

GUTSY Newsletter

Issue 5 – North Wales and West Cheshire

Spring 2010

GUTSY News

Welcome to the latest edition of the GUTSY newsletter. Previous issues have proved popular with GUTSY members; they are also circulated to patients who want to be kept informed but who can't always attend meetings. They and other information can also be found on the website at www.gutsy-group.org.uk

This issue contains a range of articles which we hope you will find informative and helpful. GUTSY is jointly organised by healthcare professionals and a small steering group of GUTSY members. At meetings you can recognise the steering group members by their red name-badges, please approach them if there is anything you would like to discuss at the meetings. If you have any ideas for the newsletter, website, fund raising or would like to write an article, let us know or email DIANE.HENDERSON@wales.nhs.uk

- **Working Together – introducing Dr Rhys Davies, GP and Macmillan GP Advisor**

Dr Davies explained that as well as being a GP in Llangollen, he is also a Macmillan GP advisor. Being a Macmillan GP advisor involves encouraging and promoting improvements in the quality of cancer and palliative care provided by GPs and primary health care teams. One area of improvement is 'Communication', this means bridging the lines of communication between different care providers, developing information for patients and carers, and making sure that develops are grounded in the views of patients, relatives and carers. Dr Davies said he was happy to answer any questions the GUTSY members had; the following points were raised:

Q. How good is the communication between the GP and the hospital teams?

A: Dr Davies said communication with the hospital is generally good and if necessary he would ring the hospital. He recognised that sometimes GPs do not have full, timely information and updates from the hospital. Ann Camps, Macmillan Nurse Specialist, said they had picked this up from a

recent survey and are now piloting a 'discharge pathway'. This includes Stella Davies, Nurse Practitioner, telephoning the GP on the patient's discharge and when necessary making follow-up phone calls. Ann reminded members that if they encountered any problems they should contact the specialist nurse as their role involves bridging services between hospital and home, which includes liaison with GPs and district nursing teams.

Q. Is there any reason for, or against having the swine flu vaccination?

A: Dr Davies said he recommends for all those at risk to have the swine flu jab. However if the patient is under 65, unless there were other health risks involved (eg, heart problems, asthmatic), they would not be in the priority list for the flu jab. It is arguable that those who have lived through previous pandemics will have picked up some immunity over the years. If you have undergone chemotherapy, radiotherapy or have low white blood count, then we definitely recommend having the vaccination. Mr Pye added that the most vulnerable are young people (teens/20's) who have not yet developed immunity.

Q. Following cancer and surgery are a patient's GP records flagged-up, to alert the GP?

A: Dr Davies said getting patients records flagged is a bone of contention; only patients in the last stages of life are flagged up. When treatment has been curative there is no flagging system in place. The difficulty with flagging is that a number of patients will have a variety of complex, serious health problems and you could in theory be flagging the majority of patients.

Some members said that they objected having to tell the receptionist the problem in order to secure an appointment. Ann advised that the best course of action is for patients/relatives/carers to contact their specialist nurse who can contact the GP on their behalf. The nurses can gain direct access to the GPs. Dr Davies said that it is helpful as the nurse specialist has the information at their fingertips and knows the patient well.

Q: When a patient requires regular food through a bottle, why should they have to go to their surgery every time to request a prescription when this is an on-going prescription?

A: Recent directives from the Local Health Board for GP prescriptions means that GP prescriptions cannot be done over the phone due to risks (which have occurred in the past), and must be done in person or by a written request. Dr Davies said they had set up at his surgery, for email requests for prescriptions; the patient can then collect at the chemist of choice. They try their best to get prescriptions out asap at his surgery.

The patient said there was always a long process waiting for the prescription to go through despite this being a regular order. Jane (dietician) explained that previously the supplier of feeds and associated equipment would contact the GP and prescriptions were sent directly to the company who would then arrange delivery to patients' homes. However, the recent directive did not allow this to happen. Patients had to get the prescription themselves from the GP and forward it to the supplier. Jane said this problem had previously been highlighted by patients and she was happy to discuss it in more detail with the patient. (Jane has subsequently done so and raised this issue at the local nutritional steering group. She has been asked to submit a report highlighting the problem.)

- **Just Ask**

Mr Pye Consultant Surgeon (pictured) regularly attends GUTSY meetings with members of the surgical centre clinical team: Ann, Stella and Lizzy (Nurse Specialists), Rachel and Beth (physiotherapists), Vicky (occupational therapist) and Jane and Kate (dieticians) are amongst the team who are available to help.



During the question and answer session they respond to questions and concerns that people may have about their condition or treatment.

Q: How many years after the operation do patients get reviewed?

A: 2 years – every 6 months; 2+ 5years – once a year.

Q: Is it normal for voice to alter following surgery, voice breaks up?

A: This can happen, affects people in an unpredictable way.

Q: Certain foods are taboo, eg, bread. At the moment we are trying fresh, gluten-free, traditional white bread from Asda.

Warburton's soft brown bread is also good.

A: Bread is not a taboo food. The majority of people can manage bread in their diet. However, if individually you find bread difficult, it is a good idea to try different types as some may suit some and not others. Each person needs to learn what suits their own digestion.

Another patient had a recipe for vegetable stew with sweet potatoes, swede, carrots, onion and beef Oxo. The sweet potato adds the flavour. Brian said he would include this information and other recipes on the website.

Q: I had surgery four years ago, but suffered violent pain last 3 weeks on eating (small portions). Why is this?

A: Portion size adapts at 18 months, as a general rule. Most are limited to smaller portions. As this is something new, need to get it checked out via your GP who will refer back to the hospital.

Q: Does Lansoprazole act as a laxative?

A: This is one of the side effects; 20% of people do suffer.

One patient drinks scotch and lemonade for his reflux, makes him burp! Another patient said he drinks Lucozade (which also helps with his energy levels).

Mr Pye said it could be that carbon dioxide neutralises the acid. The body is good at adapting; each person works out what resolves the problem. It is a learning process; tips received from other patients are good.

Q: Why do some patients have problems with food types?

A: No reason.

Q: Why, after eating, does my nose start to stream?

A: I don't know what would cause this.

Q: What part does anxiety play?

A: Intestinal problems – it is characteristic that anxiety or stress will magnify the problem. In everyone there is a connection between the brain and the gut. This is how anxiety or stress can affect the bowel.

Q: Noticed blood sugar is low, cautious about eating sweet things; feels weak and trembling. 2½ years post op. What is the best thing to tackle this?

A: Dumping is less common following oesophagectomy. Most patients are limited to the volume of food they can digest. If it is near eating time, the blood sugar drops. Suggest having food handy and keeping an eye on the time. If diabetic and on insulin, the patient would need sugar immediately. If a short, quick fix, try dextrose tablets (as a reserve). Some patients need regular eating patterns.

One patient said he eats bananas; however this could lead to potassium poisoning if too many eaten. Another patient said had problems when dining out (had tummy cancer) as can no longer eat big meals.

Q: Over last 2-3 months, coughing, something tickling somewhere. Acid comes straight away, happens anytime, okay afterwards. I had operation 4 years' ago in May. Takes Lansoprazole for reflux and sleeps on two pillows.

A: There could be many reasons for this. If the cough persists, suggest you see your GP. However as the cough is random, it may settle.

Q: Is it not a matter of course for patients to be given medication for acid?

A: This is individual for each patient. Sometimes what feels like acid could be bile or a spasmodic reaction in the gullet

One patient said Ryvita and a bit of butter helps him. Another patient takes tablets but some have side effects. Mr Pye said if it was bile, Gaviscon works better.

Q: My wife had a vomiting bug which I picked up. Found it impossible to vomit and passed out. Ambulance called. Blood pressure had dropped; also had abdominal pain a few weeks earlier. Why did this happen?

A: Mechanisms within each patient are different. As the blood pressure had dropped, maybe the lack of being sick stimulated the vagus (vasar vagal attack = faint). This would affect the blood vessels.

- **General News**

GUTSY Website:

<http://www.gutsy-group.org.uk/>

Brian asked members if they had anything they would like to be included, to please let him know by emailing him at info@gutsy-group.com

Free prescriptions: As from April 2009 all cancer patients throughout England and Wales are entitled to free prescriptions for ever, not just during treatment. In England, the patient would need to get an exemption certificate from their GP, or alternatively from Lizzy Pearce, Specialist Nurse, Countess of Chester Hospital. This cost can be back-dated from 1st April 2009 and takes about a month for the process to go through.

- **Macmillan Launch – Eating Well Booklets**

Macmillan has released 2 new booklets under their Practical Guide to Living with and after Cancer Range. They are

- Eating Well After Cancer Treatment
- Recipes from Macmillan Cancer Support



These are free to members and copies can be obtained via Pam Wedley at Wrexham or Liz Taylor at Chester (see Contact details) or via the Macmillan website: www.macmillan.org.uk

- **Helping to improve Patient and Carer Experience**

During the last two years GUTSY members have given freely of their time, and have shared their views with members of the clinical team and independent facilitators as part of focus groups.

The Clinical Team has acted upon this feedback and as a result the following actions have been made, or will be put in place as part of the services 3-year work plan:

- Patients are reviewed about 3-4 weeks following discharge by Critical Care Outreach (Anaesthetist and Surgical Nurse Practitioner who have access to other team members).
- A communication/discharge pathway has been developed and patients are offered a written summary of discharge arrangements, key points, and contacts for team members.
- Existing Home Enteral Nutrition Information and Training Pack for general Tube Feeding have been adapted to include information sheet for out of hours and Accident and Emergency involvement.
- Upper GI support clinic with Clinical Nurse Specialist and dietician implemented.
- Information given at pre-assessment includes Macmillan cancer: Support Guide, *'Hello and How are you? - a guide for carers by carers'*, and an accommodation list of hotels/bed and breakfasts near to Wrexham Maelor Hospital.
- Physiotherapy leaflets: on easing shoulder pain have been written and circulated.
- Listening and responding/'Buddying' training course for GUTSY members and relevant trust staff.

- **Adjusting to Life after Cancer Treatment**

At the end of treatment people expect to feel relieved and able to get on with normal life again. Yet, can be shocked to find that they feel low in mood and physically tired. Relatives and friends may have similar feelings and these emotions may spill over into their relationship with you. The Specialist Nurses and other members of the team are here to provide ongoing emotional support and practical advice for both the person who has undergone treatment and for family members and

friends. Useful organisation for further information include: www.be.macmillan.org.uk or telephone 0800 8080 00 00 for the booklet: *'Life after cancer treatment'*

Contact details:

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- **Help with DIY or Gardening?**

Airbus UK workforce at Broughton has a team of volunteers to help with: simple DIY, gardening, shopping. For further information contact Phil Jones, Charity-Challenge on: **07710 339173**