Reader reports from the Food Intolerance Network
www.fedup.com.au

("tinnitus" and "ringing" keywords only)

[1548] Pulsatile tinnitus from salicylates (November 2019)

Has anyone else experienced pulsatile tinnitus from salicylates? I'm doing my sals challenge at the moment (started last night- so not even 24 hours in) and today my right ear is experiencing pulsatile tinnitus intermittently for the last 5 hours after eating high sals foods. It's really irritating. I constantly feel like I have a blocked ear (which I don't think I do). There's a lot of info about normal tinnitus on here, but curious about the pulsatile kind in particular.

Update one week later: After about 48 hours it went away- but slowly over the few days. Since cutting sals back out I've had no more of it at all! – Emma

(Pulsatile tinnitus (PT) is a symptom that affects nearly five million Americans. The sensation of hearing a rhythmic noise, such as a heartbeat, swooshing or whooshing, from no external source, is, at best, a little unsettling; for many, the near constant sound exceeds annoyance and becomes completely debilitating - https://radiology.ucsf.edu/pulsatile-tinnitus)

from [1501] Reactions of the fragrance-sensitive – facebook thread (September 2018)

Nausea, tinnitus, extreme tiredness, coughing, phlegm in the throat, sometimes chest constriction & pain – Sally

from [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

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

[1477] Tinnitus responses from Facebook page (February 2018)

Absolutely, sals = tinnitus for me. I have been able to eat the odd moderate salicylate containing food without nausea, and I've been doing this daily. It is very loud in my ears! But I'm able to not be too troubled by it so I still indulge. As soon as I get nausea though, I pull back. – Sally

Yes just being low chemical I find I don't hear the ringing anymore. If I overload on higher (mod-high salicylates) I get ear ringing when I lay my head down to go to sleep – Serena

Salicylates can exacerbate this condition we have found at Royal Prince Alfred Hospital Allergy Unit – RPA Dietitian

I'm an audiologist. There are a number of causes for tinnitus, it is a symptom not a disease. Even at uni we learn about aspirin potentially being a cause. Anything that puts the body under stress can cause or make it worse. Illness, food intolerance, stress. In my own experience yes food intolerance was a major cause. I remember failing amines challenge ohhh the noise. (Not the only trigger in my case but was the worst) – Jackie

[1429] Positives (some unexpected) from failsafe (February 2017)

No more brain fog, tinnitus or black bags under my eyes – Lynda

[1396] Salicylate challenge: rough skin, headache, shortness/acid persona, buzzing/whooshing in ears (June 2016)

I have never felt better over Christmas than I did this year on the elimination diet ... The salicylate challenge resulted in a small breakout of rough skin on the face, headache, shortness/acidity creeping back into persona, and in the quiet of going to bed I became aware that my ears had a buzzing/whooshing sound pulsing in them... The next day they felt as though they were blocked and I couldn't clear them or hear properly, like I had a cold but I didn't. – Vanessa

[1372] Major Depression, anxiety, muscle pain and other symptoms overcome with the help of a recommended dietitian (December 2015)

I hope my experience is of help or encouragement to someone.

I first did the RPAH Elimination Diet (strict dairy and gluten free) in 1997 after experiencing chronic hives. I had the help of a dietitian and had seen an immunologist. The diet showed I was sensitive to salicylates and amines. For many years I successfully managed my hives by taking a daily antihistamine and also by reducing my intake of very high chemical foods, although I wasn't very strict at all with managing the food side of things.

Over the last 5 years, I rarely had hives anymore, and thought maybe I had outgrown my intolerance. So I gradually increased my food chemicals again. Then in 2012, I experienced a Major Depression for 8 months. I was feeling so low, so hopeless, and crying all the time, it was the darkest time in my life. I work as a Graphic Designer, and I found my creativity totally vanished when I was depressed. This was very frightening, being creative always came so naturally to me, and losing this ability had a big impact on my livelihood too.

I was perplexed as to why I would be depressed, my life was wonderful, I couldn't see a reason for the melancholy that had overtaken me. I remember telling my GP that it felt more like a 'chemical thing', like something was out of balance with my internal chemistry. In hindsight, I should have trusted my instinct on this... instead, I took my GP's advice and I tried therapy, exercise and rest, and then antidepressants (SSRIs). Nothing worked and the antidepressants gave me nasty side effects (nausea, migraine with aura, hot flushes, diarrhoea, nightmares, anxiety, muscle twitches, split tongue, light sensitivity, foggy brain, blocked ears), and then some nasty withdrawals (brain zaps, teary, lack of appetite, insomnia). During the depression, I was also suffering badly with muscle pain. I was seeing a physio very regularly, and taking maximum doses of Panadol every day, but still had chronic pain.

At the time, I was taking fish oil supplements because I believed it may be beneficial in treating depression. I was also taking probiotics, believing it would boost my immune system – I never felt well! I stopped taking probiotics after I saw no measurable benefit, and when I stopped taking them, I noticed my muscle pain actually improved a bit. Then the penny started to drop... maybe my food intolerance symptoms had switched from hives to depression and muscle pain! I realised that the fish oil supplement I was taking was very high in amines, so I stopped taking it, and noticed a further improvement with my muscle pain and eventually my mood. Then I started searching online to see if depression and muscle pain were known symptoms of food intolerance. Back in 1997 I don't recall being informed that these could be symptoms, but sure enough I found myself reading about other people's experiences on FedUp! Thanks to you for all the work you have done and continue to do, to shed light on this complex and misunderstood issue. Your forum and website, and cookbook really helped me put the pieces of my own health puzzle in place.

So then I also began to reduce my food chemicals, and other chemicals such as perfumes, and cleaning products, and I saw a slow but steady improvement in my depression! I wanted to be sure I was on the right track, so I booked a dietitian to help me through the RPAH Elimination Diet again. I started elimination with a local dietitian, only to quickly realise she didn't have enough experience or knowledge in this area. For example, she advised me to liberalise my diet as I went through the challenges, adding back any foods I didn't respond to. I knew that this was likely to confuse my results, and immediately lost confidence in that particular dietitian. I voiced my frustration about this on your forum and thankfully another member recommended a marvellous failsafe dietitian to me. I was so happy to find that she was able to help me straight away. It was such a relief to have her insight and also her support through the rest of the process. She really took the time to consider my case, treating me as an individual, and showing great compassion towards any struggles I had. With anxiety and depression being triggered during my challenges, she was wonderful at encouraging me to stick with it until the end.

The results of my elimination this time were much clearer and more accurate than last time, and this was mostly due to her attention to detail, and ongoing support. She was very generous with her email support and this made all the difference during the tricky challenges. I am now finished my challenges, and have discovered that salicylates trigger ringing ears, acne, restless sleep, mouth ulcers, and anxiety. Amines cause depression and muscle pain. Food has always been a real source of joy for me, and although it is tough to accept that I have to restrict certain foods, it is immensely empowering to be able to manage my health this way. My lovely dietitian is now helping me to liberalise my diet, and has been brilliant with offering me a few different approaches for how to manage this stage too - Rachel by email

[1362] Ringing in ears due to salicylates in chia seeds (November 2015)

I am 63 years old and just realized that I am sensitive to Salicylate in foods. I ate two tablespoons of Organic Chia Seeds ground and put it in my smoothie. Thirty minutes later I thought my head was going to explode with eye and ear pains and extreme ear ringing. - Gail

Sue's comment: Although chia seeds have not been tested by RPAH for salicylates, chia is a member of the mint family which is very high in sals. People who are sensitive to sals have reported reactions to chia seeds to us. Ringing in the ears is widely recognised by doctors as a typical reaction to salicylates in drugs such as aspirin, though less widely recognised as a reaction to to salicylates in foods because most people don't know about salicylates in foods. Most salicylate reactions do not occur so quickly unless a big load of salicylates has already been consumed and the food last eaten is lilterally the last straw.

[1127] "I had no idea what was causing the headaches, foggy head, and ringing in my ears" (September 2012)

After going to Sue's talk I have read the Fed Up books and cut out salicylates and glutamates mainly. My headaches have almost disappeared in a week! (I have had a constant headache/migraine basically all year!). I have also had loud ringing in my ears, pressure in my head, pins and needles down my arms and hands, fatigue, foggy brain all symptoms are improving. It's amazing!!

I am definitely feeling a lot better avoiding salicylates (mainly all fruits (except pears) & tomatoes at the moment), amines as much as possible (no supermarket meat and careful choices at the butcher), wine, glutamates (making my own stock instead of using "Campbell's Real stock" (which I thought was ok, I didn't realise yeast extract was bad!) and not using any soy sauces etc). Every time I slip up and have something I shouldn't, I get a headache within 12 – 48 hours later. It's quite easy now to trace it back to something I've eaten, which is a good thing as I had no idea what was causing the headaches, foggy head, and ringing in my ears a few weeks ago. I haven't had any pins and needles in my hands now since eating 'failsafe'.

I have also decided to go 'gluten free'. I have suspected for many years that I could be a little gluten intolerant and avoided eating bread mainly. However, I have noticed that lately oats have been upsetting me too! The gluten free muesli, muesli bars and other recipes in the book are fantastic!

My family are really enjoying all the different recipes that I have been trying and don't seem to be missing tomato based sauces (which we had quite often). We haven't come across a failure yet! I love cooking and trying new ideas. We very rarely have take-away food or packaged, highly processed foods so eating 'failsafe' hasn't been a huge, radical change for us. - Jenny (Melbourne) by email

[1108] Food intolerance story 20 years long (April 2012)

My story is similar to many of yours but it has taken us until Jan this year to work it out!

My daughter is 20 and has suffered bloating, runs, painful wind and, at times stabbing stomach aches which had her writhing on the floor and necessitated rushes to the doctor for pain relief, calls to afterhours drs, and hospital emergency. For the following days she was lethargic and her whole tummy area hurt. These awful symptoms which seemingly came with no warning at all were very distressing for a young girl living away from home in a Uni college, attending university and working part time.

She moved out of college accommodation this last year and has been in a shared house. Her symptoms got worse as the year went on until at the end of last year she was a mess. (I suspect she was eating 'healthier foods' since moving away from the college.) She didn't want to eat anything as everything she felt all food was the cause of her painful bloating every night, headaches and migraines, not sleeping well (she told me later she was living on panadol and would take sleeping tablets if she had to work early the next day) After Xmas lunch she was in a lot of pain and it was very noticeable she was losing weight.

When i think back we had been to the dr with various symptoms since her birth. In late high school, after a particularly bad stomach attack our dr. could only recommend wind tablets. It is interesting to note that she had glandular fever the previous year in year 11.

During her college years her dr recommended an elimination diet. Yay! Unfortunately it was the FODMAPS elimination diet which is full of salicylates. It seemed to make some difference for a while probably due to less additives and preservatives and of course she fell off the wagon as the improvements were minor.

Our next step was to have her tested for coeliac. We were desperate although from reading I was pretty sure that was not her problem. I was right. Expensive, invasive tests for nothing. She has not wanted to do anything else for a year or so but I did say to her in November last year that when she had finished her exams and moved house she would need to see a dietician. (In the past we had only seen what was really a weight control dietician.)

Late December 2011 I spoke to a friend about my concerns and she said one of her daughters suffered greatly from stabbing pains after Xmas dinner! Her eldest daughter who has just completed a degree in nutrition and suggested her sister might be sensitive to salicylates.

I went into research mode and found a list of symptoms for salicylate sensitivity. All of the symptoms she had been having were there plus many we did not realise were part of her problem. Ringing ears, ulcers in the mouth (at the time she had 5) weeping eyes, irritability (we thought that was hormones) awful rashes under her arm. Just about everything except chronic fatigue and some eye tic!

I continued reading and helped her start the elimination diet. The bucket affect was a revelation. No wonder we could not pin point the problem foods. I read everything and borrowed Sue's books from the library and passed all the info onto my daughter. I will buy the Failsafe Cookbook. She was quite upset as looking at the list of what she couldn't eat and combined with how unwell she was, she needed lots of support. I found recipes and went shopping. She came home for a few days and we cooked and shopped and read labels. So much is just knowing the alternatives. No honey but golden syrup fine, no olive oil but canola fine. So many simple changes that are so easy. We didn't cut out amines as she was upset enough at what she couldn't eat. I thought if she still had symptoms and she was in a more cooperative mood we could cut them out later. Also she had been to Zimbabwe to visit her boyfriend's family and she had been really well. They ate a lot of aged meat and I bet their produce is stored and picked differently to ours. She gave me the food from her pantry she couldn't eat and I sent her back with foods she could eat and patties and dips and muffins.

After about a week her physical symptoms were almost gone. No more bands of heaviness in her head, or headaches, really only some mild bloating when she made a mistake with labels. Not many mothers would be happy to get a text from their daughter saying they just had their second proper poop! But I was.

She has been very busy moving, house hunting, and finishing summer school and had some special social engagements so we have not progressed to the challenges. We planned the social events and she went prepared and still enjoyed herself. She was a little bloated (which seems to be her default symptom) but managed well. She will start the challenges when she is settled. We are looking forward to it as we want to have a better idea of what is actually the main culprit. I know it may be more than one. I suspect salicylate sensitivity, flavour enhancers and maybe some preservatives. She certainly doesn't want to avoid food she doesn't have to!

Last night I got a text from her that said she felt she was not as scattered in her thinking and did not get upset and weird about things. She feels more in control and settled. Wow! These comments were after 3 particularly busy and stressful days. The physical improvements were the most noticeable at first but now the mental and behavioural improvements are showing. This has all happened in a month.

When I think back I think she has suffered since birth. She had reflux and after falling asleep would wake and cry for hours. Of course everyone said colic but even colicky babies settled sometimes. When I look at her baby photos she just looks pained and unwell. After about 4 months my husband joined me at the drs as my health centre nurse was concerned she was not putting on weight (no wonder! All her milk was on my clothes!) He told the dr we had to do something now as things were becoming desperate at home. The dr prescribed a drug that helped keep the flap at the top of her tummy closed after eating. I am pretty sure we also changed to the bottle because I was exhausted and she needed to put on weight. Well, in about a week we had a new child. Happy, smiling, sleeping putting on weight. I always attributed the improvement to the drug but now suspect it was changing to the bottle! In affect I was poisoning my baby!

She was quite good through primary school. Probably there were not as many additives and preservatives in the food and our fruit and vegetables were picked ripe. She did have some aches and pains, a rash here and there and we did joke about her lack of concentration. Nothing that really impacted her life; that was just her.

High school was ok but she was a child that always seemed to some ailment or other. Nothing too serious though. She found Year 11 and 12 difficult as she found it difficult to concentrate for long periods of time. Also she had glandular fever. I am actually very proud of her to get through year 12 with an OP 8, work part time and live away from home since she was 17. In fact the part job she has had for the last 2 years has been a guest service agent in a busy Brisbane hotel. It is very demanding. Also she has worked really hard in 2011 in her studies and achieved excellent results. I actually feel so excited for her now as she has done this well with a huge health disadvantage, I can't wait to see what she does from now on. We have a dietician from the failsafe recommended list (email confoodnet@ozemail.com.au for this list) who is actually one of my daughters friends mum and she is helping with the challenges and reading my daughter food diary when things go wrong. I have purchased The Failsafe Cookbook.

If my daughter had been born now I am pretty sure we would have gone through the trials so many parents I have come across in my reading and on the DVD. This probably shows how much our food has changed over the last 20 years. At least parents today have to deal with it early in their child's life. I know this has been difficult for them but I think it is better than our experience as it has been over so many years and during some challenging teenage times for my daughter. Then again I have read of people not getting the answers until their later years and I bet many have never come across the right answers.

I really wanted to write my story and also to sincerely thank Sue and Howard and all the parents whose stories I have read. All helped piece the puzzle together. – Sylvia by email

[1055] 320: Winning entry in the "Worst additive competition" (from submission to FSANZ 2006)

In my opinion the worst food additives are those in the range of antioxidants 310-312 and 319-321 "The Nasty Antioxidants". As antioxidants are not considered to be preservatives (by regulators), and the suppliers/manufactures are not required to list these on the label, they are the most frustrating additives by far. At least with colours, you can readily see them and hence avoid them. Same with most other additives, they are usually on the labels in some sort of description. But the good old nasty antioxidants are secret unless you go to extreme lengths to ask the supplier of the food and then the manufacturer of the contents eg. vegetable oil what exactly are in their oils.

There are alternatives to the nasty antioxidants which are failsafe and haven't been associated with cancer in rats and possible genetic changes and also nausea, vomiting, ringing in the ears, delirium and collapse, children's behaviour just to name a few.

Even 'safe' foods like 'natural' ice cream cones can't be trusted. They change their oils on a regular basis and also the use of antioxidants from friendly ones (300-309) to nasty ones (310-321). I only found this out after my son experienced an ADVERSE REACTION to these cones and I telephoned the supplier and was told that they had changed their oil and it included BHA (320) & tBHQ (319).

What hope have we got for our children and ourselves if such nasty things are HIDDEN in our foods? I would just love for my son to be able to tolerate eating the occasional fish 'n chips on a Friday night just like I used to when I was a child. Is that so much to ask for? – mother from Victoria.

[603] Arthritis started after a car accident (February 2008)

My arthritis started after a car accident at the age of 19, also ringing in the ears. The arthritis was to the point where I would soak my hands in hot water each morning to get them ok to work. Both my arthritis and ringing in the ears disappeared totally on failsafe, it was incredible. Four years on, it remains largely stable, is clearly affected by mainly salicylates and sulphites and to a lesser extent amines and MSG. Medication was generally ineffective. - by email, Qld

[559] ‘Ultra-healthy’ diet led to asthma and debilitating health issues (May 2007)

My mother and I have known for years that we are allergic to aspirin. We both react with ringing in the ears, nausea, vertigo, lethargy, and I even lost consciousness once. I avoid salicylates in cosmetics and toiletries at all costs, but my health has steadily declined (I am 24). My mother and I both have had doctors mystified for years with strange and debilitating health issues. They told my mother oh you have lupus, no you don't, yes you do, no ... so on and so on. Now they have decided that we both have fibromyalgia. 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.

Everyone made fun of me calling me a "health nut" because of the supposedly ultra-healthy diet I was on. I was trying to follow the USDA guidelines and eating lots of fruits and vegetables - especially citrus, broccoli, and spinach. The heart healthy recommendations include lots of processed tomato products and using as many different herbs as possible (to give flavor instead of salt). I also was trying to eat as many "naturally sweetened" things as possible. I was eating a lot of fresh oat granola, but it was loaded with honey, almonds, and pretty much anything that comes up high in the sals. I also was using olive oil for cooking, salad dressing, and with herbs instead of butter on bread.

It's no wonder that I was getting worse. I was having so many migraines that I only had about two days a month that I could function without excruciating pain in my head, I had chronic tendonitis, chronic fatigue, if I ever did get to sleep I felt more tired when I woke up than before I slept and I was still gaining weight. Now that I am on the right track I have only had two migraines in two months, and I have only had a tendon problem one day. I was diagnosed with adult onset asthma and was using an inhaler every day and now I only have to use it when I get exposed to salicylates.

My mother and I have both been improving so drastically that everyone is asking us what is going on. – from the USA

[436] Amines: depression and hungover (August 2006)

This father who was doing the elimination diet to support his son chose to do the amine challenge first because he thought he wouldn't react. 'How wrong can you get!' he wrote in his account of the challenge:

'I had a violent reaction within a few hours and have never felt so awful in all my life. Here are some of the symptoms: depression, suicidal tendencies not just thoughts, melancholy, looking for an argument, feeling the whole world was against me, lethargy, shakes, pressure on the skull and tingles in the extremities, feeling of hangover, inability to focus on thoughts, ringing in the ears, inability to sleep. The hungover feeling lasted until the next day. Not the best 24 hours but at least I know there is a cause for symptoms that I have experienced in the past.'

[350] Hearing loss and tinnitus from salicylates (Nov 2004)

I've known for 30 years that I am salicylate sensitive since suffering temporary hearing loss - and the top of my head felt numb - after taking one regular full day's dosage of aspirin (8 tablets in 24 hours) prescribed by my doctor. My symptoms cleared up in several days after I stopped the aspirin. But it is only recently that I put two and two together and got four - food salicylates may have played a big role in my steady hearing loss and increasing tinnitus over the years. I discovered this when I started taking noni this year and my hearing loss accelerated, I got terrible tinnitus, and my head felt "funny". Then I discovered noni may be high in salicylates. - by email

[189] "Antioxidants are the most frustrating additive" (September 2002)

Antioxidants (310-312, 319-320) are the most frustrating additive by far. You can usually see colours and other additives are usually on the label in some sort of description. But antioxidants are not considered to be preservatives by regulators, and the manufactures are not always required to list them on the label, so antioxidants are a secret ingredient unless you go to extreme lengths to ask first the supplier of the food and then the manufacturer of the contents.

There are alternatives to the nasty antioxidants which are failsafe (300-309) and haven't been associated with cancer in rats, possible genetic changes, nausea, vomiting, ringing in the ears, delirium, collapse and children's behaviour, just to name a few.

Even failsafe foods like Betta Natural Cone Cups can't be trusted. I found this out after my son experienced an adverse reaction to these cones. When I telephoned the supplier, I was told that they had changed their oil and it now included BHA (320) and tBHQ (319).

What hope have we got for our children if such nasty additives are hidden in our foods? – Jenny, Warragul, Victoria