



GUTSY Newsletter



Issue 3 – North Wales and West Cheshire

June 2009

GUTSY News

A very warm 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 make meetings.

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 you would like to include anything in the newsletter, or if there is anything you would like to discuss at the meetings. The Steering Group meet before GUTSY meetings to plan events and put forward members' views. The Steering Group are presently looking at developing a website which will help to keep everyone informed, they are also busy producing regular newsletters and exploring fundraising ideas to enable GUTSY to go from strength to strength! So, if you have any ideas or would like to write an article let us know!

Macmillan Shooting Star Information Centre

The Macmillan Shooting Star Information Centre is a dedicated information centre based at Wrexham Maelor Hospital in North Wales. It is staffed by Pam Wedley, Macmillan Cancer Information and Resource Facilitator, and volunteers who provide valuable assistance in the day-to-day running of the Centre.

A wide range of information on issues such as specific cancers and treatments, diet, cancer screening, health awareness, local and national support groups, travel insurance etc is available. There is free access to a computer and cancer information can be printed free of charge. There is also a lending library of resources, including DVDs and audiotapes. Centre staff offer time to patients and relatives to talk in a relaxed and confidential environment; they work closely with clinical nurse specialists and are able to refer people on when necessary.

Services at the Centre are available to anyone affected by cancer - patients, relatives, partners or friends. Information can also be provided to staff, community services, voluntary organisations as well as members of the public. You do not have to live in Wrexham to use the Centre; people can just 'drop in' appointments are not necessary. Opening hours are between 10am-4pm weekdays only but these can vary, so it is best to ring the centre before hand if you are making a special journey.

For further information contact:



Pam Wedley Centre Manager - 01978 726188
(24-hr answer phone available) Email:
macmillan.shootingstar@wales.nhs.uk



Pam works closely with Liz Taylor fellow Macmillan Support and Information Manager based in the Countess of Chester Hospital, whilst the 'Countess' doesn't have a dedicated information centre Liz can still provide a similar service to Pam. To arrange an appointment ring: 01244 364948 or email:
elizabeth.taylor@coch.nhs.uk

Sharing your experience of being a Carer?

Before the GUTSY meeting on the 17th October 2009 we are hoping to hold a Focus Group to gain the views of carers' (wives, husbands, partners, relatives, friends) or anyone who provides care for someone living with, or beyond cancer. The Focus Group will start at 12.30pm and will be held in Rossett Hall Hotel, if you are interested in taking part please contact: Janet Robinson on 01978 727164 or email
janet.robinson@wales.nhs.uk

My Story by Bob McCormack

8th July 2006 was the day that was to change my life and that of all my family. After a routine check up and endoscope which I had asked for, Dr Ian London, my Gastroenterologist, had found a "small lesion" in my oesophagus, he had taken a biopsy and it had tested positive.

Words can't describe how I felt when I heard him say that word... Cancer, I was dumbstruck. Like most people when you hear the word cancer the next word you think of is death; I honestly thought at that moment my life was over. I did not feel ill in any way, I was fit and healthy or at least I thought I was. I had no symptoms at all, apart from reflux and indigestion from which I had suffered for many years and for which had been on medication.

That afternoon my wife Michele and I had to tell our family the news, it was the most difficult and sad thing we have ever had to do. Even though we were both in turmoil and extremely scared, we decided we had to be positive, at this point we knew nothing about oesophageal cancer.

I was told on Saturday. A CT scan was arranged for the following Monday, then an appointment with the Surgeon who was to treat me, Mr. David Monk from the Countess of Chester Hospital, was arranged for the next day, Tuesday. Over that weekend Michele and I learnt all we could about this particular form of Cancer, what we discovered did not make us feel any better whatsoever. Prior to our first appointment with Mr Monk, Michele and I had assumed that I would be in hospital having surgery before August. It was at our first appointment that we learnt the true facts, we learnt about the staging process, what we had to go through before it could be confirmed that I was suitable for surgery. Mr Monk explained the process and I had all the tests over the next week or so. At our second appointment with Mr Monk we were told that the tests were OK and that he could proceed with the surgery required. Prior to my treatment starting, Michele and I had decided that we would face the following weeks of treatment and surgery with a positive attitude and remain optimistic; our family was of the same mind and provided us both with amazing strength and support.

My chemotherapy started Monday 7th August which was the first of two sessions over five weeks, the second starting on the 30th August. Chemotherapy is not the most pleasant thing I have experienced but an essential part of the treatment which went well with few complications. During the treatment we continued with our positive attitude, and I continued to play Golf between sessions when able. My date for surgery was set for 19th October, seven weeks after my second session of chemotherapy; a lot more time to think and wait around, we tried to maintain our normal routine and kept on working until ten days before I was due in Hospital.

Michele and I decided to take a short holiday in Scotland, so in early October we went to our favourite Hotel in Perthshire for four days and both had a wonderful time together. It was a bizarre situation to be in, we were both very happy and very sad at the same time, but spending that time together made us more determined to face our situation and stay one hundred percent positive.

Soon after my diagnosis I became very aware of the effect my illness had on the people closest to me; we are a very close family and we are in contact every day due to the fact we have a business which we all work in. The business is a massive responsibility and takes a lot of time, effort and travelling, so not only did they have to contend with my situation they had to continue to be at hand to deal with the day to day running of the business and of course Michele had to look after me when I was not at my best. Watching them going through this ordeal was a great source of stress and sadness to me, our two sons, Gary and Chris, where under a great deal of pressure at work and were constantly travelling up and down the country and dealing with the fact their dad was gravely ill.

I suppose people tend to focus on the patient in this sort of situation but there are many other people – family, friends and colleagues, who are badly affected when a person takes ill and they all face their own turmoil, usually in silence. On the 18th October I was admitted into the Countess of Chester ready for my surgery the following day, we arrived at 11.00am and went through the pre-op routine and waited. That evening, about 7.30pm, Mr Monk came to see us, he had the most dreadful cold and felt awful. He explained that he wasn't comfortable performing

such a complicated procedure whilst feeling that way and was going to cancel for the following day, we were both devastated but fully understood; a new date was set for the 25th October.

At 7.00am on the morning of the 25th Michele, Gary and Chris were allowed on to the ward to see me before I went to theatre; it gave me a lot of strength just seeing them and although I was apprehensive I was happy it was finally taking place and I was prepared for what was to follow.

Michele was home by 8.00am and the boys went to work, it wasn't until 6.00pm that evening that Michele received a call from Mr Monk to say that all had gone well; they told me later that it was the worst ten hours of their lives waiting for the call. They came to see me in ITU that evening. I spent three nights in ITU, six nights on HDU, then onto Ward 44. I was allowed home on the 9th November. All went well with a few complications, the good news was all the lymph nodes were removed tested and were all negative.

The following weeks were difficult at times, I had some problems but we had a Great Christmas together. I was back at work in early February for a few days a week and I was back playing golf late February, not very well but it was just part of getting my life back together.

It is nearly three years since I was diagnosed and I am doing well, I work three days a week sometimes four if I am allowed (by Michele). Words can't describe my gratitude for the care, help and expertise received from Dr London who diagnosed me and Mr Monk and his team for treating me and their continuing monitoring, and of course my family, my wife Michele and my sons Gary and Chris, without their love and support I could never have completed this journey.

My life has changed, I have changed, I am not as big as I was, I am not as strong as I was, my general health is probably not as good as it was, but my life is still as full as it was. I continue with my work, my sports and hobbies, I have travelled more, seen more and enjoyed it more. I am optimistic about our future and we all remain as positive as we started.

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), and Jane (dietician) 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: *Why do I keep regurgitating first thing in the morning (4 months after the op)?*

A: This will improve with time and is quite common. If the operation has taken place on the gullet, the stomach will be in a new place. Most bodies adapt to this. Suggest sleeping more upright or put bricks under the legs at the head of the bed. One suggestion is to use Gaviscon. One suggestion is to use Zotan Fast-tabs. One member suffered from reflux before his operation but no longer suffers!

Q: *Still has burning in the throat eight years following surgery, but snores when sitting! Doesn't eat after 7pm and finds this helps.*

A: Mr Pye advised not to eat too late, as you are not giving your body enough time to digest the food.

Q: *I had my operation 3 months' ago but still have to be stretched every 4 weeks.*

A: Some patients have this, many only need 1 or 2 stretches. A few patients, however, need many stretches before settling; the intervals between will get longer.

Q: *Socialising can be difficult. Sometimes you eat and are OK, and then other times you are in pain. It is difficult to control food portions in restaurants and cafes.*

A: The volume of food and quantity of food is very important. Each person is different in what they can eat. Most people have a

definite level of tolerance, after that it can hurt. When dining out, suggest asking for a child's portion or for two starters. Light bites are often a good size.

Q: *What causes a dry cough?*

A: Many things can cause a cough. The operation is next to the airway so sometimes the first mouthful of food goes down the wrong way and the mechanism causes the cough. Symptoms can vary from person to person.

Q: *Are you more prone to chest infections after having had this surgery?*

A: When the operation is through the chest, the lung is interfered with, which leaves a residual weakness. This affects one or two patients.

Q: *Had a problem with PEG line at a weekend, which was leaking. Went to A&E and put staff into a state of panic (not at the Maelor). They could not find anyone able to change the line and had to wait till Monday for the District Nurse. This meant he was not able to feed all weekend. Better training for staff is a major requirement on how to deal with such problems. The GP did not know of an available nurse.*

A: When a patient is first transferred home following surgery, a plan of action is put in place which includes who to contact. Jane (dietician) said she would look into this on behalf of the member. It was not good practice for a patient to rely on one person only. Mr Pye said by highlighting this problem, it would also help other patients.

Q: *How much care should they expect from their GP (very little support provided)?*

A: Practices vary. A patient should telephone their Upper GI Nurse for assistance. This cancer is a small specialist area and would not expect GPs to know everything, but there should be someone available to talk to.

Q: *Since operation and two chemotherapy sessions have had problems with cramp and numbness in feet. Is this caused by the chemotherapy?*

A: It can be related to chemotherapy. If the symptoms happen during the chemotherapy the dosage can be altered.

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

Contact details

Ann Camps, Macmillan Nurse Specialist:
01978 291100 email: ann.camps@wales.nhs.uk

Stella Davies, Nurse Practitioner: 01978 727858 email stella.davies@wales.nhs.uk

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

Sally Forrest, Welfare Rights Officer:
Gladman Buildings, Unit 5 Edison Court, Ellice Way, Wrexham, LL13 7YZ
Telephone: 01978-298258

Do you need help with DIY or Gardening?

Airbus UK is very supportive of GUTSY; the workforce at Broughton has a team of volunteers to help with:

- Simple DIY
- Gardening
- Shopping
- Trips out

If you need any support in these areas do not hesitate to contact Phil Jones, Charity-Challenge on: **07710 339173**



