OESOPHAGEAL PATIENTS ASSOCIATION
Oesophageal And Gastric Cancer Support
Registered Charity No 1062461

Leeds Regional Branch

A critical analysis of the operation of the oesophageal/gullet cancer surgical pathway of Leeds Teaching Hospital by patients and their carers

Introduction

At the meeting of the Leeds Branch of the Oesophageal Patients Association (OPA) held on 17 January, 2015 Mr Jeremy Hayden, consultant upper GI surgeon at Leeds Teaching Hospital (TH) made a presentation on recent developments in oesophageal/gullet (OG) cancer. During the course of his presentation he outlined and explained the current Leeds TH OG cancer surgical pathway and the changes proposed. In subsequent discussions, it was proposed that members of the OPA Leeds Branch should, at their next meeting on 18 April 2015, critically analyse the surgical pathway in the light of their experiences as patients and carers.

In preparation for the meeting of 18 April, John Taylor (Chair) and Margaret Nickels (Vice Chair) met with Mr Jeremy Hayden and Sharon Huntley, upper GI specialist nurse on 30 March 2015.

It was agreed that there should be an opportunity for members to reflect on the strengths of the surgical pathway they experienced and to express their views on how the experience might be improved. There were also preliminary reflections concerning post operative pain relief, communications with partners of the patient during the course of and immediately after surgery, meeting the consultant surgeon immediately prior to surgery and the timing of the signing of the consent form.

It was agreed that a report of the discussions would be forwarded to Mr Hayden when the exercise was completed.

Process

Fourteen members attended the meeting of the OPA Leeds Regional Branch on 18 April and were invited to work individually and to identify on individual “post-its” their experiences of the surgical pathway that were particularly impressive and those they felt could be improved. Different coloured post-its were used by carers and patients so that the experiences could be distinguished. The content of the post-its was explained by the contributor and members were invited to vote for the experiences they considered most pertinent.

At the meeting eleven contributors were patients and three were carers. Of the patients, nine operations occurred at St James's and two at the Nuffield. Two initial diagnoses occurred outside Leeds one in York and the other in Surrey. Seven of the operations occurred within the last five years and two occurred over ten years ago.

Observations

Commendable

1. **Speed of progress through referral and pre-operative stages**

   Many referred to the speed at their initial referral from their General Practitioner (GP) for an endoscopy and the subsequent speed in arranging the tests necessary and the explanation of their relevance

   "Speed with which GP referred me for an endoscopy...saved my life!"
   "Tests carried out quickly + all explained."
   "I was amazed at the speed of which my treatment began after being diagnosed."

   The liaison between York District Hospital and Leeds TH was praised as was the flexibility of Leeds TH in responding to a referral from Surrey. The pre-operative work at York District Hospital was considered "faultless".

2. **Accessibility to and the positivity of surgeon**

   The positive approach of the consultants was applauded by patients and carers and they were considered accessible and easy to approach. Consultants were thorough in explaining each procedure and were neither patronising nor pompous.

   "Approachability/Level of surgeon – not pompous… treated as equal not looked down on."
   "Easy access to the consultant once the hospital process began."
   "Never patronized – always given good info."
   "Consultant and GI nurse taking me through each procedure thoroughly."
   "My surgeon gave me and my family such positive thoughts from the outset. I can only describe St James's as 5 star treatment."
   "Surgeon was very positive and even used the word CURE!"
   "If anything worries you; call us."
   "Explaining the process to myself and family."

"Honesty at all points of my husband's treatment."
"Clear explanations of what was to come in a language we understood."

3. **Pain relief management**

Patients and carers considered staff were reassuring about pain management prior to surgery and effectively managed it following the operation.

"Reassurances about pain management – "it will be uncomfortable but it will not hurt. We can manage pain."
"Pain management post op from the nursing staff was excellent."

4. **Teamwork**

All members were impressed and thankful for the sense of teamwork they observed throughout the surgical pathway. The team diagnosis and preparation of treatment plan aided by leading edge equipment, the care, attention, support and positivism of chemo, High Dependency Unit (HDU) , Upper GI specialists and ward nursing staff were all applauded.

"Feeling safe in the care of a complete team of medical professionals."
"After operation when moved to ward, nursing very good. I have been made to feel all through my treatment that I was important and my feelings mattered."
"Upper GI nurse was as caring for my carer as for myself."
"Kindness from medical and non medical staff."
"Courtesy/Professionalism/Respect in general treatment eg MRI/CT."
"Empathy/Understanding."
"Sense of humour/chirpiness of nurses."
"Facilities/cleanliness/cleaner wiping down blinds."
"Junior doctors very helpful."
"Once on curative path; positive approach from staff."
"The encouragement of optimism in the hospital."
"Amazing care in hospital – even as far as creaming my dry skin."
"Kind offers of alternative foods after the op. eg yoghurts/ice cream."
"Designated Upper GI nurses."
"Having been in Intensive Care."
"My Upper GI nurse was as caring for my wife as she was for me."
"Everyone was caring including the upper GI nurse who rang me up at home to ask how I was after spending 5 weeks in hospital."
"As a carer, able to talk to staff when feeling low."
"The care, love and devotion given to my husband and myself."

"Even dark days there was always fun and humour."

Potential for Improvements

The major focus of discussion related to the impact of patient confidentiality on carers, quality of food and nutritional advice, follow up after discharge from hospital and the epidural procedure.

1. **Patient confidentiality and carers**

   There was much discussion and sympathy for the circumstances of the carer at the time of initial diagnosis, treatment, surgery and post operative recovery. Members recognize the importance of patient confidentiality and the associated legal framework. However, there was a consensus that at times carers were needlessly anxious and ill informed regarding the progress of their partner because their role to receive information had not been clarified from the outset. Members felt there should be greater pro-activity in seeking clarification at an early stage and as to what information can be provided to the carer about the patient's progress at the different stages of the surgical pathway.

   Members recognize that patient's curiosity regarding the nature of their disease, the procedures to be followed and the risks involved varies with the individual. However, we felt this is a matter that is worthy of further reflection by the professionals to see if there is a way forward that meets both the legal requirements, and the individual needs of the patient and the carer.

2. **Food and nutritional advice**

   There was major concern regarding the quality of food and the scale and nature of the nutritional advice available. The concerns regarding the quality of food were particularly important, not in terms of its epicurean delight but the significance of meeting nutritional requirements following the nature of the surgery and the associated nutritional implications including B12 in many cases.

   "Food – unappetizing, cold, would not enjoy even before operation."
   "Food very poor at St James's."
   "Post op food not related to the operation and the staff had no idea of the requirements at the LGI."
   "Food and nutritional advice poor."
   "Lack of dietary information."
   "In hospital dietary requirements not dealt with properly."
   "Dietary information was lacking."
   "Nutritionist's advice was too general and the attitude that 'you'll have to live with diarrhoea' was misleading"

3. **Epidural procedure**

A significant proportion of members encountered different problems with the epidural procedure including timing of insertion, nature of procedure and associated pain at insertion, unscheduled withdrawal and some considered there was a need for a better explanation of the anaesthetic procedures.

"Tried four times to insert whilst awake but couldn't do it and so it was done whilst I was under anesthetic."
"Epidural came out once back on ward leading to worry and stress."
"Epidural could not be put in whilst I was awake. Put in when under anaesthetic."

4. **Discharge from hospital and follow up**

A variety of problems were encountered during the course of the discharge from hospital and the subsequent follow up from the hospital and GPs.

"Wrong types of medicines given on discharge."
"Delay from Pharmacy that delayed leaving by some time."
"instruction re medication upon discharge not clear enough."
"Nausea after discharge from hospital. Not much help from GI nurses or doctors."
"More proactive follow up – including nursing support." "Cold feet/hands not followed up."
"Follow on treatment and having to repeat what treatments you have undergone for doctors – time wasted."
"Post op – GPs mostly unaware – only one at my practice understood."
"Found little understanding of implications of oesophagectomy implications when undergoing subsequent emergency surgery and follow up treatment eg need to lie flat and withdrawal of central line."
"Need to see actual surgeon – never seen since the op."
"I have to phone about follow up appointments as they do not always come through at the expected time."
"Follow up post op – 2-4 weeks immediately afterwards – what to do? Explanation needed."

5. **Other issues**

Pre-operative

Some explained the difficulty they felt in reaching a decision when offered the opportunity to participate in a trial and others felt they did not have enough information about all of the treatment options available when considering an oesophagectomy.

“Decision on chemotherapy – given a choice of trial – how do I know?”
“Not clear enough explanation of the options available before making decisions about operation etc.”

Intra-operative

Some incidental issues for carers and patients were raised regarding parking on the day and preparation on the morning of the operation.

“Parking - explain freely available for carers.”
“Waiting time on day of operation.” – “some significant delays experienced.”
“Is it possible to walk to the theatre rather than be pushed?”
“Pain from back (use of metal sleeve for back incision).”
“Better explanation of anesthetic procedure pre/post op.”

Post-operative

Individuals found certain procedures painful and staffing problematic.

“Removal of drains – painful.”
“Need to have continuity of specialist professional – not bowel doctor!!”
“Nursing Agency Staff.”

Next Step

A draft of the report was forwarded to Sharon Huntley to assist in a peer review process and was approved by members, without amendment, at the meeting of the Leeds Branch of the OPA on 27 June 2015.

Members enjoyed engaging in the critical analysis and will be pleased to produce further feedback in the future if this would be helpful.

John Taylor
On behalf of the Leeds Branch of the OPA