

Bile acid malabsorption

Introduction

You have been given this leaflet as your recent scan confirmed that you do not absorb bile salts properly from your intestine. This is probably contributing to the bowel problems you are experiencing. This leaflet explains what bile salt malabsorption means and how it is best treated.

What is bile salt malabsorption?

Bile salts are made in your liver. When you eat a meal, especially if it has fat in it, bile salts are released from your liver and gall bladder into your upper intestine (duodenum). Bile salts help to digest the food as it travels through your small bowel. When the bile salts reach the far end of your small bowel, they are mostly absorbed back into your body and travel back in the blood stream to your liver. They are stored here until they are needed for your next meal.

There is one specific area of the small bowel which is responsible for absorbing these bile salts. If this area becomes diseased, has been removed during surgery or damaged, for example by radiotherapy, it may not be possible for enough of the bile salts to be absorbed back into your body. If, as a result of failed absorption, too much bile salt reaches your lower intestine (colon), bile salt will cause fluid to be pumped into your colon by your body, which will cause diarrhoea (loose or watery stools).

How will bile salt malabsorption affect me?

Diarrhoea can lead to a need to go to the toilet urgently. Sometimes, this diarrhoea can be pale and greasy looking. Bile salt malabsorption may also cause cramp-like pains in your abdomen; which can be very severe. You may also suffer from very smelly wind and very erratic bowel movements. Very occasionally, if too much bile salt is lost, sufferers start to lose weight. This is because they do not have enough bile salts to help digest their food properly. Untreated bile salt malabsorption can increase your risk of forming gallstones and kidney stones. Vitamin B12 is another vital nutrient which is absorbed into the body at the end of the small bowel. If this area of the bowel is not working properly, people with bile salt malabsorption may also become short of vitamin B12. This can make them feel tired and short of breath.

What is the treatment for bile salt malabsorption?

There are a number of medicines which may help the symptoms caused by bile salt malabsorption (see below). It can take several days before diarrhoea starts to improve and it often takes several weeks for smelly wind to settle. You should keep taking the medicines that you have been prescribed for 10 days before deciding they do not work. If you stop sooner, you may not have given them enough time to work properly. It is very unlikely that having had a diagnosis of bile salt malabsorption that it will improve without treatment. You will need treatment for the rest of your life. If the treatment is effective and you stop it or run out of medicines, your symptoms will almost certainly return either immediately or within a few days.

Will changing my diet help?

Please do not change your diet without advice from a qualified dietitian to ensure that you do not become deficient in essential nutrients.

- **Low fat diet:** A strict, low fat diet (40g of fat per day) may improve bowel function to some degree even if you have severe bile salt malabsorption. A strict low fat diet should only be considered under the supervision of a dietitian. If you have a history of weight loss or a low body weight, it is not advisable to restrict your fat intake as fat is a valuable source of energy in the diet. The main problem with a low fat diet is that it is limiting and you will not know how much fat has been used in cooking especially if you go out for a meal.
- **MCT diets:** Replacing a large proportion of one specific type of fat in the diet (long chain triglycerides) with a different type of fat (medium chain triglycerides). Many people find medium chain triglycerides unpalatable. Do not try this type of dietary change without specialist supervision by a qualified dietitian.

Medication

There are two medications that can be used to help your bile salt malabsorption. These are anti-diarrhoeal medication and bile acid sequestrants.

- **Anti-diarrhoea medicines** such as codeine phosphate or loperamide (Imodium). Anti-diarrhoea drugs are usually much more effective if taken 30-60 minutes before main meals and are most helpful for people with mild bile salt malabsorption. Taking a regular dose at the same time(s) every day seems to give the most benefit. However, most people find that they still get unpredictable episodes of diarrhoea even when taking regular anti-diarrhoea drugs. Anti-diarrhoea drugs are least likely to help people with bile salt malabsorption with frequent greasy, pale stools.

- **Bile acid sequestrants:** These are a very specific treatment for bile acid malabsorption, which work by binding with the bile. Currently, there are two different types of bile acid sequestrants available in powder and tablet forms.
 - Powders: There are two similar types of powders, colestyramine (Questran) and colestipol (Colestid), which have been available for years. Most people need to take them regularly once, twice or even three times every day depending on how bad their symptoms are. Very occasionally, a dose on alternate days is enough. Around one in four people cannot take them because they cannot tolerate the taste, the powders make diarrhoea worse, or they cause intolerable nausea, heartburn, wind or bloating. Most people report they work better and are easier to take if you take them with food (and not on an empty stomach as the manufacturer suggests).
 - Tablets: Colesevelam (previously known as Welchol and now called Cholestagel) is also available. Most people take between two and seven tablets a day in two or three doses, usually after food. Colesevelam is only licensed in the UK to treat high cholesterol and it does this by binding bile salts in the bowel. However, it can be used for other reasons such as bile salt malabsorption but this does mean that if a patient in the UK developed some sort of serious problems as a result of taking this drug for bile salt malabsorption, it might limit the drug manufacturer's liability. Also, most general practitioners in the UK are unlikely to be prepared to write out repeat prescriptions for you for this medication because it is not licensed for bile salt malabsorption. This means that you will have to return to us for repeat prescriptions.

Colesevelam can potentially cause the same side effects as the powders; however, it seems to be better tolerated and is easier to take. We will usually prescribe one of the powders first before trying Colesevelam.

What are the possible side effects of using these medications?

If you can tolerate them, the bile acid sequestrants powders are safe drugs. As the tablet is quite a new drug, we have less information about its long term safety. However, as it works in a similar way to the powders and is not absorbed from the bowel, it seems likely it will have a similar safety record to the powders. So far, there are no concerns at all about the long term safety of the tablet. Colesevelam is a large tablet which a few people find difficult to swallow but you must not cut it up before swallowing it. A very small number of people develop a headache and abdominal pain, but this usually happens when people are approaching the maximum dose. If either of these happens, reducing the dose for a few days before trying to increase it again slowly, often prevents these problems from occurring a second time.

All forms of bile acid sequestrants may lower cholesterol levels when taken for a long time, but there are three possible problems with them:

- Bile acid sequestrants can with time, lead to low levels of fat soluble vitamins because they can interfere with the way these vitamins get into the body. Therefore, anyone taking bile acid sequestrants should have a blood test after three months to look at their blood levels of vitamin A, D, E and K and have a repeat blood test yearly. If their vitamin levels fall, this can be corrected with a vitamin supplement prescribed by the doctor. Vitamin B12 levels should also be checked yearly.
- Though good for cholesterol, these medicines can occasionally lead to increases in a different sort of fat in the blood (triglycerides). Very high levels of triglycerides may be harmful so triglyceride levels should also be checked with an annual blood test if someone is taking one of these drugs long term.
- Bile acid sequestrants may interfere with the absorption of other drugs you might have to take. This is not usually a problem as the drugs can be spaced out at different times through the day. However, whenever you are prescribed new medicines for whatever reason, you need to tell your doctor and the pharmacist that you take bile acid sequestrants.

Who should I contact if I want further information?

For advice on medicines you have received from the hospital, call Medicines Information from Monday to Friday between 9am and 5pm on: 020 8869 2762.

St Mark's Hospital, Watford Road, Harrow, Middlesex HA1 3UJ

General Trust Information

Patient Advice and Liaison Service (PALS)

PALS is a confidential service for people who would like information, help or advice about the services provided by any of our hospitals. Please note that this service does not provide clinical advice so please contact the relevant department directly to discuss any concerns or queries about your upcoming test, examination or operation.

If you would like this information in an easy to read format, large print, braille, different format or language, please contact the PALS team on 020 8869 5118 or email lnwh-tr.PALS@nhs.net. We will do our best to meet your needs.