

Reader reports from the Food Intolerance Network

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("tics", "tourette", "tourette's syndrome" keywords only)

[1286] ADHD: "three weeks on failsafe and all his symptoms have stopped" (November 2014)

My son has been on ADHD medication for 5 years (he's now almost 12) - while it served its purpose in the beginning, in the last 12 months he'd been aggressive, had a racing heartbeat and severe verbal and physical tics. Two weeks off his medication and three weeks on failsafe and all his symptoms have stopped and his teacher says he's more focused in class. I wish I had of been informed of the diet option before being told medication was the only solution. What's safer for our children? Dosing then up in medication (even if it is working) or changing their diet. I almost feel I was a lazy parent for taking the easy medication option without even looking at possible alternatives - Larissa

[1282] Tic disorder and "immediate results by cutting out the additives" (November 2014)

Oh what a journey I have had! As I said before my 5 year old son developed a chronic tic disorder and I was at my wits' end, I took him to so many doctors who told me that nothing can be done, then I found your website.

I noticed immediate results by cutting out the additives but I could not get him to baseline. I then contacted one of your recommended dieticians. I cannot speak highly enough of this lady. She has been a light in the darkness. As I have told her myself she was the first person to say "yes I can help you" when so many others didn't want to know. With her help we got to baseline (which means symptom free!!!) within about a month and worked through the challenges. He can now have mod to high sals, mod amines, glutamates on occasion and no additives at all! But he looks normal and is getting on wonderfully at school. I have learned so much about how food affected both my children's behaviour as well – even though this was not why I was doing the diet.

Doctors and dieticians here are amazed at our story and results!

Thank you from the bottom of my heart, for without your work my adorable little son who was born perfect, would still be living with this chronic condition, and I have no doubt that the knock on effect of this on my entire families mental health would have been a negative one - Karen

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

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

[1187] One liners (February 2013)

My son has eye motor tics, since he has been failsafe his tics have vanished - Rachel, UK

[964] One-liners (October 2010)

We have been following Failsafe eating for three months and it has made an enormous change to our 5 year old boy. Pre-diet he was very aggressive and had developed a range of tics, now all the tics have gone and his lovely, funny nature is shining through. So far the challenges that have affected him have been dairy and salicylates – Karen, by email

[898] Wow!!!! sums up effects of diet on tics (February 2010)

(At the start) We have an appointment with your recommended dietitian in 2 weeks, which can't come quick enough. Our 9-year-old son has had (with hindsight) intermittent tics for the last couple of years. Last weekend he was so agitated and had particularly bad tics which seemed to follow him having an ice cone with some terrible colouring/flavouring over it which someone bought him with the best intentions! Traditionally, we have always had plenty of fruit and veg and I think has contributed also. A trip to the GP resulted in being told they were habits which we should ignore and if they hadn't gone in 2 months to go back.

So, we started failsafe last weekend and are now on day 7 having had him off school with a cough, cold and generally irritable. Things improved loads today until a friend of his gave him a starburst earlier this evening at the village movies and within an hour at the most he was incredibly twitchy...is it possible for him to have such an immediate reaction to something?..then improve within a couple of hours?

We have gone through thoughts of Tourette's syndrome, some of the symptoms he seems to have - sniffing, twitching, vocal tics, though the GP said this was unlikely ... he was definitely agitated tonight though we don't know if it was due to the noise / busyness of the place or could have been the starburst. His favourite foods are orange juice, olives, mushrooms, salami all of which have been eliminated, and we are thinking salicylates maybe the culprit ...

(12 days later) Just a quick update on things, it's been an interesting week! Our son's tics had been improving, but he had a terrible cough and kept spiking temps so he is now on antibiotics for a chest infection, and is improving cough/temp wise but his tics seem to have really worsened again. Looking at the ingredients on his meds, it's reassuring to think we are on the right track. We have managed to stick to the elimination diet and he has been really good at chomping his sprouts etc ... not enthusiastically ... but eating them!

(After 5 weeks) Thought it time I put an email together to update you on our son's progress !... wow!!!! sums it up nicely! We have been to see the dietitian twice now and are fine tuning our failsafe eating. I would say he is 80% improved, hardly any physical tics, occasional vocals and bed wetting is still a problem but we are hoping with the fine tuning we may be able to help that. He is more focused on homework, even doing extra to catch up!! It has been a revelation and continues to be so, my husband has lost weight (it needed to go!)and his BP has dropped to normal limits so everyone is better all round.

(After 6 months) Another update! Things all went a bit off track a few months ago and I think the pressure of everything all got a bit too much, especially for our son. However, with the relapse in

diet the tics returned and so we have gone failsafe again but without the pressure and fuss this time. Meals out and parties are relaxed and he can have whatever is on offer! Most of the time we are failsafe at home without anyone really realising it ... it has become a way of life! Plus the tics have disappeared which is reassuring to know that we are doing the right thing. Another trigger we are almost 100% sure of is scented candles, we had one of these in the lounge around the time of the return of the tics!

I cannot thank you enough for all the info you and Sue have put together, your books and Friendly Food have to be the most well thumbed books in our house! – Amanda, by email.

[580] Tics disappeared on day 10 (September 2007)

Our son was diagnosed with Tourette's at the age of six. He had substantial tics, but no behavioural problems. I decided to apply the complete elimination diet (not an easy process.) By day 7, I was quite despondent with no obvious improvements and then miraculously, by day 10, his tics had disappeared. He had been experiencing severe eye, mouth and head jerking tics for over 2 years. I haven't yet narrowed the tics to any specific reaction. Thanks for your amazing website - it definitely saved our boy from a very troubling syndrome. - by email

[578] Tics related to salicylates in summer fruits (September 2007)

My son very suddenly developed mild facial (rapid blinking eye and lip biting) and vocal tics (sounds like a quiet grunt or throat clearing sound) at a time when I think his hyper/silly behaviour and other food intolerance symptoms escalated, probably in response to his increased consumption of summer fruits, salads and juices. Other symptoms included: loud voice, bed wetting, sinusitis, teeth grinding. All of his favourite foods were high in salicylates: strawberries, apricots, rockmelon, tomato, cucumber, capsicum, broccoli, vegemite, spag bol, apple juice etc. His diet contained few foods with colourings, flavourings and preservatives as I've always tried to encourage "healthy" foods which he has been very willing to eat.

We noticed some improvement (in behaviour, bed wetting, teeth grinding but not tics) over a week just by changing fruits to pears and bananas, stopping vegemite and tomatoes and switching to low sal veges and Bakers Delight bread. We visited a dietitian and Joe (not his real name) started on the elimination diet. He had a very obvious reaction to sals - hyper like I've never seen him within about 4 hours of starting the challenge. I wouldn't have believed it but my parents witnessed the reaction too! When they visited, he was his usual self, undertaking some quiet activities requiring concentration (jigsaw puzzles, colouring etc), chatting and on his (usual) best behaviour. Within about an hour and half of their arrival he changed into this wild, racing, hyper thing heart racing, unable to stand still, almost a "mad" look in his eyes, silly silly silly etc...the worst of it finished within about two hours and he basically collapsed exhausted and couldn't even stay up to wait for dinner guests that he had been looking forward to seeing. Very strange but so similar to the stories I've read on your web site.

We didn't manage any other challenges before Christmas - felt it too unfair to restrict his diet so severely during the holidays, although I did continue to restrict sals and he doesn't eat many processed, flavoured or coloured foods anyway. We continued along on this basis, watching his sals

intake over a day and over a week, and the tic went completely. His behaviour was much more predictable and stable and very much like the boy I know. He is still bed wetting although I am convinced it is worse when he has had sals (e.g. salad) in his dinner and this seems to be improving, particularly since we have been focussing consistently on his sals intake. Teeth grinding and sinusitis very improved. So I am absolutely committed to continuing our new approach to Joe's diet as we really have seen some big improvements. - by emails over a period of 3 months

[577] Motor tics related to amines (chocolate) and additives (lollies) (September 2007)

We have been following the diet for several years and we have seen the positive effects a failsafe diet has on our hyperactive 6 year old daughter. She does have trouble with expressive language and has been having therapy for a year. If she eats something eg a chocolate or lollies for several days, she starts to stutter really badly and she also makes "jerking" movements with her body. - by email

[471] 319: 320: Chronic tic disorder from synthetic antioxidants (November 2006)

My three boys have been avoiding a number of additives for many years now because of obvious affects on their behaviour and health. Last year my oldest son (then 8 years old) was diagnosed with Chronic Tic Disorder (one step before Tourettes Syndrome). He could not sit still, having tics in his face, neck, shoulders and arms. After a period of time, I realised that this behaviour coincided with an increase in eating hot chips. I stopped my son eating hot chips and THE TICS WENT AWAY. I have since tried him on hot chips and the same thing happens. The culprit ingredient/s here is the synthetic antioxidant 320 (and/or 319) that appears in most chips and oil used for deep frying, however manufacturers of frozen chips, and other products such as packet chips/crisps and dry biscuits do not need to list the additive on the label if the oil is less than 5% of the product. NOT GOOD ENOUGH! How can I help my son be tic free if we don t know when these nasty additives are in certain foods? – by email, Vic

[230] I felt I had a potential psychopath on my hands (February 2003)

I am 42 and live in Sydney with my husband and 2 children. My story centres around my son, Alex who is now 6 years old. Alex is a little toughy, one of those kids who is highspeed, enthusiastic, in your face, adventuresome etc (and that's with a positive spin on his life).

He was born 2 weeks early, but a big boofy boy at 4kg. For the first 6 months he was a wonderfully placid calm child. Feed well, slept well, grew well, didn't seem to cry - dream baby. (Apart from having chicken pox, bronchiolitis and 2 fits in this period he was healthy and strong - though perhaps these illness should have given me a clue).

At six months he suddenly became incredibly restless - people would comment on him being active and a real 'tiger' - Looking back 3 things changed at this time - he started solids, started formula and he started daycare. I also remember noticing his face change. He had had a beautiful round baby face with bright blue eyes, and when he started on solids he got dark circles and creases under the eyes, and his eyes turned green - I remember crying at the loss of my beautiful baby boy.

His first year in day care was diabolical. In a class of 15 babies, with 4 carers they could not cope with Alex. He walked at 9 months and spent his time running around the other babies (that were still immobile) snatching toys, jumping on the babies, shrieking, and escaping - he seemed incredibly bright and had the mobility of a child at least 6 months older. Every evening I was met with the litany of what he had done that day to terrorise the class. The carers always looked frazzled and worn out. Their only solution was to give continuous time out as a unishment - he spent hours every day in a cot that he eventually broke - at the time I lived through it thinking it must get better - in hindsight I see their approach as completely inappropriate - he was too young to be punished - it didn't help to modify his behavior, rather it set it in stone.

He continued through daycare being rough and ready, and some days violent - he found their order and routine hard to take. When he wanted to run in the garden, he had to listen to the story, when he wanted to keep painting, he was told painting time was finished - the structure and lack of freedom drove him mad. And this was a university based childcare with great facilities and high staff to student numbers!!

Our life at home was crazy as well. It was like living with Jekyll and Hyde. Sometimes he would be a delight, other days he would be totally uncontrollable - usually incredibly defiant - he could stick to his point hour in hour out - it was impossible to win an argument - normal parenting didn't seem to work. He also had a habit of making loud repetitive noises.

Going out was a nightmare - he would run away, run into traffic, swear at strangers, try to strangle other children, and on a really bad day would threaten to kill people. There were many times when I felt that I had a potential psychopath or serial killer on my hands. Another characteristic was that he couldn't be told anything - he always wanted to learn first hand.

Harm minimisation seemed to be the best policy - I taught him to cook, use knives safely, chop wood with an axe, use power tools etc at a very young age - on the basis that he was going to find and use these items anyway, no matter what I did to try and stop him. Although he had a few accidents (mainly burns from cooking) this strategy has meant that he is still alive.

At 3 we discovered he had asthma, and glue ear - he had his first set of grommets inserted and could finally hear. At that stage I thought the hearing was the answer to all his behavioral problems, and I am sure he must have felt better being able to hear (Since then we have had another 3 sets of grommets inserted). He also changed to a community based, child centred pre-school/school which

was far better for him. They worked with what he wanted to do and let him learn and explore at his own pace. The other children were attracted to him in an odd way - they were always excited to see what daring deed or brilliant idea he had - he never lacked for incredible ideas or enthusiasm. Despite this, successful social interaction and aggression was still an issue, and friendships were dicey due to his unpredictability.

Another habit he had was ticcing - eye tics, snorting, touching other children, kicking - At 4 he was diagnosed with Tourettes by a paediatrician. (I followed up later with a neurologist who specialised in Tourettes who said that he was just a naughty boy who needed counselling).

I was also seeing the local health centre psychologist -but this seemed to be no more than a chance for me to talk - never really got to address Alex's needs.

Interestingly I found his behavior was always better in winter, and was diabolical by term 4 (I now think this is fruit related!).

By the end of pre-school several parents had started a petition to get him removed from the school - luckily I had the support of the teachers and many other parents and this was stopped dead in its tracks.

I noticed that there were several different levels to his behavior - what I think of as 'full on' and then 'psycho'. I noticed that he became psycho after certain drinks - being sceptical about colour related behavior I started to read the labels whenever he went truly demented and psychotic - of course you can guess what I found - 102 At the time I had no idea that other people knew it was bad - I just thought I had the only child in the world who reacted to yellow colour - particularly as the popular wisdom of the day all said that red colour was the problem. So for the last 2 years I have avoided 102 - this helped a bit - but not totally.

The local health centre's counsellor visited the school and reported that his behavior was Oppositional Defiant - first time I had ever heard of it. The solution was to maximise his 'good interactions' - so once again no real help, and leaving it up to me to be a better parent.

Alex started school at the same child-centred preschool/school last year - he had a reasonably good year but was chronically sick - temperatures, stomach aches, head aches. However as he is so hyperactive, he often didn't realise he was sick, and I had to fight to get doctors to look at him. For example, I took him to hospital with severe asthma/croup - however as he was running around casualty making chicken noises he was not seen to as a priority case - when they finally looked at him, his oxygen levels were dangerously low and he was gasping for breath.

Another time we sat in a waiting room, left till last as he was jumping on chairs (and apparently well) - when he was finally seen the doctor couldn't believe he was racing around - his temperature was 41 and he had acute tonsillitis and a ear infection. He also had a severe salmonella infection last year and was losing considerable quantities of blood, but because of his high energy levels I was told it was just gastro and I was exaggerating his symptoms - it was finally diagnosed as salmonella and he had 2 weeks off recovering - I now know that when Alex is sick I have to force doctors to look for the worst. While I know he is ill, to anyone else he seems too full of beans to be sick - time and time

again the doctors have been surprised when some odd illness turns up (ie scarlet fever, pneumonia, bronchiolitis, to name just a few)

At the end of last year I took Alex to yet another pediatrician - this time about his health - after a year of infections and unexplained temperatures I was thinking that there was something seriously wrong - he took his medical history and noted his pallor, and dark circles under his eyes - and pronounced food intolerance!!!

In December I started him on the diet given to me by this doctor - we removed milk, honey, colours and preservatives - and were told he could eat fruit, vegies and only cold pressed oil.

So - no result - if anything he became worse. While I thank this doctor for pointing me in the direction of food intolerance, his diet did nothing to help. A family friend recommended your cookbook to my mum. Since then I have spent the holidays reading Fed Up, and the cookbook and going failsafe.

We have cut out diary, amines, salicylates, and all the artificial additives, colours, preservatives etc. My mum has been a fantastic support. She is making all the 'extras' ie: jams, mayonaise, biscuits etc. Without her I couldn't have achieved so much. She also rings up food companies and asks them to clarify what their ingredients are, and what type of oil they are using! We haven't taken out gluten yet - not sure whether it is necessary.

And Alex? It has taken a while, but by the end of the holiday he was so much better. He was able to play consistently with children without it erupting into a major argument. Parents and friends have noticed the difference. I have also noticed that he is now able to be disciplined. He can hear what I am saying and understands when his behavior is wrong and I can now win an argument.

Last week was the first week back at school - first day was fantastic and I received lots of comment about how he changed. Then he started cheating and eating roll ups, muesli bars, chocolate cake and sweets from his friends - by the weekend he was making repetitive noises, chatting constantly, being selfish, crying and was unable to control himself. He visited a friend on the weekend, who had seen him a week before in his good phase, and she couldn't believe the difference - she is now a convert to the idea of food intolerance. In her words it is like he is on a drug trip, and we all just have to wait for him to come 'down'.

So we are back trying to get him adhering to his diet again - he says he wants to - I just have to wait and see. I want to get him back to the point where we can try some controlled challenges!

And the rest of the family? None of us are totally failsafe yet, and are all cheating when we are out, but I believe we all have symptoms that warrant the diet. My 9 yr old daughter is incredibly artistic, but unable to read, and has temper tantrums, I suffer migraines, mood swings, arthritis and occasional depression. Interestingly, my daughter did some market research for a new hyper flavoured snack food a few weeks ago. She came home in an uncontrollable rage to the point that she was throwing herself around the house kicking furniture etc. I have never seen her like that before - and just think, those snacks are about to do that to all our kids - it's criminal. -reader, Sydney

[149] Taking back control through diet (April 2002)

"I came across your book by accident and decided to do the elimination diet before considering drugs for our son, as I have been on drugs for years myself for ADD associated with Tourette's Syndrome. As it turns out, I react VERY strongly to amines. We've only tested salicylates and amines so far. I have been able to reduce my medication by half. It's early days yet, as we've only been on the diet for 32 days and I daren't get my hopes up too much. My son didn't react to salicylates or amines. He is much calmer on the diet; certainly not in need of medication. We already know he can't tolerate gluten, as he has had a lifetime of diarrhea until he went off it. It's exciting to be able to take back some control of one's life through diet." - by email

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