

GUTSY Newsletter

Issue 7 – North Wales and West Cheshire

Sept 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. You can find more information about GUTSY on their website 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, telephone or email Janet Robinson or Diane Henderson on: 01978 727164 / 727125

janet.robinson@wales.nhs.uk
diane.henderson@wales.nhs.uk

Baby News – it's a girl!

Mr Pye was happy to announce that Stella had given birth to a little girl called Megan, mother and daughter are doing fine.



Telephone Buddying Scheme

When things happen in life people often find it reassuring and comforting to talk to someone who has been through a similar experience. This sharing and mutual support happens naturally when people attend GUTSY. However, not everyone can get to the meetings, and sometimes even those that can welcome the opportunity to talk further outside the meetings.



Therefore, GUTSY are developing a structured 'Buddying Scheme'. Buddying is an excellent way of making contact with people who can offer understanding, practical tips, and empathy to people who are newly diagnosed or undergoing treatment.

GUTSY's scheme has been developed in-line with good practice recommended by Macmillan and in the main involves offering telephone contact and support.

To operate the scheme a number of volunteers will be recruited, who will

undertake training in listening and responding skills. In line with best practice volunteers must be 2 years post treatment.

It is hoped that we will have a spread of people from across West-Cheshire and Wales and that we will have some volunteers who are Welsh speaking. Ann Camps, Clinical Nurse Specialist, will co-ordinate the scheme and will match Buddies with people who have asked for someone to contact them. Anyone interested in becoming a buddy should contact Ann Camps (01978 727161) or Diane Henderson, PPI Manager (01978 727125).

Just Ask



Mr Pye Consultant Surgeon (pictured) regularly attends GUTSY meetings with members of the surgical centre clinical team: Ann, Michelle 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: Will I suffer with vitamin deficiency after the operation?

A: If all the stomach is removed, then Vitamin B 12 injections may be given but otherwise if you are able to eat a healthy varied diet, vitamin supplements are not normally required.

Q: I have tried vitamins but now taking Ferris tablets, will I take this forever?

A: It depends on your blood count; this is an individual thing.

Q: What about Ensure?

A: This is a food supplement and is prescribed to give patients calories; it is very different to vitamin supplements.

Q: I am on B12 injections, the level in my body fluctuates and my fingers sometimes tingle. I sometimes have the injections 2-monthly, otherwise 3-monthly.

A: The chemotherapy is most likely to affect the fingers, not the B12. The body stores B12 in the liver and it lasts about a year, so I would expect the levels to be okay for 3 months following injection. It is dispensed from the liver as the body requires it.

Q: Acid comes up into my mouth in spasms and I take Lansoprazole every night.

A: Following surgery the mechanics of the body are different and acidity comes up more readily. If this is a persisting problem, medication can help. This does not happen for everyone.

Q: Prior to my operation, I took cod liver oil and glucosamine, but have now stopped. I thought cod liver oil was beneficial for the joints but it does not seem to have made a difference.

A: I have no idea if it actually works. Some people say it helps them. If you find it helpful carry on, if not, don't take them.

A: Following my operation my stomach feels as though it is in my throat. I also have numbness where the drain was.

A: This will subside, continue with the medication. It is early days yet. It takes about 18 months for the body to settle.

Q: Six weeks after operation (oesophageal), I feel drained after eating.

A: It is a bit early, it takes months to recover. The body has to come to terms with the changes. Take it gently. Keep amounts of food small but often. Avoiding bread may help.

Q: I had my stomach removed 2½ years ago but still have trouble with eating.

A: If this is how your body is after 2½ years, then this is how it will be. There is usually little improvement after 18 months.

Q: Since the operation 7 months' ago I have had outbreaks of coughing especially on reclining and as a result of reflux

A: Liquid in the stomach probably hasn't cleared and this causes the coughing. Try eating small meals and having your last meal early to allow your stomach to empty. Try sleeping propped up if possible, and perhaps

elevate the head of the bed with bricks under the legs of the bed.

Q: I am starting a 16 weeks of gym exercise, is there anything I shouldn't be doing?

A: No, go for it!

Q: Where does photo-dynamic treatment lie?

A: On the periphery. We seldom see cancers that benefit from this; this has been better than other treatments used in more advanced cancers but there is no proof that it works.

Q: If not eating a balanced diet, should I take vitamins?

A: Yes, speak to a dietician for the best advice. It you can't get calories into you, vitamins may help.

Q: Is there an alternative to possible frequent repeated dilatation?

A: No. A bypass will work for blocked arteries but not for the gullet. The number of dilatations varies with each individual, some patients have no dilatations.

What do you think?

Ann Camps, Clinical Nurse Specialist, is the nominated lead at the Surgical Centre for patient and carer issues. Please contact Ann direct with any concerns, ideas or suggested improvements.

Contact Details:

Ann Camps, Macmillan Nurse Specialist, Maelor Hospital: Tel: 01978 727161, email: ann.camps@wales.nhs.uk

Michelle Curtis, (covering for Stella's maternity leave), Maelor Hospital: Tel: 01978 727858, email: Michelle.Curtis@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

Pam Wedley, Information & Resource Facilitator, Wrexham
Tel: 01978-726188 or email: Macmillan.shootingstar@wales.nhs.uk

Lizzy Taylor, Information Facilitator, Countess of Chester: Tel: 01244-364948 or email: Elizabeth.Taylor@coch.nhs.uk

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



Travel Insurance Tip

A GUTSY member had tried to get travel insurance for Canada and had been quoted £1000 for 3 weeks plus basic cover. He heard on the radio programme "You & Yours" about a woman who had set up her own insurance company following being diagnosed with breast cancer.

He contacted the company Insurepink.co.uk and was quoted £330 for 4 weeks in Canada and £550 for 3 months in Australia. If over 65, basic insurance cover will also need to be taken out.

Macmillan also provides guidance on holiday insurance, details which can be found on their website.

