GUTSY Newsletter

Issue 4 – North Wales and West Cheshire October 2009

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.

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!

- **"Easing shoulder pain after your operation" by Beth Davies, physiotherapist**

Following an oesophagectomy many patients experience shoulder pain. Much of this pain is caused by the position you are in during the operation for a prolonged period of time. In addition to this, due to the wounds and chest drains you may be reluctant to move the arm on the operated side which may cause it to become stiff and painful.

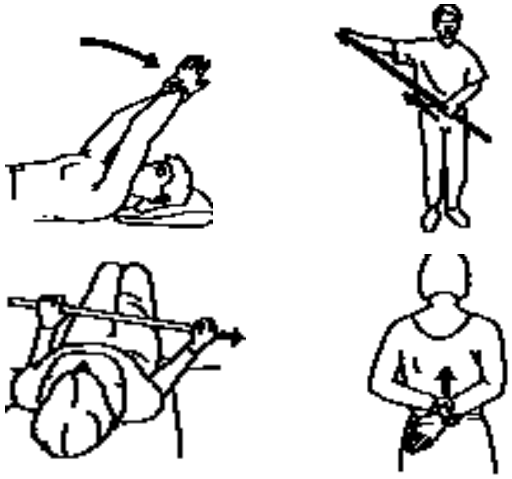
There are several things that can be done to help ease your shoulder pain:

Exercise

First and foremost, exercises should be done to ease shoulder pain after the operation and can be ongoing. Exercises should be done up to the point where you start to feel a stretch or pain. Do not push through pain or overstretch. These exercises should be done little and often.

1) Pendular exercises – these should be done if your shoulder is stiff and painful to move.

2) Active-assisted exercises – these are done to regain range of movement once the pain is better controlled. These are done with the help of the unaffected arm.



Ice and heat

If there is pain and heat around the joint, you may find it useful to use an ice pack to reduce the heat and inflammation and therefore reduce the pain. Leave this on for 10-15 mins 3-4 times per day. If however the main problem is pain and stiff, you may find it useful to use a heat pack such as a hot water bottle or wheat pack on the joint. This helps to relax and loosen the tissues and stimulates blood flow to the area. The heat should be used for about 20 minutes and should never be used if sensation is poor as there is a risk of burns.

Painkillers

Simple painkillers or anti-inflammatory tablets and creams which you can buy at the chemist's can be helpful, but you should not use them for more than 2 weeks without seeking medical advice. Please also keep your surgical specialist nurse aware of any concerns.

Posture
Check your posture. It can be tempting to sit leaning forwards with the arm held tightly by your side. This position can make the problem worse, especially if some of the pain is coming from your neck. When sitting, try to keep a pillow or cushion behind your lower back, with your arm supported on a cushion on your lap. Some people find that placing a cushion or rolled towel under the armpit and gently squeezing onto it can ease the pain.

If your shoulder is painful to lie on, try the following positions to reduce the discomfort:

- Lie on your good side with a pillow under your neck. Use a folded pillow to support your painful arm in front of your body. Another pillow behind your back can stop you rolling back onto your painful side.
- If you prefer to sleep on your back, use one or two pillows under your painful arm to support it off the bed.

- **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), 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.

Mr Pye was joined by Dr Gollins, Consultant Oncologist at Glan Clwyd Hospital. Dr Gollins stated that whilst there are standardised treatments based on best practice and clinical evidence, there is no such thing as a 'standard patient' and that each person's treatment and management plan is discussed by your multi-disciplinary team. So, the administering of chemotherapy varies from person to person.

Q: ***After effects of chemotherapy – why do I suffer from tingling toes?***

A: Nerve damage can be a side effect of some chemotherapy drugs; this is called peripheral neuropathy. It usually starts with pins and needles in the fingers or toes, there may be some numbness which is progressive, rather than instant. The nerve damage is not usually permanent although it can be and is thus important to tell your nurse or doctor if you are experiencing this symptom. It normally gets better slowly with time, after the course of treatment has finished. Other parts of the body can be affected too. You should tell your chemotherapy team if you have problems, especially during treatment so the dose can be reduced as appropriate

Q: ***My hearing has gone in my right ear and is distorted in the left, is this due to nerve damage?***
A: Chemotherapy can occasionally cause a degree of high-tone hearing loss which can be progressive with increasing numbers of cycles.

This can be permanent and it is thus important to tell your chemotherapy doctor or nurse if you experiencing a deterioration in your heaing whilst on chemotherapy.

Q: What about other side effects such as tiredness, mouth ulcers and feeling sick?
A: Most side effects are temporary and patients are given information about the most common ones. Patients are individuals and react in different ways, so you should discuss any concerns with the chemotherapy team. Contact details are always reinforced for out of hours help and advice for each hospital within North Wales and those treated from Chester at Clatterbridge. The nurse administering the chemotherapy will be talking to you about how you are feeling, extent of symptoms and how best to manage them to ensure you are able to cope.

Q: ***Why are some patients given chemotherapy before and after surgery?***
A: The chemotherapy given is based on 'gold standard evidence' following rigorous clinical trials and varies on the type of cancer the patient has, and the patients' general state of health. In relation to oesophageal and stomach cancer, recent evidence has shown that overall having chemotherapy drug treatment before surgery can improve your overall outcome of the

surgery. This will be discussed with you by your local team and a referral made for you to see the oncologist. Two or three, three-weekly cycles of chemotherapy are normally given before surgery. Following major surgery further chemotherapy is sometimes recommended but not always possible to deliver because you are still in the early stages of recovering and not up to this treatment. Whilst there are standardised treatments based on best practice and clinical evidence, there is no such thing as a 'standard patient' and each person's treatment plan is discussed by a multi-disciplinary team.

Q. ***Why give radiotherapy after the operation as well as chemotherapy before?***
A: It is unusual for a patient to be given radiotherapy after surgery. This approach is more commonly used in the USA but can be quite toxic for patients to tolerate and is thus not often used in the UK. Some minority cancers avoid surgery and only have radiotherapy, or chemotherapy combined with radiotherapy.

Q: ***I had radiotherapy about 4 months ago and still feel tired; does this wear off after a time?***
A: Tiredness can occur after radiotherapy but it would be unusual for this to be the cause of tiredness four months after treatment. This is where your GP plays a key role in supporting you in the community. Following completion of treatment you are normally reviewed by your Oncology team

Q: ***How long does radiotherapy relieve the pain for?***
A: This varies from patient to patient. Some patients will benefit greatly in terms of improvement of pain but others less so or not at all. It is impossible to predict for an individual patient how well their symptoms will respond to chemotherapy. Keep in touch with your specialist nurse and GP who have access colleagues who specialise in pain control and other symptoms if they need advice.

Q: ***Four weeks into the chemotherapy I had an embolism, could this be from the chemo?***
A: Having cancer does make the blood more prone to clotting and this is the most likely cause of the embolism. Blood thinning injections such as Clexane, given daily for a period of time would be used to treat the embolism.

Q: ***I feel like I have a ridge in my windpipe where food lodges on scar tissue, I try and force it down but this causes coughing.***
A: If the problem is food sitting in your gullet then you may need a scope examination of this repair. How food goes down is complicated and if the food spills into the airway this will cause coughing.

Q: ***I had cancerous cells in the lymph nodes and had some which might recur elsewhere. Why is this not monitored?***
A. The monitoring of patients following cancer depends on which cancer is being monitored because they all show different characteristics. Some produce molecules in the blood called tumour markers that can be monitored. Some show characteristic changes on x-rays at an early stage of recurrence of the disease. There is little evidence from trials that doing additional scans in the absence of new symptoms increases the outcome for patients. For this reason the follow up is on a clinical basis. If new symptoms appear then they should be investigated. If no new symptoms appear then doing scans just for the sake of it does not provide any new information. Monitoring of symptoms is the key.

Q: ***How significant are the lymph nodes?***
A: Lymph nodes are positioned throughout the body in defined locations. They protect the body from infections as well as cancers. Because cancers will sometimes spread to lymph nodes, lymph nodes have been used as a method to determine how far the cancer has spread. Lymph nodes have a defined catchment area, in other words, if you have a problem in the mouth or throat they will drain into the lymph nodes in the neck. If you have a problem in the foot it will drain to the lymph nodes in the groin. With oesophageal and gastric cancer the pattern of spread from the different locations has been worked out and we use this map to determine whether a disease is at a stage that can be curable or whether it is at a stage that is incurable. If the cancer is contained within the lymph nodes next to the oesophagus or the stomach then there is a chance of a possible cure if the cancer and all the lymph nodes are removed at operation. This is why we use lymph nodes as one of the indicators to tell us how best to treat each individual cancer. If lymph nodes are involved then this may put some people at a higher risk of the cancer coming back

Q: ***What job do the lymph nodes do?***
A: The lymph nodes defend the body against infection. They are also useful as a pathway to remove debris from the tissues. An example of this is the carbon present in smoke, either in cigarette smoke or industrial smoke. Carbon cannot be digested by the body and is collected by specialised cells which will then store the carbon in the lymph nodes in the lung.

Q: ***Are the lymph glands connected?***
A: Yes, the lymph glands are connected, but there is a defined pathway that either cancer cells or infection will follow. There is a chain of lymph nodes down the centre of the body with smaller groups of lymph nodes more widely spread. The groups of lymph nodes are inter-related and can connect through a central pathway.

Q: ***I was sent for a PET CT scan before the op which can pick out cancer cells, is this the way forward to diagnose?***
A: PET scans detect activity of cells using special glucose injections. Activity can relate to infection as well as cancer so on occasion there can be false positive results. We know that in terms of being helpful that PET scans work very well for staging oesophageal cancer, but they have proved to be more disappointing with stomach cancer so we only ask people to have a PET scan as a routine with oesophagus cancer, and do not usually arrange a PET scan for patients with stomach cancer. The PET scans are done in Manchester. They used to be done in Cheltenham, but now that Manchester can provide a good service it is clearly much easier for travel to stay nearer home. There are very few PET scanners in the country which is why people have to travel to the nearest one.

Q: ***Before my cancer was diagnosed I had a persistent cough; I saw four GPs, three of whom were locums, who gave me cough medicine. I was eventually referred to the Maelor for investigations; should there be more awareness of the symptoms of oesophageal cancers for GPs?***
A: Awareness is important. GPs see so many different presentations of an illness and sometimes it is not easy to put all the bits together to reach a diagnosis. However keep persistent in contacting your GP for ongoing medical review.

- **General News**

GUTSY Website under construction: the Steering Group are currently looking at setting up a website for GUTSY which will include a Question & Answer section. Brian Lewin, GUTSY member, has volunteered to keep the site updated the web-address is:
http://www.gutsy-group.org.uk/

- **Adjusting to Life after Cancer Treatment**

At the end of treatment people expect to feel relieved and able to get on with normal life again. Yet, can be shocked to find that they feel low in mood and physically tired. Relatives and friends may have similar feelings 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 include: www.be.macmillan.org.uk or telephone 0800 8080 00 00 for the booklet: *'Life after cancer treatment'*

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: Telephone: 01978-298258

Pam Wedley, Macmillan Cancer Information & Resource Facilitator, Wrexham 01978-726188
Macmillan.shottingstar@wales.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**