

GUTSY Newsletter

Issue 9 – North Wales and West Cheshire

Summer 2011

GUTSY News

GUTSY is jointly organised by healthcare staff and a small steering group of GUTSY members. Many of the Steering Group have been trained by Macmillan in listening and responding skills. You can recognise them by their distinctive badges. Please ask them if there is anything you would like to discuss at the meetings. You can find more information about GUTSY on their website

www.gutsy-group.org.uk If you have any ideas for the newsletter or website contact: Janet Robinson or Diane Henderson on: 01978 727164 / 727125
janet.robinson@wales.nhs.uk
diane.henderson@wales.nhs.uk

Also please let them know if you no longer wish to receive information regarding GUTSY.

GUTSY Telephone Support Scheme

The GUTSY Telephone Support Scheme is now running providing support for patients and families across North Wales and Cheshire. It means that former cancer patients will be on the other end of the phone line for others going through the same experience. The scheme is backed by Macmillan in every Community, who trained the volunteers.

The scheme was officially launched on 27th April 2011 at Rossett Hall.



(Left to right) Brian, Linda, Bob and Michele

Brian is the Lead Volunteer for the scheme. The helpline number for the GUTSY Telephone Support Scheme is 0800 707 6907. Brian Lewin can be contacted at brian@gutsy-group.org.uk



GUTSY Telephone Support Group members, accompanied by Mr Pye, Consultant Surgeon and Anne Mart from Macmillan

Oesophageal Patients Association: another source of support

Mr David Kirby, Chair of the Oesophageal Patients Association (OPA), and his wife were welcomed at April's meeting. Mr Kirby explained that the OPA is a registered charity formed in 1985, when a few former oesophageal cancer patients met and found tremendous reassurance in sharing experiences. Since then, they have helped over 26,000 patients and carers.

They are now recognised as a knowledgeable body and are widely respected. They work with the medical profession for earlier diagnosis, better treatments and improved outcomes. Anyone is welcome to register with the OPA, there is no cost involved. By registering, you will become a member and receive newsletters and other information. The Web address for the OPA is www.opa.org.uk The OPA runs a telephone helpline: 9am-5pm, Mon-Fri. Ring 0121 704 9860

Other useful contacts:

Stella Davies, Maelor Hospital:
Tel: 01978 726273,
email: stella.davies@wales.nhs.uk

**Lizzy Pearce, Upper GI CNS,
Countess of Chester:** Tel:
012440680444, ext 3210, email:
Elizabeth.pearce@coch.nhs.uk

Welfare Rights enquiries:
Tel: 01978-298258

Just Ask

Mr Pye, Consultant Surgeon, regularly attends GUTSY with members of the surgical centre clinical team. During the question and answer session they respond to questions or concerns that people may have about their condition or treatment.

Q: I had my oesophagus removed 2 years ago. I take Lansoprasole but found reflex acid worse when taking. Can I stop? A: Some patients get acid, some don't. Lansoprasole helps if the symptoms are troublesome. Another member recommended Lemon Grass and Ginger Cordial or Holland & Barrett's ginger tablets.

Q: Does the intestine work harder following a gastrectomy? Three weeks after coming out of hospital, I ate bacon and onions with no problem. I also have a potential hernia. I am eating more, moving more, but getting cramps. I also get pains as soon as I drink after a meal. A: The intestine digests what is thrown at it, but as there is no stomach the volume of food can cause problems. You cannot eat as before. Eat less but more frequently, a little but often works better.

Q: Is it better not to drink with a meal? A: Drinking adds volume and may add to the problem. Many people find it better to drink separately, but this does vary from patient to patient.

Q: I had a full gastrectomy. I now get severe hiccups when eating and sometimes have to stop eating. A: The cause can vary. It may require a barium meal to find out if there is a problem.

Q: Is there any disadvantage to taking Nexium 80mgs long-term? A: Nexium cuts down the acidity in the stomach. There is no evidence so far that taking it long-term is a bad thing.

Q: If patients are taking high doses of medication, does this cause a lack of iron? A: Iron deficiency is more common after gastrectomy. Another member said he was tired all the time. He had a blood test which showed that he had been iron deficient for some time. His GP had not picked up that he was taking a high dose of antacid.

Q: Has anyone looked at genetics? A: This has been looked at but there is no common thread.

A Patient's Story

I first noticed a problem in 2009. I was eating a burger and found it sticking in my gullet instead of swallowing easily. My GP immediately said he wanted tests to be done, especially an endoscopy. I told my GP that I had terrible gag reflex, but he insisted that I should go. I attended the Maelor within a couple of weeks. I knew of a workmate who had died of similar symptoms, I realised I probably had the same condition.

At the Maelor they tried to put the endoscope down but even putting the "guide" to my mouth gave problems and the procedure was terminated. My GP arranged for a barium meal X-ray to be done. The person who carried out the test told me to see my GP immediately. That confirmed my opinion that I had cancer. My GP said he would send me to see a specialist; he did not say a word as to the diagnosis.

I saw the specialist 3 weeks later, now quite a bit of time had elapsed with only one test and no diagnosis. The specialist was babbling on, asking if there was anyone with me. He then asked me what I thought I had. So after 3 months of seeing my GP several times, two doctors at the Maelor, and a specialist, no-one was prepared to give me a diagnosis. I said "Cancer", to which he replied, yes. That was the end of the consultation. He did not say what they or I should do next, other than they had specialist nurses who could help. After some moments of silence, I left. Should I have asked or should he, have been more forthcoming and helpful?

I then had an appointment with Mr Baker; he was the first who told me about my condition and what possible courses of treatment were available. He wanted more tests done especially the endoscopic examination. He listened about my problems with gagging and arranged for it to be done under anaesthetic.

The tests were done and Mr Baker said I would have chemotherapy, then an operation to remove the tumour either by

keyhole, or by opening me up. I was to see the chemotherapy specialist and Mr Baker would see me again after the treatment.

It was now mid October and the appointment was at the Maelor in November. This was a waste of time, it was more about filling in consent forms, being given a brief outline of what was to be done and the side effects, and meeting with the Macmillan nurse who explained the process and gave me some leaflets about the treatment.

I had to wait for an appointment at Glan Clwyd Hospital. My biggest thought was why couldn't I have had it all done at Glan Clwyd on the one day? I had a line put in for the chemo. Whilst waiting I overheard a conversation between an elderly lady who was receiving treatment and a nurse. The lady had oesophageal cancer and could not swallow tablets. The nurse was urging her to swallow with something like yoghurt. Later I was also given drugs to counter the effects of the chemo. When I told the nurse about my gagging problem, she changed the tablets to liquid medicines. The old lady would have been better if she should have been given the same.

The courses of chemotherapy went by without too much of a problem. I asked if the line had to be left in as I couldn't remember what I had been told. After the operation I think it would have been better for it to have been left in as staff had trouble getting into my veins.

I saw Mr Baker; he reiterated the risks of

the operation. Even though the risks are high, without it the outcome would have been terminal. I attended a *GUTSY* meeting before I started chemotherapy I was advised by a member to shave off any body hair as it made it less painful when pulling plasters off. I followed his advice and it made changing plasters a doddle! I also shaved hairs from my chest before I had the chemotherapy, so had no problems with dressings etc.

I had my operation in January 2010 at the Maelor. The team were superb and I virtually felt no discomfort afterwards. I was surprised to feel so good in myself. I was discharged after 7 days. This was only possible due to the skills of the surgeon and his team, and the care and attention I received. From my initial appointment with my GP to having the operation it took six months. Until I met Mr Baker no-one wanted to give me a possible diagnosis, or what treatment I could have. I realise the team must do a lot of work behind the scenes. It must be stressful for doctors and staff to be breaking bad news and having to deal with patients' reactions. Is that why they are cautious until they are 100% certain of the outcome?

Following my treatment, my advice to future oesophageal patients would be to (1) be offered drugs in liquid form where possible; (2) for men to shave off their bodily hair; (3) for husbands/wives on their first visit to HDU to bring a toilet bag in for the patient. ****Please note: new evidence states not to shave before surgery, as broken skin can increase the risk of infection.***

