

Reader reports from the Food Intolerance Network www.fedup.com.au

("autism", "autistic", "ASD", "spectrum" and "aspergers" keywords only)

[1298] Rants about seeing health professionals - facebook thread (February 2015)

I have been told by many doctors and specialists that being failsafe is ridiculous. Apparently I am desperate, all because I have a difficult child and he has autism. Being failsafe is hard, but it has improved all of our lives. It has really improved my son's behaviour too - Claire

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

Our 12 yr old son was diagnosed with high-functioning autism, and we'd experienced over 15 school suspensions between year 1 and 2 due to periods of uncontrolled violence. Since we found the Failsafe diet 7 years ago, our lives have turned around, and it is so easy to love him, including his wicked sense of humour and self-confidence - Natasha

[1231] Aspergers thread from facebook group (October 2013)

My son has just been diagnosed with Aspergers. Just wondering if anyone has tried fs or other options for Aspergers such as pres and add free? - Kelee

Not Aspergers/FS as such but I worked with a little boy (5) who has autism and when on a FS diet he was back to all normal development until he had something not on the diet...and then he would literally be in the corner of the room banging his head on a wall and no speech at all - Tallara

My ex-husband had/has Aspergers and when I was able to limit those foods which i knew had negative effect he was a lot more emotionally and socially connected - however as an adult who refused to acknowledge the diagnosis or that FS can work he would often eat foods he was 'addicted to' (bread with 282 was his major addiction)... I honestly believe that if he reduced those foods he was able to cope a lot better – facebook member

Yes my daughter is off completely artificial chemical free, a few natural chemicals she has reacted to I have eliminated. Nearly completely dairy free and now I'm going gluten free. She has recently been diagnosed with Asperger's and although this is not a cure it has made amazing changes in her behaviour for the most part. Gluten apparently affects their speech and such and most cannot tolerate dairy - Haylee

Yup we are additive free, I have also found that foods such as bananas can effect his behavior. The kids

themselves hate the diet! Esp if they have food aversions. It takes a good week of horrible to see the effects - Carolyn

My autistic boys have several food sensitivities. Fruit, dried fruit, salami/cured meat, 160B is a HUGE one. I avoid MSG(natural ones too). I limit the amount of bread and milk they have- Tess

My aspie son went from sitting under his desk chewing his shirt all day at school (we were told that he'd never pick up a pencil) to an A grade student thanks to fs diet / gluten and dairy free. Best thing we ever did for him - Kim

Went pres, additive, colour free, 99% failsafe, autism tendencies disappeared. Also switched to A2 milk (if can tolerate dairy)- Kath
I did for my daughter many years ago. It worked - Margo

My son has Aspergers and is on a gluten and dairy free diet and that has helped but the biggest surprise was removing anything red - tomatoes, apples etc - Different child completely without the red. And when I say dairy free I mean all milk products are goat milk products - this diet has helped him majorly with focus and attitude in all areas - Anna

We went Full elimination for my HF Autistic 12 year old son 12 months ago and had amazing results. Teachers could not believe the difference. I only wish we had known about Failsafe when he was younger - Michelle

There are many more Aspergers stories in this collection <http://fedup.com.au/images/stories/SCautismAspergers.pdf>

[1194] One-liners (March 2013)

We have been really pleased by the change in behaviour of our 8 year old son who is diagnosed with Aspergers (and ADHD). His oppositional tendencies in particular have markedly reduced. My thinking is this is related to taking most salicylates out of his diet; however, I think I now need the help of a dietician to guide us through a more specific diet to ensure we are not excluding foods that are actually fine - Marg by email

We are day 6 into the elimination diet, and having amazing results. My son (8yrs) was diagnosed with Aspergers a few weeks ago and within days a lot of his symptoms are reducing. The meltdowns are nothing to what they were. Plus, the skin rashes are almost gone too, yet we are still working on the night time bed wetting – Nicole from facebook group

From [1117] One-liners after Fedup Roadshow (August 2012)

We attended your talk a few months back and it has changed our lives. We have a six year old son who suffers from Aspergers and ADHD and since going additive-free his behaviour is much improved, his

social skills are coming along in leaps and bounds and his fits of rage are completely gone.- Heather by email.

[1115] PDD, ADHD, anxiety disorder, borderline anorexia nervosa (July 2012)

I happened upon your site late last year while searching for help for my eldest son who was diagnosed with PDD, ADHD, anxiety disorder and high level language disorder as well as bordering on anorexia nervosa all at the ripe old age of 10. Doctors were not helping and all the drugs they threw at us weren't helping either. I was at a loss as to how to help him as his behaviour escalated out of control and my husband and I nearly split up because of the stress on both of us. It was a nightmare trying to manage all his problems as well as look after our other three children. His behaviour was so extreme that I didn't think diet could help but remembering that I was a Feingold kid for many years myself I figured it certainly couldn't hurt and I had been only too willing to make him take drugs because it was an "easy" option that didn't require a lot of effort on our part.

We started FS in January before school went back and now only a couple of months later my son looks and acts like a "normal" child. We have had easily an 80% improvement in his behaviour, autism symptoms and mood. I say only 80% because I'm still fumbling to get the diet right for him because he seems to be sensitive to just about everything and he is living on the elimination diet at the moment. It's a sharp learning curve though and we pay dearly for mistakes with a slide back into his worst behaviour and autistic traits within half an hour usually and the effects can last for days.

Thank you so much for the work you and your husband are doing for families like ours. by email, Qld

[1102] Maple-flavoured syrup flavour causes meltdown (February 2012)

Freedom Foods Ultra Rice Maple Crunch was recommended for our 3 year-old as part of a dairy free/gluten free diet. Because he's on Autism spectrum he can be quite fussy with food, but he loved it so much, he ate three bowls for lunch (I was so excited, as he's been hard to feed).

It is clearly marked as Gluten-Free, Wheat-Free, Nut-free (great) and also clearly states that it contains nothing artificial. Silly me, I didn't read the label and see that it was Maple FLAVOURED syrup, not the pure stuff. What followed was a total regression in his behaviour: 2 hours of hell. Behaviours that hadn't manifested themselves for the past month suddenly reappeared including, stripping off his clothes (4 times in 30 minutes), drawing on walls, climbing up bookshelves/kitchen benches. Before diet modification this behaviour would have been done separately (ie we'd have a day or week of stripping off, then maybe a day of drawing on walls, with some climbing thrown in another day) so it was very rare for all these behaviours to appear all together, and in such a short period of time.

Once I realized there was a reaction, I read the box properly (yes, I know I should have done it beforehand), and noticed that it included Butterscotch as an ingredient (under the heading Nature Identical). It's a mistake I won't be making again - Maria by email. (Freedom Foods responded that they are working to replace this flavour with a nature-identical flavour within 6 months, which might be failsafe)

[1091] One-liners (January 2012)

We attended your talk a few months back and it has changed our lives. We have a six year old son who

suffers from Aspergers and ADHD and since going additive-free his behaviour is much improved, his social skills are coming along in leaps and bounds and his fits of rage are completely gone.- Heather by email.

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

See more at the Fedup Roadshow 2011 report

'We've been on the GFCF diet since October – it has helped a bit but over the last 2 weeks he has been really terrible again – angry and throwing his train set around the room', said the mother of a 4 yo autistic. We worked out that SoyLife vanilla yoghurt was introduced 2 weeks ago. This yoghurt (but not Soygurt brand) contain annatto 160b. (A US study earlier this year showed that the GFCF diet alone does not work for autism and this is just one example why, you have to avoid a lot more than just gluten and casein).

'We read your website and only made 3 changes – took out Vegemite, margarine, and switched to A2 milk. And all our son's problems went away. We are going to pursue it further - but I still find it hard to believe food can have such a huge effect.' This father had been referred to our website by his young son's paediatrician for possible autistic symptoms, and told his story with utter amazement

[1044] 320: Stomach and behavioural reaction to unlisted antioxidants in ricemilk (from submission to FSANZ 2006)

I have two young boys with autism and severe food intolerances. They become exceedingly ill when consuming any gluten, dairy or soy product, and I have kept these products from their diet successfully for the past 5 years. My children are also severely intolerant of various food additives, including BHA. Two days ago I purchased a carton of Rice Milk, and after one glass both of my children suffered stomach pains and diarrhoea; and the elder son suffered shaking, sweating, and fever. Both boys behaviour became extremely hyperactive and suffered erratic mood swings. (Thanks to this mother and the one below for contacting the manufacturer, the Vitasoy range is now free of nasty antioxidants) – N..., WA

[1008] Fragrance: Our sensitivity to perfumes and fragranced products (March 2011) COURAGE AWARD

I've become increasingly sensitive to perfumes and fragrances. For me it triggers an intense, immediate burning headache, dizziness, nausea, and a reflexive instinct to want to get away. The longer I'm exposed to the smell, I find it hard to look up, hard to make eye contact with people, my heart rate speeds up and I feel hot and a bit shivery. I feel like I have to keep an eye on the ground to know where it is, have trouble telling where objects are around me, and kind of lose my sense of where I am in space.

Background noise seems to become louder as well, and I feel a rising panic and need to escape. I had a 'brain episode' about 3-4 yrs ago, some kind of massive seizure that had symptoms similar to a stroke. Since then, my problems with perfumes have increased dramatically, though I think I've always had a slight problem with scents. In March 2009 I was prescribed Methotrexate (an immuno-suppressant) as my psoriasis had become so severe it almost landed me in hospital with a life-threatening version. This has side effects of nausea, vomiting, diarrhoea and dizziness, which have gradually lessened over time, but still rear up at least a couple of times each week. Since being on this drug I find it particularly difficult to cope with perfumes. From what my two ASD boys have been able to tell me, I think their responses are fairly similar, but they have difficulty describing the sensations, and they tend to go into Autistic

withdrawal / blocking behaviours.

A couple of weeks ago we took the boys to a cinema to watch Despicable Me. A teenage girl entered with a small group of friends and sat in the row in front of us. The perfume smell was so strong I had to shift the four of us back 3 rows to escape it, and still left the cinema with a headache.

The worst places for the boys and I to enter are public toilets with automatic fragrance sprayers. One was introduced to our local shopping centre, and we were caught unawares. I sat down on the toilet, and was suddenly sprayed by a fountain of this horrible scent – it triggered off a bout of vomiting which meant I was stuck in there with the scent. When I finally escaped, I found that hubby had encountered the same problem on taking the boys into the Men's toilet. The elder was biting his hands and pulling his hair, and the younger was bouncing and squirming uncontrollably. We abandoned the idea of grocery shopping and went home to recover. Now we make sure we go to the toilet at home before we leave.

Windex and whiteboard cleaning spray have an appalling effect on my elder son, trigger out of control behaviours, self harm, high temperatures, headaches, vomiting and diarrhoea. Perfumes and body sprays such as Impulse are awful, incense sticks are a nightmare, car and toilet deodorizing products are the worst, possibly due to the confined, airless space. – by email

[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

[991] Speech: Diet got rid of disfluency and stutter (March 2011)

My 5 year old son has suffered from disfluency in his speech since he started to speak! He was an early speaker, and was putting sentences together very early, but would always talk in a very monotone evenly paced voice, a trait we are now told is quite common with kids who have auditory processing issues. We have recently had him diagnosed with a 'severe' figure ground problem. [the louder the background noise, the more trouble he has in processing what he hears - his actual hearing is perfect] I put 'severe' in italics, because he was tested at a time where he was not baseline; at a time where other factors were in play. Both the audiologist and the speech pathologist had other explanations for the stutter, which was most common at the beginning of sentences. Once he got started, the speech was more fluent, but still monotone.

The speech pathologist said his brain was moving faster than his tongue. He had an amazing grasp of language at an early age and his tongue would catch up with time. We discussed techniques in 'smooth talking' and 'bumpy talking', but aside from that the advice was that he would grow out of it.

The audiologist said that the processing difficulty could be linked to the stuttering as a delaying tactic while the rest of the information becomes accessible.

I don't disagree with these experts, but as time has gone on, I am convinced that other factors are more responsible for these symptoms than either of the explanations above.

We noticed, over time, that sometimes his stutter was worse than other times. A noisy environment always made things worse, supporting the figure ground hearing assessment, but at other times there seemed to be no obvious contributor. Tiredness, we thought? Perhaps new developmental stages?

We had already suspected that colours and preservatives made him 'high' and had eliminated all of those anyway. I made most things from scratch and bought very little processed food.

In about April of this year, we happened upon the 'Fed Up' information. We had just had about 3-4 weeks of hell at home. I was tearing my hair out and the tension in our house with the behavioural problems was unbelievable. His stutter was so bad, that it would take him 3-4 minutes to get through a simple sentence. I was trying to be patient and not draw attention to it as the speech pathologist had told us, but it was not only driving me mad, but for the first time, it was really bothering him. " Mu..Mu...Mu...Mu...Mum..... I....II....I....I.... wa....wa. wa...wa..... Uh, what was I saying mum? " If I'd put in every stutter, it would take up more than a page! Upon reading various fact sheets on the website, I had an epiphany! I had put dried apricots in his lunchboxes for the 2 kinder days and 1 day care day a week for about the last 3-4 weeks. Just 3-4 each time, but I cut them out immediately while I kept researching.

Within 4-5 days of removing apricots [and no other changes], the stutter had improved, but was still apparent. After another week, other people started noticing the improvement.

That was the beginning. While the stutter had not vanished at this point, it was enough to make me convinced that there was something to all this 'intolerance stuff'. We got more serious, and finally started to see the gorgeous little boy that we knew was in there somewhere. The aggression all but disappeared, the frustration and the stutter were much improved but there were still times where things would go downhill again.

After hearing Sue talk, I decided to get much more serious, and undertook the complete elimination diet, including the elimination of dairy and wheat. Prior to starting, I spent about 2 weeks trying recipes, building up my pantry items, stocking the freezer etc. I believe that if I had not done that, I might have given up, fallen in a heap and put it all in the too hard basket. The changes in the household were amazing. I was spending a couple of hours extra in the kitchen every day, but with the elimination of wheat [I am convinced] I had the extra energy to do it. A week in, and his stutter had all but disappeared. It was as if he had suddenly grown up an extra year or two. He took adversity in his stride, he shrugged his shoulders instead of clenching his fists, and any remaining disfluency in speech I felt was because of habit rather than anything else. His voice became more interesting, his pitch patterns varied and I am sure that he coped with noisy situations better. All of the 'autistic' tendencies which we had seen for years were improved. He read social cues better, spent much less time with his fingers in his mouth, coped with loud noises better; generally it was an amazing difference. His kinder teacher, who has watched this process with interest, remarked that it almost looked as if we had sedated him!

We are lucky in a way, to have a son who reacts so quickly and obviously to things. It makes identifying problems a lot easier. During our salicylate challenge, he went off the chart for silliness, and the stutter got worse. During a course of antibiotics for a bad bacterial skin infection, he got aggressive, angry ... and the stutter got worse. Every time we have slipped up with food, the stutter gets worse. It is our main indicator that something is amiss.

I have no absolute proof. I am not a scientist. I am not a speech pathologist. I am a mum - plain and simple. But I know my boy. I know who he is and who he isn't and these past 7 months I have watched him like a hawk. I know when he is up and I know when he is down. And I am absolutely convinced that his disfluency is directly connected with his diet. I am not saying that the diet is fully responsible, but added to other issues that he has, the diet is what has made the difference for him. A year ago, I was so worried that when he starts school next year, he would be teased because of his stutter. Now, I know that while we will always face issues with diet and behaviour, at least at baseline, he won't be that different from any other child.

And of course, I will be eternally grateful to Sue, and all who contribute to the Fed Up website. Without it, life would be a great deal more difficult. The one thing I am thankful for, is that I never let things go. If I had just listened to the experts and not used my brain and my intuition, then who knows....- Kylie, by email

[927] A2: Brief reports on A2 milk and rhinitis, autism and weight gain (March 2009)

My allergic rhinitis (stuffy and runny nose, chronic cough, congestion, hayfever during pollen season) appears to be entirely related to A1 but not A2 milk. For the last two years I have enjoyed unlimited A2 milk after 12 years on soymilk.

A failsafe-friendly dietitian reports the use of A2 milk during an elimination diet for a boy with autistic type behaviour: 'I placed him on a milk-free elimination diet, but allowed A2 milk. He consumed several cups of this per day whilst on the diet. His behaviour, concentration and sense of humour all improved. However, when we challenged with normal milk, concentration etc deteriorated. So it is back to the A2 milk whilst we go through other challenges.'

The dietitian asked my skinny 7 year old son – who tested negative for coeliac disease - to go gluten free and he felt better but lost a lot of weight. Then three months ago we switched to A2 milk and now he is doing really well. He has even been able to go back on gluten.

[915] Autistic 10 yo affected by additives in Lovan medication (June 2010)**

I know that you and your group are petitioning for food labels to be specific with regards to all ingredients. I would also like to see this extended to all medications.

My 10 year old son is autistic. Diet (additive, salicylate, amine and dairy free) is an enormous help, but it is not the only solution to all our problems and he is also on medication. We recently swapped over to Lovan, an anti-depressant, and were having terrible behavior. Once I did a full MIMS search on it (only accessible to health professionals), I found that it contained either peppermint and aniseed oil (tablets) or two artificial colours (capsules). I suspect the behavior was due to the cocktail of unlisted ingredients, rather than the drug being a failure. Our paediatrician was quite impressed with the fact that I figured it out; he often prescribes the dispersible tablets, and had not even thought of what the ingredients might

be.

We have changed over to Fluohexal (one of the generics) capsules, which we take out of the capsule case and mix with syrup, so that way we have no problems with the colours in the capsule case. We are also trialling Ritalin, which as I found out today, contains lactose! Why do they still use lactose as a filler!!!! Surely there are alternatives!

I can understand that capsule cases etc have to be coloured, as this helps with identification of drugs when not in their original containers. I just want clear labeling on boxes, including if there is gluten or lactose in the formulation. – by email, Qld

[892] Wild and extremely violent behaviour due to undiagnosed coeliac disease (February 2010)

Three years ago I stood in the bookshop with 'Fed Up' in my hand debating whether to part with \$20. Your book has repaid itself a thousandfold. I send my heartfelt thanks.

My youngest son's problems are a long saga, suffice to say that eliminating additives and low amines as suggested by your book provided the answer for some time. Then at nearly nine, out of the blue, he had some sort of breakdown. The teacher suggested Asperger's but he soon became worse - quite autistic, wild and extremely violent. He was off school for three months. The doctors I approached turned their backs on me. I couldn't believe it. I can only think they thought that as he already had a disability (Central Auditory Processing Disorder) it was part and parcel of the condition and didn't realise how extreme his behaviour was. I insisted that he be screened for a variety of degenerative diseases, but they came back negative.

Finally realising that no one else "gave a stuff", I turned back to your book. If it was diet before, then maybe, it's diet again, I thought. I tried eliminating salicylates, he got worse; I tried wheat, no change; I tried dairy no change. Eventually I tried eliminating both dairy and wheat and he improved.

He spent two years on a wheat free, dairy free, no additive, careful about amine diet and he could manage if he had a small dose of Ritalin 5mg breakfast, 5mg at lunch as well. Our lives were back on track, he was progressing at school, having a go at different sports, and excelling in his favourite sport. But it was all because of the ritalin - and diet.

Without the medication it was still like living with a drunk - he could be fun sometimes, but more often silly and tiresome, and aggressive too often. I always felt that the child that he had been was still there deep down, intact and undamaged, although why I believed it, I don't know. In November when he turned 11, I contemplated the thought that maybe he did have irreversible minor brain damage, but I couldn't accept the notion.

Then, by chance ("Mum, I don't want Rye bread this morning, I want Rice cereal") we realised it was the GLUTEN. I never suspected it, because I'd known a baby who nearly died of coeliac disease and the symptoms were quite different from my son's. I followed up your footnote in Fed Up and read Professor Duggan's article in the Aust. Med. Journal. My son was diagnosed with Coeliac disease a month ago and I am absolutely delighted by his response to the gluten free diet.

As you can see I am much indebted to you. It was only fine reading of your book that has helped me tease out my son's difficulties. I shudder to think where he'd be now (at a special school, I'm sure) if it hadn't been for your persistence in acquiring all this knowledge and for passing it on - Anne, Qld

[881] 160b: Week-long rages from annatto 160b (November 2009)

Our family has been (mostly) failsafe since our older son was diagnosed with autism and multiple food intolerance in 2003.

Last year for some months I was allowing a chocolate coated icecream on a stick containing annatto 160b, once a week I bought a box to share with the kids after shopping.

I had thought it would be ok as our very food sensitive older son didn't react noticeably to the 160b challenge.

Our now 5 year old younger son's behaviour rapidly went downhill until he was a truly horrible little boy, who physically attacked his siblings, flew off the handle at the slightest little thing, roaring and shaking with anger, things were broken in our house including a glass door and a bucket over his brother's head which drew blood! The behaviour followed a pattern each week of a couple of truly horrible days slowly getting less awful over the course of a week. So I had already figured out it was a food eaten once a week, around shopping day, but still hadn't thought of the icecream. Of course as soon as I woke up to it, the icecream was out the door, and our lovely boy and calm home returned. I've since tested annatto 160b a few times both deliberately and accidently and the horrible week long rage returned. Annatto 160b would have to be one of our family's most hated baddies! - Karen, Qld

[880] 160b: Autistic symptoms due to yellow and annatto colorings in the US (November 2009)

We were told by pediatricians and individuals in the child development field that my son was autistic when he was 2 1/2 years old. He was extremely sensitive to certain fabrics and clothing against his skin. He could not speak so that we could understand him (he had his own language) and would display fits of anger when we could not understand him. He would close himself into his own little world at times and not want to socialize with our family or other children. He could not jump, he could not run or do simple movements that most children his age had already mastered.

We enrolled him in a special program for children who were developmentally delayed - he was in speech therapy, occupational therapy, and physical therapy 4 days a week.

He progressed well in the program but continued to have additional setbacks. He developed asthma and eczema and the fits continued. He started kindergarten with an IEP (Individual Education Plan) that continued to include the different therapy sessions and also added intervention for him with regard to the regular classroom activities.

I would find cheese wrappers behind our recliner, his favorite food was ANYTHING with cheese. We continued to work with different therapists and the school system up until he was in second grade.

By the grace of God, I was in my chiropractor's office waiting to be seen and I picked up a book in his waiting room that was about ADD, ADHD, ODD and Autism in children. I randomly opened it to a chapter that described my son in every sentence. Until I read that chapter I had never even paid attention to Annatto or Yellow food colorings. It was worth a shot.

It took me almost 6 weeks to clear my son from any artificial yellow food coloring. It was like living with a child drug addict. He craved anything yellow and would cry uncontrollably, throw temper tantrums, and sleep and sleep. A short while after we cleared his diet (I even packed his school lunches) his teacher asked me in for a conference. His reading score had gone from a kindergarten level to a second grade

level in almost 9 weeks!!!!

My son is now 12 years old and will be going into the seventh grade. He no longer has an IEP or any therapeutic intervention. He is an Honor Roll student, plays football and is active in the Boy Scouts. He no longer needs any medication for asthma and his eczema is gone. He knows that he has an addiction/allergy to annatto and yellow food coloring so he also is very aware to read every label and "just say no" when offered something that he can not have.

The yellow food colorings cause him to be hyperactive and then he crashes. The Annatto however, seems to be the additive that causes him to have the addictive symptoms. I read once that the annatto seed was once made into a paste and used as war paint in a particular tribe. Well, after watching my son once he has had the annatto I can see why warriors would be successful in battle under its influence.

In addition to affecting him through his food colors also affect him through medications and hygiene products. We noticed that once when he used shampoo with artificial yellow the skin on his neck broke out every time he showered. Also, chapstick or other products that go on skin make him itch.

This school year my son begged me to let him eat some things that our school cafeteria provides. I reluctantly agreed, after all he is going to have to make his own decisions about what he puts in his body as he gets older and is out without me more. It isn't that he was eating things that contained yellow or annatto but he was eating foods that are processed. He has had the stomach flu twice and has had headaches more frequently, plus his muscles have begun to cramp more and more. Last week we made the decision for me to resume packing his lunch and I think that we both already notice a difference.

There is no doubt in my mind that the rise in autism, ADHD, ADD, etc. is a direct consequence of our trend toward processed "quick" food. I feel so blessed to have read that chapter and found my son. Thank you for making a difference. – Rhonda, USA

[866] From extreme ADHD & mild autism to 'normal, healthy, well behaved child' (November 2009)

My sister is a devoted fan. Her daughter was in serious trouble with her health and behavioural problems before she came across your work. She has met you at talks and has your books and has her entire family on a low chemical diet.

Her daughter needless to say has gone from being diagnosed as extreme ADHD with mild autism to being a perfectly well adjusted, normal, healthy, incredibly well behaved child, who is doing extremely well in school now.

Depresses me when I mention food as a cause of ADHD to other mothers who won't listen, or say "maybe for your child, but it won't help mine!" People prefer to be ignorant! – Stuart, NSW

[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 salts and amines in flavours they are only suitable for people who are additive-free)

[843] Diet or Testing for ADHD (August 2009)

I have a five year old boy who is currently going through the diagnoses and testing for adhd, but who also displays mild asd symptoms as well. I decided about a month before we saw the specialists to try the failsafe way of eating, but I did not put him on the strict diet, I simply printed out the list of additives that are no-go and completely stopped buying anything with them in it. Within two weeks his behaviour still needed (and still needs) a lot of work but has drastically improved. - Anthea, by email (children who improve on an additive free diet may do even better if they reduce their salicylates and/or amine intake too - S).

[711] Heart symptoms from benzoates, bread preservative and sulphites (December 2008)

My 14-year-old son has Aspergers syndrome. He experiences arrhythmia and severe heart palpitations every time he consumes any additives 211, 282, 220 etc. If he has been free from these additives for over two weeks then he will get away with the first exposure and then it accumulates and gets worse. We saw a heart specialist and he found no problems, just blaming it on anxiety. He also gets more aggressive and violent once it accumulates... like Jekyll and Hyde. Sadly it is so hard to convince and be believed by doctors and his psychiatrist that these additives affect him. – Therese, by email

From [700] One-liners (November 2008)

I love your site and have referred to it for years and years. I was given a low salicylate diet to reduce agitation in my Aspergers son when he was 2 years old, and now he is 15 and a half, he is a fantastic, responsible, loving teenager. - Teigan, by email

From [574] One-liners (August 2007)

My autistic son has gone without Gatorade, PowerAde and coloured drinks for just three days, and already his behaviour is improving - such a small thing to do for such a great result.

[570] PDD-NOS and failsafe (August 2007)

Our daughter Beth is five and a half. At four she was diagnosed with Pervasive Development Disorder - Not Otherwise Specified, a bit of a mouthful but it sounds like Asperger's shadowing. She is not ASD but has a lot of symptoms in common: developmental delay in speech, fine motor and gross motor, attention deficit, poor eye contact, argumentative, very poor social skills, being in her own world.

...THEN we went failsafe and what a blessing it has been!!!! ... Ten days after starting failsafe, Beth suddenly began running around with all the other kids talking and interacting with them!! Every week, I hear new things that she is doing at preschool. At home she is constantly surprising us with new things that she says and does. It's great!! It is as if a block has been removed in Beth's brain and suddenly she has the possibility of being a normal little girl. Going failsafe is not easy but I had to give her the chance. Even though it may not fix all of Beth's difficulties, it seems to have removed a lot of them, see the full story here: <http://fedup.com.au/factsheets/symptom-factsheets/pervasive-development-disorder-pdd-nos-symptom-discussion>

[552] A psychologist comments on story [539] (May 2007)

I'm just reading the latest FIN newsletter (#51) and came across Reader's Story [539] "The school counsellor ... went on to tell me 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."

As a Psychologist who used to work in education, I am so disappointed for this family. There seem to be a number of responses that I would hope were the exception rather than the rule of a counsellor's professional practice. Diagnosis should never be made without interaction with the person in-question. Theory and empirical-based study are important, however that "importance" should be balanced with a few other thoughts - 1) the causes/criteria for illness are frequently "refined" over years despite each change being based on the alleged omniscience of empirical data, and 2) life on earth has never been 100% contained and explained by research based theory - there are always exceptions, and to dismiss the possibility (particularly when the individual has possibly never done a literature search on the topic themselves) is to choose ignorance. Carl Jung made a profound statement on this - "Learn your theories as well as you can, but put them aside when you touch the miracle of a living soul." I know the difficulties I face getting parents and other professionals to even consider diet as a factor in their children's behaviour and/or learning challenges. I want to commend and encourage these parents for their intentional pursuit of their child's wellbeing. Perhaps a respectful suggestion to visit (or provision of) the extraordinary list of research links on the FIN website might open the eyes and mind of this counsellor. In the end, it is still our responsibility as parents to make decisions (albeit informed decisions) for our children - not doctors, not teachers and not counsellors. Well done for standing firm. – Psychologist, by email (Note that we now have a number of failsafe-sympathetic psychologists on our list of health professionals – you can obtain the list by emailing Howard: confodnet@ozemail.com.au)

[540] Heading towards a diagnosis of autism before - the difference in him is so dramatic the paediatrician was in shock (January 2007)

When I originally wrote to you, my three-year-old son had a severe speech delay, many behavioural problems, refused toilet training, was having upwards of 6 dirty nappies a day and the paediatrician was heading towards a diagnosis of autism.

The first two weeks on the elimination diet were "HELL". My son's behaviour was so bad I was in tears when the day was over and he was in bed asleep. My husband and I were determined to give this a go and we stayed strong together to get him through the rough patch. Four weeks after starting, his behaviour improved each day, the tantrums decreased dramatically, he became calmer, his attention span increased, he was happy to try sitting on the toilet for me, the autistic traits stopped, he would sit and do activities with me and the most impressive of all in one week he said - "Dad", "Mum" and his own name "Sam". He has never called me mum & it brought tears to my eyes - he has since then said love you mum and tries hard to string words together.

The difference in him is so dramatic the paediatrician was in shock, he is a non-believer of diet having an effect on children, however, after seeing the difference in Sam he was blown away. He said he was pretty sure after the last visit he would end up making a diagnosis of autism for him, now after seeing him six months later he is thinking it is just speech delay and is not so worried about the minor autistic traits. We are focused on sticking to the diet especially with the progress Sam is now making. He does on occasions slip on behaviour - but he is only three. We feel we have our beautiful little man back. – by email, Qld

[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])

[441] Tim's world (shadowings of Asperger's) (August 2006)

When we had our son Tim assessed for Asperger's, we found that his way of viewing the world was different from ours. The tests highlighted his strengths such as maths, eg he scored 17 out of a possible 19 for this area, comprehension and reading skills. They also highlighted his weaknesses in motor coordination and his differing ability in various social situations.

Tim's world can be black and white. He doesn't cope well to change and is like a sponge soaking up written information. He was described as a little adult trapped inside a child's body. This can vary from day to day, depending whether Tim is in what I call 'child mode', happy to play with trucks and toys and his brother, or 'adult mode', needs specific jobs to do, be busy, needs to know and plan ahead.

Tim's overall score fell just a few points short of the criteria for diagnosis. When this happens, the person is described as having shadowings or ghostings of Asperger's, that is, enough of the traits to be a huge concern. This has helped us to find ideas and strategies to cope with his condition.

An occupational therapist with a special interest in sensory/tactile areas explained such things as why Tim likes to wear specific clothes, bounces up and down, spins (though this only happens every now and then) and why his hearing and sense of smell are so acute. These actions and sometime making noise help Tim balance himself. We were advised not to stop these actions, but find ways of directing them into a more socially acceptable form eg bouncing on a trampoline.

Overall, if we can improve his motor skills, his social skills and behaviour will improve.

Tim struggled socially at school last year, but this year things seem much better. We have had friends around to play, though I'm always on hand to help direct the play and social skills needed for a happy afternoon, and I can honestly say Tim is not the lonely little boy he was eight months ago.

My advice to other parents who feel there is something different about their beautiful child, but no one will seem to listen: don't give up. We were patted on the head by doctors for three and a half years ('he's just highly strung, he will grow into himself' - what a great help that was!) and it was my own sister who suggested Asperger's due to an article she had read.

Having put a name to and found a reason for Tim's behaviour has empowered us to help our beautiful, bright and unique child to be happy. Tim seems sensitive to any artificial products, either additives or smells. We have seen him react to smells such as air fresheners and roadwork smells such as tar. We were also told to watch if his ears go red as this can often be a warning that something is not agreeing with him chemically and we have found this to be true. He can eat salicylates but is limited on amines. – Elaine.

[434] My daughter's epilepsy (August 2006)

This is about a mother's struggle with her daughter's epilepsy and what it took to give her daughter's life back to her. (from Andrea Collins' epilepsy list)

"My daughter is 7 years old. She has development delay, autism and was diagnosed with Lennox Gastaut Syndrome at the age of 2. She began the Ketogenic diet Jan 2000, and came off of it July, 2003. She was on the diet for 3 years and 3 months. She became seizure free 14 months after the diet was started. (It took 9 months to wean her off all the drugs and another 5months to take out all the foods that were causing her problems.) I found the diet very difficult as I didn't have the medical backup to see me through it. Found a Paed 3 months before she became seizure free who believed in what I was doing. A mum off this list was my only support. I would not have done it without her. I was so tired and felt so sorry for my daughter being on such a restricted diet and yet still having seizures but I had to see if the diet actually worked on its own. Her last seizures were all occurring during her sleep and I thought "at least she's not hurting herself" but I was forever running into her bedroom to help her get through her seizures. I was so frightened that I had done the wrong thing, weaning her off of all her drugs and the seizures were not getting any better. I was lucky to find a Paed that believed in what I was doing. She actually advised me not to reintroduce the drugs. The best thing I ever did was getting rid of the drugs altogether because I was then able to fine tune. What I did find however, that whatever she ate really affected her. Two days before she became seizure free I removed carrots from her diet because that was the only food I was giving her in the last meal that wasn't "failsafe" and a miracle happened. The following night she had a cluster of 20 very slight myoclonics and that cluster was the last seizure she ever had (April, 2001) and has been off the Keto Diet since July 2003, however she remains on the Failsafe Diet and Dairy free. I have since tried her on carrots and found her to be having staring sessions (were they absence seizures??) and keep her off of foods with beta-carotene. It's paid off in the long run. She is talking, doing well at school, playing with other children, enjoys her food (although I still have her on a mild diet watching what she eats) and is generally happy 100% of the time. I don't know what I would have done without the Ketogenic Diet and Failsafe foods."

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

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

The first symptoms that we came up against were reflux, eczema and a lot of skin rashes. My third child, Jessica, was extremely miserable and seemed to be in a lot of pain. She'd started refluxing from one week and was started on prescription medications. Luckily the paediatrician was able to identify a rash around her bottom as being associated with lactose intolerance so we went the road of trying various formulas until we got to nutramigen which settled her demeanour but did nothing to alleviate the reflux side of things, so we had unwittingly started down the right path. She also had a constant post nasal drip from very early on so we were shovelling her full of various antihistamine type medicines trying to alleviate that and she had eczema. My fourth child Zac knew that breast milk just wasn't for him so at two weeks he decided to starve himself in preference, refusing the breast. He also was covered in eczema and had silent reflux. Luckily for him he was put straight on to neocate, for during the couple of

years leading up to his birth, our family paediatrician who by this point had all four of my children in his care had seen the flurry of symptoms food intolerance can produce.

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

To top it off, Jessica, had started doing the parkinsons shake (she was still refluxing terribly and was also on both Zantac and Prepulsid syrup medications). Levi's teacher asked me to have him assessed by an Occupational Therapist who diagnosed him as having dyspraxia, a developmental condition that makes them have to have constant repetition as they have to relearn everything over and over because they can't retain it. I knew that it wasn't a developmental problem as he had always been in advance of his age appropriate milestones and I'd spent lots of time with him, he could climb trees, jump, skip, ride a bike without training wheels from 3 years old, and had great hand eye coordination prior to this happening. All of that coupled with the ADHD stuff just wasn't right. So I made an appointment for the paediatrician (his regular paediatrician wasn't available so I asked for the one that was now looking after my other 2 children). He was dumbfounded. He'd remembered seeing Levi from time to time when I'd had to go for appointments with the others and he didn't have a clue what was going on. So he ordered several blood tests, a CAT scan and an EEG. Everything came back clear. I remember saying to him at that stage that it had all started when the syrup antacid was introduced but I couldn't understand why it was still happening. I of course got a Tsk Tsk for pointing my finger at the medication. So I battled onwards for a couple of months, racking my brain, I rang the reflux support group and the lady I talked to said that her son who was on these medications was also ADHD. I was at my wits end, Levi's symptoms were getting worse, I resorted to ringing the drug company who manufactured the antacid and talked to one of the medics who worked in the lab. She told me that she had heard of this sort of thing happening before and that it was probably due to the alcohol, or the preservatives and flavourings used in the medicine as they are really concentrated in ALL syrup medications. BINGO. Now I was facing a dilemma. How could I treat my children's reflux without the medications, I could see what it was doing to my kids - all 3 were on the same medications. I found a naturopath who made a tonic catering for my children's reflux symptoms. In a matter of weeks I was able to control the older 2 with the herbal treatment alone. Within 7 weeks Levi's ADHD had settled down, his balance and coordination had returned and when we saw the neurologist at this point he agreed that Levi's problems were due to the preservatives and flavourings in the medications and felt that he was a normal 5 year old. Funnily enough Jessica was cured of the parkinsons shake and Levi stopped falling over.

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

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

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

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

From [381] One liners (November 2005)

My little girl child is diagnosed with autism and in the last two weeks I've eliminated all of these numbers from her diet and she's already looking healthier. - WA

From [368] One liners (March 2005)

My cousin is 4 weeks into the failsafe diet and is reporting great effects for herself and two daughters (one with ASD) – by email.

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

I have taken my 3yo son off all commercial bread products (it's become quite a crusade for me!) with marvellous 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 email

From [356] One-liners (Nov 2004)

- First let me tell you how impressed and grateful I am: I work with children with autism, ADD and learning difficulties and the best way to tell people about the effects of what their children eat is to lend them one of your books. – WA
- 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
- My four year old autistic son's pain threshold seems to have decreased on the diet – he used to be barely aware of pain if he injured himself, but now responds as any "normal" child would. - NSW

From [338] ONE LINERS (July 2004)

- We have been weaning ourselves off non-failsafe stuff for over a week and my autistic son and I are already seeing and feeling the benefits.

From [325] Autism - on or off-diet during assessment? (April 2004)

My autistic son has been on the diet strictly now for nearly 2 years. He looks terrific and is very healthy with only a very mild sniffle since going failsafe.

He starts pre-primary school this year. It is the school where he went to kindy last year so they are very aware of his requirements such as: no hairspray, aerosol deodorants, perfume etc and are using enjo gloves in the classroom to avoid any chemical being used during the day. Big relief.

We have a five-month wait for the formal disability services assessment to obtain aids for school. I don't know whether to take him off the diet for the period of the assessment. On the diet, although excellent, autistic signs are still evident, for example: no eye contact, no imaginary play, everything is black or white, no flexibility etc. If we take him off the diet we get a severe reduction in speech, more tantrums, aggression, argumentative, rashes, red ears, hypersensitivity to noise, dislike of being touched and the list continues.

I am an avid failsafer and can't now imagine life without failsafe (my son has failed all challenges on a number of occasions and is also intolerant to airborne salicylates). Could I have input from other failsafe mothers on what they think would be best during the assessment? - reader, WA.

[324] Autism and diet at school (2) (April 2004)

About 18 months ago you helped us put our son Ryan (now nearly 5 years old) on the elimination diet, after we had been to RPA for Ryan's hyperactivity, ADHD and autism. Three months later you helped us find a problem with wholegrain wheat and antioxidants that had pulled us undone. Salicylates turned out to be our main problem although antioxidants are a close second, with amines and other additives a problem too.

Our son is now in his second year at special school, where he has made great leaps and bounds. When Ryan started school he was already on the diet. Months later when we'd allowed bananas to become more frequent than one half every second day, his teachers actually came to me and asked was Ryan eating something he shouldn't be. It took us three weeks to figure it out, and cut back on the bananas. Through this incident, they really came to see what we were talking about. Interestingly the school has strongly supported us, always keeping us up to date with what's coming up for 'tasting' in cooking classes, and seeking alternatives for Ryan. I'm very grateful for this! - reader, NSW

[317] 'Absolutely foul' to 'wonderful' 13 year old in three weeks (April 2004)

We are trying the failsafe diet for my 13-year-old nephew, Lachlan, who has come to live with us. Lachlan has ADHD and I believe a huge dose of oppositional defiance as well as Aspergers and I am finding him unmanageable. We noticed a bit of an improvement on the first 3 days of our failsafe diet but he then reverted to absolutely foul - defiant and oppositional!!

Two weeks later... I think that Lachlan's behaviour is better overall but I still get defiance at times. We have been on the diet for 3 weeks now and he has been off his dex for 1 week. He says he doesn't notice any difference, but I do.

Three days later... We had a wonderful day with Lachlan yesterday - so different from our daily experience a couple of weeks ago. I have decided to leave Lachlan off his medication indefinitely at this stage as he seems to be a much nicer person when not taking it. He even seems to be understanding some of the basic maths concepts that were just beyond his grasp in the past. - reader, Qld.

[300] Dramatic improvement in speech delay (December 2003)

Our nearly two year old twin girls are awaiting a psychology assessment to determine whether they have autism. They both have a few symptoms especially lack of language - only use the words Mum, Dad, Nan, Bub, no and hello. Their understanding is slow although we feel this is improving. Although both show a few signs they also have signs that keep us hopeful that the girls do not have autism. They have fairly good eye contact and are very affectionate little girls. After researching for hours on the internet, I started the girls on a gluten free and dairy free diet last week. By the end of the day, one of the twins (who would normally use maybe one word a month) had not stopped using her basic words and was making new sounds. Within days they had both improved very noticeably. At first I thought it couldn't work that fast but whilst reading your books I have a different view and realise it might be lack of the bread preservative. - Reader, Tas

[271] Autistic sound sensitivity improves on diet (June 2003)

We discovered failsafe over a year ago when my son Liam was four. Ironically, because of the failsafe internet support group he was diagnosed with Asperger's Syndrome a while later.

He used to hate loud sounds and either shut down, cringing in a corner with his hands over his ears, or more often, he rose above it with the most aggressive behaviour and loudest noise he could muster. One time I had the blender on for one minute and he screamed and threw a chair across the room, quietening down as soon as I turned it off. This has dramatically reduced now. It was not instantaneous with the introduction of diet but somewhere in the course of last year it improved. I have found that this is the improvement which most intrigues other parents of autistic kids. Liam still doesn't like loud noises such as fire alarms but he is content to hold his hands over his ears.

For Liam, the diet has been like unfogging his brain and allowing him to catch up where he is delayed, mainly socially and in his emotions. But the most interesting thing was watching his drawing develop. When he first started Kindy, he drew like a two year, all scribbles. After he started the diet, his drawing just took off and in a matter of months we watched him improve to above his age level. Literally every week there were new dimensions. It was so exciting and a very visible reminder of how the diet now allowed him to develop.

Liam is gluten, dairy and egg free as well as failsafe and he has soy only once every four days. I could not say he is perfect, but he is light years ahead of where we were. - Caroline (finb and Failsafe group)

[215] Autism and diet (October 2002)

My son is 3 ½ and was diagnosed with Autism at 2½. He also presented with almost all of the criteria for the hyperactivity side of ADHD. The diagnosing doctor gave us very little information to go ahead with. By good fortune my husband picked up Sue Dengate's Failsafe Cookbook the weekend after our son was diagnosed, when I was still reeling and had no idea which direction to head in. We went looking for triggers for our sons hyperactive bouts, he was always active, preferring to permanently run rather than

walk, and he had no attention span, but sometimes he would just go off, usually for about two days, where he would literally climb the furniture, sitting on top of the bookshelf, watching TV upside down, while lying on top of it, and he was causing his older sister, not to mention his parents, huge amounts of grief.

Early intervention has proved a godsend, but even so, we couldn't get him to sit still, or even sit down! and ADHD drug trialling was mentioned, if we couldn't improve his behaviour. This made me very nervous because previously any medication, bar panadol, for more than 3 days, sent him berserk. I now understand this to be the flavourings in all children's medication (I thought I was covering my bases buying colour-free!) Before I went to RPAH I had done quite a lot of work on his diet myself, and we had discovered a lot ourselves, but after I'd read Sue's book and been to RPAH I was able to make a real difference for our son. His biggest problem is salicylates and colourings - why didn't anyone know to tell me that bad nappy rash is always a sign of salicylate intolerance? That sign was present from when he was a baby. I always put it down to teething - how wrong I was! What a huge amount of grief we could have been saved if we'd known.

Our son is a typical limited Autistic eater. We were told that he was eating a good nutritious diet and we shouldn't interfere. After RPAH and Sue's book, we learned that almost everything our son was eating was bad for his intolerances. I'd tried Helgas Rye bread thinking I was avoiding bread preservative 282 - with no idea that vinegar was a problem! He drank lots of diluted apple juice - so I bought the one with no flavourings and thought he would pee out what he didn't need, which he did. I thought it was good that he drank between 2 and 3 litres a day - the chemist told me it wasn't a problem. RPAH told us he was consuming the equivalent of 10 - 12 apples a day and he is salicylate intolerant!!! Since we removed the fruit juice, he doesn't crave it any more and now drinks about 1 litre of water a day - and it was far easier than I could have imagined!

So even with lots of knowledge under my belt and advice from all the so called "experts" before I went to RPAH I still was far off base. Three days on the elimination diet and our son was a changed child. Preschool reports that he now walks instead of runs. As a result he has slowed down enough to take an interest in the activities around him. He has broken the diet a couple of times, so one week in we inadvertently challenged salicylates and colourings, both with obvious results.

The good news is that he is allowed to still eat wheat, pears, and drink diluted pear syrup from tinned pears, and he has adapted beautifully - something I never thought possible.

Our son is still Autistic - it's not a cure - but it has certainly made a difference to his hyperactivity and therefore he is now far more teachable, with a wider interest base, and the ability to pay attention to things better than before. Grandparents who were sceptics of the diet have noticed that he is calmer, and can only attribute it to the diet. He has even started looking at his grandad, for the first time in two years!

We are only in the second month of the elimination diet, with several mishaps already under our belts, but I really wanted to encourage anyone who is thinking about the diet, dealing with Autism or ADHD - give it a go - you'll learn a lot. It has lowered the stress on our family, particularly his five year old sister, considerably, and has made our son far easier to deal with. Also, when he is not affected by a food infringement, his eye contact improves, he is coming out with new words every week, and is approaching other teachers, apart from his regular carer, something he's never done before.

Interestingly, before we went to RPAH, Sue Dengate told us the main problem would be salicylates but I couldn't face it, I thought it was too hard. It really wasn't that hard, and the fast results were well worth it. Sorry about the long email, but I hope I can encourage others out there to give it a go. - from failsafe2 group

[178] Ratty behaviour (September 2002)

My son aged 10 is autistic. Our speech pathologist suggested that a big part of the ratty behaviour he often exhibits could be from additives in our everyday food and said what you are saying about our daily bread containing more additives. I have eliminated soft drinks from his daily intake and what a remarkable difference I can see already. - email, Vic

[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 [a small amount of pizza flavoured biscuits led to] 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). ...

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

Our family is what is commonly referred to as a "blended family". When we were married 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 away from him. We enrolled him into

preschool. We felt that perhaps if he were to become 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 downright 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 paediatrician 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, except for 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

[036] 282: Jack's story: severe speech delay associated with bread preservative (April 2000)

I have been meaning to write to you for years to thank you for your books. We were on the right track with our then four year old son, Jack (now coming up to 10) when I read "Different Kids". I already suspected ADHD and knew very well that he reacted to food as do I. Jack had his first food reaction at 20 weeks gestation! I ate some of those awful red sugar-coated peanut things and he just went berserk, looping the loop and throwing himself all over the place for about an hour or so. So we were prepared.

I breastfed him for nearly three years - breastfeeding was only time I got to lie down and rest. He was a "windy" but fairly normal baby early on and I did avoid any foods in my diet that seemed to cause problems. He never liked to be left alone and would panic if put down while awake. From three months constant movement and novelty was required to keep him happy. When he was happy he was radiant and when he was not he was grizzly and constantly squirming with this giving way to frantic screaming if the boredom lasted for more than a few minutes. Out shopping, strangers loved him as he responded with such joy to any attention and he was a very attractive baby. I had to carry him on my back in a sling, the stroller was too boring, too far away from me and not social enough. I accepted all this as I had been told I was a very, very difficult baby - colic - and my expectations were therefore "realistic".

At four months I began to introduce solids - rice cereal with breast milk to mix. The novelty seemed to appeal to Jack! Then I began to mix a small amount of orange juice in with the cereal to boost iron absorption. From there I introduced apple, ripe banana, pureed vegies (broccoli, pumpkin, etc.). He wasn't so keen on this but I heard about adding cheese to make the vegies more appealing, so I did this, often using parmesan cheese as well as milder cheeses. Jack loved bolognaise sauce mixed in too. Another favourite was avocado. He loved apricot and yogurt. He had a small amount of mashed prune to counteract a tendency to constipation. I was so pleased that he ate well and proud he had such a good appetite and such an ideal diet. When others asked how he slept (pretty awfully) I could at least say, "But he eats really well".

Meanwhile our little boy was getting more and more grumpy and demanding and more and more miserable when he wasn't amused. I looked frantically for the "ideal toy" the thing that would hold his attention. Each new item was met with delight and then discarded within thirty seconds and the grizzling began again.

Jack woke at least twice a night. He was into everything and seemed to always want more - more - more. He wasn't babbling - ba ba ba & da da da at 10 months. (In retrospect, the first sign of his problems with auditory processing that later resulted in speech delay and difficulty in learning to read.) He never sat and played. He never sat! He went straight from crawling to being dissatisfied because he couldn't yet walk.

From the 4 months we put his "difficult" and unhappy behaviour down to "teething". The first tooth didn't appear until eleven months.

When Jack was four months old I ate a small amount of dark chocolate in an ice-cream and about one hour later breastfed Jack. Within half an hour he was screaming inconsolably and instead of being tense as crying babies are he just lay back in my arms in an almost relaxed way as he screamed (low muscle tone no doubt). I identified the chocolate as the most likely culprit - I'm now sure I was right. After Jack went to sleep I sat up and expressed my other breast out into a nappy!

He was still a delightful, smiling, social child as long as he had the undivided attention of someone and a constant stream of novelty.

I've gone into this first year in detail because it really shows most clearly what was going on even if it was not obvious at the time.

My second child, a daughter called Ellen, was born when Jack was nearly 3 and a half. Jack was delighted and adored his little sister. The pregnancy was complicated by my blood pressure going high from 23 weeks. My mother came to look after us all as I was meant to be resting as well as taking anti-hypertensive medication. My mother just couldn't take Jack's behaviour.

I had been avoiding wheat in Jack's diet as I believed I had a problem with it. (My problem was actually with calcium propionate (282), of course, but cutting out all wheat did solve my problems of fatigue and fuzziness and so for years I thought I needed to avoid wheat). For convenience we changed to normal white bread from the supermarket. Jack loved it after the drier rye bread I had used formerly. I had not a clue about the preservative in the bread. Jack's behaviour went from bad to atrocious.

Jack's behaviour was at its all-time worst between the ages of 3 and 4. It was during this time he was eating the preserved bread. He put his hand through a windowpane during a tantrum. He woke with nightmares and screamed madly about and it was impossible to get through to him.

He went to bed late, reappearing often saying he was hungry and wanting (surprise, surprise) another slice of bread. He would wake at 4.30 in the morning wanting to be entertained. The only toy he persistently liked was his ride-on car. His behaviour and manner were almost autistic but for his insatiable sociability. His speech was very delayed and I don't think he really understood a lot of what was said to him. He was however very imaginative and inventive and liked to play pretend games, but always with someone. He had no liking for being read to but preferred to have me act out stories with both of us taking roles.

Needless to say I was exhausted and miserable. We lived half an hour out of town. My husband, Nick, was at that time managing farms. It was a very similar situation to yours, I think.

Jack was going to preschool in town a few days per week. Although they did not complain about Jack's behaviour (he has never been physically aggressive towards other people, even at his very worst and he's

never said "I hate you" either - he is a very gentle character) When pressed they would say he was a bit weird, hiding in the playhouse and refusing to come out when the others were sitting on the mat listening to stories and taking off outside at inside time, etc, but he was only three so a lot of immaturity was allowed for.

My mother and my husband, Nick and I discussed Jack and his behaviour and decided that his things had got much worse around the time of the change in bread type. I took Jack off all wheat. The change was astonishing. He could have his socks put on without going berserk. You could talk to him and he would act on what was said. He didn't scream through everyday tasks such as bathing, dressing etc. When he went to preschool that week I dropped him off and didn't say anything about the changes. When I picked him up the teacher approached me and said "What have you done - he's a different child - he's playing with the others and listening to us."

Just before Jack went off wheat he had been assessed by a speech therapist at the preschool. She diagnosed, as best she could -we couldn't really keep Jack in the room much less anything like on-task - a severe expressive language delay and a moderate receptive language delay. Six weeks, later when off the wheat products, was reassessed by the same speech pathologist, using the part of the test that Jack had not done due to being non-cooperative. This time he seemed to have no significant receptive language delay and was only mildly delayed in his expressive language. She said she had never seen a child change so dramatically within such a short period of time.

Of course avoiding wheat meant avoiding a lot of foods, such as sausages. So Jack's diet also became generally blander and so did Jack. He was still difficult but at least he was "on the planet" now. He was only four but used to ask me "Why am I so happy, Mum?"

After a couple of months I screwed up my courage to do a challenge for wheat. I cooked some pikelets so I knew just what had gone into them. No reaction other than a very happy child - yummy pikelets!

I challenged with bread, planning to do two-week-on -- two-week-off challenges to see if any difference was apparent. That challenge lasted for two slices of bread fed to Jack at 4.30 on a Friday afternoon (timed so as to coincide with the weekend when Nick would be about)!! Within forty-five minutes, Jack was off his brain. Screaming, upset by everything - he finally went to bed and woke at 4.30 and was off again. This reaction lasted as a major thing for three days and Jack was unsettled for at least a week afterwards. Nick strapped Jack into his car seat and spent a lot of time driving around checking the property that weekend! We have never rechallenged this one as Jack himself has no desire to repeat that particular experience and neither have we.!!

The clinic sister I went to for Ellen was very supportive of my efforts to unravel the cause of Jack's problems with diet. When I had identified bread as being a huge problem she pointed out that bread did contain a preservative. She did not know anything particular about this preservative and its effects and she only mentioned it because preservatives were believed to be a cause of behaviour problems in children. Unfortunately I didn't take this too seriously at that time - I still believed that they wouldn't put anything this harmful in our "daily bread" and therefore the preservative couldn't be that harmful.

I spent the next year or so thinking our problem was yeast. I also noticed that a lot of Italian food caused major problems and made Jack pale and blobby looking as well as affecting his behaviour.

It was around this time I found and read "Different Kids" and it all began to make sense. What I had been doing as a mixture of the observation that the blander the diet the blander the children, my little clinical-trials-with-one-(or two, three or four) participant(s) and intuition could now be done with structure. I think you saved us another three to four years of misery, money wasting and mucking about.

These days my husband says he feels better and doesn't get headaches any more. I've found I react to many things and I compete with Jack for the most sensitive-in-the-family status. Ellen reacts to salicylates by becoming easily enraged and blaming everyone for everything. She is, by the way, the most un-ADD person I've every met - highly organised, very logical, and a real old head on young shoulders - very knowing and mature and reasonable. She is also extremely bright and academically gifted especially with maths.

Jack becomes hyper and idiotic and unable to learn when he has more than moderate salicylates in his diet. His salicylate reaction is a rapid-onset-rapid- resolution-type reaction. Amines used to make him irritable and as close to aggressive as he got but these days the reaction takes the form of a migraine. Jack still has academic problems related to his ADD and particularly to his auditory processing disorder. He is on Ritalin for school. I liken it to wearing glasses and tell him his sister wears glasses at school to help her eyes focus and he needs Ritalin to help his mind focus. He takes a very small dose (1 tab then 1/2 tab three hours later) and he finds it very effective. He does not take it at weekends usually although he would have a dose if we were going to do something that required good behaviour despite being bored or to help with a task requiring concentration and organisation such as making a model etc. He also asks for a dose if he his anxious to be on his best behaviour.

We also need to apply behaviour modification techniques on a daily basis - I did a Triple P course and this has been immensely helpful in managing Jack.

To put it simply, our approach to Jack's behaviour and other problems three-tiered one: First comes diet and general good health including adequate sleep and food - this is essential as if his diet, in particular, is off then nothing else is really effective.

Second comes the behaviour modification. I believe a lot of poor behaviour in children is caused by not being able to understand their environment. It seems to me that all effective behaviour modification systems provide not only rewards and punishments but more importantly they organise and simplify the social environment for all players. This consistency enables children who have trouble reading those around them to understand what is happening and they are therefore able to comply.

And thirdly, medication is the icing on the cake. It does cause Jack persistent appetite suppression and sleep problems. (The appetite suppression can be a good thing for parties though as he will only pick at plain chips and have a bit of lemonade if on medication!) Once again thank you so much for your books - and for the great website, and please sign us up for your newsletters, discussion group and kids discussion group! - Alison, Queensland

[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 took 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

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