



The GUTSY Group



WREXHAM AND CHESTER NEWSLETTER – DECEMBER 2008

Dear Friends

It is hard to believe that the New Year has crept up upon so quickly and very shortly, GUTSY will celebrate its second anniversary! Since its launch in 2007, GUTSY has gone from strength-to-strength with about 50 people attending meetings at Rossett Hall Hotel - this is fantastic! However, we do not intend to rest on our laurels; it is important that GUTSY continues to meet the needs of members. A survey of members carried out in July 2008, showed that:

- People were happy with the time and place of the meetings.
- That the group was meeting members' expectations.
- Members liked the informality as well as the companionship and meeting people who had similar experiences.
- They found the question and answer sessions with the medical team particularly helpful.
- They would like more guest speakers to discuss diet, absorption of fats & sugars, post chemotherapy symptoms and finances.

These views will help to shape the 2009 meetings which are:

Dates for your diary:

GUTSY Meetings 2009



- 11th February 2009
- 17th June 2009
- 28th October 2009
- Christmas event to be arranged

Venue: Rossett Hall

It is important that GUTSY becomes a members' group and not just something that is put on by the health team for people to attend! So! GUTSY now has its own Steering Group made up of patients who have had the cancer, or family members, or friends. The Steering Group meet before the official meetings to plan events and put members' views forward. Members of the group are: Bob & Michele McCormack, Brian Lewin, Annie Bright, Ann Camps and Diane Henderson.

At meetings they wear red-colour badges and provide a welcome for new or existing members. Please let them know if there is anything, you would like us to include in the meetings or newsletter.

JUST ASK

Jonathon Pye who is our Consultant Surgeon, Ann and Stella (Nurse Specialists), Rachel and Helen (physiotherapists), Kate and Jane (dieticians) and Vicky (occupational therapist) are amongst our team who are available to help.



Mr Pye (pictured) regularly attends GUTSY meetings with members of the surgical centre clinical team, and during the question and answer session they respond to questions and concerns that people may have about their condition or treatment. Members and their families say that the relaxed environment is an ideal opportunity to ask those niggling questions that you probably wouldn't remember to ask in a clinic appointment.

QUESTIONS ASKED

Q: Why aren't regular scans and checks done as part of routine follow-ups?

A: Due to the individual nature of this cancer, the best method of monitoring is to investigate any symptoms that are new to you; we have found that this is one of the best indicators, rather than performing scans at set intervals. So if you have any worries or concerns, please contact your Specialist Nurse, GP or Consultant's Secretary who can bring your existing clinic appointment forward for an earlier review with the hospital team if necessary.

Q: How do we know if a symptom is a new problem or as a result from surgery? Is there a list to guide a patient?

A: It is not widely understood, even by doctors, the length of healing process the body needs to go through. It takes up to 18 months for the healing process during which symptoms crop up in varying ways. If something occurs that is persistent and different (e.g. a change in

digestion), it needs to be checked out. If something is painful from the start and continues, that is part of the healing process. Again keep in touch with your Specialist Nurse – that is what they are here for!

Q: How do surgeons keep up to date with treatments?

A: We subscribe to professional associations and magazines, attend international and national scientific meetings during the year where we talk to each other about new techniques and approaches.

Q: Is it a good thing to struggle on for longer before requesting a stretch?

A: If you are unable to tolerate normal textured food and your swallowing is becoming more difficult, please contact your Specialist Nurse or consultant's secretary so a dilatation can be organised in a timely way, rather than resulting in an admission to hospital because you are unwell and dehydrated because you have been struggling swallowing liquids.

Stretches can happen many times for patients (average less than 10 over a period of time during the initial phases of recovery, but lessen in time). It again is very individual

Q: When I have felt hungry I have tried to eat more, but violent pain occurs

A: Every person's recovery is different and it depends on the type of surgery performed. Everyone is different in the amount they can eat. If pain occurs, reduce the amount of portion size and eat smaller and more often. Again, open access is reiterated to the dieticians and specialist nurses for advice and support for you and your family.

Q: Is music played during operations?

A: Yes!

HEALTHY DIETS HELP

Cutting out dairy helped his symptoms - could it work for you? By: Michele McCormack wife of Bob and Steering Group Member

After my husband had his operation he developed very bad diarrhoea, we eventually realised it seemed to be at its worst when he ate anything with dairy in it, and believe me when you start to look at the ingredients in food you will be very surprised. Changing his diet really eased Bob's symptoms and I would like to share with you some of the foods Bob and I now enjoy, you might want to try some of them.

I work full time so I have to be organised, it is not quite as straight forward as just putting a ready meal in the oven; so if it helps you, then this is what I put into action to help my husband maintain his weight and not be worried about where's the nearest loo! My first bit of advice is lists, lists, lists, prepare ahead when shopping and know what you intend to eat during the week. I will also give you a list of quick snacks as sometimes life just is not perfect, is it. If you are at home and have the time to cook then this list can just be a top up to make your life a little easier.

Useful shopping websites:

First websites; the only problem with this is you do have to pay p&p so I found that I would order enough to cover for at least a month. Yes it is more expensive, but hey you're still here and aren't you worth it? Or when it's your birthday or Christmas, ask people for them

as gifts.

Can we suggest you have a look at some of these popular websites:-

www.dairy-free.org.uk

Orange cake and lemon cake with a lovely creamy filling and icing on the top. You can actually cut them in half and freeze the other until required; nice with a cup of tea (they also do other items).

www.alotofchocolate.co.uk

Lovely chocolate for special occasions, every day bars of chocolate and better still, if you're not fussed on dark chocolate they do a really nice milk.

www.puredairyfree.co.uk

If you have a little more time to make things, this site gives you some nice all round recipes, especially savoury which to be honest is much easier than sweet.

Supermarkets:

Supermarkets have actually improved greatly so here are some tasty morsels for you to try.

Cake:

Sainsbury's do a good range of items called 'Free From' and at Christmas time they will vary the assortment, ie, mince pies, Christmas puddings etc, Easter chocolate eggs and simmnel cake – they are worth checking out.

Tesco do a range that is not quite as extensive but the chocolate cake comes highly recommended.

Asda have a range called 'Crimbles', coconut cakes with chocolate or jam in them - lovely.

Asda also do a packet of crumble mix. Buy a tub of

raspberries (fresh or frozen), top with the crumble mix, sprinkle with Demerara sugar and a teaspoon of Pure and bake in the oven for 25mins - top with dairy free ice cream, fab!

Milk: most supermarkets sell lactose free with a 'black cow' on the carton. They have a long shelf life but they are not UHT they are fresh, so buy a few as they sell out quickly. It allows you to have porridge, cereal or to bake and make cheese sauces.

Cheese: Holland and Barrett health food stores do cheddar slices, mozzarella slices (so you can have a pizza) and blocks of cheese to grate, although I have to say the slices are nicer. They also do a powdered cheese sauce mix, Free and Easy. Use with your lactose free milk on lasagnes or pasta bakes – it's lovely.

Margarine: well it's not butter, but it's not bad - 'Pure' from Sainsbury's or Asda. You can still have your toast and marmalade and do all your baking (sweet and savoury).

Ice Cream: called 'Glace Ice' from Sainsbury's and Holland and Barrett; the vanilla is lovely. Moreover, they do chocolate flavour!

Soups: believe it or not, most tinned soups have milk powder in them. Sainsbury's do a range of organic soups that are nice - the leek and potato, tomatoes and basil are good. Try one of these if you don't feel like making your own and add ready-made croutons on top (M&S or Asda).

Yogurts: lactose free with the 'black cow'; nice with some fruit that has been soaked in liquor for a light pudding.

Sweets: Holland and Barrett do lovely fudge and most shops

have Fry's chocolate cream bars, Toblerone dark, Butter Kist popcorn. We also always have a big box of jellies to nibble on each night. Sainsbury's sell chocolates with nice fillings in them from their special range.

Biscuits: Hobnobs, Fox's Party Rings, Green and Blacks chocolate with fruit and nut bars (especially nice).

I really hope this helps you to make your life a little easier; the best way is to make your own but sometimes that is just not possible.

Sound Advice

This article provides sound practical advice for a diet which can be difficult to manage well.

I would add that whilst this approach has obviously worked well to alleviate Mr McCormack's individual symptoms, very few people that have had Upper Gastrointestinal surgery will become lactose intolerant. I would advise that if you are intending to omit individual foods or a whole group of foods from your diet, which make a valuable nutritional contribution, it would be sensible to seek advice from your dietician to ensure your dietary intake remains nutritionally adequate for your individual needs. Also due to the very nature of oesophageal and stomach surgery there can be other reasons for diarrhoea and so again we recommend you seek advice from your dietician and clinical team.

Kate Howarth, Upper GI Dietician

Put the kettle on for Cancer Relief

We were pleased to support The World's Biggest Coffee Morning 2007

A small Bring and Buy event was held at October's GUTSY meeting in aid of MacMillan's the World's Biggest Coffee Morning; a total of £85.00 was raised.



The World's Biggest Coffee Morning is Macmillan's flagship fundraising events, and this year they hope to raise £8.5 million to help support people living with cancer.

Travel Arrangements Where did you stay?



Did you have to travel a distance to have surgery at the Wrexham Maelor Hospital? If so, we would like to hear your thoughts, or those of your family about how you, or they managed with travel and accommodation arrangements. For example:

- did your family want to stay but didn't due to cost, or the difficulty of finding accommodation?
- how easy was it to find accommodation, did staff give you any information on how to find accommodation?
- would you like overnight accommodation for relatives to be available in the hospital?
- is there anything else we need to know about travel or accommodation ?

Please let us have your comments by either telephone, or email by using the following contact details:

Mrs Diane Henderson (PPI Manager) on 01978 727125 (ask for Diane Henderson or Janet Robinson) or email diane.henderson@new-tr.wales.nhs.uk

Thank you and your family for considering this.

USEFUL CONTACT NUMBERS WEB ADDRESS

Ann Camps – 01978-291100 or ann.camps@new-tr.wales.nhs.uk

Airbus – Phil Jones
Tel : 07710339173
or Philip.L.Jones@airbus.com

Do you have a story or information you would like to share with GUTSY members? We would love to hear from you, the dates for submission of articles for future newsletters are end of May 2009 and end of September 2009.

By sending to Janet at janet.robinson@new-tr.wales.nhs.uk

ADJUSTING TO LIFE AFTER CANCER TREATMENT

The end of treatment is a time when people often expect to feel relieved, cheerful and able to get on with normal life again, but can be shocked to find that they may feel quite low and depressed and physically tired or drained trying to adapt to life style changes and the recovery process itself.

Relatives, friends may have feelings of sadness and uncertainty similar to your own, 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 regarding above:

Website:
www.cancerbacup.org.uk

Telephone 0207696 9003 for above booklet – “Adjusting to life after cancer treatment”

Sometimes a support group can be helpful because you may find that you can speak more openly about your feelings.

So remember when and if you feel able, please tell us your story so it can help others, by contacting any member of the steering group. And if you can help with any diet tips or recipes, that would be great. This will be reviewed by our dieticians, as any articles will be commented on in a balanced view by the relevant member of the clinical team.

At each meeting we will hand out a question slip for you to fill in with any questions or concerns that you would like answering by a member of the clinical team present. However if this is not possible, we will try to address it in the next newsletter or at the next meeting

At our meetings you can approach any member of the clinical team present to ask any personnel questions if you wish, and feedback from the group members has been recognising the support that you give to each other just by simply listening to and sharing each others recovery stories

We would also be grateful if you feel you can make a small donation to the tea and coffee in the container provided at the next meeting, it would be a great help as all costs come out of our funds.

WILL YOU NEED ANY HELP IN THE SPRING WITH DIY or GARDENING?

Airbus UK continue to support GUTSY members. The workforce at Broughton in Chester has a team of volunteers willing to help with:

- Simple DIY
- Gardening
- Shopping
- Trips out



If you need any support in these areas do not hesitate to contact Phil Jones, on 07710339173.

