

## Information sheet for patients - Gastrointestinal Stromal Tumours

**This information sheet describes the diagnosis and treatment of gastrointestinal stromal tumours (GIST). It focuses on the surgical treatment of stomach (gastric) GIST?**

### What is a GIST?

A Gastro-Intestinal Stromal Tumour (GIST) is a rare growth that is found in the digestive system. They account for only 2% of all types of tumour that occur in the digestive system. GISTs occur more commonly in the stomach but can also be found in the gullet (oesophagus) and the bowel (intestines). Most GISTs behave in a benign way (non- cancerous) but they can become malignant (have the ability to spread to other places in the body) if not treated.

GISTs are also known as 'sarcoma' tumours. This means they occur within the tissues that hold an organ in place. They are more common in people between the ages of 50 -70 years.

### Is a GIST a cancer?

A GIST is not strictly a cancer. However rarely they can behave like one and become malignant i.e. spread to other parts of the body. Around 1 in 20 of them can behave in a cancerous/malignant way: usually the much larger ones. To prevent them becoming malignant we usually try and remove them with an operation when they get larger than 2cm and if they are causing bleeding or other symptoms. Larger GISTs are more likely to behave in a cancerous way and can spread to other parts of the body such as lungs and the liver. The vast majority do not and once removed they do not tend to cause any further trouble.

### What are the symptoms of a GIST?

Small GISTs do not usually cause any symptoms. GISTs tend to bleed so the first sign is often feeling tired and having a low blood count (anaemia) and/or vomiting blood or passing blood in the stools. Other symptoms can include pain or discomfort in the stomach or bowels, feeling bloated, indigestion and feeling sick.

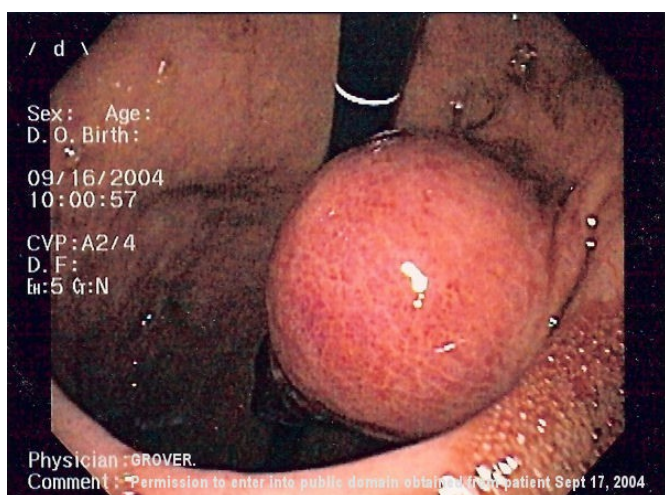
## What causes GISTs?

At present we do not know. They do not seem to be linked to any particular diet or lifestyle. They do not run in families except very rarely.

## How are GISTs treated?

Treatment for a GIST depends on the size of the tumour. Ones smaller than 2cm are left alone: they will grow very slowly and if they get bigger or start bleeding then surgery will be considered. If they are larger than 2cm the common treatment is surgery and this is often all that is needed for the majority of these tumours.

Where possible the surgery is done through a keyhole technique (laparoscopic surgery) as most of them are in the stomach. If the tumour is large or difficult to get to, an open operation may have to be performed.



***A round GIST seen in the stomach with an endoscope. The black endoscope is looking back on itself so can be seen behind the tumour.***

## Can a GIST be cured?

Small GISTs and those that can be removed surgically are very likely to be cured. Larger GISTs even if removed, may carry a risk of recurring. In these cases, regular check-ups with your specialist will be required and sometimes drug treatment is advised.

GISTs that cannot be removed are not curable but drug treatment is available which can help to control and slow down the growth of the tumour. (See section below on Glivec).

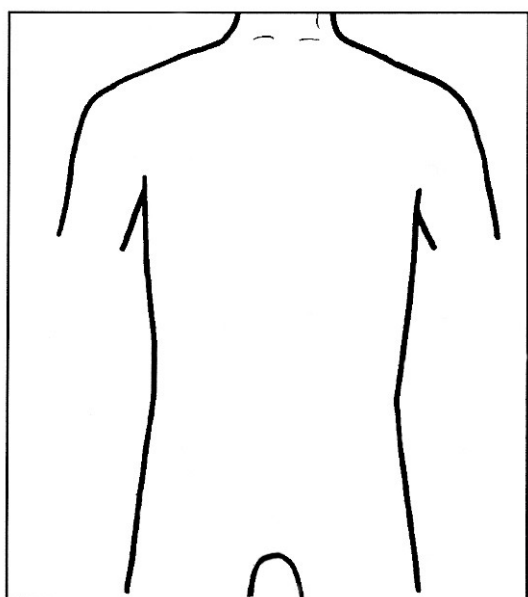
## Surgery

Surgery to remove part or all of the stomach is called a 'gastrectomy'. The type of gastrectomy depends on the location of the GIST within the stomach. Most GISTs of the stomach require a

local excision; that is removal of the tumour and a small cuff of normal stomach around it. This type of excision involves less disruption to the normal function of the stomach. If the tumour is big or located near the exit of the stomach, then a partial gastrectomy is performed, this involves removing about 50% of the stomach. The type of operation you need will be discussed with you by your surgeon.

### Positions of wounds

If you would like to know where your operation incisions will be, please ask your surgeon or nurse to draw on the following diagram.



### How long will I stay in hospital?

Most people are in hospital for between 2 - 5 days following a laparoscopic removal of a gastric GIST. If you need an open operation, your stay may be longer (7 days).

### Laparoscopic removal of a GIST

Most operations to remove a GIST in the stomach can be performed via a 'keyhole' (laparoscopic) operation

Laparoscopic surgery is always performed under general anaesthetic. A telescope the width of a small finger is placed into the abdomen through a small cut by the navel. The surgeon can see the inside of the abdomen on a video screen. In order to create space around the organs within the abdomen and provide the surgeon with a clear view it is necessary to introduce carbon dioxide gas to 'blow up' the abdomen.

Special instruments are passed through two or three other separate 5-12 mm incisions in the

abdomen as well; these enable the surgeon to retract and manipulate the structures within the abdomen and remove part of the stomach.

The small incisions will be closed using steri-strips (paper strips), dissolvable sutures or skin glue and covered with a dressing. The wounds will be sealed within 48 hours after which time you may remove the dressing and have a bath or shower.

### **What are the risks/complications of laparoscopic gastric surgery?**

- Bleeding from the edges of the stomach is a rare complication - this can result in vomiting blood or passing blood in stools and may need further surgery to stop the bleeding
- Occasionally it may prove impossible to proceed with the laparoscopic approach so an open procedure would be carried out
- Wound infection – minor wound infections do not need any specific treatment. Occasionally a more serious infection may need antibiotic treatment
- Chest problems

Any operation near the diaphragm will affect breathing afterwards; chest infection is a common occurrence after gastric surgery. About a quarter of patients will require antibiotics for this. If you have chest problems to start with (asthma, COPD or smoking-related chest problems) then a chest infection after the operation can be severe and very occasionally life-threatening.

### **Pain Control**

After a major operation, you may experience some discomfort. This is usually controlled by either regular pain killers or sometimes the epidural method of pain relief. This involves inserting a thin plastic tube in your back just before the operation. It is attached to a pump to give you continuous pain relieving medication until you are ready to take tablets. The anaesthetist will discuss this with you before the operation. It is important to make sure you have adequate pain relief so you can move around and cough to prevent complications. The physiotherapists will work closely with you to help your lungs recover and prevent breathing complications. This is the most important part of your recovery process.

### **Eating after surgery**

Once you are allowed to start eating after the surgery (usually two or three days post operatively), a dietitian may see you to advise you about your diet and give you advice about meals. Having part of the stomach removed will mean you may need to eat smaller and more frequent meals. Please do not hesitate to ask the dietitian any questions as it is important that you know what type of food you should be eating and when. You will be able to eat normal solid foods and with time you will probably manage to eat larger portions.

### **Will I need further follow up and treatment after surgery?**

Following surgery your surgeon will speak to you about whether you need any further follow up or any further treatment and this will depend on the pathology report and the size of the tumour.

Small tumours require no further follow up but for medium sized tumours (around 5cm) we like to see you on a yearly basis and arrange a CT scan intermittently.

Some people will benefit from having drug treatment after surgery. See Glivec section for further information.

## **Non – surgical treatment**

When a GIST tumour is too large to remove or has spread to other parts of the body, drug treatment is commonly used to shrink and control it. The drug commonly used is called Glivec (Imatinib). Glivec can work effectively at controlling and stopping the growth of GIST tumours for an average of 2 years. In some cases the drug treatment shrinks the tumour enough to allow an operation to be performed.

## **Glivec drug treatment**

Glivec is a drug that is extremely good at treating large malignant GIST tumours. It is a type of biological therapy called a tyrosine kinase inhibitor and the National Institute of Clinical Excellence (NICE) has recommended that it should be the first choice of treatment for people with GISTs that cannot be removed.

Glivec is a tablet and you can have the treatment at home.

Side effects can include:

- Tiredness
- Feeling sick
- Fluid retention – causing puffiness around the eyes, swollen hands and feet
- Skin rash

## **Useful contacts for further information**

[www.gistsupport.co.uk](http://www.gistsupport.co.uk)

Upper GI Nurse Specialist Gastroenterology Department  
Level 2, Centre Block  
Norfolk & Norwich University Hospital  
Colney Lane  
Norwich  
Norfolk NR4 7UY  
01603 288845 – Monday to Friday 9am to 5pm

Michael Lewis  
Consultant Surgeon  
Norfolk & Norwich University Hospital

Patient Information Leaflet for: Gastroenterology Stromal Tumours

Author/s: Michael Lewis

Author/s title's: Consultant UGI Surgeon

Approved by: PIF

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Colney Lane Norwich Norfolk  
NR4 7UY  
01603 287583 - Monday to Friday 9am to 5pm