



GUTSY GROUP

Articles:

- Cancer services in N Wales - a perspective
- CT and MRI scans
- Answers to your questions
- HELPLINE
- Information sources
- News from Wrexham
- News from Worcester

The patients, surgeons, dieticians and medical team look forward to welcoming you to our meetings

Next meetings:

**Rossett Hall Hotel, Rossett
Wed 4 December, 2-4pm**

**Fownes Hotel, Worcester
Thurs 6 Feb, 10 -12pm**



Cancer services in North Wales

Notes from a talk by Dr Matt Makin, Chief of Staff, North Wales Cancer Service, Betsi Cadwaladr University Health Board, at a recent GUTSY meeting

Introducing the meeting, Matt made the point that the GUTSY group, along with other patient groups, has been incredibly powerful in influencing the way cancer services are provided. Alongside the North Wales Cancer patient forum a new website has been launched called NorthWalesCancerforum.co.uk which will have all the patient resources and information for the N Wales area.

'Cancer is a good news story' because, although the incidence is increasing, people are living longer with cancer. Survival rates have increased significantly and because of these two factors, more resources are needed.

The NHS in the UK is changing rapidly, the overall philosophy in North Wales is to bring together public health, GPs and hospital specialists, give them the budget and then ask the clinicians to lead the planning of the health services.

In England there is split between the group of people who provide the services and those who commission them. Clinical commissioning groups (run by GPs) will decide how the budget is spent.

There are significant challenges: There is an increased burden of illness because of an increasingly elderly population - therefore there are more people with cancer and we are getting better at treating it - so more patients are living longer.

There are changes in technologies and changes in surgery. The North Wales area took delivery of probably the most advanced radiotherapy machine in the country - a Varian Trubeam linear accelerator. It is able to treat patients with radiotherapy in 4 dimensions thereby accurately targeting the tumour (It is being commissioned at the N Wales Cancer treatment centre at Glan Clwyd Hospital).

Cancer patients are surviving longer. Today it is possible to ensure a normal life span even with the disease. We need to understand the genetics of cancer cells. Chemotherapy is non-specific - new techniques are appearing all the time which target particular cancer cells.

There has been no increase in the budget for the last three years but nevertheless there is a need to provide better services. This has been done by looking at where the money is best spent to give the best results, particularly to prevent cancer in the first instance or pick it up at a very early stage. Early diagnosis is very cost effective!

We need to make sure patients will benefit from treatment. Increasingly PET-CT scans (see following article) are being used to check that the operation is likely to be successful and that no other tumours exist.

We need to make sure tumour reducing drugs will work, ie use the newer tumour specific drugs (this means prior to treatment we need to biopsy tumours or detect specific blood tumour markers).

Early diagnosis, personalised treatment, minimally invasive treatment are the trends we are seeing.

We need to consider what can be done to help after treatment and are increasingly moving in this direction. An end of treatment summary is sent to GPs but then we need to offer the opportunity for patients to come together and meet experts in a variety of settings to enable them to gather information for their future. After treatment, patients are left with all sorts of visible and invisible scars. Patients may feel anxious, depressed, may suffer from poor sleep, may worry a lot. Medics are not very good at asking about these problems. We need to give the patient the opportunity to talk about these things.

Health and well-being events are being planned to offer the opportunity to talk to pharmacists, dieticians etc. There is a project being set up called 'diagnose quickly, follow up safely'. The key is to get GPs and district nurses involved in post cancer research. The goal is to improve survival, improve quality of life and improve the experience the patient has during treatment - all done under cost control.

The Welsh vs English cancer care system presented a particular difficulty centred around the English cancer drugs fund where extra funds are offered by government for treatment which hasn't been approved by organisations like NICE. This fund is not available in Wales, so a patient could get a very new drug if living in England but not in Wales. There is a system available in Wales called the 'Patients individual funding request' for recourse to specialist drugs (See cancer network site). This can be done through the oncologist for exceptional cases.

Into the future particular treatments would be located at specialised centres.

Many thanks to Dr Makin for an interesting and concise round-up of cancer treatment in N Wales



PET-CT scans



*GUTSY volunteers with
cons surgeon Mr Pye*

WHAT IS PET-CT

18 F-florodeoxyglucose Positron emission tomography combined with computed tomography (18FDG PET-CT). Wow, what a mouthful that is, hence we shorten it to simply PET-CT. This test uses radioactively labelled glucose (18FDG) which will concentrate in metabolically active tissue, shall I translate? Once you have starved for 6 hours the cells in your body become hungry, the more active or busy the cells, the hungrier they are. Cancer cells are very active and take up a lot of the radioactive glucose. This can be seen when you are scanned with the PET-CT.

DO OTHER CELLS TAKE UP THE GLUCOSE?

Yes, any cells that are particularly active, such as if you have an infection. For example it is not uncommon to see that your tonsils absorb the glucose if you have a throat infection. Organs such as your heart and your kidneys also absorb the glucose.



*"A strong positive
mental attitude
will create more
miracles than any
wonder drug"*

Patricia Neal

WHEN IS THE TEST DONE?

This test is usually done after you have had a CT scan. If the CT doesn't show any evidence that the cancer has spread away from your gullet, you will then go on to have a PET-CT this is used to 'double check' there is no spread. You also have a PET-CT after you have completed your chemotherapy; this allows the doctors to check if and how well the cancer has responded to chemotherapy.

WHY DO I NEED TO HAVE A CT AND PET-CT?

An oesophagectomy is a very big operation; in fact, it is one of the biggest operations that we do. This means that we have to be very confident that this is the right treatment for you. Any test or scan that helps the doctors to make that decision is invaluable. NICE agreed to the use of PET-CT back in 2005 as it was shown to be more sensitive at detecting cancer cells than CT alone. So why you may ask do we not just do PET-CT: cost, plain and simple. A PET-CT is an expensive test and it is therefore only usually carried out for people for whom we think surgery is the right treatment.



*PET-CT
scan*

Thanks to Lizzy at Worcester for this info

Patients' questions and answers



Q: *3 years since op and still suffering badly from diarrhoea.*

A: Bowel changes are a common thing and could be permanent. One of the things we do during the operation is to divide the nerves which are quite important for the function of the bowel because both nerves run alongside the oesophagus and then come out across the stomach so, in a total gastrectomy or oesophagectomy, that nerve will be divided. And so, yes, for some people, having divided that nerve, the bowel doesn't work quite as it should do and it can be troublesome. Usually it will settle down for the majority of people either on its own or with the help of diarrhoea stopping imodium or other sorts of bulking preparations. It's unfortunate that, for a few people, it doesn't appear to work. After three years we would expect the problem to remain permanent I'm afraid.

Patient's perspective: As a scientist I observe everything that goes on with me all of the time and I do have a problem with diet. Everything will seem to be working happily for a while and then suddenly everything seems to fall apart and I don't know why that is. Once I thought it was bread so I stopped taking bread and everything settled down and then completely out of the blue all hell breaks loose again and it's impossible to predict what the cause might be. People blame different things, some think milk, I've noticed it can happen if something gets me up tight similar to some sort of inflammatory bowel condition. I've not detected any sort of pattern and I think it's just a problem you have to live with as long as you don't lose too much weight because of it

Q: *Op on Feb 5 - 2 weeks in hosp. 17 weeks since op. Gets severe pain after every tea time. Does anybody else get it. I was told it was nerves cut.*

A: We don't always have the answers but pain is related to severity of the thoracotomy. Also you can get referred pain due to stretching of the stomach. If you suffer from pain get it reviewed by speaking to your specialist upper GI nurse

A: It sounds like typical thoracotomy pain. You can get a small neuroma (thickening) that forms on the end of the nerve. Nerves behave a little like electric wires, and when cut, the nerves sort of fizzle with electrical impulses which reach the spinal cord which interprets it as pain. Neuralgia is typically worse in the evening or night. Pain patches can be useful - and also instant cold packs which distract the nervous system from the pain if you stick them over the painful area. There are other drugs which are sometimes considered by pain specialists such as gabapentin which suppress the nerve's activity. Speak to your specialist nurse

Q: *I've lost about 2 stone*

A: It is normal to lose weight. Although you usually stop losing weight after about 2 months. You should put some back on but you are unlikely to return to your original weight.

Questions and answers were from the June meeting in Wrexham with the surgeon and palliative care consultant supplying answers.



What foods can I eat?



GUTSY GROUP



GUTSY help-line

Having or recovering from surgery for oesophageal or stomach cancer?

Call the GUTSY help-line now and speak directly to a patient who has had treatment and/or surgery.



0800 707 6907
(Freephone)

**Patient support
helpline
0800 707 6907**

About GUTSY...

We are a support group for people diagnosed with or recovering from oesophageal and gastric cancers along with their friends and family.

The aim of the group is to provide support and information and to share our experiences

with anyone visiting the website or attending our meetings.

We hold meetings four times a year and provide telephone and email support continuously.

We're on the Web!

Find us at:

www.gutsy-group.org.uk

Useful sources of information

Macmillan Cancer Support
Tel. 0808 808 0000 www.Macmillan.org.uk

Oesophageal Patients Association
Tel. 0121 704 9860 www.opa.org.uk

Cancer Research UK
www.cancerresearchuk.org

North Wales Cancer Network Patient forum
<http://northwalescancerforum.co.uk>

North Wales Cancer Service
Search using Google

FORT (fighting oesophageal reflux together)
www.refluxhelp.org

Financial and holiday insurance advice
www.moneyadviceservice.org.uk

NHS Direct
Tel 111
www.nhsdirect.nhs.uk/

NHS direct (Wales)
Tel 0845 4647
www.nhsdirect.wales.nhs.uk/

Acknowledgements: Thanks to Macmillan Cancer Support for their help in funding and setting up the help-line

NEWS from Wrexham

The GUTSY group (Wrexham)

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**Patient support
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September meeting

Held in Rossett Community Centre. The meeting comprised the usual question and answer session hosted by Upper GI surgeon, Mr Duncan Stewart followed by a group discussion session where the meeting worked out questions and topics they would like to see at future meetings. Hence the next meeting is to concentrate on food, diet and weight gain.

Many thanks to Linda Valance whose fantastic cakes raised £36 for the GUTSY funds at the last meeting. Funding for the group relies entirely on voluntary donations and the GUTSY helpline thrives on a grant received from Macmillan.

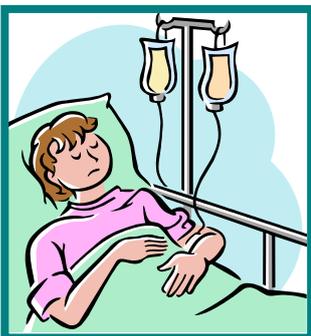


GUTSY meetings are usually held in the pleasant surroundings of Rossett Hall Hotel.

The hotel is on the B5445, 6 miles south of Chester and 6 miles north of Wrexham

Next meeting: Wed 4 December, 2pm to 4pm

Contacts (N Wales)



*What will my
operation be like?*

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Upper GI nurse specialist
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GUTSY volunteer
E: brian@gutsy-group.org.uk

Macmillan Shooting Star Information Centre
E: macmillan.shootingstar@wales.nhs.uk

Macmillan Centre, Countess of Chester
E: elizabeth.taylor18@nhs.net

Service user team (General enquiries)
E: diane.henderson@wales.nhs.uk



GUTSY GROUP

The GUTSY group (Worcester)

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NEWS from Worcester

Radio interview on 24/9/13

Consultant surgeon, Mr Martin Wadley and Cynthia Dunsby were interviewed on BBC Radio Worcester. This was aimed at raising awareness of oesophageal cancer. The signs and symptoms were discussed together with the difficulties diagnosing this early. Cynthia also discussed the symptoms she had presented with and went on to talk about the surgery and life after an oesophagectomy. The newly founded GUTSY support group was also mentioned and Cynthia highlighted the support and benefit she gained from these meetings.

GUTSY Worcester are having a Christmas party and meal. This will be held at Ombersley Memorial Hall on 5 December 7 - 10 pm. Mr Wadley, Dr Candish and Lizzy will be there. Local GPs who have been involved with patient's care will also be invited, together with a representative from Macmillan. The local press will be covering the event. Music will be provided by Classical Twist. The whole event hopes to start the Christmas festivities and to say thank you to those involved with supporting the patients and their families.

Lizzy had a meeting with Worcester Lions Club who have kindly offered their support to the GUTSY group.

Sarah Robinson, daughter of Bernard Robinson, who had an oesophagectomy under the care of Mr Wadley, ran the Birmingham half marathon on Sunday 20 October and raised a staggering £2,000 for the Worcester Gutsy support Group.

The cake sale on Thursday 8th August raised £76.

GUTSY meetings Worcester



GUTSY meetings are held in the Fownes Hotel, City Walls Road, Worcester, WR1 2AP

Next Worcester meeting: Thurs 6 February 2014, 10am - 12pm

Worcester contacts

Lizzy Pearce, Upper G I Clinical Nurse Specialist
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Kay Tandy, Macmillan cancer information centre
01905 733837/mob 079180133068 Email: Kay.tandy@worcsacute.nhs.uk



Some other support groups in the UK

OOSO (Oxfordshire Oesophageal and Stomach Organisation) - patients help group similar to GUTSY
www.ooso.org.uk

Oesophagoose - NE UK support group
www.oesophagoose.org/

Humberstone oesophageal support group
www.hosg.org

