# Reader reports from the Food Intolerance Network

# www.fedup.com.au

# ("restless legs" "restless legs syndrome", "RLS" keywords only)

Everyone is different. There really is no substitute for doing a thorough and systematic Royal Prince Alfred Hospital Elimination Diet and challenges, preferably with an experienced and supportive (both!) dietitian from this list <a href="https://www.fedup.com.au/information/support/failsafe-friendly-dietitians-and-other-health-professionals">https://www.fedup.com.au/information/support/failsafe-friendly-dietitians-and-other-health-professionals</a>.

Do it once and do it properly and then you will know for sure what affects you is our motto and then you can eat failsafe or explore other avenues from then on with confidence.

The reports below are not a scientific set, but within that limit is appears that the best place to start with Restless Legs is to reduce salicylates.

#### from [1644] Symptoms if not failsafe (facebook thread) (August 2022)

What are your symptoms when you don't eat failsafe? For me I just feel more irritable and emotionally worse. I think I get itchy skin because of it and also I had **restless legs syndrome (RLS)** but more due to anxiety – Leo

Bloating, itchy skin, facial flushing, restless leg syndrome. The **RLS** is the most random symptom isn't it lol. At first I thought my **RLS** was due to me coming off Zoloft but I'm back on them again and cut out salicylates and it's completely gone away. I challenged salicylates and it came back later that night-super weird !! — Lydia

For me it's nausea, insomnia, extreme fatigue, headache with visual aura, bowel movement alterations, stomach cramps, **restless legs**, mood swings, rosacea, difficulty swallowing, brain fog, cough, and bloating. I think that's pretty much it (!). I may get several at the same time or just one, depending on the day. Some foods trigger some of the symptoms more than others - Terrie

## from [1611] Restless legs (August 2021)

A note on my food intolerance journey: one of my myriad symptoms used to be insomnia, which was really, really annoying. My symptoms are much better now, and in recent months I've been able to incorporate a lot more foods into my diet as long as I don't overdo it. Insomnia is 95% gone. But when I do eat some of these non-fs foods, one of my exciting new symptoms is **restless legs**. This is worst when I'm watching TV before bed, not in bed, fortunately. Sometimes I feel it in bed but certain positions relieve it. So still way better than insomnia, but a strange new one. I had blood work done recently for magnesium and Vitamin D and those numbers were fine. It's quite specific to after eating higher chemical foods. Anyone else get **restless legs** from food chems? — Teresa

This was something my husband suffered from, but it eased when I stopped dairy in his diet when at home. I used to occasionally get it before I stopped eating dairy many years ago – Mary

Yes, I get them when eat something I ought not to, I also get bad cramps when I do as well! Nights not the most fun for me, although, like you - I DO seem to be sleeping better, instead of waking every 2 hours, I now can sleep 3 hours straight – Di

(Howard comment: see Factsheet on sleep disturbance and insomnia)

### [1563] "I was underwhelmed by the advice of my GP on insomnia" – facebook thread (April 2020)

I just went to my GP who said food intolerances don't have any effect on sleep and don't cause insomnia. What are other people's experiences with food intolerance and insomnia? - Mika



## **Salicylates**

Salicylates makes my 4 yo restless at bedtime and can wake frequently when his bucket is full - Lisa

I'm sensitive to salicylates, amines and to a lesser extent glutamates. I definitely experienced insomnia, along with my main symptom eczema. Since being on the RPAH Elimination Diet I have slept so much better - Kate

Both salicylates and amines badly affect my sleep - Anne

Definitely for me when I have salicylates and artificial colours. **Feeling extremely restless** and unable to sleep is my biggest complaint. I've also learnt that my sons terrible sleeping as an infant and preschoolers was also caused by salicylates - Clare

Salicylates, glutamates and artificial colours and anything listed as causing hyperactivity and sleeplessness. I include inhaled salicylates such as Lush bath products – Ruth

Insomnia is definitely a side effect...my head just 'runs' after a meal of sals....can't settle or sleep....then 'die' for a few hours....and then wake...wide awake for a while...and can then usually doze off again....but usually wake unrefreshed!?? - Jan

Salicylates really trigger my insomnia - Kylie

#### **Amines**

My son's sleep is far worse when reacting. I am definitely worse with certain amines and glutamates - Becky

I experience complete insomnia from amines – Sarah

Amines definitely give me insomnia - Maria

I've had insomnia my whole life. Doing the RPAH diet I realised it was amines that were keeping me up - Eve

Amines for me. I can handle GPs not knowing about food intolerances but I get very frustrated when they give incorrect information? – Jessica

Amines for me! On the challenges I confirmed that for me. GP, family and friends don't believe me either- but I know my body and every time I've tested amines I've had this reaction – Dannie

I have found amines to affect me sleeping, I get headaches and feel sleepy then as soon as I lay down to sleep my eyes ping open and I can't relax my brain... like i have had 20 coffees washed down with some redbull – Jackie

#### Other

If a food affects us, it always shows up as insomnia, for both of us. For example, Vanilla flavouring is a big one for me. If I was to eat vanilla ice cream, I would be awake all night!! - Mel

MSG does it for me, insomnia and restless legs like crazy - Hanna.

One of food's main side effects for me is insomnia - Anne

If I eat soy I get insomnia - Susan

Preservatives keep me awake all night! Sometimes in hidden things like plain ice cream when out! - Mary

It's the vanilla and milk that does it for me!! - Maggie

Insomnia is my top of the list reaction but since low chemical 14 weeks I'm getting sleep like I've never had and although not figured a direct cause I can see patterns emerging and when my bucket is filling up...I'm excited to report that I've had a block of 6 and then 7 NIGHTS SLEEP IN A ROW!!! — Helen

(See the science in this <u>factsheet on Sleep disturbance and insomnia</u>, a <u>blog on insomnia in adults</u> from Sue Dengate)

### [1493] Middle age lady finds out more about diet (July 2018)

Hi all, my daughter was put on the elimination diet for salicylates and amines and I thought I'd be supportive and do it with her. Well it seems that I am more intolerant than her. Who knew that was

the cause of my body pain. Thought I just got a sore tongue when I ate the wrong thing. Anyway, I'm just wondering what other common symptoms there are for a middle age lady? - Julie

I have found things like joint pain, headaches and mood swings have been big changes for me. Also things like PMS are now almost non-existent. I too did the whole thing for the kids and just felt like it would be easier to do it as a whole household rather than them and us. So glad I have found out what I have. Really life changing - June

It is definitely life changing. I've actually just done a really hard hike this morning that I would never been able to do before this ????? – Julie again

For me it has been joint pain, respiratory issues, insomnia, restless legs, hives, psoriasis - Cate

Fatigue, anxiety and racing thoughts - Di

I definitely have less fatigue. Thanks ???? – Julie again

Yes for fatigue too. Extreme irritability and likely to lose it and scream at hubby or kids, especially when connected to pms. Migraines - Margie

Nearly everything that was ever wrong with me! Main things being headaches & muscle tension, fatigue, brain fog, irritability. Things that I just thought were normal part of being a human were actually related to food I was eating. Was quite a breakthrough to discover the headaches I'd been getting, sometimes weekly, for over 15 years were caused by amines. When our council chlorinated our water supply two months ago the exact same headache and muscle tension came back. As at that stage I couldn't taste or smell it I was a bit mystified to what it was. Then I remembered that the week prior was the week they were going to start adding the chlorine, and it all made sense! - Rose

Fatigue, insomnia, eczema and other rashes, joint pain, menstrual cramps and pmt all reduced or disappeared here - Stephanie

Gluten can make you have joint stiffness and pain too. Salicylates can cause ringing in your ears and deafness, rashes and itching. Amines can make you irritable and agro - Glenda

I found, much to my amazement last summer that a low salicylate and low histamine diet made my hay fever completely disappear. This was quite groundbreaking for me, as this has been the bane of my life as long as I can remember – I grew up on a farm. The thing to remember is that symptoms can vary from person to person, i.e. the symptoms I get from salicylates might be quite different to yours. That's why it's important to do the challenges, to find out how you react to each different chemical - Rose again

All my menopause symptoms disappeared in two weeks after I went on an elimination diet - Marie

I'm another parent who discovered it by accident when doing elimination as a family: arthritis, insomnia, irritability, headache or neck stiffness, eczema on shins, brain fog - Emma

Your biggest clue as to what is caused by the food intolerance will be when you do the challenges. You'll probably notice the return of things you hadn't realised had stopped - Tracy

I'm able to be so much more active now it's incredible. I actually feel like I'm going to be able to grow old happily. ???? – Julie again

I hear ya! Same with me... my son is better off than me, in terms of how many things he's sensitive to. We're not long on this journey, it's getting easier...my symptoms are crazy joint pain, sore tongue , IBS symptoms, headaches. So exciting to understand why after a lifetime of these things but a pain in the bum too! – Sue

I used to go to bed after eating marmite on toast and a cup of tea cleaned my teeth with Colgate toothpaste and would be terribly itchy and moody and wake up with stomach cramps and sweating in the early hours wondering if I had a stomach bug. It took me a while to realise! - Serena

Just changed my toothpaste and my nose isn't running nearly as much ???? didn't realise it would make such a difference – Julie again (see <u>Toothpaste factsheet</u>).

I get tremors quite a bit, as well as other symptoms – Denise

This is fascinating! I did salicylate elimination diet with my son and my monthly mood swings, depression headaches & period pain (I used to take 8 painkillers a day!) disappeared completely! - Claire

See also [1421] Adult failsafers report success – facebook thread (December 2016)

For more about PMS and period pain improving on failsafe, see Women's health and diet

#### [1476] One-liners (January 2018)

It's difficult but also the best thing you'll ever do – Sally

I have long suffered from **restless legs** as a result of some foods and just discovered 160b in Bulla ice cream bars impacts on me. I am under meds to help me sleep through my issues and now know I have to avoid 160b it seems to be doing the trick – John

I went on this diet for gut issues but my fibromyalgia & arthritis is sooo much better & I haven't had a migraine in 3 years now!! – Sharyn

Joint pain (quite bad on occasions) was one of my symptoms before doing failsafe, as was insomnia (plus bleeding guts and the angry amine feeling). Joint pain gone completely and insomnia comes back very occasionally through FS – Rachael

I have used FAILSAFE for my sons with asthma which has had amazing results – Tracey

As an adult, I literally feel like banging my head (sometimes do hit it with my hand hard) when I have 160b. It's a horrid horrible feeling of tension and more – Chris

Just had one of those moments at my local butcher -> overheard a Mum ask Re slaughter date due to amine issues. Nearly hugged her and asked if she wanted to be my best friend forever - Sue

Annatto 160b: My six year old son will wake up a couple of times during the night if he has anything with annatto in it during the day. Artificial red (and possibly yellow) cause him to have a few night

terrors during the night after he has had it during the day and can sometimes last up to two nights – Kim from Canada

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

I saw one of your excellent dietitians for myself, then realised her office was placed with providers for children with ASD. I didn't choose her because of my / my child's ASD, but because of my being ill for many years. The dietitian proved very calm, had a good understanding of ASD, was easygoing as well as knowledgeable and assertive.

With regards to the diet, I can't commend everyone highly enough for all their work. From the information provided on the Fedup website to the Facebook Failsafe group – everyone is helping out to improve knowledge in this area.

Through this diet, my ASD child, appears more and more balanced. Our highly qualified psychologist took one look at my child in the waiting room at her last appointment (a month into the diet) and said "This is a completely different child. What on earth have you been doing to achieve this?" (The achievement being a calm, responsive and fearless child.)

I "failed" (made a mistake) with the diet whilst travelling and gave my child McDonald fries and it hurt me to see her in such emotional turmoil as a result of the food. Within half an hour of the fries, my child completely reverted to her old OCD mannerisms and state of confusion. She forced me to line up behind her at a flight of stairs, and demanded I march up and down them, following her commands. She screamed at me when I wouldn't conform or march correctly. She even screamed at my brother for "smiling at her". Through Failsafe, I can control her behaviour and emotions (and mine) and seeing her happier, more balanced and less frustrated is nothing short of a miracle.

Also, her night terrors, which used to be horrific and last over 30 minutes of her guttural screaming and trying to hurt me and ending in vomiting all over me, haven't happened since the diet was started. She still has little nightmares and tosses and turns a bit but that's not the same as safely putting her on the floor and crying seeing her so distressed and unable to be comforted.

My ASD child will never be "neurotypical" and I shouldn't try to make her "like others" who don't have autism. In fact, now the OCD, ODD and anger has lessened with the diet, I'm actually proud she's autistic as she's super funny, quirky and clever – never a dull moment. What I was trying to say was she doesn't stand out as ASD as there are less full blown meltdowns that make us the centre of attention in public spaces. She's gone over a month without scratching me intentionally in the face, whereas it used to occur every second day. If it does occur, it's when she's had one of the nasty numbers or amines.

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, making it impossible to remain still and be present. 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.

#### [1254] Growing pains - facebook thread (February 2014)

Any suggestions for likely culprits for growing pains or pains in legs for 11 yo? - Glenda

For my daughter it's amines. Natural flavours are included in this. Not sure what they are classed as but we trialled and the result was the same as amines with leg pain. It's the first sign we get that she has had amines - Tanya1

For my son it's salicylates. He also gets nose bleeds and headaches when he has gone over his threshold - Claire

That is interesting our son was complaining of headaches this arvo and the leg pains half hour later hmm time to start a food diary I think - Glenda

Amines for my two daughters - Julie

Magnesium helps - Jasmin

My 10yr old has got better off sals (salicylates) - Leigh

My son had 'growing pains' before failsafe, either amines or sals. I'm suspecting amines as I knew it was a trigger (after reading the website and book and noting the timing of our meltdowns in the past and the fact that a choc overload bought me to find failsafe lol) didn't challenge it, pains did not reappear during sals challenge (other symptoms did) - Kylie

For us, it was lack of calcium. When they drank less milk, they got the pains... Jen

A preventative that has worked WONDERS for my sons is one each of Schuessler Tissue Salts: Calc Phos (Bone Health) & Silica (Cleanser&Conditioner) each night. My two sons, especially my youngest, used to wake up screaming in the night with 'sore legs' etc. Taking these as a preventative has helped immensely - can't remember the last time they complained. We have cut back now and

don't do it every night, but if they say they have sore legs before going to sleep now, they have them (youngest will ask for them) - Tanya2

My son was at his worst with pains pre failsafe. I have since found that amines trigger his pains. He usually asks for some milk then he is fine to go back to bed after 3 - 5 mins. But now he asks for his soda water mix before bed when he feels it coming on. He is 3 1/2. Soda water drink helps him through the day only when he feels he needs it mainly due to amines in meat. Soda water mix is 30mls Schweppes soda water in a small kids cup, sprinkle of citric acid, sprinkle of ascorbic acid, sprinkle of Himalayan rock salt, sprinkle of sugar topped up with filtered tap water. Taste and adjust. Just got to get the right balance of flavour and bubbles. My other two kids don't like it. But they don't have amine Issues - Tanya3

Sals (salicylates) cause growing pain type leg pain here, without fail, every time - Susie

I wonder if the Tissue Salts that my boys have are a counter/balance for sals?? - Tanya2

A warm wheat bag also helps for the pain - Amanda

My boys have all had the same pain. It's only now we know it's when it rains or the weather has a big change coming. He's had to have panadol tonight. He's 13 - Kerry-Anne

We have worked out three definite triggers for "growing pains" with my daughter. Cadbury cocoa (amines), soy vanilla ice cream (flavours) and lemonade (even though it was the preservative free schweppes one) - Kylie

Cutting out all artificial and natural food colouring from our daughters diet had stopped all her restless legs and muscle pain! Has worked wonders for her!!! - Michele

In our case glutamates and salicylates - Adelie

It normally occurs after a very active day. And it's just that. .. growing pains. Heat and pain relief. Mine got so bad I couldn't walk and would have to crawl to my parent's room in the middle of the night and I was a very active kid - Nicole

I used to think my daughter was faking growing pains. When we did the elimination diet I was absolutely shocked to find she wasn't 'faking it' almost every night for attention and it wasn't 'normal'. The amine challenge was the only time she had them. Once upon a time sleep didn't exist in our house due to night time leg pain. Now the only time she gets them is after too much cheese (we have added mild cheese back in to her diet) and after other cheat days (at parties with friends/relatives) that include too much amines or natural flavours. Several times we couldn't work out what she'd had and then she would say, 'oh yeah, that's right.... I may have had this today, sorry' - Tanya1

My 13 year old suffered horrible growing pains. We started FS 12 months ago and have discovered for him it is additives - Tanja

I would just like to add that if your boys are having painful hips & are walking with a limp this may not be growing pains but something more serious. My youngest had "growing pains" but it turned

out to be Perthes disease (femoral head broke away). So please don't just think growing pains when it is in their hips – Roslyn

#### [1226] He had this "haze" that just made it a daily struggle (October 2013)

I will forever be grateful for all the hard work that has been put into devising this program.

One of my 4 kids was just hard hard work, behaviourally I found it so hard to parent this child he had this "haze" that just made it a daily struggle that affected all of us the older kids would be so embarrassed with some of the things my Billy would do and he was dangerous running in front of cars and would chase the school bus everyday, I ended up not taking him anywhere as the looks and comments from people were soul destroying.

We have been FS for 4 weeks and I saw a quick change in this child and he is amazing!!!!! we have spent the school holidays out doing things, restaurants, movies, parks and shopping, I managed to take him food shopping which I would normally avoid like the plague and he was perfect he just held the trolley and walked the isles chatting!!!! He is the most caring, helpful and funny little guy I know and the bed wetting, terrors and **restless legs** have gone too I just can't believe what a totally different child I have.

I have tears in my eyes thinking about all the times I would just sit and cry because I didn't know what to do and had resolved myself to the fact that I was just a crappy parent, I now feel so very blessed to have to answers so thank you so very much xxxxxx - Deborah by email

#### [1137] "almost no help from the medical profession" with Sandifer syndrome (September 2012)

I have started on the diet, currently supported by the book and recipe book. So far it is quite delicious despite the lack of our usual foods.

I have been forced to be free of preservative 220+ and flavours 621+ for over 8 yrs now because of debilitating migraines. My children exhibit various learning and attention difficulties which are inconsistent in nature (think Dr Jekyll and Mr Hyde). We suspected the little one to have Sandifers (Sandifer syndrome is a paediatric medical disorder, characterised by gastrointestinal symptoms and associated neurological features) as a baby so I went Gluten and Dairy free to help with that and it worked a charm. However I could not figure out if it was the much cleaner diet or the Gluten or Dairy that were a problem. He reacts to flavour enhancers with rashes and difficult behaviour.

Through all our various issues I have had almost no help from the medical profession and when they were trying to help it was usually with reluctance and a lot of talk about how stressed I must be. My hormones, migraines, **restless legs** and anxiety were always put down to some psychological problem that I knew did not exist. I even had a workers compensation neck and shoulder problem that my then doctor decided was due to stress and not the work desk that I was at. So I have had a gutful of the medical profession and am wary of shelling out more money to specialists.

When I read your book (referred by a friend) I was amazed. It was as though all my symptoms and the boys symptoms were also problems shared by many other people and not a result of my over active imagination. I had suspected our diet for a long time but could not pin it down. I am so grateful just to know that I am not alone in this.

(One week later) On rereading what I have told you it is crazy to think of the issues that I have not even touched on.

This is our second week Failsafe and the seriously awful headaches from the withdrawal seem to have stopped and I am feeling energetic again. I have had a nice comment from the teacher about my middle child - he is being looked at for Asperger's (seriously difficult behaviour) and I thought it would be better to try him on the diet before the \$1000 psychologist visit in November.

The Sandifers is hardly ever diagnosed I think. Many of my friends had babies that had similar symptoms but were all told they had either reflux or torticollis. I watched one friend's baby who seemed normal on waking but as soon as she fed him the neck would twist to the side just like my baby had. She asked her health professionals about it and they either had not heard of it or discounted it completely. I think that is so terribly sad.

I will get on to a dietician to start the supervised reintroduction of foods. However the amount of support you have provided is so good we hardly need it.

Keep up the great work – you are making a difference! - Shannon by email.

#### [1078] Hot flushes gone within days of starting a VLF diet (February 2012)

I had already been failsafe for about ten years when my menopausal symptoms started - fluctuating breast tenderness followed by symptoms such as **restless legs** and then hot flushes. As a result of doing the elimination diet with challenges I already knew that I was sensitive to salicylates, amines, additives and A1 dairy foods, so tightening up on failsafe eating dealt with irritability and restless legs, just as it had previously with premenstrual symptoms. But for hot flushes, I found that wasn't enough. I had already noticed that low fat eating (VLF very Low Fat) dealt with period pain and it turned out the be the answer for hot flushes as well - they stopped within days of ditching the fat.

## [906] 160b: Restless legs and sleep disturbance (June 2010)

At various times over recent months I have suffered with **restless legs** and a disturbed night's sleep. Today I decided to investigate the ingredients of the fish fingers we had for dinner last night, and found that they contained 160b. I believe that this colour is most likely the cause of my restless legs and sleep disturbance. I will therefore be avoiding it at all costs in the future.

... One month later ... Since I've stopped eating the fish fingers I've had no more restless legs. I'm convinced that it is the 160b causing them. I've since eaten the fish fingers without the batter and had no ill effects.

I've noticed that 160b is in so many foods. Bulla's mini icecreams too. What a pity. They claim to be free of artificial flavours and colours, but still contain the natural colour 160b. I was hoping to give them to my kids until I read the ingredients list.

Many times in past years I have suffered with restless legs at night and hadn't known what caused them. Perhaps it was 160b then as well. I wasn't taking any notice of what was in my food then. Thank-you for such informative and helpful reading. — Sue C, NSW

#### [557] "Giving up the victim role": a story of salicylate intolerance (May 2007)

I have been so inspired by the stories of others that I felt the desire to share my "salicylate intolerance discovery" story. I had been sick for many years and when I think about it probably since birth. Back in those days not many topical products had herbals in them so my salicylate intake was confined to food and aspirin products. And my symptoms were mainly digestive, brain fog, and numerous bouts with asthma. When I grew up and flew the coop things became increasingly worse. For years I have been in and out of the doctor's office (I am in the military health care system) and all tests ran negative, of course. And so the multiple diagnoses began - arthritis, mental illness, fibromyalgia and so on. A few years ago one of my co-workers disclosed to me that she had fibro and referred me to the guai-support website. I knew that it would be hard to convince the military doctors to put me on the Guaifenesin treatment so I decided that I would pay for it out of my pocket if it would give me back my quality of life.

On any given day I was experiencing 10-15 symptoms daily and was hardly functioning - it was very, very difficult. There were days I could not walk and my husband had to carry me to the bathroom. Just lying in bed was painful - the good days were marked with a raging fever, flu-like feelings, and a ringing headache. I did get to a point where I got used to the pain and learned to live with it - I really had no other choice - live with it or kill myself.

For some reason I knew deep inside that I didn't have fibro, it didn't seem right. But I reasoned what do I have to lose and on a long holiday weekend I set upon the closet to remove all topical sal-full products from my life. Within a week I felt incredible. When I talked to my co-worker she said maybe I didn't have fibro at all but a sensitivity to salicylates I was quite stunned. A few weeks had passed and I felt better and better but I still had some digestive tract symptoms so I went back to the guai-support site and re-read the information and one line jumped out at me - that you did not have to worry about salicylate in food as the body would break it down and it would not interfere with the guaifenesin. That led to another Google search and to other sites. I never had to beg the doctors to put me on the guaifenesin protocol as removing sal-full products and food from my life relieved all of my symptoms (listed below).

But there was still a period of "struggle" for me. I am a gardener by hobby and trade so I had to learn to cover up my body and wear gloves to eliminate contacting plant salicylates. I also have been growing and eating my own food for years. That was the hardest part and I went through the denial stage for while - abusing my body with foods I knew I could not tolerate. How do you grow vine ripened tomatoes and perfumy exotic melons and not eat them?! The mind would say - oh come on a few bites won't matter - but it really did matter! So I finally decided to quit seeing my "problem" through the eyes of a victim (poor me, why me? why am I being punished?) and changed my point of view to a position of personal power. What a huge difference. So I can't eat some food and wash my hair in botanical goodness - so what. When I totally eliminated the foods/products that caused me trouble I felt so great that I could not believe that I could deal with that much pain. And I never want to feel that pain ever again!

The nice thing about giving up the victim role is I could reclaim that negative energy and put it towards something else - last year I bought myself a motorcycle and began riding - something I had been wanting to do for years (I rode trail bikes as a kid and loved it) but couldn't do when I was ill.

Regaining my quality of life and being able to work, exercise and play again (and I am quite sure my husband is happy that sex no longer hurts) is worth giving up "bad" foods.

For all you new to this I know it can seem just miserable - take it one day at a time, be gentle and forgiving with yourself, and know that life can be rewarding and fun without some pleasures of food, drink, and beauty products. Wishing you good health - by email (with permission from another group)

Mind, emotion and behaviour symptoms: accident prone • anxiety • anger for no apparent reason • blankness • brain fogging • clumsiness • confusion • depression • detached/unreal feeling • difficulty waking up/getting out of bed (due to lack of sleep and aching muscles) • disorientation • dyslexia • hearing without comprehension • inability to think clearly • indifference • irritability • memory loss • mental exhaustion • mood swings • panic attacks • poor concentration &memory reading • restlessness • slow to process information • slurred speech • suicidal feelings

Physical symptoms: abdominal pains (thought I might have IBS) • acne • asthma & wheezing, tightness of chest • athlete's foot • bad breath • bloating (lost three dress sizes when I gave up the sals) • blurred vision • breast pain • constipation • crawling/burning sensation on skin • diarrhea • insomnia • itching • joint pain, stiffness & swelling • fatigue & lethargy (thought I might have CFS) • menstrual problems, pre-menstrual pain • metallic taste • migraines • mouth ulcers • muscles - aching, weakness, tremors & cramps nausea palpitations & racing pulse • poor balance • rashes • difficulty in swallowing • dizziness • eczema • excessive thirst • feeling drained • flushes - both hot & cold • frequent need to urinate • headaches • restless legs • sensitivity to light & noise • sleep disturbances • sore, itching, puffy, burning eyes, stiff neck • temperature fluctuations • ringing ears • weight problems.

#### [459] Dealing with ex-husbands (November 2006) COURAGE AWARD STORY NOVEMBER 2006

Hi. I can already give you some feedback, as my 3 children and I have been on the elimination diet for 3 days. My eldest child is 14 (depression, asthma, sleeplessness, fatigue, restless legs, easily irritated, unmotivated etc): this morning she got out of bed without being nagged, had a shower without being told, all while smiling! I stopped taking antidepressants 2 weeks ago, and today for the first time since, I am not feeling my normal symptoms of depression. My youngest, 3, is hyperactive and today has been a lot calmer. He also normally wakes about 6am, and today slept in till 9:30!!! My elder son, 6, who has a learning delay, woke up teary and temperamental, as he was before bed last night, but he was at out-of-hours schoolcare yesterday and ate apple, cheese and yoghurt... One thing the book 'Fed up with children's behaviour' doesn't address is what to do when in a situation where I do not live with my ex-husband and he only sees the kids once a week, how do I get him to understand that the kids need to try this? He sees their issues as being 'normal' and although none of my kids are extreme in any way I want to give them the best life they can have, now and in the future. How do you convince people that relatively 'normal' kids still can benefit?

(later) thank you thank you! Despite all of my best efforts, my ex-husband is aggressively sabotaging my efforts with my children, constantly telling them that failsafe foods are 'silly' and if they ask for failsafe foods he gets cross at them. They spent one night at his house (Day 11 of the elim.diet) and he gave them everything he could think of that was on the list of 'Don'ts'. Consequently they came home silly. Neither of the boys (6 and 3) could get to sleep that night, the littlest one crying and

rolling around in bed sobbing 'I can't stop, I can't stop'. In desperation I gave them both a half teaspoon of bi carb, thinking 'this isn't going to do anything' (I should know better!). As it tasted so awful I let them chase it with a Werther's. Within 10 minutes they were both asleep....- by email.

#### [362] Generally unwell throughout life (March 2005)

I am a retired RN and I have three daughters and three young granddaughters. Throughout my life I have visited many doctors complaining of bowel problems, nausea, vomiting and feeling generally unwell, only to be told on frequent occasions and after many investigations, that it was all in my head. As a child I can recall frequently feeling very unwell and being diagnosed as having had "bilious attacks', however I can now attribute the cause of these episodes to an intolerance to natural food chemicals.

Because I enjoy cooking I often browse through recipe books in the shops and this is how, some years ago, I came across a copy of 'Friendly Food'. After browsing through it I realised that this book described symptoms which sounded very like mine. Maybe it wasn't in my head after all! I requested a referral from my GP to RPAH Allergy Clinic and after undertaking the elimination diet, my dietician at the clinic concluded that I was very sensitive to salicylates and I also had some milder reactions to quite a few other substances but not amines.

It is now quite a few years since I was diagnosed and I am delighted that there is now a website and also your great Failsafe Cookbook for guidance. The oldest of my granddaughters has recently been "tamed" from oppositional defiance disorder by using the Failsafe Diet. She is now quite a different child, no longer having **restless legs**, eczema, or being uncontrollable or defiant. Although she is only five years old she is quite happy to comply with the failsafe food because she now feels so much better. My three daughters all recognise that they do have problems with some foods so it appears that I have unfortunately handed down the problem to both generations.

I am now without too many problems although trying to modify my diet when I attended Weight Watchers was a bit of challenge. However, I did eventually manage to lose 10kg. When travelling to UK and the States I have always come home feeling very much the worse for wear due to food intolerances so I am delighted to see that there are now failsafe contacts overseas should I venture forth again one day. Getting people to understand food intolerances is always a problem and I am now quite used to being asked to say exactly what food items I am allergic to and then I try, often without success, to explain the difference between food intolerances and allergy. I am sure that your glossy brochures will be very useful for this. - Jane NSW

### [140] Frequent urination (December 2001)

I have noticed now that I can't have much tonic water or 7 UP - even a single glass. The symptom I get is very noticeable diuretic effect. I would go to the toilet (urinate) as much as 5 times per night (small quantities) instead of normally once, occasionally never. I also get **restless legs** (drives my partner insane!!) This happens when I keep all other diet the same. Now that I know that I can tolerate a small dose of amines I find very dilute lime and soda much better for me. - longterm failsafe father

# [125] "To say I felt better would have been the understatement of a new millenium" (September 2001)

Around February of 2000 I was searching on the internet for some clues to my life long digestive problems, when I came across the food allergy section on the About.com website. The featured food allergy topic happened to be salicylates ... just out of curiosity, and for the heck of it, I clicked on the link, and started to read about it ... I first off read the list of common symptoms. As I read it the list was all to familiar to me ... I answered Yes to every symptom. Needless to say, I started to follow a salicylate free diet. To say I felt better would have been the understatement of a new millenium...... ALL of my life I have suffered from Very frequent urination, constipation, stomach bloating, short temper, irritability, inability to concentrate, memory problems, severe acne, dry skin (especially on my hands and feet), those **restless legs**, and more ...<sigh>... The worst of it for me though was the constant urination, and constipation which led to a lot of gas ... Thank you so much for your work, and your book. Both have changed my life forever. I am finally free of a problem which has literally ruined my life. In case you're wondering, I'm 37 years old ... And yes, 36 years is WAY too long to suffer with this health problem. Sometimes I don't know how I made it this long with my sanity intact. - from the USA

#### [122] Restless Legs Syndrome (August 2001)

Restless Legs Syndrome was absolutely driving me crazy. If I forced my legs to be still, they would then jerk with even greater intensity. While I was watching TV, my legs were constantly swinging, because of this urge to move them. They were not itchy - it was just like there was something under the skin driving me crazy. Apparently most sufferers go on to become alcoholics (ref: The Bulletin 2000) which I can understand. American websites about RLS basically fall back onto all sorts of medication, which I do not want to take. Within two weeks of trying the elimination diet, I was able to sit still at night, AND get into bed without fear of tossing and turning all night because of this urge to move my legs. I now know the foods I should not touch - salicylates and additives ... when I eat any of these forbidden foods there is a definite reaction. — NSW

# [101] "What an experience that was! - irritable bowel, sneaky poos, restless legs, eczema, behaviour" (August 2001)

I contacted a dietitian through our Base hospital and with their help we managed to get through the Elimination Diet. What an experience that was! My youngest son, Tim, who is three in April, had been given an uncertain diagnosis of "Irritable Bowel???" by the pediatrician. We were told to take him off lactose, sugar and soy and reduce the fruit intake. That has little effect on his symptoms. So, Brandon (5 yo), Tim and I embarked on the Elimination Diet. My husband did not want to be involved in the "witchcraft" as he called it!

I was on the phone to the dietitian after 36 hours because Brandon, who had behaviour problems, had got 10 times worse where behaviour was concerned and had come out in an eczema-type rash on his torso and upper arms. I felt he was reacting to the soy or the cashew paste (but probably the soy) as these were the only new additions to our diet. I was told to "persevere, that reactions usually got worse before they improved". After 5 days I had a great improvement in my mucous volume and felt better than I had in 5 years. After 4 weeks we had seen limited improvement in Brandon's behaviour and no improvement in Tim's symptoms so decided to eliminate wheat as well.

The results were quite amazing. After 2 weeks off wheat I realized my **restless legs** were no longer worrying me and Brandon's sneaky poos had ceased to be a problem. Tim's symptoms improvement but his bowel motions never really came back to normal. We did the wheat challenge first. Brandon was OK for 5 days but on the 6th day he obviously went over the threshold and took a full week to recover. He reacted with restless legs (which I have since discovered can happen after even a few cracker biscuits) and Tim also had a worsening of his diarrhea.

The dairy challenge was interesting - my mucous symptoms were worse but Brandon improved in behaviour almost overnight and after 3 days the eczema was gone! So I was right about the soy after all.

... Brandon reacted to salicylates as I suspected he would, I didn't. The amine challenge was a disaster! We should never both have done that at the same time. Brandon and I both reacted and our symptoms were the same and severe - aggressive behaviour with a lack of self-control, depression etc. It was like world war three in our house by the end of the week and both of us took at least a week to recover. I have read in a number of places that if we react to amines then we probably react to other additives so we have not continued with separate challenges for these. We just avoid them.

Initially I was daunted by the difficulties I faced accessing the foods we need but eventually as I learn where in the supermarket, health food store etc to find things life has become much easier ... I remember a quote in "Fed Up" from a lady who said she spent more time in the kitchen but less time disciplining the children and I have found that to be absolutely true. It is now just the way we live. I find the most difficult thing now is other people's reactions to our diet. Some of our friends though come to our place with 7UP and kettle chips to share. Thankfully my husband is now more supportive and even grudgingly admits that he is probably reacting to some foods himself. So, Sue we have come a long way in these last 6 months. I hope it makes you proud to know that your writing of "Fed Up" has contributed to such an improvement in our lives. — Qld

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