



GUTSY GROUP

Next meeting: Rossett Hall Hotel, Wed 20 February 2013, 2-4pm

Articles:

- Travel insurance
- Answers to your questions
- Information sources
- Useful contacts

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



GUTSY grows!

The GUTSY meetings have always been very successful and well attended. So much so that a second group has been set up near the Welsh border in Worcester.

This is largely thanks to Lizzy who worked as the Macmillan Upper GI nurse at the Countess of Chester and has now taken up a similar post in Worcester - we hope to share ideas and maybe part of our website with them.

As always, your feedback, help and suggestions are welcome. We are always looking for ideas for our website and meetings.

Anybody can ask questions at our meetings. If however you would prefer one of us to ask a question on your behalf, please write it down and hand it in at the start of the meeting.

In this newsletter, as well as the usual 'questions and answers' feature from our last meeting we have an item on travel insurance. This proves a

problem for anyone over 65 at the best of times, but if there is an accompanying former illness then this also has to be taken into account. There are companies who can provide insurance and sometimes exclusions can be made for existing conditions.

These days, the NHS in both England and Wales is changing rapidly. It is becoming ever more important for support groups to make their voices heard and be there to help people through any difficulties. Patient groups like GUTSY and Macmillan are there to fight for the well-being of patients and former patients. Fortunately we and they are being listened to and provide important feedback to those who run the NHS in addition to providing valuable support for us patients.



Focus on travel insurance



*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?*

If you have health problems, such as cancer, most insurers will regard this as a ‘pre-existing condition’. Each company will have a different view of the increased risk you represent. If you’re having cancer treatment, or if you’re terminally ill, you may find it difficult to get cover.

The likelihood of you cancelling your holiday because of illness is a major factor insurance companies consider when deciding whether they’ll cover you. It may also affect the price they quote. Another factor is the cost of treatment, especially in the USA where treatment is more expensive.

For this reason, if you’ve been unwell recently, or if you’ve had to visit the hospital several times in the last year, you may wish to apply directly to a specialist broker. They will be prepared to look at your circumstances in more detail. If you’re well and your cancer experience was several years ago, some insurance companies may choose to ignore your illness and give you a ‘standard’ price for your insurance cover.

Even if you and your GP think you are well enough to travel, an insurer may not be willing to take on the risk of you making a claim. However, it’s still important to consult your GP to make sure you’re medically fit to travel.

When you approach companies you may be presented with a number of options. Insurance companies may decide to:

- offer you travel insurance with a higher premium because you have or have had cancer
- apply an excess
- give you travel insurance, but with a cancer-related exclusion - this means that you would not get cover for a claim that is related to your cancer
- not offer you travel insurance at all!

A typical telephone medical screening process will take 5-10 minutes. If you have or have had other conditions as well as cancer, you may be asked similar questions about these. You should be aware that if you don’t disclose information you could reasonably be expected to know when you buy a policy, any claim you make could be refused.

Different companies assess the results in different ways, and they will probably vary in the level of cover they’re willing to provide. For this reason, it can be worth shopping around for travel insurance or getting advice from an insurance broker.

Some companies will ask for a letter from your doctor that says you’re well enough to travel. Some GPs will charge you if the travel insurance company contacts them to ask for a letter, so it’s often best if you ask your doctor for the letter yourself. It may save time if you get the letter before contacting insurance companies.

- offer you travel insurance at their standard price

Travel insurance (cont)

For further independent advice call Money Advice Line on 0300 500 5000 (English) or 0300 500 5555 (Welsh)

Or visit:

www.moneyadvice.service.org.uk
(available in Welsh)



Patients' questions and answers

Q I'm on octreotide injections for low sugars following dumping syndrome. Been on them 4 years on and off. Is it a long term solution?

A As far as I'm aware -yes but it's a question for your endocrinologist. Stay in touch with him

Q He keeps saying I need an operation so I can come off these injections?

A I would suggest injections are much lower risk than operation so should stay on injections.

Q Attending this group is a bit daunting prior to the operation. At the time, having been hit with the diagnosis, it's a bit unnerving sitting in a room full of people before the op.

A Discussed recently but what we want is to make sure that the pre-op patient is aware of the group and can easily contact us if they wish, post op. We need to make sure that our info is in the blue folder given out at the start of treatment. People who contact us tend to be those who have had surgery because it is then that they want to know if the side-effects persist and to know that they are not alone in experiencing the problems that can occur. This group particularly serves this function. We are also looking at ways to make the phone help-line a little less impersonal.

The annual operational report has been put out about the upper GI surgical centre and the GUTSY group is specifically mentioned as a sort of National Gold standard. Much credit to all those involved

Q Question about follow-up. 2 years since op and annual visit is a fairly brief affair. Had bowel cancer and the follow-up seems much more thorough - had colonoscopies, scans etc etc. Why not more follow up on oesophageal cancer?

A Its a good question. Down to behaviour of the cancers. If it reoccurs it is just as likely to happen in between follow-ups as at follow-up time. Not much we can do in the event of recurrence. No benefit in surgery if cancer, say, spreads to the liver. No real benefit. Being able to see person face to face indicates if there is a problem. Patterns of follow-up are changing. If you are doing well and feel OK there is no point in visiting clinic but we would want you to pick up the phone should you feel there are any issues.

Q Been through surgery etc and eating OK - what should anybody be looking for as a sign that something is not right?

A Can come in a number of different guises; can come as a

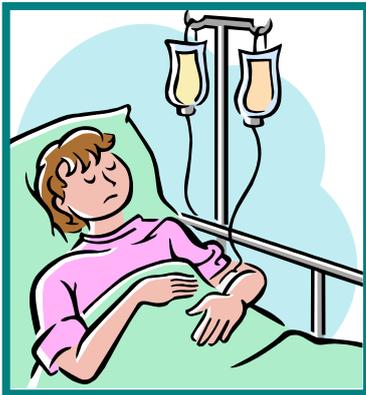
Questions and answers were from the last GUTSY meeting. The surgical team provided the answers; general comments from the meeting are in italics



What foods can I eat?



Patients' questions and answers



What will my operation be like?

re-growth in the vicinity of the previous op or in the remaining stomach or oesophagus, or as a variety of non-specific symptoms if it occurs due to spread to other parts of the body. Most important symptom would be further problems with eating. Some people get symptoms of very delayed stomach emptying which would be normally checked through further endoscopy. As long as this doesn't change then OK. But if new patterns develop - regurgitating, food sticking similar to original problem or if it is new problems - weight loss, new persistent pains somewhere, particularly focal pains, then these could be an indication of new growths. Don't want to get to morbid - most people do extremely well!!

Also everyone is different or reacts differently to the same operation, so there is not one particular symptom to look out for - it isn't like that. You will be different after the operation but if further differences occur then that is the time to pick up the phone. Some people have lot of symptoms after surgery others few. But look out for changes.

GUTSY newsletter has contact numbers for people to speak to for advice, but your GP is the main point of contact as not every ache or pain will necessarily be associated with oesophageal/gastric cancer, although it is natural to worry

that a cancer has returned.

Q Following surgery had lot of coughing and referred to speech therapist. Why?

A Speech therapist will be looking at how you can protect your airway and issues around the cough. Voice training plus co-ordination around the cough helps.

Q Have night time cough. Find sitting up while sleeping helps.

A Persistent cough may remain and is thought to be due to the scarring in the chest. Also can be reflux - don't eat before bed - make sure stomach is empty. Can use something to stimulate emptying of stomach - domperidone or Maxalon.

Q Dumping syndrome - hypoglycaemia.

A If severe refer to endocrinologist. Speak to GP.

A If symptoms occur eat Dextrosol - several people do it. See dumping info in last newsletter.

Useful links

Macmillan Cancer Support
Tel. 0808 808 0000
www.Macmillan.org.uk

Oesophageal Patients Association
Tel. 0121 704 9860
www.opa.org.uk

Cancer Research UK
www.cancerresearchuk.org

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

Financial and holiday insurance advice
www.moneyadvice.service.org.uk

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,
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Phone:

01978-727164

E-Mail :

info@gutsy-group.org.uk

GUTSY helpline

Having or recovering from 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

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 'holiday insurance' in this issue