

If you have any more questions about short bowel syndrome or any of the things mention in this leaflet, please speak to your medical team. Your team will often ask for the support of the nutrition support team who has a dietitian and a specialist nurse who can advise and help you further if needed.

Short Bowel Syndrome

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in alternative languages / formats on request.

如有需要，本传单可提供其他语言/版式
此單張的其他語言/格式版本可按要求提供

Na żądanie ta ulotka może zostać udostępniona
w innych językach/formatach.

Whiston Hospital
Warrington Road,
Prescot, Merseyside, L35 5DR
Telephone: 0151 426 1600

St Helens Hospital
Marshall Cross Road,
St Helens, Merseyside, WA9 3DA
Telephone: 01744 26633

What does the bowel normally look like?

Your bowel (sometimes known as the intestine or the gut) is made up of two parts:

The first part of your bowel is the small bowel (made up of the duodenum, jejunum and ileum) and its job is to break down the food you eat and absorb it. This normally happens in the first 150-200cm of small bowel (jejunum). To do this properly the bowel produces fluid which contains enzymes which help break the food down to enable the bowel to absorb all the nutrients from it.

The second part of your bowel is the large bowel and its job is to absorb water and natural salts like sodium (salt) and potassium.

What is Short Bowel Syndrome?

Short bowel syndrome is a rare condition and happens because there simply is not enough functioning small bowel to absorb all the nutrients, fluids and salts that your body needs.

It occurs when:

- The small bowel is unable to digest and absorb enough of the nutrients that you eat because it is diseased or inflamed.
- The available small bowel is too short to allow sufficient fluid reabsorption. This may be as a result of an artificial opening of the bowel to the tummy wall (often called a bag by patients and known as a stoma by medical staff) created in the small bowel.

High in salt

You will lose a lot of salt daily and eating high salt foods can help replace it:

- Use salt in cooking and add to meals.
- Eat high salt foods like salty crisps, crackers, cheese, bacon, ham, smoked or tinned fish.

Low in fibre

Foods high in fibre are difficult to digest and reducing your fibre intake may help reduce your stoma output. To help:

- Use non fibre cereal products, for example white bread, white rice, white pasta, Cornflakes or Rice Krispies.
- Avoid large portions of fruit and vegetables and remove skins, stalks, seed and pips.
- Avoid nuts and dried fruit,
- Reduce intake of pulses (beans, chickpeas or lentils) however, if vegetarian include one portion a day for protein but a Dietitian can help with this.

High in energy and protein

- Have protein at each meal e.g. meat, fish, eggs, quorn or tofu
- Choose full fat dairy products such as full fat milk, cheese and yoghurts
- Fortify your meals
- Add 4 tablespoons of skimmed milk powder to 1 pint of whole milk and use on cereals, puddings and beverages
- Add margarine, butter or grated cheese to vegetables, potatoes and soups
- Try adding custard, double cream or ice cream to puddings for extra energy.

Oral Rehydration Fluids

Once made up, ensure you keep these refrigerated and discard after 24 hours. The drink may be better taken if it is cold and some find it easier to drink through a straw.

To make dioralyte:

You need to add 10 sachets of dioralyte to every 1 litre of water (1 sachet for every 100ml).

Aim to drink 1-1.5 litres of your dioralyte per day.

Try to drink this throughout the day.

To make St Mark's Solution:

20g (six level 5ml spoonfuls) of Glucose

2.5g (one heaped 2.5ml spoonful) of Sodium Bicarbonate

3.5g (one level 5ml spoonful) of Sodium Chloride (salt)

This then needs to be dissolved in one litre of cold tap water, and you need to drink 1-1.5 Litres throughout the day. You can add a small amount of cordial (not sugar-free) to it, if needed.

Diet

Your diet is important to help you stay healthy. What you eat can affect how much stool your bowel produces and how much nutrition is absorbed. Therefore, your diet needs to be:

- low in fibre
- high in energy
- high in protein, and
- high in salt

What are the problems that can happen with Short Bowel Syndrome?

Short bowel syndrome can lead to the following problems, if not managed correctly:

- Malnutrition
- Weight loss
- Dehydration
- Kidney injury
- Low levels of important salts which can cause problems with the heart
- High stool frequency (diarrhoea or frequent emptying of your stoma)
- Low energy levels and exhaustion

Carefully following your medical team's advice will help prevent these problems.

Managing Short Bowel Syndrome

Managing short bowel syndrome can be broken into three steps:

1. Slowing down the movement of the bowel
2. Reducing the secretions from the bowel (the fluid that the bowel produces to help break food down)
3. Reducing the intake of non-concentrated fluids

Usually a combination of all three steps is required to manage short bowel adequately.

1. Slowing down the movement of the bowel

Your medical team will provide you with medication which can slow the movement of the bowel down to allow the small bowel more time to absorb nutrients and fluid.

The usual medications are:

- Codeine
- Loperamide (also known as Imodium). This should be taken approximately 45 minutes before meals.

These medications are often used for longer and at higher doses than in other conditions and often the dose will need to be gradually increased to find the best dose for you. Both medications are usually given four times a day but sometimes these timings are also changed to help manage your problems better.

2. Reducing secretions from the bowel

Your medical team will also usually provide you with medications to reduce secretions from your bowel. This is because the bowel produces about 2 litres of secretions a day so reducing this amount will help control how much liquid is lost from your body.

The usual medications used are:

- Anti-acid medications (medications ending in 'zole' like omeprazole, lansoprazole): these reduce stomach acid.
- Ranitidine: this is sometimes used instead of medications ending in 'zole' and also reduces stomach acid.
- Octreotide: This is sometimes used to attempt to reduce secretions from the small bowel.

3. Reducing the intake of non-concentrated fluids

People with short bowel syndrome cannot absorb fluids normally.

This is because the small bowel is leaky and any fluid that is not salty, causes salts, and fluid, to be pulled into the bowel from the blood. As a result, patients with short bowel can become dehydrated as not all the fluid that is drunk is absorbed and passes out of the body making stools very liquid. Often the fluid that is lost is more than the fluid that has been drunk, resulting in an increased thirst.

To stop this happening less should be drunk **not more**. The more that is drunk, the more dehydrated patients become. Symptoms of dehydration include:

- Thirst
- Dizziness
- Reduced urine (wee) production
- Tiredness
- Dark coloured urine

If you are dehydrated you may need to drink a salty solution (double strength dioralyte/ St Mark's solution) to provide you with fluids that stop you from losing fluid. You may be asked to follow a fluid restriction. Your fluid restriction includes all drinks, e.g. tea coffee, water, fruit juice, alcohol. It also includes liquid foods such as soup, custard, gravy, ice cream, jelly and yoghurt.

You may be advised to have between 1 Litre and 1.5 Litres of any non -salty fluid unless directed otherwise. In addition to this, you need to drink your salty fluid (double strength dioralyte /St Mark's solution), usually 1-1.5 Litres.

These salty fluids are often referred to as oral rehydration fluids.