NHS Foundation Trust

Bile acid malabsorption

You have been diagnosed with bile acid malabsorption (also sometimes known as bile acid diarrhoea), which probably contributes to your symptoms. This factsheet explains what bile acid malabsorption means and how it is best treated.

What is bile acid malabsorption?

Bile acids are produced in your liver (see diagram below). When you eat food which contains any fat, bile acids are released from your liver and gall bladder (if you still have one) into your proximal (upper) part of the intestine (duodenum). They help to digest the fat.

When the bile acids reach the distal (lower) part of your small bowel, they are mostly absorbed back into the blood stream and subsequently to your liver. They are stored here until they are needed for another meal. If bile acids are not absorbed at the distal part of the small bowel and reach the large bowel (colon), they can then cause symptoms. These may include loose stool, the need to open the bowel urgently, more frequent bowel opening, excessive wind, cramps, greasy stools and a generally quite unpredictable bowel pattern.



The distal (lower) part of the small bowel (ileum) is responsible for absorbing these bile acids. If this area has been removed at surgery (Crohn's disease, resection for tumours), becomes diseased (Crohn's disease), or been damaged, for example, by radiotherapy in the pelvis, chemotherapy or







by anti-cancer drugs (such as lenalidomide), it may not be possible for the bile acids to get reabsorbed.

If, for whatever reason, excessive bile acids reach your lower intestine (colon), this causes water and electrolytes to be secreted into your colon, increased production of mucus can appear, increased motility (movements) of bowels is observed and this all can then cause abnormal symptoms. These symptoms may not happen for over 12 hours after eating that fat. So, people often struggle to work out that there is a connection between what they ate two or three meals ago and their symptoms now.

Symptoms typical for bile acid malabsorption

- Diarrhoea (after eating enough fat to trigger the symptoms)
- Unpredictable and irregular bowels
- Bowel urgency and accidents
- Combination with pale and greasy diarrhoea (steatorrhoea)
- Abdominal cramps and bloating
- Smelly wind
- Weight loss (rare)
- Deficiency in vitamin B12 (this is absorbed in the same area where the bile acids get absorbed)
- Deficiency in vital nutrients which we have only in low amounts in our bodies normally, so called trace elements, such as zinc, selenium and copper.

Diagnosis

Currently, we use a SeHCAT (Selenium HomotauroCholic Acid Test) scan for the diagnosis of bile acid malabsorption. It measures the retention of radiolabelled bile acids seven days after ingestion. The lower the result is, the more severe the bile acid malabsorption is. Currently, we distinguish mild, moderate and severe bile acid malabsorption (<15%, <10%, <5% retention at 7 days).

What is the treatment for bile acid malabsorption?

Treatment is based on the results of the SeHCAT scan. Alternatively, if a SeHCAT scan is not available, we can perform a therapeutic trial with a bile acid sequestrants).

If the scan suggests that the bile acid malabsorption is borderline or mild, many people can manage by altering their diet. If the scan suggests moderate bile acid malabsorption, tablets or medicines are often needed. If the malabsorption is severe, then often both tablets and changes to diet are necessary.





All the treatments may take several days before diarrhoea starts to improve. You will almost certainly 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 within a few days.

Treatment options

Dietary changes

These are best supervised by a qualified dietitian to ensure that you do not become deficient in essential nutrients.

• Low fat diet

This involves reducing your total fat intake to less than 20% of your daily calorie intake (this is usually between 35g and 50g of fat per day), for a trial period of 2 - 4 weeks. If your symptoms improve on this diet, then it could be continued long term. A dietitian will help you to adapt your diet, so that it is nutritionally adequate, but also practical and enjoyable.

Medication

• Anti-diarrhoeal medication such as loperamide (Imodium). Anti-diarrhoeal drugs are usually more effective if taken 30 minutes before main meals. Another good way to use them is to prevent symptoms associated with bile acid malabsorption by taking one or two before you go out for a meal which may be more rich in fat.

• **Bile acid sequestrants:** These belong to a very specific treatment for bile acid malabsorption. Currently, there are two different types of bile acid sequestrant available in powder and tablet forms.

• Powder: Colestyramine (Questran)

The majority of patients will require one sachet (4g) daily, some of them two sachets (8g) daily. Colestyramine can cause side effects such as abdominal cramps, headache, nausea or vomiting. It is always better to take it with food. Also, colestyramine can decrease the absorption of other medication, therefore your other tablets have to be taken 4 hours before or 4 hours after colestyramine.

• **Tablets:** Colesevelam (also known Cholestagel).

Colesevelam is licensed to treat high cholesterol. It does this by binding bile acids in the bowel. A potential issue with taking a drug for a condition for which it does not have a license, is that some general practitioners in the UK are not permitted to prescribe unlicensed medication by their regional supervising committees. Yet, our experience has been that if you really benefit from this medication and we explain to the GP how straightforward it is to use colesevelam, most GPs are prepared to take on the long-term prescription and if necessary persuade the prescribing



authorities to allow them to do so. Further details can be found in The Royal Marsden factsheet *Taking colesevelam.*

Long term side effects of colesevelam

Patients can develop lipid soluble vitamin deficiencies (A, D, E, K) or trace element deficiencies. These should be therefore checked on regular basis and supplemented accordingly if required. Although designed to treat high cholesterol, these medicines can theoretically lead to increases in a different sort of fat (called triglycerides) in the blood. Very high levels of triglycerides may be harmful. We recommend that triglyceride levels should also be checked after a few weeks of treatment and then with an annual blood test if someone is taking one of these drugs long term.

Contact details

For further advice about bile acid malabsorption or its treatment, please contact:

GIANT Team

0207 811 8216 or 8106

Alternatively, please call:

The Royal Marsden Macmillan Hotline:

020 8915 6899

(available 24 hours a day, 7 days a week)



