



The GUTSY Group



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Dear Friends

On Wednesday 21st March, GUTSY was launched in the Allington Suite at the Rossett Hall Hotel! GUTSY is a support group for patients and relatives of patients who require, or have had surgery for oesophago-gastric cancer.

One of the outcomes from our inaugural meeting was to produce a Newsletter to help us communicate a wide range of matters to our members. We do hope you like our new logo. Brave as a Lion is our theme proudly wearing a Superman costume.

The development of the GUTSY group took place alongside changes in the health service that means all patients from north Wales and west Cheshire who require surgery for oesophago-gastric cancer will have their operations carried out by a specialist team based at Wrexham Maelor Hospital.



Mr Jonathan Pye, Consultant Surgeon who will be leading the Upper GI Surgical Service, gave a brief presentation on the development of the surgical centre in Wrexham and Rachel Davison; Specialist Nurse from the Countess of Chester

Hospital, led a discussion on the role of GUTSY the service user group.

Rachel said: "GUTSY is designed to create an informal situation in which patients can meet together with a range of health professionals to share experiences, ask questions about their conditions and make suggestions on how services can be improved for future patients. The group is being supported by Macmillan Cancer Support and the Oesophageal Patients Association, as well as the NHS Trusts of Chester and North Wales."

Members of GUTSY stated: "We believe that this group will be one of the first of its kind for this group of patients, although similar schemes for patients with other conditions have proved their worth in a number of locations in the UK.

"We will be able to compare our experiences, share advice and provide emotional support and understanding for others who are facing similar situations.

"Just as importantly, we will be able to talk to the clinical experts, find answers to questions that may come up after our surgery and also let them know what we feel has worked well in our treatment and where we feel other approaches might have been more helpful."

GREAT NEWS ANNOUNCED

From 2 April 2007, all patients from North Wales and West

Cheshire who require surgery for oesophago-gastric cancer will have their operations carried out by a specialist team based at Wrexham Maelor Hospital.

This team, comprising surgeons from both the Maelor and Countess of Chester Hospitals, has been established to ensure that patients are being treated by clinicians who are experienced in this type of complex surgery.



However, while the actual surgery will be concentrated in a single location, patients will continue to have their initial diagnostic tests and their aftercare provided in their own local hospital;

"This arrangement means we can offer patients the best of both worlds" said Dr Matthew Makin, Lead Cancer Clinician at Wrexham Maelor Hospital.

"After seeing their GP, patients will have any necessary tests and consultations carried out in their local hospital, in Bangor, Bodfelwyddan, Wrexham or Chester. We will then use new video-conferencing technology to enable the clinical teams from each of the four hospitals to hold virtual meetings to review each case and agree the most appropriate treatment.

"This means patients can benefit from the knowledge of staff across all four hospitals without having to travel. Then, for patients who will require surgery, they will be treated by a specialist team in Wrexham before returning home for their follow-up treatment."

"There is strong clinical evidence that patients who have their surgery carried out by this type of specialist team have better outcomes, which is why this is such an important development for the region. It has also ensured that we are providing an equally high standard of care to patients from both sides of the border."

QUESTION TIME

Physiotherapists and dieticians regularly attend GUTSY meetings. At December's meeting Kate Howarth, Dietician and Rachel Williams, Physiotherapist explained their roles in relation to the care of patients who had had Upper Gastro-Intestinal (GI) surgery. Rachel told the group that before coming to Wrexham she worked in Derriford Hospital in Plymouth who specialised in this type of surgery. Rachel felt that from a physio point of view it is important to get a patient up and moving as soon as possible following surgery, as this helps with oxygen and blood flow and helps people to clear their chests.

GUTSY members asked Rachel and Kate:

'Why do I have recurring chest infections and a runny nose?'

Despite being on medication some people still had problems with their chests and nasal mucus. The following self-help measures were suggested. Try sleeping as upright as possible

and use about five pillows on your bed. Try using steam inhalation to ease the chest for example with menthol crystals available from the chemist diluted in hot water in a bowl and inhaled. You can also get special hand-held bowls with vaporizers on them.

'Why do I have this bad taste in my mouth?'

A number of people said that they had a constant bad or metallic taste in their mouth and asked if this was normal, and what they could do to ease it? Suggested to eat some white or red grapes they help to clear the palate or alternatively drink grape juice or make ice cubes from grape juice. Sucking sweets is OK also, and best not to worry about calories at this point.

'Why do I sometimes get pain after eating?'

Some people had experienced pain after eating and wondered if this was OK as sometimes the pain was quite sharp. A number of the group members acknowledged that they had experienced pain after eating. Members felt that it is trial and error working out which foods you can tolerate after surgery.

'Will my taste buds and appetite return?'

Many people said that following surgery they had a much reduced appetite and that their taste buds were not the same, this appeared to be a common theme amongst the group and the following suggestions were put forward by the members. Eat little and often, chocolate seems to be OK it soothes the throat. If you are losing too much weight add full-fat to your diet, for example have cream in your porridge in the mornings. Pastry seemed to be

hard to digest for some people.

'Should I be concerned about cholesterol and fat content in food?'

People asked about the high fat in some foods such as chocolate and cream, they were using these foods to tempt appetite and regain weight lost as part of their condition. Kate (dietician) advised that at this stage in people's recovery she did not feel that this was a problem as the main priority is to build strength, stamina and regain some of the weight they had lost. She advised if anyone had any particular concerns about their cholesterol they should visit their GP.

OPA OFFER WORDS OF WISDOM FROM LYNNE WATSON

In 1985 the Oesophageal Patients Association was formed with five patients sharing their experiences and drew great comfort from knowing they were not alone.

From those early days we have built a solid and well-respected charitable organisation which now has over 20 regional branches and over fifty trained volunteers that are based strategically all over the UK. Based in Solihull, West Midlands, we respond to over 2000 calls a year to our national helpline, hold a database of over 4500 patients, which grows daily, and have one full time member of staff and two part time employees.

Our initial ethos of 'former patients helping new patients' combined with superb co-operation from Consultant Surgeons, Clinicians, Specialist Nurses, Pathologists, Dieticians, Researchers and other professionals within the NHS,

has withstood the test of time. This unique and privileged position also carries a great deal of responsibility from which we have never shrunk. We never guess answers.

We provide medically approved information booklets and fact sheets on nutrition and quality of life aspects for those who are treated for cancer of the oesophagus and latterly cancer of the stomach. We make no charge for supplying patients, their families and their medical teams with this printed information. We also provide a free newsletter twice a year which is distributed to medical teams around the country and to 3000 patients. Our website is simple, informative and is being used more and more frequently both here in the UK and around the world.

We support wholeheartedly the role of the clinical nurse specialists at treatment centres around the country and, where they are keen to form their own support groups for patients and their families, we are pleased to encourage them to do so and offer our resources and support if needed. We see our role as complementary to the local medical teams, and our main concern is that all new patients are told that there is support available, do not feel isolated and have access to good information and support as soon as they need it. All patients who register with our Association are automatically invited (and most welcome to attend) any regional meetings we may organise in addition to their local support groups which may be organised by their own specialist nurses.

The vision we had over 22 years ago remains as valid as ever. On behalf of all of the Oesophageal Patients Assoc, I wish 'GUTSY' every success and

look forward to working together to improve the quality of support for patients and their families in the Wrexham and Chester cancer network region.

MY STORY

It started for us in July 2006 after a fantastic holiday in the Caribbean, my gorgeous Husband who appeared to be perfectly well apart from indigestion which he had suffered with ever since I have known him, some twenty years. Nothing seemed amiss which is the scary part of all this. We had decided it would be appropriate for him to have

another check up after a long time on medication for his indigestion, better safe than sorry never a truer saying, although we had no idea what was to come. To our shock and horror my Husband was diagnosed with oesophageal cancer, we felt numb. The thought of a three month wait while they did a staging process was unimaginable, but time waits for no man and after several scans and lots of stress later we were told it was operable.

It started with chemotherapy in August and September, for the first time ever I saw my Husband being violently ill. I was broken seeing him like this but he needed my strength to get him through this first stage of the treatment so I never dared to show him my weakness.

I would not allow him to have any contact with people even close family members when he was at his most vulnerable. I was terrified he would catch some sort of bug that his body could not cope with. I was like someone possessed in keeping him safe and well. I even refused to kiss him on the lips

just in case, much to his annoyance!

It is amazing how careless people are with hygiene, Coughs and colds, but when you are in this situation you are much more aware of it.

CHEMO as people call it sometimes off the cuff is not something to accept lightly, you do not need any further complications that can be avoided with a little more care. We took his temperature every day and I watched him like a hawk, I was on high alert every second of my life, as he is my life.

I felt as if I was on another planet most of the time I had to keep telling myself that my gorgeous man has Cancer and might die. I found it very difficult to say the word let alone think of the operation that was to follow.

Three long and difficult months after hearing the diagnosis our time had arrived, 25th October 2006, operation day, it's a very strange feeling because its something you want but at the same time dreading it. We were one of the lucky ones who are offered this option, and we must remember those who aren't. I keep having to tell myself what's the alternative.

It feels surreal as my man is still eating well and looking good I have to remind myself that he has got Cancer.

I had made a joke to our fantastic surgeon not to do anything hazardous like riding his bike that could delay this op. By this stage in the proceedings this is the man I am putting every ounce of my faith and trust in, no one else will do. On the evening before the op fate struck, our surgeon had flu and would be unable to

perform surgery the next day. However he rearranged it for the following week . We knew this was the right thing to do under the circumstances and I did my best to calm my husband. But that night for the first and only time in my life I thought I was having a heart attack with the build up of stress.

The day my darling husband was taken to surgery we looked at each other in the corridor outside the theatre and both thought this might be the last time we would ever see each other again in this world, the pain in your heart is indescribable. I was empty and numb, I went home and did something very strange I cleaned all my kitchen cupboards from top to bottom thinking all the time about our wonderful life together from the moment we met to.....I had to put all my trust in the wonderful professionals to take care of him, the most precious thing in my life and that's what I did.

I had prepared myself for seeing my husband after the op. my two strong handsome stepsons who had been with us every step of the way always giving us a positive on the situation had kept telling me to be strong you know what to expect don't fold .I didn't. I saw him first he looked poorly, then the boys, I wasn't expecting their reaction . They were crying after seeing there lovely dad in intensive care why him? It broke my heart. I stayed the night in a visitor's room, nothing could have stopped me, I needed to be close.

We saw each other at five am in the morning it was sheer bliss to speak to him and see him looking a little better. We new this was not going to be plain sailing but you have to

stay strong and positive He was in hospital for about two weeks and yes there were some complications along the way and we had to deal with them as and when they occurred, and put our trust in the Upper GI Team.

The day he came home my work started, you seem to be fighting every day to keep him going just to do normal tasks that we take for granted but I had already told myself this is what I have to do. And do it I will.

Six months later. Yes he did lose a lot of weight, more than we thought.

Yes he does have some digestive problems but we hope this is temporary.

Yes he is eating really well.

Yes he did go back to work in at the end of January 2007 for three days per week.

Yes he did start playing 18 holes of golf every week in from March 2007.

And yes we will be forever grateful to the professionals in the Upper GI Team at the Countess of Chester Hospital and the OPA.

GUTSY is going to be our support network and we hope it can be yours.

We will support there journey as they have supported ours.

We have joined the lottery of life, but we are in it together, we have had a very difficult and emotional journey, and feel that our bad luck became good, and that is what we focus on to stay positive.

Good luck.

AIRBUS TO ADOPT GUTSY

Below is a poster we would like to draw your attention to. Endorsed by MacMillan Cancer Support, the workforce at nearby Airbus UK at Broughton have a team and volunteers willing to help us.

As indicated below, resources are at our disposal to help with a wide variety of gardening and outside DIY opportunities. The Airbus team have completed 42 projects in the Chester area and are keen and anxious to make an even bigger impact in the months ahead. The support network is growing from strength to strength and Airbus are keen to make an impact in particular in the Wrexham area where many of their workforce live.

HELPING HANDS FOR GUTSY GROUP

MACMILLAN. CANCER SUPPORT

Yes, we really want to encourage you to enlist for help and support from the Airbus Charity Challenge scheme. For the next 12 months, we have been offered help and assistance by the workforce at Airbus UK at Broughton. If you answer yes to any of the following questions then it could well turn out to be your lucky day. Airbus are offering their services free of charge to help you with a wide range of activities.

- Have you any simple DIY which needs addressing ?
- Suffered any storm damage, any of those panel fences which might need repairing?
- How are those large conifers - ready for a trim yet ?
- Is your garden looking tired after the winter, how about a makeover ?
- Do you need any help with your shopping ?
- Are any of your family ready for a little treat or trip out.

TO FIND OUT MORE DETAILS AND REGISTER KINDLY INFORM A MEMBER OF OUR STAFF AND THEN CALL PHIL JONES ON 07710-339-173

Chairman of the AIRBUS UK

charity challenge

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