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**Unlucky Shirl**  
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# Bile Salt Malabsorption after Cholecystectomy

Posted over a year ago

I had my gallbladder removed 11 years ago and have suffered with

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chronic diarrhoea since, but the condition is getting worse. I've been diagnosed with bile salt malabsorption. Most people lose weight with this condition, but unfortunately for me, I have gained around 3 stone. Has anyone with this condition had the added problem of weight gain. I'm at the end of my tether as I can't lose this weight.

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**mario** • over a year ago

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hi i had my gallbladder removed in 1990 and have had problems with the bowel ever since. but apart from my very closest family i never spoke about it until last year 2011 in december i had a sehcat test done and was diagnosed with bile salt malabsorption i also have b12 anemia which i think is connected has it is the same site that both are absorbed in. my own research through the net. but even if i was told that i would end up with permanent bowel problems i would still of had the operation because i was ill in the end. 21yrs i suffered in silence due to embarrassment what an idiot i was i feel better just knowing my accidents are not my fault im only 44yrs old now, so i suppose the older you get the less you are willing to leave things , i think that the ratio of people left with problems after gallbladder removal is alot higher than what is recorded it is just hard to speak about when you are young sorry for the ramble finely ive come to terms with this all the best to you .



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mario • over a year ago

yes i put weight on after and have never managed to loose it again and im busy,i go walking the gym and swimming. just easier not to eat if going somewere,so as not to have an accident wether this makes the weight worse probably does metabolism an all that.

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reply to mario



★ 1

buckers • over a year ago

I also have this condition, but I loose weight not gain it, we are all different, not sure if you great people are aware of the help with toilets if you need them, here are a few I have found :-

The National Key Scheme (RADAR) gives you access to public toilets for disabled people throughout the country. These are very useful and you can buy a key by visiting their website at [www.radar.org.uk](http://www.radar.org.uk)

NACC - Card £ 12.00 for the pack [www.nacc.org.uk/content/home.asp](http://www.nacc.org.uk/content/home.asp)

phone apps to find a toilet - [www.betomorrow.com/2011/09/02/ou-sont-les-toilettes/](http://www.betomorrow.com/2011/09/02/ou-sont-les-toilettes/) free

hope this helps

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reply to buckers



dottiepops • over a year ago

★ 1

I had my gallbladder removed 2 yrs ago. I've had constant problems with my bowel ever since. I haven't lost weight, I've gained it. Some weeks have diarrhoea other times I am constipated. Been told its a side effect of the op. Some people get better others don't.

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★ 1

**Georgie66** • over a year ago

I just got prescribed Colestyramine for this condition .. early days but seems to be helping so far as it helps with the absorption so that food doesn't pass through quite as quickly! Might be worth talking to your doctor about it.

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★ 2

**trex** • over a year ago

There is more than one reason why people have body parts, namely a gall bladder and doctors play with peoples lives as if they are dealing with mechanical objects taking things out of peoples body and not replacing them. Doctors and scientists can do anything these days but they dont want to create an artificial gall bladder with all its entire functions because it will cost them money. On the other hand they can create artificial hearts and valves - who are they to judge what organs people need or dont need. They tell you that you dont need your gall bladder but as you all know it from experience, you do. If all the people took some action we would all go a long way.

They could just take out the stones just like they do from a kidney without unnecessarily removing it and do the same with the gall bladder and stitch it up inside but nooo, they want to be efficient and save money.....by making patients, you suffer. As you can see the gall bladder is a very important organ, apart from the usual it also has bowel and weight regulation function, it has an affect on hormones and other body parts. After the doctor has done his job in theatre, which is not to cure the problem but to make it worse, which they wont admit to, are the side effects you suffer from this surgery. They usually do not have an answer to your problems after the operation. They will give 101 excuses and blame other things or your other perfectly healthy system. They will not want to admit the side effects are true nor will they want to deal with it anymore. The short answer is you have stones, take out the whole thing.

Has it not occured to anyone with an average intellience, you need your gall bladder and removing it is not the answer. Even when the gall bladder is removed you continue to accumulate stones. The problem is not the gall bladder. The problem is diet - you need more fibre and water and eat healthy. If you dont do that you're liver will get congested and as result bile flowing from the liver will be sluggish and if there is not enough water and too much of the wrong type of waste it will harden and turn to stone.

The liver and diet is the cause of gall bladder disease not the gall bladder and removing the gall bladder wont do any good but to make problems worse. The main problem is if the gall bladder is removed bile will flow down through the digestive system and into the bowels, over time, this will cause irritation and will get worse which will result in bowel problems.

Patients need to do everything to get a replacement gall bladder if they opt to have it out otherwise go for conservative treatment, if a lot of pressure is applied on the doctors they will do what you want them to.

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 reply to trex



**amanda74** • over a year ago



i also had my gallbladder removed back in 2011, and last june was diagnosed with Bile salt malabsorption.

looking back i think i may have had it beforehand, but having my gallbladder removed just made the

symptoms alot worse. i went from constantly going the toilet to living my whole day running up and down the stairs going at least 20 times a day.

now im finding i have put weight on, although i follow a very healthy diet, eating alot of fresh fruit and veg, using the slimming world diet, i go to the gym at least 3 times a week, i dont drive so walk everywhere, and go to aqua fit, yet i cant lose weight no matter how hard im trying. i have been on colystyramene since last june so symptoms are now under control but feel im not getting anywhere.

♥ 0 votes

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↩ reply to amanda74



**Georgie66** • over a year ago



Just an update ... Switched to cholestagel and it is definitely improving my upset stomach. Would recommend that you ask your doctor to prescribe and give it a try. Nothing to lose and hopefully everything to gain!

♥ 0 votes

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↩ reply to Georgie66



**lisa1973** • over a year ago



I was diagnosed with bile salt malabsorption back in 2002, I haven't had my gall bladder removed, after having my second child in 2001 the symptom's started, back then I spent approximately £5000 seeing a private specialist

over a period of 12 months to be diagnosed with this. He prescribed Questran for as long as I needed it, 11 years later I take between 10 and 12 loperamide a day just to control it, sometimes a lot more, it's miserable, and up until recently nothing came up on google regarding the condition. Sorry for intruding, I just feel a lot better (no offence meant) seeing that other people have this condition too xx

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 [reply to lisa1973](#)



★ 1

**philippa22** • over a year ago

I haven't had my gall bladder out, but was diagnosed with bile salt malabsorption last year after 2 years of them testing for everything else. I thought that having a diagnosis would be the answer to prayers, but unfortunately the symptoms continue.

I too take cholestigel, but find the side effects (crazy headaches) which I find unbearable, so only take it when I have to.

I have put on 3 stone and have just signed up for a gym session of 12 weeks to get my core muscles back. I am also about to embark on a series of acupuncture sessions in a bid to try and get some relief.

I'm 51 and basically incontinent, and I don't want to live my life like this. Little is known about the causes or a cure, so we have to help ourselves.

I'll post back on here once I've started the acupuncture if it is of help to anyone else.

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 [reply to philippa22](#)



**Georgie66** • over a year ago

★ 1

Oh what a shame that Questran/cholestagel hasn't worked for you ... if you haven't tried it already, how about having some Kinesiology treatment. I have that on and off and it helps for all sorts of ailments ... Calcium is also good for the colon so might be worth looking into that. On cholestagel I have the occasional blip (usual hormone related!) but am definitely seeing a dramatic improvement on how I was. Good luck and keep in touch.

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↩ reply to Georgie66



**goody1** • over a year ago

★ 1

I could cry having seen this discussion. For over 15 years I have suffered from bile salt malabsorption after a cholecystectomy. The first two years I was literally attached to the bathroom. I had test after test until a professor at St. Mary's Hospital in Paddington gave me a sehcat test and from then on it has been Questran before every meal. The reason I could cry is that I have felt like the only person on the planet with this condition. It is so hard to talk about with friends or family. It is an unpleasant way to have to live because even though Questran is a help it doesn't remove all the symptoms and I still have days when I feel extremely debilitated. I was interested to read that another person here has to have B12 injections as I do as well. But this week I was suddenly plunged into anxiety about Questran when I discovered quite by chance that it has been recalled by the manufacturer! This is an MHRA Drug Alert, Class 2 Medicines Recall. And it was issued on 3rd June 2013. Nobody could tell me anything about why this had happened. So I phoned the manufacturers Bristol Myers who told me it was due to possible contamination with a bacteria. I trawled the internet and found the certificate about the recall and then discovered that the bacteria is Enterococcus Faecium. If you're anything like me, the thought of not taking Questran is rather terrifying. The pain. The accidents. Basically the inability to live a near normal life. So I have always made sure I had a reasonable supply stockpiled. When my pharmacy kept telling me that there wouldn't be



any supplies for many months I wasn't initially too worried because I figured I'd have enough. But having discovered this Class 2 Recall I have to admit I'm horrified that my GP hasn't informed me about it. I looked into this further with the BMA and it seems that telling patients about this isn't something they have to do. Enterococcus Faecium happens to be an antibiotic resistant bacteria. I find the whole situation really worrying and I'm quite stunned that the fact that boxes of this medication have had to be quarantined and sent back to the manufacturer isn't considered serious enough for GPs to have to inform their patients that they could be at risk of contracting this bacteria. I'd be really interested if anyone has been told about this too. And thank you so much to the person who started this discussion. It means a lot to know there are others in this unfortunate situation.

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★ 1

**aneata** • over a year ago

I suffer from bile salt malabsorption which got so bad a year ago i was referred to hospital, but i still have my gale bladder.

i had sechat scan and other tests to diegnose as there is UC in my family. i was taking 6-8 Lerpermidie a day along with codine, but it didnt help. going loo 6-12 times per day and getting a very sore bottom.

Questran has been a life saver. i no longer need to plan each day and each moment out of the house around the toilet 😊 just take one dose with each meal, easy.

i told my consultant that i was having difficulites getting questran since March (chemist still owe me 1 box from my last percription) and he prescribed Colesevelam instead. he told me it works the same way as questran, but it is in tablet format, a little more powerful and more expensive.

it is working, but i have been getting bloated, very smelly gas and bellyache. i never got these with questran.

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 reply to aneata



**Georgie66** • over a year ago



Aneata, I had the bloating etc when i first started the tablet form. Suggest you alter your dose .. i now have one tablet before breakfast and one tablet before lunch (sometimes two if I am having a big meal) and then do not have one in the evening. Might be worth trialling a few different ways of dosage. Hope that helps you.

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 reply to Georgie66



**trex** • over a year ago



I feel sorry for everyone who is suffering the after-effects of gall bladder removal. Doctors can remove stones from kidneys but they wont remove stones from gall bladder that is so pathetic and the only reason they dont is because it will cost them more in the long run and that is stones will form in the gall bladder again. That is true but removing the gall bladder is not the answer.

The problem is liver congestion. If we all follow a good proper diet we can cleanse our liver and stop stone formation which actually accumulates in the gall bladder by simply dripping into it and sitting there. We could do even better if the doctors got to the root of the problem rather than just grab the gall bladder and bin it because they think that is the cause of the problem - its not. The gall bladder is just simply a storage sack.

If you all did you research then you would understand the same, I am lucky I have not gone for surgery although I have stones. Its not painful yet but I have been offered surgery to have it out voluntarily - that is without the pain coming on yet and before going to A&E.

I have done my research and I understand but I cant live the fat-free life of the yummy food - who cant ? anyway, there is one thing we all need to do is...and that is get the doctors to change their way of thinking - no gall bladder removal but stone removal - which ever way they can but to leave the gall bladder there intact. I am sure you can all see for yourselves the consequences of gall bladder removal. I am sure there are other ways to zap the stone but it would cost them but the fact is we pay our taxes and they get paid. So, the doctors need to change.

So, lets start doing something about it - what have you gotta lose ?

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↩ reply to trex



**swats73** • over a year ago

I am so glad I found this, I have my gale bladder but have been suffering for years. I was diagnosed with bile salt malabsorption in 2013 and also osteopenia at the same time. At the moment I am taking in the morning Folic Acid(slight deficient), Loperamide, 60mg Vitamin D3 and 2 hours after Questran 4g sachet. then in the evening I am taking 10mg Cetirizine(allergy tablet), Loperamide, 60mg Vitamin D3 and 2 hours after Questran 4g sachet. Have so far found this not helping a lot but have now had my dose of Questran 4g sachet put up to 4x a day. Was wondering if people have any recommendations on ways to split it up? as my Doctor has suggested just to double the morning and evening intake, but reading this it looks like taking it at regular intervals may be better?

Also I am suffering a lot of weight loss now I am using the sachet (2 stone in 5 months) although I am waiting for an appointment with the dietitian in the

new year.

any help or suggestions for a new diagnosed sufferer much appreciated.

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 reply to swats73



★ 1

**aneata** • over a year ago

Hi guys. I started a support group on Facebook for anyone that suffers from bile salt malabsorption. [https://m.facebook.com/groups/176952655839795?ref=bookmark&\\_\\_user=789734461](https://m.facebook.com/groups/176952655839795?ref=bookmark&__user=789734461) feel free to join this growing group

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 reply to aneata



★ 3

**designergirl12** • over a year ago

I have my gallbladder complete with 13mm stone. My doc won't entertain my having the GB out as it will cause my chronic Diverticulitis to explode!

Having read this board I am glad that I am suffering minimal pain. I agree with not taking out the GB but I don;t know about removing stones! The gallbladder shrinks and expands all the time so stitches would bot be a viable option.

Kidney stones are made up of different stuff to the cholesterol that gallstones are. You can pass a kidney stone out, gallstones get stuck in the bile ducts, one of mine was and it was not pleasant. They can also get into the pancreas and then you are in real trouble. My stones were caused by taking Levothyroxine for an underactive thyroid and now my colon is full of diverticular things.

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 reply to designergirl12



**designergirl12** • over a year ago



Thanks for posting the link, i have applied ot join. i'm not suffering from this but I still have my GB and a stone so you never know.



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reply to designergirl12



**sarah27062** • over a year ago



I have suffered tremendously for five years but suffered mildly for about fifteen prior. Five years ago is when I had my gallbladder removed I was going fifteen times a day and it was pure liquid. I live in the US and they do not do the SeHCAT test here. I've done a lot of my own research since most doctors do not diagnose Primary Bile Acid Malabsorption and just say it's IBS. I started on Questran but it did not help that much and made me sick because of it being a powder. I now take Colestid (Colestipol) or Welchol (Colesevelam HCl) up to 12 pills a day. Because these meds absorb vitamins I take Vitamin A, K, D with Calcium and iron (which are all supposed to make you constipated). I recently added a pain killer that causes constipation. Since most of the pain I was having with the diarrhea was from my bowels spasming I take a mild muscle relaxer. So far this is the best I've come up with but my condition seems to worsen with time. With all these meds that would constipate a normal person for a month I still have bowl movements three times a day but they are not completely diarrhea because of the meds.

The light at the end of the tunnel for me is that they think our condition comes from a lack of a hormone FGF19.

[http://www.interceptpharma.com/pdf/2013\\_DDW\\_Walters\\_OBADIAH\\_Final.pdf](http://www.interceptpharma.com/pdf/2013_DDW_Walters_OBADIAH_Final.pdf)

They have created a drug that should be on the market in about two years

or so that has shown to treat this condition in trials.

<http://ir.interceptpharma.com/releasedetail.cfm?ReleaseID=765923>

There is a possibility that the drug will be marketed to treat overweight people which leads me to believe lacking this hormone is causing the added weight I've been carrying.

I hope this information is helpful. I know this is an everyday struggle that forces me to find acceptance more and more every day. It amazes me how not alone we are.

♥ 0 votes

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↩ reply to sarah27062



**maggie91094** > **sarah27062** • 5 months ago



Hi, I found your message on this website, which I note was over a year ago, but I was very interested to read your post. I have never heard of the lack of hormone FGF19, being linked with bile malabsorption.

However, I am not sure that this applies to me. In my case I have lost quite a lot of weight since being diagnosed with a SeHCAT test which was done at the Royal Marsden in London (there is a very good doctor there that specialises in damage to the bowels caused by radiotherapy). I had radiotherapy way back in 1991 for cervical cancer and my problems with diarrhea, tummy cramps, sickness and urgency developed over the years. I too, take Colesevelam I take 2 tablets 3 times a day after food (625mg) I was told that taking any more than this would not make any difference. I have 3 monthly injections of B12 but did not realise that this drug can absorb vitamins, so I think I might take a supplement, as I am quite thin and worry about brittle bones (I am 60 years old by the way).

Although this drug has helped control the watery diarrhoea I still have days when I have up to 12 BMs and always have to be near the loo. A

Its great that we can all share our experiences, offering each other

support, and hopefully some day soon we can get a "cure".

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