Reader reports from the Food Intolerance Network

www.fedup.com.au

("fragrance", "perfume", "scent", "aroma" keyword only)

[1320] My young son has learnt his "happy" and "cranky" foods, but perfumes are the worst (March 2015)

My 3yr old son Jack is salicylate and benzoate intolerant. I began this journey after googling head banging and your website appeared with a wealth of information on annatto160b. I eliminated everything we were consuming Kraft cheese, yoghurt, ice-cream etc and noticed a drastic improvement. My toddler no longer banged his head on the floor or the walls.

After doing a supervised elimination diet, we spent the greater part of last year learning about failsafe eating and adapting our lifestyle accordingly. We went through the stage of convincing pre-school and family members that salicylate intolerance really does exist and after providing them with fact sheets from your web site they are more understanding.

Jack has learnt his "happy" and "cranky" foods and even asks if certain foods have salicylate or colours in them. A great learning tool was the weekly grocery shopping. The fruit and veg department became our classroom as we would talk about salicylate and foods that make us feel happy or cranky. The curiosity of a then 2yr old is amazing.

Benzoate was our hidden problem though. It was not until severe reactions to phenergan and valium that we joined the dots. Jack required a CT brain scan so sedatives were prescribed. After giving Jack valium, 6hrs later and we were still driving around with a 2yr old singing Playschool songs in short hand and stating I feel funny. Finally he fell asleep - yes that lasted for all of 15mins, we got the scan done and he was still bouncing off the walls at 11pm that night!

I have since learnt that poor Jack has been reacting his whole life. Baby panadol, bonjela, infacol - yes all salicylate and or benzoate as ingredients! In reality we have been making things worse for Jack by giving him over the counter medications that people use everyday in an attempt to ease pain.

Since managing most of the food issues we are now noticing reactions to chlorine, air fresheners (at Nan's) and perfume (visiting aunts). A weekend visit to relatives has become a minefield of scents and hidden benzoates.

Like others I have read about we too notice a difference in behaviour after weekly swimming lessons in a chlorinated pool. After many attempts we have finally got Jack to wear goggles, but he seems to compulsively lick or drink the pool water (I am assuming he is getting some kind of fix from it). The level of aggression following lessons is what led us to draw the link.

It is a constant battle with one so young who cannot fully verbalise what he is feeling, he just reacts with kicking, hitting, head butting, talking gibberish and constantly rubbing his nose and playing with his tongue. Jack's reactions last 8 days and at the end of the reaction he gets very upset and clingy.

Dealing with food intolerance can be very isolating. When you hear comments that your child is a "horrid vicious child", as I have had said to me, it is upsetting. Or being told it would be good if you came to the birthday party late so we can have all the GOOD FOOD (junk full of colours and preservatives) before you arrive.

Perseverance does pay though and family and friends are noticing the difference. My parents can now distinguish between toddler behaviour and a chemical reaction. I would like to say a BIG THANK YOU for all the time and effort you put in to providing us novices with such a wonderful resource. There seems to be an endless amount of information we need to process in order to protect our children and your web site and cook books have been of tremendous assistance. Your efforts keep us sane!

UPDATE 3 years later: to re read our story (above) made me cry. I had forgotten just how far we have travelled on this journey to a new way of living. We still have our good and bad times, but food is under control, it's just inhaled salicylate/benzoates that cause us the most grief.

Jack is now 6yrs old and in year 1 at school. I spent a considerable amount of time educating the principal and his teacher last year on food intolerance and fortunately they were open to being educated! The Principal even made note of a new student having chemical intolerance in the school newsletter, and requested parents be aware that wearing fragrance in the classroom would have an adverse effect on one of the students.

As we all know this doesn't guarantee people will abide by the request, but after years of slogging away, to have the Principal accept the literature we provided him & be willing to assist, was a relief. He did liken food /chemical intolerance to when nut allergy firstly came about. He remembers a lot of scepticism re nut allergy & was willing to accept that food intolerance was a real issue for Jack; the greater community just wasn't aware of it.

The school toilets with the automatic air fresheners are our biggest problem at school. Again though the Principal arranged for Jack to use a toilet in the administration block that did not have an air freshener. This worked for most of kindergarten, but kids being kids the teasing about being different has kicked in, so now Jack is unwilling to go to the administration block for bathroom breaks (which is understandable).

Most of the kids in his class are fine about Jack having his own treats for special occasion days at school, but there are always 1 or 2 kids who like to remind him his food is different (yes, tastier/healthier and home made!). I take cup cakes to school at the start of each term for class birthdays and leave them in the freezer. The lady who runs the school canteen has been lovely, and lets me take homemade pizza or chicken nuggets in and she heats them up, so Jack can have a lunch order just like the other kids.

On reflection we have been blessed with the staff we have encountered at school. I have gotten quiet good at smuggling my homemade chicken nuggets and French fries into McDonalds birthday parties. I did approach them about re-heating nuggets for me, but food safety standards wont allow them to. Now I heat them just before I leave and travel with a heated medipack in an insulated lunch bag. Then there is another one with an ice brick in it for the homemade ice cream cake!

As I said food is the easy part. Shopping centres, toilets, theatres and hotels are still places we try and not frequent too often. Even going to the Doctors is an issue, with other patients in the waiting room wearing fragrance, the hand sanitisers and air fresheners.

We love our **Rainbow Air** and are no longer scared about staying in hotels. Though I still do spend a lot of time researching establishments that we can access without going through lobbies/foyers and elevators. Caravan parks with cabins or your old fashioned single story motels are safest.

Again Sue, I want to thank you for your tireless efforts in guiding us and reminding us we are not alone. To be honest the bad days can be really bad when trying to calm a child high on chemical overload. It is exhausting. To know others in this forum understand and are experiencing similar is comforting. Those in my circle of friends try and understand, but until you see an outburst first hand, you can't fully understand. - Nicole by email

See more: **http://fedup.com.au/information/frequently-asked-questions/perfume-and-chemical-sensitivity-questions#rainbow**

http://fedup.com.au/factsheets/support-factsheets/fumes-and-perfumes

[1208] Nasal screens work for fragrance sensitivity (July 2013)

A dietitian put me on a simplified version of the RPAH diet 9 months ago. I'm fine on a very restricted diet, but am finding that fumes (strong flowers and incense) are immediately producing the same symptoms. As a nun, there are times when I can't avoid them. Do you have any experience with nose filters, which I see advertised on the internet (I was looking at the First Defense Nasal Screens). I wondered if they would do the trick, and enable me to be exposed to some fumes without being hit by the ghastly symptoms. It would be great if they work, as I'm currently having to sit outside our part of our Chapel for Mass when the priest uses incense, and I'd much rather be inside. (Even so, I can still smell the fumes in the room almost 24 hours later, and it is affecting my health for the rest of the week brain fog, fatigue and sometimes a migraine too.)

Two months later ... Good news! The nasal screens have worked really well for me. I've been able to try them 5 days in the past week. It took some getting used to putting them on correctly so my breathing wasn't impeded, but I've improved with practice. I have been able to remain at least an hour in a room with incense, strong solvent glue, and even clean the brass with Brasso, all with no ill effects. During that week I had one day when I was exposed to Pledge furniture polish for about 5-10 minutes and didn’t have the nasal screens on. The result? Within minutes I was confused, unable to think clearly, rather irrational, and then wasn’t up to doing much for the next day or so.

I’m really delighted with the result. It means I should be able to safely make a trip to an important meeting in Australia, which I was a bit apprehensive about, as the thought of being in a planeload of perfumed bodies didn’t exactly please me. If anyone else has a really bad scent sensitivity that is preventing them from doing important things, I would recommend they give the nasal screens a try. The manufacturer said you can actually wear a pair for up to 24 hours I haven’t needed to try that, as I can usually control my exposure, but I did have them on for nearly 13 hours one day.

I eventually obtained mine through the US Company, as the Australian Distributor didn’t reply to any of my emails. They only took 5 days to get to me in NZ, so that was fine. - by email, NZ

[1041] 319: Serious breathing difficulties due to 319 TBHQ (from submission to FSANZ 2006)

I have always been sensitive to perfumes and cleaning products. Until I was 27, the worst allergy that I had suffered was to hair dye which resulted in an all over body rash and swollen lymph glands.

Then about two years ago I had an allergic reaction to some potato chips. This reaction caused my tongue to swell and slight breathing difficulties. However the swelling went down and my breathing went back to normal with antihistamines. Originally I suspected that flavour enhancers were responsible for my reactions. However I have since eaten food with these additives and have not had any reactions. I began avoiding dairy products believing that I had had an allergic reaction to some milk powder in flavouring on the chips. Following this incident, maybe a few weeks later, I went out to lunch with a work colleague to a fast food restaurant and ordered the chilli. As I was still under the impression it was dairy at this point, I felt it was a safe choice. However about 15 minutes after I had finished eating, I started to have difficulty breathing. This was a feeling of a tightening throat and heavy chest. I took antihistamines and could tell that it was not working. So I was driven to a doctor straight away. The doctor almost immediately gave me adrenaline. With this my breathing returned to normal and I was taken to hospital for observation overnight.

As a result of this reaction I was sent to see an immunologist. After discussing my reactions and having skin prick tests done for "standard" allergens (which were all negative), I was instructed to keep a food diary and cross reference the food ingredients that were in my "bad' foods to see if a process of elimination could determine the allergen that had given me my reactions. My immunologist contacted the fast food restaurant to obtain the recipe for me, so that I could begin to eliminate ingredients that had not caused my reaction.

The result was two food additives: 319 (in the oil the potato chips were cooked in) and 385 a preservative used in the beans of the chilli. My immunologist had never come across anyone with this type of reaction to 319 or 385, but agreed with my food diary analysis. Since I discovered this I read the label of everything that I eat. Unfortunately I have had one more serious reaction to food additive 319, due to a misunderstanding between myself and a relative who used oil with additive 319 to cook otherwise additive-free fresh meat. So I now avoid foods (mainly oils and foods cooked in oils) with these additives and have not had a reaction since. My sensitivity to perfumes and cleaning products has become worse since the development of my allergy. My sensitivity to perfumes and cleaning products has become worse since the development of my allergy and I was warned that since my allergy developed as an adult that there may be other additives that I can become sensitive/allergic too. – Caroline, by email (Presumably the original allergy to a hair dye was to 319 TBHQ, see LaCoz reference in **320 Synthetic Antioxidants Factsheet**)

[1023] Victoria's CFS & perfume sensitivity story (May 2011) COURAGE AWARD

My daughter Victoria is now 13 years old. When she was five she became very unwell with a gastro bug and was quite ill for three weeks (vomiting, diarrhoea, nausea). The sensation of nausea did not go away after she recovered. After some weeks we were referred to a paediatrician who diagnosed nervous dyspepsia. I knew this was not right and asked to be referred to a gastroenterologist. The GP reluctantly did so. The paed gastro specialist did an endoscopy and found a helicobacter ulcer which was then treated with antibiotics. Unfortunately the nausea remained, and diarrhoea started to become more of problem.

We were referred to a dietitian who dealt with intolerances and followed her elimination diet to the letter with very little improvement. I understand now that this dietitian's diet was quite relaxed and included many foods in the moderate category (yoghurt, mangoes, just ripe bananas, Colby cheese etc). We abandoned the diet after three months and just ate home-cooked plainish food with no artificial additives (this did include a range of organic fruit and veg).

For the next six or so years we battled with Victoria's health. The tummy problems continued (nausea, diarrhoea). Her immune system was poor (she caught everything going around). She was irritable, impatient and not affectionate. She constantly had dark circles under her eyes. And then about three years ago she began to suffer frequent headaches mainly sinus ones. She was just never well.

We went everywhere and did everything to try to help her (blood tests, acupuncturist, paediatric allergist, naturopath, eye tests, physiotherapist, ear/nose/throat specialist you name it we did it with no improvement).

Now it is relevant to talk about myself for a moment. For 20 years I have had turns where after eating out I would become really unwell. This was usually at a restaurant. First I get nausea, then feel faint and break out in a cold sweat followed by vomiting or diarrhoea or both. Sometimes I do actually faint. Even though we had not had any success with the early (relaxed) elimination diet I did learn about food chemicals at this time, and realised that it was ultra high-amine foods that I was reacting to (e.g. camembert cheese followed by aged beef with wine gravy etc).

Now cut back to mid last year one evening I prepared a meal of very fresh roast organic chicken (with skin) and homemade gravy, potatoes, broccoli, cauliflower and peas. After eating some of her meal, Victoria had a similar reaction to the ones I described above. This was the first time she had had the same type of turn as me. I recognised that this meal was high in amines (but not too high for me) and realised that amines were a problem for her.

So then I read your books and went to a new dietitian (dealing with intolerances) and discovered that Victoria needs to eat a diet low in all food chemicals. If she does stay absolutely strict she is reasonably well. The nausea problem has reduced dramatically, as has the diarrhoea. She is less irritable and more affectionate. Her headaches have reduced. Her immunity is better. We have seen a real improvement!

Her diet is very limited. (Unfortunately, she is also intolerant to raffinose, so she can't even eat all the vegies in the low category!) We have to get our meat from a butcher who phones me the day the beef arrives from the abattoir, and I go that day and buy (and freeze) meat for the next month. She is very sensitive.

Victoria's sinus headache problem is certainly affected by food chemicals - it has improved quite a lot on the elimination diet, but a whole range of environmental allergens seem to trigger it too. The grass being cut affects her. Walking through the detergent isle in the supermarket affects her. The smell of perfume and cosmetics affects her. Household chemicals affect her. Some particular irritants:

- Hairspray and other spray-on hair products: She feels an urgent need to remove herself from the smell of these products. She feels she can taste them and they cause her a serious headache. We can't go to a normal hairdressing salon - she says they are toxic. We have our hair cut at a home salon and the hairdresser doesnt use any products on us.

- Dust: she is aware of dust if it is around and finds it unpleasant because it irritates her nose, but it is not until later that she develops a sinus headache. These headaches can be quite bad and last for many days.

- Perfumes/aromatherapy scents: these smells are all really distasteful to her. She feels nauseous and headachy in environments that are scented. She has a strong feeling that she needs to leave.

- Garden smells and pollens: she is very aware of them - they make her nose feel sneezy and occasionally she develops a headache.

- The smell of clothes washing detergent and other cleaners are most distasteful to Victoria. The skin on her face flushes and feels irritated, and she develops a headache if exposed to the smell for more than a couple of minutes. For washing sheets and pillow cases I often just use a hot water cycle with no detergent and dry them in the sun. They look and smell clean to us. For washing clothes I use the skin care cycle on our machine which uses more water and does an extra rinse, and just use a little OMO Sensitive or Earth Choice Sensitive. Once again, things come out clean, even with less detergent. We can't detect a fragrance after washing and drying in the sun.

- If we happen to wear a garment that has been washed in normal fragrant powder for whatever reason, we both feel unwell and get a headache. I developed a very severe headache that lasted for days once (years ago) as I had lent a shirt to someone and they returned it after washing it in normal detergent and using Fabulon during the ironing process. I foolishly wore it to work and became so unwell and dizzy that I had to go home sick! We ourselves use Mitchum unscented deodorant, QV non soap alternative, Bod ultrasensitive fragrance free shampoo and conditioner purchased online from Biome or Simple shampoo and Conditioner ordered in by our local pharmacy.

- Victoria notices and dislikes the smell of petrol, cigarette smoke and basically anything else with a strong smell.
- Oppressive humid weather gives Victoria (and her grandmother) a sinus headache.

I suffer from sinus headaches too, and all of the above affect me, but I am not nearly as sensitive. Victoria and I both have a fantastic sense of smell. We can both smell cigarette smoke from a neighbour smoking in his back yard four big house blocks away. We are both super sensitive to food smells as well, especially protein foods (which of course comes in very handy with catering for an amine responder!)

One of the many specialists we have taken Victoria to is a paediatric allergist. She took one look at Victoria and commented that she looked like an allergy sufferer. She noticed (amongst other things) the dark circles under Victoria's eyes and a wrinkle or line across her nose that indicated constant rubbing of her nose. Victoria was tested for a wide range of commons allergens, but the skin prick tests did not reveal allergy. The specialist said that she was surprised, and recommended Victoria use a saline nasal spray (which she does) and use antihistamines when needed as she may be allergic to things other than what she was tested for.

The whole body load issue is certainly relevant for Victoria. How badly she responds to irritating food and smells certainly varies according to the load on her body school stress, PMT, illness etc. She is definitely doing better on a diet of all low chemical foods, but it does not take much to upset her balance.

When Victoria is not doing well she feels overstimulated very easily by light, noise, smells (of course) and other stimulants. She also has poor volume control at such times, even though she is usually a quiet girl. Another recurring problem is urinary tract irritation not pain or burning just a constant feeling of needing to dash to the loo.

I have two other things I wanted to mention (for what they are worth):

- Victoria is gifted. She was accelerated a whole grade in primary school and excels academically. I nearly choked on my tea when I read in one of your books that we 'should not blame bad behaviour on giftedness' - I had been blaming her prickliness, impatience and irritability with others on giftedness to some degree.
- We have very recently discovered that Victoria's blood levels of Vitamin D are in the normal range (55), but only barely. Our dietitian (from the failsafe list) says that in her opinion the bare minimum should be 75 and we should be aiming for 100. She says that recent overseas research indicates that there is a link between intolerances and low vitamin D levels. We are trying to get Victoria into the sun for safe periods every day to improve this, and will test again in 3 months …

Update 3 months later: We have actually been faring better over the last month or so. We had a re-test for vitamin D levels and to our surprise discovered that despite trying to increase sun-exposure, Victoria's levels were still at the low-normal level of 55 (normal range is 50-300). Our dietitian had suggested previously that we should aim for higher than 100. So I decided to try a failsafe vitamin D capsule. I don't know if that has helped, or it is just a co-incidence, but after a couple of weeks Victoria seems to be back to faring quite well on the low-chemical diet. I am cautiously optimistic.

What a long story - and this is only a small part of it! Thanks very much for your wonderful work. Your books and website are fantastic. I am very grateful. - Carol, by email

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

I've become increasing 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 of 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

[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.

[804] Fragrance free spray on deodorant for fussy hubby makes a difference (June 2009)

Just a quick note to say thanks! I react very badly to any synthetic style fragrances and hubby refuses to use a roll on. My pharmacy ordered in the QV unscented spray deodorant you recommended and fussy hubby has used it no problems. I also bought the Schick sensitive shave gel (unscented) that was mentioned in the newsletter (Big W stocks it). No more headaches, watery eyes and sneezing for me in the morning now. WooHoo! – Danielle, by email

[799] Warning: Perfumes in masks for kids' anaesthetics (June 2009)

I work in an operating theatre. One day last week we had a few kids on the list and I asked what the awful smell was. The result after process of elimination was, it was the oxygen masks. It seems that the kid size oxygen masks now come scented. I'm referring to the masks they hold over the face as the patient is going to sleep. I asked why they are scented and apparently it's supposed to be less stressful for the kid if it can smell something nice.

SO, to the parents of kids that are sensitive to smells, make sure you ask the anaesthetist about the masks if your child needs an operation. I don't know if we've still got unscented ones, I couldn't find any (but that doesn't mean anything). I made a point of letting them know it could cause major issues for kids with problems and all I could get as a response was, "but it's non allergenic". AARRGGGHHHH!! We've got cherry and strawberry, which don't really smell like they should. - Jane, by email (Like the fruit they represent, strong fruit flavoured perfumes will be high in salicylates).

[700] One-liners (November 2008)

- I recently brought some 'Pledge Grab it Orange Citrus scent' use-once dusting cloths because I couldn't find the unscented ones, and I didn't think these would be too bad, but they were. Very strong smelling and gave me a headache. I should have just stuck with the wet dishcloth for dusting. – by email

[633] Severe eczema related to salicylates and fragrance (February 2008)

I posted very early on when this site first started with my son's story of very severe eczema (on the soles of his feet) which took three months to clear, and was related to salicylates. We started Failsafe though because of behavioural problems and had the added bonus of the eczema clearing up completely. He also reacts badly to heavy chemical fumes such as chlorine, ammonia etc (airborne salicylates).

Anyhow, recently he had a major behavioural reaction, I was absolutely sure it was not food related. He was attending Vacation Care at the time. Recently he came home and just happened to mention that one of the ladies had sprayed something on the table he was sitting at, and when he asked what it was, was told 'Don't worry Chris, it won't kill you' (grrrr from me - what if he had been asthmatic?). Anyhow I decided to investigate this, as I could find no food reason for the deterioration of his behaviour.

Turned out that they had been spraying Dettol (or something that smells very similar) on the lunch tables, and regularly spraying air fresheners. (I have since talked to them and they now make sure he is nowhere near when they are spraying stuff around, and he has been fine since).

Anyway, that was the same time he started complaining that his feet were sore - I checked and there was eczema on the soles of his feet again (first time in two years of being Failsafe). Just thought this might be helpful to some out there! It can be more than food! – Jenny, NT

[632] Affected by fragrances – 4 reports (February 2008)

Fragrances have been my bugbear for years, and I find if I go anywhere where there are fragrances, I am usually 'unwell' for 2 - 3 days afterward depending on the length of time of exposure. As a consequence, I try to avoid doing my shopping myself, and also avoid attending church in the hot weather, as this increases the effects of the fragrances in the air. – Merryn, Vic

When I was a child I used to be unreasonably uncomfortable when in the hairdresser, and could not handle being around people with strong deodorant or aftershave or perfume, and I still can't. - Michael (now 25), NSW

I always get a rash from perfumes but never suspected that perfume could be the cause of my headaches too, until I read your website. - Marilyn, Qld

I read in your newsletter about a mum who has trouble with her kids when she enters shops and toilets – in the past I have bought various 'Impulse' type body sprays, and within a few minutes I feel anxious and very touchy. – Michelle, by email

[531] ODD reaction to spring flowers and Floriade (January 2007)

A reply to the question in newsletter #50: my oppositionally defiant amine-sensitive daughter is having a hard time at the moment and I am wondering if it might be due to spring flowers?

The question about ODD and spring flowers in the last newsletter rang a bell with me. My daughter Louse also gets really cranky and her ODD symptoms worsen during the period when all the wattle begins to flower, and then in early spring when the flowers start to bloom in abundance. Unfortunately, this also happens to be the exact time when she has to be most in control of her temper and emotions due to her Irish dancing commitments - the state and national championships.

This year was particularly bad - there seem to be so many more wattle trees around here now, and they started blooming at the start of July. Louise was extremely bad-tempered - her quality of schoolwork declined, her spelling declined (even though she is now a voracious reader) to the point of going backwards, maths dropped back to grade 3 level (age-wise, she is year 8) and there have been many arguments and temper tantrums with all family members. It got to the point where I was beginning to doubt my sanity! and also, whether she was sneaking non-failsafe food from other sources - but I know my friends wouldn't give her anything unsafe, and her friends just don't like her behaviour when she deviates from the diet, so that wasn't a factor.

I was thinking that the culprit might be pollens. It was totally validated when we went to Canberra in the last week of September for the Australian Championships. One word – FLORIADE - Canberra's flower festival. Yee-hah. All that pollen in one convenient location! Louise’s dancing was shocking during practices, she argued with her friends over the dancing (SHE wasn't making mistakes, EVERYONE else was), arguing with her teacher (who she loves), crying, picking fights, "I wish I'd die, then everybody would be happy, because nobody wants me around" - I'm sure you can imagine the rest!!!

It's getting better now, I've cracked down on a few infractions, and she is asking her friends not to spray their deodorant near her (and at dancing, spraying deodorant, hair-spray or perfume inside the hall is now banned) and she's taking a claratyne daily to help with the pollens. She's definitely a reactor when it comes to pollens and spring! – reader, Vic

[410] Thank you so much for giving us our darling little man to us (May 2006)

I was lucky enough to come and see you talk recently. Our son is nearly 8 years old and I reckon for 7 of those years he has been very hard to handle, episodes involving throwing things at me, chasing me, yelling, getting so upset he would go blue and lose his breath. We have taken him off a lot of foods you recommend not to give your children, and his behaviour improved, episodes consisted of whingeing or crying for 10 minutes instead of hours. Since seeing your talk, we have cut out a lot more foods, and I have stopped using my beloved Red Door perfume, within a week we have seen an amazingly different child, he now sits with us, not hyperactive, yes mum, no mum. I said to my husband I am overwhelmed as for the past 7 years I have known a naughtier child. We both want to thank you so much for giving us our darling little man to us. We have the opportunity to give him a better way of feeling and acting, it is all to you, although I miss my perfume, I have now given it to my mum and my husband and I are enjoying some special days with our child. We now only feed him fresh foods - no processed foods, home made cooking for school lunches. Thank you so very much - parent, Victoria.

[353] Sensitivity to perfumes, jasmine and basmati rice (Nov 2004)

Have just discovered your website and it's a great relief to find out that I am not the only adult in the world to have sensitivities (specifically fumes and especially perfumes - solved by getting off buses, changing carriages or seats in trains, changing seats in cinemas and theatres; food additives – and the ubiquitous jasmine and basmati rice - solved by avoiding all Thai/Indian and some other Asian eateries and even some coffee shops and restaurants.) It's been too long a time whereby non-sufferers usually laugh at my "discomfort" and disbelieve: "you're making it up - it's your imagination!" Thank you. - by email

[325] Autism - on or off-diet during assessment? Readers' opinions, please (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, 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.

[260] CFS and failsafe (June 2003)

A bad case of Glandular Fever triggered my CFS, which resulted in two miserable years of bouncing from one medical practitioner to another trying western medicine and other alternatives such as acupuncture. The responses were often unsympathetic and showed a complete lack of understanding about the condition.

It was through a recommendation from the CFS society in Melbourne that I saw a failsafe allergist.

It took nearly three months on a very strict elimination diet before I felt my old self again and the glands in my neck no longer felt like golf balls. It wasn't long after the three months that I was back working in the outdoors. With hindsight the recovery was remarkable after spending so long with little to no energy.

The nature of my work made it very difficult for me to effectively reintroduce all foods so I am still unsure of all the chemicals that affect me. However, MSG is a shocker!! as are most preservatives. When I start feeling the CFS symptoms coming back I put myself back on failsafe.

Despite a careful diet I still need more sleep than most people (9 - 10 hours a night) to function effectively. I rarely drink alcohol, this makes the CFS symptoms worse and I seem to be very sensitive to strong smells such as deodorant and perfume. I definitely feel better when living outdoors.

Without a doubt, going failsafe saved me from years of depression and frustration. I never take my good health for granted after being so deprived of the lifestyle I love. - Amanda, Melbourne

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

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

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

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

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

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

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

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

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

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

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