Reader reports from the Food Intolerance Network

www.fedup.com.au

("sleep", "apnoea", "apnea", "night terrors", "difficulty falling asleep", "insomnia", "nightmare", “bad dreams” keywords only)

55 minute interview with Sue Dengate on
food intolerance and sleep apnoea (20Mb download)

[1323] Salicylates and sleepwalking (March 2015)

I have a 5yr old daughter who is intolerant to natural foods. She becomes violent when she eats carrot and it can last for a few weeks on and off. She also cannot tolerate most fruits and unlike the violence from the carrot she acts drunk when she has fruit. We now limit her vegies, only give her bakers delight breads as we found she reacted to the vinegar from the supermarket breads and we have her on failsafe butter too.

Since changing her foods we have a happy child who is now more relaxed, we can now speak to her without her going off. She is calmer and much nicer child.

We have noticed that when we feed her something with salicylates she also sleepwalks very badly. Another thing, before we changed her diet she had ear infection after ear infection. I had her to an ear specialist who thought she needed an op but now looking back since changing her diet she only has an infection as often as a normal child - Mel (report received August 2011)

See factsheet on sleep and story collection on sleep issues

[1321] 160b: “I had to lie on him to get him to lie still to fall asleep” (March 2015)

I have listed the effects on my boys 2 and 4 years plus other results if you are interested. We started the elimination diet 6 months ago and I can safely say that the challenges were one of the hardest things we have ever done - if I was in paid employment I would have been on stress leave!

Fortunately we have all survived (including the marriage) and have come out the other end in a much better place. Why did we start - my eldest was having major problems at kindy - his behavior at home has always been challenging but escalated in a group environment. A few labels were mentioned ADHD, PDD, SPD - but he didn't really seem to fit fully into any of those categories. My other concern was we were going to have the same problems with our youngest when he went to kindy - as he is a " mini me" to his big brother. I took my eldest to a place called Learning Connections (in Brisbane) and they suggested diet. We worked with a dietician at Mooloolaba and these are the boys’ reactions below.

Interestingly we were doing daily homework that the OT had set - handwriting and jumping jacks while we were doing the challenges (same exercises everyday), some days he couldn't even hold a pencil and others he was too clumsy to complete a jumping jack successfully. My youngest no longer has asthma like symptoms and only one case of tonsillitis this year, both only 1 cold this year that lasted 1 day - last year a cold would last minimum 2 weeks, and both had 3 cases of tonsillitis. Both have allergic reactions to a number of antibiotics - penicillin, erythromycin and cephalexin so maybe they are extra sensitive or maybe their reactions have escalated the problem?

160b annatto: 2 yo - sore legs; 4 yo - sleep disturbances (I had to lie on him to get him to lie still to fall asleep, then he was up 4 times during the night with nightmares) Both - hyperactive, restless, wet pants, screaming, angry, arguing. This was within 2 hours of eating yoghurt, fortunately my husband was home when they reacted as we had to separate them for their own safety and we just exercised them for two hours straight then gave them a bicarb bath. Lasted 24 hours. Wednesdays for some reason were always 4yr olds worse day at kindy - it was litterless day - he couldn’t have any packaging in his lunchbox so I used to scoop out some of his dad’s yoghurt into a container :). Both boys used to be really "restless" at bedtime even when I knew they were tired. They used to have custard for dessert.

Salicylates: 2 yo - dirty pants, whingy, hurt the dogs; 4 yo - long time to complete tasks, no eye contact. Both - touching, poking, prodding, breaking, arguing, impulsive, noises, loud.

Amines: 2 yo - wet and dirty pants emotional, defiant, hypo, screaming loud. 4 yo - space cadet/not listening and not responding.

282 propionates: crazy, consistently getting in trouble, emotional (2 yo more than 4 yo).

Soy milk: 2 yo diarrhea

Wheat: minor in 2 yo; major reaction in 4 yo, said he felt tingly, had the worse day at kindy ever - hurting other children, couldn't sit still very busy but very tired also, poor coordination, soiled pants, stomach pains.

Life has definitely changed for the better for us - we still aren't there yet but we have come a long way. I recorded one of my youngest outbursts on my phone and play it back when I forget why we are now so strict with their food - believe me a scary recording. My eldest no longer needs the special education teacher aide to follow him around at kindy making sure he can survive the day but is now making friends and loving his kindy day. He still has some neurological delays but is catching up really quickly. Thank you so much - if I hadn't been pushed to evaluate their diet (which I thought was healthy) I would not have read your book and my son would have a label :(. - Lisa (report received August 2011)

[1295] Amines: ”I'd love Failsafe to become common practice in my country (December 2014)

After four years of incessantly visiting medical professionals in two different continents (yup), I stumbled upon the FEDUP site while researching MSG and food dyes "snide effects", as I had empirically determined their nocivity (“ability or capacity to cause harm”) to my kids.

My 12yo daughter has begun Failsafe two months ago.

She's today mostly free of her blinding incapacitating migraines, sleep apnea, general brain fog and learning difficulties, mood swings, heartburn, bad joints pain, which turned her from a dancing, swimming and Tae kwon do competitor into a foul-mooded, sleepy, couch potato, etc... we are currently moving on to tackle her autoimmune Hashimoto, with a very positive outlook. This is the girl that underwent isotopes checks, CTs, MRIs and countless blood tests... the girl we were kindly advised "would not have a really 'normal' life" unless she took medications meant for epileptic and schizoid patients (and how "normal" is that?).

This WE I challenged her with amines (slow cooked meat and chocolate) without waiting for your book to arrive... bad idea all over and she's been home since. But at least we remember it used to be "like that" all the time.

Needless to say, her endocrinologist, gastrologist, ENT,and neurologist, are for the most part dismissing my enthusiasm, or even the causal link with the dietary change. But hey, we don't need them so much any more. Our beloved, pediatrician is convinced but adamant that he can't offer parents such a "hard" diet to follow lest he be dubbed a dangerous extremist. And it's for people like him, and the dozens of families he could help, that I'd love Failsafe to become common practice here.

My 7 yo son has gone from a "Dr Jekyll and Mr. Hyde" personality, which included plain meanness, virulent on-and-off, ODD, and actual violence, followed by heartrending bouts of crying and heavy "drugged" sleep, to showing the world and his school the all-around nice, bright kid I knew he was, and his honors roll presence is exactly correlated with his "sticking by the Failsafe rules" periods. Our asthma inhalator sits unused for weeks already. Son's jaw- grinding, bedwetting, sleeves munching, and shouting all kinds of weird "war cries" at the most unbecoming moments, his bouts of self-hitting, his nightmares, are a thing of the past (did I say "thank you" already?). For him too, the amines challenge was... let's say premature - family from France

[1293] KB's story: severe chronic Insomnia caused by red gel toothpaste (December 2014)

In October 2104, Howard and I embarked on a long, high, difficult six week trek in the remote Dolpo region of Nepal. Our guide, KB, was brilliant - young, fit, strong and clever, he spoke excellent English and we enjoyed his company. However, on the 14th day of the trek, KB admitted he was having terrible trouble sleeping at night. The problem had started on the first night of the trek and was getting worse. He had also become extremely sensitive to night noises such as barking dogs. He didn't have to tell us that because we'd already noticed that he would spend his nights throwing rocks at noisy dogs and even, rather bizarrely, ask mule train and pack horse drivers to remove the bells from their animals' necks.

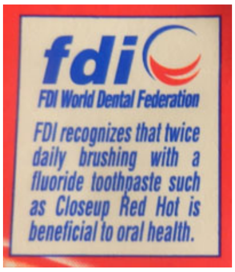
This was a puzzle. Insomnia and hyperacusis – an increased sensitivity to everyday sounds - are commonly associated with some food additives and natural food chemicals, but I knew what KB ate because we were eating the same: additive free local foods mostly roasted barley flour porridge and two big serves a day of rice, lentils and vegetables. I checked that his drinks were okay, mostly water and weak milky tea, and that he wasn't using chewing gum.

Then I asked about toothpaste. You have to consider everything that people put in their mouths because additives can be absorbed through skin, whether you swallow the toothpaste or not. KB looked stunned. We read the label on his toothpaste. Bingo. It contained five colours, but even I couldn't tell what they were, because toothpaste labelling is not covered by the same rules as food. It is one of the dirty tricks that manufacturers use to hide nasty additives from concerned consumers: they use Colour Index numbers. So the list read "colours mica/CI 77019, CI 16255, CI 17200, CI 177491, CI 77891".

I usually look those numbers up on our website, but here we were in one of the most remote places on the planet and I didn't have access. We could see the toothpaste was red. Get rid of it, I suggested. "But it is recommended by the World Dental Federation", KB said.

Out went the toothpaste and KB's problem disappeared overnight. I later confirmed that one of those numbers is artificial colour E124. When used in European food, it has to carry a warning about adverse effects on children's behaviour and attention, Another one - naphthalene red - isn't even permitted in food, so no one knows what the side effects might be. I was furious with toothpaste manufacturers, governments and therapeutic goods regulations for permitting this confusing labelling, and with the dentists in the World Dental Federation for endorsing such a product.

There was one fact I wanted to look up when we got back. What exactly is the World Dental Federation? Turns out it's a professional group that runs congresses for dentists, and it is funded by … wait for it … the same multinational company that makes KB's toothpaste. - Sue Dengate


fdi

FDI World Dental Federation

FDI recognizes that twice daily brushing with a fluoride toothpaste such as Closeup Red Hot is beneficial to oral health.

More information: http://fedup.com.au/factsheets/support-factsheets/toothpaste

[1274] One-liners (August 2014)

It is worth doing the RPAH elimination diet; my son is currently on it. He is 4 and was waking every night - thank god I did not persist with sleep school which was what everyone wanted me to do... Now he sleeps when we stick to the elimination diet. I too had the looks from my husband but he has now seen the proof and believes me now! – Frederikke

[1273] What has failsafe meant for you and your family? (August 2014)

Bub was up hourly, all night every night, on a good night. Now sleeps 12 hours. (Started elimination in February when he was 8 months) – Karissa

From tummy aches, ear infections, motor tics, sleeping issues and behavioural problems to happy and healthy boys who maintain beautiful relationships with friends and family - Jenny

[1248] *Happy Dance* (October 2013)

So I have now cut out all artificial flavors/colours/preservatives, changed milk to A2 - but he doesn't really have a lot only in mashed potato etc, Bread to Brumbys, restricting fruit to mainly pears with the odd piece of other fruit, and we already used Nuttalex etc for about 2 weeks now and I must say although we are not on the Strict Elimination - WOW what a difference!!!! I'm really impressed!! There has been a huge change in behavior and his sleep patterns and he is managing on his own without any medication to help him sleep. I truly do hope this continues. I even had my mother mention last night that it was a very peaceful night and how lovely it was, so it's not just my imagination.

Oh and a big one I forgot to mention is that my son’s tutor called me into talk with her and mentioned how happy she has been with his progress over the past 2 weeks and have I been doing extra work with him at home. I don't think that I have, I just seem to think that he is taking it all in better! *Happy Dance* It's just so so lovely to see him this way – Mandy from facebook group

[1243] Statins caused insomnia so I lowered my cholesterol levels through a healthy diet (October 2013)

I was diagnosed with a heart valve problem late last year and also with 2 out of 3 coronary arteries being blocked by 20%. The latter was not enough for the specialists to intervene but a wake up call for me! One cardiologist wanted me to lower my cholesterol levels through medication. When I said to him I would like to try it through diet the answer was: "That is not easy, I wish you good luck". I really had the idea that there should be a natural way through diet.

Seven months later my conclusion is that a vegetable based diet very low in fats with some grains and legumes is at least as good as being on statins for both the cholesterol level and protection against heart attacks. Taking the side effects into account, I think it is actually much better since the side effects of a healthy diet are much more far reaching than heart disease. Hence I’m no longer using statins and the cardiologist is quite happy with my cholesterol levels.

Apart from achieving good cholesterol levels, improved energy, much better skin and a clearer head, I discovered that the rates of heart disease, strokes, diabetes type 2, cancer and even autoimmune diseases like arthritis, lupus, MS, Crohn’s and more are actually heavily influenced by what we eat. Strangely enough this does not seem common knowledge, not among our specialists either. Currently it is not reflected in our dietary guidelines.'

Update after 14 months on the low fat plant based diet, avoiding all processed foods: My total cholesterol has come down by 27%, the LDL by 38% without any medication (total/LDL was 5.3/3.4 on 1 Sept 2012 mmol/l = 205/131 mg/dl and on 6/11/2013 this was 3.9/2.1 mmol/l or 151/81 mg/dl); my dry and cracked sometimes bleeding skin is gone; my excess weight has come down about 7 kg. I feel good and energetic and never hungry. I know that salicylates affect me with IBS and severe amplification of feelings, so now I eat any veg but stay away from fruits and garlic and that seems to be OK for me.

- Peter, by email. See the full story at http://users.tpg.com.au/freestro/The_Ideal_Diet.pdf

[1222] Tresillian ‘controlled crying’ didn’t work (August 2013)

I was sent with my eldest son to the sleep clinic at Tresillian in Sydney (from Canberra 16 years ago) where they fed him bread, tomatoes and vegemite of the first time in his life. Of course, he got worse!!!

He went down to 4 x 15 minute cat naps in 24 hours and they told me he was just stubborn/difficult and to stay the course. After 8 months of persisting with 'controlled crying', I gave up (thank god!) It was only when I found RPAH that he got any peace. 4 month old babies aren't stubborn or difficult - they react entirely to environmental and dietary input.

The child health clinics need to provide this avenue of info – Sheryl by email.

[1221] 202: Night terrors and sleep disturbance in a senior related to potassium sorbate preservative? (August 2013)

I came across your web site when I was trying to find out if potassium sorbate could cause sleep disturbances. My sister aged 61 was awake for about three hours and kept repeating the words "I'm terrified" and I believe it was from the potassium sorbate that was in the sweet cider we were using to make her fruit smoothies. She had no headaches for several days, then had one on Saturday. I asked the Aide if she did anything different and she mentioned the cider. I checked the label and saw the preservative. Then that same night my sister was awake with the night terrors. I had also noticed a slight rash on her face and found that the preservative can cause rashes also. I poured all that cider away and bought some that has no preservatives and she slept good for me the last two nights. - Leanda, US, by email

See also [797] 202: Behaviour and night terror induced by potassium sorbate (202) in Panamax (June 2009)

[1210] Bedwetting thread from facebook group (July 2013)

Within a week, my little one stopped bedwetting and stopped having night terrors. For years, both would only happen as part of a reaction. It can happen - Tracy

[1205] Failsafe has completely changed our family for the better (July 2013)

We were previously struggling with our eldest daughter, she was five at the time and we were concerned about her difficulties sleeping and her behaviour. As a baby she was quite unsettled, something we didn't realise until our second daughter was born and actually settled and slept well, showing us it was possible! Due to family history of depression I was also worried about my daughters' future and began reading to find out if food could be an answer. We originally went almost sugar free for one year and saw some improvement (most likely due to cutting out most fruit and making most food from scratch) but knew there was more going on.

We discovered Failsafe 14 months ago while we were spending almost a year travelling Australia, I cried reading the story of your little girl, she sounded just like ours in many ways. Following Failsafe our little girl started going to sleep at night, her extended meltdowns disappeared, she played nicely and didn't overreact to little problems, she came out of a fog and listened to us, she slept at night without nightmares, she didn't cry when her sock was twisted inside her shoe!

Doing FS while travelling in our camper was great- no invites to birthday parties, no school, we just ate our own food and could watch our little girls as we challenged- dairy in Broome, Sals in the Kimberley, Amines at Uluru. Our eldest daughter and myself failed the same things (sals, amines, glutamates) and our youngest daughter and dad passed them all.

Our daughter has now started school and is thriving, pre-FS I didn't think she would cope with school. So many little and big improvements have occurred for our daughter and for myself that we are only reminded of them now when we make a mistake with our food. We also returned home from our trip pregnant, conceived naturally (we had previously needed fertility treatment) and have a new baby boy.

We credit Failsafe with changing the whole dynamic of our family, our kids are still ratbags at times but they respond to discipline now and we are not despairing of how to raise them, we are enjoying them so much - Bonnie by email

[1180] 621: Lack of sleep and vivid nightmares (February 2013)

I only got to your website after another bad reaction to a meal, this time at a very western pub in Fitzroy, where I had a meat-pie. Of course, it was not long after I was feeling very thirsty and restless. In the middle of the night, I was waking again and again from nightmares and spending long periods of time trying to fall asleep again, while feeling flushes of heat / itch all over my body. I know that again, I will have a second night of bad sleep as it generally takes about 24 - 48 hours to clear up, and not even sleeping pills help me most of the time.

I have actually spent all my life with incredibly bad sleeping patterns and bad asthma, especially when I was a child. I used to live in Peru and clearly remember an always present bottle of Aji-nomoto on the table. I am now 37 years old and still suffer from terrible insomnia, which got even worse when I spent time working in Hong Kong and Singapore, where I regularly ate the local food. The lack of sleep then included these vivid nightmares, where I was sometimes aware of being in dreams that I tried to wake myself from. I think I have become more sensitive to it and the bad sleeping patterns have led me to a level of depression.

At my return to Australia, I talked to a few people about this and suggested it could be the MSG used in food preparation. The more I read the more contradicting information I found, especially because I could still recognise the symptoms (flushes of heat, sudden short-breathiness, thirst, itchiness) like last night after eating non-Asian food.

5 months later: When it comes to improvement, I have certainly tested MSG as the main culprit. Most of the times I can recognise the symptoms within a short time if I ingest something with it unknowingly - Carlos, by email

[1166] 282: Defiant, hyperactive, impossible to reason with, plain silly, very loud, noisy, annoying to others, demanding, pushy and tantrums (December 2012)

My daughter, who is now 7 years old and who began the failsafe approach at age 3, reacts in the following ways whenever she has 282 in bread. She becomes defiant, hyperactive, impossible to reason with, plain silly, very loud, noisy, annoying to others, demanding, pushy, and if something doesn't go her way...watch out...fully blown tantrum including slamming doors, storming out the house, screaming, yelling, crying that goes on for a long time. Can't and won't follow simple instructions, becomes distracted easily, goes off track and off task, becomes destructive She also finds settling at night really difficult ... can't seem to switch off. The next day she realizes that it was the 282 that made her feel that way ... and she genuinely can't refrain from behaving in this way. We are pleased though that as she grows her reactions seem to be becoming slightly less severe. I think this has to do with more careful diet, increased body weight, and increased maturity on her part.

Prior to going failsafe, life was unbearable. She had night terrors every night for 4 years etc, etc, etc. We made many trips to specialists and psychologists and others, with no explanation as to why we had a totally uncontrollable child. We chose to try Failsafe before we filled the prescription for Ritalin that we had been given, and thankfully it worked!

Thanks to your book, Fed Up, we have seen incredible results and are now on track. - Debbie, Victoria

[1160] 160b: Annatto is in everything! (December 2012)

Our 4yo son's behaviour really (apparently) deteriorated while I was pregnant with our second. It is hard to know if it's because you get lazy with the food whilst pregnant and go with more convenience products or a myriad of any other things. But I certainly recall during my pregnancy knowing that this couldn't go on! His day time behaviour didn't seem terrible, just the terrible two's, right? He would play quietly by himself for long periods of time and only if you asked him to stop doing the thing that he was enjoying, the reaction was over the top response. His tantrums were unbelievable. It would start with a simple over reaction to something and he just would be quite literally hysterical. No amount of comfort or words would ease the tantrum. The only way to deal with him was to usher him to his bed where he would scream it out. He would then sheepishly come out and we could move on.

The saddest, scariest day for me, he came out of the kitchen carrying 5 toys (as kids are known to do) he dropped one, and then all of them, he just lost the plot! Screaming, out of control, and the look on his face told me his head was in agony. I knew that if he was a teenager feeling what he was feeling, there is no doubt in my mind that he would suicide. What other way out is there? He didn't sleep well, not more than 2 hours at a time, and it would generally take 3 hours to get him to sleep. Draining.

We were introduced to food being the root of our problem, thanks to my mum. First thing we pulled out of the cupboard was Heinz Baby Fruit Bars. Checking every ingredient and it is the last ingredient that is the problem: Annatto (160b)! According to The Chemical Maze "May cause irritability; head banging; hives; headache; sleep disturbance; restlessness" Our boy, of 2 and 1/2 was suffering from all but the head banging, and hives, although I would argue that he had hives on the brain, as I would describe it.

Annatto is in everything! So even though I was giving him a variety of foods, he was still getting a good dose of annatto every day. the fruit bars, vanilla ice cream, fruit drink concentrate, crumbed deli products, cereals, noodles, caramel rice cakes, almost every aisle in the supermarket contains annatto in it. And this poor little fellow was like a junky. He would go scratching at the pantry door trying to get at the products that contained his fix. I marvelled at how he knew that was what would fix his pains. But I was the same with dark chocolate, I didn't know it caused the headaches, I just knew that it made them go away. Immediately all things with annatto were removed from the cupboard and given away, with much guilt I might add. Within 3 days it was plainly obvious that he was feeling great. We had a few incidents early on, learning what products really do contain 160b. It's hard for people to understand unless they see it firsthand too. I was really lucky that Mum had stayed for the whole week and saw the turn around. And, although it wasn't a hard sell for her, she already understood the link between food and the body; it is always great to see positive results.

From there you could start to see more ups and downs, that other things were causing troubles. And every time I researched, it brought me back to www.fedup.com.au and salicylates. It took a little while to figure out that was what we needed. I read Sue Dengate's book, Fed Up with children's behaviour. The entire book was light bulby for me, my child hood would have been so much better had this information been available to my mother. All I kept thinking while reading the book; was that this is the book that should be read by mothers when they come home with their newborns. You are told to look for reactions, but you really don't understand what that means. We are also told there is no manual for babies, but I really feel that the Fed Up book is a great start.

It was pretty much a no brainer to go failsafe, but the approach was tricky, as change always is... But after a slow two week start, which I had declared we would use up what we had in the house but only buy failsafe things. Didn't work out too well, I couldn't in good conscience actually cook with any of that stuff. Before you know it we were boxing the food up to give away.

It took me a few months to find my feet, many nights crying myself to sleep, and many days worried sick. It was only after moving to rural Queensland that I was able to meet with an Allied Health dietician that familiar with the RPAH Elimination Diet and could be helpful. But this was 12 months after we had started, and I really had found my feet. We got there in the end, the transition was painful. We now live on the strict elimination diet now. Only low chemical for us. Any challenge we make ends in negative results. So there is no deviation from the path for us. My previously fussy eater is now expanding on his food palette. I would never have thought it possible. But it seems that a lot of kids with food intolerance are fussy eaters. Somehow their brain has the food/feeling connection but it just doesn't tell us.

As it turns out, my mother doesn't fair well with Annatto in products either, it gives her terrible dreams and for her, it is just best avoided. Of course, I would advocate for its removal from our food. Is it really necessary, it is just a colour, a colour with other safer alternatives? – Jayne from Qld.

[1158] Is it really epilepsy – or benign nocturnal myoclonus? (October 2012)

Rhythmic jerking while asleep which stop if gently woken are frequently misdiagnosed as epilepsy in children. A British Medical Journal reports 15 cases of misdiagnosis, seven of which resulted in anticonvulsant medication for periods ranging from three months to seven years, without benefit. And a reader reports it's not just children.

A few years ago, while living in the UK, my then 32 year old very fit healthy husband started to have nocturnal partial seizures (or so it seemed). He was extensively and exhaustively investigated, which was very reassuring. He was told he had epilepsy, put on carbamazepine, and had to leave his job as a result as his work involved driving.

On our second and final visit to the neurologist he was told "there is nothing wrong with you". I took issue with this and asked why in that case he was on antiepileptic drugs, had been told to revoke his driving licence, and had been told he had epilepsy. Eventually we were reduced to the degrading situation of borrowing a video camera to tape these episodes, we felt so much like no-one believed us. On watching the recordings, he was clearly experiencing episodes of paroxysmal nocturnal myoclonus - which I later discovered as an entity in the small print in big fat textbooks.

To cut a long story short, I concluded the problem was stress related - or more accurately, bullying at work (in a very subtle, unobtrusive way) - the bullier (a colleague) took a dislike to him when he made a polite request of the boss to work elsewhere as the open plan office which was full of smokers was causing him some discomfort.

I have learnt from this that stress can cause all sorts of symptoms - and that when specialists say there is nothing wrong with the patient, what they mean is they don't know what is wrong - and frequently have not looked beyond the physical in their considerations. - by email, NZ

Further reading: Benign sleep myoclonus of infancy mistaken for epilepsy
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1125884/?tool=pubmed

Differentiating between nonepileptic and epileptic seizures.
http://www.ncbi.nlm.nih.gov/pubmed/21386814

[1154] 282: Bread preservative and seizures, extreme sleep disturbance, 'out-of-control' behaviour (October 2012)

I have a 2 year old son whose diet I have recently changed due to the behavioural problems that we were experiencing with him. My son was a big bread eater. While I was pregnant with him I was eating 10 slices of bread a day with 282 bread preservative and by the age of 18 months my son was eating the same amount. He was always a very difficult sleeper and has been having seizures since he was 18 months old. Since changing his diet to preservative free bread , he has gone from a monster to a reasonably placid child, he sleeps well, and his seizures have improved remarkably. **Update:** in the last 6 months he has had only three seizures. – by email, NSW

[1145] Delaying babies due to difficult first babies (October 2012)

I am a midwife. I came to your talk because of what I am finding with my clients. Those who are having second babies have often left it as long as possible because their first babies were so difficult - crying and unsettled for hours at a time, and sleeping poorly. It seems to be increasingly common. As a nurse, we tell them to eat everything in moderation while breastfeeding but I realise now they may need some more information – from Fedup Roadshow 2012.

[1120] Amines really affect my 14 year old's mental health (August 2012)

I have been wondering how many other unhappy, 'hormonal' teenagers there are out there who might be helped by the diet. Amines (and might also be salicylates) really affect my 14 year old's mental health and on the diet she is so much happier.

My daughter has always been a very anxious child and teenager. In recent years she has been a glass-half-empty girl, where any outing or party was 'okay' but there was always a negative slant on it. She was always too uptight to sleep in and would have sessions where she would cry for no reason, which I put down to hormones. Essentially, she is a lovely, loving child and we are very close, but she was wearing me out.

Since the diet, she and her sister have barely exchanged a cross word, she takes life in her stride and comes home positive about her experiences. She has a busy sporting schedule but rather than complaining about getting up early and being tired, she gets on with it and has improved greatly since the diet. She sleeps in on the mornings she doesn't go to training, trusting that I will wake her in time to go to school. She will never be a super-confident girl and she still has occasional times of grumpiness, but she is now a happy child. The funny thing is that she couldn't see the change in herself, even though it was so obvious to my older daughter and me. But she did see the effect when she once ate some rubbish they created in Food Tech at school (chocolate, coconut and m&m balls!) and now chooses not to eat those foods as far as it is possible.

Thanks so much for all your work in this area. I found your book in a waiting room and haven't looked back. - by email

[1119] Night terrors gone (August 2012)

Our 7 year old daughter has been living in anxiety and terror at night and also in the day has to be with someone else in the room. I have been trying the diet with her for one and half weeks no amines, glutamates and moderate salicylates only. Last night was her first fear free night. I could cry with relief. - Rachel by email

[1105] "can manage more salicylates" (February 2012)

Thanks for your research about chilli! I have found I can manage more salicylates e.g. pumpkin, sweet potato, rockmelons - but I had a rough night last week when I took some leftover sweet potatoes from the fridge for a snack at work & didn't eat chilli first. That night I was right back to the salicylate reactions - difficulty falling asleep, insomnia, and bad dreams that have plagued me for years – and I forgot about ENO (that's another one, forgetfulness). – Lydia, Qld

[1094] Dietitian smoothed the way when having to deal with doctors (January 2012)

I am new to food intolerance but I have had my 4 yo son to the doctors in the past (and just been fobbed off) for pains in his legs, tummy aches, stuffy nose and mouth-breathing. He grinds his teeth at night, over-reacts to situations with anger or tears, does not seem to sleep much and complains about loud noises.

... One month later ... We have been to a dietician from the list you sent. It was great advice as it really smooths the way when having to deal with doctors and other govt. agencies - they are now very accommodating. We are into day five and I have already noticed the voice volume decrease and far less fighting between the two children. So thank you to you and everyone who contributes info, it saves so much time and mistakes. - Anna, NZ

[1088] Severe anxiety from salicylates (January 2012) COURAGE AWARD

My daughter Rose is 7 years old. Since she was about 18 months old, we had problems with her waking every night with nightmares. Although her behaviour was not exceptionally good, it was not an issue at the time. When Rose started 4 year old kinder we started to notice that her eczema was getting quite bad and that it was not responding to any remedies that we tried. We saw doctors who just said that she might grow out of it. When Rose started school, there was a huge turning point. Her behaviour I would say was ADHD behaviour – tantrums, itching all over her body, stomach pains, still having nightmares, oppositional defiance and the list goes on, and the worst of all, severe anxiety with me leaving her. Rose's anxiety was so bad that she had to be physically removed from me when I left her at school, even punching and kicking at the teachers. Rose would not leave me at all, even on weekends.

With trying to counteract the behaviour part, I stopped all additives and preservatives. Rose's behaviour became so much better. We noticed that her sleep, and feelings of anxiety did not improve.

After reading your book, I made an appointment with a dietician and started on the Elimination Diet. Everything started to improve with Rose, in leaps and bounds, except the anxiety. With many trials, I have now established that Rose is very sensitive to SALICYLATES.

I now have a daughter who is very confident, well mannered, has no problems sleeping, no eczema, nor does she have anxiety.

I can only say that without your help, I had no idea where to turn. The professional field let me down big time.

We have been doing this for about 12 months and I am a true advocate of Failsafe. I want to introduce this to our school. When my daughter was in Prep we had a lot to do with the Principal, as Rose spent a lot of time in her office, as they believed she was being naughty. Last year I was determined to prove them wrong by showing them that food did contribute to children's behaviour. I did often say that it was the food Rose was eating, but I know they did not believe me. I can now truly say that Rose's behaviour was as a result of the food, its additives and preservatives, as she is a different student. Well mannered, high achiever, leader material. Thank you. - Sharon, Vic

[1081] Our toddler was a little tornado on salicylates (December 2011)

My husband was one of the first children to go on the Feingold diet in Australia in 1973. His parents still talk about the amazing improvements they saw although on that diet he was allowed pineapple, dates, cauliflower and mushrooms. I think some of the improvement was that they had a local butcher, they made their own bread, and they never ate out because there was no eating out then. They had a wonderful local chemist who made them toothpaste.

Because of that you would have thought we would twig much earlier to our son but we didn't. We avoided tomato and orange a lot because from when he first went on solids he broke out in a rash and did again a few times so we just didn't eat them. But he got worse over time. At 15 months he would run up our very steep street and then do 4 blocks of the neighbourhood, with us trying to keep up. I'm now pretty sure that was the kick he was getting from the salicylates. His absolute favourite was apricot teddies. We used to only let him have 1 or 2 every fortnight but that, along with all the other high foods kept him like a little tornado.

My husband's mum told us about salicylates when we went away on a holiday. His eczema got really bad and we thought it must be from the chlorine when we went swimming. She suggested fish oil tablets so we got some for kids but they also had high salicylates. He just went hyper in no time. He kept asking for more of them and that night he screamed and screamed all night and kept scratching worse than he ever had. He had welts all over him in the morning.

We tried cutting out just salicylates and saw some improvement but it just got bad again. Then I went hunting on the internet, found your book and we talked with our doctor about doing the RPA elimination diet. The change was noticeable, the biggest being less extreme mood swings and going to sleep at night. Bedtime used to be a 2 hour stint every night and then he would collapse in exhaustion.

We have seen head banging on two occasions, well after we started the diet. My sister gave him some yoghurt by mistake with Annatto 160b in it and he was a very loud very angry little boy. He didn't really have tantrums as such but did quite a bit of banging his head, wouldn't let us near him. He didn't want to be touched at all and kept threatening his little brother with all kinds of nasty things. A lot of yelling. He did not sleep at all well that night needless to say. It was the same the second time. – Susan, by email (Please report similar annatto 160b reactions to suedengate@ozemail.com.au)

[1068] Grandmother's night terrors, anxiety, paranoia, depression and brain fog helped by diet (July 2011) COURAGE AWARD

My daughter bought the Fed Up book to help her son, my one year old grandson who was cranky, unable to sleep, hyperactive and constantly cleared his throat. After reading the book, I saw myself in the symptoms of night terrors, anxiety, depression and brain fogginess. So I joined him on the diet (we all live together) and I haven't had one night terror since. (Prior to this I was having at least 5 night terrors a week and hated going to bed.) I have had the occasional bad dream when eating off the diet, but nothing like they were. My anxiety lifted, the depression went away and for the first semester since returning to university I understood what they were saying, I participated in class and starting talking and laughing like a 'normal' person.

Before that I was constantly anxious, paranoid, stressed and felt 'stupid.' I thought people didn't like me, I wasn't good enough, and I was unmotivated to reach my goals.

My husband didn't believe in food affecting people, and was critical of our changes, however has seen remarkable changes in the baby and in me. He said to me recently 'what's the matter with you?' as I was sullen and quiet. I admitted I ate something off the diet (but I used to be like that most of the time). Now he cooks me failsafe meals at night and reads labels before buying foods.

I stay away from additives, salicylates, amines, glutamates and dairy. It can be difficult to eat a limited diet, but the world is so much more fun, it's worth it!

Thank you for writing the books and creating the DVD. It's given me back the opportunity to experience the wonderful life I have. - Monica

[1066] Anniversary: 12 months failsafe for severe eczema (July 2011) COURAGE AWARD

Sleepless nights... what an understatement! We were averaging 2/3 hrs sleep a night when the kids' problems hit a peak. This went on for months.

We were at a loss as to what had taken over our family and was slowly breaking us all down to a point of no return. As parents, feeling helpless, exhausted, and desperate was quickly becoming our normal. For our children it was far worse, they were struggling constantly with scratching, bleeding and screaming in pain, day and night. Finding our 4 month old son bleeding in his cot was a regular occurrence. Then there were the times holding our 6 year old daughter while she screamed, thrashed, and clawed at her flesh causing it to bleed. All too often they were in unison and my husband held our baby trying to comfort him as he suffered the same way while I held our daughter.

A vicious cycle of skin infections, constant discomfort, and numerous trips to doctors who assured us it was just eczema only added to our desperation.

We knew the kids had allergies and avoided all the allergens as directed by specialists but unknowingly we were contributing daily to their severe discomfort by what we were feeding them - and it wasn't even a bad diet ... or so we thought!

Our life line came the day we saw Sue on the local news, she mentioned itchy skin rashes and I took notice! Life changed that day. Slowly but surely we eliminated the foods and personal care products that were causing this chaos.

It is our anniversary this month ...12 months failsafe and our gift is 2 beautiful children with silky smooth skin (we regularly run our hands over it amazed at the difference), no more rashes, itching or screaming through the night & guess what?... they are both calmer & more engaged ... behaviour was not our original motivation to become failsafe but we have noticed the changes in them in this area as well and what an absolute bonus that is.

Thanks Sue and Howard for your many years of research and hard work and also for giving us a place to turn when there seemed no where else to go, we are forever grateful – Deb (Deb is organising the Fedup Roadshow talk in Taree 2011)

[1053] 320: Mislabelling by a major food company (from submission to FSANZ 2006)

Six months ago our daughter developed severe behavioural problems, including depression, lack of motivation, poor sleeping habits, lethargy and loss of enthusiasm. These were very uncharacteristic of a hard-working fulltime student and a complete puzzle to her concerned teachers. As a consequence, her exam results declined, as did her study performance.

Her problems were eventually traced to her consumption of home-baked products containing Dairysoft, a butter-oil blend manufactured by one of Australia's largest companies, the Murray Goulburn Co-Operative Ltd.

Our daughter is known to be affected by antioxidants 310-312 and 319-321 and several other food additives. Before she started using Dairysoft, verbal advice was obtained from Murray Goulburn that there were no antioxidants in the oil which comprised 22% of the product.

After months of increasing problems, we contacted Murray Goulburn again and were now that informed that the canola oil in the product did in fact contain 320, Butylated Hydroxyanisole.

Our daughter removed Dairysoft from her diet and she has since made a complete recovery, although there can be no compensation for the six months of pain and uncertainty which she suffered. Following complaints, Murray Goulburn have now correctly labeled this product, although without any food recall, product safety or public apology notice. – parents from Darwin.

[1042] 320: Night terrors and oppositional defiance from fries with 320 (from submission to FSANZ 2006)

We know that our 5 year old daughter is intolerant of all the nasty additives, colours, preservatives etc. I was very surprised in the 'Food Tables for People Sensitive to Ingredients or Allergens' (http://www.mcdonalds.com.au/PDFs/AllergenList.pdf) at what they are claiming - no additives in their nuggets or fries!! Certainly not what my daughter's additive radar indicates because last time she ate there, we had her up in the night screaming with "night terrors" and three days of ODD attitude. – K...., Vic

(Antioxidants are not regarded as preservatives so are not listed in the Ingredient and Allergen table. In the full ingredients list you can see that the fries are cooked in canola oil blend with BHA 320 http://www.mcdonalds.com.au/PDFs/IngredientListing.pdf)

[1007] Fragrance: Angry, tantrumy boy punching himself in the head due to airfreshener (March 2011)

A couple of months ago I decided to put an airfreshener in my 6 yo autistic's room because it smelt like urine due to him wetting the bed a lot. The next day he turned from a calm placid little boy to an angry, tantrumy boy who would constantly punch himself in the head causing big bruises, crying and screaming like there was something in his head and he couldn't get it out. He also didn't sleep much while the air freshener was in his room. It took two days to figure out what I had done to my beautiful boy and once I removed the offender and aired his room out naturally, within a 2-3 hour period he was his calm self again. I hope this can help someone. - Jackie, by email

[1006] Rosy cheeks, colic, poor sleeping, terrible nappy rash due to salicylates (March 2011)

I can't tell you how much I love your work!! We came across FAILSAFE after months of my infant son suffering from such a terrible nappy rash that he was quite raw. I wasn't helping matters by using baby wipes & soothing creams that had orange juice etc in them (Gaia brand). The Dr wouldn't believe that I was using the steroid cream he'd prescribed, & made me tell him exactly how I was using it - is there another way to use it? Finally, through our local Child & Family Health Clinic, one of the Nurses mentioned salicylates. My journey was far from over, however, going through the public health paediatric dietitian (who recommended that I feed my son rockmelon you should have seen him after I took that advice!! Poor little tyke!) & several other Drs & nurses before I stumbled onto a Dr who, when walking past us to her next patient in the waiting room (we were there to see another Dr), looked at my son & remarked Looks like he might have a reaction to salicylates those rosy cheeks that everyone kept telling me was teething was really a dead giveaway!!

From there, our lives improved so much, thanks to a supportive & knowledgeable Dr, dietitian & your Failsafe Cookbook. Our son could finally sleep, and his pesky colic disappeared after only a few days! All that we had been told was normal in a baby, and that we were made to feel like whingers for bringing up, were anything but normal when we got his food right (& mine, as I was breastfeeding).

He’s now 3 years old, and it’s so easy to tell when he’s had something to eat that he shouldn’t! He’s very sensitive, even reacting to red delicious apples. We’ve now got another bub, a little girl, who has been so lucky that she has never had any real food issues, as I was Failsafe the whole time when breastfeeding her & of course feeding her solids. Still makes me feel guilty that my son had to go through almost a year with such pain, but at least we’re all better off now, knowing about this issue. We still get funny looks from people who seem to think we’re on some kind of fad diet, but we know what happens when we don’t follow it. My main problem is that our family, and even myself, think of ordinary food as being a treat so we do give him non-Failsafe foods occasionally. What I need to remember, and I think I’m getting there, is that even if he enjoys eating the food, the way he then feels & acts for the next 3 days is definitely not a good thing. Making my son feel sick, irritable or aggressive is not a treat for him, or any of us. I am getting there, but I wish my family would stop asking me when he’ll grow out of it and suggesting that he’s getting better (only because he’s eating Failsafe!! He wouldn’t be if he wasn’t!) and tempting my son with offers of when I’m babysitting you we’ll go out & get some REAL food chiko rolls and hot dogs & coke . Real food indeed!! Grrr!!

Thanks again, Sue, for everything you’ve done, and continue to do. It must bring you such a feeling of vindication & joy when you read through the many different stories people have I’m often amazed at the different ways people react to various things. Without you, our lives would all be much harder and I thank you sincerely from all of our family. – Lyn, by email

[1005] ‘Huge ankles’ and other symptoms due to diet (March 2011)

I went through the RPAH elimination diet about 3 years ago. The dietician confirmed I was intolerant to dairy, wheat, salicylates, amines and glutamates. Despite following a strict regime I have not been able to reintroduce any of the foods that caused an intolerance reaction. My symptoms I have now as a result of low exposure are: IBS, sinus pain, fluid buildup around my eyes, feet and ankles swelling, sleep disturbance, severe cramps in feet and legs. I am asthmatic. ... Update 3 weeks later: I cleaned up my diet (herbs, coffee and some vegies that I had included are now gone) and immediately had migraine type headaches. But since then it has all been much better. So this is the first summer in 20 years that I have been able to wear short trousers and not needed to hide my huge ankles. - Fiona, NSW

[983] Annatto 160b: yellow addiction, nightmare behaviour (March 2011)

After reading on your website the letter from Helen in NSW titled ‘Yellow Addiction’ I felt compelled to write to you.

I realised the adverse effect 160b had on my family approx 3 years ago when my now 6 year old son was about 3. Even at the age of three he was very good at sitting and concentrating at a task, be it drawing, lego or watching tv – except that was if he had consumed 160b within 24 hours. He became a completely different child. He couldn’t sit still, he couldn’t concentrate on anything and authority meant nothing to him – he was literally a nightmare. With hindsight prior to taking 160b out of my son’s diet, yellow was absolutely positively his favourite colour. I can’t remember him being attracted to only yellow foods – he has always been a fairly good eater but definitely yellow “things”. He always had to have the yellow cup and the yellow plate and if he didn’t there would be hell to pay. If you asked him back then what his favourite colour was it was most definitely yellow. His favourite colour today is unknown – it seems to be different every day. Until I read Helen’s letter I hadn’t made the link but who knows maybe it was linked to his 160b intolerance.

Today, obviously I keep 160b out of the house but I can tell straight away if my son has consumed it whilst at a play date! If I personally consume 160b I generally have a terrible night’s sleep and/or are very restless during the day. As you’ve mentioned on your website, 160b does seem to be creeping further into our food supply lately and it is driving me crazy. Aldi in particular seems to be extremely guilty of this. Sue, what can I do to try and get this revolting colouring out. (Contact manufacturers and see our Now Targeting section - S). Obviously we don’t eat a lot of processed food but just being able to let the kids select an icecream treat every now and again has turned into a nightmare. – Donna, by email

[964] One-liners (October 2010)

I am a coeliac, my two sons have coeliac indicators and one has marked behavioural allergic issues. Our home became a far calmer place within just two weeks of beginning the elimination diet. A full night’s sleep from our youngest after 3 1/5 years of multiple nightly wakings is such a gift to us all!! – Vincent, NSW

[946] 160b, 635: Poisoning my family with 635 and annatto (October 2010)

When I started to really read food labels, I was horrified by the fact that I was poisoning our whole family - especially with 635 and annatto. You asked me how we are affected by these additives.

635 - Myself (main symptom is migraines): dried, red lips. It looks like I have lipstick on. I feel dehydrated and get migraine style headaches. Photosensitivity in my sight. Lethargy. Unfulfilled feeling of thirst. Frequent urination that seems very diluted. Mmy 4 yo son (main symptom is defiance): dried, red lips also. Dehydration and thirst. Frequent urination. Sooky or whingy type of demeanor. My 2 yo daughter (main symptom is urticaria): After having a piece of bacon the size of a 10 cent piece, it sent her into massive hives. It seemed like she had a headache or faceache and she screamed at a high pitch and then cried for about 20 mins. I nearly called an ambulance. Very out of character for her and she barely cries for more than a minute normally. Our 635 foods were French Onion Soup Powder – I would use in casseroles, potato bake, soups - Smiths brand Crisps, sausages from the butcher, tinned soup such as Spring Lamb with Vegetables, and takeaway BBQ Chicken and chips.

Annatto (160b) - Myself: insomnia, anxiousness, a shaky type of sensation sometimes - a bit hard to articulate it but its sort of like I have a vibration or fluttering going on in my body. I "snap" easily and it does not take much to make me get angry. My son: Difficulty falling asleep. Disturbed night sleeps. Silly behaviour and noises like a monkey (jumps around, clumsy, unable to sit still and focus for longer than 5 mins). Sometimes aggressive with no apparent trigger. Unpredictable around other children. My daughter: disturbed sleep. She was a good sleeper but started to go away from her past pattern of falling asleep by herself and changed into shorter sleeps and waking often at night. Once we took it out of her diet she started to sleep through the night and sleeps for a solid 2 hour stint during her day nap. Our annatto foods were Kraft singles, yoghurts (with Bob the Builder) and ice cream. – Rose, by email

[938] 220: Lying awake my heart pounding for hours (October 2010)

I was just reading your article about the link between sulphites and ventricular arrhythmia in the latest newsletter. I could relate to many of the symptoms experienced by Michiko. On several occasions (usually after a dinner party or night out at a restaurant), I've had a similar experience, lying awake that night unable to sleep and my heart pounding for hours. Just like Michiko I felt like I was 'buzzing' as though I'd had some hype-inducing drug. Sometimes I would also feel breathless and I noticed this often happened after drinking white wine or champagne. I'd never heard of anyone else having this experience and wondered what could be causing it. Thanks to this article I now have a good explanation, and will avoid preservative 220. - Michelle, by email

[919] Snoring, sleep apnea, swollen tonsils and macroglossia due to additives (June 2010)

My five-year-old daughter's two years of snoring escalated a few months ago to sleep apnea. After three weeks of apnea, I consulted two doctors and then decided to feed her only natural foods - nothing out of a package of any kind. After six days, her apnea was gone. After about a month, her snoring was minimal. After two months she rarely snores. Tonight, after feeding her corn tortillas - with preservatives - for dinner, she fell asleep and immediately began snoring.

It was the second doctor, a GP, who noticed her swollen tonsils (I hadn't) and said there was no infection but that they were chronically swollen. After I asked if he thought it could be a reaction to contact with processed foods - because she gets a rash on her face after contact with various sauces - he replied "possibly" and that the darkness under her eyes was a sign of allergies. That was when I decided to take her off all packaged foods on my own until we could have an appointment with an allergist - usually a 2 to 6-month wait here.

We saw a Pediatric Allergist two days ago and she was tested for all the standard things like milk, soy, wheat, dust, cat, dog, etc. and was fine. The allergist suggested she may be sensitive to sulphites because I am allergic to sulpha drugs.

Her face has always turned red exactly where any sauces and liquids out of packages touched her cheeks and mouth. Kraft salad dressings, Heinz ketchup, and canned apple pie filling, plus pear cooler which dribbled over her bare tummy have all cause the redness. I figured that the swollen tonsils - like golf balls - were her internal skin's reaction to a food sensitivity because of how we saw her external skin reacting.

Before removing additives, my daughter's face was always a little chubby-looking with a double chin, although she wasn't chubby. It was the swollen tonsils that were causing the double chin. Now she is more normal in appearance without chubby cheeks and an oversized swollen tongue [macroglossia] that made her speak oddly. Even her voice is no longer nasal. My friends used to comment that she sounded like she had an accent. She also had darkness under her eyes. She is very blond with blue eyes and she always had pinkish-purple bags under her eyes. They are now gone along with her snoring right through the night!

Also, her defiant behaviour really improved and she is far more peaceful after I was able to be very strict with her "no packaged foods" diet. We now have real butter and cream in our house. I make our bread and ice cream too.

I am relieved not to have to put my daughter through surgery to remove her tonsils and adenoids, which is very common with children who have apnea. I feel strongly that everyone involved in a child's health should do all they can to find the cause of the symptoms rather than just treat the symptom by removing the tonsils. - Maree, Canada

[916] AAaaaaaaagh! - Reaction to Colour Free Panadol medication (June 2010)

My 5-year-old son has been kept completely free of preservatives, flavours, flavour enhancers and colours for just over 12 months to control behaviour and it has worked wonderfully!

Recently, he had a temperature so I very hesitantly gave him Colour Free Panadol (and only the minimum dose.) Oh my God what a nightmare! Since giving it to him, he went back to his pre diet ways, crying non stop, angry, and rages for the stupidest reasons - completely irrational. It took 4½ horrible days to get out of his system. We had periods where he lay there and would hit, kick and throw anything he could get his hands on, till he would wear himself out - not a nice thing to witness - and of course the night terrors that he had in the past returned. I am reminded of how much of a nightmare my life was prior to going additive-free. Yet other than being highly food sensitive he is a perfectly healthy, intelligent 5-year-old.

Are there any other options for reducing a child’s temperature that will not result in him going crazy for days afterwards? (Katie, by email – and see Q&A)

[908] 160b: irritability, defiance, head and body banging (June 2010)

We adopted our son from Russia two years ago (he is now three). He is sensory seeking and delayed in speech. We have only recently uncovered a link between his food and behavior, particularly with Annatto. It makes him hyper, sleepless, defiant, irritable, and a body banger against furniture (not limited to head banging), starting within 1-2 hours and lasting up to 24 hours.

Our son had been seeing an occupational therapist 2x's per month for sensory seeking behaviors. The OT recommended looking into a link between nutrition and behavior. We met with an allergist first. Her tests proved negative for protein allergies. She suggested that we start saving food labels any time we suspected reactions and compare them for common ingredients. The first food we noticed was Pepperidge Farm Cheddar Goldfish Crackers. Our son was very stimulated and not able to nap. I saw Annatto listed and wondered what it was. I did an internet search and found your website and others. The next time I saw a reaction, Annatto was in the peach yogurt I had fed him. On this particular day at naptime, he sat backwards in his rocking chair and banged it continually into the wall.

We started the Feingold program here in the U.S. and, as you probably know, it does not address Annatto so we eliminated Annatto as well. Our son's issues decreased within the first week. He was less hyper, more compliant, and able to sleep better, except for one noticeable withdrawal episode - his first on-the-floor kicking temper tantrum. My favorite result to cite is when I asked him to put books away. He answered "Okay, Mama" and did it right away. This is the sweet little boy who was there all along. I hate the idea that the foods I thought were good for him were causing him to misbehave and causing me frustration. We are happy to be Annatto-free now.

We are finding it hard to identify products with Annatto since it is not always stated by name or number in the ingredients list. We are learning to stay away from products with "natural flavors & colors" even if Feingold approved. There are many products that we have since cut out of his diet after discovering the Annatto link.

Changing our son's food and skin care products was easier than I ever imagined. He hardly notices, except for the times I have to say no to certain foods that do not have good things in them for him. It does take extra effort but it is well worth it. Still, I look forward to the day when the food-behavior link is widely accepted, forcing companies to eliminate these harmful additives from our supermarket shelves. – by email, USA

[907] 160b: agitated, uncontrollable, full of energy, hyperactive (June 2010)

I have 2 boys, aged 3 and 1 who both react badly to annatto. About half an hour after our 3 year old has had something with annatto in he is uncontrollable, agitated, full of energy, really full on. Hyperactive is how someone has described it.

I had read about annatto by chance and at first didn’t think much of it but I mentioned it to my husband who said he reacted to red and yellow colours as a child so I stopped buying anything with 160b in it. I can’t say I noticed anything for a while but one day we had dinner at a friend’s place and our 3 yo was offered some ice cream. I didn’t think to check it. Within half an hour our son was a nightmare. Kicking, screaming, purposefully doing things to annoy/upset us, refusing to sleep and thrashing out etc. My husband and I were shocked - what had happened to our child? Suddenly the penny dropped and I called to ask if the ice cream had 160b in it - it did! Since then we’ve also seen reactions to cheese, custard and yoghurt (at daycare until I asked not to give annatto to him). – Silvia, NSW

[906] 160b: Restless legs and sleep disturbance (June 2010)

At various times over recent months I have suffered with restless legs and a disturbed night’s sleep. Today I decided to investigate the ingredients of the fish fingers we had for dinner last night, and found that they contained 160b. I believe that this colour is most likely the cause of my restless legs and sleep disturbance. I will therefore be avoiding it at all costs in the future.

… One month later …Since I’ve stopped eating the fish fingers I’ve had no more restless legs. I’m convinced that it is the 160b causing them. I’ve since eaten the fish fingers without the batter and had no ill effects.

I’ve noticed that 160b is in so many foods. Bulla’s mini icecreams too. What a pity. They claim to be free of artificial flavours and colours, but still contain the natural colour 160b.I was hoping to give them to my kids until I read the ingredients list.

Many times in past years I have suffered with restless legs at night and hadn't known what caused them. Perhaps it was 160b then as well. I wasn't taking any notice of what was in my food then. Thank-you for such informative and helpful reading. – Sue C, NSW

[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 subequent 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 is 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

[888] 160b: Defiant, teary, mega tantrums after annatto (February 2010)

I have had great results with my daughter now 4 with a generally additive free, low chemical diet with improvements in behaviour, going to sleep etc (used to have many major tantrums, defiance, took 2 hours to go to sleep). 160b is a big culprit. It makes my daughter extremely defiant, teary and she throws mega tantrums. (It’s so hard to educate my mum - as 160b is in so many "healthy foods" yoghurt, icecreams, etc). Our friends’ son is a headbanger when he eats annatto. – Tamsin, Vic

[879] Miraculous change in extreme sleeping problems (November 2009) COURAGE AWARD

I was a single mother living alone away from family support, breastfeeding and juggling a wonderful son who at 12 months was barely sleeping 4 hours a day. Most days he looked as if he had drunk a can of "red bull" - eyes rolling, twitching and distant - and sleep only ever seemed to come lightly for short periods once he was beyond exhausted.

He had a rash all over his body that just kept spreading and it made me cry watching him tear at it all day and all night without any relief.

At 12 months I put him into a local day care centre for 2 days a week for some sort of break (sleeping sometimes in the car just around the corner too tired to make it home to sleep after dropping him off). He was a real handful there as he would not settle and ever sleep and would upset all the other babies with his screaming.

I was beside myself by the time I swallowed what pride a new sleepless mum had left and sought every kind of assistance I could - my baby health nurse, my local doctor, and then another doctor all said it was normal (as they all shrugged their shoulders) and the eczema was a lifetime hereditary thing ...

I was even assessed at a local government "sleep clinic" on the gold coast - an awful experience with him not sleeping at all for them and them saying 20 hours without sleep "may be normal for him " - (bugger me !!)

After my lowest darkest point whereby at about 14 months he barely slept in 40 mins increments I was sent to the state children's sleep school in Brisbane. The basic program philosophy is about controlled crying - but that wasn’t his problem …

It was a 5 day hellish event I would wish on no one. He screamed and cried for the first 3 days solid and set new limits in sleep deprivation - made easier the 3rd day only because he totally lost his voice and his screams couldn’t be heard !!! By day 4 he slept (passed out) from sheer exhaustion - so that was apparently a success and I was sent home day 5!!

After only a day or two at home it was obvious there was no improvement.

The next few weeks as I contemplated our future without support, sleep or potential for work as things stood really took its toll, until I was blessed to come across a pharmacist in our local pharmacy. She sat me down and really talked me through the failsafe approach - and really took the time to make it sink in. I was an unwilling participant as when you are so exhausted anything new seems to be insurmountable.

It took 4 days!!! only 4 days !! from having someone waking 8 times a night to 2 times a night!!! from sleeping 4 hours a day to 8 hours - and 10 hours by the end of the week. Once I switched to A2 milk the loop was complete and he started sleeping the night through by the end of week 2. The change was nothing short of miraculous.

For my son to go from the least favourite boy in his kindy to the favourite almost within a week!! It was like someone had handed me a new son.

He became an affectionate loving inquisitive boy that every mum would be so proud of - no tantrums, no fits of rage, renewed energy and able on concentrate on things so much better he simply bloomed, like watching a wilted flower come back to life after rain.

His rash completely healed - completely!! He is now 2.5 years and it has never returned!!

When I tell people about all the positive changes we have had on the diet, they seem to think the diet I fed him before failsafe was really poor. They assume it was full of red cordial, McDonalds, coloured commercial lollies etc but I was aware of colours and MSG and he NEVER had those. At the time I was following the diet recommended by the child care centre. It was the sulphur dioxide in dried fruits, the hidden nitrates in meats, and natural colour 160b I wasn't aware of, that were our biggest problems, also I was breast feeding at the time and was having more "junk food" and stimulants from comfort eating to keep me functioning so he was getting it that way. I realise my mistake in overdoing a "healthy diet" mostly consisting of a mega high salicylates, high amines and glutamates!! and although I was careful about colours and some preservatives, my son's biggest and most immediate reactions came from fish/ meats/ and preserved fruits.

Having followed all the information you have put out there in the Failsafe Cookbook my son has thrived!! He has come from behind to be the tallest and fittest in his class. The effect this failsafe lifestyle has had on Patrick has been evident to all who knew him "before diet" as we call it.

I often have people ask me about your work, especially from his childcare centre as they have followed his progress and it's so rewarding to see the individual but still dramatic change it has on other babies, toddlers and children.

I get angry when I think of the torment and the lost first 12 months of his life - and that a children's hospital in a week could not assist or pick up what a pharmacist did in seconds - but promise in my own prayers of thanks for you and the pharmacist that I will do my best to help those similar suffering mums that cross my own path. Thank you. - Patrick's proud mum, Qld

[878] Sleeping problems solved - thanks to sleep webinar (November 2009)

Calvin was an easy baby, slept well, settled after feeds beautifully and was just lovely. Once we started solids, things started changing for the worse. By 12 months he was waking 3-6 times a night screaming and was impossible to soothe. Only sheer exhaustion put him back to sleep. I looked into all sorts of options for sleep training, but none of them sat well with me as I was sure it was a pain issue, not a sleep issue, so I resisted urging from friends and family to control cry and looked into the possibility of food intolerance.

At that same time, Sue was advertising a webinar on sleep and food intolerance. I registered and joined in on the night. I listened and took notes, but still wasn't convinced this was us, I just hated the idea of a restricted diet for Calvin.

By 14 months things were desperate and my husband and I were chronically sleep deprived. We booked into a failsafe dietician and started the elimination diet. Calvin improved a little, and then had textbook withdrawal after a week and a half. In week 3 he slept through the night for the first time in 15 months and then slept through for another 3 nights after that. We have had some up and down nights since then, but nothing like the screaming fits he used to have. 7 weeks on, he has slept through 10 full nights and only woken once or twice for a pat most of the other nights. Now we are slowly introducing challenges, but our need for sleep catch up and Calvin's age has meant that we have opted for the slow route rather than overload challenges. This means we still have a long way to go, but have felt very encouraged by the Fed Up website, book and cookbook - Thanks Sue for all your hard work!! - Pippa, by email

[853] Additive-free, but favourite foods were tomatoes (August 2009) COURAGE AWARD

We're 3 weeks in to Failsafe, and I feel as if I've won the lottery!!! 3 kids aged 10, 8 and 5, all extremely active and slightly frenetic. The oldest was diagnosed with Aspergers and ADD at about 6 years of age, but concerns were noted since he was about 4 - very fixated on certain activities, difficulty being aware of his environment, very impulsive etc. He repeated reception as he was really struggling, very highly strung. We cut down on additives with some improvement, but he was still very hooked into his own thoughts and obsessional in thinking and behaviour, talking out in class, struggling academically. He was still incontinent of number ones and twos, as he had such poor awareness of his body, and inability to attend to more than one thing at a time (ie concentrating on schoolwork or a game, and bodily sensations).

He was placed on Concerta (a type of Ritalin) at 8 years of age, which led to a very noticeable improvement in ability to concentrate in school, and less impulsivity. This was the very thing we had not wanted to do with our child, but we couldn’t continue with daily sneaky poos, constantly spacing out at school, and that level of impulsivity was taking its toll on the whole family. While I do believe medication is over-prescribed and should only be a last resort, we had done everything we could, and it did help. I strongly believe parents should not automatically be judged for medicating their children, we are all doing our best, with whatever information we have.

He began to really shut down about 18 months ago, becoming very isolated, spending every school break time alone reading, and not even responding to questions at home, instead preferring to read alone. He was very sullen, on bad days yelling at schoolmates who tried to engage him. He had no friends, and swung between a sullen and angry boy, or a highly impulsive, giggly and inappropriate "in your face" kid.

We had been additive free for some time, and he had a blood test which showed he was intolerant to wheat, strawberries, dairy and cocoa so those were out also. We had done the rounds of psychiatrist, psychologist, social skills training, occupational therapy, etc.

He is now in year 4 and just prior to commencing diet, he dirtied his pants at school and then told a classmate about it! I panicked, I could not pinpoint any additives that would have led to the behaviour, and I felt desperate. I went to the Autism SA resource centre where I found "The Failsafe Cookbook", and I haven’t put it down since!

Our oldest son's favourite foods were tomatoes, and Nonna's pasta and meatballs - he would scoff a whole punnet of cherry tomatoes in one go if he could. Our second child could have best been described as a fruit addict, regularly eating 5 apples after school (I would find the cores littered around the house). He is an academically capable kid, but could be very oppositional, and was diagnosed as having an auditory processing disorder. He was very hyperactive also. Our youngest daughter had an almost normal diet, I think because I was so exhausted from meeting the needs of the older two that I didn’t have the energy to say "No", to be honest!! I did notice that she was much harder to settle to sleep than the other two, especially after eating raisin toast (even with "no preservatives on the pack!), and flavoured snacks, which were given by friends etc.

Since the diet, the improvements have been extraordinary! I had to have a meeting at home with a colleague, and my children played lego together, without arguing mind you, for about 1.5 hours!!! My oldest has dry pants at the end of the day, responds when asked questions, engages in appropriate conversation, and most heartwarming of all, has had several successful playdates with a boy from school. I was able to leave all three with my mother last week while I worked without her having a breakdown. She was shocked at the difference, and my father reported that my oldest pruned a whole row of grapes for him!

The "fruit addict" is the most changed! He is polite, helpful (someone pinch me, please!). Our daughter is sleeping better, still has made an artform of irritating her brothers, but our home is overall much more harmonious, and I am so grateful.

My husband and I are both southern European, and it seems strange that our children could be intolerant to tomatoes and the like. I'm still a bit puzzled, but I chatted about it to my dad, who migrated from southern Italy in 1960. According to him, my nonna only cooked with tomatoes once a week, for a Sunday lunch of pasta, with the rest of the meals being pasta with beans or lentils, or a vegetable soup. Unfortunately most Italian cuisine now involves a tin of peeled tomatoes and regular flavourings of wine and cheese in almost every recipe, so that's a real challenge for us.

It makes me incredibly angry that even basic foods are laced with additives that are harming our children. I see parents at breaking point and children whose self esteem and learning are compromised, and it is incomprehensible. I for one am TIRED of it.

Thank you so much for your care and compassion in the important work that you do. - by email, Adelaide

(Natural Confectionery Lollies are NOT failsafe due to sals and amines in flavours they are only suitable for people who are additive-free)

[835] Alzheimers, asthma and apnoea (July 2009)

I thought I would share with you briefly my experience of treating my wife who was diagnosed with early onset Alzheimer's. Apart from the Alzheimer's diagnosis, she suffered from asthma, sleep apnoea, was unable to speak more than one word at a time and was going down hill very fast. After a lot of research I decided to put her on to a 90% raw food diet and after one month, she started to speak the odd phrase. This was marvellous and only encouraged me to continue. However the amazing thing was after a few months her asthma symptoms began to disappear and she was able to reduce her dependence on puffers. After six months even the preventer puffer was reduced to almost zero and a year later in consultation with the doctor stopped using puffers altogether. Two and a half years later, she has been symptom free for two winters so confidently predict it has gone forever. Oh by the way her sleep apnoea has gone as well. This experience of curing asthma with raw food is not unique as I have subsequently found out. When visiting your website I realised the raw food diet was eliminating additives. Commercial raw food has other problems i.e. pesticides, growth promoters etc but the experience of using commercial raw food has been worthwhile. Would like to eat organic but currently that's not possible. When visiting, we eat normal food and don't expect others to provide the food we use at home. - by email

[833] Apnoea – brief reader reports (July 2009)

- A nine year old boy from the NT suffered from snoring and sleep apnoea. The elimination diet revealed that a few food additives were responsible sunset yellow (110), the bread preservative (282) and MSG (621). When he later developed the problem while avoiding his food triggers, fumes from a new mattress turned out to be the cause.
- A forty something father who had struggled with sleep apnoea and narcolepsy for twenty years discovered through the RPA elimination diet to his surprise that his problems were due to dietary amines.
- My son had chronic apnoea, at 4 we had his adenoids out and ears cleaned in hospital, fixed the apnoea straight away, little did I know I could have fixed that with taking him off cow's milk. He now has fresh goats milk from Woolworths.

[831] 282: Runny nose due to bread preservative calcium propionate (July 2009)

My fourth baby had the same terrible broken night sleep pattern as the other three. After struggling for eight months, she did start to settle down, waking perhaps once a night. This was great until I started her, at 10 months on bread. She immediately returned to night waking - for no apparent reason- and also had a clear runny nose. I found that the bread had preservative 282 in it so we stopped feeding it to her. Within a couple of nights (I guess it had accumulated in her system) she again settled down to a peaceful nights' sleep! AND her nose cleared up! I can't believe that it could have been that simple!

[828] 621: 635: Better sleep and behaviour without glutamates (July 2009)

I have been a huge fan of your diet, site, book, cookbook and dvd since it helped us sort out why our 2 year old girl was misbehaving. We did the full elimination diet very strictly and passed sals, amines but failed glutamates. We also avoid the nasty additives but haven't formally challenged those.

My little girl is now 3 years old. Her behaviour, sleep and eczema are so much better when she doesn't have glutamate or additives, however I have felt recently that there must be something still in her diet that is affecting her as she sometimes has mood swings, defiance, silly behaviour. I have been giving her home made stock and slow cooked casseroles thinking they are OK because she passed the amines challenge and I thought it was just amines that increased with ageing and cooking time but I recently read in Friendly Food that glutamate does too. – Michelle, Vic

[825] Weird dreams due to green food colouring (July 2009)

After I eat green food colouring, first it gets to my head. It confuses my brain and I can't get to sleep until 9 or half past 9 (usually I go to bed at 8 o'clock). That night I can't get to sleep and my mind is set on funny things and I have these weird dreams. In the morning I'm a big tired and miserable. – Six year old talking on our DVD

[824] Vivid dreams reduce on diet (July 2009)

For more than 20 years I had dreamt vividly and had woken each morning exhausted until I started on the diet and in the last couple of months I have had about 10% of the dreams I used to have. Shona, by email

[823] Salicylate dreams ‘like war movie’ (July 2009)

I started on failsafe ten years ago when I was a teenager. Salicylates are the worst for me. They cause what I call 'salicylate dreams'. They’re like watching a war movie, and I am unable to stop it. – by email

[822] Lying awake half the night from megavitamins (July 2009)

I am a 68 year-old with no health problems except the beginning of muscular stiffness. I’d like to know if [a certain all natural megavitamin supplement with bioflavonoids and strong fruit extracts] contains any additives not noted on the labels. I honestly cannot note any difference except that my sleep pattern has changed. Previously a 'go to bed and drop off' person I now find myself either lying awake half the night or going to sleep and waking in the small hours of the morning– from Questions in Failsafe Newsletter #59 . (It is common for natural vitamins especially when chewable to contain very strong fruit extracts that can cause this kind of salicylate reaction. In a similar report to the same supplements a mother wrote: ‘all four kids reacted for a week - silly jumping around, wouldn't listen, couldn't concentrate, fighting with each other - the little ones were the worst - I couldn't believe it, just from one tiny little pill’)

[821] Snoring and sleep apnoea due to foods and new mattress (July 2009)

A nine year old boy from the NT suffered from snoring and sleep apnoea. The elimination diet revealed that a few food additives were responsible sunset yellow (110), the bread preservative (282) and MSG (621). When he later developed the problem while avoiding his food triggers, fumes from a new mattress turned out to be the cause. – from Failsafe Newsletter #1. See http://www.chem-tox.com/beds/frame-beds.htm for hundreds of reports of health problems mostly in adults due to chemicals in new mattresses.

[820] Sleepwalking from synthetic antioxidants (July 2009)

We’d been failsafe for several years when we ate some hot chips (BHA 320) several times while on a holiday. My son’s sleep talking and sleep walking which had stopped on the diet came back again the nights we had chips. – by email See also Failsafe Story [596]

[819] Night terrors gone in two weeks on diet (July 2009)

“My sister’s 3 yo son suffers from night terrors. He is a bright, happy boy during the day but his constant inconsolable screaming at night is distressing. He eats large amounts of fresh fruit and vegies.

3 weeks later: “My sister cannot believe the difference. She is making everything failsafe. Her son has had his first week in more than two years, without waking, screaming etc.” – by email

[817] Nose full of swollen tissue – now sleeping better (July 2009)

My 6 year old son is allergic to dust, cats, and sensitive to some food additives. So far we have had reactions to 621-635 and 160b and are looking at 282 now. Just wanting to thank you for putting us on the right track to start with. Our son's nose was 90% full of swollen tissue. He was working 20% harder to breath giving him terrible headaches etc. He is now starting to feel better, sleeping better, behaving better (prev we were told it was adhd - have my doubts now) and generally feeling better - by email

[813] Amines causing a 'locked in' reaction in a 2 yo (June 2009)

I had to email you to say THANK YOU for saving my sanity!

My 2 yr old was having some terrible behavioural problems, in the form of waking up either from her day sleep or night sleep in an absolute distraught state. She would be inconsolable and it would go on for nearly an hour until I could somehow 'break' it. I could never predict what mood she would wake up in and I dreaded it every day. I described her as being 'locked in' and I couldn't reach her. Her eyes would glaze over and nothing I did could snap her out of it. All I could do was let her burn out. I knew something wasn't right because why should any child wake up in a tantrum? But it was worse than a tantrum.

Thankfully I mentioned it to the right mums at playgroup who got me onto your book. What an eye-opener!!!! I think every mother should be discharged from hospital with their baby under one arm and your book under the other arm!

After educating myself with your book, I ransacked our pantry and threw away about 50% of what I had. I found the Vegeta seasoning I used nearly every night on our dinner was full of MSG. I found the cheesy rice crackers the girls were having every day were also full of MSG. This was not good.

However, I finally pinpointed what it was that made her so volatile - amines!!!! She was having bananas and grapes every day, some days she would even have two bananas. I quickly banned these two foods and the difference in my child was amazing. She now wakes up a happy child! Recently I let my guard down and let her have bananas again and saw the effects after about 4-5 days of having one each day. I even suspected she was having night terrors. And then I remembered the amines! After three days of no bananas, she was back to her usual self.

Thank you! Thank you! Thank you! – Pauline, QLD

[812] Asthma researchers ignore the evidence - breathlessness, sleep apnea, tachycardia, pins and needles, anxiety from preservatives (June 2009)

What is amazing to me is that the researchers don't seem to be aware that some preservatives and flavour enhancers can also give you asthma or make symptoms worse. I've experienced this first hand. I regularly consumed a so called healthy cereal every day that contained dried fruit which was laced with preservatives. My symptoms of breathlessness, sleep apnea, tachycardia, pins and needles, anxiety etc. kept getting worse. I ended up in casualty at the local hospital several times, but they could not discover the cause. I had heart checks, x-rays, stress tests and still no answers.

Finally at a party one of the guests refused certain food and proceeded to tell me about her allergic reactions to food additives. As she was describing her reactions, I realised her symptoms were identical to mine. She told me about your website. I went home that night and threw out everything in my pantry with food additives and I slowly recovered. I'm very careful now, but eating out is a challenge and that is where I get caught out, even when I choose healthy options such as a salad or sandwich. At the airport I had a turkey and salad sandwich and within 20 minutes I was really struggling to breath - Miryana by email.

[801] Potassium sorbate makes my son clingy, crying (June 2009)

I have a 6 year old son who I already knew was intolerant to some foods. He has periods of eczema (which we have been able to control with his diet) and we have avoided these things for years. Luckily, because he was basically born with eczema, I had been very careful about introducing foods. I started giving him crumpets for breakfast when he was 2. He would be fine after eating them, however when he woke from his sleep he would be screaming and hitting me, very violent and uncontrollable. I initially thought it was hunger, as I found that when I gave him something to eat he would calm down. Anyway, to cut a long story short. I found out about preservative 282 and cut it out completely. He was normal again!!

On and off over the years I discovered other things that affected him, so I added those to my list of things to avoid. A few months ago we went over to Europe. When we came back he went back to school and started getting very clingy, crying and not being able to read or write properly and was not able to concentrate. I have had trouble with these symptoms on and off over the 1½ years. I mentioned this to my friend, she gave me your book and I started an additive free diet.

After about 1 week everything had improved dramatically. I waited about 4 weeks before I introduced additives, one a time … He reacted to 202 (potassium sorbate) in a drink of juice by crying and becoming clingy. He had it at dinner time, then had trouble getting to sleep. The next day he was very sensitive and cried a lot and hid in his room when our visitors arrived and would not come out until they had been there for several hours. He got better after he had his lunch (which he ate by himself in his room). He then came out, but didn't talk much and sat right next to me. He only had it the once, as I did not want to make the situation worse. He can drink fresh juice with no problem. - Michelle by email

[790] A case of cystitis – "OUCH" (June 2009)

I recently had a case of cystitis (or urinary tract infection) - fairly mild but still uncomfortable.

I didn't want to try herbal remedies because I knew they weren't failsafe but in the end I did because I was so desperate!! "OUCH" is all I can say about the whole experience. None of the herbs or naturopathic remedies I tried did anything at all to help relieve the infection and as expected, a fresh herbal mixture from a naturopath made me feel terrible - fuzzy head and a terrible night's sleep with lots of weird dreams!

Luckily, after some frantic research, I found info on d-mannose and it was the only thing that finally worked for me. Once I got some of the powder, I started taking a dose every two hours for a few days and it gave me relief very quickly and cleared the problem within days. Having been an IBS sufferer (pre-Failsafe) I was worried I might get some adverse reactions from it but it didn't seem to bother my tummy.

I'm also staying well clear of the salicylates too. I definitely agree that they are a contributing factor (they really do cause their fair share of problems don't they!) – Jodie, by email

[789] Failsafe plus low fat for peri-menopausal symptoms (June 2009)

I am a woman in my mid 40s and have been failsafe for 5 years or more. I notice I am starting to have a little more insomnia, and irritability, and some other symptoms which I attribute to peri-menopause. Thank you so much for your extra information about low fat diets for menopausal symptoms. It really makes sense. I know when I indulge in a big steak with potatoes, lots of butter and whole milk I get extreme breast tenderness the next day and feel warm all over. I will keep you posted, but I really think this could greatly help some of my symptoms. 6 months later: Thank you for your information regarding menopause, it seems to be working - by email, U.S.

[706] Turned into a terror overnight on artificial colours (November 2008)

Our little boy was a perfect baby who turned into a terror overnight at about 18 months when we started giving him adult yogurt containing artificial colours. It took a little while for us to figure it out but two days after stopping the yogurt, he became an angel again! We'd managed to figure this out for ourselves but were perplexed when he'd have 'episodes' of difficult behaviour even though we thought we'd eliminated all artificial additives. Your book was a revelation. We are now aware of the not-so-obvious additives and think our little boy has a mild sensitivity to too many salicylates.

My husband and I are also happier, healthier and more relaxed now that we have eliminated additives etc from our lives. I now look back on times in my life when I suffered from insomnia, anxiety and stress and can see that this could have been attributed to my diet of commercial pasta sauce and cheap wine. We are all so much better off now... so thank you so much! – *Nikki, NSW*

[700] One-liners (November 2008)

- Thanks so much for all your wonderful information. My family is now able to sleep and focus because of the information I found on your website and in the Failsafe Cookbook. – *Angela, USA*

[694] 220: Ventricular arrhythmia and sulphites (2) (November 2008)

In reply to reader story [640] ventricular arrhythmia from sulphites, those are the exact same symptoms I get when having any sulphites. If I have too many I also get tongue swelling. This reaction happened out of the blue a few years ago at the age of 42. Wine and beer affect me the most and I avoid sulphites in any foods I eat – although I can have sips of wine and small bites of sausages etc with no ill effects, once I have the equivalent of about 3/4 glass of wine with sulphites, I suffer. I always wake up about two hours into sleep, with a temperature and my heart going crazy – then I get stomach cramps, nausea and a strong urge to use my bowels. The next day I feel lousy and my heart feels like it's got an extra beat for a couple of weeks. I'm happy to have preservative free wine, beer and sausages in my life but 220 and 223 are in way too many products – and for no use at all – my preservative-free sausages last for 4 days beautifully in the fridge. MSG doesn't affect me (I had a challenge of it in hospital) and I don't know if the other flavour enhancers bother me, I avoid them and haven't had them for three years. Although nothing is ever quoted in the medical literature, my immunologist is very familiar with these types of reactions. We have been conned by the manufacturers into believing food requires additives for our benefit but I agree with Michiko, ventricular arrhythmia is a terrible and frightening experience! – *Corrine, by email*

[691] 220: Racing heart (tachycardia) and asthma from sulphites (November 2008)

In response to your newsletter regarding 220 effects to the heart, I first had a reaction to wine a couple of years ago. I woke in the middle of the night with my heart absolutely racing - I paced the floor, drank plenty of water and tried to relax. Eventually I was able to go back to sleep. This has happened regularly since and loving wine I have found it difficult to control. Fortunately we have a cellar of aged wine and over the time I have found that I am able to tolerate aged red wine and better quality white wines without effect. A single glass of some white wines, however, will give me palpitations and wake me through the night with my heart racing.

Recently I have also been able to link my reaction to episodes of asthma. The first at the age of 30, and the second at 35. On the second occasion I had been drinking 2-3 glasses of white wine every day during a two week holiday. Whilst I was able to select wines that didn't affect my heart at that level, by the end of the second week I experienced my second ever bout of asthma. Recently I also ate some cheese and suffered palpitations. Checking the label showed that it had sulphites listed. – *Amanda, by email*

[cheese does not normally contain sulphites unless flavoured, e.g. – Mersey Valley sweet chili contains two sulphites: 223 listed as preservative and 221 listed as antioxidant.]

[679] Menopausal symptoms, hot flushes and failsafe (September 2008)

I put myself on the diet five years ago as I was suffering severe hot flushes, was continually tired, felt sick most times after I ate, felt fuzzy in the head, got cranky for no reason and did not sleep well at all. My life changed - I now sleep well, I am not tired all the time, the hot flushes stopped, my head is clear and I very rarely get sick. If I have a lousy day or night I can always trace it back to something I have eaten the day before or two or three days before. The worst offenders are additives and salicylates. I have always been a big fruit eater especially watermelon, and it has been one of the hardest things to give up, however if I do binge on fruits high in salicylates especially watermelon I pay for it with hot flushes and a sleepless night. I also get hot flushes if I eat chicken that is not organic which I avoid at all costs now.

I see a lot of women I work with suffering with menopausal symptoms and I think myself extremely lucky that I found and was prepared to give failsafe eating a try. Unfortunately you can take a horse to water but you can't make it drink. These women as many other people I talk to don't believe it could be that simple and are not prepared to give it a go, silly them. - *by email*

[654] 635: Flavour enhancers and a breastfed baby (September 2008)

Thomas was born a very healthy full term baby. A couple of days later he had little red pimples on his face that after two weeks became quite red and covered a quarter of his cheeks, Clinic nurses noted that it was a bad hormonal rash, but it never went away, it only got worse. Thomas was also an irritable baby needing feeding at least every two hours he didn't sleep for any more than 2 hours at a time.

With two other children and hubby to feed, time was precious, so I started whipping up quick casseroles to feed the family. In the casseroles I would put in meat and fresh veg I had in the fridge, and for the flavour we were used to I would throw in a packet of beef & veg cuppa soup and thicken it with Gravox. Things were going from bad to worse. Thomas was covered all over in a red rash. The doctor diagnosed eczema and gave creams for it but it only got worse and infected.

On one particular occasion I remember vividly, I made the casserole for dinner on Friday night, and while having a cuppa and chat next day noticed that Thomas became quite irritable and his little head came out in beads of sweat, which later became a crusty layer. It suddenly dawned on me that this happened every time I made the casserole, I would eat it about 6 pm and by 12-1 pm the next day (18 hours later) this little time bomb would go off in Thomas. The next day Thomas was a ratty all day, his whole body was red and his scalp crusty.

When Thomas was 4 months old we got into a Dermatologist who listened to our story and nearly laughed at us and explained about Cuppa soup (flavour enhancers) and Gravox (salicylates) his words were ‘it's like a time bomb’. We discovered from that trip that Thomas was allergic to dairy, eggs, peanuts, and probably intolerant to the nasty food colourings, preservatives and additives given his reaction to flavour enhancers and salicylates. Although he had never ingested these foods directly, he had got it all through my breast milk. Thomas was weaned onto Neocate Formula then to soy at 12 months of age. He has since developed allergies to soy, all nuts, potato, gluten, house dust, cats, dogs, horses, many grasses and weed pollen. He also suffers from asthma. He now drinks rice milk and is on a strict egg-free, dairy-free, nut-free, potato-free, gluten-free low salicylate diet. Now at six years of age Thomas is a healthy active boy despite all this.- *by email.*

[647] Can't believe the house is so silent (May 2008)

After only 2 weeks of making a thin edge of the wedge start on failsafe, we are seeing drastic improvements in our 4.5yr son, 2.75 son and 1yr old daughter, and me too. No rages, no nightmares, easy to bed, sleeping all night till a reasonable time and no 5pm meltdowns. My mother visited for the first time in about seven weeks – she is interstate - and couldn't believe her eyes. The conflict between the boys - normal! - is short lived and resolved mostly unassisted and she said that she thought they were great kids who simply got tired and a-copic (my son, 4.5 - he is so articulate - would sometimes scream 'I don't know why I am upset, I have run out of coping today.') in the late afternoon. Now we know that a fabulous salicylate platter - I mean fruit platter! - every afternoon was just stacking the deck against them. My 3pm to 7pm is now very nice indeed and at 7.05 my husband and I look at each other with all 3 of them asleep in bed and can't quite believe that the house is silent. Thank you for battling to make this information accessible to us all. We are grateful - Becc, NSW

[642] Asthma update two years on (May 2008)

Richie's original story ([402] March 2006) described how limiting his intake of preservatives and sulphite containing foods such as mince meat, prawns, pizza, processed meats etc had helped him with breathing problems he'd suffered for over 20 years.

His update in April 2008 reads: You probably get many emails of thanks and I have sent one or two previously but what the hell, I'm going to send you another one just to let you know how much my life has improved since taking your advice. I thank you with every positive emotion I have for who you are, what you stand for and for changing my life. I have no more breathing difficulties, no more sleep problems, no more anxiety and all this leads to no more stress. No money can buy this. I have been educating the people in my life on how damaging additives, preservatives, sulphites etc. are and sent links to your site to everyone in my address book - Richie, Vic.

[636] Insomniac due to fish oils (March 2008)

My daughter was taking fish oil capsules prescribed by our homeopath (and yes, I have taken notice of your comments in the Checklist of Common Mistakes about homeopathics possibly causing more problems, just what I didn't need to hear) and within days she became an insomniac! It took us several weeks to come up with the connection and as soon as we stopped them, sleep returned to normal.

[617] Nearly crazy with fatigue and confusion –baby's insomnia (February 2008)

Since birth, my son Noah had trouble with sleep it didn't matter what I did or what time of day or night it was, it would always take him at least 2 hours to get to sleep, and then if I put him down in his cot, he would wake 10 minutes later screaming. Then it would take another 2 hours of pacing the dark hallways before he'd doze off again. In the end, I spent the first 12 months of Noah's life sleeping in the rocking chair with him, just so he would sleep. I nearly went crazy with fatigue and confusion. I tried everything I (and everyone around me) could think of.

In the end, I insisted that there was something going on because the times he wasn't crying, I could see that he really had a very social, gentle and loving nature that was at odds with the furious, red screaming insomniac he was the rest of the time! He was breastfed and everything got much worse when I introduced solids. I was advised by a homeopath to stop eating dairy and give him slippery elm powder to help settle his guts. Everything got so much worse after that. The only thing he could have been reacting to in the slippery elm was salicylates so she put me on a low-salicylate diet. Noah improved but I didn't take it fully seriously I was naughty a lot! I continued drinking coffee and some other things like that. Finally, when Noah was 18 months old, I discovered your website. It changed my entire life, and you will never truly know how indebted I am to you for the work you do. – Alison, Qld

[616] Getting to sleep was a major problem - additives (February 2008)

I have had my 7 year-old daughter on an additive free diet (eliminating colours, preservatives, flavour enhancers and synthetic antioxidants) for one week and I cannot thank you enough. I have got my beautiful girl back. Looking back now I can see that she has probably always been intolerant of additives. The dramatic change in her in nothing short of amazing. Getting to sleep was always a major problem. Extremely emotional outbursts were constant, this is only to mention a couple of problems we were dealing with. The last two nights she has fallen to sleep within 20 minutes of going to bed. It used to take anything up to 2 and a half hours (frustrating for both of us). This morning I was able to brush her hair without tears for the first time in her life.

Two months later … She is still going along really well and we have been able to add back some food back into her diet. The main ones she had reacted to are orange flavour and Twisties and any take-away food along the lines of McDonalds burgers or Hungry Jacks.- Kerri, by email

[602] Diet helps aching joints that began during pregnancy (February 2008)

I began the elimination diet after reading Fed Up with Asthma. I was pregnant with our second child. My first pregnancy was fraught with pain from aching joints, hips especially, from which I d never suffered before. The pain was very great and continued after childbirth, though not troubling me much, just now and then. My joint movement continued to be impaired. In this pregnancy the pain began in the first trimester, whereas it had begun late in the previous pregnancy. I suffered much sleeplessness and worried how I would last 9 months like this. After 2-3 weeks on the diet (dairy and gluten-free as well) I no longer needed ventolin at all, just one puff daily of my preventer (I'd been using ventolin up to 8 times daily with little effect and 4 puffs of the preventer). Also, no joint pain at all, and the return of a normal range of joint motion. - Elizabeth, by email

[596] From 'severe inattentive ADD' to 'normal' due to diet (November 2007)

In 2006 my quiet 7 year old daughter was diagnosed by her paediatrician as having severe inattentive ADD. He offered Ritalin to help the symptoms. I was not comfortable giving her this as a first step because in the 2 weeks since our last appointment I had read 10 books and scanned the net. A common theme kept coming up. If your child has an intolerance to a food group there is a likelihood of more than one intolerance which can lead to behavioural issues. I felt I had to investigate this before trying medication because we already knew she had a dairy intolerance as a baby.

I chose to follow the Fed Up elimination diet by Sue Dengate. Following are the results when food groups or additives were re introduced.

Colours - anger followed by tears, inattention, lack of concentration, memory loss, head banging and rocking

MSG/635/Glutamates - nausea and stomach cramps

Benzoates - aggression

Antioxidants (310-312, 319-320) - nightmares and trouble going to sleep and staying asleep

Propionates 282 - bedwetting and daytime bladder control issues

Dairy - nausea, stomach cramping, diarrhea, inattention, fatigue

Soy - stomach aches

It has been 14 months since adapting to my daughter's dietary needs. She has been reassessed for ADD with a normal out come. Her school work has progressed. She is able to concentrate. She can tie her shoes, hold a knife and fork, remember her phone number, ride a bike, and skip a rope. She is able to follow multiple directions and hold attention to the task at hand. She has friends. We have also discovered she is a budding artist.

Through dietary changes we helped many of our daughter's physical and behavioral issues including fatigue, tearfulness, emotional outbursts, inattention, lack of short term memory, lack of application at school, bedwetting, vaginal irritation, rash, insatiable appetite, imbalance and clumsiness (she could not ride a bike, skip, hop), nausea and stomach cramps.

My daughter did not need medication. She has food intolerances. As grandma said 'Whatever you are doing keep doing it. She is a different child' - Trudi, NSW

[595] Filling our house with laughter (November 2007)

My husband and I watched a news program on the children at Nana Glen Primary School. We were so impressed we thought we d try it with our two boys, aged 10 and 6. Both boys suffer with asthma and croup and both are very loud and active. Our oldest has always found it very hard to go to sleep, most nights he was still up at 11.30pm. We've tried various relaxing techniques, CDs, quiet reading and after two weeks on the diet he is asleep in 15 minutes. Fantastic!!!!! He is happy to sit quietly with a book and wants to talk about stuff going on. The standard answer I used to get was 'nothing's wrong'. He was always so sad and serious about everything. The biggest change has been him giggling and throwing his arms around his dad and saying 'I love you guys'.

Our 6-year-old has been a very emotional child. Always close to tears, unable to put into words what is making him frustrated, angry, and teary. Now he is talking about how he feels and reasoning with other children rather than coming to me crying. They are both filling our house with laughter once again.

We bought your failsafe book and the difference in our boys is amazing, to the point of other people are commenting. Thank you for simplifying all the numbers and facts and giving us back our two beautiful boys who for a long while had been lost.

My husband and I now sit on the couch and listen to the sounds of two boys playing well together and enjoying each others company, no more fighting to the death near enough. - by email from WA

[564] 635: "An attack of 635": anxiety, racing heart, headaches, rash (May 2007) SHARED COURAGE AWARD STORY FOR MAY 2007 NEWSLETTER

I was suffering with what the doctor said was normal for my age 39, higher blood pressure, heart palpitations, not able to sleep on my left hand side, rash around my groin and armpits that I couldn't get rid of, weekly headaches and to top it of waking up at 2-3am every morning with a anxiety attack.

I was attending a anxiety meeting every week and seeing a psychologist but the problem was that I couldn't identify with any of the other people that came to the anxiety meeting. It seemed all of their complaints of the 100 or so different people that came to the meeting related to cyclic thought process that brought on the anxiety and kept them in that loop. I on the other hand felt a little on edge but was very relaxed about life. I delved into unresolved tensions with my psychologist but still no relief. Yoga and relaxation exercises seemed to help but what it truly did was let me watch my body go through the symptoms while I watched it happen in the third person. Because my symptoms didn't fit the norm I refused to take any form of medication. I felt it was stupid to compound the problem until I knew what was causing it.

Finally I had yet again another anxiety attack. This time it was unbearable and my heart went over the 199 bpm that my machine could measure. I tried everything to relax but my system went into overdrive. My mother came around and my wife was there to help. I am amazingly good at relaxing my body but nothing seemed to help. I called nurse on call and they called an ambulance immediately upon hearing my symptoms. The ambulance arrived and went through the routine of checking me over and in the time they were there my body stabilised to around 100bpm. They gave me the option of going to hospital and waiting in the waiting room for 4-6 hours or stay at home and try and get over it. I took the wait at home option. The interesting thing from all of that is the male ambulance officer who leaned against the door frame for the whole time they were there said "gee you look like my wife does when she has a attack of 635" I thought he was full of
it and ignored him at the time. I felt like I had run a marathon.

The following day I looked up 635 on the internet and noticed the rash and the headaches that I had were the same but nothing else rang a bell. Having nothing else to go on I looked into what had 635 in it as an ingredient. I was amazed to find my pies, pasties from the local bakery had beef booster and hence 635 + 621 that was Monday nights explained then a lot of chips + crackers that I had for lunch - even ones from the health food section of my local supermarket that state quite clearly on the packaging that 635 is not 621 and therefore is not bad for you. What a laugh! I must stress I had no belief that 635 was the cause of anything but my rash and headaches. I have not changed my lifestyle in any way except for removing 635 + 621 from my diet and only very recently removed 282. But a key interesting note is the 12 hour delay from eating the food to the full blown symptoms. I still eat selected junk food, I still exercise the same amount, I have even more pressure at work and I still get broken sleep from my now 2 year old.

When I would go to my doctor, her face would drop in that "not you again look" she would listen to me with bored expression and write in her notes, anxiety related. Please also note that my doctor since then acknowledged she has absolutely no knowledge of food intolerance re 635 – 621 and their symptoms. How are you expected to be helped if they are blind to these issues? The way I wish to truly express myself as to how I feel re their mainstream blindness is limited by my overriding desire to keep this letter polite. I have not read anywhere a person with my exact same experiences but I know it is simple. I have stopped eating 635 + 621 and I am back to how I remember the way I used to be.

From that week….

My multiple rashes of many years cleared up completely!

Not one single headache!

I have not had a single heart palpitation!

Not one single anxiety attack!

No hand or body tremors!

No racing heart!

No feeling of tension!

The only exception to this was when I went to a mothers’ group party and ate some salt and vinegar chips laced with 621 + 635. I had a bad night sleep that night. I checked the chips at the supermarket the following day and found the suspect ingredients. I will not eat any food that I cannot check the ingredients. Hungry Jacks will not return my calls to tell me what foods have 635 in, and Nandos will not return my calls as well. It is of interesting note that the American version of Hungry Jacks (Burger King) + KFC list their ingredients but the similar Australian version of the web sites have the ingredients list missing. I FEEL LIKE A NEW MAN – Wayne, by email

[558] Muscle spasms (May 2007)

I am a 55-year-old woman who recently worked out for myself that I have a muscle spasms as a strong reaction to 220 (sulphites) and minor reactions to others which I haven't identified yet. The muscle spasms are usually in the limbs and are worst when I sleep. I am a very fit and active person, so when I finally sit in front of the TV after tea and relax, this is when I feel the spasms. When mild it is usually any one muscle at a time in my legs and usually every 30 seconds. The affected muscle tightens or twitches and can occasionally jolt my leg or finger etc. When I have a worst reaction during the night, again it is like a tightening of, possibly, a muscle in my chest, or hip, or shoulder, head etc. When it is in the chest, some times it actually knocks the breath out of me as I awake with a jolt. Have you ever had the electrical impulses on your body when you are at the physiotherapist and a muscle tightens - that is how I feel. Sometimes of a night I feel as if I have a "motor" running in my chest or sometimes my head (sounds crazy doesn't it!) I can also quite often get a tingling (or motor sensation) feeling down my legs.

I went to four doctors last year and not one knew what was wrong, with one referring me to a neurologist. I become hyperactive in the evening – full of energy when everyone else is wanting to go to sleep - and have constant insomnia. When I am at my worst my muscle spasms (during sleep) wake me every few minutes and I experience hallucinations or bad dreams. Strong sleeping tablets don't eliminate these muscle spasms. It wasn't until I realised the 220 preservatives were in the "healthy" foods: dried apricots, sultanas, most yoghurts - that I was able to get my health back into order. It took me nearly a year to work out what was wrong with me. Since watching my diet I am sleeping so well it is unbelievable; I haven't slept like this for possibly 7 years and only have mild muscle spasms resulting in bad sleeps occasionally when I'm not aware of the preservative in the food. I guess I am still finding it hard to check everything before eating!!

The last 12 months have been very scary for me when I didn't know what was wrong - I feel so strongly for our children who also must be suffering and unable to communicate how their body feels. - by email, Victoria.

[539] Possible autistic spectrum if not failsafe (January 2007)

My husband and I have two lovely children. We have been through the whole thing of oppositional, erratic and violent behaviour and for us the worst part was insomnia and extreme restlessness at night. No-one ever got a rest. This all was cured with the invaluable assistance of your books, and a profound response to the elimination diet especially for our youngest child who is a 7 year old girl, Lily. She is extremely sensitive to everything – salicylates, amines, chemicals - you name it. Our son is affected, but not as badly.

At times I have wondered if Lily perhaps has Aspergers, or is somewhere on the autistic spectrum, but we had her assessed at age 4 (after being failsafe for three months) and were told that she is bright, possibly gifted, and that she can be extremely anxious because she is clever enough to be able to think about things and therefore worries about things. We prepared her very carefully for school and so far have had no problems - until this month.

Twice this month Lily has lashed out at school, due in part to chemicals. She started swimming lessons every day and the other thing was a class party with heaps of bad food which no-one helped her to avoid. Today she has been "red-booked "and placed on detention for the second time, for hurting someone. The school counsellor who was called in told me "there are NO studies that prove that food intolerances are in any way related to behavioural disturbances". She went on to tell me that it was all in my head, and that it is coincidence that withdrawing a food substance or chemical would have a positive effect on our daughter. She then proceeded to tell me that Lily probably has Aspergers and that the paediatrician probably didn't want to tell me that. I am feeling so enraged. She hasn't even met Lily.

We follow the failsafe lifestyle to the letter, and are eternally grateful to you and your family for sharing your stories, and for your tireless work. Our family wouldn't have survived without Fed Up and how some one can say the things that this counsellor said belies belief. Our son who is now 13 is easily able to make good food choices and knows only too well what bad choices do to him. He was shocked at the response of the school counsellor. My husband - who was a total sceptic 4 years ago - was absolutely livid with that school counsellor. He knows how bad it was here, and how much work I have put in to making our little family happy and calm. I guess we will just keep soldiering on and spreading the word, but this person nearly got the better of me. – by email, NSW (see comment on this story at [552])

[532] Soy and depression 3 - unexplained "fevers" and hallucinations (January 2007)

As a baby and toddler, my son had constant unexplained "fevers" as part of his never ending list of reactions. It wasn't till he was 6 years old and he had had a few unexplained fevers with hallucinations that we found these came from soya beans. He has always been "picky" with soy products, usually refusing them himself – but mum didn't always trust him fully - now I know they do him no good!

His hallucinations were shocking to witness – they happened only in the evening or night, usually just after falling asleep or when disturbed in sleep, e.g.picked up for toileting. He often didn't have a high temperature according to the thermometer but woke in an unconscious way with eyes open and talking and listening. He saw terrifying things around him and removal to another room with comfort helped a little but only usually for seconds. The only solution that worked properly for us was cool wet towels for reducing fevers round his neck and forehead whilst cuddling him. He usually dropped off to sleep again with these. On a bad night this continued again after a couple of hours.

As usual doctors here were at a loss to explain these and claim them to be most probably fevers related to viruses. They suggested continued treatment as we do perhaps with paracetamol too keep it at bay. It was only after that I connected intake of soya beans 36 hours previously on the last occasions and I tested it with a very small intake which showed a minor reaction - still hallucinations but for a much milder and shorter period. Consequently soya beans are off our menu and I respect my son's taste buds when he refuses foods – he is usually allergic or intolerant of them. Allergy specialists here avoid giving soy milk to milk allergics as much as possible due to the close connection of the two allergies and the fact they believe soy allergies develop quicker in such cases. – reader, Sweden

[479] 635: Domino's pizza (January 2006)

What can we do about this?? We had Dominos pizza last night - a rarity for us. My husband had quite a reaction (itchy, headache, swelling in the mouth, muscle aches, sore chest, chest pains) and when I phoned to enquire about the ingredients they were very defensive and apprehensive about giving me a full list. I was finally advised after much frustration on my part that the olive tapenade has 635 in it (this is after he said it 'pretty much' only has olives in it). I had a mild reaction as well (itchy face, swollen mouth, itchy eyes, pain in chest).

Why don't they have to advise people that it has this nasty additive in it? A FULL ingredient listing should be provided or someone (some food authority) should make people aware that this can happen. It should be law, as I understand the consequences can be quite serious and even life threatening. My husband didn't get to sleep until well after 2am – even though the pizza was consumed at around 7pm. The scary thing is that I have allowed my children to have some pizza but thankfully they both declined last night. I know the onus should be on the individual to be aware of what they are eating, and hey, we all know junk food isn't good for us, but every now and then it's nice to not have to cook dinner.

We've had a radical think about fast food as well as processed food and will now just make the effort to make dinner ourselves no matter what – even if we don't feel like cooking! - sincerely annoyed Rachael by email.

(later) I did forward a copy to FSANZ (for what good it will do). And I will forward a copy to Dominos as well. I've got extremely itchy hands today and my face is getting itchier and more sensitive as the day goes on - it's also a bit puffy and I'm sneezing lots.

[474] One-liners (November 2006)

- My three-year-old son has been on the diet for three months now and it has been a miracle for our family. He has no eczema, his behaviour is fantastic (the sweet gentle caring child I knew was hiding in there somewhere), his faeces are back to normal, he has not had a runny nose since starting the diet, no abdominal pain and he goes to sleep and sleeps all night with no night terrors (we were dealing with three or four a night). WOW, what a difference. We have found he is sensitive to amines and salicylates.

- My hayfever has completely disappeared and my two children have become angels on this diet - my 2 year old has stopped her temper tantrums and is sleeping better and my 5 yr old son is like a new boy, happily playing on his own for hours, drawing, building blocks. He realises that "food with colours and chemicals make me silly" - I can't believe he is actively trying to avoid those foods because he feels so much better!

[459] Dealing with ex-husbands (November 2006) COURAGE AWARD STORY NOVEMBER 2006

Hi. I can already give you some feedback, as my 3 children and I have been on the elimination diet for 3 days. My eldest child is 14 (depression, asthma, sleeplessness, fatigue, restless legs, easily irritated, unmotivated etc): this morning she got out of bed without being nagged, had a shower without being told, all while smiling! I stopped taking antidepressants 2 weeks ago, and today for the first time since, I am not feeling my normal symptoms of depression. My youngest, 3, is hyperactive and today has been a lot calmer. He also normally wakes about 6am, and today slept in till 9:30!!! My elder son, 6, who has a learning delay, woke up teary and temperamental, as he was before bed last night, but he was at out-of-hours schoolcare yesterday and ate apple, cheese and yoghurt... One thing the book 'Fed up with children's behaviour' doesn't address is what to do when in a situation where I do not live with my ex-husband and he only sees the kids once a week, how do I get him to understand that the kids need to try this? He sees their issues as being 'normal' and although none of my kids are extreme in any way I want to give them the best life they can have, now and in the future. How do you convince people that relatively 'normal' kids still can benefit?

(later) thank you thank you! Despite all of my best efforts, my ex-husband is aggressively sabotaging my efforts with my children, constantly telling them that failsafe foods are 'silly' and if they ask for failsafe foods he gets cross at them. They spent one night at his house (Day 11 of the elim.diet) and he gave them everything he could think of that was on the list of 'Don'ts'. Consequently they came home silly. Neither of the boys (6 and 3) could get to sleep that night, the littlest one crying and rolling around in bed sobbing 'I can't stop, I can't stop'. In desperation I gave them both a half teaspoon of bi carb, thinking 'this isn't going to do anything' (I should know better!). As it tasted so awful I let them chase it with a Werther's. Within 10 minutes they were both asleep....- by email.

[452] One liners 2 (August 2006)

Last night my son had 3 night terrors close together, where he screams and his legs cramp and he twitches. I phoned his day care as he spoke about eating glue. I found out it was a thing the school calls 'gloop' to tailor fine motor skills. It is made with flour, water and (yesterday) green food colouring.

[447] ‘Fear of the dark’ really a food reaction (August 2006)

We started the diet nearly a year ago for my son, a sweet 5 year old who would become an aggressive, extremely hyperactive and an emotional monster nearly every day. I saw you on A Current Affair and after taking muesli bars and sultanas (which I had thought were healthy) out of his diet I noticed most of his aggressive behaviour disappear.

After that we started the full diet and not only did our son become an angel, we noticed that our daughter was a very strong amine reactor, becoming uncontrollably emotional, depressed and ‘full on’, as well as having frequent nightmares and bedwetting. Unfortunately since we have moved 2 months ago our son has gone backwards fast, I now think as a result of amines in meat from new butchers. It is so upsetting to see all the progress disappear, and he has had HUGE problems at school this term. I have traveled back to our old butchers to stock up on meat and am started to see some improvement after one week.

The biggest shock for me however, was when I recently discovered I was a food reactor!! I was a junk food addict and would eat about 5kg of chocolate a week. I can’t believe now I had so many symptoms, and I never even put them together as symptoms, let alone found the source of the problem! I was getting migraines, I constantly had a headache behind my eyes, I felt very faint and disoriented, had stomach pains that felt like needles - usually after eating lollies, and I was always bloated - something which really upset me.

The weirdest thing to attribute to food however was my extreme ‘fear of the dark’ as I called it. I would be terribly scared of the dark, I would think that my mind thought it could see little people and things out of the corner of my eye, even though I knew they weren’t there, I would open my eyes every 10 seconds while trying to get to sleep, just to check if there were monsters or robbers there, and every time I closed my eyes all I could picture in my head was horrible things that would scare me. I was a bit worried I was starting to go crazy, then I stopped eating chocolate and didn’t even notice all these symptoms disappeared.

It wasn’t until I splurged on a whole chocolate cake over two nights that I discovered what had caused these problems. After eating the cake I was completely on edge. I couldn’t sit down for ten seconds without turning around to make sure there were no monsters or robbers behind me. Eventually I had to sit with my back to the wall so I wouldn’t think there were things behind me. That was the last time I ate chocolate, and the thought of ever eating it again scares me! – by email.

[436] Amines: depression and hungover (August 2006)

This father who was doing the elimination diet to support his son chose to do the amine challenge first because he thought he wouldn’t react. ‘How wrong can you get!’ he wrote in his account of the challenge:

'I had a violent reaction within a few hours and have never felt so awful in all my life. Here are some of the symptoms: depression, suicidal tendencies not just thoughts, melancholy, looking for an argument, feeling the whole world was against me, lethargy, shakes, pressure on the skull and tingles in the extremities, feeling of hangover, inability to focus on thoughts, ringing in the ears, inability to sleep. The hungover feeling lasted until the next day. Not the best 24 hours but at least I know there is a cause for symptoms that I have experienced in the past.'

[400] Amine-related migraines since the age of 3 (March 2006)

My 7 year old daughter Caitlin (not her real name) has had migraines since she was about 3 years old. We had no idea what they were for several years. She usually gets a fever with her migraines and because of the fever the doctor would always put it down to a virus, prescribing painkillers. I would often give her panadol for 4 days straight just to keep the headaches at bay. She goes limp and listless, her eyes always droop, she lies there and sleeps for hours until the panadol wears off and then then the pain and fever return. Most times she will scream and cry, grabbing her forehead and pleading with me to take the pain away, "Mummmy Mummy my heads hurts, please stop it." She has always complained of feeling sick (nausea) when she gets them too, and 'sore legs'. As well, she has had problems with nasal congestion and had been using Rhinocourt nasal spray daily. She has always been a nail biter & a teeth grinder at night.

One year after she started getting the migraines,we were referred to a pediatrician who could find no medical reason for them either. He thought it may have been an attention grabber or perhaps the start of a cold. The migraines continued on and off with no regular pattern that I could work out, once a week, then maybe another in 6 weeks times, then 2 months. It varied greatly.

Two years later … the migraines became more frequent and she started throwing up with them. She would go to sleep with a migraine and wake at 3 am and throw up in bed or the bath (with the migraine and fever). I said enough!! No more Panadol, Nurofen or Painstop! This time her pediatrician ordered a cat scan which was clear. He offered my 6yr old a daily dose of betablockers or a trial using riboflavins or diet manipulation …guess which one we chose?

We have been eating failsafe since about March this year and have never looked back. On day 2 of the amine challenge, Caitlin got a migraine, droopy eyes, became listless, and a fever. School rang and asked me to collect her again. She stayed unwell for several days with the headache.

During the challenge, she also got a blocked nose, sore tummy, sore nose, nightmares and was badly constipated. Since the end of the amine challenge (3 months ago) we haven't had one migraine! No more snotty nose or blocked nose, nasal sprays, nightmares, sore tummies,nail biting, teeth grinding, or sore legs - her nails are growing for the 1st time in her life. So, no more amines for Caitlin! – by email, NSW

[390] "I was angry because I couldn't fall asleep" (March 2006)

My 6 ½ year old son, Tim (not his real name) is currently undergoing investigation of mixed depressive disorder with anxiety and obsessive ruminations. We have used the failsafe diet in the past with one of our other children, but had not ever thought of foods being linked to Tim's mood problems. When you mention the "gifted and depressed" child in your recent talk my ears immediately pricked up and took note. Tim has been identified as highly gifted and everyone has been saying that is the cause of his problems but I have always felt there was something else underlying that was contributing. We will be contacting our GP today and hopefully starting the failsafe diet ASAP…

Two months later … Since starting the elimination diet Tim has not self harmed once! He is much calmer and has noticed this in himself. He no longer seems to be as restless and has been falling asleep easily at a reasonable time in the evenings. We started with the salicylates challenge this week and there seemed to be no reaction, until day 5/6 when we started to notice his behaviour was getting worse. We will stop this challenge tonight and wait to try some other groups. His GP and Clinical Psychologist are both thrilled with the change as are well!

One week later ….After I emailed you we finally had the BIG reaction we were looking for. It happened on Day 7 of the salicylate challenge - we had already stopped the challenge that morning. Tim went to bed as normal then began to write swear words all over his bed, his sheets and his body. ("I was angry with you because I couldn't fall asleep") This is the behaviour and obsessive ruminations this poor boy was experiencing on a daily basis before. - WA

[379] Behaviour due to hairspray, airfreshener (November 2005)

I stopped wearing hairspray about 6 months ago when we went totally failsafe and saw great results with our children's behaviour. Two weeks ago I was going out without the kids, so after putting them to bed I sprayed on some Sunsilk hairspray and liked the way it looked. So the next day I did it again and within a couple of hours my 3 year old son's behaviour changed. He was overactive, very fidgety, hitting and kicking, and headbutted his sister hard enough to give her a blood nose. As time went on he was crying a lot with loud silly behaviour and wanting demands met immediately. That night he could not get to sleep. I wore the hairspray for three days not putting two and two together then we realized it must be the hairspray as their diet is so failsafe it couldn't be the food he was eating. I stopped wearing hairspray and his behaviour returned to normal. I have also noticed that when I visit my mum who uses airfreshener - lots of air freshener - my son's behaviour deteriorates after a few hours. – Vic

[366] 282: “My babies woke up 8 times every night” (March 2005)

A friend gave me your book "Fed up" to read and I simply can't believe the difference it has made to our lives. I have four children. Three of them have been terrible sleepers right from birth. I have spent a week at Tresillian house with my 3rd child, where he was handed back to me at the end of the week unchanged. My babies all woke up on average 8 times every night and I have been so sleep deprived over the past 8 years that I became postnatal. I have a Degree in Early Childhood and have worked as a Director in a Pre-School for many years, and thought that I could control their behaviour by employing techniques acquired through professional training. It was frustrating to find that I couldn't cope. My first child was such a shock! I simply couldn't leave the house with him.

This book came in time for my 4th and final child. My daughter fell into the same terrible broken night sleep pattern as the others. After struggling for 8 months, she did start to settle down, waking perhaps once a night. This was great until I started her, at age 10 months, on bread. She immediately returned to night waking - for no apparent reason - and also had a clear runny nose. I found that the bread she was having had 282 in it. SO we stopped feeding it to her. Within a couple of nights she again settled down to a peaceful nights' sleep! AND her nose cleared up! I can't believe that it could have been that simple!

My question to you regards my children when they were babies, constantly struggling to sleep - could this additive (calcium propionate, 282) have been passed on to the baby through my breastmilk, causing a similar reaction??? [The answer is of course, YES, food chemicals are passed through breastmilk – Sue] – by email

[363] Vulnerable new mothers (March 2005)

Before the diet, my son presented with headaches, itchy skin (in elbows, on legs, usually scratching until it bleeds), black circles under his eyes, "jumpy" behaviour, irritability, day and night pants wetting, pains in the tummy and awful loose bowel motions, blocked ears and sleep apnoea as well as incessant snorting and inability to breathe at night. As a baby he had eczema, colic, could not sleep and fussed with breast milk from 4 months ... somebody needs to support vulnerable new mothers to help their fussy kids, not make it worse by shoving disguised dairy foods (or whatever the particular issue is) down their throats, and then advise the mother to let them scream it out because they obviously have us fooled with sleeping and behaviour problems! – by email

[357] 282: A typical email about the effects of 282 (December 2004)

I have taken my 3yo son off all commercial bread products (it's become quite a crusade for me!) with marvelous results. He was going to be assessed for autistic disorders in a few weeks, but since taking him off 282 he has changed (he talks now! and his behaviour is so much better) and I know that his paediatrician will be amazed at his progress. At 18 months my son was only just babbling, and was considered to have the language skills of a 9 month old. After 6 months of speech therapy he was starting to mimic animal noises with prompting. By 27 months he had he had just two words - mummy and no. At 30 months I took him off commercial bread and at 34 months, he just started talking one day. At 36 months (last week) he now has the normal vocabulary of a 3 - 3.5 year old, and the understanding of language of a 4 year old. He is still having problems with actual speech, he only uses 2 word phrases most of the time and stutters occasionally, but the change in him in 4 months was amazing. He also has less tantrums, sleeps better and is generally easier to get along with. - by em

[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

[355] 282: Six slices of bread a day (Nov 2004)

I removed the bread preservative 282 from my 7 year old son's diet after coming across your website and recognising many of the behavioural problems we were experiencing with him. He was extremely defiant, flatly refusing to do the simplest thing asked of him - homework was torture for all involved. He was loud, argumentative, talked non-stop, very anxious, had frequent bad dreams and was prone to angry outbursts. Much of this we had grown to live with since he was identified as a preschooler as being highly gifted but I was increasingly concerned about our family dynamics as we spent most of our time yelling at him and wondering how much longer we could survive, and how he was going to cope as he grew older - and therefore stronger and possibly dangerously violent.

He has always loved bread and, being a vegetarian, eats a lot of it, averaging six slices a day. The difference once we started making our own bread was astounding. He immediately became so much calmer and quieter that my husband asked if he was still in the house while he was getting ready for school in the mornings. He became much less defiant and argumentative, was able to stay still while I put his school tie on, much more polite and affectionate.

It was a lovely change to have him come home from school and give me a spontaneous hug, which is a very rare event as he is so sensitive to touch. He also seems to be able to think more clearly. I removed 282 a few days before the end of term 3 so was able to monitor changes over the holidays, which were the most pleasant we've ever had. In the first week of the new term he came home with a merit award for “staying cool, calm and collected" when faced with a situation which usually would have had him in tears. That same week he gained a further stamp towards a different award, and the following week another one for his homework!

As a visual-spatial learner with a central auditory processing disorder and an IQ in the top 2% he was probably always going to have trouble fitting into a mainstream school, however the difference the removal of 282 has made is so marked we are all going to attempt the failsafe diet.- reader, NSW

[343] Depression: Female hormones and depression (Sept 2004)

I always had horrible periods. I was a chronic bitch for two weeks out of every month and also suffered severe cramping with heavy bleeding and frequent clots.

Straight after my son’s birth I knew something was wrong. When I got home I just sat in bed staring into space. I couldn’t get out of bed, couldn’t do anything, couldn’t sleep. I would start panicking when I heard the baby cry. My mother had to come and look after us, doing all the work and bringing my son to me for feeds. It was awful. I didn’t want to take antidepressants but it was something I had to do to make myself better.

After my second child was born the same thing happened but I went on the diet for her eczema when she was 4 months old and it really helped me, I felt better than I had for months. Then when I weaned her I went back on my normal diet and started feeling anxious and overwhelmed and I couldn’t sleep even though I was on antidepressants. I know I should have realised I needed to go on the diet again but I was in denial. It all seemed too hard. For me giving up chocolate was a really big thing. I had to decide that feeling good was more important than being able to eat chocolate when I was stressed.

After my daughter was born, I took antidepressants for 12 months, then I spent 18 months weaning myself off them very slowly, because if I went any faster I had withdrawal symptoms. During this time I went on the elimination diet for myself. My PMS, other menstrual problems and depression all disappeared. Challenges showed that I am sensitive to nearly everything. If someone had told me when I first got postnatal depression that my problems were due to food intolerance, I would have gone on the diet straight away. I've been on this diet for months and now I can't really remember what it's like to be depressed.' - reader, ACT

[338] ONE LINERS (July 2004)

* It just hit me like a brick that my sons have gone to sleep well since we started the failsafe diet a month ago, instead of getting up every 5 mins for 2 hours every night. A miracle!

[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 so 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 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 kindy 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

[311] Sleep and behaviour problems due to asthma medication (December 2003)

I was lucky enough to see you speak in Launceston in September. My husband and I have been at a loss regarding our three-year-old son's frequent nosebleeds, lack of sleep, temper outbursts and all of the other problems associated with a 'normal' toddler's wellbeing. When reading in depth Fed Up With Asthma we now realise this was probably caused by Singulair Tablets. When our new doctor took him off these he sleeps!!!! and a lot of the other symptoms have subsided. We have an appointment with a failsafe dietitian next month and have been failsafing the pantry over the last 6 weeks. The temper tantrums have been halved with the severity at least a quarter of what they used to be. Thank you for being the one person to listen to a mother in need. - Toni, Tas

[289] The Clayton's diet … the speech therapist was so amazed (September 2003)

A friend of a friend with two young children visited a dietitian who put them on what I can only describe as a Clayton's failsafe diet ... not quite fully failsafe. For example, the dietitian told her that it was perfectly ok for her children to eat McDonalds/Red Rooster chips...

She was introduced to my wife and got into a conversation about real failsafe diets. After 4 days on the real diet, she rang my wife crying with happiness. Her son had settled down to what she considered a 'normal child' to be. His aggression was gone, his tendencies to distraction had disappeared and his sleep had increased by two hours a night. In his first speech therapy session since starting on the real diet, he suddenly managed to recognise 40 words (from picture cards) as well as all primary and secondary colours, where his previous best attempt at word recognition was 8 words. The speech therapist was so amazed that she has already started researching failsafe dieting. The dietitian who put her on the Clayton's diet has now started looking seriously at the failsafe diet instead. It's been two weeks now and our friend is seeing the pediatrician who put her son on Ritalin this week to see about getting him off it completely. She's 100% sure that he doesn't need it at all any more. And remember the sister? She was a chronic asthmatic, but she hasn't needed a puffer since a few days after starting the diet. - from an email discussion group, with permission

[282] Bad insomnia from MSG and preservatives (September 2003)

I have recently discovered an intolerance to food preservatives and MSG which result in bad insomnia. Since I realized what was causing my problem I have mostly had really good nights' sleep but occasionally I get caught out and eat something with preservative or MSG without realising. It was probably easier for me to identify the connection between preservatives and insomnia than for most people as we live on a farm and butcher our own meat, hence sausages and mince with little else added, and additionally my husband has a cholesterol problem so I am very careful with our diet. - Karen O'Connor, Victoria.

[225] Andrew Driffield's quest for gold (November 2002)

My name is Elizabeth Jenkins and I am Andrew Driffield's Mother. It sometimes feels as if I have always been known as "that’s Andrew’s Mother".

Andrew was a beautiful but exhausting child. He went to sleep at a normal time … then woke about 1am and stayed that way until about 5am, then dozed till about 7am. As he got older he would climb out of his bed, and head straight for my side of the bed. He would lie there quietly in my arms, only needing the security and warmth. Until he was fifteen years old this remained a habit. My memory of these events is a blur as by the time he was five, exhaustion had replaced recall.

Andrew’s only word was "Mum" until he was about four. His language was so obscure that I had to translate even to his father. He was destructive. He destroyed toys, other children, and household furniture. To do any housework that would have taken my eyes of him for a second, I had to lock the doors and windows. I vividly remember the day guests arrived at the front door and Andrew left unnoticed by the back door. The panic started as we realised he was not amongst the visiting children until a phone call from the local supermarket let us know that a little blonde haired boy was riding the rocking horse in the entrance. When asked how they knew whom to ring, they said that he was being guarded by a small black dog called Benjie who was wearing his identification. Horses and dogs remain a big part of Andrew’s life to this day.

When Andrew was five we went to a Specialist Unit. He was tested and we were observed as a family unit. Andrew evidently passed but I failed. I was told I was overprotective, and I needed to allow Andrew to discover consequences for himself. That afternoon he wanted to ride his bike with the other boys - and he was hit by a car. From then on I decided I wanted a live five year old, not a dead one.

Andrew started on an early intervention program at Newcastle University where he attended a unit with one-on-one teaching for the morning and then returning to the public school for the afternoon classes. It was a disaster. It was the beginnings of 'integration'.

They failed to see how children who are already different do not gain acceptance by being treated differently. In one year he learnt to write his name 'Andrew' with difficulty. They were still claiming that he was just a slow learner and would catch up. My observation was, had I had a monkey in the same circumstances, I would have had the same outcome. The public school wanted to expel him. He was disruptive, angry and aggressive - and he was only in first class.

A Steiner School had opened in the region and after five minutes of hearing their philosophies I sent Andrew. It was like rain and sunshine on a small plant. He thrived. He learnt to listen, he learnt to speak and the aggression gradually decreased. Andrew was now nine years old and still a handful. I eventually took him to a pediatrician, left him in the waiting room, and told the doctor I was there under false pretensions, that I'd come as a stressed adult, remembering I was still to blame for all his behaviors. Andrew was brought in, and off he went - over the desk, under the desk, etc. As luck would have it, the pediatrician had just attended a conference run by a leading Sydney professor who had described Andrew's features and symptoms to a T. We were sent to the professor in Sydney, who ordered blood tests and announced that Andrew had what he called a fractured X chromosome. He said that when enough children registered similar symptoms it would be given a name. That was in 1983, prior to the genetic testing available today, and the recognition of FRAGILE X.

At this stage Simon, Andrew's older brother, started riding horses, and I was instructing at pony club, so I enrolled Andrew as well because he was always wandering off and worrying me. I threw him up on a horse just to know where he was.

He had a natural ability, and somehow the horses seem to know that they had to protect him. It was also the only animal that Andrew could hug and not cause a decapitation.

Andrew tried harder than anyone I know, and still does. Riding put Andrew on a par with his peers, so when he got upset about not being able to read and write like other kids, we were able to point out that if they tried to ride they would probably fall off - everybody had something they were good at and could do well, and his was riding.

Andrew became Pony Club rider of the year in 1986, runner-up in 1987.

Andrew who still couldn't read or write, managed to learn dressage tests by walking on the lounge room floor from letter to letter and learning it by pattern, followed by replica in size to the real thing he walked, trotted and cantered around on his own two feet, THEN he graduated to four hooves for the real thing. He also learnt to find and remember his way around a cross country courses. For this we photographed Andrew and his horse jumping each jump at the practice day, put them into a small album, and it was his bedtime story for the two weeks prior to the competition. He also learnt to remember show jumping courses. He had the very best of coaches and everyone liked him, because he kept trying and never gave up.

In the late 80s my first marriage broke up and Andrew and I moved to Darwin and it was here that I met my new husband Stephen Jenkins.

One of Andrew's goals was to attend 'normal' high school and eventually he did. Darwin High School had a wonderful Special Education Unit, headed by an incredible women, Lauren Tinapple. She remains a devoted Andrew fan to this day, and has always been there for me in the disastrous times. There were times when I felt we had pushed Andrew past his capabilities, as he didn't seem to fit into an acceptable mold. His expectations exceeded his abilities, and my heart ached on many occasions. Even though he was teased and made fun off, he is glad he did it, and developed yet another strength of character. Through various government employment options Andrew tried many jobs, some of which were total failures. He was happiest when he went to the Katherine Rural College and did a six month Jackaroo course which they then extended into a 'work experience' for an additional six months as he needed extra time to learn. He eventually got a live-in job with a family in the middle of the territory for six months before the wet season set in.

Andrew is so driven, and one of his goals has always been to ride for Australia in the three day event just like his old pony club friend Matt Ryan does. It was hard to say to him or find a way of saying that it would be very hard for him to be selected, but that did not deter him.

Andrew was accepted as student at the NSW Equestrian Centre with Heath and Rozzie Ryan, who had been his instructors since he was seven. He lived, breathed and rode horses with the best for six months. He finally realised that this goal may be a little too hard to reach. In 1997 it was suggested that Andrew join Riding for the Disabled. As his abilities exceeded all the students, Andrew became an Assistant Coach at RDA and loved helping all the children to ride and benefit from the experience.

In the October of 1997 Andrew rode as a member of the Northern Territory State Team at the RDA National Championships. He was now riding and competing against others of similar disabilities. Andrew started to shine, placing 2nd in his first National competition, coming closer to his goals.

To allow Andrew to reach his full potential, and access regular coaching, we made the major move to South Australia. Since then he has improved each year, and in 1999 was selected on the RDA National Squad. He is now among the top riders in Australia and hopes to be selected to represent Australia at the next World Championships.

This is quite an achievement especially when his Grade, Grade 3E for intellectual disability, is not recognised at international competitions, so he rides against able minded, but disabled body riders in Grade 3, a grade above his, and riding against the likes of Julie Higgins who won double gold at the Sydney Paralympics.

By far the most significant change in Andrews's life has been our discovery of Sue Dengate's book FED UP in 1998. Through use of the Fed Up diet and avoiding all intake of natural and artificial chemicals that Andrew reacts to, his mind is clearer, and he is able to control his actions and tempers. As he says, he hates it when he eats the wrong foods because it makes him feel bad and depressed. Before discovering the diet we had some hellish times, including major temper tantrums which in the main were triggered or caused by the wrong foods. Andrew is 6 feet tall and very strong and broke his Step-father's ribs one Xmas, while giving him a Xmas morning hug, so if he is in a food related temper tantrum, beware.

Andrew still aims to reach his goal of representing Australia and is hoping for selection onto the Australian Paralympic Team.

Andrew was recently assessed by a leading psychologist, and has a measured Full IQ of around 65 and an Overall Adaptive Functioning cognitive measurement below the 1st percentile, so it is amazing that Andrew is not doing what a specialist once told us was all that was possible, to expect nothing more than having him working in a sheltered workshop doing repetitive tasks. Although eligible for a full disability pension Andrew has foregone it to work 5 days a week on a recycling truck so he can afford to reach his goals and keep his mind and body active instead of sitting at home watching TV.

If there is one phrase that says it all about Andrew it is these words from Calvin Coolidge: Nothing in the world can take the place of persistence. Talent will not; nothing is more common than unsuccessful men with talent. Genius will not; unrewarded genius is almost a proverb. Education will not; the world is full of educated derelicts. Persistence and determination alone are omnipotent. And without the fed up diet, he certainly would not be where he is today, in mind or ability.

[224] "After four weeks, he was able to go without medication altogether" (October 2002)

It's been 7 weeks now since we switched to Brumby's bread. Within days, my 10 year old ADHD son started improving and we halved his dose of dexamphetamine medication. After four weeks on preservative free bread, he was able to go without medication altogether.

You've no idea how much this child has changed. It's huge. I no longer get calls from school, he's bringing home merit awards, he entered himself in a maths competition, studied for it and won the first round . He does his homework without being asked. Half the time he goes to bed and is sound asleep before we say anything. Before, we used to get excited if he got to sleep by 11 pm. One day we were late for school and he said "that's OK, if we're late, we're late". Before, he would scream at me and kick the door. The change is unbelievable.

My older son has changed too. He is a very calm and loving child but he used to be so forgetful - like he was in another world. He would get very frustrated at forgetting things and sometimes he would snap. Now he remembers everything the first time.

We've seen improvements in the whole family - all five of us - except for the last two weeks, when we on holidays and we couldn't get Brumby's bread. We bought a bread labelled "no preservatives" but we all got worse. Then someone told me about whey powder. When I checked the label, it had whey powder in it.

My husband and I have noticed we have so much more energy and are less moody on preservative-free bread. With 282, I'm so tired all the time, I can't hold a conversation without losing people, my handwriting is terrible, I write some of my letters backwards, and I've even reversed phone numbers (02 instead of 20). This is really important in my job.

Three of us (me and two of the kids) are asthmatics. On the Brumbys bread we've all been asthma free and medication free for 3 weeks. That's a long time for us.

I'm angry. They think because they put a number on the label, they can put anything they like in our food. But we don't know what it is or what it can do to us. I don't want my child medicated if there's another way. - Anne-Marie, Hunter Valley, NSW

[216] "Had to walk out of the house" (October 2002)

My daughter is 3.5 years old. Last year when she was 2 years old she had two nights where she only slept for 2 hours, and was a flailing, intolerable child. I literally had to walk out of the house, I was very close to losing it. I realised that this reaction was likely caused by the 'party foods' she had eaten for the first time at a playgroup Christmas party. I took her to the doctor, and was then referred to a paediatrician, and then onto a child psychologist. The psychologist agreed that her diet needed to be taken into account, as she was a very busy little girl, who never stopped, and never slept much. But the sudden outburst of defiance had me worried. He gave us practical advice, and we went on our way. Six months ago, a friend gave me your book 'Fed Up'. During the first two weeks of the elimination diet, our little devil turned into an angel … - by email

[209] Falling asleep (October 2002)

My daughter went on the diet nearly a year ago. The change that has made the biggest difference to my quality of life is her ability to fall asleep. Since she changed from a cot to a bed, I have had to stay in her room till she went to sleep which could be an hour or more.

As she grew up, she would stay in her bed but quite often be awake when we went to bed 2 or 3 hours later. Being afraid of the dark, she would end up in our room sleeping on the floor or I would fall asleep next to her on her bed.

Once she was asleep, it didn't mean she would stay asleep and most nights for 10 years she would call out or get up 2 or 3 times a night.

Now at 11 years old she still hates going to bed but once there she falls asleep within a few minutes and stays asleep all night. She is also doing much better at school, and her teacher is amazed at the improvement in her hand writing. - by email

[182] 282: "wonderful changes" (September 2002)

My son was experiencing behavioural and learning problems. Through diet (eliminating 282, other additives and some salicylates) I have seen some wonderful changes in him, especially in his sleeping. For the first time in his five years of life, he is sleeping 12-14 hours a day. - email, WA

[180] 282: "Already noticing a difference" (September 2002)

My jaw dropped to the ground after seeing your show on Today Tonight and thinking "that's my son!!" I thought I had tried everything to work out what was wrong with my son as a baby - he is 4 now. He wouldn't sleep. I was lucky to get 15 minutes sleep out of him day or night - doctors were saying it was colic, no remedies would help - nothing would work - he just constantly screamed and screamed and screamed. I thought I was going mad. It wasn't until I weaned him off breast milk that he started to calm down a bit - but he is still difficult and hard to live with. My other two children are not like this at all.

I could never come to any conclusions and neither could anybody else. I noticed recently after I ate certain foods, I would feel tired and have to lie down and in two incidents recently I could not keep my eyes open and had to immediately lie down and sleep. I thought this was to do with fats (margarine etc).

But after seeing the show it is like the light has dawned. It has been one week now and we have been buying preservative free bread - and I am already noticing a slight difference in my son. I intend to eliminate other preservatives and get to the crux of it all. Thank you and I feel that I am at the beginning of the trek to a new and improved life.

[176] "I could not find a doctor who could help" (September 2002)

My daughter, now 10, demonstrated all the behaviors outlined in the Today Tonight story as well as constant ear and throat infections plus skin rashes, itchy feet and hands, nightmares, could not sleep, agitated behavior, and running sores. I could not find a doctor who could help so at 3 years old we took her to a naturopath. He took her off all milk and grains except corn.

The result was so remarkable that we have religiously kept her off all grains for 7 years. She did return to diary products in moderate amounts without problems. She has learned not to eat wheat as when she breaks this diet she often becomes ill. Although she has never had bowel problems we have assumed she is coeliac. She has not been tested as we refuse to make her go through hell for 3 months before the doctors can test. After watching your research I was wondering if she is really only sensitive to the additive in bread and I assume some other products … - email

[156] Unexplained fatigue, dizziness (June 2002)

We are doing the elimination diet to try and help my oldest daughter.. She is 8 years old. Her main problem is that she has suffered from regular, unexplained and excessive fatigue for several years. We have also recently realised that she suffers a lot of dizziness and light headedness too. She has good days and bad days, as well as long good stretches and bad stretches of 1 - 4 weeks. When bad she can miss quite a lot of school, hates getting up in the morning, hates school, and spends all the after school period on the couch, until bedtime. Other symptoms which bother her are periods of excessive irritability, difficulty getting to sleep at night, being very sluggish in the mornings, difficulty focusing and applying herself, daydreaming and being slow to get anything done, being very pale in the face at times, fainting (at sight of blood), periods which seem like depression, and at times, poor appetite and feeling of nausea after eating. It was only after thinking through everything written in Fed Up that I realised she had so many symptoms. These things have become apparent gradually since she started school, but seem to be trending to get worse. On the plus side, she is very clever, has always put in a big effort at school and is consistently a very high achiever, is well behaved, patient, sensitive, thoughtful, kind, and hardly ever gets into trouble. In fact, one teacher thought she was "too good" - which could make it hard for her to stand up for her own needs.

She has had blood tests a few times, which found nothing, but she is absolutely terrified of medical procedures (and will faint) so we have chosen to explore dietary options. We are in the second week of our elimination diet, it has been very interesting. I think I believed nothing would happen. We took ages to get ready (mentally and in terms of stocking the pantry) so we were additive free for a month or so before starting. During this time she was gradually improving but nothing drastic. On day 3 and 4 of elimination she "lost it" - picked fights, became over emotional, almost hysterical, restless, teary, irrational, and claimed we were all against her. I was a bit scared as this was not in the least her normal behaviour. She also had some nausea. However thankfully these withdrawals eased off by day 5. The first improvement she noticed was that she didn't feel irritable any more. Then she started to say she had more energy. She has clearly been getting more involved in activities and spending much less time on the couch. She has been focused enough to do good piano practice, and she has stopped saying she hates school. - by
email

[155] A Brush with Pizza Snack Biscuits (June 2002)

My sons are severely food and chemical intolerant. Their diets are severely restricted, just to enable them to cope with day to day life. Their adherence to the restricted diet literally enables them to survive. We avoid additives in food at all costs, and we avoid chemicals wherever possible as they affect the boys equally to the wrong food choices. They are aged 6 and 3.

My eldest son has commenced school and is in Year 1. Considering his dietary challenges, he copes with food and school incredibly well – but there have been and will always be the occasional slip ups. Pressure from peers is already impacting and will continue to do so as he journeys towards adulthood.

Late in the Kindergarten year, he was with some team mates after a Teeball game. He was eating his customary rice and drinking plain water whilst the other kids were tucking into soft drink and a box of pizza snack biscuits – the kind people might eat with dip. He was fairly unfazed as he is used to it, but the problem kicked in when he had finished – still hungry - and the others still had plenty to eat. He resisted their offering and the temptation to indulge until they reached the bottom of the box. It was then that he succumbed to the hunger and I daresay, the curiosity, (he has never eaten them before!) and he ate some crumbs from the box – less than would cover a 10 cent piece. He later remarked that he didn't even like how they tasted!

Within 3 hours, the reaction started. He was due to go to a birthday party – I always stay with him for moral support because he can't indulge in what others enjoy at parties – and as we arrived, the rot began to set in! He was no longer able to communicate with me in the way he usually would. His responses to questions were more a grunt than a reply. I had to physically manipulate his face to make eye contact with him and get his attention – and his eyes were wild!

He generally perspires freely even though he is only 6, but now he was perspiring profusely. His shirt, hat and shorts looked like the ones on Pat Rafter after a 5 set Final – and this is truly without exaggeration. He was soaked. He was moving in an agitated manner- his actions were jerky rather than smooth, and he was lashing out at things and people. He became surly and very defiant. He was irrational when compared to his usual behaviours. He hurt 4 friends at the party in 4 separate incidents whilst playing tips on and around some playground equipment. I had been observing and intervening – there was nothing malicious, but he had lost his finesse and the ability to be able to judge the other kids level of involvement. He had become face blind – oblivious to their anxiety and distress, and unable to see that they wished to cease the game. His need to continue the game was insatiable.

For the first time ever, these kids were actually scared of him and what he was doing, and they thought he had hurt them on purpose. He was at this point doing some real damage to the fragile relationships he had worked so hard to develop. The area the party was conducted in was also open to the public, and my son managed to get into 3 fights with slightly older boys he had never met before. In each instance, both parties were equally at fault, however the new children seemed to take an instant dislike to his overall behaviour and this was the impetus for the conflict. He was now unable to make good judgements about his actions and he took offence at the situation. Instead of altering his behaviours to become more socially acceptable, he lashed out and hit the other child – and so the fights began. My time was spent alternating between apologising to everyone profusely, heading his ill-considered choices off at the pass and repairing his crumbling relationships whilst helping out his inadvertent victims – his mates were suffering his horrendous reaction to flavour enhancers, flavours and preservatives vicariously.

Going home was no better – we were only two hours into the reaction and things weren’t going to get better in a hurry. I tried to keep him doing things outside to wear off as much energy as I could. Something happened and he was hurt. I think he took a bump on a tooth that was threatening to come out, but was nowhere near ready just yet. The bump made the tooth a little looser and it bled. I tried to soothe him and clean the blood without his knowledge, as blood worries him. It was no use because he became hysterical. His hysteria was very different to his usual teary fussing (as many 6 year olds do when in need of TLC). He began to scream and squeal a very high pitched squeal, he was rocking and flapping, he was panicking, he wanted comfort but kept pushing me away and he interspersed the screams and squeals with frenetic pleas of ‘Help me! Help me!’ He was inconsolable and it took me more than 1 ½ hours to calm him down to a reasonable state. He then continued to rock and sob on my lap.

Without the pizza shape irritants in his body, I would have been able to calm him right down within half an hour and he would not have exhibited the rocking, flapping and squealing behaviours (which are found on the Autism Spectrum along with face blindness and tactile defensivity – not wanting his personal space invaded, oversensitivity to touch, pushing me away despite wanting comfort). He also would not have pushed me away after the initial pain subsided. Consequently, he distressed his baby brother and his father – the whole house had been disrupted by the ingestion of the miniscule dose of pizza shapes only hours earlier.

The next phase of the reaction involved him not being able to go to sleep, and then once finally asleep, waking all through the night. He finally succumbed to sleep at 11.30pm after his usual Catapres dose and some Panadol several hours earlier. His body was still too irritated to properly settle down. Massage was useless because now he was oversensitive to touch. Whilst asleep, he did not lie still all night. He was thumping, wriggling, tossing and squirming all night. You could not say he had a restful evening and neither did we.

He was awake at about 6 am despite his late and unsettled night and the irritated, angry behaviours commenced immediately. He had an argument with his brother over the TV that ended in a fight, because he couldn’t step back and get help to sort it out without using his hands and body. He was physically and verbally aggressive and violent. His defiance was escalating and every single thing that went on in the day was a bone of contention. If we said it was black, he swore that it was white despite any evidence to the contrary. If his brother looked at one of his toys, or dared go near his bedroom door, then he hit him without even blinking. I spent this day diverting, refereeing and taking my son out of the house to separate everyone and try to reduce the exponentially increasing stress levels. Bedtime was no better tonight either.

He also began to exhibit physical symptoms today. He now had patches of eczema under his armpits – these only ever appear when he is reacting to something – he had a pre eczema scale – like ichthyosis - all over his torso that he constantly scratched at. He had heartburn, his belching increased, he had wind that you could hear in his digestive tract, he had ‘allergic shiners’ (large dark circles under his eyes), he had greyish skin tone, he had a red burn mark with skin peeling off his behind from the irritants passing through his digestive tract and burning him as it went. There was nothing I could use to relieve his discomfort as nothing would stay on his skin. These physical symptoms would remain until his body was finally clear of what he had ingested.

Upon waking the following day, it was still evident that the aggression was present, although a little milder than yesterday. I managed to encourage him to have some solitary play in his room. He was still irrational and oversensitive and not coping and lashing out. By the time school began, he was in tears clinging to my legs. He was suffering terrific mood swings and his anxiety levels had really increased – he becomes very anxious when his body is compromised by the wrong foods or chemicals and this directly affects his behaviours too. I let his teacher know and organised to collect him early as I knew a whole day of school would be too much. His ability to perform his work had significantly decreased compared to the week before and he needed much more support to complete tasks. His behaviours in the playground were more frenetic and wild, but fortunately he didn’t get into any scrapes that might be finished physically.

In the afternoon, he exploded again – tiredness and the pizza shapes a volatile combination. I rode a rollercoaster of violence, verbal abuse, screaming, aggression, hugs and apologies. It was all I could do to get the situation calm enough for us all to co-exist when Dad got home from work. Unsettled sleep was still an issue. This pattern of morning irritation, school, early pickup, irrationality, abuse and calm continued for another 6 days before things significantly improved. It was a hell of a long time to suffer for such a piddling amount of additive laden Pizza biscuits! Another unfortunate feature that reared its ugly head during this horror period was a return to very negative self image; calling himself stupid and an idiot, saying and believing that no-one liked him and no-one loved him, and believing that his friends didn’t like him anymore either. When he has a reaction like this, he believes he is not a good person. This is a very heavy burden for such a small person, but it has been a part of his reaction pattern since he began to speak. When he was eating a lot more foods when very small - before we had pinpointed the problem (and life was hell for everyone), he would sometimes self harm and sometimes even say ‘I wish I was dead’. It is a very scary and affronting thing to hear your two year old say, "I’m a yucky person! I wish I was dead!"

I always take great pains to point out the wonderful things about him and his achievements and I try to provide lots of situations where he will feel success, but it is undermined very quickly when something like the pizza biscuit incident occurs.

Oh, and what additives were in the box? A combination of at least four glutamate flavour enhancers, some colours, added flavours, vegetable fat (that is likely to contain one of the harmful antioxidants but which doesn’t have to be listed because it represents less than 10 percent of the final product), cheese powder (also usually has added flavour enhancer in the manufacturing), spices… I think anyone reading this will get the picture!

What can be learned from this horrible but true story?

- Food additives DO hurt children.
- Food additives vicariously affect others.
- Possible reactions are many and varied. If you’re lucky, you may only exhibit a few minor irritations. If you are unlucky, it will affect your whole life until you can overcome the dosage.
- Physical, mental, social and emotional health can be affected equally.
- Reactions are dose related. The more you have, the more likely you are to suffer a reaction.
- Reactions are individual, and depend on your tolerance.
- Society eventually pays for the individuals who cannot cope with the additives in their diet but are not aware of the connection: mental illness, conduct disorder, depression, drug dependency, costly and often ineffective medication to treat a sufferer's great variety of symptoms, property damage, incidents of rage, family and relationship breakdown, compensation paid to people who end up the innocent victims of others who themselves are really the victims of the food industry… All of this has a cost, whether just an emotional one, or a monetary one. Incarceration of food ’victims’ is yet another cost – and one better spent in prevention and better health outcomes for all.

Many of the additives now permitted for use in our foods were not permitted as recently as 5 years ago. If we didn’t need them in our food then, and they can have a harmful effect on children and adults alike, then WHY are we allowing them into our food now?! - Sheryl, ACT

[153] Nicholas: Our Six Year Journey (June 2002)

Our family is what is commonly referred to as a "blended family". When we were arried in January 1992, Steve inherited a "package deal" which included my two children, auren and Mark, from my first marriage. Nicholas was born in October 1993.

Our six-year journey with Nicholas began early in 1996 when he was almost three. We were living in Wagga Wagga. Steve and I were in our late thirties, and Lauren and Mark were 13 and 10 respectively.

We are a Defence Force family, which means we are required move around a fair bit. This also means that we endure complications and added stresses that most non-transient families can only begin to imagine.

When Nicholas was born he came into this world in the usual way, a normal pregnancy, and no problems during labour or childbirth. He was a completely normal child in every way until around the age of three. He started to become difficult to manage from a behavioural point of view.

I was 30 weeks pregnant at that time, with Elise, and due to complications I was confined to bed for the last 10 weeks of my pregnancy. Steve was not allowed to take leave so we had to fly my mum down from Brisbane to help out for the first five weeks, and then for the last five weeks we had Steve’s parents, also from Brisbane, stay with us to help out until I was back on my feet. We put Nicholas’ bad behaviour down to having to cope with different people, different sets of rules, different ways of doing things etc. and told ourselves that everything would return to normal in time.

Elise was born in August and things did not improve. I mentioned Nicholas’ behaviour to the clinic sister when I took Elise to be weighed and measured, and she felt that perhaps he was feeling neglected because his new baby sister was taking a lot of the attention way from him. We enrolled him into preschool. We felt that perhaps if he were to ecome involved in something special just for him, something to improve his self-esteem, his behaviour would improve.

He settled into preschool really well and thoroughly enjoyed it. He was always very well behaved at preschool but the behaviour at home did not improve. This became the pattern of our lives for the next six years. He became obsessive about little things such as his bath. It was either too hot or too cold. It didn’t really matter what temperature it was, it was just never the way he wanted it no matter what we did.

We survived fairly well for the rest of that year and remained in Wagga Wagga until the end of 1997. Nicholas’ behaviour did not get any worse, nor did it improve. We told ourselves that since we seemed to skip the terrible two’s that perhaps this was just a bad case of the terrible three’s instead. I hasten to add that I did not experience any of these behaviours with Lauren or Mark, nor did I go through much in the way of the terrible two’s with them. Lauren and Mark were always very well behaved both in the home, and out and about, so this was a whole new experience for me.

At the end of 1997 Steve was posted to Darwin, and we spent an enjoyable Christmas with our families in Brisbane en route. We arrived in Darwin in mid January of 1998 and this is where our journey really started to get rough.

Nicholas started preschool five mornings a week and he became very tired with no energy. We put the tiredness and low energy levels down to the humidity and extreme heat of the tropics and the fact that up until our move to Darwin, he had lived all of his life in a cold climate. Nicholas was born in Canberra, and had spent the past two years living in Wagga Wagga before moving to Darwin. He started to lose weight, which we put down to the fact that Steve is very tall and that Nicholas had inherited the "tall" gene and was starting to grow. We decided he was going to be a tall, skinny child and didn't think too much more about it. The behaviour was getting steadily worse but still only at home and never at preschool.

In March of 1998, I decided it was time to take Nicholas to the doctor because he was now 3½, still a bed wetter at night, and still no improvement in his behaviour. We were referred to one of Darwin's best paediatricians. Nicholas had an ultra sound done on his bladder to rule out any nasties. This indicated that he had a large bladder capacity, which meant that he should be able to store the urine and make it through the night without any problems. Our paediatrician only ever used medication as a last resort after exploring all other options, and we were in total agreement of this. It was decided to put Nicholas back into night nappies, which we did, and given a bit more time and maturity, hopefully things would fall into place.

Initially, the bed-wetting was the bigger concern and the behaviour was secondary. Gradually, the priorities were reversed. Nicholas' energy levels deteriorated and his weight loss continued. The dreadful behaviours worsened. As time went on all these things became serious issues. The volume of urine each night was no longer contained in the night nappy, and the behaviour went from bad to worse, to down right disgusting, with many violent outbursts. He became more obsessive. He had to have the yellow bowls and plates in our multi coloured dinner set, and he had to have his shoelaces the exact same length. If he didn't get his own way, a huge tantrum would ensue.

Nicholas' weight loss continued and he was now looking so thin and unhealthy that he looked like a prisoner of war. His energy levels were so low that he would be playing on the floor of our living room and tell me he was tired. I would tell him to go and have a rest but he didn't want to. By the time I turned around to do something, and looked back at him, he would be asleep on the floor mid play.

Our paediatrician decided to try a medication called Periactin, which was supposed to kick start Nicholas' appetite. Unfortunately it didn't seem to work. Our paediatrician then decided the behaviour might improve with a change in diet. He started to tell us about the chemicals in food, both natural, and added. He had a basic knowledge of this but decided to refer us to a dietician.

The dietician that we saw also only had a basic knowledge of food chemicals. She did her best but really couldn't answer any of my questions and was of no real help except for one very important piece of information. She wrote down the name of a local lady by the name of Sue Dengate, whom she said had a support group for people like us, and knew a lot about diet. She did not have a contact phone number or any other details. She also recommended that I buy the book Friendly Food that was recommended by RPAH. The book was about avoiding allergies, additives and problem food chemicals.

I went straight from the dietician's rooms to our local bookshop where I purchased the Friendly Food Cook Book. The woman who ran the bookshop asked me if I'd read the book Fed Up by Sue Dengate. I hadn't, and the store was out of stock. This prompted me to try to find Sue's phone number in the local phone book. Prior to contacting Sue, I phoned my mum in Brisbane to ask her to try to get hold of the book and send it to me.

I eventually got my copy of Fed Up and was shocked at what I read by both the natural and the added food chemicals. Nicholas was much worse in Darwin than he was in Wagga Wagga and our paediatrician said that it could be as simple as changing our bread. He said that in Darwin, because of the humidity, the breads had a lot more preservative in them than the breads down south. In the tropics the bread goes mouldy much quicker. I began reading food labels for the first time in my life and discovered that our bread which we all ate at least once a day, had preservative in it. This was only the beginning. After making contact with Sue I began to realise how fortunate I was to have her, especially living in our local area, because she has saved our lives on numerous occasions over the years.

The biggest hurdle for me in coming to terms with the failsafe diet was that I had to completely change my way of thinking when it came to foods. I had been raised on a diet of fresh fruit and vegetables and this was how we were raising our children. The obvious additives and preservatives were things that I could comprehend very easily as being "nasty" and I was more than happy to eliminate things like red cordial and "junk" food, although we really didn’t eat a great deal of junk food.

The most difficult thing for me then, and even now, was coming to terms with the natural food chemicals that seemed to be in just about every fresh fruit and vegetable imaginable. In our early days of the failsafe diet, I went through a very real period of mourning. I mourned the fact that my son could no longer eat many of the fresh fruits and vegetables that most people ate and took for granted in their daily lives. I also mourned the fact that I had to take away many of the things which he truly loved, such as bananas, cheese, burritos, and much more. I was concerned about his nutrition because this new way of eating did not leave him with very much, and his weight from the age of three had always been a concern to us.

I quickly discovered the importance of reading the labels on everything I bought at the supermarket. It is something that you have to be totally diligent about because what is considered "safe" one week could be considered "unsafe" the very next week. A simple thing like a change in the ingredients can make a huge difference between a "safe" product and an "unsafe" product. One mistake could be the difference between whether the diet was successful or not.

In the beginning we made many mistakes but with trial and error, and the guidance of Sue, we managed to make our way through this dietary minefield and come to some semblance of what could be called our new normality. A diet with very limited fresh fruit and vegetables in comparison with our past life of a diet, which consisted of no limits at all, when it came to "healthy" foods and fresh fruits and vegetables.

We implemented the failsafe diet (the elimination diet recommended by RPAH), and with Sue’s guidance we managed to avoid a lot of the common mistakes and pitfalls. It is not an easy diet to do as a beginner and so to have her help in this was invaluable. Initially, the whole family went failsafe in order to support Nicholas. We remained failsafe for quite a long time but eventually we all went back to our normal diet, except of course for Nicholas.

We still don’t eat chocolate or any of the stuff he really loves in front of him. We try to "escape" if we feel the urge to be a bit naughty as we are very aware of his feelings. Nicholas did show considerable improvement once we got past the dreadful withdrawal symptoms, however, the improvement although noticeable was not enough and so we continued in our search to get our lovely little boy back. The calm, gentle beautiful little boy that we once had and were not prepared to give up without a fight.

We noticed that Nicholas used to get particularly irritable just before meal times, so when Steve mentioned this to our paediatrician he told us to try an over the counter complex sugar called Poly-Joule. We left the surgery shaking our heads in exasperation and thinking "yeah right" that will work. We were extremely surprised to discover that it did in fact work and he was the best he'd been in a long time.

Nicholas had already been tested for diabetes because his paternal grandfather is an insulin dependant diabetic, and so are two of his cousins. The success of Poly-Joule prompted our paediatrician to put Nicholas in hospital for two days and a night for some specialised fasting tests. Bloods and urine were taken at specific intervals over a 24hr period of total fasting except for water. At about ¾ of the way through the testing Nicholas started to have a "hypo" which resulted in an immediate halt to the tests.

The official results of these tests were that Nicholas had a very rare form of Hypoglycaemia called Ketotic Hypoglycaemia. We were then advised by our paediatrician to give Nicholas regular doses of Poly-Joule so that his sugar levels remained stable instead of up and down like a roller coaster. We then decided that the Ketotic Hypoglycaemia was the main cause of these dramatic mood swings and behaviours.

We continued with the failsafe diet as well as the Poly-Joule and again we saw some improvement, but once again it was not enough. The disgusting behaviours continued and I again contacted Sue in desperation. She suggested we implement 1,2,3 magic and very generously loaned us the video. We were very impressed with this simple technique so we decided to try it. The implementation of this behavioural technique saved our lives, and to this day, continues to play an important role in our lives. Once again, over time, we saw some improvement, and once again it still wasn't enough.

We again went back to our paediatrician who decided to put Nicholas on a one- week trial of Ritalin. By this stage we were desperate people and willing to try just about anything. At the end of the week we again contacted our Paediatrician and told him that it really didn't seem to have any effect on the behaviours. We now know that medication, like diet, requires fine-tuning, and adjustment to be effective. It was unfortunate that the paediatrician did not mention this to us at the time. We were, at this stage of our journey, very much in a period of trial and error.

He referred us to a visiting psychologist who said he'd like to hypnotise Nicholas and put Steve and I on medication. I decided this was somewhat extreme to say the least and informed our paediatrician that I would not be going back.

We resigned ourselves to the fact that this was pretty much as good as we could get, although things were still not good, and that is putting it mildly. The bed-wetting continued and so we were referred to a visiting neurologist who asked us to measure the capacity of Nicholas' urine output. We did this and were told that he definitely should have the capacity to be able to store his urine overnight. He also recommended the bell, pad and alarm system to try and rectify the problem.

Our paediatrician decided that Nicholas was too young for the bell, pad and alarm system, so he prescribed Minirin, a nasal spray medication that is designed to stop bedwetting. We were told to give him half the minimal dose for his age and weight and after only three doses Nicholas was rushed from school to hospital in an ambulance because he was having a seizure. Blood tests taken at the time showed low sodium but nothing more. Seizures were one of the known side effects of this drug but it was extremely rare. Nicholas was one of the rare ones.

During these years Nicholas' behaviour remained disgusting and it continued to be that way, but only at home. He never showed any of the violence at school, and never at the paediatrician, or our local GP. I would tell the doctors and teachers about his behaviour at home, and they would look at me as if I was some kind of neurotic woman. I began to feel as though I was from another planet. I also began to doubt my skills as a parent.

Relationships in our house were strained to say the least. There were times when Steve felt like leaving, and there were times when I felt the same way. Fortunately, we never both felt this way at the same time. I had many desperate teary phone calls to Sue during this time and several similar desperate calls to our paediatrician. I enquired about respite care because I felt I desperately needed a break. As a Defence Force family we were completely on our own with no extended family for support.

Relationships between Nicholas and our two teenagers were also strained. My eldest daughter wanted to leave home because things were so bad and so desperate, and she'd had about as much as she could handle. My eldest son just couldn't stand Nicholas and every time he was near him he would pinch, prod, poke, or annoy him in some way. I would never catch him doing it but I would always catch Nicholas retaliating and that would result in immediate time out for Nicholas.

In those days Nicholas had such dreadful behaviour that I made the mistake of blaming him whether it was his fault or not. It took me a number of years to catch on to what big brother was doing. I remember one occasion where things got so desperate that I went back to our GP and asked him what we should do. We had been going to our aediatrician for over two years and still did not have the result we desperately needed.

Our GP gave me this piece of very important advice. He said, "love this child, he is not doing this on purpose, no child ever wants to be like this". I have remembered this piece of advice and over the years it has helped to keep me going. I kept telling myself when things got rough that it was not deliberate, but that these behaviours were uncontrollable.

Time out and behaviour management strategies were effective up to a point, but Nicholas would never go to his room voluntarily. He always had to be carried there, kicking and screaming. I lost count of how many times he broke my watchband in the ensuing struggle to get him up two flights of stairs to his room. The older he got, the bigger and stronger he became, which made him much more difficult for me to deal with. He was super strong when he was in full tantrum mode and I started to have real concerns about how I would manage him, as he got older.

The years of difficulty and stress really took a toll on us as a family. My enquiries into respite care led to a dead end because there was none available to us in Darwin at that time. I had reached desperation and was seriously considering fostering Nicholas out because I was reaching the point where I was afraid that I might lose control one day and hurt him. At that stage the only thing that stopped me was my love for my son, and the determination I had to keep going, and to keep trying, and my unwillingness to give up. I felt that if his own mother couldn’t deal with him, then who could?

I used to suffer badly from hormonal, monthly mood swings with every menstrual cycle so I made the decision to have a hysterectomy. I felt that if I was in one of my "moods" at the same time Nicholas was having one of his violent tantrums, that this was a combination, which was destined to end in disaster.

My GP was supportive of my decision because I’d had four children, two girls and two boys, I had just turned forty, and I definitely did not want any more children. My hysterectomy was never considered to be a drastic measure on my part; it was simply necessary for me to survive. It was, for me, the best thing I could have done, and I have no regrets about that what so ever.

Nicholas in the preschool year was never disruptive or badly behaved in that environment. He did not join in very much with the other children, particularly in singing or dancing, or anything where he had to really let himself go and have fun. He was always very stiff and controlled. I remember seeing his teacher once grab both his hands and physically move his arms to do the actions for a song they were singing up on stage. He hated it. He showed very little in the way of emotions, he very rarely smiled, and was very rarely spontaneous with anything, both in conversation, and in the form of gestures. He had a marked delay in his speech and I was forever explaining to people that if he did not answer a question straight away, he was not being rude; it simply took a while for him to process his thoughts.

In his first year at school he was fortunate to have a teacher who was very supportive and who also had a son with ADD. She asked me if Nicholas had ADD and I said no, our paediatrician had never even mentioned this as a possibility. Nicholas has always been an excellent reader, and very good at maths. His writing however, was very poor. It was very difficult to read and I was worried at one stage that he might have been dyslexic. He wrote a lot of his letters and numerals backwards or like the mirror image. He never completed any of his written work. In the first year of school this was not too much of a concern, and on his report it was written that he is a good, well-behaved little boy who daydreams. His teacher suspected processing problems of some sort and so it was recommended that we take him for hearing and eye tests, both of which came back saying that everything was fine.

In his second year of school his teacher had trouble getting him to stay on task. She tried keeping him in at lunchtime; but he didn’t seem to care, and still did not complete his work. I mentioned his inability to stay on task and complete his work to our paediatrician. He was not overly concerned because Nicholas was so good at reading and maths. Nicholas became very clever at covering up his weaknesses.

At the end of his second year of school, our third year in Darwin, we were offered a posting to Sydney. We thought long and hard about accepting this posting because our eldest daughter had just completed year eleven, which would make this move a particularly difficult one for her. In the end we decided to accept the posting because we felt that in Sydney we would have access to a greater number of experienced professionals. We pretty much thought that if we had no luck in Sydney with Nicholas then this was perhaps as good as it was ever going to be.

We were referred to a very experienced paediatrician in Sydney who listened to what we had to say and gave us two questionnaires to be filled out and returned. One was a parent questionnaire, and the other was a teacher questionnaire. The result of these questionnaires was that Nicholas had, in her opinion, ADHD. Our paediatrician felt that Nicholas was not bad enough to require medication even although the disgusting behaviours continued.

Once again, I had to explain to yet another paediatrician that these behaviours were only ever exclusive to us at home. I began to get the feeling that we were being perceived as having some sort of bad home life that was causing these behaviours. My gut feeling was and still is, that two things caused these behaviours. One was diet related, and the other was frustration from learning difficulties at school. I learned very early that if I allowed Nicholas to digress from the failsafe diet that we were in for a very rough ride, always with violent behaviour. School was something that I was unsure about until we started to have huge battles over homework.

A month after arriving in Sydney, Nicholas' behaviour became worse. We put this down to the fact that we had just moved, he was missing his friends from Darwin, and all the stresses and strains associated with changing schools etc. We felt sure that with the passage of time things would improve. They did not. He started punching, head butting, kicking and screaming. When he was sent to time out he kicked a hole in the wall. This became a common occurrence.

After one such session I phoned our paediatrician in tears and said that I couldn't do this for much longer. I tried increasing the Poly-Joule and this seemed to have no effect. Our paediatrician decided to admit Nicholas to hospital and re do the testing for hypoglycaemia. The result of this was that Nicholas had now outgrown the hypoglycaemia, which we were originally told he would outgrow at around the age of nine. The decision was made to stop giving him the Poly-Joule.

We were then referred to the enuresis clinic at Westmead Children's Hospital to try and address the bedwetting. Nicholas was 7½ by this stage. The specialist that we saw recommended the bell, pad and alarm system. We had great success with this method and within three nights Nicholas was dry for the first time in his life. He has never wet the bed since.

Prior to leaving Darwin, Nicholas' eyes became very sensitive to all kinds of light from different sources including, sunlight, and computer screens. He had a CT scan to rule out any nasties. In Sydney he was referred to the eye clinic at Westmead Children's Hospital where we were prescribed two different types of eye drops for viral conjunctivitis. The eye specialist was very good and when I explained Nicholas' sensitivity to foods he prescribed preservative free eye drops. The viral conjunctivitis was cured, however the light sensitivity remains.

Our paediatrician told me that she believed only 4% of children were affected by food intolerances and so I began to educate her on this matter. At every visit I would tell her "we had pizza the other night, I let Nicholas off his diet and he went totally off the planet". Another time we had Chinese take away as a treat for Elise’s birthday, (something we hadn’t had for years), I let Nicholas off his diet and within minutes of eating it he had thrown a major tantrum and broke one of our kitchen chairs. After two weeks of swimming at school, on a Saturday at home, he was told "no" to something and he broke a solid wooden door on our entertainment unit.

Our paediatrician always listened to me but I always felt that I was still being perceived as some kind of neurotic woman who was speaking a strange language that no one else could understand. I phoned her one day in tears after one of these episodes and said that I was afraid that I might hurt him if things didn’t improve. She told me she could arrange for respite care if I needed it. After that phone call, at every visit, Nicholas was asked to take off all his clothes with the exception of his underpants. He was checked thoroughly from top to toe. I know that these children are considered "at risk of abuse" and I realise how close I have come to hurting this child on a number of occasions, but I have to say that this was one of the most humiliating experiences I’ve ever had to deal with.

At this point, I started asking questions like "who protects the parents?" It seemed that it was okay for Nicholas to kick, punch and head butt me, but it was not okay if I lost my temper one day and hurt him.

I remember sending him to time out on one occasion and I was bending down holding one leg to remove his shoes. He swung around with the other leg and kicked my nose. On another occasion he threatened to break my glasses. Another time, he told me he was going to break my arm and he kicked me so hard in the forearm that I actually thought he did. I went to our local GP who said that it wasn’t broken but that the deep muscle tissue was badly bruised.

There are other instances where he has kicked and bruised my legs, and these have been recorded on my medical documents. These dramatic violent outbursts were always followed by periods of remorse where Nicholas would come to me crying and feeling bad about whatever it was that he had done. I always took full advantage of these times and we would sit down on the couch and have a cuddle and talk about it. These times actually reinforced to him, that we did still love him very much, and they reinforced to us that he truly didn’t want to be the way he was. Nicholas behaviour continued its decline. Who would have thought that this was possible? He spent a lot of time in his room in time out. He would throw a tantrum for no apparent reason. He would kick, punch, and head butt. All it would take was for us to look at him in the wrong way, whatever the wrong way was, or to tell him "no". It got to the point where every time he was sent to time out, he had to be physically restrained otherwise there would be another hole kicked in the wall.

Often it would take 20 to 30 minutes for him to calm down. At times I would have to lie on top of him on the floor to restrain his arms and legs. He was always very strong during these episodes and he could easily lift me off the floor with his legs. If I let go to steady myself then he would be free to kick, punch and head butt.

Our paediatrician referred us to the Department of Nutrition and Dietetics at Westmead Children's Hospital. We were concerned whether Nicholas' very limited diet was adequate on a long-term basis given that he had now been failsafe for four years.

We had to measure, weigh and record everything he ate and drank over a three-day period. This included his medication and brand names of the food that he was fed. This information was entered into a computer and analysed, the end result being that with a few minor modifications his diet was not ideal, but adequate.

Moving to Sydney brought with it some complications that we weren't expecting. Brumby's bread, which we took for granted in Darwin was no longer easily accessible. Our failsafe sausages were hard to come by. I bought a bread maker but Nicholas did not like the bread we made. I found commercially available failsafe bread but Nicholas did not like that either.

I decided to let him try Helga's bread because he liked it, and remembering that our paediatrician believed only 4% of children were food intolerant, I thought I'd give it a go. Nicholas' behaviour got worse over a period of time so we made the decision to get the bread that we knew was safe and that we knew he liked. We decided to make the effort and do the one hour drive to the closest Brumby's bread shop.

He started to eat his school lunch again. Prior to this he was throwing it in the bin. We knew this because we happened to be at school one day and actually caught him doing it. Sausages were another problem. I had asked my local butcher to make up a special batch to a recipe out of Fed Up. He assured me there were no preservatives or additives in them. I was not totally convinced about this, so we again made the decision to travel to a butcher that we know we can trust. Unfortunately this was in the opposite direction to Brumby's.

Our paediatrician decided to refer us to a psychologist for a behavioural assessment with a view to using medication. The referral stated that in her opinion the mother was maternally depressed. I was pretty annoyed about that to begin with but after some thought I decided she was right. Who wouldn't be? Given the number of years and the many stresses we endured during this journey. At this stage she still felt that Nicholas wasn't bad enough to need medication.

We had the assessment and the psychologist initially thought that he had Aspergers Syndrome. She did a questionnaire with us and decided that he did not meet the criteria. However she did recommend medication, even if only as a temporary basis, to help restore very fragile family relationships. An anti depressant was also recommended and because of Nicholas' delayed speech she asked that we see a speech pathologist. Our paediatrician decided against an anti depressant for Nicholas but agreed to try him on Dexamphetamine. Nicholas started taking Dexamphetamine in July 2001.

Nicholas did not do well on Dexamphetamine. He became very teary and emotional, more so than usual. He lost weight more rapidly, which was not good as he was under weight to begin with. He also had a lot of trouble getting to sleep at night; often he would get out of bed and play with toys late at night, in the dark, before falling asleep out of sheer exhaustion.

We persevered with Dexamphetamine for a while because we wanted to give it a fair go and also because we noticed that Nicholas' written work had improved dramatically with his homework. Prior to medication homework was like a battleground. He would sit for hours and write three words, some days he would write nothing at all. He would now complete all of his homework and sometimes even illustrate his stories.

In the end, the weight loss, lack of sleep and the emotional ups and downs just weren't worth it so we asked our paediatrician if we could try him on Ritalin. I had heard of some excellent results with Ritalin and I wanted to give it a try. Our paediatrician was somewhat reluctant to make the change because we were finally booked in, at my request, to the Immunology Department at Westmead Children's Hospital, to do the double blind capsule challenges. She did not want to make any unnecessary changes at this stage.

I had seen such an improvement in Nicholas' written work with the Dexamphetamine, and also glimpses of a lovely little boy, in between the nasty tantrums, that I decided to stand my ground on this issue. We started the Ritalin in November 2001 and after a couple of "settling in" weeks Nicholas started to improve out of sight. A month later at our next visit to our paediatrician, Nicholas' weight had remained the same. This was a good sign because it meant he had not lost any more weight. He had started to sleep much better at night and the emotional ups and downs that he experienced with the Dexamphetamine seemed much less once he started taking the Ritalin.

Our paediatrician recommended that Nicholas should only take Ritalin during the school week, never on weekends or during school holidays. This has proven to be very effective.

At the same time we were referred to a speech pathologist that also thought that Nicholas had Aspergers Syndrome. In September 2001 she did a language assessment that showed that Nicholas has high-level receptive and expressive language problems in the areas of semantics, pragmatics, auditory processing and verbal reasoning. He relies on visual information when listening to instructions, and finds listening alone, without pictures, more challenging. He has poor semantic organisation, including weak word finding skills. Verbal reasoning and critical thinking in the form of problem solving is also a major area of weakness.

The speech pathologist still felt that Aspergers Syndrome was a consideration and recommended that we see another psychologist, one who is very well known, and who specialises in the Autism Spectrum Disorders.

We saw this psychologist who also thought that Aspergers played a part in all of this. He did the Aspergers questionnaire with us and decided that Nicholas did not meet the Aspergers criteria. However, he phoned me a couple of hours later and said he'd had a rethink after reviewing the results. He now felt that Nicholas did have features of Aspergers Disorder. Nicholas has now been diagnosed as having a variety of developmental disorders. These include ADHD, high-level language impairment, and features of Aspergers' Disorder.

We implemented some anger management strategies, and learned other ways of saying "no". We re-trained ourselves to say, "not right now, maybe later" instead of using "no" as an answer; this strategy is simple but very effective. Other strategies included the use of social stories. These are stories that Nicholas wrote with the help of the psychologist about what he can do when he feels angry. We also used many types of small rewards to reinforce good behaviour.

Our psychologist report stated that Nicholas required Integration Support in the classroom to assist attention, on task behaviour, to adapt tasks, and to specifically implement social, communication, and empathy programs. This report assisted the school in obtaining Government funding to provide some extra assistance for Nicholas in the classroom.

We have been very fortunate to have a school that is supportive of special needs children. They have placed Nicholas in a class with a girl in a wheelchair who has an aide on a full time basis. When the aide is not required to assist the girl, she is free to give Nicholas whatever assistance he needs. He has an integration teacher who assists him for one hour each week, one on one, and he also has access to other integration teachers on an as needs basis. He has visits at least once a term at school, from both his psychologist and speech pathologist, who will jointly monitor his progress over the coming years.

The double blind dietary capsule challenges were only ever done on weekends and during the Christmas school holidays. Remembering that Nicholas only takes Ritalin on school days to enable him to stay on task and complete his schoolwork. This enabled us to get a very clear result and record only the food related behaviours. It also enabled us to record the behaviours accurately without any other outside influences.

We began the double blind dietary capsule challenges at the beginning of December and they were completed at the end of February. The results were as I’d suspected. No great surprises. He is highly sensitive to MSG, calcium propionate, sodium benzoate, sodium metabisulphite, salicylates, antioxidants and food colourings tartrazine, sunset yellow, erythrosine and azorubine. It was a huge relief for us to finally have an official, clinical diagnosis from the immunologist. These results confirmed my suspicions in relation to food related behaviours.

Most challenges that he reacted to were with violent reactions such as kicking, punching, head butting, throwing things or ripping posters off the wall in his room. There were a couple of challenges where he reacted with babbling and increased hyperactivity.

It took me five years to find the courage to do these challenges and when we were almost finished them, Nicholas came to me, and said that he didn’t want to do any more because he didn’t want to be naughty. He realises that some foods exacerbate his oppositional behaviour. He also realises that some foods make him unwell.

We occasionally have burritos for dinner, which is one of his favourite foods. On these rare occasions I let him off the diet. He always has at least three or four, plain, with no filling, exceptfor maybe a small amount of grated cheese. At bedtime when we are tucking him in and saying "goodnight" he often tells us that he "doesn’t feel well". In addition to this, and because of the additives and preservatives in the burritos, he becomes noticeably hyperactive.

Since Christmas 2001, Nicholas has undergone a complete transformation. Time outs are no longer a big part of his life. The delay in his speech is all but gone. He smiles, laughs and does things spontaneously, something he seldom did before. He comes home from school, takes his afternoon medication and sits straight down to do his homework with no prompting from me and no arguing from him. Homework is no longer the battleground that it once was. He completes all his written homework and pretty much all of his written work in class.

He is developing a wonderful sense of humour and is an absolute delight to be with. So far this year, he has earned three merit certificates at school. He was voted as a school representative council member for his class. He received a special smiley pencil award for sitting up straight and behaving beautifully during assembly. He was also Super Kid for the month of April, which earned him a Super Kid badge that entitles him to politely go to the front of the queue at the canteen. Unfortunately this was not very useful for him because he couldn't really buy much that is failsafe, however, it was great for his self-esteem and he was very proud of this achievement. He also got to have morning tea with the Principal. He was let off his diet for that special occasion and when he got home, I asked him what he ate. He said, "I can't remember, but it was fun".

I cannot put my finger on any one thing that we have done differently, for these wonderful changes that have taken place. After five years of the failsafe diet, almost five years of behaviour management in the form of 1,2,3 Magic, the final piece to our puzzle has been medication, in the form of Ritalin. It is my firm belief that no parent ever wants to medicate their child, especially one so young. We had spent the past five years exploring and implementing diet and behaviour management. During these years we saw some improvement but not enough for us to survive. Medication was our last option. In our case, we needed the multi-modal approach, and no one thing would work without the other. The combination of diet, behaviour management and medication was, and still is, the key to our success. Diet for us was not enough, however, I believe that without implementing the failsafe diet all those years ago, Nicholas would have needed a much higher dose of medication. I also believe that his developmental disorders, ADHD, high-level language impairment and features of Asperges Disorder would have been much greater. His behaviour was often so violent that I was convinced he would one day be in a juvenile prison, or worse.

In conclusion, all of Nicholas' violent behaviours and reactions were in my opinion, caused by two things, food intolerances and the frustrations associated with learning difficulties. The food intolerances are controlled with diet. Without diet, the violent behaviours return. Medication helps Nicholas to stay on task, which enables him to complete his schoolwork and homework. This helps to overcome the frustration associated with learning difficulties.

Regardless of whether or not Nicholas is taking medication, we know that if we allow him to break his diet, and we sometimes do on special occasions, we can expect a return of the violent behaviours. On these occasions behaviour management is still required.

We still have a long way to go in terms of monitoring Nicholas' education and assisting him with overcoming these learning difficulties. We are fully aware that there will be some rough patches as our son navigates his own path in life, but for now, the most important thing for us as a family, is to finally have our loving, gentle, caring, beautiful little boy back with us again. He is a pleasure to be with, and a son to be truly proud of. Relationships during these past four months have started to heal and we have finally found the light at the end of a very long tunnel, something that for many years we thought we were never going to find.

I would like to thank the following people for their support and the individual roles they played in helping us to achieve our happy ending.

Paediatrician: Dr Ross Diplock – for his advice in trying diet before medication.

Author: Sue Dengate – for her continued support with helping us to navigate the dietary minefields, and for keeping us on track with her unfailing belief of foods and the way in which they affect behaviour.

Paediatrician: Dr Patricia McVeagh – for assisting us in the final stages of our journey, and the implementation of controlled medication.

Consultant Psychologist: Lizette Campbell – for her recommendations for speech therapy and medication.

Speech Pathologist: Philippa Greathead – for her continued support, her referral to psychologist Anthony Warren, and for her language assessment, which really brought home to us the many learning difficulties that Nicholas was experiencing.

Psychologist: Anthony Warren - for his continued support and for his report that was integral to obtaining Government funding for extra assistance in the classroom.

The Failsafe Discussion Group: This group of people primarily discuss the failsafe diet, but also discuss many other challenges faced by special needs families. Their wealth of information and support knows no bounds. I would not have survived these "challenging" years without these people. I have learned so much from this group and we are all still learning. Together, we can all make a difference, and we can all find that light at the end of the tunnel.

- Susan, June 2002

[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 day 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

[146] Restless babies from tartrazine (yellow #5, colour 102) (February 2002)

Thank you so much for the "Restless Babies" article. I recommended it to a distraught mum in the USA via a breastfeeding support bulletin board. She was shocked to discover that the artificial yellow colour tartrazine (102) was hiding in many 'healthy' foods. Within just two days of changing her diet, her baby had a normal sleeping pattern. Not only that, but her two-year-old 'spirited kid' is much calmer, and has stopped throwing incessant tantrums. Other board members have benefited from the article, including one mum who recognised the frothy 'cappacino' poops mentioned. She had asked her pediatrician about it, but he had no idea what caused it. Changing her diet to exclude tartrazine cured both the frothy poops and the night waking.

Here are the foods that the USA mother was surprised to find tartrazine in: potato bread, yoghurt, canned soup, margarine and cough syrup. She was also eating, and feeding her two year old, cakes/cake mixes/donuts/muffins/snack cakes, ice-cream, cookies and crackers, drink mixes, lemonade, pudding mix, boxed meals, rice and pasta dishes, cheesecake, butterscotch candy, jelly and chips all containing this harmful additive.

[150] Insomnia a major issue (April 2002)

I have been an insomniac since I was 16. From my mid 20s it has been a major issue in my life. I have lived on approximately four hours sleep a day. I have spent thousands of dollars in trying to find the answer. I have seen naturopaths, homeopaths, medical doctors, Chinese herbalists, acupuncturists. I have been to a sleep centre where they tried to teach me to sleep. I have tried every imaginable trick to try to sleep. For three years, I stopped drinking or eating anything with caffeine. I would drink warm milk before bed. I would take a run before bed. I would read a book before bed. Have a bath before bed. You name it, I have probably tried it. By the time I turned 30, I decided that I had to learn to accept my insomnia - 'this is as good as it gets' sort of thing. In the worst scenario I would read till all hours of the morning. Having said that, I had to also accept the fact that I was tired most of the time.

I had my son at the age of 31. He was a colicky baby, a terrible sleeper. He also had heartburn at night, which his ped attributed to the fact that my son still breast fed at night, up to the age of 25 months. I never understood the relationship between breastfeeding at night and heartburn, so continued doing it. My main resource and my inability to accept my ped's advise was due to my own travels to primitive cultures, where I saw babies and toddlers breastfeeding constantly; 24/7 days a week and these babies were NOT colicky, did not suffer heartburn. In fact, they seemed very happy, content, and rarely cried. When they did cry, it was more of a whimper rather than the cries I hear in western society.

Being a 30 something Mum, I also was fully aware of what sort of Mum I wanted to be. I had clear visions of being a compassionate Mum; this entailed no spanking, no yelling, but rather validating feelings, finding alternatives whereby both of us would be happy, and in the worst scenario just accepting that my child and I would not always agree, but I would still respect this difference rather than fight it. My son' s temperament, however, tested me to the core and I failed often in living my maternal visions. Yes, I have yelled at my son, yes I have spanked him (to date, three times - he is 2.5 years old and each time I think about it, I do cringe with disappointment with the evidence of my weaknesses). My son, from an early age was high need and wanted full on hands on care, was constantly on the breast, slow to unwind, wanted in-your-face attention, constantly in my arms. In a nutshell I found him draining, and highly strung. I remember when he was only five months old, having this real desire just to throw him across the room and the reality of my feelings shocked me to my core. I am by nature sensitive to other peoples feelings, gentle, gracious, etc. I took him to a sleep centre, where the staff tried to teach me to help my son to fall asleep on his own and all I kept thinking about was "seen this movie before". I thought I was going insane; my son took two hours to unwind before he would fall asleep and when he did, he would sleep only for one hour, waking up and then would demand the breast to go to sleep again. After the sleep centre experience with my son, I decided to go by my instincts; one thing I was sure about was that I would never let my son cry it out, no matter what. Part of my reasoning stemmed from 'what if he has the same problems as me? Maybe its genetics?' another real reason for me was 'he must be waking up for some reason?'...to my mind, it may be hard to fall asleep, but once asleep, a person wakes up for a reason...so I decided that if my son woke up every hour, I would just learn to live with that too and together we would get through it. I put up with it literally till my son was 25 months old and by that stage, I am sure the night nursing was more a habit rather than a real need, ie, whatever was causing the night waking as an infant/baby, no longer existed by the time he was a toddler.

He was a very active little boy, who seemed too busy to sit for any period of time. His thoughts also were busy, talking constantly without taking a breathe. As a result, he always looked like he was misbehaving because he seemed to have no physical self control, although he was very gentle, loving and extremely aware of the needs of others. But then, he would all of a sudden display vocal aggression, and physical aggression, seeming to get pleasure in hurting. I could not understand this Jekyll and Hyde personality.

Most people that I turned to, either suggested more discipline, in the forms of spanking or severe punishment. Others suggested that I was giving him too many sweets. Others suggested that I train him at home, for instance sitting with him for ten minutes today, then fifteen minutes tomorrow. Others suggested that my son and I were too attached and he was playing on my weaknesses. Others implied that I was not a consistent mother regarding discipline. But I saw my son for the person he was. I had these real glimpses of his real personality. I thought about taking him to a naturopath or a homeopath. I resisted though because my real fear was that his behaviour would become an issue in our life like my sleeping disorder became an issue in my life. Again, I turned to my own common sense here and decided that I preferred to accept the package rather than fight it all the time. Then I stumbled on your book at a health shop and bought it.

I have only read probably one quarter of your book. But the next day I eliminated wheat, dairy and all preservatives/additives. Within two days, the son that I only had glimpses of suddenly emerged for a period of five consecutive days ... and I suddenly found myself able to fall asleep in ten minutes. My son would still wake up, and I would still respond in the same manner, but again, I would be able to fall asleep without any problems. Day six was the day that I cried. I have spent the better part of my adult life wanting to sleep and feeling tired. I have wasted years of my youth thinking about sleep. I am at times angry and at times relieved to just get out of the woods. I just can not believe that I no longer have to describe myself as an insomniac. My son now sleeps much better, but I have realized only today that I think he is also salicylate sensitive and probably so am I. Both of us, I realize now, demonstrate aggression for unknown reasons. I can control that side of me because I am an adult, but my son is more honest with himself and his world.

Today, my son was pushed over the edge, so tomorrow, I am getting stricter with salicylate and amine side of the challenges - but I feel good about it. I know where I am going now, I have direction and that my undiscipled boy does not need more discipline. In fact in the five days that he was his real self, I had absolutely no problems. There was such harmony between us that my heart upon just writing that, is swelling up ... more importantly, it has nothing to do with my adequacies as a mother, or my sons personality. It is all external to the problem. This makes me feel more confident than ever ...

I wanted to tell you my story and to thank you from the bottom of my heart. If only someone had told me at 16 what was causing my insomnia ... but then, I also know that my insomnia stopped me from resorting to ignoring my son's cries and if I was not going to find the motive of his behaviour and cries, I was just going to accept this boy as he was ... for better or worse ...

I have learned one thing in life and that is, that it is the worse situations that are character building and through them I can choose the path I decide to tread ... I am just happy that you wrote your book 'Fed up' and I am just happy that I chose to read it ... thanking you very very much ...

- Ingrid, Melbourne

[143] How diet helped me beat CFS - Emma's story (February 2002)

"I was diagnosed with Chronic Fatigue Syndrome (CFS) in June 1998. At the time I was at university, plus working morning and night teaching aerobics, and training for competition aerobics every day. As well, I had an active social life. With glandular fever five years before, I was probably overdoing it.

I was finally diagnosed with CFS after seven months of severe weight loss and fatigue, and various other debilitating symptoms including headaches, blurred vision, memory loss, inability to sleep, and chronic bowel and stomach irritations. This diagnosis came from a wonderful doctor who I still see regularly today. He was the only doctor not to diagnose me with an eating disorder or a mental illness!

My weight plummeted from an athletic 58kg to a frightening 32kg in the space of about 9 months. It seemed the more food I ate the more weight I lost. Taking a gamble, my doctor sent me off to the food allergy clinic at RPA in Sydney, and we found what was to be the turning point in my battle with CFS. I was extremely sensitive to chemicals both natural and artificial in foods and perfumed products.

I was put on an extremely restricted diet of boiled white rice and white fish and within days many of my symptoms had begun to disappear. I no longer suffered from stomach pains and wind, and my mouth ulcers were reduced in number. For someone who loves cooking and food this was very difficult to come to terms with but since I was facing death if I kept going as I was, I was willing to give anything a go and stick to it rigidly. The side effects of not being disciplined were too great and the consequences too risky.

So I followed the chemical free diet and within one month I had started to regain weight. It took about four months before I could start introducing the most basic of items such as green beans or potato and it didn't take much to tip me over the edge, but using the time I had (lots of it) I became very creative in the kitchen.

Within six months we could all see that this diet and way of life was the way in which I would fully recover. It has taken me until only a few months ago really to be able to go out to a restaurant, for example, and eat a meal but even so the choices are limited. To others I know my diet is still so restricting, but to me I am now in foodie heaven enjoying the odd mango along with limited dairy products and while I used to hate frozen peas I just can't get enough of them now. Gluten for me is still definitely a no go zone, but everything else I can cope with most of the time in moderation. Hey, I even enjoyed frozen Christmas pudding this year and felt great the next day.

I cannot say how much this chemical free diet has helped me. I am now fully recovered from CFS after a very long four years and am back to a healthy weight. I am married and have started my own business called Floradiction - a wedding and event floral and candle design business. I will always be restricted in what I eat but the positives far outweigh the negative effects that occur should I stray too far from the 'rules'. Moderation is now the key. I know what works for me and that is important. My FAILSAFE recipe book is huge and I love adapting 'normal' recipes to suit my needs. I haven't had any complaints from my husband Glen yet so things are looking good. Funnily enough when he has a meal that is out of the ordinary from what we eat at home he always feels worse for it.

I have experienced so much with my illness, but I am actually glad it happened to me. So many good things have come into my life because of CFS – my close relationships are even closer and I have a greater appreciation for the simple things in life and what it means to be able to get out of bed in the morning. I can now use my experiences to help others who have CFS and help to promote a very misunderstood and still poorly accepted illness. Raising the awareness of Australians of the serious effects that food chemicals, both natural and artificial, can have on the health of some individuals is also an issue close to my heart.

All the candles that I sell and decorate through my business are unscented. The reason for this? People like me can't tolerate the perfumes and it is important that there are products available for others like myself." - Emma Pilcher

Emma is now a phone contact for us, see website contact list. Emma's candles make great gifts for failsafers. More details at www.floradiction.com.au

[131] We just love the effects of the diet (December 2001)

"We have recently gone onto a fairly strict version of the elimination diet - and have seen fantastic results in our 4 year old son. He is sleeping better, has become very loving and affectionate with his father, more agreeable, less tense and generally calmer and more 'angelic'. We just love it. The hardest part was just getting used to what foods were safe and allowed."- reader, email

[129] "I am an early childhood nurse …" (November 2001)

Our dear Rosie was born August 2000. She is our second child, so we expected that she would be a tad easier than her brother. Alas, our Rosie had many new tricks in store. For the first 4 months or so she was 'OK', I just called her 'highly strung', and 'a hormonal girl'.

By 5 months she was really quite miserable, irritable, constantly grizzling and wanting to be held (except of course when we went out anywhere, where she played the cute, smiley happy babe). Sometimes she seemed to be in pain, and we gave panadol with some relief for only a short time. We tried the reflux, colic, etc avenues, with no improvement. My husband was very understanding and supportive, as he lived with unhappiness, and my Mum saw the other side of her, but most of my friends didn't understand our problem, as she really was a 'street angel and home devil'.

Her sleep was poor by day, but strangely, she rested reasonably overnight, some nights only waking once or twice, and generally able to resettle quite well. I think she was so exhausted after her strung out days. For the bad nights she mostly slept in our bed, where we could all get some sleep.

I am an early childhood nurse, and had great support from my two wonderful colleagues, one saw her in a really sad state when visiting us at home. We had tried me off all dairy products at 5½ months, as Rosie was fully breastfed. That seemed to improve things a bit, but I still felt that babies should be happy, unless they had good reason not to be. Finding the reason was the trick. We also tried a naturopath, who felt she could help with a range of herbal remedies, which we started on.

Then I read your article called "Restless Babies", in the Nursing Mothers Magazine. I felt the article was about us!! It was the start of a big change in our lives. We saw our local dietitian who gave us the booklets from RPAH, and discussed it. As I was breastfeeding, and she was on some solids, Rosie and I started the elimination diet when she was 7 long months old.

My very supportive husband was quite sceptical, she was such a beautiful fat healthy looking babe, how could it be diet related?? Anyway after only 3 full days on the diet, he was very apologetic for his scepticism. Our little girl was significantly happier, and so were we.

Each day seemed to get better, she now seemed able to relax her body at times, and was able to play alone for very short periods. I found sticking to the diet quite easy, as the improvement in Rosie was well worth it. Eating was a great source of pleasure for Rosie, so the diet did not worry her at all. The added bonus for me was that those extra 'hard to shed' kgs fell off me. That gave me a needed confidence boost as well.

We had a bad experience early on. Rosie was pretty miserable with a cold, so we gave her some panadol drops and put some Vicks rub on a tissue under the sheet as we put her to bed. An hour later she woke and was 'high'. She tried to get back to sleep, but her body was so restless and I hate to think what her head felt like. I took her to our bed and held her to try to control her body for her. She finally fell off to sleep after about 4 hours.

Rosie is now 14 months old. I weaned her at 10 months, as I began to crave some tasty food. I was too scared to do any challenges, so we were on the very basics. Rosie continues the elimination diet, and still loves her food. We finally tried some challenges, wheat is OK in very small doses. Salicylates were a disaster, (pumpkin twice a day for 2 days and a granny smith apple core), she became irritable, clingy, whingy etc, then vomited, with no associated illness. We will try them again one day to be sure. We are trying amines at present, just banana to start with, OK so far.

I feel this experience has been wonderful for me professionally, and my colleagues too. I also recently heard that our dietitian who helped me with the diet (who has since moved) has tried the diet to get a feel for what she was prescribing, and has seen changes in her family she was not expecting. I have also had chats and given some of your info to our child psychologist who has quite an interest in ADHD. I will keep pushing the cause, I worry about all these behaviour problems, and see that some could be so easily sorted with food.

So thank you so much Sue, I hate to think where our family would be without your big input. I am converted. My husband is too, but he is a little nervous about how I will go when our children start school and I have some input into the tuckshop! Many, many thanks again from all our family. - Cath, by email

[100] Ginny's story 26 years on, the full story (August 2001)

Ginny was my second child. Her older sister had been a model baby, always smiling, rarely cried but she developed chronic asthma at age 8 months and required frequent hospitalisation. She was 2 ½ when Ginny was born.

From day one Ginny was a very unsettled baby, didn't sleep much and cried a lot. At 2 months of age I had to physically keep her awake between 6pm and 10pm so that I could feed her, put her to bed and (hopefully) get 3 hours straight sleep. By 4 months of age she had developed chronic eczema on her face, scalp, neck and creases of arms and legs.

By 12 months of age she had major ulceration on her bottom and an allergy specialist suggest we try soy milk as it could be a cows milk problem. At that time I had to get the soy milk through the chemist on prescription and it didn't really make a huge amount of difference. We tried the soy milk for 6 months and then went back to cows milk. She was getting more and more restless and would sleep for 1 hour and then wake up screaming. When Ginny was 14 months old I had child number 3. Gareth was the most placid, easy going little boy you could ever imagine. Sardi (the oldest) was still having major asthma attacks and hospitalisation. Ginny was still waking every hour on the hour - this went on day after day, night after night, month after month. Gareth developed croup and would have really bad nights where I would be up with him for hours with the steam running in the bathroom.

By the time Ginny was 2 years old, when she wasn't screaming through the night she was getting into mischief through the day or throwing dreadful tantrums because she couldn't get her own way. Climbing in dangerous places, falling up, through, on or off anything there was in sight to climb on.

A sixth sense woke me early one morning and I went into the kitchen to find her sitting on top of the oven. It was one of those stoves which had the oven and hotplates side by side with the controls for the electric hotplates at the back. She had climbed on to the hotplates and then up on the oven and had reached over and turned on all the hotplates. When I got there she was sitting looking at them glowing red and just laughed at me and said "look at the pretty colours, mummy".

She still woke every hour throughout the night and the only thing I could do to get her back to sleep was to give her a bottle which was usually filled with cordial, as the doctors told me not to give her too much milk and if I used too much fruit juice I had the nappies to contend with!

During our frequent trips to the doctor Ginny was always an angel. When I asked if it could be something she was eating, they just laughed at me and the doctor told me that I was overanxious. I came close to having a breakdown. When I wanted to get another opinion I was sent to the hospital. They wanted to put me in hospital to calm down. When I said "no", they asked me would I like them to put her in hospital to give me a break.

They said that she was just a naughty girl and to just let her scream as "she would stop sooner or later" and that she only screamed because I went into see her. Not very easy to do when she screams for 3 hours in the middle of the night and dad has to go to work the next day and the other two are awake and crying.. The doctors then decided to try Ginny on Vallergan to "quieten her down" because they believed she was just boisterous and I just was not coping with motherhood.

At age 2 ½ I was at the end of my tether and one day I picked her up and held her against the wall and started to shake her and bang her against the wall. I had tears running down my face and thank god something inside me said to me to put her down or I was going to do some dreadful damage.

About 2 months after this I read an article in a magazine which was talking about Dr Ben Feingold's book "Why your child is Hyperactive". It talked about the relationship of food colours and preservatives and children's behaviour. The article gave a list of about 14 symptoms and said that if you could answer 'yes' to any 6 of them, there was a darn good chance that food colours were playing a major part in the child's behaviour. We answered "yes" to 12 of the 14. The book was unavailable in Australia at that time and I had one of the City bookstores order a copy for me.

I read the book and then went to discuss it with my doctor and was told it was a lot of "maybe" and that nothing was proven. I discussed it with my brother (also a doctor) who told me that kids were being unnecessarily labelled hyperactive and it was predominantly a discipline problem. I tried to discuss it with others who just didn't want to know.

We still had Sardi going in and out of hospital with asthma and Gareth up through the night with bouts of croup. Their father was working late into the evenings (I think so that he didn't have to come home to the chaos) and by this stage our marriage was starting to collapse.

My husband and I discussed the diet recommended in the book and decided that it couldn't do any harm as things couldn't be much worse. The only problem was that the book was written in the USA and the diet was designed for the American market, so many of the products were not available here. I took the book one day and started to go through the pantry cupboard. I checked every label on everything in the pantry and filled 2 garbage bags with food. I went to the supermarket and read the labels on everything I bought. What I wasn't sure about I telephoned the manufacturers and asked them what the products contained. We started from scratch. I made everything we ate from scratch, bread, cakes, biscuits, ice-cream, icy poles etc. etc. We all ate the same food.

After 1 week, Ginny had started sleeping for 2-3 hour stretches.

After 2 weeks, she had stopped throwing tantrums

After 3 weeks, she was sleeping right through the night

After 4 weeks I had, for the first time, a normal child in the house.

After 3 months, her eczema had just about totally cleared.

"Coincidentally" (or not) her older sister's asthma had, by this stage, lessened to the stage where she no longer required frequent trips to hospital and was manageable to home and her brothers bouts of croup had stopped.

What really annoyed me was that about 4-5 years later the Royal Children's Hospital in Melbourne had adapted the diet and were using it as breakthrough treatment for behavioural problems.

As Ginny was able to communicate better and someone (usually a well meaning grandma!) would give her something nice like a red icy pole (and then send her home to me!) she would tell me that she had a "big head". As she got older, she later explained that when she had something off limits, her head felt as though it was going to explode.

Ginny is now 27 and has a 9 month old daughter. She still checks labels and she does all her own baking and cooking and rarely uses pre-packaged goods (although I noticed that the ones she tends to use are the same products I used when I changed our diet all those years ago) I have every confidence that her little girl will not have to go through the hell her mother went through. Even now, as her poor partner found out the hard way, she still reacts badly to Cherry Ripes! He would bring them home and she would occasionally eat them. Until one day when she had too many. He's now banned them from the house.

My message to everyone out there : I wish I'd had the benefit of Sue's book 25 years ago. Diet really does work. Hang in there - it gets better and better.

- Rosemary (Silly Yaks Bakery Café, Melbourne)

[066] "I was wondering about coping with school next year" (September 2000)

Although my child had never been diagnosed as ADD or ADHD, he was just a very active little boy who did not sleep much or very well. He wasn't interest in reading, writing or drawing and I was becoming very concerned about how he was going to cope with going to school next year.

After two weeks of eliminating all fruit (except pears) and preservatives from his and our diets he is a changed person. He writes his own name and started to write other letters and is very happy to sit and draw for at least an hour! (he couldn't sit still for at least 5 mins before the diet). His new favourite word is "preservatives".

[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

[011] Epilepsy and food chemicals (May 1999)

Epilepsy is a little-known side effect of food chemicals. Kerry from chapter 4 of Fed Up has noticed that her seizures are triggered by salicylates and tartrazine colour (102). Another university student noticed that some foods trigger his seizures. Of the foods he mentions below, chocolate and orange juice are both very high in natural food chemicals called amines (May 1999)

Thanks for your book Fed Up and web-site. They're very useful and an eyeopener, especially since I suffer from epilepsy.

My epilepsy is well controlled by medication so it is difficult to determine what causes a seizure. However, I know that feeling fuzzy headed, over-talkative & rambling, are precursors to a seizure - especially feeling fuzzy headed. I notice the fuzzy-headedness, first, after not sleeping well.

I will experience a bad night's sleep through restlessness and at some point during the night I will wake up and start scratching my forearms. Waking up in the morning is difficult. The next day I can't think, especially to do math, or to perform conceptual thinking such as writing an essay. Reading is a problem during these times - I'll find that I can't concentrate, nothing seems to "get in" and I keep re-reading the same sentence hoping to extract meaning (eventually I give up).

The worst foods are chocolate and dairy (but I have to eat a lot of dairy for about a week before I notice any effects). I went on the "fit for life" diet and noticed that juices were causing similar problems - I sort of became addicted to orange juice and was having major mood swings. The same problems occurred when I tried the "liver cleansing diet." Chocolate is, by far, the worst.

I find that I am not good at sticking to diets, but I keep trying - especially when things get bad

[009] Sarah and Callum - two children with autism (April 1999)

My name is Julie, and our family consists of my husband Ian, our daughter Sarah aged seven, and our sons Callum aged three and Devon aged 16 months. Last year in April Sarah was diagnosed as autistic and in November Callum also received a diagnosis of autism. Pretty interesting year, I can tell you! I knew nothing about autism, all I knew was there was something about my daughter that just wasn't working as it should. Both the children are what they call "high functioning" autistic. Which in everyday terms means that there is no intellectual disability and they have a lot of skills.

I remember now people commenting on how 'busy' Sarah was as a toddler. As she was my only child, I never knew any different. She very rarely slept, we used to be up until 1 or 2 am rocking her, pushing her, anything to get her to sleep. When she did sleep it was only for a few hours at a time. She started coming out in terrible rashes over her arms, legs and torso when she was around fourteen months old. I went to a naturopath who placed her on a very restricted diet and everything cleared up. Sarah's behaviour improved and I thought I had cured the problem. I now realise we had taken most of the problem-causing areas out of her diet. We were told that after Sarah's immune system had time to recover we could more or less resume a normal diet which after 12 months we did. The rashes never returned and we thought we had it licked.

But all that happened is the symptoms appeared in a different manner. Sarah became withdrawn, anxious, and suffered severe night terrors. When she was three, Sarah started Montessori school and then we started to notice other things. Sarah was exceedingly shy, she would not communicate with other children even after she had known them for a long periods of time. She had no recognition of colour and never described anything by its colour. We had her eyes and ears tested, but nothing showed up. When Sarah was four, Callum was born. When he was three months old we moved up to Tom Price in Northern Western Australia. We are fairly isolated here, our main centre being five hours drive.

Sarah started preschool and would vomit for no apparent reason in the mornings before school. She was tested and pronounced hypoglycaemic. I was told to feed her more often. Grade 1 presented more problems, huge anxiety attacks and night terrors lasting two hours. I would pick her up from school and find her sitting crying under her desk. Still I was told it was developmental and she would grow out of it. In desperation I rook her out of school and went back to Perth. I put Sarah back in Montessori and everything stopped - no anxiety, no night terrors, no vomiting. I eventually had Sarah assessed and we received a diagnosis but not a lot else.

Later that year Callum started repetitive behaviours such as pushing his head along the floor, staring at fans, complete withdrawal, no eye contact and delayed speech. By the time he was diagnosed I was drowning. I wanted to go back to the city, anywhere where I could get some help. I even withdrew from life myself. It was too hard to go out, I got sick of people staring, making helpful or unhelpful suggestions, it just all got too hard.

Then in November 98 a friend gave me Sue Dengate's book Fed Up. I started that day and on the first night of the elimination diet my two children slept through the night. That was the first whole night's sleep I had for nearly seven years.

I am convinced! Sarah is managing mainstream school without the stress of last year. She has made friends. Her communication skills had improved so much within two weeks of starting the program that her teachers asked me what had changed. Callum now makes eye contact with people and laughs and talks. He is just getting better and better, his vocabulary is so vast now it makes me gasp! He enjoys playgroup and is even starting to play with others.

I know a lot of autistic children will only eat a limited amount of food, and Callum is definitely in that category but I believe that it is so very beneficial to make the food they eat failsafe. I also found that after they withdrew from our previous diet, which with Callum took around six weeks, their tastes had completely changed so they didn't mind the failsafe food at all. In fact, Sarah has asked me never to give her food that isn't good for her because it makes her body feel bad.

I am grateful to Sue for writing her book. I has completely changed our lives and it has, I'm sure, completely changed my children's future. - Julie

[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 tympogram 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 home made 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 houseservants 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 acidy 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 weeks 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 talks 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 fact 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 general 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 got to a seminar through work on food intolerance and allergy run 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 starting giving his 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 Danial 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, Nuttelex 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

[001] Jessica's story: vomiting and sleep problems (February 1999)

"Jessica was born a normal healthy 7lb baby. One of the first problems we had with her was with vomiting after breast-feeding. My sister, who came to stay with us when Jessica was 3 months old, asked me whether we had noted that she vomited after I had eaten certain foods e.g.chocolate cake one day meant that she was vomiting the next. We had noticed this.

We returned to NZ from Germany when Jessica was 5 months old and continued to have problems with her. She was very active, tiny and walking at 9 months. By the time she was one she was constantly wanting food but would eat very little of anything and would hide the rest round the house. She hardly ever slept through the night, crying for attention a lot. She seemed genuinely distressed. We were still concerned about the amount of times she vomited and the crying but were told that we were neurotic. It got to the stage that we thought, as there was nothing wrong according to the doctors that we must have hygiene problems. Her high chair was washed with hot water just before she sat in it (always using a clean cloth). The plates she ate from were rinsed with hot water before the food was put in them. But she still used to be difficult about eating and vomit a lot. Two things that we noticed her having difficulties with were yoghurt that her older sister loved - after two spoonfuls she became grizzly and refused food, and fish fingers that most children loved. Some nights my parents-in-law would keep her for the night just so that my husband and I could have a night's sleep.

By the time she was two I was expecting our third child and as I desperately needed rest we put Jessica into daycare three mornings a week asking them to give her lunch there as that removed the battle from me. This continued up until we left NZ even though she was so often sick during the afternoon when she came home from daycare. For me that bout of vomiting in the afternoon was worth it if I could have some rest in the mornings.

When Jessica was 27 months we borrowed my parents' caravan and took a holiday in the Bay of Islands. While we were there we took the children to visit a dairy farm we saw a cow being milked and Jessica drank some of the milk. Unfortunately being her she did pick up a bug from this and started vomiting and having diarrhoea. She very quickly started dehydrating and we took her to the local doctor who suggested that the best thing to give her would be Raro sachet drinks mixed up as that way she would get some energy and fluids. Over the next 18 hours we tried to get her to drink this but the more she drank it, the sicker she became, her temperature was so high that she seemed to be hallucinating and was having fearful screaming fits. We stopped the drinks and went back to plain water. The next day the doctor reluctantly agreed to prescribe stemetil to stop the vomiting and suggested we return to Auckland to be nearer a hospital if it was needed. The medication did work. We later realised that these Raro drinks were full of food colouring.

Over the next few months we settled back to our pattern of broken nights. The doctor did suggest to us that occasionally we should give her Junior Panadol to help her sleep. I told him that I thought she might not be able to have it, as she seemed to vomit it straight back after taking it. His reply was that she was difficult and we should hold her down and make her swallow it. Much to our shame we tried this and found that it did not matter how long we held her and made her keep her mouth shut for she would end up vomiting it back up within 20 minutes. Junior Panadol at this stage had the colouring E102 in it.

The weekend that our youngest daughter was born is one of our worst memories. Jessica had been quite difficult that week and on the Friday night David got up to her in the night as she was vomiting. At the same time I realized I was going to have the baby any minute. So we left her with my parents-in-law and dashed to the hospital. The next day she was still not at all well so David rang the doctor who said give her fluids but as she did not have diarrhoea as well they would not see her. On Sunday afternoon David carried her into the hospital to see me and I was shocked as she looked all teeth as she was so dehydrated. I found out from my husband that his parents had said yoghurt was good for settling stomachs and given her yoghurt. I begged him to make sure his parents were very strict and careful about food and gave her fluids. My mother-in-law told me they found Jessica in the bathroom with her toothbrush getting water as she was so desperate for fluids and then she was sick afterwards. As happened many times she was vomiting mostly bile as there was nothing left to vomit. Finally on the Monday somebody suggested that she try lemonade ice blocks as a way of getting fluid in slowly enough and that was a big breakthrough.

Six weeks later we left NZ and shifted to Germany where we had some frustrating times with feeding Jessica but also made our biggest breakthrough. For our first year there Jessica's life went on as before - she was always on the go, always hungry but would not eat all sorts of things and was often sick. She was still not sleeping through the nights.

We had awful trouble keeping home help and babysitters as nobody could cope with her at nights or understand her eating patterns. She continued to gain reasonable amounts of weight during this time. By the time she was five she weighed 21 kilos and was still very difficult at nights while her older and younger sister slept calmly. The vomiting was starting to get worse and we were having to eliminate a lot of foods with cream or fat from her diet. She was also refusing to eat any of the sliced breads that could be bought in the supermarkets in Germany.

Christmas 1985 was a nightmare, she had not been well with a nasty cough and started vomiting but did not seem to get better. While she kept some foods down her weight was dropping and over three weeks her weight dropped to 18 kilos and she had vomited 21 days in a row, although she did keep some foods down.

By this stage we were with a new doctor who was very sympathetic to our plight and said that she could not continue like this and agreed that we start looking more deeply into the problems. We did find out that she was allergic to chocolate but as that was something that had been suggested to us by several people and Jessica was not eating it anyway as it made her sick. She eliminated many more obvious things with blood tests and then said that she thought the problem was additives to which I replied " but we don't eat many additives." We were amazed when we took a closer look at everything and realised how many additives she was getting.

Our doctor first of all put Jessica on an elimination diet and within 2 weeks she was sleeping calmly through the nights. We all used to stand at her bedroom door in wonder and watch her stretched out calmly instead of being the tense little bundle we had had for years. It took no time at all to convince us that additives must have been our problem but I was not sure that I believed that you had to eliminate every additive from children's diets so I asked the doctor how we could find out which ones were the problem.

As our doctor knew of somebody else wanting to test additives for an adult patient of theirs they decided to approach one of the university hospitals and see if they could have capsules made up of different additives to use for testing. Once a week we would take Jessica down to the surgery with an empty stomach and they would feed her a capsule every hour and test pulse, blood pressure etc during the morning. It soon became clear that she showed no alteration in temperature, heart beat etc. and that there were three main causes of her problems.

The day she was given benzoic acid she stopped eating for several days because her tummy felt funny. The same thing occurred with a blue colouring. Two yellow colourings had no effect but tartrazine produced the most interesting reaction. After the first dose she became a little restless and would not play games with us or read. After the second dose she kept on taking her clothes off as well getting even more grumpy. By the time she had a third dose she was running round wildly and throwing things at the walls. We decided that a fourth dose was unnecessary. One of the foods we had noticed that was upsetting her was pre-packaged breads in the German supermarkets. These breads had a long shelf life. We cut these out and bought a bread fresh from the baker in our village. This was a plain loaf that would not keep longer than a day. We never had trouble with bread in NZ.

On reading some information that the doctor gave us we eliminated yoghurt, nutmeg and cinnamon from her diet as well as it was suggested that if she were intolerant of benzoic acid she would also have difficulties with them.

These tests made the most tremendous difference to her life and ours. We now eat many additives that we know she can tolerate. She leads a normal life, keeps healthy and active but sleeps well. Because she had vomited so much over the first few years she was having gall bladder problems and could not tolerate cream, milk fats etc. This is why she vomited so much before they started testing. Once she was on her additive free diet we were able to get her gall bladder back to normal too. Sometimes when we are out she will unknowingly have something she cannot tolerate and she is very quick to notice. There are occasions when two mouthfuls are enough for her to know that she needs to be careful." - Anonymous