Reader reports from the Food Intolerance Network

www.fedup.com.au

("lifesaver", "saved my life", "saviour", "life-threatening" or "ambulance" keyword only)

Excerpts: click on links to see the full stories online

[1418] "this diet has literally saved my life" (December 2016)

For me personally, this diet has literally saved my life. Last year I was very sick with constant diarrhoea for months on end, I lost 20 kg in weight & was so weak I could barely get out of bed to use the ensuite. My husband took me from doctor to doctor, naturopath to naturopath & no one had any answers. The more things I took to 'heal' me, the worse I got. We had resigned ourselves to the fact that I would die. I rewrote my will & wrote farewell letters to my boys. It wasn't until I developed hives, that I thought this might be food related. I scoured the internet & found this site. After reading about this diet everything made sense to me. And I haven't looked back since starting it.

My grandmother died last year at the ripe old age of 100 & never had any health issues. Some of that is genetic but I now believe it was also the traditional diet she ate. My parents are both in their 80's & they eat the same diet & are very healthy. Most of what they eat is on the low level - porridge, fresh meat, green beans, choko, eggs, brushed potato, with a few mods as well, carrots, pumpkin etc. They don't eat much fruit & when they do its usually apples & bananas —" — Sharyn

Josephine's story from [1421] Adult failsafers report success – facebook thread (December 2016)

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

[1413] Autism Spectrum Disorder (ASD) diet success for my child which also "saved my life" (November 2016)

For me, I have spent 10 plus years in and out of doctors, holistic practitioners, and have undergone over a thousand dollars' worth of testing and examinations. Until Failsafe, I have had a permanent headache, brain fog, sinus problems, dizziness and angry outbursts (from amines). Through Failsafe, my headache / food hangover that took place EVERY DAY ... all gone within a month Truly life changing. I can now run again (my passion) and do yoga without procrastinating for fear of my bones aching. I have lost 7 kgs and am the lightest I have been since I was in my 20s, BUT I am eating well and healthily. Being able to exercise, and not feel so sick has meant my depression is not as severe and I am able to focus on what's going on around me rather than sit in my own food induced pain and anger. I am also diagnosed autistic and the wrong foods cause my shutdowns and meltdowns to

worsen, so it's not always a social emotional reaction, but a reaction to food that has me feeling so unwell and foggy that I have to shut the door to the outside world. Instead, thanks to Failsafe, it is really nice to feel more connected through all my senses. Lights aren't so bright, sound is not so loud, and my partner can touch me on the arm more without me jumping a mile.

With salicylate reduction — I can empty my bladder!!! I used to get up at least six times a night (and that's not counting the six times I would go before falling sleep). I woke two hourly because of the nerve ending feeling of not being able to empty completely. When I went low sals, I woke once a night. And my restless legs (which I didn't realise I had...until this diet) reduced dramatically. Sleeping is SO MUCH BETTER. I actually didn't realise it could be normal to sleep five hours' straight. For most of my life I've woken two hourly and it has been completely broken. Same goes for my ASD child. Now we wake once a night. Failsafe saved my life — Anonymous, Qld.

[963] Depression and social phobia: diet a lifesaver (October 2010) COURAGE AWARD

I can't tell you how happy I am to have found out about FAILSAFE (by accident). It's only day three and I feel like a different person. However, I will be aware of any withdrawal symptoms over the next few days or weeks.

If this diet works, as I'm sure it will, you will have literally saved my life. I was on the brink of giving up. I felt my life was over. Words can't describe how ill and depressed I had become. Life was miserable. No doctor wanted to help, couldn't help or just didn't believe me. One doctor told me my symptoms were all psychosomatic.

I went to the shops today and didn't have social phobia. That in itself is a miracle. My depression has lifted. My nerves are calm and my tummy is happy. It's not a chore in any way to eat the foods recommended and avoid the others

Update after six months – I am happy to report ongoing improvements in overall mental, emotional and health conditions. I have had around 40 people now, tell me how amazing I am looking (I must have looked terrible before). They ask me what's my secret? I am happy to tell them- FAILSAFE!! I will never go back to eating the way I was. This diet is for life. - Liz, NSW

[526] Diet has been a lifesaver (January 2007)

We have had excellent results with diet for our five-year-old daughter who had severe asthma attacks with daily singulair, ventholin, atrovent and also 3 lots of prednisilone within the space of about 3 or 4 months at the beginning of 2006. Since going failsafe in August, not even a cough. I attribute a big part of this success to eliminating both sulphites and artificial colours in particular.

I always felt that there was something more we could do, but just didn't know where to start. My children had what I thought to be such a healthy diet, no cordials, lollies and lots of fruit and dried fruit for snacks. Now I know better - Monica, NSW

From [1395] Depression: an update on what I'm calling "the diet that saved my life" (June 2016) COURAGE AWARD



This diet is freaking amazing! I have had extremely severe ADHD and Aspergers diagnosed from when I was six and depression so serious that I have been suicidal for the past two years and have had such bad anxiety that I only leave the house about every couple of weeks when I absolutely have no choice. I mainly just lie on the sofa, feeling angry, bitter, exhausted, depressed and resentful of my horrible headspace.

But today ONE FREAKING DAY ON THIS WONDER DIET, today I got up, showered and got dressed (a genuine achievement), got ready and went out to town! I have had the best day in months and months, I did my errands, I wasn't in a bad headspace, I wasn't anxious, I was sensible, productive and most of all – HAPPY

Update one month later: ...

I can honestly say that since I first started this diet, my life has been unrecognisably changed for the better ... Before this diet I was surviving, and now I am genuinely, for the first time in my whole life, living life to the full. And I'm not about to stop - Ffion

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

At my absolute worst, with a diagnosis of fibromyalgia, chronic fatigue and IBS, with speech issues, constant headaches, psoriasis, untold medications and a very real chance of having to use a wheelchair, I can easily say FS saved my life. I'm now fit and active, run a business, teach belly dancing and thoroughly enjoy life – Sue

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

I notice your correspondence is commonly from parents thanking you for the assistance with their children and their behaviour. Well, I am 35 years old, and the failsafe method actually saved my life.

Who knows how this may have ended, if there was inadequate information out there about the chemicals in foods (in my case particularly the natural chemicals in fruits etc). Thanks for your tireless efforts. – Liz

[960] Breastfeeding: unsettled 6 mth old became a new baby after 3 days (October 2010)

I first had contact with Sue way back in 2001, when her article called 'Restless Babies' in Nursing Mothers magazine saved my life!! I went failsafe as I was breastfeeding our unsettled/ ratty 6 mth old baby. We were amazed after she became a new baby after 3 days of diet!! That baby is now 9, and very conscious of the additives that affect her, and knows that by avoiding them, she feels better.- by email. '





I would like to share my personal story of hell from eating flavour enhancer 635. I have been suffering from a maddening itch and rash for over 2 years now, and I am quite sure that I would still be suffering from it had I not found your website I am a 33-year old American female, and was riding my push-bike up the east coast of Australia, from Byron Bay to Cairns. Somewhere around Gladstone, I started to break out in the itchiest hive-rash I have ever had in my entire life ... The rash just itched and itched to the point where I scratched the skin off, and I just wanted to rip off my flesh ... The itching was absolutely maddening ... This rash made me completely weak and debilitated, to the point where I turned down job offers and could barely even function. For a while I really did think I was going to die

... I went to more doctors. I was tested for everything ... Some internet research the next day led me to find your amazing site after two years of hell, and I wept as I read so many stories exactly like mine. Finally I could prove that I was not crazy. Two months later, my rash has completely cleared up after eliminating 635 from my diet. After two years of trying everything else and having no results, the rash is gone.

One thing I know for sure is that this additive is a killer and it must be removed from all food in Australia and elsewhere in the world. If my body rejects it so violently, imagine how a small child may react – Jennifer Qld.

[034] Chronic fatigue (January 2000)

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

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

'We've been following your books for 3 years and it saved our lives' said one couple. 'I know others say that, but it did'.

[1420] ADHD diagnosis and failsafe - facebook thread (December 2016)

Omg yes!!! This diet is a lifesaver!! We were on the school speed dial list before term finished, anger issues, couldn't control emotions, discipline of all degrees made no difference. 3 weeks on the diet and I have a different kid!! The days when I mess up accidentally I can tell and so can the school. — Madonna

[1267] Salicylate intolerance and dermatitis "I'm living again instead of dying" (July 2014)

Your site is a life saver. I've been suffering from many of the symptoms associated with salicylate intolerance, especially dermatitis. Poisoning myself on what I thought was an extremely good diet. What an education. Thank you from the bottom of my heart.

Four months later: My symptoms have completely resolved, simply through steadfastly following failsafe eating. When you've been ailing as badly as I was and to now to be well, merely by eliminating certain foods, that's proof. I have healthy skin, hair and stronger nails. No more frequent urination, no more constipation and my sleeping patterns are normal. I breathe easily, have strong energy and a clear, happy frame of mind. I'm living again instead of dying. The old saying "the proof is in the eating" is true. Failsafe eating works. My doctors agree.

Failsafe eating is being kind to your body and eating what's right for you.

Your research, diet and site is a life changer. Sincerely, I can't thank you enough - reader from Victoria.

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

I notice your correspondence is commonly from parents thanking you for the assistance with their children and their behaviour. Well I am 35 years old, and the failsafe method actually saved my life. Who knows how this may have ended, if there was inadequate information out there about the chemicals in foods (in my case particularly the natural chemicals in fruits etc). Thanks for your tireless efforts. - Liz by email.

From [581] Three responses on behavioural effects of Down Syndrome (September 2007)

"A great improvement in my son who has Down Syndrome"

About two years ago our son who is now 11 and has Down Syndrome, began soiling his pants on a daily basis, rarely at school but often up to six times in the evening As I'm sure you've heard over and over, I thought we were providing him with a really healthy diet and couldn't understand why he would be unwell all the time. Anyway we took the plunge, and within maybe three days of starting the diet the soiling had ceased and there were no more stomach aches. ...

After going low salicylate and cutting out other nasties, we also noticed a definite behavioural improvement in our son. ... On the strict diet, he seems to be so much more agreeable and able to be redirected or reasoned with..... His school teachers have commented on how well he concentrates this year, they were unaware that we had made any changes to his diet. The teachers have also commented that he no longer acts the fool to gain attention, and is much happier to sit and do school work, and be like everyone else.

I have also discovered that he is intolerant of MSG. He used to be addicted to corn chips, we cut those out early on in our failsafe journey. When he later ate other flavoured chips I noticed every time he had them he would cough continually for several minutes. At first I thought he was choking on the chips, as he sometimes has trouble swallowing but then it clicked - it was basically MSG causing an asthma attack. The low salicylate diet has been a life saver for us with our son. I am a huge fan of failsafe!!! - by email

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

.... the behaviour went from bad to worse, to downright disgusting, with many violent outbursts. He became more obsessive ... developmental disorders, ADHD, high-level language impairment and features of Aspergers Disorder ... His behaviour was often so violent that I was convinced he would one day be in a juvenile prison, or worse.

We began the double blind dietary capsule challenges at the beginning of December and they were completed at the end of February. The results were as I'd suspected. No great surprises. He is highly sensitive to MSG, calcium propionate, sodium benzoate, sodium metabisulphite, salicylates, antioxidants and food colourings tartrazine, sunset yellow, erythrosine and azorubine. It was a huge

relief for us to finally have an official, clinical diagnosis from the immunologist. These results confirmed my suspicions in relation to food related behaviours.

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

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

[1415] Extreme mood swings and self-harming behaviours due to Strattera (December 2016)

I just wondered if you had heard the news about Strattera, a medication prescribed for ADHD that has only been used here in Australia on about 2000 patients, 1400 of them children. It turns out that the medication causes extreme mood swings and self-harming behaviours.

My son took it for six months and that's exactly what we saw in him. He got so bad he said he wanted to kill himself and he was only 10 at that time! His mood swings were so extreme I asked his psychiatrist about bipolar disorder!!! We stopped the medication cold turkey without the support of his doctor and that's when desperation led us to the failsafe diet, purely by accident as I stumbled upon your website while searching for something, anything to help my son.

Fast forward a year and I'm sure I've emailed you before about the happy, well adjusted, stable, "normal" child he is now, moving on to high school next year which we never thought was possible and only last month receiving his black belt in karate.

Your diet literally saved his life and every day I say a quick prayer of thanks that we have found the failsafe way and completely changed the course of his life. He was on the verge of being sent to either a special school or a psychiatric ward and now, while he still has some slight autistic tendencies that we are teaching him to manage, he is going to lead a normal life and hopefully he will be able to do whatever he wants to do with his future. Thanks again for all you do — Lu

[1258] My little Firecracker is now a fierce warrior (February 2014)

My failsafe baby started high school this week. Twelve years ago I was at breaking point trying to find a reason my baby was covered in eczema, never slept, did frothy green poos, and never smiled. Sue Dengate saved both our lives, literally. My little Firecracker was one of the first babies to join Sue's support group and the affirmation and support I received from others on those groups has seen me forge lifelong friendships. Today my daughter is a fierce warrior. She is eating foods, her body continues to lead the way and we all listen. It's not an easy road by any stretch of anyone's imagination, but this works.

I've recently been reminded of what life was like before Sue pointed me in the right direction and I realised how far we've come. My little Firecracker is the best person she can be, and it's all thanks to you. But it's not just about her and babies. Failsafe also gave me my life back and I do my bit to pay it forward. Thank you Sue, for showing me how — Blanca

[954] 635: OMG! (May 2010)

I found your site quite by accident Googling and I had an 'OMG' moment - I have suffered from rashes on my torso for more years than I can count, also itchy dry skin and bowel upsets when I ate different things. I read about 635 and I was saved. I went through my pantry and was gobsmacked at how many items I was consuming with this additive in it. Since disposing of them all (and believe me there were many) and checking what I buy but mostly sticking to food that looks like food all my problems have disappeared. I cannot tell you, nor would I know myself, how much money I have spent on creams, lotions, powders and tablets, and the misery my life has been because of this -and how it is a different as night and day since I found out about it. Thank God for your site or I would still be oblivious to what was causing my suffering....who would have thought that I would still be learning at age 64!!!!!! - Maev

[872] 635: Increasing episodes of tachycardia, arrythmia and ectopic heart beats (November 2009)

I had been suffering increasing episodes of tachycardia, arrhythmia and ectopic heart beats - two to three episodes a day. Despite escalating testing with various cardiac specialists over the past 6 months, nothing was determined apart from the fact I had high blood pressure and was placed on a low dose of appropriate medication for that. No known cause for my cardiac anomalies.

Last Tuesday (tis Wednesday of following week now) I ate a delicious bowl of my home made potato and leek soup for lunch. I experienced my usual (but scary and increasingly strong) palpitations and (frustrated, a little frightened and upset), I broadly Googled "heart palpitations" on Australian sites. Up came your website that mentioned 'soup' in the first Google lines that came up. Thinking "that's funny, I just ate soup, I'll have a look at that one before I find what I'm really after", I looked at it. Well, that's what saved me. What I found there were countless, comforting, case studies of people just like me, suffering consequences to MSG (635 in particular), just like me, who didn't know what was causing it. Just. Like. Me.

For me, it was a revelation, an epiphany. I was euphoric. My God, what have I been poisoning my family with, for so many years? Weekly, particularly in winter, I lovingly make risotto, casserole, beef in red wine, soup, etc, etc. Thinking I'm making healthy foods for my husband and my children, I've made all these dishes with more than a liberal dash of commercial stock (cube and/or liquid), all of which (no exceptions, I find) are loaded with MSG.

I stepped, willingly, into the world of chemical additives, flavour enhancers, neurotoxins, excitotoxins and ribonucleotides.

To cut a long story short, I have strenuously avoided any flavour enhancers (particularly 635) and all MSG in its myriad disguises since that bowl of soup on Tuesday. I did not expect things to settle

immediately, but I've gone from having 2-3 cardiac episodes a day and thinking I was going to die like my father, at 46, to NOT ONE EPISODE IN MORE THAN A WEEK.

Gotta be something to this and I'm sincerely and eternally grateful for the information you have on your website and the comfort and advice it gave me. I think you saved my sanity and my life. – Shannon

[258] 635: Afraid for my safety (April 2003)

I began to suffer strange, itchy swellings about seven years ago and spent a lot of time and money going back and forth to my doctor to try to ascertain the cause and a treatment. As you guessed, he couldn't find a cause. I gave up asking and had to suffer in silence. I have consulted doctors only when the swelling occurred in my tongue and throat to such a degree that I was very afraid for my safety. These swellings have probably occurred on a two-monthly basis for several years, with some incidences being more extreme than others.

Since the article appeared in the Melbourne Sunday Herald Sun about 635, I have tried to be very careful about what I eat, and check, where I am able, that any foods I consume do not contain 635. I have noticed a reduction in occurrences, although one morning I woke up looking like Eddie Murphy in the Nutty Professor.

It was interesting to read that rotisseried chicken can be a culprit, as this is one thing I have eaten recently, before suffering an occurrence which I could not explain otherwise.

Thanks for getting the information out there. You may just save some precious lives. - Cathy, Vic

[257] 635: One day someone will die (April 2003)

My 21 year old daughter came down with an allergic reaction on Christmas Day. She went to the doctor the next morning with this awful raised red rash all over her. He said 'it's only a reaction' and sent us home with over-the-counter antihistamine. As we were leaving she passed out but the doctor said it was only a faint. That night we had to take her to emergency at the hospital where they didn't know what it was either. She ended up staying in for 3 days and was on cortisone injections. She went to an allergy specialist who said it was a virus and did nothing. The hospital ruled out virus as they did all the tests. Thank you for your work. My daughter did eat turkey for Christmas dinner but I would never have dreamed it would be something in the turkey. It was so stressful not knowing what the cause was.

I would like to see something done as one day someone will die. I certainly wouldn't want my daughter to go through that again. - Charmaine, Qld

[259] 635: Call an ambulance (April 2003)

I am a 33 year old mother of two. I woke up one Sunday morning with an angry red blotchy rash all over my body and my legs were burning. I asked my husband to call an ambulance as I nearly fainted and felt like vomiting at the same time. A doctor put me on Prednisolone tablets for a week. I also took antihistamines and smothered myself in Calamine lotion but nothing seemed to ease the rash

which turned to severe hives all over my body. I couldn't sleep and would be awake in the night clawing at my skin for some relief. I ended up bathing in Pinetarsol Solution which eased the itching. I was told that looking for the cause of the reaction was like "looking for a needle in a haystack" and I could not think of anything I had done differently. So to see your story on A Current Affair was fantastic. I am sure my reaction was from eating Continental Oriental Fried Rice packet mix on Friday night and also Saturday night for tea. I had a slight rash on my stomach on Saturday afternoon but it wasn't until Sunday morning that the severe reaction occurred. I checked my cupboards and 635 was also in Continental Macaroni Cheese as well. Thank you, and let's hope it can be removed from foods before someone has a fatal reaction.

[990] Behaviour & diet: extraordinary tantrums gone (March 2011)

First of all thank you for being my saviour!! My 4 year old little boy had been getting increasingly worse in his behaviour and we had pretty much become isolated due to his extraordinary tantrums that lasted anything up to 2 hours 3 or 4 times a week. I never knew when they would happen and it was normally as soon as we met up with friends in a play centre he would become aggressive, loud, uncontrollable and impossible to calm. Many times I have left a shop or playcentre with him folded under my arm, kicking and screaming, biting anyone or anything that came in his way.

We had already been seeing a paediatrician as he was also under weight and under height for his age. They hadn't found anything wrong but his blood tests were not quite right either. I was getting desperate and he is starting school next Thursday and I couldn't imagine what they were going to say!!

Until 'Fed Up'..... We have been following the elimination diet (mostly) for the last 2 weeks with dramatic results. We have not had any tantrums for 10 days. He is a pleasure to be around and he is sleeping much better. We are not there yet, but so much better. I can't quite believe he's the same child!! - Fay, UK.

[640] 220: Ventricular arrhythmia link to sulphites (May 2008)

I just thought I'd tell you that although my cardiologist never questioned my diet, after two hospitalizations in emergency for ventricular arrhythmia, and nearly two years of fearing for my life, feeling my heart jumping all over the place, and being miserable, I finally linked a very bad episode to a wedding and consumption of red wine, and then to the foods in my cupboard. Since eliminating sulphites, I have had NO problems. None of the medication I was given worked, (medication rarely does for arrhythmia). I wonder why didn't anyone mention this, not when I went to the doctor, not when I was in hospital fearing I was going to die. I've tested this three times, having been 'arrythmia free' for months, and then drunk champagne or wine, eaten foods (everything you would normally eat and drink at a function) and each time, 4 to six hours after, my heart goes crazy and I can't sleep for the whole night. It's like I'm 'buzzing' and restless, with my heart banging around. This is the honest truth, I have no symptoms, and I'm medication free, and even felt so good I've got back into exercise without fear of dropping dead! It's been six months (since the wedding that triggered the biggest attack ever, and the linking to red wine), that I've been 220 free, and free of symptoms (apart from the three 'tests' which were one night tests). The link was obviously cumulative, the more 220 over the day the worse the problem that night and the next days. Alcohol with 220 is a big

trigger - so much for drinking red wine every night for your health! My normal diet was toxic, I was eating Vegemite, sun-dried tomatoes, dips, fruit juice cordial, I ate cereal with dried fruit (and 220) every morning, and sauces (it's in everything) and consumed dried fruit as snacks, thinking it was 'good for me'. Only asthma is mentioned on the official government additive information site, but this is a message I wish could get out, so others could at least try it, as it won't cause harm to avoid this preservative - Michiko, WA

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

I was suffering with what the doctor said was normal for my age 39, higher blood pressure, heart palpitations, not able to sleep on my left hand side, rash around my groin and armpits that I couldn't get rid of, weekly headaches and to top it of waking up at 2-3am every morning with a anxiety attack ... Finally I had yet again another anxiety attack. This time it was unbearable and my heart went over the 199 bpm that my machine could measure. I tried everything to relax but my system went into overdrive. My mother came around and my wife was there to help. I am amazingly good at relaxing my body but nothing seemed to help. I called nurse on call and they called an ambulance immediately upon hearing my symptoms. The ambulance arrived and went through the routine of checking me over and in the time they were there my body stabilised to around 100bpm. They gave me the option of going to hospital and waiting in the waiting room for 4-6 hours or stay at home and try and get over it. I took the wait at home option. The interesting thing from all of that is the male ambulance officer who leaned against the door frame for the whole time they were there said "gee you look like my wife does when she has a attack of 635" I thought he was full of it and ignored him at the time. I felt like I had run a marathon.

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

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

From that week....

- My multiple rashes of many years cleared up completely!
- Not one single headache!
- I have not had a single heart palpitation!
- Not one single anxiety attack!
- No hand or body tremors!
- No racing heart!
- No feeling of tension!

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

[1386] Life-threatening reaction to anti-inflammatory drugs plus blackberries: "A&E seemed totally unaware of the salicylate link" (March 2016)



I had an heart attack 4 years ago at the age of 48, had two stents fitted, and was told that I would be taking aspirin every day for the rest of my life.

I had been treated for asthma for decades until my heart attack, only to realise afterwards my heart that was leaving me breathless not asthma. For a few months I felt I had been given a new pair of lungs, but my health gradually declined, with pain, cramps, nausea, and rashes/hives.

I had been prescribed two medications. A consultant suggested cutting out the aspirin and sticking with the Prasugrel. In the following months my condition improved to the extent that I took up hiking and trekking and everything seemed to be going fine.

One day at the gym I felt feverish, lethargic and started suffering with vertigo. Assuming I had Meniere's disease, my own doctor gave me a double dose of an anti-vertigo drug that was followed accidently by another double dose from an ENT consultant. This quadruple dose had severe effects on my heart and I started getting palpitations. When they realised what had happened, I was given

anti-inflammatories to see if the vertigo could be helped by allowing the middle ear to drain more easily. Instead my condition worsened as I began getting chest pains, shortness of breath, swelling of the lips and severe throat pain and rashes.

The next episode finally solved a lot of issues. While on a walk through the English countryside, my girlfriend and I stumbled on some wild blackberries and picked about a kilo. That night, we made blackberry jam/jelly with occasional tasters. The next morning I awoke with some rashes around my elbow but thought little of it and put it down to a mild side effect of the anti-inflammatories, went to work as usual, however the following morning I felt very lethargic but managed to get up for work and while doing so ate a slice of toast liberally lavished with a good dollop of homemade blackberry jelly. Later that day I found virtually all my arms and neck covered in hives and rashes, I had difficulty breathing and was eventually taken to Accident & Emergency in an ambulance ... My partner was aware of my rashes etc and after we had joked about it being the jam/jelly, she did some research and discovered that blackberries are very high in salicylates which is also the reason that people have an allergic reaction to aspirin. When I mentioned this at A&E they seemed totally unaware of this link, and carried on treating me for a suspected heart attack.

I visited my doctor today who has now advised me not to take anti-inflammatories as they are likely to contain salicylates and has now put a note on my records that I am not to be prescribed any medication that contains them. Why was it not obvious to trained medical staff that if you have an allergic reaction to aspirin, it is quite likely that it is because of salicylates and that care should then be taken when prescribing further medicines?

In general I am beginning to lose faith in the medical profession:

- I was treated for asthma instead of heart disease
- I was given life threatening drugs for someone with heart disease
- I was given medicine that contained ingredients to which I might (very likely) have an allergic reaction.
- they did not make a connection between Aspirin and Salicylates

My advice for anyone who has suffered from heart disease and advised to eat plenty of fruit and vegetables for a healthy lifestyle: if you've had a reaction to aspirin or other anti-inflammatories, be cautious of salicylates in food, drink, medication, toiletries and even cosmetics. - Tony, UK

[560] Reaction to aspirin (May 2007)

Our 13-year-old daughter suffers extreme sensitivity to salicylates and our 12-year-old son suffers mildly (or so I thought). During Easter we had relatives visit and I had gone for a walk with the younger children. My son had a growing headache when I left, and our care for that is a warm carob and lying down in a quiet room. While I was gone he asked if his aunty had anything for a headache. (Incredibly irresponsibly!) she gave him an aspirin. By the time I returned from my half hour walk he had developed severe swelling of the eyes, upper lip, ear lobes and generally puffiness of his face; also urticaria over his whole body centred on his neck and under his jaw line. At first I didn't know

about the aspirin. After much questioning, research and deliberation I came to the conclusion that it could only have been the aspirin. He became very agitated, very frightened, and very unlike his usual self. It took over 48 hours for all the symptoms to disappear. Needless to say, my children have never been given aspirin before, and it will never be allowed in my house again. — by email, see Salicylates factsheet for the aspirin-salicylate connection.

[1399] Another account of food intolerance apparently triggered by medication use (July 2016)

When I was about 24 I regularly would take feldene, I think it was, after footy without incident. One night I had severe stomach cramps and a friend gave me a couple of her naprogesics. I went into anaphylactic shock and was admitted to hospital. A few weeks later after footy I used feldene again as per my habit and went into anaphylactic shock once again.

I get itchy from many foods and many of the symptoms you discuss on your web page. Thanks for the page. Quite informative. I am now 45. - by email

Sue's comment:

Feldene (active ingredient Piroxicam) and Naprogesic (active ingredient Naproxen) are nonsteroidal anti-inflammatory drugs (NSAIDs) used as painkillers. NSAIDs are not suitable for people who are sensitive to salicylates because they can cross-react with aspirin which is a salicylate sometimes used as a salicylate challenge.

Professor Peter Gotzsche, a co-founder of the Cochrane Collaboration, the world's foremost body in assessing medical evidence, says that non-steroidal anti-inflammatory drugs - commonly used for arthritis, muscle pain and headaches - should be used as little as possible. He estimates that 100,000 people in the United States alone die each year from the side-effects of correctly used drugs, especially NSAIDs.

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