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## Short Bowel Syndrome - Your guide to eating and drinking with a stoma or fistula



*Name:* \_\_\_\_\_

*Date:* \_\_\_\_\_

*Dietitian:* \_\_\_\_\_

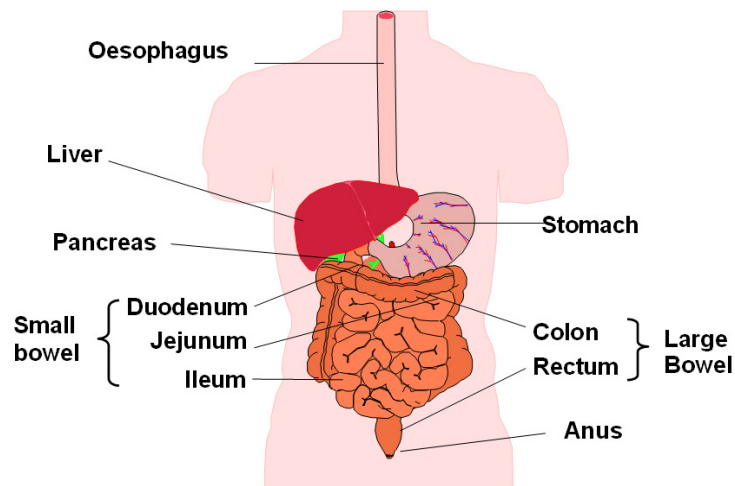
## What is short bowel syndrome?

Short bowel syndrome is a rare condition in which

- a) the small intestine is unable to digest and absorb the correct amounts of nutrients.
- b) the body does not reabsorb fluids, including digestive juices, normally produced by the intestines (gut).

This can lead to problems such as malnutrition, weight loss, diarrhoea and dehydration.

To understand why this happens, it is important to consider what happens in a person without short bowel syndrome.



**DIGESTIVE SYSTEM**

## Additional Information

For a translation of this leaflet or for an English version in large print, audio or Braille, please ask a member of staff or call 08007834372.

The North West London Hospitals' Patient advice and Liaison Service (PALS) is a confidential service for people who would like information, help, or advice about the services provided by any of our hospitals. Please call 08007834372 or email [pals@nwlh.nhs.uk](mailto:pals@nwlh.nhs.uk) between 9am and 5pm.

## Useful addresses

### **PINNT**

**(Patients on Intravenous and Nasogastric Nutrition Therapy)**

PO Box 3126

Christchurch

Dorset

BH23 2XS

[www.pinnt.com](http://www.pinnt.com)

### **St Mark's Hospital**

Department of Clinical Nutrition

Telephone: 02082354120

This booklet has been produced by the Dietitians at St Mark's Hospital which is part of the North West London Hospital Trust. Please contact us for more information on 02088692666 between 9am and 5pm Monday to Friday.

**The team at St Mark's are always happy to advise health care professionals regarding the treatment of short bowel syndrome.**

## The digestive process

Digestion is the process in which the food you have eaten is broken down into small nutrients. These are then absorbed by the intestine and go into the bloodstream to feed the body.

### **Stomach**

Digestion begins in the mouth which is why it is important that you chew your food thoroughly. Food is then swallowed and enters the stomach where it is churned into a liquid by the acid produced in your stomach.

### **Small bowel**

This liquid is then released into the first part of the small intestine, the duodenum, where it is mixed with more digestive juices from the liver and pancreas before entering the next part of the small intestine, the jejunum. Most nutrients are absorbed in the first part of the jejunum. About four litres of fluid are released each day to aid digestion which is reabsorbed further down in the next part of the small intestine, the ileum. This is the same part of the intestine where vitamin B12 is absorbed into the body.

### **Large bowel**

The remaining fluid that has not been absorbed will pass into the large bowel, the colon, which absorbs water and sodium (salt). Stool is then stored in the rectum until you open your bowels when it is released through the back passage, the anus.

### **Short bowel syndrome**

When you have had a large part of your bowel removed it is difficult to absorb all the nutrition you need and you may lose weight. It is also difficult to absorb all the digestive fluid produced by your intestines to digest food and because of this you may become dehydrated.

**This booklet aims to help you change the way you eat and drink to prevent weight loss and dehydration.**



If you think you are dehydrated, a **random urinary sodium** is the best test and you should ask your GP to check this for you. If it is below 20 you are dehydrated and should contact the St Mark's team as soon as possible.

Please show this leaflet to any other health professionals you may come into contact with, such as your GP or District Nurses. You may find that you are given incorrect advice by people who are not used to caring for people with short bowel syndrome.

If you ever need to seek treatment elsewhere it is important to let whoever is caring for you know that you have short bowel syndrome and are a patient at St Mark's.

- Eat more cakes, doughnuts, biscuits and chocolate
- Try frying foods such as meat, fish and potatoes
- Use more butter or margarine. Spread thickly on bread, biscuits or crackers
- Eat pastry such as sausage rolls, Cornish pasties, Danish Pastries and apple pie
- Eat scones with butter and jam or cheese
- Have ice cream as a dessert or snack
- Try dishes made with cream or cheese sauce such as macaroni cheese or lasagne
- Try adding custard, double cream or ice cream to puddings for extra energy
- High energy desserts such as sticky toffee pudding, chocolate sponge, chocolate cake, crème caramel, cheesecake, fruit crumbles, pies or tarts

### **Ways to increase your energy intake Food fortification**

This is an easy way to increase the amount of energy in your meals without having to eat more food

- Try adding sugar to drinks, cereals and puddings
- Add jam, marmalade, honey or syrup to milk puddings, porridge or full fat yogurts
- Add butter or margarine to potatoes, rice or small portions of vegetables
- Drizzle oil on pasta, rice and noodles
- Add salad cream or mayonnaise to sandwiches or have with a baked potato or chips
- Add double cream to breakfast cereals, hot drinks and soups
- Full fat milk powder can be added to porridge, milk puddings, mashed potato, sauces and soups

## Protein

Eating foods high in protein may help you increase your strength and increase or help you maintain your weight. These foods are all high in protein. Try to eat 3-6 portions every day.

### Meat and Fish

- Eat tinned fish such as tuna, salmon, pilchards, mackerel or pilchards in a sandwich or on toast
- Meat pies, casseroles, stews, sausage rolls or pasties
- Try fried fish or fish in a sauce
- Frozen ready meals like lasagne, shepherds pie or fish pie
- Takeaway foods such as burgers, fish and chips, fried chicken, kebabs or pizza

### Eggs

- Try fried, scrambled, boiled, poached or omelettes
- Quiche or egg custard

### Cheese

- Have cheese and biscuits, cheese on toast or in sandwiches
- Sprinkle on potatoes, vegetables, scrambled eggs or soups
- Make cheese sauce for pasta or fish

### Yogurt or fromage frais

- Use full fat or thick and creamy Greek style yogurts instead or low fat or diet varieties

### Milk

- Use full fat milk instead of semi-skimmed. Drink cold or use to make hot drinks such as coffee, hot chocolate or malt drinks. Choose milky puddings like rice pudding, custard, sago, tapioca, mousses or whips

## Long term monitoring

The treatment you are offered and advice given in this leaflet may help prevent you becoming malnourished and dehydrated. It is important that your progress is monitored regularly. When you attend the outpatients clinic you will be weighed, have blood taken and be asked for a urine sample to help us monitor your condition.

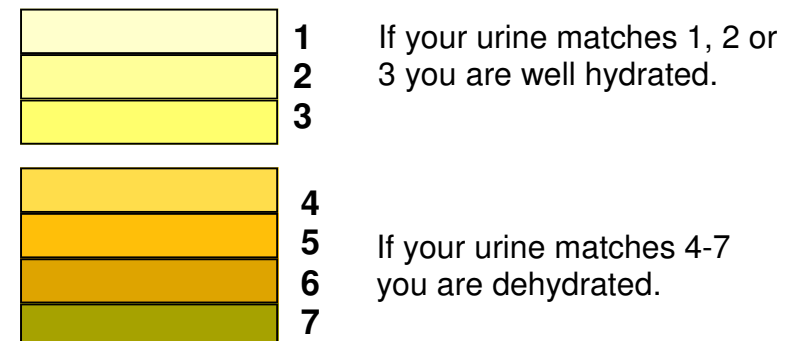
## Weight

Your weight is important because it tells us how well nourished you are. Your weight will fluctuate daily due to the amount of fluid in your body. It is important that you weigh yourself once a week at home and if you are losing weight, please contact a member of the St Mark's team on the contact number at the back of this leaflet.

## Urine

Your urine is important because it tells us if you are dehydrated. The colour of your urine is a good guide to see how well hydrated you are and the guide below will help you assess this.

Please check the colour of your urine everyday.



## Medicines used in short bowel syndrome

The medicines prescribed for people with short bowel syndrome work in one of two ways, either slowing down the passage of food and drink in the intestines (anti-motility) or reducing the amount of acid produced in your stomach (anti-secretory).

### Anti-motility medications

- Loperamide
- Codeine Phosphate

**These need to be taken 30-60 minutes before food to work best. They are usually prescribed in much higher doses than for someone who does not have short bowel syndrome. Your GP will be advised of this.**

### Anti-secretory medications

- Omeprazole
- Ranitidine
- Lansoprazole

Any fluid used to take your medicines should come from your fluid allowance, so you may find it helpful to take your medications with electrolyte mix.

It is important that you do not take any other medicine from a chemist or health food shop without discussing it first with your doctor or pharmacist as they may interfere with your prescribed medications.

If you have had the last part of your small bowel (ileum) removed, you will require vitamin B12 injections every three months to prevent anaemia.

## Fibre

Foods high in fibre include cereals, pulses, fruit and vegetables. Fibre is not completely digested by the body. Foods high in fibre pass through your gut quickly and changing to foods lower in fibre may help reduce your output.

### Ways to limit your fibre intake

- Use white bread instead of brown or wholemeal
- Use refined breakfast cereals such as Cornflakes, Rice Krispies instead of high fibre varieties such as All Bran, Bran flakes, Weetabix, Shredded Wheat or Muesli
- Use white pasta and rice instead of brown varieties
- Try not to eat the skin on potatoes
- Eat biscuits made with white flour such as Rich Tea, Marie, Malted milk, Nice, custard creams, chocolate chip cookies rather than wholemeal biscuits like Digestives or Hobnobs. Try to avoid biscuits with fruit or nuts such as Garibaldi, fig rolls, fruit shortbreads
- Eat crackers made with white flour such as cream crackers, Ritz biscuits, water biscuits and breadsticks instead of Krackerwheat, Ryvita or Hovis biscuits
- Limit your intake of pulses (beans, chickpeas or lentils) unless you are a vegetarian when you should include one portion a day for protein
- You may include one small portions of cooked vegetables but avoid skins, stalks, or seeds
- You may include one small portion of fruit but avoid skins, pips, seeds and piths if necessary. For example, tinned fruit, stewed fruit and peeled fruit
- Avoid nuts and dried fruit

## Meal Plan

### Breakfast

Cereal with full fat milk and sugar  
Bread or toast with butter/margarine and jam/honey/  
cheese/chocolate spread/marmite  
Bacon/sausages/egg

### Mid morning

Biscuits/cake/pastry/crisps

### Lunch

Meat/Fish/Chicken/Cheese/Egg  
Potatoes/rice/pasta/noodles/bread  
Small portion of well cooked vegetables  
Full fat yogurt/sponge and custard/ice cream

### Mid afternoon

Crumpets/plain or cheese scone with butter  
or cake/chocolate/biscuits

### Evening meal

Egg/spaghetti/cheese on toast  
Sandwich with meat/cheese/egg/fish  
Omelette with ham/cheese or Pizza  
Fruit crumble with custard or cream

### Bedtime

Crackers and cheese/biscuits/toast/breakfast cereal with  
full fat milk and sugar

## Tips to help you take your electrolyte mix

- The electrolyte mix is best served chilled
- It can be frozen and taken as a slush
- Try drinking it through a straw
- You may wish to add a **small amount** of squash, fruit juice or cordial to improve the taste. This is best added while making up the solution rather than adding to each glass so that the salt content remains high
- Fresh lemon or lime juice may be added

When it is hot, we sweat and lose salt and fluid from the body. In this situation people with short bowel syndrome are more likely to get dehydrated and you may find you need to drink more electrolyte mix to replace these losses.

## Tips to help you stick to your fluid restriction

- Sip all fluids, including your electrolyte mix, slowly throughout the day
- Use smaller cups and glasses
- Suck boiled sweets or mints
- Suck ice cubes or ice lollies as part of your fluid allowance
- Try to keep busy so you are not thinking about feeling thirsty

## Alcohol

Any alcohol you wish to drink must be included in your fluid allowance. Some medications should not be taken with alcohol, please discuss this with your doctor or pharmacist.

## St Mark's electrolyte mix

### How to make electrolyte mix

You will need to make up the solution fresh each day.

- Six level 5ml spoons of glucose
- One level 5ml spoon of sodium chloride
- One heaped 2.5ml spoon of sodium bicarbonate
- mixed in 1 litre (1000ml) of tap water

You can buy the powders from any pharmacy and some supermarkets or prescribed from your GP. Sodium chloride is table salt and sodium bicarbonate is also known as bicarbonate of soda or baking soda.

If you need to get electrolyte mix prescribed, please show your GP this leaflet. They will need to prescribe it in the following way in order for the community pharmacist to be able to supply them to you.

Rx St Mark's Electrolyte Mix

Formula: - Glucose                    20g  
              Sodium chloride        3.5g  
              Sodium bicarbonate 2.5g

If you are finding it difficult to eat the amount of food recommended then your dietitian may suggest high energy supplements. Your dietitian will advise you if these supplements need to be included in your daily fluid allowance. These supplements are available on prescription from your GP.

Supplement	Frequency

### Salt

Each day you lose a lot of salt (sodium) from your stoma or fistula and it is important to try and replace these losses by following a diet high in salt.

- Salt should be added when cooking potatoes, rice, pasta and vegetables
- Salt should be added to your meals at the table
- Flavour foods with soya sauce, garlic or celery salt
- Use tomato ketchup or brown sauce with meals

The following foods are high in salt and should be eaten regularly:

- Cheese, bacon, ham, gammon, sausages, meat pies, burgers and scotch eggs
- Smoked fish such as kippers, salmon and mackerel
- Canned fish such as tuna, sardines, salmon, pilchards and mackerel in brine
- Meat and fish pastes
- Tinned foods such as spaghetti and ravioli
- Use Oxo, Bovril, gravy granules or stock cubes to add flavour and make sauces/gravy
- Yeast extracts such as Marmite and Vegemite
- Salty crisps, savoury biscuits and crackers
- Pot noodles and packet savoury rice

## Drinking

Avoid drinking at mealtimes as too much liquid can decrease the amount of food your bowel can absorb and as a result, may reduce your output. You should try and aim to separate food and drinks by at least half an hour.

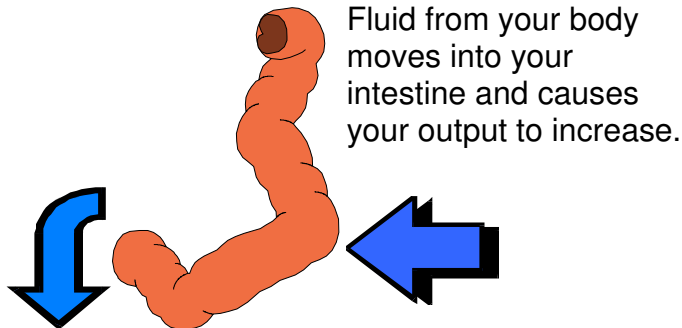
Your colon absorbs fluid and salt but if part of it has been removed then you may experience diarrhoea. Losing fluid and salt in this way causes thirst and dehydration

**To stop this happening you have to drink less not more. The more you drink, the more fluid and salt you will lose which will cause you to become more dehydrated.**

It is important to remember that this **only** happens to people with short bowel syndrome. In a person without short bowel syndrome if they feel thirsty and drink more, they will not become dehydrated. If you become dehydrated regularly you may be advised to restrict your fluid intake and to drink a salty drink known as St Mark's electrolyte mix.

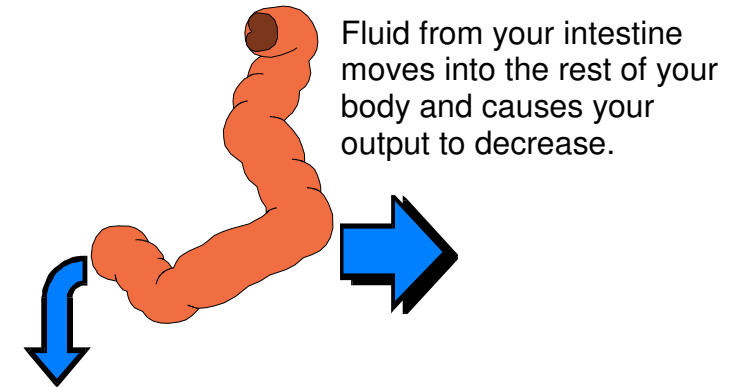
Drinks low in salt will cause fluid to move from the rest of your body into your intestine and will cause dehydration.

### Drinks low in salt (water, tea, coffee, juice, squash)



Drinks high in salt will cause fluid to move from inside your intestine into the rest of your body. This may reduce your output and help prevent you becoming dehydrated.

### Electrolyte mix (high in salt)



### Your fluid allowance

It is recommended that you drink \_\_\_\_\_ml of electrolyte mix each day. Please try to restrict your intake of all other fluids to \_\_\_\_\_ml day.

## Dehydration

It is important that you learn to recognise the signs of dehydration. You may experience thirst, a reduction in how much urine you pass, tiredness, cramps, dizziness on standing up, dry skin, or notice dark circles under your eyes. If you think that you might be dehydrated please contact a member of the St Mark's team. Our contact details are on the back of this leaflet.