was now gone. The diet had resolved about 10 years of painful gastric symptoms for me.

I'm just wondering whether there might be other adults or children who have had the same experience. As people are so keen on physical evidence, maybe someone could pool the results and put out a paper? - reader, NSW We would love to hear from any others with similar stories: please write to confoodnet@ozemail.com.au

[399] Reflux medication causes ADHD symptoms and the Parkinsons shake (March 2006)

Having four children who have all been milk and soy intolerant from birth, intolerant to artificial additives and sensitive to levels of salicylates and amines I've seen possibly every symptom food intolerance can produce raise its ugly head at some time or another. Unfortunately due to either being uneducated or narrow-minded, many mainstream medical practitioners including specialists just wouldn't go the food intolerance path so it took me several years to really get to the bottom of what was happening with my children.

The first symptoms that we came up against were reflux, eczema and a lot of skin rashes. My third child, Jessica, was extremely miserable and seemed to be in a lot of pain. She'd started refluxing from one week and was started on prescription medications. Luckily the paediatrician was able to identify a rash around her bottom as being associated with lactose intolerance so we went the road of trying various formulas until we got to nutramigen which settled her demeanour but did nothing to alleviate the reflux side of things, so we had unwittingly started down the right path. She also had

a constant post nasal drip from very early on so we were shovelling her full of various antihistamine type medicines trying to alleviate that and she had eczema. My fourth child Zac knew that breast milk just wasn't for him so at two weeks he decided to starve himself in preference, refusing the breast. He also was covered in eczema and had silent reflux. Luckily for him he was put straight on to neocate, for during the couple of years leading up to his birth, our family paediatrician who by this point had all four of my children in his care had seen the flurry of symptoms food intolerance can produce.

As my eldest child Levi was still on syrup medication for reflux until just before he started school, his paediatrician felt it would be a good idea to see how he went, off medication. I was able to get him through with the occasional dose of over the counter antacid for a couple of months until he started school when his reflux exacerbated, so the prescription medication was reintroduced. I took him for his paediatric review a few days later and was told to start him on a prescription syrup antacid as well as he'd been complaining of heartburn symptoms. Within 3 days something was going wrong. His teacher asked me what had happened to him, he was bouncing off the walls and displaying ADHD symptoms, being loud and disruptive. I rang his paediatrician and told her that I was taking him off the prescription antacid and told her what was happening. But things were going down hill fast, his ADHD symptoms were becoming worse, his coordination had plummeted and he'd lost all sense of balance (which had never been a problem in the past), he'd fall over for no apparent reason, there were times that he would behave like he was drunk or high, giggling and slouching, and his eyes would zip from side to side really quickly (I was told the medical term, I think it was nystagmus...)

To top it off, Jessica, had started doing the parkinsons shake (she was still refluxing terribly and was also on both Zantac and Prepsid syrup medications). Levi's teacher asked me to have him assessed by an Occupational Therapist who diagnosed him as having dyspraxia, a developmental condition that makes them have to have constant repetition as they have to relearn everything over and over because they can't retain it. I knew that it wasn't a developmental problem as he had always been in advance of his age appropriate milestones and I'd spent lots of time with him, he could climb trees, jump, skip, ride a bike without training wheels from 3 years old, and had great hand eye coordination prior to this happening. All of that coupled with the ADHD stuff just wasn't right. So I made an appointment for the paediatrician (his regular paediatrician wasn't available so I asked for the one that was now looking after my other 2 children). He was dumbfounded. He'd remembered seeing Levi from time to time when I'd had to go for appointments with the others and he didn't have a clue what was going on. So he ordered several blood tests, a CAT scan and an EEG. Everything came back clear. I remember saying to him at that stage that it had all started when the syrup antacid was introduced but I couldn't understand why it was still happening. I of course got a Tsk Tsk for pointing my finger at the medication. So I battled onwards for a couple of months, racking my brain, I rang the reflux support group and the lady I talked to said that her son who was on these medications was also ADHD. I was at my wits end, Levi's symptoms were getting worse, I resorted to ringing the drug company who manufactured the antacid and talked to one of the medics who worked in the lab. She told me that she had heard of this sort of thing happening before and that it was probably due to the alcohol, or the preservatives and flavourings used in the medicine as they are really concentrated in ALL syrup medications. BINGO. Now I was facing a dilemma. How could I treat my children's reflux without the medications, I could see what it was doing to my kids - all 3 were on the same medications. I found a naturopath who made a tonic catering for my children's reflux symptoms. In a matter of weeks I was able to control the older 2 with the herbal treatment alone. Within 7 weeks Levi's ADHD had settled down, his balance and coordination had returned and when we saw the neurologist at this point he agreed that Levi's problems were due to the preservatives and flavourings in the medications and

felt that he was a normal 5 year old. Funnily enough Jessica was cured of the parkinsons shake and Levi stopped falling over.

I at that stage really started to read labels. With careful monitoring I was able to avoid foods that contained artificial colourings, flavourings and preservatives so the kids reflux and behaviour was settling down. At this time you could buy rice milk and oat milk as an alternative to cow's milk and soy so the reflux for the 3 older ones was controlled purely by diet alone. I was able to see symptoms occurring when they'd eat a particular food or have a drink of juice. Jess was still in a flurry with the post nasal drip which would cause a persistent cough where she could barely catch a breath in between. At our next appointment with the paediatrician (I now had only Jess and Zac going), I told him about what foods would cause what symptom and he suggested going into the RPA clinic. So off we trotted, it was a big day that day, we found out Levi was anaphylaxis to peanut (I'd known he was mildly allergic and avoided it entirely) and I was educated about salicylates and amines. We did the elimination diet and with the reintroduction of certain foods it caused chaos. We lived a couple of years of pretty bland, I've found that they certainly improve with age, but I still have to be pretty strict with what Jess and Zac eat.

When Zac was two he was taken off the neocate. Our paediatrician suggested a follow on formula that was cow's milk based but the protein was broken down into small chains. Within days the poor child was on the tantrum rollercoaster, throwing tantrums which generally lasted around half an hour at a time, where he'd hurt himself, belt into things, bash anyone who was around, and he'd have 6 to 8 of these a day. I was genuinely concerned that he was going to hurt himself or someone else. I rang the paediatrician (by now I was well and truly on a first name basis) and told him that I wasn't giving him any more formula and that he'd have to get by on rice milk. Now you can get calcium enriched and vitamin enriched rice milk so that's somewhere else to go if you need to.

I've also seen dairy cause speech problems (this happened to Zac when he was on the follow on formula), tantrums, dyslexia (they can't get their tongue around words, mirror write letters and misspell words), very pale skin complexion, behavioural problems, ADHD symptoms, along with the gummy symptoms, reflux, eczema, and postnasal drip and that's just in my children. I understand that dairy and wheat are now being looked at as being causes for mild autism.

If you're at your wits end, if your child displays any of these symptoms or has a learning difficulty especially if there's something happening with each of your kids, even if their symptoms are different, food intolerance is worth looking into. It runs in families. Dietary modification may be the answer you're looking for. My children are now medication free. If your GP doesn't want to go there, find a doctor that will. You need to be strong and assertive because you're going to encounter a lot of doctors and specialists who think it's all a crock, but you have to ask yourself why are there so many kids with ADHD, behavioural problems, learning difficultiesunfortunately a lot of the food you buy from the supermarket has artificial additives, for the sals and amine intolerant remember that a lot of the fruits and veg that years ago were seasonal are now available all year round not to mention what they do to them to ripen them and keep them fresh, and for the dairy intolerant look to your genes for the answers, there are several races that are known can't tolerate dairy. It may just change your life. - Sandra Madden, Heathcote NSW smadden@iprimus.com.au (Sandra now coaches children with dyslexia and learning difficulties and is happy to hear from others, please put food intolerance in the subject line)

[356] One-liners (Nov 2004)

- Our three and a half year old son is a lovely child with a few difficulties when on failsafe food but before diet, he had enough symptoms to class him as autistic: little or no eye contact, spent hours alone fixated with various objects ie string, sand, wouldn't accept hugs or show affection, constant

tantrums, his development regressed a lot from about 18 months or 2 years with regard to loss of speech, and for quite a while he said only one word repetitively, as well as severe reflux, diarrhoea, eczema and sleep disturbance. – Qld

[337] Jessie's tantrums (July 2004)

My daughter Jessie is three and a half now and from the moment she was born we have had nothing but problems.

In the first three months she was always crying, not able to sleep, she was given medicine for reflux and colic and her formula was changed on a weekly basis. At 6 months she threw her first tantrum, I remember it well as it was over a set of car keys. She was chewing on them and then decided to ram them into the back of her mouth, so I took the keys from her. She turned around and grabbed at my face, screaming and trying to bite. That was the start.

As she grew older she stopped her daytime sleeps well before she was one and moved into bed with me. I didn't mind because she slept so much better. She was never able to amuse herself and would rather sit and scream than do something for herself. She often had ear infections and colds. Before she was two her sister was born, much to her annoyance.

My second daughter was and still is breastfed so both girls were in my bed. Jessie's night terrors were getting worse, and even though she loved her sister she didn't like her one little bit. Once again, I believed the nurses and doctors putting it down to terrible two's and a new sister. Her behaviour got worse as she got older and it was nothing for her to headbutt the cement from one end of town to the other end till her head was blue, for no reason but a toy put in a plastic bag so that she could carry it. When she was three she hit the peak period.

A typical day would start off with her wanting the light on in the morning, so I would turn it on. "Get it off", she would say, so I would turn it off, trying to stop the tantrum. "No, turn it back on", so I would turn it on, and then she would start, "Get her away from me, I don't want her any more" (that's her sister), then the screaming would start and the kicking and the biting and this was from the moment she opened her eyes! She would scream and yell until she wet herself and then just lie in it and scream some more.

When she was finished in the bedroom she would go and destroy the next room. She was so loud that in the middle of summer with the aircon on and all the doors and windows shut the neighbours three doors up could still hear her. After an hour of morning tantrums then it was time for the next one usually over something stupid. The tantrums could last up to two hours with her hitting, screaming and biting herself and me. When she was so angry there was nothing I could do to help her, timeout didn't work, smacking made it worse and holding her was pointless. She would be screaming out for me "mummy mummy I need you" but if I dared go near her "get away from me, I don't want you" and she would hurt me with what ever was closest. Not a day would go by that she was not like that all day, in fact out of a whole 12 hour day I would say that she would be calm for about 3 hours.

I turned to the doctors and nurses for help but all they could say was go to parenting classes. I knew that there was something else wrong. When a friend recommended Fed Up with ADHD, I almost cried.

We started the diet in a month ago and within 3 days her behaviour had changed, no more kicking, hitting and biting and the look of pure hatred that she would give you before she started the tantrum had gone. We removed colourings and preservatives first and then went on the elimination

diet. She got better and better. Everyone noticed! When we made a mistake, like kindly giving her chocolate, she would wake the next morning complaining of sore eyes, and then the LOOK would start and I knew we were in trouble!

Suddenly I had my little girl back, the one that I spent three years looking for. She is nice to her sister and even nicer to me! I can not thank you enough. You helped when no one else could. -reader, Qld

[152] The first 19 months - Dani's diary (April 2002)

Birth - Chris is born nearly 2 months early. We stay in hospital until Chris is a month old. Staff regularly comment on the huge amount of crying he does and his restlessness. They put this down to a consequence of being prem and assure me he will be more normal and settled by the time he was due to be born.

2 mths - Chris doesn't settle - he gets worse, screaming and crying all the time all day and night. Regularly passes out from lack of oxygen. We try every colic remedy available - nothing helps. I even try giving him a range of formulas on the doctor's advice - none of these make any difference so after a few days on each I go back to breastfeeding.

2 1/2 mths - we notice Chris has a serious hernia and needs an emergency operation - his stomach is split right across and the muscles are trapping the arteries going to the testes - we hope no permanent damage is done - staff and doctors tell me it was probably caused as a result of the bad colic he has and him pushing in pain all the time. They assure me he will be a lot better when his stomach heals and should settle down - a bit of a contradiction but I go home and hope.

3 1/2 mths - I am totally exhausted and can not cope at all anymore - sick of the lack of support and everybody telling me that babies cry and I should just get over it. They all think I am a hypochondriac. I start colouring behaviour charts showing his screaming/crying/grizzling and sleep. I now know I am not exaggerating or pulling things out of proportion - the charts show he is worse than I thought. He is crying and screaming for about 18 hours out of 24. When he does sleep out of exhaustion it will be for one or two hours only - generally throughout the night. He rarely sleeps during daylight hours.

I ring my doctor in desperation. I am afraid I might hurt Chris if I don't get some sleep soon and get him sorted out. My doctor admits us to hospital. The staff take over Chris and I get to sleep. Staff are amazed at the amount Chris screams - at first they think it is just because he is away from me and home but I assure them he is the same at home. His crying continues non stop even after being in hospital over a week and in my arms a lot of the time. The doctor suggests we try the elimination diet. We see our local dietitian. I start the diet. The dietitian suggests we don't give Chris any solids for a while. I read somewhere that he shouldn't get them until he is about 7 to 8 months old.

4 1/2 mths Chris is getting a lot better. He isn't screaming near as much though is still crying a fair bit. We really notice it when I eat anything on the no go list - we have to cope with his screaming within 24 hours. Chris's diarrhea is nowhere near as constant. He is now sleeping for 4 to 5 hour blocks at night and settling quickly after a feed and change. His body language now shows more tiredness rather than pain symptoms when he is upset. His reflux has disappeared.

5 1/2 mths My behaviour charts show that Chris is improving a lot. He is now crying more than screaming. He is slowly getting over all withdrawal symptoms of the many chemicals in the foods that I was eating that were affecting him. I still can't get him to sleep during the day. (The diet is not

as effective as it should be because I am making salicylate mistakes like drinking way too much lemonade and eating lots of carrots and pumpkin - but I don't find that out for another 10 months.)

7 1/2 mths We start using management strategies to try to get Chris to sleep during the day. Our doctor thinks he can't sleep as he doesn't know how and is not in the habit. We succeed after a week and now Chris is sleeping for 2 hours in the morning and afternoon. We also introduce some solid foods. Chris's crying and grizzling improves hugely. He is now actually appearing to be really happy sometimes.

12 mths Chris weans himself and has been on Neocate ever since - other formulas such as soy cause instant unpleasant reactions - back to no sleep and crying a lot.

14 mths Chris goes off all carrots and pumpkin - makes it really hard for me to find foods to get him to eat as he eats a huge amount of each of these. We notice a big change in Chris - he stops grizzling altogether and is suddenly really easy to manage. He is a lot more agreeable!! Have a look through my books and discover that pumpkin and carrot are moderate in salicylates - I thought they were low!! No wonder he wasn't 100%. He was obviously getting too many salicylates!

19 mths Chris is now fantastic. We are really enjoying him. He reacts to all the things avoided on the elimination diet still so it is not much fun when we try challenges. We really pay for it - he reacts differently with different chemicals. Salicylates, preservatives and amines make him scream in pain and he gets diarrhea. Preservative 282 in bread is by far the worst - within 3 hours Chris is screaming in agony and has chronic diarrhea. When I was breastfeeding and ate 282 he would react within 12 hours. Colours make him really hyperactive, uncontrollable and he ends up getting hurt. - Dani, WA

[151] "We were doomed from the start when you look back on it" - Rita's baby (April 2002)

"We were doomed from the start when you look back on it."

I grew up on the Great Lakes in Canada. My father worked at Allied Chemical (located on the water) for 20 odd years. We ate fish that he caught in the Lakes two or three times a week. I remember tumours being common in these fish in the latter days. I do wonder what effect living in this environment and eating the fish has had on the situation I am presently in.

I used to be a hairstylist, but had to give it up due to reactions to colours, perms, allergy to latex gloves and sensitivity to customers' perfumes. I also have hayfever. My husband has asthma and seasonal allergies and his whole family has asthma.

From birth, our daughter never slept more than 40 minutes at a time, day or night, and by the second week she screamed most of the time. Nobody understood why she wouldn't "just fall asleep" in her pram or her crib or the car. She was seen by a quite a few doctors, midwives and early childcare nurses but no one did much except to label it reflux and say it would correct itself. Tresillian (mother and baby program) gave a different answer every time. Nursing Mothers put me on a high salicylate diet and told me to feed her around the clock. Needless to say she was totally out of sorts, crying all the time and inconsolable!

Then an early childcare nurse lent me a copy of Fed Up and sent me to a dietitian. I immediately started on the elimination diet. My baby calmed down in the beginning, but it wasn't a cure all. I was to the point of just eating rice, chicken and egg and trying to keep my milk supply up to breastfeed. When my baby started losing weight we went to RPAH and started on Neocate. It took a few weeks to wean her but once she was feeling better she accepted it.

Once she was settled we tried to slowly introduce foods from about 6 or 7 months. Except for a small amount of potato and chicken she reacted terribly to everything. She would wake all through the night screaming, refuse a nap and scream all day, refuse her formula and food in general. She was irritable, had loose bowels several times a day, and would be very aggressive.

I also try to stay away from all chemicals in the house for cleaning. She has had terrible reactions to paint fumes in the early days when I didn't realize how sensitive she was. We were trying to renovate our house, that's on hold for a long while.

I had never heard of this before. Allergies to nuts and things yes, but food intolerance and everything that goes along with it, no

- Rita, NSW

[071] Last night I actually got to sleep six hours (September 2000)

I am currently reading your book "Fed Up". I have a 3-year-old as well as an 8-month-old whom I'm breast-feeding. Both my children have suffered with severe colic and reflux as well as skin allergies. I have been convinced for a while now that it had something to do with their diet. I did not know where to start in finding out what may be the cause as every doctor that I have been to see just wanted to give me more medication. I have started both my children as well as myself on the elimination diet. It has been three days now and I am noticing a big change in my 3-year-old's behaviour where she is not depressed when she wakes in the morning. My 8-month-old has stopped vomiting. Last night I actually got to sleep six hours straight without having to see to the baby two or three times ... I would like to seek help from a dietitian who agrees with the elimination diet ... Thank you so much for your book. It makes so much sense to me.

[068] "I am a 20 year old mother ..." (September 2000)

I am a 20-year-old mother with a very restless, hard to manage 18-month-old son. He has been hard to manage from the start with colic, chronic wind, constipation, reflux and eczema. He would have us up usually every 2 hours just screaming the house down for no apparent reason and my doctor stressed NOT to put him on soy products as "in his opinion, they were of no help", so my son remained on an AR formula to help his reflux. As he gets older, he is very active, running every where, bouncing off walls and furniture, falling over all the time ... more trips to the doctor, nothing mentioned about diet.

It wasn't until my parents saw the article on A Current Affair that I even thought about diet other than lactose intolerance and they both encouraged us to try it. I was sceptical at first and then one night he had me in tears and, being pregnant with our second child, decided to give it a go anyway.

It has been 8 days now and there has been a noted change in his attitude. He is slowing down enough to smell the roses and his attention span has lengthened a little. although he is still waking up at night, I am a lot more rested from not chasing him around all day! What brands of bread are best for him? I have asked around at small bakeries and they either can't tell me if there are any preservatives or admit that they do ... I am getting a little frustrated at their ignorance. [Brumby's is FAILSAFE. Other than that, can you buy Vogel's? Read the label carefully. In some places they do not add 282].

Thank you once again for your help and for bothering to try to make a difference when no-one else really cares!!! Reader, email

[065] "A difficult baby" - reflux, colic, crying, rash, sleeping problems (September 2000)

Right from the day she was born, my third child was a difficult baby. The sisters at the hospital commented on day one that she was acting like a day three baby - all unsettled because of the milk coming in and hormonal changes. At 6 weeks she was diagnosed as having reflux and was given suitable medicine, not enough, at 8 weeks she was prescribed a herbal medicine to have in between doses (peppermint base), at 9 weeks she was diagnosed with colic as well and we treated her with all three medications to no avail.

By 12 weeks somebody suggested she will be fine once she starts on some solids (she is obviously just one of those really hungry babies). She cried all the time, she would not go to sleep, she would not stay asleep, and she was only happy if she was being nursed, if you could call it happy. I feasted on my saviours, champagne, burritos, curries (well, Indian babies survive!), and treated myself to a strip of licorice just about every day. I knew she did not like me drinking champagne, but I joked about being in denial about it, thinking I deserved it.

Our new baby had a fine rash covering most of her body, we all thought that makes sense, her big sister has eczema. Her irritability was I thought lactose intolerance maybe, I am slightly lactose intolerant. She had 7 ear infections in 5 months and had grommets put in at 8 months, but I had ear problems, sinus problems, and grommets as a child as well. We went to a sleep clinic to try and get her to learn how to go to sleep, we thought that maybe she did not read the book about how third children are supposed to fit in to our routine and lives. FINALLY after many trips to the doctor and an allergic reaction to an antibiotic, my clever doctor suggested a salicylate- free diet for our baby (not me though because the sensitivity was not really the problem just another thing to try).

Things improved, sleep was achieved when she rolled over on to her stomach, and crying was reduced from 50 minutes of controlled crying to now 20 minutes of controlled crying, every night, every sleep, 4 to 6 times a day. Hell hath no fury like a mother of a child who does not sleep, if baby is woken up. She was still waking up at night like a clock-watcher, and was usually unable to be settled without a breastfeed and then not usually under an hour.

12 months old... still having problems. We have now discovered she is allergic to milk, eggs, bananas, peanuts, Keflex, BBQ spices, and is still on her salicylate free diet (well low salicylate anyway, because it's not really a salicylate intolerance it just makes us feel like we are doing something). She is still waking up at night, but getting better to settle. Some nights she actually sleeps through.

After 12 months (plus the 5mths I suffered with indigestion during pregnancy) of sleep deprivation, the rot had finally set in and I have succumbed to many illnesses that I could not fight off, so, I gave up breastfeeding.

Well you could knock me down with a feather. The child sleeps. Goes to sleep. The rash disappears. Her first plasticine poo ... 14 months old ... where do we go now? It seems that her new food allergies are becoming more frequent and more aggressive since I stopped breastfeeding.

This brings me to you. I found your book!!! I sat down and started reading your book, not in order, and found her symptoms all over the place. I also found my 8 year old, who scored 3s on eczema, growing pains, restlessness, difficulty falling asleep, night wakings, anxious, vague, concentration, unmotivated, disorganised, easily distracted (she scored a 5 here), moody, irritable, and 2's on fidgety, "jumpy" behaviour. ... What I have benefited most from so far is the relief that I am not crazy, nor the only person in this situation. Thank you for taking the time to write your book.

P.S. Can you tell me if McVities Hobnobs biscuits are okay? The ingredients are: Rolled oats, wholemeal flour, sugar, hydrogenated vegetable oil, vegetable oil, partially inverted sugar syrup,

raising agents(sodium bicarbonate, ammonium bicarbonate), salt. [There are probably antioxidants (310-321) in the vegetable oil, so you would have to limit the quantity]. - reader, email

[007] Emily Rose: obstructive, obstinate, defiant and plain horrible to tantrum-free (March 1999)

Part one

Having just finished reading Fed Up I felt compelled to speak to you - your book struck such a chord! For two years now we have been battling with our daughter's health and behavioural problems and have been fobbed off left right and centre. It was such a wonderful relief to speak to you and read of your experiences and know that we are not alone in this.

Right from the start Emily Rose was a 'difficult child' - never slept for longer than two hours at a time at night and had only two short catnaps of about 30 minutes during the day. She cried a great deal, wanted to be held constantly and often woke up screaming. Clearly this was going to be a challenge. After four months the sleep deprivation really hit home and we began doing the rounds of the doctors in an effort to establish the nature of the problem. We had no answers apart from maybe it's colic, watch your diet, cut out brassicas, fruit juice, yellow stoned fruit, onions and garlic. No one mentioned cutting out dairy, tomatoes or tea!

We thought we ate healthily - no pork or processed meats (having worked at a food company and seen what goes into sausages, ham, bacon etc, we came off them in 1994), drank herbal tea, didn't drink coffee or fizzy drinks, had very little alcohol, didn't eat much in the way of processed or preprepared foods, don't eat take-aways and had a high proportion of fresh fruit and veg in our diet with little in the way of fried food. At one stage we stuck to the Fit for Life Diet for at least 18 months. We struggled on and wondered how it was possible to have a baby like this - did parents survive such an experience without going insane or committing infanticide? Here we were, both with post graduate degrees, fairly competent people, reduced to grovelling wrecks - the baby running our lives. Thank God, my husband David was very supportive I can't imagine how much worse it might have been had he not been there for ER and I.

During her first nine months, Emily Rose had three ear infections and was put on antibiotics. Although we do not believe in antibiotics we were desperate enough to give it a go. The problems with her sleep continued. We insisted on a referral to a paediatrician in an effort to establish whether there was a physiological cause. The paediatrician was most unsympathetic, of course ER was as good as gold there and didn't exhibit her usual crying or fretting, she gave Emily Rose a cursory examination and pronounced her a 'bright' baby (began to crawl at five months and proficient at getting around by six and a half months, sticking her hands into everything within reach). Her whole attitude was 'look, I have a three year old and he still doesn't sleep well, so just learn to live with it!' We were referred to [a health department facility for mothers and babies] and had a day stay as well as two home visits - the upshot of that was we were told we had a 'naughty baby' who should be taught to sleep (controlled crying etc and left in her cot for up to an hour at a time, very distressed, crying and screaming). I couldn't believe that at five months a baby could be naughty (it went against the grain of all my psych training and experience) and the controlled crying etc was nearly the undoing of me. We stopped using [the health facility] or their advice - I refused to be made to feel guilty and did not like the implication that we were bad

Finally when Emily Rose was about 11 months I contacted the Government Audiologist and asked for his advice and a referral - she had just blown a fourth ear infection and I was not satisfied with the doctor's comment that this is normal for young children - 'they have an average of 13 infections in their first year!' We were put into contact with a GP who specialises in distressed infants and it was the first turning point. This doctor's hypothesis is that some infants from families with histories of

allergy/intolerance exhibit sensitive tissue which overreacts to irritants. This view is unfortunately not well accepted in the wider medical circles here in Perth. However, we thought it made sense in our case as we both have history of sinusitis and I am subject to migraines. Emily Rose's reflux caused irritation of her oesophagus and the lower end of her Eustachian tubes setting up an environment ripe for infections. It was a relief to find a reason and to be able to begin to treat the cause rather than the symptoms. Whilst we are very grateful to [this paediatrician], it is my personal belief that she does not emphasise the food intolerance aspect enough and tends to concentrate on the antibiotics and grommet course of treatments.

On her initial visit, Emily Rose was given a tympanogram and we found that both her ears were effused - obviously she had been in significant pain for most of her life. She had probably had more ear infections than we were aware of as she exhibited asymptomatic otitis media. No wonder she did not sleep well, if she lay down for any length of time, the pressure built up in her ear drum until she woke crying/screaming. More antibiotics, and we were advised to move her off milk based formula for her complementary feeds to a soy based formula. I breast fed her until she was just under two but we had to start complementary feeds at about nine months - I think I was too exhausted to continue on my own. We used soy formula for about four months during which time her bowel motions became increasingly loose. Eventually we agreed to the grommet route because we did not want to continue with antibiotics, she was looking ill and peaky with dark circles under her eyes, and when read stories about children going to bed would clap her hands over her ears (we took this as an indication that she associated bed with pain). Within two weeks of her operation the difference in the child was astounding - she gained some colour in her face, the dark circles receded and she began to pick up weight. parents!!

However, her irritability continued and in fact began to get worse. We began to explore whether her behaviour was in any way related to food and took her for vega testing. We were astounded by the results: wheat, dairy and soy intolerant as well as sensitive to salicylates. Controlling her diet more closely produced even better results. In May 1998, when we took her off the soy and reduced her fruit intake, her irritability subsided, the runny nose also began to clear and she began to look healthy and rosy!

Over the last few months we began to slowly reintroduce wheat and dairy into Emily Rose's diet. She loves her rice milk and is a good eater when she is well and has an appetite. She eats a broad range of fruit and vegetables and is not what I would consider a fussy eater - apart from not liking chicken! On reflection I realise that we did not have enough information about food chemicals such as salicylates and this is where we have gone off the rails again. Thinking we were doing the right thing we introduced cranberry juice into her diet to provide her with vitamin C and gave her crushed almonds for calcium.. She loves olives and will go the fridge to help herself to them. We tend to eat a lot of homemade tomato sauce on pasta and rice and lavishly pour olive oil on our steamed veggies and salad! We made sure Emily Rose had at least two - three pieces of fruit a day: watermelon, apples, grapes, nectarines, pears or banana.

The slide into the intolerable behaviour has been so insidious that we did not make the connection with food. Emily Rose has become increasingly obstructive, obstinate, defiant and plain horrible. This is more than just the terrible twos! The tantrums started about six weeks ago and are unbelievably dreadful - she will cry and thrash about for over an hour and on one memorable day had three tantrums! There is no identifiable behaviour which triggers the tantrum nor a particular time of day when they occur. What upsets us the most is the fact that she tries to hurt herself during the tantrum either head banging or biting her arms, wrists and hands causing bad bruising. Time out in her room was out of the question as it resulted in bruises and egg sized swellings on her head (banging her head on the closed door) as well as split lips and blood all over the show. We have

learnt to sit and restrain her, all the while talking her through the episode. Very debilitating for all concerned.

We seriously wondered about the wisdom of our even considering having a second child when we obviously couldn't handle one! Needless to say David and I are both exhausted and somewhat depressed - our life revolves around how ER is behaving. Is it going to be a good day or one of those horrors? We don't seem to have any time to ourselves as we spend so much time and effort trying to deal with Emily Rose. She continues to be difficult to get to sleep - it can take us one and a half to two at night to get her to go into a deep sleep. We have very few uninterrupted nights - sometimes she will only wake once, other occasions it is at least three or more wakings. None of our friends seem to have these difficulties with their children. My sister has a dream child - you wouldn't even know that her daughter is in the house. Why us ???? As migrants we have no family support or the gaggle of house servants we had at home. My greatest desire is to have a whole weekend of uninterrupted sleep whilst ER is farmed out somewhere!!!

The light dawned as I read Fed Up - this child is very sensitive to salicylates and we need to cut out all those foods. I now have enough information on what foods contain salicylates to begin to do this in a logical and constructive way. Previously when we went for the vega testing we were just told to cut out certain foods but not given enough information as to why or how. I am now very motivated to start on the elimination diet and finally establish exactly what her problems are ... David has said he will also do the diet in an effort to sort out his recurrent sinusitis so this will be a family effort.

Part two

We are on day two of the elimination diet and I must admit that I am finding it hard going especially as we are also dairy, wheat and soy free. Emily Rose is already so much better, not as good as she could be, but an improvement. Since withdrawing the cranberry juice 10 days ago we have been tantrum free - just crying fits which are easier to deal with. The other great thing is that her snotty nose has cleared up for the first time in months. She is still very irritable and easily frustrated but I am sure that will improve. We just have to hang in there for the next three weeks and will challenge with wheat first because I reckon cooking will become that much easier if we can have wheat! - Simone

[004] Daniel's story: severe colic and reflux (June 1999)

From the minute Daniel was born, he was a very unsettled baby. We went home on day three and I expected he would improve when my milk came in. I work as a midwife, so I had some idea of sleepless nights etc, but nothing had prepared me for a baby who screamed constantly when awake and slept very little. My mum said I had been a very colicky baby and my mother-in-law said my husband David had been an extremely colicky baby - so we presumed Daniel was the same.

After three doses of mastitis, I put Daniel on the bottle at five weeks of age. He was just as unsettled on formula as on breast milk. He continued to have several loose green bowel actions a day. The next day we left for the U.K. - my husband David was transferred over there for what was meant to be five weeks but turned into three months. I think ignorance is bliss, when I look back and see myself taking a screaming six week old baby half way across the world to live in a shoe box hotel room. In the U.K. Daniel continued to be very irritable and unsettled. He posited after every feed and only very occasionally vomited. The only place he was happy was in the bath, so we bathed him four times a day some days to keep him quiet. When I look back on my diary of this time, he began interrupting his feeds at about 8 weeks of age. A normal night out for tea (we had no cooking facilities in our room) would be David that would walk out on the pavement with a screaming Daniel

while I ate and then we would swap. I remember feeling physically sick myself some nights, he would scream so much.

We visited a doctor for Daniel's immunisations and I told her of his constant screaming - she told me it was colic and that it would improve by three months of age. I started him on solids early in case he was hungry (rice cereal and tinned pumpkin) and changed to a formula for hungrier babies. He seemed better for a couple of days but then was just as bad.

When we arrived back in Australia I took Daniel to a local GP, the one I had seen as a child myself. Daniel was screaming and it was 11 am. This doctor gave me a lecture about colic (by this stage Daniel was four months old) and said, "how could there be anything wrong with a child that has such good weight gains?" I tried to explain that it was taking 1-2 hours to feed him a bottle, but he just gave me a lecture on midwives not making any better mothers. He threw a referral at me for a paediatrician on the way out the door (I think only to cover himself).

I tried making an appointment with the paediatrician, but being Christmas, there were none available for another month. So we continued to battle on and tried Daniel on a soy formula which seemed to help for a while, but then he just went back to square one. He got worse with his feeds, arching his back. We would bang toys on his bottle to distract him. At this stage most nights he was sleeping though and I think that was the only way we survived. He continued to scream and whinge all day and I'm sure he was exhausted at night and that is why he slept. Despite all this he continued to gain weight and reach all his milestones. I lost weight rapidly and was lighter than before falling pregnant. We contemplated that he was just an attention-seeking baby because when we played on the floor, or took him somewhere different, with different toys, he was okay.

The feeding continued to get worse so two and a half months after seeing the GP, when Daniel was six months old I took him to a paediatrician. He immediately diagnosed reflux and oesophagitis (inflammation and ulceration of the oesophagus) and started Daniel on Ranitidine (Zantac) which reduced the acid in the stomach, to stop the 'heartburn' type pain. I will never forget what a relief it was to get a diagnosis; little did I know that this was only the start.

Daniel's feeds immediately improved on the Zantac but he continued to be very irritable and whiny between feeds. Three weeks later we started him on Prepulsid (Cisapride) which increases the rate of the stomach emptying, but it didn't seem to make a great deal of difference. We tried him on Nutramigen, in case he was cow's milk intolerant. It seems to help for a couple of weeks, but then he just went back to the old irritable Daniel.

I had become suspicious of a few things in his diet. We went camping over Easter and I gave him a Heinz tomato based baby food - it came out the other end looking nearly same as it went in and Daniel was extremely unsettled all weekend. A booklet from a support group for reflux babies mentioned avoiding acidic foods for reflux babies so we presumed that was the reason it was upsetting him. Luckily, for this reason, we didn't give him Kiwi fruit, oranges or fruit juice.

At eight months of age he was still whingeing all day and throwing huge temper tantrums (head banging the dishwasher) so our paediatrician organised a barium swallow. He also started him on Mylanta four times a day. The first week on Mylanta he was wonderful and that week he had the barium swallow, which was normal, much to my disgust. The next week he was worse than ever. I stopped the Prepulsid at 12 months and started Daniel on cow's milk, which made no difference. At this time I went back to work two days a week and left my mum to cope with Daniel - there was no way a child care centre would have taken him. I think going back to work was the best thing. I would come home after my two days and feel ready to cope with another week of life with Daniel. My mum says she even dreaded him coming for the two days sometimes.

Around this time I tried a naturopath, masseur and chiropractor, but nothing really helped.

By fifteen months of age he was no better. A normal day was leaving him scream to get him to have his afternoon sleep and to settle at night. I would put him in his room several times a day on a bad day and sit for ten minutes and try to calm myself down. Normal daily tasks such as cooking meals and washing were all done while he screamed.

I returned to his paediatrician and he referred us to a gastroenterologist at the Royal Children's Hospital in Melbourne. He told us that he doubted Daniel's behaviour was due to reflux (Daniel smiled at him and played with the toys in his room!) He advised I stop the Zantac and organised for him to have a pH study (monitors acid in the oesophagus over 24 hours) and gastroscopy (tube to look at the stomach and oesophagus). After stopping the Zantac, David actually seemed a little better and stopped his head banging.

The pH study showed 'mild' episodes of reflux. His gastroscopy showed moderate to severe inflammation and ulceration of his oesophagus and suggested that there may be an allergy involved. They suggested we see the allergy department at the Royal Children's Hospital. They put Daniel on the Neocate diet. He was only allowed Neocate formula, rice, zucchini, apple, pear and potato. The doctor at the allergy department also advised me that these children get into such bad behavioural problems that once they're fed and changed you just have to leave them scream! The diet was a disaster to say the least - to try to get an 18-month-old to drink this formula, that you gag on yourself it's so foul tasting, was impossible. Daniel screamed all week and was so bad by the end of the week I had to take time off work. He was constipated from only drinking small amounts of water.

In desperation we were referred to a surgeon about the possibility of surgical correction. He wasn't convinced - so he sent us for a gastric emptying study, which was very distressing for Daniel - they put a large dome over his face and stomach. This showed he only refluxed once. The surgeon suggested trying Losec (Omeprazol) which stops acid production in the stomach and helps heal the oesophagus. We started Losec - after about a month we noticed a big difference in his behaviour - he was a much happier little boy and he actually sat and played with toys for short periods of time - something he had never done before.

I was suspicious of food colouring and artificial additives at this stage, as some evenings we described Daniel as 'bouncing off the walls' he was so hyperactive. For this reason we only let him drink plain milk and water and filled him full of 'healthy' fruits, vegetables and cheese!

Like everything else the effect of Losec was wearing off. Daniel was starting to complain of his 'tummy burning' and pointing to his oesophagus. He required constant amusement and was generally a very unhappy little boy. I was finding him nearly impossible to live with and constantly comparing myself to the other mums in playgroup and wondering why they all got so much enjoyment out of their children.

When Daniel was around two and a half years old I happened to go to a seminar through work on food intolerance and allergy run by the team at the Royal Prince Alfred Hospital in Sydney. I couldn't believe what I was hearing at the lecture - it was Daniel all over! I immediately sent away for the elimination diet books and got a copy of Friendly Food.

I started off by leaving him on dairy and wheat products. After 1-2 weeks we noticed a difference in his hyperactivity on the diet but he was still having many days of irritability and complaining of his tummy burning. His loose bowel actions were persisting. We stopped dairy products and put him on soy and we started giving him Losec in pear jam instead of yoghurt. He had watery diarrhoea for two weeks after stopping dairy products as a withdrawal effect. Unfortunately what we didn't know was

the Losec is not absorbed properly unless given in something acidic like yoghurt. After one month of giving the Losec in pear jam, Daniel's stomach pain was severe.

After being unwell for three days with a high temperature and complaining of shoulder tip pain, Daniel was finally diagnosed at the Royal Children's Hospital with pneumonia from aspirating on his vomit. (I had seen two other doctors who told me children don't know where their pain is and that he had a viral infection.) The pneumonia was in the back of his lung and was pressing on his diaphragm, which was giving him shoulder tip pain. I have never seen Daniel so sick - we thought he was going to die.

Again in desperation we returned to his gastroenterologist who advise another pH study and returning to the surgeon for fundoplication, which kinks the oesophagus to stop food refluxing back from the stomach. He felt he might have a physical problems as well as an intolerance, which caused hyperactivity. So when he was three, Daniel had fundoplication. We stopped the Losec the night before surgery. The surgery was major - four days in hospital and two days on a morphine infusion. As soon as the morphine stopped Daniel started complaining of his stomach burning but now he pointed to his stomach rather than his oesophagus - the surgery had only moved the pain. We recommenced his Losec on leaving hospital. Daniel's weight had dropped from above to below average, as we struggled to maintain his nutrition on vitamised elimination diet. I hit rock bottom. I was waking at night in a sweat over what I had put him through. I rang the Royal Prince Alfred Hospital Allergy Clinic in Sydney, beside myself, and they suggested that we bring Daniel up to Sydney. I only wish we had done it prior to the surgery.

At the clinic, his behaviour chart revealed that Daniel was very high for hyperactivity and learning problems and we were told we were dealing with severe food intolerance and ADD. We were advised to try Daniel off pears as he is very salicylate sensitive.

Daniel is now nearly four and in the last month he has been consistently much better. He only tolerates rice, potato, cabbage, beans, chicken, lamb, Nuttex and restricted amounts of sugar. He is still on Losec which we have increased in the last month to combat his stomach pain. We have found he is no longer reacting as badly to perfumes since stopping pears and maple syrup. Since stopping rice bubbles his aggressive behaviour have ceased. He will actually sit and play with toys now, although his concentration is poor at times. We have tried him on Ritalin but if he's having a bad day food wise, Ritalin only makes him worse.

The last four years all seem to blur into one big nightmare but I realise I was becoming very bitter about the whole thing. I have resolved to look ahead only. Daniel is really a beautiful little boy underneath all the problems he has had. I try to make the most of the good days and not dwell on the bad days.

It is in the hope of preventing someone else living our nightmare that I do the telephone counselling for D.I.S.A (Distressed Infants Support Association of Vic) and have agreed to be the Melbourne contact for food intolerance in Sue Dengate's book Fed Up. – Jenny

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