

Eating After GI Surgery

FOR GIST
(**G**astro-**I**ntestinal **S**tromal **T**umour)



gist
canceruk

a guide for patients by patients



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 stomach or bowel surgery to remove their GIST tumour.

This booklet has been written by patients with first-hand experience of stomach and bowel surgery, 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.

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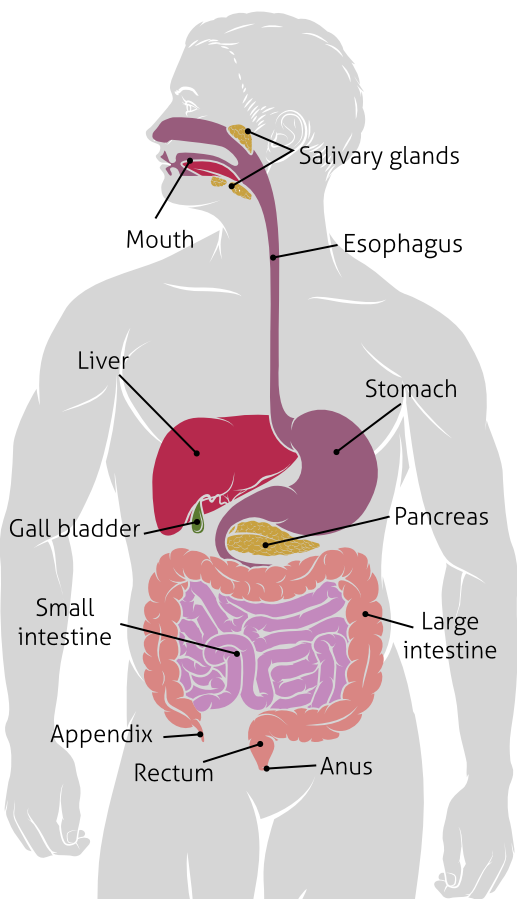
DISCLAIMER

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

There are many sources of information about healthy eating, but not specifically about recovering from surgery on the stomach or bowel to remove a GIST. This leaflet is about the experience of patients and what they found helpful. It does not consider the effects of more complicated surgery to remove GISTs which have spread to several organs in the GI tract, or to the liver.

GASTROINTESTINAL (GI) TRACT



HOW THE HEALTHY GUT WORKS

In order to understand the effects of surgery, we need to know a little about how the healthy GI tract works.

The Gastro-Intestinal (GI) or digestive tract 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. The GI tract has several sections of the tube, which have different functions and so look very different.

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 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 bring about the breakdown of large molecules into smaller ones, for example, insoluble starch is turned into the small soluble glucose molecule. 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 passes 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.

WHAT ARE THE POSSIBLE EFFECTS OF SURGERY?

The most important fact to remember is that we are all different. No two GISTs are exactly the same and no two operations are exactly the same. This means that not everything stated here will apply to you.

Surgery to remove GISTs will probably involve removing parts of various organs, depending on exactly where the GIST is, and what it is attached to. If the GIST is attached to the stomach, then part of the stomach will be removed too. Occasionally, the whole stomach has to be removed. (Please see our booklet entitled “No Stomach” for more detail).

If the GIST is attached to other parts of the GI tract, like the spleen, oesophagus, large or small bowel (duodenum, jejunum and ileum), or rectum, then parts of these organs will be taken out with the GIST.

The diagram on page 3 gives an idea of how the various organs are arranged in the body. Omentum tissues hold things in place, and bits of this may be lost too. This is because it is important to remove all the tumour cells to reduce the risk of the GIST coming back. Tumour cells/GIST returning is called recurrence.

LIFE AFTER SURGERY

Our experience is that surgery to remove part or all of the oesophagus or stomach, generally causes more eating difficulties than surgery to remove part of the colon or small bowel. Of course, if this results in a colostomy with a bag from the bowel, this has other difficulties which are not covered in this leaflet.

After surgery on any part of the GI tract, some people find they have no further difficulties after the first few weeks. However, some people do have more long-lasting problems. Immediately after the surgery you will probably not be allowed to eat or drink until the doctors are sure the GI tract is not leaking. Then water is allowed, then clear fluids, then a semi-liquid diet with soups, yoghurt, custard etc, and finally a light diet, taken in small quantities.

After surgery on the bowel

Eating can return to normal fairly quickly if the surgery has been on the small or large bowel. A mild laxative may be recommended, to avoid straining abdominal muscles and while you are eating a light diet with less fibre than you might normally eat.

After surgery on the stomach

After removal of part of the stomach, (a partial gastrectomy), the first days will be very much the same as after surgery on the colon or small bowel, but the after-effects will sometimes last much longer. These will depend on how much of the stomach has been removed and whether any nerves have been damaged. If the tumour has been growing on a stalk, which does sometimes happen, then very little stomach will have been removed and recovery will be quick. The other factor which will affect the speed of recovery is whether the surgery was done laparoscopically (key-hole surgery), or by making a long cut in the abdomen. Laparoscopic surgery is usually done to remove small easily

accessible GISTs and recovery is quicker than if the abdomen is opened up. What usually happens is that a “wedge” of stomach is removed, leaving a smaller stomach. You may need to eat much smaller meals and more often. Six meals a day is often recommended, and even then, snacking is encouraged. It is also often suggested that drinks should be taken an hour before or after food, but this is difficult to manage with six meals a day. The idea is that drinks fill up the stomach without giving much real food, and there is then no room left for the meal. See what works best for you. It is however, important to drink plenty of water, little and often.

If you have lost a lot of your stomach, or all of it, it may be difficult to keep your weight stable. Weight is often lost during the first two weeks or so after surgery, but after this it should be possible to stop losing weight. Nibble chocolate, eat high energy foods such as biscuits, butter and cream: just experiment to see what works for you. If your stomach feels a bit “jumpy”, peppermints often settle it. You can also get peppermint oil from the chemist, supermarket or health food shop. Just add a few drops to a little water and drink when required. Failing this, you can try antacids. Neither of these has side effects, but don't tell your dentist about the peppermints!

Some patients have found that after gastric surgery, the GI tract does not digest food normally. You may be able to see undigested food in your stools. If you notice that your stools are light coloured and floating in the toilet, it may be that there is undigested fat in them. Or in spite of trying to eat as much as you can, you are still losing weight. The nerves or muscles of the GI tract may not be working properly. Or for some reason, the stomach, pancreas or small intestine are not making enough enzymes. You can get digestive enzymes to take with food from your oncologist or GP, and these can sometimes be very helpful in stopping further weight loss, so talk to one of your doctors. There are various types of enzyme preparations you can get. Some patients have found that pills work better than capsules. The amount of enzyme needed is a question of trial and error. It may be necessary to take them before, during and after a meal.

Another result of your GI tract not behaving normally, may be that you do not absorb the vitamins or minerals from your food properly. You may also be anaemic because of losing blood during the surgery. A general multi-vitamin and mineral tablet taken every day may be useful. There are also special drinks you can get from your GP. If you are anaemic, you should try to eat plenty of eggs and red meat, or take an iron supplement prescribed by your GP, or do both.

If your spleen has been removed, you may be more at risk of infection than you were before. This is because the spleen helps to fight bacterial infections. Your GP may prescribe an antibiotic, usually penicillin, but do check that you are not allergic to it. Your GP will also want you to have all the immunisations available, and the flu jab every year. (People with no spleen are in the high priority group for this.)

SPECIFIC PROBLEMS SOME PATIENTS HAVE

A. Soon after gastric surgery

- 1 Loss of appetite.** This is common after gastric surgery, but is usually a short-lived. However, in a few patients part of the vagus nerve, which produces the feeling of hunger, has been cut, so you will never feel hungry again. You will need to look at the clock to find out whether it is a meal time.
- 2 Feeling full after a tiny meal or drink.** This has two causes: changes in sensation if the vagus nerve has been damaged, or simply because the stomach is smaller. This problem gets better with time as the stomach stretches.
- 3 Diarrhoea.** This is common in the first weeks after surgery, and can also be another result of nerve damage. It can be very urgent, (very inconvenient), but usually settles down. Ask your doctor about using loperamide or codeine. Changing your diet may not help this kind of diarrhoea. If the problem persists, talk to your GP.

- 4 Early morning vomiting.** Some people find they have stomach pain when they wake. This is relieved when they are sick, losing clear fluid and possibly some yellowish bile. This sickness can often be helped by taking anti-sickness tablets or antacids, or some plain biscuits on waking. If this does not help, and the vomiting continues, it may be possible to do more surgery to reduce the problem. It might help to raise the head of the bed to reduce fluid build-up in the stomach.
- 5 Acid reflux.** If the ring of muscle between your oesophagus and stomach, the cardiac sphincter, has been removed, you may get acid or food from the stomach rising into the oesophagus. This is uncomfortable and can damage the oesophagus lining. There are drugs that your GP or oncologist can prescribe which reduce the amount of acid your stomach makes, or you may find regular use of antacid or peppermints just as good, with fewer side effects. You may find that you need to stay sitting fairly upright after eating, and sleep with your head and chest well propped up.

If you have lost all or part of your oesophagus, this problem may be more serious, and you will probably need expert advice.

- 6 Early Dumping or Type I Dumping.** If the ring of muscle at the base of the stomach, the pyloric sphincter, has been lost, there may be other problems. This muscle normally stops food leaving the stomach while the first stage of digestion is taking place. In the normal GI tract, the partly digested food passes into the small intestine in small amounts. If the sphincter is missing, or sometimes even if it is not, the food may pass into the intestine all at once. The intestine cannot cope, and an effect called “early dumping”, or Type I Dumping, takes place. What happens is that you may feel 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 falls suddenly. It usually happens soon after a meal. If this happens, you need to lie down, drink lots of 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 eg after lunch? Does travelling after a meal produce it? Sometimes there is a particular cause for you, but not always. Do some experimenting. If you think it may be caused by one thing, like bread, do try several times. You don't want to stop eating something nice, just because you have a problem once. It could have been just coincidence. Early dumping usually gets less frequent after time, and may eventually stop altogether.

- 7 “Late Dumping” or Type 2 Dumping.** This 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, from the stomach into the small intestine, causes a rush of insulin into the blood. This causes a fall in blood sugar, and this in turn may cause lightheadedness, visual disturbance, disorientation, diarrhoea or 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.



Like early dumping, late dumping usually gets less of a problem after time, but it can take years, and may never completely go away. There are lots of doctors who do not understand about these two effects. You will probably need to work out your own coping strategies.

B. Problems appearing after some time

1 Poor absorption of food, minerals and vitamins. When you go for your checks at the hospital, you will usually have blood tests to make sure that you are not short of anything.

The most common things you may be short of are:

a. Calcium: You can be prescribed calcium and vitamin D tablets

b. Iron and vitamin B12: You may need to take iron tablets. If you have lost all your stomach or the top of the small intestine, the ileum, then you will need to have vitamin B12 injections. This is because a chemical called “intrinsic factor”, which is made in the stomach, combines with vitamin B12 in your food, and the combination is absorbed in the ileum.

2 Stricture of the Anastomosis. This is a long name for a simple problem. If your stomach and oesophagus had to be stitched together, the scar at the join (the anastomosis) may tighten after some weeks. The oesophagus may suddenly go into spasm when you start to eat. This is very painful. Food which is in the oesophagus may be vomited, as it cannot enter the stomach. Conscious relaxation and some deep breaths may enable you to finish your meal a few minutes later.

This problem can often be cured very easily by stretching the scar with a tiny balloon. The flat 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 Food Intolerances. Because parts of your GI tract are now missing, the parts that are left may not work as well as they did before surgery.

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 feel better if they avoid dairy products like milk and cheese. (If you do this, you may need a calcium tablet every day. Ask your GP about this.)

Other patients find that fatty food is not digested. They either avoid fat, or use digestive enzymes to help. Again, your GP can help.

Some patients find bread difficult to digest. Oat cakes make a good substitute. Sugar-free muesli is an easily digestible food which seems to suit many patients who have little or no stomach. If you cannot find a diet that works for you, and you continue to lose weight, or not feel well, do ask to see a specialist nutritionist for advice.

- 4 Continuing pains.** When the scars are healed and you are getting back to normal life, you may feel pain in unexpected places. This is always frightening, and the first thought is that the GIST has come back (or something has come unstuck). You should of course go back to the team looking after you and get it checked out. But be reassured that the pain may well be because of adhesions. These are bits of the tissues inside sticking together where they shouldn't. During the surgery, lots of the tissues holding organs in place get moved about, and may not go back exactly as they were. These stuck bits are called adhesions. Unfortunately, they do not show up on your normal CT. However, they usually get better in time. If they

don't, and everything else has been checked, it might be necessary to have a small surgical procedure called a laparoscopy to have a good look, and if possible to free the stuck bits.

GETTING BACK TO NORMAL

There is life after GIST surgery! It may be different, and we all have to learn how to manage our new GI tracts. Your full recovery is in your hands, but use the experts available to you. Ask your Clinical Nurse Specialist, or Key Worker for help if you do not know who else to ask. Other patients may be able to offer helpful tips for specific problems, so contact GIST Cancer UK. (admin@gistcancer.org.uk)

Discover which restaurants will serve children's portions. But do not worry when you are unable to eat everything. Have a partner who will finish your plateful, or will share some of your meal. Or learn to get over the rules instilled in us in childhood to "finish your plateful". No, don't if you feel full! Get used to carrying the new life support tools: peppermints, oatcakes, antacids and a bottle of water, or whatever works for you. GOOD LUCK!



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GIST Cancer UK

Reg Charity Number 1129219

www.gistcancer.org.uk

Other useful organisations for information and support

GIST Support International

An independent patient group based in the US

www.gistsupport.org

The Liferaft Group

A GIST patient group based in the USA

www.liferaftgroup.org

Macmillan Cancer Support

Tel:0808 808 2020

Macmillan has many information leaflets on all aspects of cancer including information on statutory UK benefits.

www.macmillan.org.uk

Sarcoma UK

A UK charity for Sarcoma patients and carers.

We work closely with them.

www.sarcoma-uk.org

NOTES



www.gistcancer.org.uk

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