

## Bile Acid Malabsorption- Patient Information Leaflet

### Bile acid malabsorption

You have been given this leaflet because your Gastroenterologist or GP has recommended taking either **colestyramine powder sachets** or **colesevelam tablets** to treat bile acid malabsorption. This leaflet explains what bile acid malabsorption is and how it is treated.

### What is bile acid malabsorption?

Bile acid malabsorption is sometimes called bile salt malabsorption or bile salt diarrhoea. These terms mean the same thing. In this leaflet it is called bile acid malabsorption. Bile salts are made in the liver, and help you to digest your food, particularly fat, as it travels through your small bowel. The bile salts are released from your liver and gallbladder when you eat a meal, and enter your small intestine. When they reach the last part of your small bowel, otherwise known as the 'terminal ileum', the bile salts should be reabsorbed and recycled back to your liver. If the bile salts are not reabsorbed (malabsorption) in the ileum, they continue on in your gut into the colon, where they draw a lot of water into the bowel, creating ongoing problems with diarrhoea.

### Why do I have bile acid malabsorption?

There are different reasons that people get bile acid malabsorption, and they have been grouped into three types:

**Type 1:** problems with your small intestine or ileum. For example, it has been surgically removed following Crohn's disease or cancer treatment, or it has become inflamed.

**Type 2:** there is no obvious cause or reason for the bile acid malabsorption and your small intestine looks normal. This is called idiopathic or primary bile acid malabsorption and is by far the commonest type.

**Type 3:** other diseases or problems with your gut, for example coeliac disease, pancreatitis, removal of your gallbladder, after radiation therapy, or peptic ulcer surgery.

### What are the symptoms of bile acid malabsorption?

People with bile acid malabsorption generally find that they need to go to the toilet urgently, often after eating, with watery, pale stools (poo). They often have abdominal pains (cramps in the tummy) and bad smelling wind.

Bile acid malabsorption can severely affect your quality of life. Some people find they have bouts of diarrhoea more than 10 times a day and are nervous about going out if they are too far from a toilet. The diarrhoea may have been going on for a long time. Some people find that they start losing weight because of the diarrhoea.

### How is bile acid malabsorption treated?

Treatment of any underlying condition, such as coeliac disease or Crohn's disease, will help the bile acid malabsorption. All types of bile acid malabsorption may be helped by following a low-fat diet, and in mild cases, this may be all that is needed to help ease the symptoms.

Your doctor can refer you to a dietician for support with this, particularly if you are underweight or have other medical conditions that affect your eating and drinking.

In moderate / severe bile acid malabsorption, it is likely that you will also benefit from taking medication that binds the excess bile salts in your gut, preventing them from drawing in water to the colon, which helps to prevent watery diarrhoea. These medications are called **bile acid sequestrants**.

When you are taking an adequate dose of bile acid sequestrant, it should:

- Regulate your bowel function and improve your stool consistency
- Reduce the need to rush to have your bowels open
- Reduce the number of times you need to open your bowels
- Give you better control over your bowel function

### Bile acid sequestrants

There are 2 types of bile acid sequestrants available: **colestyramine powder sachets** and **colesevelam tablets**.

### Colestyramine powder sachets

Colestyramine comes as powder in a sachet and needs to be mixed up with liquid before it is taken. Some people find the texture or taste unpleasant. If this is a problem for you, then try adding the powder to fruit smoothies, juice, sauce or even to a pudding or custard with high moisture content (see product patient information leaflet inside your medicine box for more details). Mixing well and refrigerating the mixture can also help. The sachets should be taken at mealtimes where possible.

The main side effect of these medications is constipation, which generally just means that you have taken more than you needed.

The dose needed varies from patient to patient. The maximum number of sachets which you can take per day is nine.

This patient information leaflet will advise you on how to find the right dose for you by starting with a low dose and gradually increasing as needed to stop the diarrhoea. See the table below for the suggested way to start treatment. If you have any problems, contact the gastroenterology team who diagnosed your condition. (Please note that your gastroenterology team may give you an individual plan which differs from this leaflet).

Time from starting treatment	Dose	Comments
Starting dose	1 sachet TWICE a day with meals	Stick at this dose if your diarrhoea is controlled after 1 week. If diarrhoea is still a problem increase dose as per table.
1 week from starting treatment if diarrhoea persists	2 sachets TWICE a day with meals	Stick at this dose if your diarrhoea is controlled after 1 week. If diarrhoea is still a problem increase dose as per table.
2 weeks from starting treatment if diarrhoea persists	2 sachets THREE times a day with meals	Stick at this dose if your diarrhoea is controlled after 1 week. If diarrhoea is still a problem increase dose as per table.
3 weeks from starting treatment if diarrhoea persists	3 sachets THREE times a day with meals	This is the maximum dose. Do not increase further.

Because colestyramine can interfere with the absorption of other medicines, take other medicines at least 1 hour before colestyramine or 4 to 6 hours after your dose of colestyramine. Taking it with lunch or an evening meal often works well, but if you are on a lot of other medications, you may need to work out a new schedule for your medicines (and take colestyramine at a time other than with meals) - your pharmacist or GP will be able to help you with this.

### Colesevelam tablets

If you are not able to tolerate colestyramine powder sachets or they have failed to improve your symptoms, then colesevelam tablets are an alternative.

Colesevelam tablets are a newer treatment for bile acid malabsorption which are used off-licence for this condition. Off-licence means that a licence has not been granted specifically for use in this indication. However, there is lots of experience of using this medication for the treatment of bile acid malabsorption and it is recommended in the British National Formulary.

The dose needed is very variable between patients. The maximum dose is 6 tablets per day. Rarely, as the dose builds up, it can cause bad abdominal pains or severe headaches. We therefore suggest you gradually increase the dosage over two to three weeks.

This patient information leaflet will advise you on how to find the right dose for you by starting with a low dose and gradually increasing as needed to stop the diarrhoea. See the table below for the suggested way to start treatment. If you have any problems, contact the gastroenterology team who diagnosed your condition. (Please note that your gastroenterology team may give you an individual plan which differs from this leaflet).

Time from starting treatment	Dose	Comments
Starting dose	1 tablet TWICE a day with meals	Stick at this dose if your diarrhoea is controlled after 1 week. If diarrhoea is still a problem increase dose as per table.
1 week from starting treatment if diarrhoea persists	2 tablets TWICE a day with meals	Stick at this dose if your diarrhoea is controlled after 1 week. If diarrhoea is still a problem increase dose as per table.
2 weeks from starting treatment if diarrhoea persists	2 tablets THREE times a day with meals	This is the maximum dose. Do not increase further.

If new severe abdominal pains or headaches begin soon after starting colesevelam, the drug may be causing these symptoms. Reduce the dose to the level at which you last had no problems and then after a couple of days try and increase the dose again more gradually. Most people find they do not have a problem the second time.

If you only have two meals a day, it is fine to take three tablets with each of those two meals rather than the two tablets with each of three meals described above, but we would also advise that you build up the dose slowly over a few days rather than starting on a full dose immediately. If needed six tablets can be given once a day with meals.

Because colesevelam can interfere with the absorption of other medicines, take it 4 hours before or after other medicines. Taking it at lunchtime often works well, but if you take other medicines at this time then talk to your pharmacist or GP about how to fit these medicines in.

#### What are the risks of bile salt sequestrants?

Bile salt sequestrants can interfere with the way in which your body absorbs fat soluble vitamins (vitamins A, D, E & K). If you are taking bile salt sequestrants regularly, take an A-Z multi-vitamin and mineral supplement. In the UK, a supplement containing up to 1000 units of Vitamin D (equivalent to 25 micrograms) is recommended for everyone to take between October and March each Winter, and may be beneficial to take all year round.

You will need a blood test after three months of starting this medicine and then annually, to check your levels of vitamins A, D, E and K. Vitamin B12 levels should also be checked annually.

All forms of bile acid sequestrants may lower cholesterol levels when taken for a long time. Although generally beneficial, these medicines can occasionally lead to increases in a different sort of fat (triglycerides) in the blood. Because very high levels of triglycerides may be harmful, their levels should also be checked 3 months after starting treatment and then annually. This involves a fasting blood test – taken first thing in the morning before eating.

Occasionally, bile salt sequestrants interact with other medicines and reduce their effectiveness. This is particularly important if you are taking medicines where a small change in the dose could be very serious. Such medicines include those taken for epilepsy, to control heart rhythm abnormalities, chemotherapy, thyroxine, combined oral contraceptive pills and blood thinners. It is important to tell your pharmacist or GP about all other medicines that you are taking. Your pharmacist or GP will

then be able to help you schedule your timetable for taking all your medicines to reduce the risk of interactions.

What will happen if I stop taking my colestyramine sachets or colesevelam tablets?

It is very unlikely that your condition will improve without treatment. If you stop taking the treatment or run out of medicine, your symptoms are likely to return immediately or within a few days.

How soon will my symptoms improve?

It can take several days before diarrhoea starts to improve. It often takes several weeks for unpleasant wind to settle.

Can I take any other diarrhoea remedies?

Simple anti-diarrhoea medicine such as loperamide (Imodium) may help ease your symptoms by slowing down the activity in your bowel. Some people find that this works just as well as bile salt sequestrants and can be used instead of sequestrants or with them.

**Resources:**

GUTS UK (<https://gutscharity.org.uk/advice-and-information/conditions/bile-acid-malabsorption/>)

BAD UK <https://www.bad-uk.org/useful-links>

**The information in this leaflet has been adapted from an original document from University Hospital Sussex NHS foundation Trust with their permission.**