

GIST Support UK

Although GIST is an extremely rare disease you are not alone. It is estimated that there are around 700 new cases in the UK each year.

A sophisticated Internet information and support structure has been built up to help GIST patients wherever they may live.

Founded by people with GIST for people with GIST and their families, GIST Support UK aims to provide up-to-date information and support. GIST Support UK is also a member of the Global GIST Network which allows information on GIST to be shared by patient groups around the world.

GIST Support UK provides opportunities for you to share your experiences of living with GIST via our website and at patient meetings which take place around the UK. We also campaign for access to the most effective treatments.

For more details visit our website:

www.gistsupportuk.com where you can also read about the experiences of other people with GIST.

"GIST is a rare condition which no one should have to cope with alone"

Dave Cook of GIST Support UK

The Liferaft Group is a US based patient support group which welcomes UK members and offers open access to the latest information on research and clinical trials. It also runs email chat lists exclusive to patients and carers. See:

www.liferaftgroup.org

This leaflet has been provided by
Sarcoma UK, PO Box 128, Ludlow,
Shropshire, SY8 1YL
Email: info@sarcoma-uk.org

Where to find more information and support

Freephone telephone help services

CancerBACUP	0808 800 1234
Macmillan Cancer Relief	0808 808 2020

GIST support on the Internet

GIST Support UK	www.gistsupportuk.com
The Liferaft Group	www.liferaftgroup.org
GIST Support International	www.gistsupport.org
Global GIST Network	www.globalgist.net

General information on sarcoma and its treatment.

www.sarcoma-uk.org
www.cancerhelp.org.uk

Clinical trials explained

www.cancerbacup.org.uk/Trials/Understandingtrials
www.nelh.nhs.uk/clinicaltrials/

Information on Clinical Trials

www.cancerhelp.org.uk/trials/trials/default.asp

State Benefits

www.macmillan.org.uk/abetterdeal/homepage.htm
Macmillan Benefits helpline 0808 801 0304

CancerBACUP information about treatments and trials are also available as booklets, free of charge from: 020 7696 9003



You have been given this leaflet because you have been diagnosed with GIST – also known as gastrointestinal stromal tumour. It is a rare cancer that develops in the soft, supporting tissues of the stomach and gastrointestinal tract.

This leaflet tells you more about GIST and its treatment, and gives sources of information and support which can be accessed by patients.



Sarcoma UK is a company limited by guarantee with charitable objectives. It works closely with the GIST support community to inform and support patients..

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What is GIST ?

Gastrointestinal stromal tumour is a rare cancer of the GI tract. It belongs to the class of cancers called sarcomas - a group of rare cancers that occur in connective tissues – bones, muscle, cartilage, nerves etc.

About 40-70% of GISTs arise from the stomach, 20-40% from the small intestine, and 5-15% from the colon and rectum. GISTs can also be found in the oesophagus (<5%), omentum (<5%), mesentery, or retroperitoneum. There are about 700 cases diagnosed each year in the UK.

GIST should not be confused with more common cancers (carcinomas) of the GI tract, such as stomach or colon carcinomas; carcinomas may occur in the same parts of the body, but their origins and treatments are completely different.

What causes GIST ?

The causes of GIST are not known. There is no known family history of the condition, although there are a few very rare cases where several family members have been diagnosed with GIST.

How is GIST diagnosed ?

Diagnosis may follow a series of tests and investigations (which might include surgery) or may follow emergency admission to hospital with bleeding and anaemia.

A biopsy will confirm the diagnosis. This involves analysis of tissue samples from the surgery. They are reviewed by a pathologist with expertise in diagnosing GIST. Using various tests he will be able to ascertain that the KIT protein unique to GIST, is present (or not). The KIT positive indication is the definitive test for GIST. The term c-Kit or CD117 may be used to describe the test.

How is GIST treated?

The best and most effective treatment option currently available for GIST is surgery. ***If a tumour has been removed cleanly and completely it is possible that the patient may never have another problem.***

When tumours are large it is possible that a drug called imatinib (its trade name is Glivec®) may be prescribed to try

and reduce the tumour size before surgery.

However for some patients surgery is not possible and for others complete excision cannot be achieved. In these cases too imatinib may be prescribed.

Because it is usually diagnosed late GIST tumours have often spread before the patient is diagnosed. Spread beyond the place where tumours first appeared is known as metastatic disease and with GIST is most often found in the liver. Patients who have had good surgery may develop metastases after time. Imatinib also has an important role in the treatment of all these patients.

It should be noted that metastasis in the liver is not liver cancer, it is still GIST and will be treated as GIST. GIST is very resistant to traditional types of chemotherapy and radiotherapy and they have little place in its treatment.

How do I take imatinib ?

Imatinib is taken orally. The normal dose is one 400mg tablet a day.

It is important to keep taking the tablets. In clinical trials it has been shown that tumours can become active again very quickly if the patient stops taking the drug, although once it is re-started the effect will be the same as it was before it was stopped.

Imatinib is not a chemotherapy. It is one of the first of a new generation of cancer drugs and is costly, so the rules for prescribing it on the NHS are quite strict. You will be closely followed up and will have regular CT or MRI scans to keep a close check on your progress.

Imatinib should be taken at the same time every day. It is best taken in between courses at a meal, taking it with plenty of water (half-pint recommended).

How does it work ?

Imatinib works by disabling the GIST tumour's ability to reproduce itself by turning off the cell's signalling system. As a result tumours can be stabilised, may shrink, and in some rare cases they can even disappear altogether.

What are the side effects of imatinib ?

Unlike chemotherapy, which is very toxic and has unpleasant side effects, imatinib is generally well-tolerated although there are some side effects. The most common ones are fatigue, diarrhoea (which will usually subside after a short while) and skin rash.

Some patients find that it causes stomach problems. This is usually resolved by ensuring that you take each dose with plenty of water and time it to coincide with a meal.

Please let your doctor or nurse know about any side effects, and if they are giving you any problems. They may be able to help. For a few patients the side effects will be severe and then the doctors will advise on the best course of action.

Is there treatment after imatinib ?

It has been shown that resistance to imatinib can build up after a time. It is not possible to predict how long this period may be – it differs widely between patients. There may come a time when the doctors will advise that imatinib is no longer having a valuable effect and should be stopped. In some cases tumour shrinkage may make further surgery feasible; in the liver this may be with RFA (radio frequency ablation) – one of the latest techniques.

Other treatment options for this situation are:

- Increasing the dose of imatinib to 600mg or 800mg a day
- Combining imatinib with another drug. (this may be available in a clinical trial)
- New treatments

One promising new treatment is sunitinib (Sutent®). It is expected that this will receive a licence as a second line treatment for GIST in 2006 and become available on the NHS some time after that.

Who is researching new treatments?

Research into new GIST treatments is a worldwide effort. The leading centre in the UK is at the Royal Marsden Hospital in London, although several key regional cancer centres contribute to that research.