

Reader reports from the Food Intolerance Network

www.fedup.com.au

("doctor" and "GP" and similar keywords)

These are some edited reports, not exhaustive, most from just the last two years.

See links to full stories for more information.

See [list of experienced and supportive dietitians](#)

POSITIVE

I am new to food intolerance but I have had my 4 yo son to the doctors in the past (and just been fobbed off) for pains in his legs, tummy aches, stuffy nose and mouth-breathing. He grinds his teeth at night, over-reacts to situations with anger or tears, does not seem to sleep much and complains about loud noises ... One month later ... We have been to a dietician from the list you sent. It was great advice as it really smooths the way when having to deal with doctors and other govt. agencies - they are now very accommodating. We are into day five and I have already noticed the voice volume decrease and far less fighting between the two children. So thank you to you and everyone who contributes info, it saves so much time and mistakes. – Anna [\[1094\]](#)

For the last 15 years I have known of intolerance's and have had the book "Friendly Food". I have tried half heartedly to follow the diet but never with help and always with weight loss. I am now 40 and can see that at least 4 of my children suffer symptoms though not all the same as mine. It is hard for us to get supplies up here. **A recent doctor's visit introduced me to your website.** It is wonderful. I finally feel that I am not the only one - Adelle

I have recently broken out in hives all over my body and **my specialist has recommended your website. It's a great website with lots of helpful information.** I was told to stay away from foods that are high and very high in salicylate – Anita

I have been on the RPAH low salicylate diet for many years with tremendous success in controlling very severe asthma ... **My doctor ... has been very interested and supportive of all the food intolerance information. He is quite a convert!** As well as asthma, I also had very bad nasal polyps. Had two lots of very painful surgery to remove them. When I stopped using the nasal spray the specialist prescribed they went away and never came back. My GP was totally convinced!!! - Krys aged 78 [\[1606\]](#)

I am 23 years old and I have had Chronic Fatigue Syndrome for two years now. I thought I was never going to get better. It seemed the healthier I thought I ate (lots of fruits and veges!) the sicker I became and the more weight I lost, along with many other symptoms including headaches, muscle soreness and weakness, bowel disorders. You name it I experienced it! At my lowest weight I was 32kg which was a total loss of 30kg. After being an elite athlete I can assure you this was very frustrating. **It was only when my fantastic doctor happened to come across another patient who had the same problems as me** that he was pointed in the direction of the allergy clinic at Royal

Prince Alfred Hospital. Through a dietitian there I was put on the FAILSAFE diet and dramatically improved within two days. Even though this meant that I only ate fish, rice and chicken for four months I didn't mind because I no longer had stomach pains. I am now able to tolerate most foods on the low list although not dairy or gluten. That may not sound like much but to me I can eat a huge variety compared to what I started out with. I have managed to put on 12 kg and am almost ready to return to a bit of part time work! **I can honestly say that this diet saved my life** - Emma, Sydney [\[034\]](#)

Haven't been in hospital with anaphylaxis since I began diet. Was going every 2 weeks, covered in hives swollen like a balloon constantly, on daily nebulisers and worsening asthma. I am only 36. Now no migraines, arthritis died down, no pms, cholesterol now normal, blood sugar normal, hives anaphylaxis gone, asthma improved and in combo with Fodmaps goodbye IBS. **Immunologist who put me on diet has literally saved my life** – Josephine [\[1421\]](#)

NEGATIVE

Received after this story collection was mentioned in [blog](#):

I can't express how grateful I am to you for the information on fedup.com.au, I have suffered with several intolerances for about 15 years. I've had no luck or help from multiple GPs...

Gut issues are such a common problem now as is arthritis, and, as a sufferer of both, I greatly appreciate your dedication and commitment.

At 71, looking back, I can see that heredity can play a big part in gut issues. My father had them, resulting in having a part of his bowel removed which then resulted in very painful adhesions. He was told by his doctor that he probably had cancer, which turned out to be incorrect! My daughter also suffers from gut problems.

My son constantly wet the bed, soiled his pants and had serious behavioural issues with dramatic and stressful outcomes. The soiling went on until he was well into his teens. Unfortunately, at that time, there was no internet access, and no information or help available from any of the professionals we talked to. We had no idea it could all be caused by the food he was eating. After years of being in and out of several rehab centres and courts, stints in jail and drug use, he died of a drug overdose at 26. It breaks my heart.

A very heartfelt thankyou for everything you do – Lorna [\[1655\]](#)

I am new to food intolerance but **I have had my son to the doctors in the past (and just been fobbed off)** for pains in his legs, tummy aches, stuffy nose, he over-reacts to situations with anger or tears and does not seem to sleep much ... One month later ... We have been to a dietitian from the list you sent. It was great advice as it really smooths the way when having to deal with doctors and other govt. agencies - they are now very accommodating. We are into day five and I have already noticed the voice volume decrease and far less fighting between the two children – Annette NZ [\[1094\]](#)

None of my doctors have ever mentioned that salicylates are in foods. After coming across this information I realised that almost every diet change recommended to me by the doctors has caused my salicylate intake to be astronomical. It's no wonder I've been in and out of emergency rooms – from USA [\[559\]](#)

This time last week my 3 year old son was crying in pain from the welts, open sores and eczema that covered his entire body. I had ice packs on him and was dosing him up with pain medication, steroids and anti-histamines... again. He has suffered like this from 4 months old. We have done everything under the sun to help him (and his older brother) but nothing has really worked. We use steroid creams every single day, as well as wet wraps etc....**Their skin specialist denied that eczema has anything to do with allergies or food intolerances.** Over and over she said "they are born that way, the creams are the best way to help them". Well, after much research and getting in to see a dietician, I started my 3 year old on the strict failsafe diet on Monday (we were already gluten and dairy free). Within 24 hours the redness in my son's skin was gone, he had stopped scratching. Within 48 hours his sores had stopped oozing and started to heal. Just 7 days in and his skin actually feels human and not reptilian. He keeps telling me how much better his skin feels and for the very first time in his life he slept through the night. The WHOLE night!!! I'm blown away and kicking myself for not doing this years ago AND very scared to start challenges. I have had them on an organic fruit and veges diet, full of fermented and cultured foods, bone broths etc. turns out I was making them worse. But all in all, a result I had never even thought was possible! You can see the massive improvement in the pictures! – Emma [\[1454\]](#)

Comment after story [1096] 2012 was published (bedwetting due to 282): Thank you for all the additional information. I will definitely follow up on your suggestions. I want to do the full elimination diet for the whole family, but given our time restriction with the upcoming school trip, I might just start by cutting out all the colourings, additives & preservatives, the salicylates, and maybe even dairy for Robyn since several of your case studies implicate dairy in challenging wetting cases, like Robyn's. **I have to ask what is wrong with our Western medical system when Robyn can make it straight from a GP to a Urologist, who is above considering anything non-drug or surgery-related, without anyone first asking basic questions about what she eats, what her sleep patterns are like etc – Betty**

I have stumbled across your web site on a quest to find out more information about the dangers of colours in foods. I have a three year old daughter who suffered through the first three years of her life with horrible self destructive tantrums and irritable bowel. **I was told by several medical professionals that "raising a toddler is very hard and you should take some parenting courses"** and "we can try her on ritalin and see how she does" I refused to believe it was either and have self diagnosed her with an intolerance to dyes in foods and drinks. Our family including her 6 year old brother (who we raised quite well without any courses!) have all had a much happier time just being a family. Your website is a very good and informative one. Thank you and I look forward to your next newsletter – Carol

I wish that every-one in the medical profession would learn more about Intolerances and be more open minded about how foods affect our children... you are a true inspiration. You have helped many families to have healthier, calmer kids – Sandra

Needing help desperately! I have a now 10 month old baby with suspected Cow's Milk Protein Allergy. Would the failsafe diet work for him? People say that I can't give him soy as he would react to that as well, what should I feed him? I'm concerned about his calcium intake once he goes off his formula/breast milk. He is on medication for reflux, and most days he has very irritable periods, especially mornings and evenings. You could describe his as a demanding baby, but of course he is gorgeous :). Also, I have a 3 1/2 year old with chronic constipation and has been on osmolax since he was 12months. His diet is "healthy" in my opinion, but could it be possible that I am feeding him the wrong things? Is there anyone that you could refer us to?....**I'm done with paediatricians who say there is nothing wrong** - Kelly

I have come up with a huge rash on my lower back, legs, arms, hips, bottom and face. I went to the GP today and they said it isn't shingles. I bought your book and I am currently reading it. I have had allergies now for 30 years and absolutely no one has told me what you have told me in the 1st three chapters of your book. Doctors originally thought it was acidic foods, so I didn't eat anything but potato, carrots, pumpkin and sweet potatoes and sometimes peas for the 1st 5 or so years of my life. I then went to a dr that said try preservatives, that helped but I was still having issues. I then "grew" out of it until I was 17, then my hands wouldn't stop flaring up. **Every dr thought it was toxic chemicals and did nothing**, then at the age of 23 I got an IgA/IgG test done and it came up that I was allergic to dairy. So I didn't eat any dairy. Now I am here with a huge rash on my body and quite frankly had enough of no one knowing or caring what is going on with me – Rennie

Matt also suffered from 'glue ear' which is also being blamed for a lot of his gross and fine motor problems. He was three years behind when he started with the O.T. In three months he has caught up 12 months. **His Eustachian tubes are now clear yet the E.N.T doctors just said he was "in the too hard basket". I believe that food intolerance is responsible for most of my son's problems and that if I had known he would not have wasted four years of his life. It makes me so angry the way we mothers are treated by health professionals.** There was an article in the Sunday Herald Sun magazine just recently which was an interview with a mother who said the diet helped her son's asthma. On the same page there was an interview with the head dietitian at the Royal Children's Hospital in Melbourne saying that the relationship between health and behavior was debatable and that it really hadn't been proved. BULL!!!! ... It can be really hard (I am a single mother without a great deal of father support) but really rewarding at the same time. Laughing and crying at the same time makes life interesting. I wouldn't swap my son for the world. – from story [\[075\]](#)

Monique cried a lot as a baby and suffered with severe asthma from just a few months old. I sought doctor's advice - there was not much support with the excessive crying but she was prescribed medication to treat the asthma ... The medication did relieve the breathing but it hyped her up and caused agitation ... I breastfed and I now believe due to her food intolerances that breastfeeding may not have been the best option for her. Our diet often consisted of tomato based pasta dishes, and also fruit and vegetables that I now know have a high salicylate content, which of course would have filtered to the baby ... As the years passed we were dealing with behaviours of agitation and frustration ... I knew she did not want to be like this. **On the rare occasions that I would address the problem with a doctor in many ways I was relieved that a diagnosis was not offered because I did not want her on medications that are usually prescribed for the aforementioned conditions. Nor did I believe that medication was the answer ...** The doctor still really did not have much to offer. So I asked him "have you ever heard of salicylates?" He said he had, so I further asked he had any

lists of the foods that contain salicylates which fortunately he did and gave it to me ... reading about salicylates and learning where they are helped me to eliminate the foods from her diet and this was the answer. Life soon improved for everyone especially Monique, including no more asthma - Annie [\[1652\]](#)

After four months the sleep deprivation really hit home and **we began doing the rounds of the doctors in an effort to establish the nature of the problem. We had no answers apart from maybe it's colic, watch your diet, cut out brassicas, fruit juice, yellow stoned fruit, onions and garlic. No one mentioned cutting out dairy, tomatoes or tea!** ...The paediatrician was most unsympathetic ... she gave Emily Rose a cursory examination and pronounced her a 'bright' baby ... Her whole attitude was 'look, I have a three year old and he still doesn't sleep well, so just learn to live with it!' - Simone [\[007\]](#)

I had IBS (lots of other issues, too) and **my Dr. put me on the FODMAP diet. I didn't find it to be helpful for me.** But posted on the FODMAP Facebook and a wonderful Dietician told me that I probably had an issue with "naturally occurring food chemicals" – Karen [\[1630\]](#)

Failsafe changed our lives. Our son couldn't stay on task long, struggled to deal with other people changing what he was doing/playing with, etc. We have been failsafe for over a year. **We did doctors first but got nowhere even with sample testing, hydrogen tests, ultrasound tests, etc** – Donna [\[1612\]](#)

Countless doctors looked at us puzzled, one day a different doctor put it down to allergic rhinitis and prescribed a nasal steroid ... [BUT] her extreme emotional outbursts were a result of yeast extract (MSG) like vegemite and it lasted for 3 days before it wore off Danielle [\[1607\]](#)

I have had food and chemical intolerance since the 1970s, diagnosed in the US. I am 77 and really my whole life has been a struggle with allergies! Now I live **in the UK where doctors are very scathing about these problems,** particularly the seizures. I have been ridiculed and shouted at by medical staff and had concussion when I was allowed to fall on the floor – Sarah from UK [\[1605\]](#)

The doctor was mystified at my prostatitis since I had never had any prostate issues at all, had no infection, and didn't even have the enlarged prostate ... because as a vegan I do not follow the Western diet. After 72 hrs I stopped the four hi-sal foods. The pain disappeared completely within 24 hrs and has not recurred within the following 14 months. It seems likely to me that this incident was caused by excessive salicylates - Tom [\[1600\]](#)

My son is 4 months old, breastfed and was waking every 45 minutes at night and very unsettled / uncomfortable all day. I knew it was food related but **struggled to get the doctor to even acknowledge this was possible.** Having gone on meat and veg he is sleeping 4-5 hours in a row - Beth, UK [\[1595\]](#)

A doctor looked at my frequent hypoglycemic episodes and diagnosed insulin resistance. I was put on a strict low carb diet. It helped because I cut back drastically on fruit and I lost heaps of weight. But I was miserable, hungry all the time. It wasn't until I discovered salicylates that I learnt I was reacting to the salads and not the bread – Jen [\[1579\]](#)

For several years I had trouble swallowing food. I had gastroscopies to eliminate a diagnosis of gastro-oesophageal reflux disease (GORD) and Eosinophilic Esophagitis (EOE) but everything was completely normal. **My doctors all assumed it was an anxiety symptom, even though I didn't feel anxious about anything other than having difficulty swallowing food ...** I started the failsafe diet in August last year on the advice of my dietician ... now I have no trouble swallowing food ... I've realised something important about myself: when in doubt about the cause of anything weird going on in my body, it's probably food – Thea [\[1566\]](#)

It's very frustrating, **I went to the doctors for a good 4 years and kept being turned away and told it was IBS** in the end I thought I was going insane! – Jan [\[1556\]](#)

The following all from [\[1298\]](#)

After seeing the paediatrician yesterday and telling him that I have started on failsafe I was expecting some sort of support from him, not just being told that "there is no evidence that those kinds of things work blah blah blah, but I won't tell you what to do, it's your choice" - Jessy

A lot of paediatricians react like this, it's not uncommon unfortunately. These paediatricians do not have to live with us when our children are at their peak. Rest assured there are some paediatricians out there that do support and even suggest the failsafe way - Alex

A lot of doctors do not like the elimination diet. My doctor is certainly one of them - Serena

I had my doctor ringing me and asking me what book I had read because he had a patient like me in his office - Tracy

There is evidence for the RPAH elimination diet, just that most Doctors lump all diets together - Shelly

I am a senior and I have been getting the "there is no evidence blah,blah, blah" reaction all my life and it is so frustrating - Michele

Some practitioners are only slowly catching up with what naturopaths have been saying for years. After hearing GPs say for decades that studies show no link between dairy and allergies, hayfever, asthma etc (MANY people experience otherwise) there was a program on ABC's Catalyst program last year linking diet and gut health to a myriad of diseases (oh what a surprise). Even the GP that was hosting the program made a passing comment that he had taken himself off dairy after repeated sinus infections. Wow! What an admission/revelation! - Bron

There is evidence. The RPAH is a mainstream hospital, using evidence-based approaches which include diagnostic challenge and confirmation. Unfortunately, there are a whole lot of other diets often recommended, for which there is little evidence, and which simply claim any benefits as due to the restriction without ever checking if it's the diet itself that's responsible. I imagine most are very tired of having people present with all kinds of ideas that they found on the internet - Tracy

I don't even mention food intolerance to Drs anymore. All the ones I have come across (except the ones at Westmead who recommended it) are negative about it. I can see the difference, a huge difference and it makes all our lives much much easier. I don't need a GP to tell me it doesn't work when I CAN SEE results myself. It would just be nice if they were more supportive - Shell

A lot of Drs base a lot of their advice on their own beliefs, old fashioned views that are biased. We are 3 months in massive change. I was worried it wasn't making a difference, but when he consumed amines and went off his dial I can see just how much - Corina

My last paed appt cost \$370 (before Medicare rebate) and I left with the advice that 'I don't believe in reflux' and 'there is no point doing elimination diet' as well as 'yes as you've discovered he has issues with dairy, how long do you want to breastfeed, I'll give you a script for formula' to which I replied thanks but no thanks - Vicki

Doctors aren't trained in nutrition! They honestly have no idea - never take nutrition advice from a doctor unless they have additional training. There is a list on line of doctors who also have qualifications in nutritional and environmental medicine www.acnem.org/find-a-practitioner - Tara

I haven't mentioned it to our GP as I feared exactly the same reaction. The dietician I saw was wonderful though. I saw a doctor friend last week who had done the diet for her own son (she works at Westmead and diet was recommended by a colleague there for her son's asthma). If only there were more doctors who had this sort of personal experience! - Aila

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

My doctor also told me there's no scientific evidence that food has any effect on children's behaviour. I don't need scientific evidence. If my kids eat chemicals... they go nuts!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! End of story. AND I'm asthmatic... and have been drug free since we eliminated the nasties from "my kids" diets. First time no drugs in 30 years! - Cristi

At an emergency chemist I was given red medicine for my boy. I explained to the pharmacist that my boy has ADHD and was intolerant to red colouring. Thought I would relay the conversation:

Pharmacist: Well it isn't red, its pink so should be ok

Me: Pink is red colouring, he is intolerant to red

Pharmacist: But if you tell him pink isn't red then it'll be ok

Me: No, he can't have anything that is red colouring; red, pink, orange, or purple. If he does he starts spinning around and acting crazy.

Pharmacist: How about you hide it in something

Me: If someone is allergic to nuts, spreading vegemite over peanut butter doesn't make them less allergic. Just like red food colouring.

Pharmacist: Oh, you could mix it with milk to make it paler.

Thankfully at this time a senior stepped in, before I throttled the guy – Julie

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