

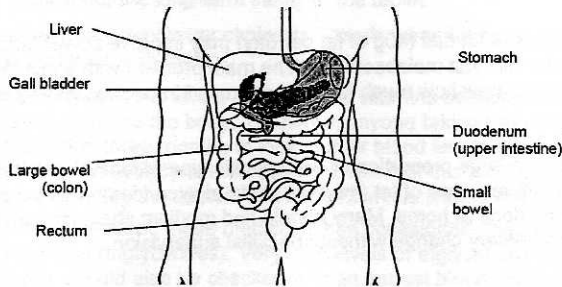
## Patient Information

### Bile salt malabsorption

Your recent scan confirmed that you do not absorb bile salts properly from your intestine. This is probably contributing to your symptoms. 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 (see diagram). When you eat a meal, especially if it has fat in it, bile salts are released from your liver and gall bladder (if you still have one) into your upper intestine (duodenum). They 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 the next meal.



There is one specific area of the small bowel which is responsible for absorbing these bile salts. If this area becomes diseased or has been removed at 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 get 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. These 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 treatments which may help the symptoms caused by bile salt malabsorption. It can take several days before diarrhoea starts to improve. It often takes several weeks for smelly wind to settle. You should keep taking the medicines for 10 days before deciding they do not work. If you stop sooner, you may not have given them enough time. 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.

### Dietary changes

These are best supervised by 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 in severe bile salt malabsorption. 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). This is very difficult to do and can only really be done at home. Many people find medium chain triglycerides unpalatable. Do not try this type of dietary change without specialist supervision.

### Medication

- **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. They are most helpful in 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 the anti-diarrhoea drugs regularly. Anti-diarrhoea drugs are least likely to help those people with bile salt malabsorption who have frequent greasy, pale stools.
- **Bile acid sequestrants:** These are a very specific treatment for bile acid malabsorption. Currently, there are two different types of bile acid sequestrant available in powder and tablet forms.
  - **Powders:** There are two similar types of powders, colestyramine (Questran) and colestipol (Colestid). These have been available for years. Very occasionally, a dose on alternate days is enough. Most people however need to take them regularly once, twice or even three times every day depending on how bad their symptoms are. About one in four people cannot take them because they cannot tolerate the taste or because the powders make diarrhoea worse or cause intolerable nausea, heartburn, wind or bloating.
  - **Tablets:** Colesevelam (also previously known as Welchol and now called Cholestagel). 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. 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 because it is not licensed for bile salt malabsorption, so you will have to return to the Royal Marsden Hospital for repeat prescriptions.

Colesevelam can potentially cause the same side effects as the powders. However, our experience at the Royal Marsden since we started using it in 2003 is that it seems to be tolerated much better and is easier to take.

We will usually prescribe one of the powders first before trying Colesevelam.

### **Possible side effects of the medication**

If the patient can tolerate them, the 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.

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

- they 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. Triglyceride levels should also be checked with an annual blood test if someone is taking one of these drugs long term.
- They may interfere with the absorption of other drugs patients 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 a bile acid sequestrant.