



OESOPHAGEAL PATIENTS ASSOCIATION

1985 - 2010

25 Years of Oesophageal and Gastric Cancer Support

Registered Charity No. 1062461

Issue 15 Autumn 2010

This publication is kindly sponsored by *Hampshire Press*



Above; Medical Tags; alerting the medical service or first aiders of a Gastrectomy or Oesophagectomy patients' special needs in the event of an emergency.

See PAGE 7 for details

* * * * *

Nutritional Supplement article on PAGE 3

Regional Branch Meeting information on PAGE 6

****ALSO ENCLOSED WITH THIS ISSUE****
CHRISTMAS CARDS 2010 ORDER FLYER!

OPA

Address:

22 Vulcan House
Vulcan Road
Solihull
West Midlands
B91 2JY

Telephone:

0121 704 9860
(9am - 3pm Mon - Fri)

Email:

enquiries@opa.org.uk

Website:

WWW.OPA.ORG.UK

Trustees:

David Kirby OBE
(Chairman)

Richard Martin
(Hon. Treasurer)

John Seston BA(Hons)
Sue Burson
Richard Steyn FRCS

Staff:

Dawn Williams
(Patient Support)

Mark Reynolds MInstF(Cert)
(Fundraiser/Administrator)

On the evening of 3rd August 2001, my wife Barbara and I were out with the family celebrating my parents 55th Wedding Anniversary. Barbara and I did not have much of an appetite and my daughter even wondered if we had had a disagreement. It could not have been further from the truth. Just three hours earlier a Doctor had said to me, "There is no easy way to tell you, - you have oesophageal cancer". I did not want anyone to know and spoil the occasion, especially not my daughter who was getting married in three weeks time (however, she prised the news out of me later).

The cancer had been discovered as a result of investigating another health problem and came at a time when I had never felt better; no symptoms, problems or any signs, although I had a bit of a clue, when after the recent gastroscopy, the Endoscopist shook my hand and said; "All the best for the future!"

I think you all know the roller coaster of events that followed: Surgeons, Oncologists, Nurse Specialists (etc, etc). Fortunately the tumour had been discovered fairly early on and there was no metastasis.

Thanks to the good offices of the excellent Mr. Super and Ivor Lewis at Heartlands Hospital in Birmingham I am still here to tell the tale (for those of you who are not familiar with the name Ivor Lewis, this is the clinical procedure introduced by the pioneering surgeon of that name in 1942).

My daughter's wedding went ahead as planned; it was a wonderful but emotional day. At 54 years of age I did not know what the future would hold. After the chemo' came the big day on 26th October for surgery.

There were many ups and downs in the days ahead, and I did not know whether I would ever be able to resume a working life again, but what I did know was that recovery takes place in the mind as well as the body.

With a strong will and determination, a strong Christian faith, good friends, four supportive children, and a devoted, patient and ever-loving wife, progress was made



Above, John & Barbara Seston

until I was back working a 60 hour week within a year, and have been more or less ever since.

It was in those early days after surgery that I first encountered David Kirby who visited me on the recovery ward and provided much appreciated advice and encouragement, and, from that time on, I discovered just how valuable a service the OPA provides both to patients and their carers.

When I had my surgery we had just one lovely 7 month old grandson. Now we have four beautiful grandchildren that I could never have contemplated and on the 27th June this year (2010) my wife Barbara and I celebrated our Ruby Wedding Anniversary. I am so blessed, but ever mindful that there are many travelling on the road I have travelled.

Wherever you are on that road I say keep going, remain positive and 'phone the OPA if you need help, advice or just a listening ear. Finally, may I applaud the many carers like my dear wife Barbara for all that loving care.

Carers are the real sufferers, sometimes feeling helpless, frustrated and desperate - but we only come through with your dedication and care.

Thank you.

Food for Thought; 10 Ways with Nutritional Supplements

If you have lost weight recently, are struggling to maintain or gain weight, have lost interest in food or are missing meals, it is important to eat nourishing foods. On discharge from hospital you may have been given food fortification advice to help maximise your nutritional intake. On occasion, additional nutrition may be required and the use of nutritional supplements could help with this.

Here are just a few ways that nutritional supplements can be included in the diet:

Scandishake, *Calshake* and *Enshake* are powdered energy drinks that can be mixed into a wide variety of meals. Try stirring an unflavoured sachet into soups or sauces. A vanilla flavoured sachet mixes well into porridge, custard and yoghurts without increasing the volume.



Ready-made milkshake supplements such as *Fortisip*, *Clinutren* and *Ensure* come in a wide variety of flavours and do not have to be taken straight from the bottle. Try warming a chocolate or coffee flavoured drink to take as a snack. Alternatively mixing a drink with some double cream and then freezing will make ice cream.

Maxijul is a super soluble calorie powder that dissolves to be tasteless. One tablespoon will mix into yoghurts, puddings, stewed fruit, mashed potato, soups and baked beans.

Juice based drinks such as *Fortijuice* and *Resource Fruit* can be made into jelly by mixing with jelly cubes or crystals and adding a little hot water.

Liquid supplements such as *Calogen* and *Procal Shot* are available in a variety of flavours. 30mls of the unflavoured variety can be added to any soft or liquid food such as soups, custard, mashed potato and milky drinks to boost calorie intake.

Pudding supplements such as *Fresubin Creme* and *Ensure Pudding* do not need refrigeration and can be carried around as a snack. Try serving them cold or warmed with fruit or ice cream for variety.



Polycal Liquid will mix well into drinks and can be sipped throughout the day.

All nutritional supplements are available on GP prescription and *Complan* has recently been added. *Complan* sachets are available in cereal, soup and milkshake varieties and make an easy snack meal.

Savoury supplements such as *Complan Savoury* and *Fortisip Savoury* are available for those who do not have a sweet tooth. Served with bread and butter they can make a nutritious meal when something quick and easy is required.

It is important to remember that nutritional supplements are changing all the time as new formulations and flavours come onto the market. If improvements in your diet have not helped you to maintain or gain weight then please ask your Dietician or GP about new and improved nutritional supplements for trial.

A wide range of nutritional supplements are available and should only be prescribed with professional advice.

Please discuss your own personal dietary needs with your GP or Dietician.



With grateful thanks to
Donna Williams, Senior Dietician
(formerly at Frimley Park Hospital
now at St Georges) for compiling
this article.



Autumn 2010

Another indulgent piece of nostalgia for the Association's 25th year; how it all started.

My surgeon, Mr (later Professor) Hugoe Matthews is a remarkable man. His pioneering operation has given me 30 years of very good quality life, for which I am of course eternally grateful. He also had a deep concern for his patients' wellbeing and wanted to be able to improve their treatment so that more would survive and be able to enjoy life. By chance, when I was recovering in hospital, he found me reading a book by a particular favourite author of his – I didn't know that he was an avid collector – and this link helped us to get on well together.

I offered to be helpful, if there was anything I could do when I had recovered, as we all tend to do, and three years later he took me up on this.

Hugoe was concerned that oesophageal cancer was regarded as a Cinderella subject. Surgery then was generally performed by thoracic surgeons, most of whom were more involved with lung surgery, and the cardiothoracic surgeons, dealing with the heart, got all the headlines. There was no research going on into any aspect of oesophageal cancer and Hugoe wanted to create an appeal to fund research into its treatment.

This would mean setting up a laboratory at Birmingham Heartlands Hospital and appointing a doctor of Registrar level to undertake a research project. A fundraising committee was to be set up and I was invited to join it. As a management consultant running my own business I had many contacts in various manufacturing fields and began writing to all the Managing Directors I knew asking them for support for this very worthy cause.

I also learned about grant making Trusts and Daphne spent all her spare time in our local library looking through the directory to get the names and addresses of suitable Trusts for us to contact.

A number of these responded favourably and I'm glad to say some of them are the ones supporting the Association now in response to Mark's appeals.

The Oesophageal Cancer Research Appeal (OCRA) was formally launched at a lunch at Birmingham Council House in July 1984 attended by the Lord Mayor, a local MP and many influential business people. Most importantly for me was meeting two other former oesophagectomy patients for the first time and finding such empathy with them.

When the OPA came into being in 1985 the three of us formed the committee, but at that time our main concern was raising money for OCRA.

Many people became involved;

The theatre nurses organised a fashion show given by Country Casuals;

A charity auction was held;

A dance took place in Solihull Civic Hall, attended by the Mayor and Mayoress and featuring a raffle of a Gold Disc donated by Duran Duran;

And a sponsored walk was held at Junction 2 of the (then unfinished) M42.

That was where I first met Stan Allen, a recent patient of Hugoe's and a keen athlete, who went on to run several marathons including London and the very tough Snowdon marathon.

The OCRA funds were sufficient for the first OCRA Fellow to be appointed in 1986 and laboratory staff were recruited. In charge of them was Dr Jane Darnton, a histopathologist who, although now retired, continues to keep us up to date with new research and who is involved with the training days for volunteers.

At Heartlands Hospital she worked alongside the OCRA doctors whose research was aimed at finding a chemotherapy cocktail which would benefit oesophageal cancer patients.

This enabled her to get to know those patients who were involved in the trials, who valued her concern for them and the fact that, like today's specialist nurses, she was always there when they came to the hospital. The OCRA Fellows were appointed for a year; most were surgeons but two were physicians who went on to become consultant gastroenterologists.

The post was a stepping stone for them that led to a successful career and we are still in touch with most of them. As most people know, preoperative chemotherapy is now standard treatment and we can be proud that Birmingham was involved from the start.

PATIENT EXPERIENCE

Margaret Brown of Norwich

My operation took place on 14th February 2008. I first received your Newsletter some time after that and have found the articles and letters very interesting and informative, especially those letters describing other peoples' experiences.

In 1961 at 19 years old I was diagnosed with a 'nervous stomach' and have had problems on and off ever since, so when in early 2007 I had difficulty swallowing (and found I had to chew food very well) I thought it was the above condition in a different form.

However during a meal out with a relative I choked, had to leave the table, and after coughing for some time brought up a large string of mucus. Some months later during a routine check up I mentioned this to my GP. A couple of weeks later it happened again, and two weeks after that I had coughing fits (bringing up more mucus) about nine times.

I saw my GP just days after that and explained all the symptoms and a description of where I felt there might be a blockage in my gullet. He arranged an appointment straight away at the Norfolk and Norwich Hospital for a gastroscopy which took place two weeks later. The doctor who carried out the procedure explained to my husband and I that there was a tumour (and an ulcer) and that a biopsy had been taken.

Ten days later we saw the doctor again and were told that I had squamous cell carcinoma of the oesophagus. About ten days after that I had the first CT scan. A few weeks later I had the first of two sessions of chemotherapy at the hospital over five days (each time).

After the second session of chemotherapy an appointment was made for me to see a consultant surgeon. The surgeon explained that although the tumour had been reduced, it was felt that surgery was a better option for me than radiotherapy.

I had the cancerous part of my oesophagus removed by Mr Van Tornout and his team at the Norfolk and Norwich University Hospital.

(Photos above centre).

After the operation it took quite a while to adjust to eating and drinking with a smaller stomach and coughing when my left lung fought for space when a full, though small, stomach pressed upon it.

With small meals eaten frequently it seemed that for many months my days were spent eating and then sitting quietly while my stomach gradually emptied! However, I gradually regained my strength and now am putting on weight again, mainly because I like fattening foods!

In April 2008 the results of the biopsy indicated that the cancer cells were contained in the tumour (and had not spread to any lymph glands) which was great news; the cancer had been in very early Stage 1. Throughout I found everyone involved

most helpful, kind, understanding and always prepared to answer questions even if it meant repeating something they had already told me.

The care on the wards was very good and it was also comforting to know that I could 'phone the hospital ward or Rod

White (the co-ordinator of the OPA Norfolk branch) any time.

I do have one tip for ladies with medium sized or larger busts; there are bras available that are not under-wired but still give good support (Marks & Spencer have a good range).

I found that once I had a soft but supporting bra it helped to stop some of the 'dragging' of my bust on the tender operation area. I am also careful to either not eat, or eat very little, fruit or vegetables if I am going out the next day!

My habits and lifestyle have had to change but I feel I live an almost normal life now. I am just grateful that the operation was available.

It is marvellous what can be done for people who have cancer these days. The dedication of all the medical team involved in its treatment is something for which I am very grateful.



REGIONAL BRANCHES AUTUMN MEETINGS

These meetings are held for patients who have had, or are about to have, major surgery for the removal of part (or all) of their oesophagus and stomach. Local specialist surgeons, nurses, dieticians and physiotherapists are always invited to attend to answer your questions so that you can learn more about what has happened to you. The meetings all have a friendly format and you will be made very welcome, with former patients available as hosts for new patients and their carers. People who have made contact with the OPA to inform us that they have had an oesophagectomy will automatically be invited.

Please note that it is inevitable that most patients attending these meetings have had, or are going to have, surgery. All oesophageal/gastric cancer patients are most welcome but this emphasis is to be expected in discussions.

If you would like any further information about these meetings please contact the OPA Office, Solihull

Birmingham – Meeting at Edgbaston County Cricket Ground on Saturday 6th November

Brighton – (date and location of next meeting to be confirmed)

Derby – Hilton Village Hall on Saturday December 4th

Exeter – Meeting at Exeter Racecourse on Saturday November 13th

Frimley – At The Lakeside International Hotel, Wharf Road GU16 on Saturday October 2nd

Guildford – The Holiday Inn, Egerton Road GU2 on the last Thursday of every month at 6pm

Leeds – (date and location of next meeting to be confirmed)

Lincoln – Meeting at Wragby Town Hall on Saturday November 6th

Liverpool – At Royal Liverpool Hospital (date to be confirmed)

London – Charity Centre, Directory of Social Change NW1 2DP on Saturday October 2nd *and*

London – Guys Hospital, Robens Suite on Saturday November 20th

Luton – At Luton and Dunstable Hospital (date to be confirmed)

Northern Ireland – Meeting on Saturday October 9th

Norwich – At Norfolk and Norwich Hospital (date to be confirmed)

Oxford – Meeting at the Churchill Hospital, Out Patients Department on Saturday October 30th

Portsmouth – (date to be confirmed)

Reading – Meeting at the Reading Moat House Hotel on Saturday 30th October

BRANCH NEWS - LINCOLN

Our year (2009) opened with our 'Winter Warmer' fund-raising day, well supported by the hundred or so people who sat down to lunch provided by our wonderful team of volunteer helpers; a most enjoyable and happy day. Our three meetings through the year are very informal, providing, I believe, a relaxed atmosphere to give support, information and care to our patients and their families. We have a team of former patients who stand by to help new patients either by telephone or at a meeting. Over the years the group has been meeting, strong friendships have been forged in this way.

We are forming strong links with Nottingham City Hospital (Barclay Ward); the Nursing Manager came to our meeting in April 2010 and we still enjoy the support of Caroline Marshall, Upper GI CNS at Lincoln County Hospital, who gives her time to speak to patients individually at our meetings.

In December 2009 we once again had a Christmas luncheon at the Holiday Inn, Lincoln; we were looked after very well, all diets and portions catered for. New patients who came along to the meal commented how much it had helped them to see that a social life is still possible.

We are fully committed to the OPA, but our patients and carers direct our meetings, and we support, learn and care together.

*Marilyn Thornicroft
(Branch Co-ordinator,
Wragby, Lincs).*



We know from experience that losing the oesophageal sphincter, the valve that joins the stomach and the oesophagus can cause problems, not least when lying down.

Almost all of the patients who register their details with us sleep with their head and shoulders raised. It becomes a way of life, one of the small changes following the operation that has to be made.

For those who risk lying flat on just one pillow, the eventual presence of acid and bile in the mouth can be distressing and frightening, leading to coughing and vomiting.

So imagine falling ill and becoming unconscious.

The first thing the ambulance crew do is to lie you flat.

At the hospital you remain lying flat.

If you need surgery and a few days recovery, again you remain flat.

Friends and relatives would probably not think to inform nursing staff about the loss of the sphincter. This of course can lead to serious complications, with bile and acid entering the lungs. This has happened to a number of patients; fortunately they all made a good recovery.

Medical Tags are a way of telling emergency services about your situation. They tag are very similar to an SOS Talisman).

We have negotiated a discount with a Birmingham company called Medical Tags. **If you order any of their tags, bracelets or necklaces you will receive a 10% discount.**

All of the tags feature the 'Staff and Snake', an internationally recognized medical alert symbol.

You can visit www.medicaltags.co.uk and use the discount voucher MEDTAG or call 0121 233 7455. We do have a limited amount of leaflets and order forms; please contact us if you require one.

Our suggested engraving on the tag is;

**OESOPHAGECTOMY/GASTRECTOMY
DO NOT LAY ME FLAT**



Most patients are transported to hospital alone, without relatives or friends to discuss possible life saving medical history.

By wearing your medical information near your main pulse points, your neck or wrist, it is more easily noticed by emergency staff.

In these vital few minutes this is often the only way of conveying your vital **medical condition** that the medics need know about and so treat you effectively.



Many different designs are available



Despite the continuing threat of perilous financial times in the UK at large it is pleasing to be able to report to our membership that the OPA has had another solid year of obtaining grants to fund our work.

It is also heart warming to know that we have several grant making bodies that have been making regular grants to the OPA since I began a Trust fundraising programme back in 2003.

With this kind of regular funding the Association can look to the future with some confidence.

I am also pleased to let readers of the last issue know that I did indeed complete my Cornwall north coast walk in 4 days during May and, being completely misinformed by my internet research, actually walked over 90 miles not the 80 I was expecting to tackle!

Finally, I hope that you like the designs of the new cards (and if you would like to place a substantial order please return the flyer before the end of October to guarantee delivery of larger quantities). As ever, I am typing this article in the summer and worrying so much about Christmas; fundraising was ever thus...

Work Experience at the OPA

Chloe O'Connor

In early July the OPA took part in the national work experience scheme for secondary school pupils in year 10. Dawn and Mark welcomed Chloe O'Connor from St. Peters RC School in Solihull to OPA's office. Chloe offers the following thoughts on her time helping to run the Association HQ for five days:

"At the age of 14, oesophageal cancer was something that I had never come across, meaning that on my first day at the OPA I knew little about the disease and the effects it has on people. But after spending my week at the Association I can now see clearly what a wonderful job they do helping patients and their families with their day to day troubles. This week has not only informed me about the facts of this cancer but has also opened my eyes to the problems I did not stop to think about; the problems of getting on with life after the operation.

Being the only charity of its type, the OPA is a unique organisation that is brilliant at its job, producing a variety of methods to aid those in need of some advice. The telephone help line is run efficiently giving advice to many patients a day.

The booklets are sent out to help those in need of some extra information and these two processes are only snapshots of the things the OPA does to make a difference to peoples' lives.

The work that takes place in the office is inspirational to watch and a pleasure to be involved with. My week here has been both a remarkable and inspiring time working alongside such wonderful people and seeing how much of a difference a charity can make to people's lives."



FUNDRAISING COUPON

I am pleased to send a donation of [£] Date of donation [/ /]
(Please make cheques payable to OPA and complete your details below)

If you are an income tax payer, ticking this box [] will enable the OPA to recover tax on this, and any future donations you may make, under the Gift Aid Scheme, provided you have paid income tax or capital gains tax equal to the tax reclaimed by the OPA on the donation(s) in the tax year.

I would like to organise a Tea Party for OPA, please send me a Tea Party pack []

I would like to play TLC Lottery on behalf of the OPA, please send me a leaflet []

FROM:

Mr/Mrs/Miss/Other
NAME
ADDRESS
.....POST CODE
Telephone NumberEmail