

# No stomach?

a guide for patients by patients



**gust**  
cancer **uk**



We are a network of patients and carers, all of whom are affected by GIST (**G**astro**I**ntestinal **S**tromal **T**umour) cancer.

We are here to help GIST patients and their families and friends.

Sometimes the treatment for GIST results in a patient having their stomach removed (a total gastrectomy).

This booklet has been written by patients with first-hand experience of stomach surgery and total gastrectomy, in the hope that some of their experience and strategies for coping will be of help to others.

If you would like to comment on this document, or maybe share your experience, please get in touch with us.

## CONTACT US

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## DISCLAIMER

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This booklet has been written by patients. The information is not intended to replace expert medical advice that you may be given. We have done our best to ensure that the information we publish is accurate, but any decisions about your treatment should always be made after discussion with your consultant, preferably a GIST expert.

## INTRODUCTION

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Losing your stomach may sound drastic, but it is a part of you that you can live without. It will change the way you eat, particularly at first, but it does get easier with time. Although this booklet has been written mainly for patients suffering from a GastroIntestinal Stromal Tumour (GIST), other patients who have had a total gastrectomy may also find it helpful.

No two patients are the same, and no two operations are the same, so the suggestions given here are only suggestions, and you will need to experiment to find out what works best for you by a process of trial and error.

Doctors are still discovering new things about the way our digestive system is controlled, so they probably cannot answer all your questions, but they will monitor how you are getting on, with blood tests, scans, post-surgery check-ups and further treatment. They can also introduce you to specialist nutritionists.



## HOW THE NORMAL GASTROINTESTINAL TRACT WORKS

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In order to understand the effects of surgery, we need to know a little about how the normal gastrointestinal tract works. Often referred to as “the digestive system”, it is basically a long tube from the mouth to the anus. Its job is to digest our food, making the useful chemicals soluble, then to absorb these chemicals into the blood, and finally to get rid of the indigestible fibre. There are several sections of the tube which have different functions, and so look very different. Each section of the digestive system is responsible for absorbing a different selection of vitamins and minerals from our food.

Digestion starts in the mouth when we chew our food. This chewed food is then pushed down into the oesophagus, through a ring of muscle called the cardiac sphincter, and into the stomach. Food normally stays in the stomach for several hours. Acid and an enzyme which digests protein, are secreted into the stomach by cells in the stomach wall. *(Enzymes are chemicals which break down large molecules into smaller ones. e.g. insoluble starch is turned into small soluble glucose molecules. Each enzyme only acts on one kind of food.)* The muscles in the stomach wall churn the food about mixing everything thoroughly, and eventually the food becomes rather like a thick soup.

At the base of the stomach is a ring of muscle called the pyloric sphincter. When this relaxes, small amounts of the partly digested food pass into the small intestine. It is here that digestion is finished. A mixture of enzymes pass into the top of the small intestine from the pancreas. Bile is added from the liver, and the wall of the small intestine itself produces other enzymes as well as mucus.

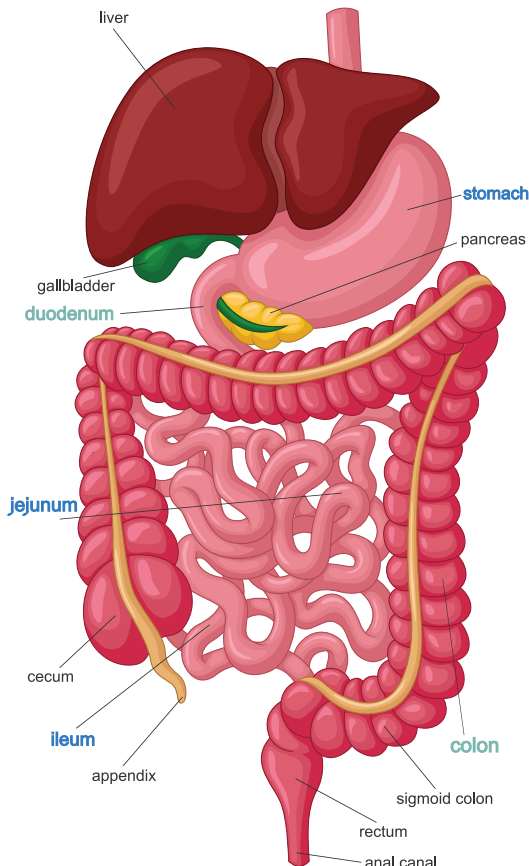
Eventually, the food will have been made into small molecules, which can be absorbed into the blood, and the roughage or fibre which can't. The small molecules are mostly glucose, amino acids, fats, minerals like salt, and vitamins. Absorption of these chemicals mostly takes place in

the lower end of the small intestine, or ileum.

When absorption of the food is finished, the fibre and water pass into the large intestine, or colon. This is where water is absorbed. Finally, what is left becomes the faeces or stools, and passes out from the rectum through the anus.

## ABSORPTION

Each section of the digestive system is responsible for absorbing a different selection of vitamins and minerals from our food.



### Stomach

- Mixing
- Release of digestive enzymes
- Some mineral absorption

### Duodenum

- Food sensing
- Release of hormones
- Release of digestive enzymes
- Some mineral absorption

### Jejunum & Ileum

#### Absorption of:

- Sugars
- Fats
- Amino acids  
*(The building blocks of proteins)*
- Vitamins
- Minerals

### Colon

#### Absorption of:

- Salt
- Water

## WHAT HAPPENS IF YOU HAVE NO STOMACH

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If your stomach is not there, the things that should happen there don't. There is no acid to kill bacteria. There is no enzyme to start protein digestion and the churning to turn your chewed food into a soup-like consistency doesn't happen. Perhaps even more importantly, there is no storage, and the chewed food goes straight into the small intestine.

Experience shows that even though the rest of the digestive system is still there, it will have been interfered with, and it sometimes does not work normally again for some time. The reasons for this are not fully understood.

The results of all this are:

1. You will need to eat very small amounts of food, and very often.
2. You will probably need to separate eating and drinking to allow enough room for your food.
3. You need to chew your food very well, or use semi-liquid food. (A blender is very useful).
4. The food you do eat may not be properly digested, which may be because your pancreas is not making enough enzymes. You will know this because your stools seem different:

**Density** - if there is undigested fat, your stools will float in the toilet

**Colour** - a lighter colour indicates undigested fat

**Smell** - a penetrating smell may be due to undigested protein or to bacterial overgrowth. This can also hamper food absorption.

Sometimes people benefit from taking **digestive enzymes** with their food. Your GP may be able to prescribe these, or may ask for a test on a stool sample, or get advice from a specialist, before making this decision. The amount of enzyme needed varies between people, and you may

need to increase or decrease the dose over time, until your stools come back to normal.

## **Bacterial overgrowth**

It is not uncommon for people who have had their stomachs removed to develop an overgrowth of bacteria in their small intestine.

Although some people who have had a total gastrectomy may have bacterial overgrowth with no symptoms, it can sometimes cause problems, producing significant quantities of foul smelling gas and light coloured stools that will not flush. Bacterial Overgrowth can be diagnosed with a “hydrogen” or “methane” breath test.

If you are experiencing the bad effects of bacterial overgrowth it can be treated with antibiotics, but repeated courses may be needed as it tends to come back.

One patient at least has found that mixing large spoonfuls of “off the shelf” puréed garlic with food is as effective as taking antibiotics in controlling bacterial growth.

## **OTHER POTENTIAL PROBLEMS TO OVERCOME AS A RESULT OF THE SURGERY**

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- 1. Feeling full very quickly.** There is not as much room in your gastrointestinal tract as there was. Your system will adjust after some time to larger quantities of food. Persevere and eat small amounts of food regularly.
- 2. No longer feeling hungry.** This happens when the vagus nerve has been cut. You just have to remember to eat!
- 3. Diarrhoea** can be a problem, especially in the first weeks after surgery. It can be very urgent, (and very inconvenient), but it usually settles in a few weeks. Ask your doctor about using

loperamide hydrochloride (Imodium) or codeine. Peppermint oil based preparations such as Colpermin can help. Changing your diet may not help this kind of diarrhoea.

4. **Early morning vomiting.** This sickness can often be helped by eating a couple of dry crackers when you wake, or by taking anti-sickness drugs such as metaclopramide. If this does not help, and the vomiting continues, in exceptional cases it may be possible to do more surgery to reduce the problem.
5. **If the ring of muscle at the base of the oesophagus, the cardiac sphincter, has been removed,** you may get partially digested food passing back into the oesophagus. This is uncomfortable, and can damage the oesophagus lining. You may find regular use of Gaviscon or peppermint helps. You may also find that you need to stay sitting fairly upright after eating, and sleep with your head and chest well propped up.
6. **If you have lost part of the oesophagus as well as your stomach,** these problems become more serious, and you will probably need expert advice.
7. **If you eat too much or too fast,** the intestine may not cope, and an effect called “**early dumping**” (sometimes called “**Type I dumping**”) may take place. What usually happens is that you get abdominal cramp, and then rush to the toilet with violent diarrhoea. You may feel sick, vomit, feel dizzy or actually faint. This is because your blood pressure has fallen suddenly. It usually happens soon after a meal. It may be caused when sugary or starchy food moves suddenly into your small intestine. Your small intestine draws in water from the blood to help break down the food. The amount of water that enters your small intestine can be as much as 1.5 litres (3 pints). If this happens too fast, there is the sudden fall in blood pressure. You need to lie down, slowly drink some water, and wait for things to settle again. You will probably feel back to normal within 30 minutes.



It may be helpful to try to find out what the cause or causes are for you. Is it one kind of food? (Fresh bread, curry or sugary foods for example) Does it usually happen at one time of day, e.g. after lunch? Does travelling shortly after a meal produce it? Sometimes there will be a particular cause for you, but not always. Do some experimenting. This dumping usually gets less frequent after time, and may eventually stop altogether.

8. **“Late dumping”** (sometimes called **“Type 2 dumping”**), has rather different effects. It usually happens between one and three hours after a meal. It is thought that a sudden flow of food, usually containing sugar, into the small intestine, causes a rush of insulin into the blood. This causes a fall in blood sugar, and this in turn causes light-headedness, visual disturbance, disorientation, diarrhoea and even fainting. The cure is to take some sugary food or drink immediately. Always have some sweets in your pocket if this problem affects you.

Generally, it is better to take sugary food, immediately followed by some long acting energy food (e.g. a banana or toast), to avoid a repeat of the low blood sugar 2 hours later.

Like early dumping, late dumping usually becomes less of a problem after time, but it can take years, and may never completely go away.

There are a lot of doctors who do not understand about these two effects so you will just have to work out how to cope with them yourself.



## PROBLEMS APPEARING AFTER SOME TIME

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### 1. **Poor absorption of food, minerals and vitamins**

Even when the immediate problems caused by the surgery have improved, your digestive system still may not work properly. This means that some important parts of your diet, particularly fat, may not be very well absorbed. When you go for your checks at the hospital, you will usually have blood tests to make sure that you are not short of any minerals or vitamins.

The hospital will probably test for:

#### **Calcium**

You can be prescribed calcium and vitamin D tablets

#### **Iron**

Most patients will be anaemic after surgery, and it may be difficult to eat enough iron-rich food, so iron supplements of some kind will probably be needed for a time. Sometimes iron injections are needed. Vitamin C seems to help with the absorption of iron so try drinking some orange juice when you eat spinach or red meat.

#### **Vitamin B12**

You will certainly need to have vitamin B12 injections about every three months, because this vitamin is only absorbed in the stomach.

#### **Folic acid**

This is another essential B-vitamin you might become short of.

Watching for shortages of vitamins and minerals is important for total gastrectomy patients. As well as the vitamin B12 injections, lifelong multivitamin replacement is recommended. Regular follow-up with a nutrition specialist is also recommended.

### 2. **Stricture of the Anastomosis**

Your oesophagus and intestine had to be stitched together and the scar at the join may tighten after some weeks. This can make swallowing difficult and the oesophagus may suddenly go

into spasm. This can be very painful. This problem can often be cured very easily by stretching the scar with a tiny balloon. The un-inflated balloon is passed into the oesophagus while you are sedated, and then blown up. Doing this just once may be enough, but it can be repeated if necessary.

### 3. **Weight loss**

There is certain to be some weight loss in the first weeks after surgery. However, if you continue to lose weight after a couple of months or so, it is very important that this is addressed. There are special drinks available from your GP which you can sip during the day. These contain nutrients which need little or no digestion and so are easily absorbed. However, some of them can actually provoke dumping syndrome. If so, it is not that useful for increasing weight. There are several kinds of drink available so do some experimenting. Some patients have found a “Fod Map” diet has helped with weight gain.

The rules for normal “healthy eating” don’t apply to you. Eat whatever you find works. Fruit and vegetables may be difficult, so try juicing or blending them. Try bananas mashed with custard. Bread may be difficult, so use oat-cakes. Eggs in any form usually work, and so does fish. Cheese can be nibbled but it may need to be low-fat cheese. Nuts may help you keep your weight up, but they must be chewed well. Some patients report that muesli eaten a few spoonfuls at a time during the day is well tolerated as well as being nice. But take everything in small amounts, and try to eat small amounts of high calorie food at least every two hours. It is a question of finding out what suits your new digestive system. Do some experimenting. If you cannot find a diet that works for you, and you continue to lose weight, or do not feel well, insist on seeing a consultant nutritionist for advice.

If nothing seems to work, it may be necessary to use a feeding tube at night. This either goes through the nose into the digestive

system, or a tube is put semi-permanently through the abdominal wall into the digestive system, a percutaneous jejunostomy. Either way, pre-digested food passes straight into your intestine while you sleep. These both sound unpleasant, but **it is really important not to let your weight get too low**. Either of these rather drastic-sounding measures will probably only be needed for a short time while you recover from the surgery.

Keeping a food diary will help you tailor your diet to your individual needs. There are apps such as “My Fitness Pal” that you can use to record your food intake and help you check that you are taking in enough calories.

#### 4. Food intolerances

Because part of your digestive system is now missing, the parts that are left may not work as well as they did before surgery. This may be because of damage to the nerve which controls the digestive system, the vagus nerve.

In particular, the pancreas may not respond to changes in blood sugar levels as well as it did. Some patients find they cope with this by avoiding all sugary foods.



Some patients find that they have developed intolerance to dairy products. This can be addressed by using alternatives such as lactose-free or soya milk. (If you do this, you may need a calcium tablet every day. Ask your GP about this.) Again it is a matter of finding ways to eat what your new digestive system can cope with.

## TAKING MEDICINES

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Drugs for adults are usually in pill or capsule form. They have a coating to protect them from the acid in the stomach. Now that you have no stomach, this is not needed and may make it difficult for them to be absorbed. Many drugs are available for children as liquids, so ask for these instead, but check the dose! If the drug you need is only available as pill or capsule, you can often crush the pill or empty the capsule, using Marmite, jam or honey to mask the taste. Check that this is OK for you with your pharmacist.

Contraceptive pills are a particular issue, since the dose needs to be very accurate. It is probably advisable to use another form of contraception.

## PAIN

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After the first couple of months or so, you should not be in pain. If you are, and there seems to be no obvious cause, you should discuss this with your doctor. One possible cause is the presence of adhesions. These occur when parts of the digestive system which have been moved about during surgery stick to the wrong things inside you. This needs to be discussed with a surgeon to see if something can be done about it.

## MOVING ON

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Life goes on without a stomach, but it will be different. Always remember to carry something to eat with you. Nibble or snack frequently, even if you don't feel like it. Get the support of family and friends. If you go out for a meal, just take some of the nice bits off your neighbour's plate or order an hors d'oeuvre or child's portion!

Life can be a challenge. Demand expert help and experiment to find what suits you. Most patients say that "it becomes easier with time".



## GETTING INVOLVED

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Many patients find it helpful to get into contact with other patients in order to share tips and experiences. You can do this by joining GIST Cancer UK's private email group and by coming to the patient meetings that take place in various parts of the country.

## CONTACT US

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By email: [admin@gistcancer.org.uk](mailto:admin@gistcancer.org.uk) or by phone: 0300 400 0000

You can find out more about our patient meetings from our website:  
[www.gistcancer.org.uk](http://www.gistcancer.org.uk)

## Other useful organisations for information and support

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### **GIST Support International**

An independent patient group based in the US  
[www.gistsupport.org](http://www.gistsupport.org)

### **The Liferaft Group**

A GIST patient group based in the US,  
and supported by Novartis  
[www.liferaftgroup.org](http://www.liferaftgroup.org)

### **Macmillan Cancer Support**

Macmillan has many information leaflets  
on all aspects of cancer including  
information on statutory UK benefits.  
*Tel: 0808 808 2020*  
[www.macmillan.org.uk](http://www.macmillan.org.uk)

### **Sarcoma UK**

A UK charity for Sarcoma patients and carers.  
We work closely with them.  
[www.sarcoma-uk.org](http://www.sarcoma-uk.org)



[www.gistcancer.org.uk](http://www.gistcancer.org.uk)

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