Reader reports from the Food Intolerance Network

www.fedup.com.au

("fodmaps", "fodmap", "fructose", "sorbitol" keyword only)

[1465] One-liners (November 2017)

I was on the Fodmap and it wasn't working and now I going low Salicylate foods and I'm improving a lot - Karen USA

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

Hi, all! I just discovered the Failsafe elimination diet after talking with my yoga instructor, who found it helped determine what foods caused her Al disease to flare. After reading up on it, though, it seems to be geared more towards children with behavioural disorders. Are there any adults that have found success for other conditions with Failsafe eating? Specifically, my problems are gastrointestinal due to IBS and SIBO as well as frequent headaches, fatigue, and joint pain. I have been following low FODMAP for quite some time now and it has only made things worse. — Jessica

Failsafers respond:

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

Failsafe has helped me with stomach issues and headaches. There is very little overlap between Fodmaps and failsafe vegetables, so quite likely that if Fodmaps made things worse, failsafe could be very helpful! – Ruth

[1214] FODMAPs not enough for my IBS (July 2013)

I was diagnosed with IBS about 2 years ago and told to follow the FODMAP diet to reduce symptoms. The last few months my symptoms flared right up again and so I dragged myself back to the doctors and a dietician and I have now been told I have to cut out salicylates and amines (at least initially) as that is likely to be my problem. After one week on the elimination diet I have noticed a huge improvement, apart from the fact I am missing all my usual fare like spinach, coconut, berries, tomato and the list goes on! I am so grateful though for the relief, I actually feel normal again. Thanks! — Lisa

(see also FAQs http://fedup.com.au/information/frequently-asked-questions/diet-questions#fodmap and http://fedup.com.au/information/frequently-asked-questions/diet-questions#fodmap)

[1122] Forgetful and stomach cramps on FODMAP elimination diet (August 2012)

I have been suffering from various IBS-like symptoms for several years and have finally decided to do something about it. A couple of months ago I went to see a dietitian and following her advice tried a FODMAP elimination diet for a month. Although there was improvement in some areas there was a decline in others. I became VERY forgetful and suffered stomach cramps when eating what turned out to be foods high in salicylates. — Sharon

[1121] FODMAP diet made my gastro symptoms so much worse (August 2012)

I'm a coeliac with ME/CFS who is still having major problems with food reactions (particularly gastrowise; I get so much pain/bloating/cramping/malabsorption etc that my life is severely affected by it) despite following a strict GF diet. I have a feeling salicylates may be a big problem for me, and I can see that my diet is very high in them. I was trialled on a FODMAP diet by my dietician but it made my symptoms so much worse, and I suspect this may be because the 'safe' FODMAP foods are actually those that are highest in salicylates. - Alison, UK

[993] Low salicylate versus low fructose diet (March 2011)

My 4 year old son' behaviour has always been challenging, but has been particularly bad in recent weeks. After complaining of bloating, diarrhoea etc a breath test revealed that he was fructose intolerant (Note: about 50% of people have a positive breath test, so it is not very useful - Fructose malabsorption factsheet). So we started on the strict fructose elimination diet. My GP asked me a couple of weeks later how the diet was going. I responded that it was going well and that my son had not complained of bloating, stomach pains, etc since. However the thing I had noticed the most was his improved behaviour. I'm sure my GP thought I was a little odd, and commented that it wasn't something he'd heard of before but perhaps my son's behaviour is better because he doesn't have tummy pains. I wasn't convinced.

After a few weeks, we started a challenge by reintroducing the high fructose foods. He seemed to tolerate them well as long as he doesn't eat too much fruit each day. However, his behaviour has been foul! He seems more angry than ever, and last week I was wondering if he may be ODD. The Magic 123 which worked well for so long, now has no impact as he is just so defiant.

So, I started FAILSAFE eating 6 days ago. We haven't done it perfectly as his diet is very restricted due to food allergies and the fructose intolerance. But I've removed the high salicylate items, particularly tomatoes, strawberries and cantelope; and we're really just having the good ol meat and 3 veg for tea every night. I've cut his fruit intake to 1 serve every 2-3 days.

Day 1 perfect behaviour although it was still like walking on egg shells.

Day 2 bad morning, good afternoon.

Day 3 good behaviour a little less eggshells!

Day 4, 5, 6 great behaviour.

When things are good he is the perfect gentleman, well-mannered a real angel. But when things aren't going his way he still gets grumpy but most of the time he can now control the anger. A week or more ago, he just couldn't.

Update 3 months later after doing the elimination diet with a dietitian: Things went really well for some time. However, my son was desperate for some of the non-failsafe foods, particularly tomato sauce and jam. So I gradually caved in, and allowed him to have some. Initially it was a little bit every few days, then a little each daily. Although I'm still careful with his diet, he mustn't be able to tolerate even these quantities as we've started to notice some of the same old behaviour. The salicylates seem to have a cumulative effect on him. Whilst his behaviour hasn't been as aggressive or defiant, I'm certainly noticing that he is loud and unsettled. He can't concentrate on playing with his toys, but instead races around the house and jumps on the furniture! So this week were back on failsafe - strictly! — Carly, by email.

What the researchers say: (See page 14 of the RPAH Elimination Diet Handbook 2009 available from www.allergy.net.au): 'Having excessive amounts of fruit especially fruit juice and dried fruit can cause symptoms such as bloating, reflux, abdominal discomfort, wind and diarrhoea. Although incomplete fructose absorption can cause stomach and bowel symptoms, it does not cause other symptoms such as headaches, fatigue or skin rashes ... improvement of symptoms after going onto a low fructose diet is most likely to be due to the simultaneous reduction of intake of natural chemicals in fruits and vegetables'.

[728] Needed to be failsafe and reduced fructose for full results (June 2009)

I am still struggling a bit here trying to deal with fructose malabsorption and failsafe, plus other malabsorptions (raffinose and sorbitol) that mean I don't tolerate well any fruit, veges or legumes except for potato, celery and lettuce. If I increase my salicylates then I get anxiety and other symptoms. Basically pears, onions of any sort and leeks are on the banned list (as well as other veges and fruit) - which I have been eating a lot of! This explains why I wasn't getting full results on failsafe eating. Jane, VIC

[726] Fructose intolerance diagnosis not the whole answer (June 2009)

My eight-year-old daughter has been diagnosed with fructose intolerance and while we have seen a dietitian it seems that we have recently hit a brick wall and she is constantly getting tummy aches. I am exploring other causes at the moment but was wondering if you could give me any information about preservatives and spices (which I am suspicious of) that could help me manage her better. The attitude I have had from doctors is here is the diagnosis good luck and seeya later, I really wonder how much they really know. I am literally alone doing my own research and homework ...

Three years on: Together with your help, our dietitian and the web, our daughter is growing, is a lot happier and not as sick as often. As well as fructose, we avoid flavour enhancers (MSG 621 and others) and suspect sulphites (220-228), salicylates and cheese are an issue for our daughter too. All

in all we as a family are a lot happier, family and friends are now more understanding and accepting of our daughter and her food issues and we are constantly learning. We have also learnt that the key is "listen to your body". by email, SA.

[550] IBS: 'nice, big, healthy bowel' needed dietary modification (May 2007)

I have been aware of the RPAH diet for over 10 years and largely stuck to it during that time to help with symptoms of MS (multiple sclerosis). I have also suffered bowel issues for many years, predominately constipation but sometimes diarrhoea. My symptoms primarily include bloating, constipation and terrible pain. Initially, I thought it was the cause of my MS (bowel and bladder disturbance can be a problem) so just figured I had to live with it. When my lower bowel pain became quite severe - particularly after eating wheat and despite being failsafe - I decided to consult my GP again. She referred me to a gastroenterologist who preceded to do a colonoscopy to see if some inflammatory bowel disease was present and an endoscopy so she could take a biopsy and take a definite diagnosis on whether I had Coeliac disease or not.

Fortunately, all my results came back clear and the gastro told me that after examination she concluded that I had a 'nice big healthy bowel' (I guess that's a compliment to the gastro fraternity!) As she had eliminated all other possible diseases, she further concluded that I simply had IBS which has no real treatment. She said that dietary modification could help however, and referred me to a bowel dietician.

The dietician explained to me about fructans (a natural sugar) found in the onion family, wheat, chicory and asparagus. Having been failsafe, I knew about the amine and salicylate intolerance I have but thought that eliminating fructans could help considering I found leeks, spring onions and wheat appeared to affect me despite them all being failsafe and despite my not having Coeliacs. This all really helped so now I have refined my diet again and have eliminated all the trigger food chemicals (MSG, Salicylates, Amines) as well as fructans (leeks, spring onions, wheat, asparagus). This has helped my IBS greatly. I am now just trying to give up percolated coffee every morning as that appears to trigger IBS symptoms. This fructans information may just be another piece of the puzzle for some people who suffer IBS. – by email.

[386] Effects of 'sugar-free" polyols (January 2006)

A few months ago I started chewing sugar free chewing gum several times a day and since then, my stomach has been almost continuously bloated. On occasions the amount of gas in my stomach is so extreme that I have to force myself to burp to relieve the pressure in my stomach - Male, 30s, Australia, sorbitol and maltitol, twice daily.

I was suffering with a sort of what I thought was "gastritis", causing extreme obnoxious embarrassing gas and bloating, and after an hour or two, constant gas every 10 minutes for hours and hours it was so bad I wanted to run away from myself, I know that's funny but it was quite disgusting, the doctors told me I had a spastic colon but I noticed the "health" food candy bars I thought were healthy had sorbitol and my stomach feels perfect since I've been reading the labels and staying away from the sorbitol - female, 30s, USA, sorbitol, daily

I ate 5 caramels that I thought were safe because they were free of artificial colours and other additives. A few hours later I had excruciating stomach pains and sudden diarrhea – female, 40s, Australia, maltitol, one serve

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