



# GUTSY GROUP

**Next meeting: Rossett Hall Hotel, Mon 1 October 2012, 2-4pm**

**Articles:**

- Dumping syndrome
- Answers to your questions
- Information sources
- Useful contacts

*The patients, surgeons, dieticians and medical team look forward to welcoming you at our meetings*



## A new newsletter!

This is YOUR newsletter!

The newsletter this time has been produced by the GUTSY group members.

Over the coming issues, as well as the usual 'questions and answers' feature we will include items frequently requested by you.

In this issue we have included an item on 'dumping syndrome' a condition discussed at most of our meetings! Future issues will feature items on diet, medicines and any other issues you would like to see discussed.

GUTSY members are sometimes reluctant to speak or stand up at meetings with their questions. At the next meeting we will provide forms where you can write your question down to be read out at the meeting (anonymously or otherwise). This form will also have a section for suggestions for topics to include in future newsletters and meetings.

We will be rotating the chairperson of meetings and if anyone would like to become involved with the organisation of the group - then your help would be greatly appreciated.

To keep everyone on their toes we will be varying the days of the week on which our meetings are held. This is to allow different consultants, whose free days vary, to attend.

It is also our intention to help spread the awareness of the signs and symptoms of oesophageal and gastric cancers more generally to the public. We can do this by attending local events and organising campaigns. More about this at the next meeting.

Remember, this is a group run by patients, for patients. Your feedback, help and suggestions will always be welcome.



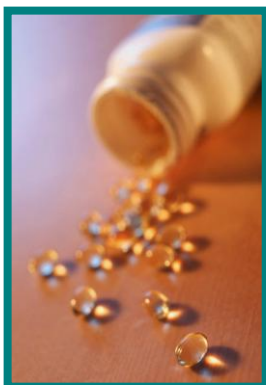
## 'Focus on 'dumping syndrome'



*GUTSY volunteers with  
cons surgeon Mr Pye.*



*“A positive attitude  
may not solve all  
your problems, but  
it will annoy  
enough people to  
make it worth the  
effort”*



*What are the  
medicines I'm  
taking?*

Dumping syndrome is caused by food leaving the stomach too quickly or if the stomach has been removed altogether. It is divided into two types: early dumping syndrome and late dumping syndrome. Each of these has different processes and symptoms.

### Early dumping syndrome

This usually happens within 30 minutes of eating a meal. Symptoms include: nausea, vomiting, abdominal pain, cramps, diarrhea, dizziness, lightheadedness, bloating, belching, fatigue, heart palpitations, rapid heart rate. These symptoms may last for about 10-15 minutes.

When food rapidly leaves the stomach area entering the intestine, it causes a large amount of fluid to enter the intestine from the surrounding organs and tissues to compensate. This results in stretching of the intestine and a drop in blood pressure.

Early dumping syndrome often gets better on its own over a few months. It can be reduced by eating slowly and choosing small, frequent, dry meals and having drinks between meals, rather than during them.

It can also help to avoid foods that are high in added sugars. It's important to eat some sugars as these are a good source of energy (calories), so don't cut them out of your diet completely. Try taking them as part of a mixed meal rather than as sugary drinks.

Eating meals that are high in proteins, such as fish, meat and eggs, and starchy carbohydrates, such as pasta, rice, bread and potatoes can help. Resting for 15-30 minutes immediately after meals can reduce the problem.

### Late dumping syndrome

This occurs usually a couple of hours after meals or when a meal has been missed. Symptoms include: sweating, weakness, fatigue, dizziness, light-headedness, shakiness feelings of anxiety, nervousness, heart palpitations, rapid heart rate, fainting, mental confusion.

It is caused by stomach contents that are high in carbohydrate being released into the small bowel. This causes a rise in the level of glucose in the blood as the carbohydrate is absorbed. Large amounts of insulin are released into the bloodstream as a response to this. The insulin levels continue to rise after the blood glucose levels have begun to fall. It's the high insulin level that causes the symptoms.

If you have this problem, follow the same advice for early dumping syndrome: take small regular meals that are low in processed carbohydrates such as sugar but do contain starchy carbohydrates, such as bread, potatoes and pasta or rice. If you feel the symptoms coming on, taking glucose tablets may help you feel better. Eating food and

## Dumping (cont)

drinking fluid at separate times may also be useful in preventing late onset dumping syndrome. If your symptoms continue or are

severe your doctor may prescribe a medicine such as octreotide, or a similar drug.

## Patient's questions and answers

**Q: I have problems with dumping six months after my operation; probiotics help.**

**A:** There is no clinical evidence that probiotics help. Time, changes to the gut and diet all help. However if it helps, take what you like.

**Q: If I eat small amounts, I have no dumping. Why?**

**A:** Speak to a dietician with regard to the volume of what you eat. Also try to separate liquids from solids when eating, drink either 10 minutes before a meal or 30 minutes after.

*Mr Monk asked how many patients suffered from dumping. About 50% said they did. Fewer said they found symptoms persisted 12 months after surgery.*

*Dumping does improve with time. There is a debate as to whether the gut does improve or if it is due to a change in the patient's perception. After an oesophagectomy the stomach empties more slowly. Dumping does come with this type of surgery, but it can be managed.*

**Q: Do fatty foods add to this effect and are our arteries safer?**

**A:** No, if you are absorbing fat, then you are at the same risk as normal people. However, after a

gastrectomy the body is less tolerant of fat and it is absorbed less readily. Dieticians advise a high fat diet before the operation to allow for weight loss following surgery.

**Q: I have had a cough following my operation twelve months ago. The doctor advised Oramorph to ease the pain, but I did not want to get hooked. I also had reflux. I cough any time but mostly at night.**

**A:** The stomach empties more slowly and leaves a residual amount of fluid in the stomach. A barium study could be done or a balloon procedure might help.

*Mr Baker asked how many had a dry cough following an oesophagectomy but not following gastrectomy. Scarring in the middle of the chest following the operation can irritate the airways to cause the cough. Reflux can also cause coughing.*

*Lying flat on the bed makes the cough worse, a teaspoon of Gaviscon may help or tilt the bed.*

*Over the counter Gaviscon is OK although a doctor's prescription medicine is much thicker and stronger.*



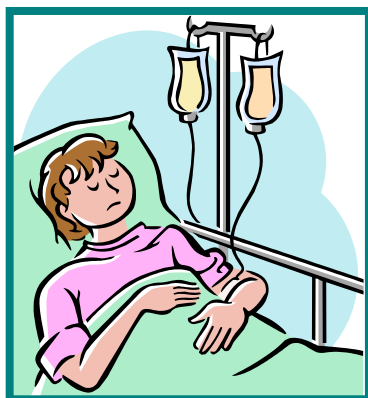
Questions and answers were from the last GUTSY meeting. The surgical team provided the answers; general comments from the meeting are in italics



What foods can I eat?



## Patient's questions and answers



*What will my operation be like?*

**Q:** I have developed a nasty taste and dry mouth.

**A:** Not everything you experience following the operation will be related to your operation.

*Six years after my operation, I still get a dry mouth but find a pint helps!*

*Try chewing gum or sugar free sweets from the chemist.*

**Q:** I sleep with a slight raise to the bed and lie on my side, so do not get a dry mouth now.

**A:** After oesophagectomy if you lie with your left side up you will get more reflux. Reflux varies, the higher up the join in the chest is, the less reflux. Omeprazole does help but the dose required may vary.

**Q:** If reconnection surgery is required, is it recommended?

**A:** There is a balance of risk and benefit. The conduit does not survive being taken up to the chest. The decision is down to personal desires. This is a major procedure and carries similar risks. It is a valid operation but a balanced informed decision as to whether to go through another big operation or staying as you are with artificial feeding and a bag on the neck. This is not an easy decision. Reconnection surgery does happen but not commonly as it is not always successful.

**Q:** Can I be an organ donor - I have been given the all clear?

**A:** I don't know the answer to this. Your immune system is likely to have been disturbed by having an operation. Immunity may revert to normal after some time, but transplant teams probably won't take the risk.

*Lizzie said the corneas only can be donated, nothing else.*

**Update from Pam Wedley:**

*I did ring the national organ donation team and Cancer patients can register for organ donation. Each individual is assessed independently. There is no age restriction and the only two diseases that cannot be registered for organ donation are HIV or CJD. People can ask to restrict which organs can be used and ultimately the organ donor team will liaise with staff and family members at the patient's time of death regarding suitability for donation.*

*You can also donate your body for medical training see: <http://www.hta.gov.uk>*

## Useful links

Macmillan Cancer Support  
Tel. 0808 808 0000  
[www.Macmillan.org.uk](http://www.Macmillan.org.uk)

Oesophageal Patients Association  
Tel. 0121 704 9860  
[www.opa.org.uk](http://www.opa.org.uk)

Cancer Research UK  
[www.cancerresearchuk.org](http://www.cancerresearchuk.org)

North Wales Cancer Network  
<http://www.wales.nhs.uk/sites3/home.cfm?orgid=456>

Patient UK oesophageal cancer guidelines  
<http://www.patient.co.uk/health/Cancer-of-the-Oesophagus.htm>

Further links are available on the website



## Contacts



Jane McGrath  
T:01978 291100 bleep 5976

Stella Davies  
T:01978 726273 bleep 5005

Michelle Curtis  
T:01978 726273 bleep 5264

Brian Lewin  
T:0800 7076907

Pam Wedley  
T: 01978 726188

Diane Henderson  
T:01978 727164

Macmillan Clinical Nurse specialist  
E: jane.mcgrath@wales.nhs.uk

Upper GI nurse specialist  
E: stella.davies@wales.nhs.uk

Upper GI nurse practitioner  
E:michelle.curtis@wales.nhs.uk

GUTSY volunteer  
E: brian@gutsy-group.org.uk

Macmillan Shooting Star Information Centre  
E: macmillan.shootingstar@wales.nhs.uk

Service user team (General enquiries)  
E: diane.henderson@wales.nhs.uk





# GUTSY GROUP

## The GUTSY group

Service user team,  
Betsi Cadwaladr University  
Health Board,  
Ysbyty Maelor,  
IM&T Building,  
Croesnewydd Road,  
Wrexham, LL13 7ZH

## Phone:

01978-727164

## E-Mail :

info@gutsy-group.org.uk

## GUTSY helpline

Having surgery for oesophageal  
or stomach cancer?

Call the GUTSY helpline now if  
you would like to speak directly to  
a patient who has had treatment  
and/or surgery



0800 707 6907  
(Freephone)

Patient support  
helpline

0800 707 6907

*We're on the Web!*

*Find us at:*

[www.gutsy-group.org.uk](http://www.gutsy-group.org.uk)

## About GUTSY...

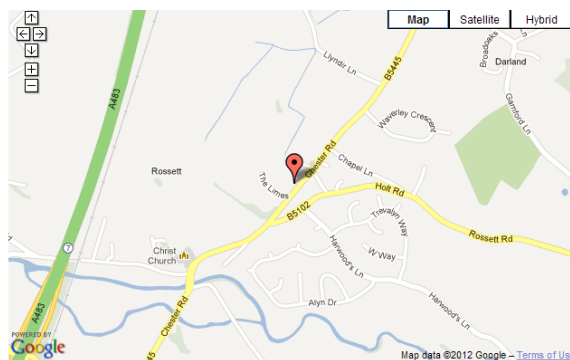
We are a support group for  
people diagnosed with or  
recovering from oesophageal and  
gastric cancers along with their  
friends and family.

The aim of the group is to  
provide support and information  
and to share our experiences

with anyone visiting the  
website or attending our  
meetings.

We hold meetings four times  
a year and provide telephone  
and email support  
continuously.

## GUTSY meetings



GUTSY meetings are  
held in the pleasant  
surroundings of Rossett  
Hall Hotel

The hotel is on the  
B5445, 6 miles south of  
Chester and 6 miles  
north of Wrexham

Acknowledgements: Thanks to Macmillan Cancer Support for their help in funding and setting up the help line and also for the information on 'dumping syndrome' in this issue