

THE NEWSLETTER

OESOPHAGEAL PATIENTS ASSOCIATION

Gullet & Stomach Cancer Support

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Registered Charity No. 1062461

Oesophageal Patients Association
Former patients helping new patients

Helpline
0121 704 9860
9am to 5pm Weekdays

Email
enquiries@opa.org.uk
Other ways to contact us

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Support Near You

COMING SOON

Find a support group near you »

Welcome to the Oesophageal Patients Association

New OPA Website

The new OPA website will be live very soon; it will offer you the latest information on meeting dates, the latest OPA news and - closer to home- you will have access to your own regional news pages.

Great Effort by The OG's at Luton's Cancer Research Relay for Life!

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Find out on page 3 how a Barrowful of Booze helps cancer patients

OPA - Experienced patients helping new patients

Luton's Oesophagogastric Support Group RELAY FOR LIFE

For 24 hours from noon on Saturday 17th September 2011 members of the Luton and Dunstable Oesophagogastric Cancer Patient Support Group took part in the Cancer Research 'Relay for Life'. The purpose of the relay is to have team members lapping the Athletic Track at Stockwood Park, Luton for the whole 24 hours.

The 24 hour event commenced with a Survivors' Lap of Honour. The OG's team comprised a number of survivors who have had surgery for Oesophageal or Stomach Cancer with their family and friends, led by their team captains; Heather Simpson & Wendy Shearsmith (the Upper GI [Gastro-Intestinal] Clinical Nurse Specialists).



The Survivors Lap of Honour -
12 noon and ready to go!



There was also a very moving Candle of Hope Ceremony in the evening to remember those touched by cancer (see left).

This was a family fun weekend too, with a programme of entertainment and stalls for everyone to enjoy. Our enthusiastic team had a bottle raffle to win a wheelbarrow full of quality drinks! Our team's brilliant effort, both on the track and on the stall raised £2,214:03. Overall the relay raised £70,609:56 for Cancer Research UK. Organisation of the Relay for 2012 is already underway and the OG's pink wheelbarrow is waiting to be filled in anticipation of another fun weekend!

The OG's team organised a rota to cover the 24 hours with several camping and walking overnight to cover the night shift!

Our Newsletter direct to your inbox?

You may have seen reports in the press recently about the proposed increase to the cost of stamps, each one rising from 36 to 55 pence! OPA postage costs will then be more than our office rent, heating and electricity bills combined. To help to reduce the impact, would you like to receive your future copies of the newsletter by email? Please leave your details at enquir-

ies@opa.org.uk including your name, address and postcode, if you do.

Of course if you do not have access to email we will still be happy to pop one in the post to you; **you do not have to notify us if your preferred option is to receive it by post.**



Thank you, Orla & Joanna

We would like to thank Orla Hynes, Upper GI Surgical Dietician, and Joanna Taylor, Upper GI CNS. Both work at Guys and St Thomas' Hospital in London. Using their very precious time and expert knowledge they have revised our booklet 'A Guide to Life After Oesophageal/ Gastric Surgery'.

The revised version will be available very shortly.

OPA REGIONAL BRANCH 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 on Saturday 12th May in the Marston's Suite, Warwickshire County Cricket Ground, Edgbaston, Birmingham, B5 7QU at 10.30 onwards.

Brighton - Meeting on 11th April, 11th July, 10th October, 5th December (2-4pm) at The White Horse Hotel, Marine Drive, Rottingdean BN2 7HR. Contact Verena Smith 07964 925 494. All dates are Wednesdays.

Colchester - Meeting on 15th March, 19th April, 17th May, 21st June, 19th July, 16th August, 20th September, 18th October, 15th November, 20th December, at Colchester General Hospital, Turner Road, Colchester, Essex, CO4 5JL at 6.30. All dates are Thursdays.

Derby - Meeting on 2nd June, 8th September, 8th December at the Village Hall, Mill Lane, Hilton, Derbyshire DE65 5GP. All dates are Saturdays.

Exeter - Meeting on Friday 11th May, Saturday 10th November at The Kenn Centre, Exeter Road, Kennford, Exeter EX6 7UE, Devon. Also 30th March, 27th April, 25th May, 27th July, 31st August, 28th September, 26th October, 30th November at The Force Centre, Corner House, Barack Road, Exeter, EX2 5DW at 1pm onwards. All dates are Fridays.

Frimley - Lakeside International Hotel, Wharf Road, Frimley Green, Surrey GU16 6JR at 10.30–12.30pm. Dates to be advised.

Grantham - Meetings on 26th May, 25th August, 24th November at Great Gonerby Social Club, 8 High Street, Great Gonerby, Grantham, NG31 8JP at 10.30am. All dates are Saturdays.

Guildford - Meeting on 29th March, 26th April, 26th April, 31st May, 28th June, 26th July, 30th August, 27th September, 25th October, 29th November at Conference Centre, The Holiday Inn, Egerton Road (next to Royal Surrey County Hospital) Guildford GU2 7XZ at 6pm onwards. All dates are Thursdays.

Lancaster & Morecambe Bay - Meeting on 8th March, 12th April, 10th May, 14th June, 12th July, 9th August, 13th September, 11th October, 8th November, 13th December at Slyne Cancer Care Centre, Slyne Dales, Lancaster, LA2 6ST. All dates are Saturdays.

Leeds - Dates to be arranged for Headingley Golf Club, Back Church Lane, Adel, Leeds LS16 8DW.

Lincoln - Meeting on 3rd March, 7th July, 27th October at the Village Hall, Louth Road, Wragby LN8 5PH, Lincs. (In village centre, signposted). All dates are Saturdays.

Liverpool and North Wales - Meeting on Saturday 17th March at Cardiothoracic Centre, Outpatients Department, Liverpool Heart and Chest Hospital, Thomas Drive, Liverpool, L14 3PE. Monthly meeting, last Thursday of the month 1.30-3.30pm

London - Meeting on Saturday 26th May at Guy's Tower, Guy's Hospital, London, SE1 9RT at 10.30am onwards.

Luton - Meetings on Saturdays 5th May, 11th August, 11th November, in the Comet Centre at Luton and Dunstable Hospital .

Maidstone - Meeting on 6th March, 12th June, 4th September, 4th December, at Maidstone Hospital, IMACCS Building, Hermitage Lane, Maidstone, Kent, ME16 9QQ at 6.30–8.00pm. Telephone Michelle George on 07525 967656 or 01622 729000 for more details. All dates are Tuesdays.

Manchester - Meetings on 21st March, 16th May, 18th July, 19th September, Wednesday 21st November at Wythenshawe Hospital, Southmoor Road, Manchester M23 9LT. Contact John Shuttleworth 0161 427 3446 for further details. All dates are Wednesdays.

Northern Ireland - Meeting on Saturday 31st March at Beechlawn House Hotel, 4 Upper Dunmurry Lane, Dunmurry, BT17 9RR at 10.30 onwards.

Norwich - Meeting on 28th April & 27th October 10.30am to 12.30pm at The Benjamin Gooch Room, Norfolk and Norwich Hospital, Colney Lane, Norwich, NR4 7UY. All dates are Saturdays.

Oxford - Churchill Hospital, Out Patients Department, Headley Way, Headington, Oxford Dates to be confirmed.

Reading - Venue & dates to be confirmed.

Southampton— Meeting Tuesday 3rd April Dibden Purlieu Golf Club 2–4pm



MEDICATION DRUGS WHAT THEY DO....

This information provides an overview of some of medication available to patients. Please consult a doctor or pharmacist before using the following drugs.

Acid Reflux

H2-Antagonists (decrease gastric acid production)

Ranitidine
Cimetidine

Proton Pump Inhibitors (decrease gastric acid production)

Omeprazole
Lansoprazole
Esomeprazole

Antacids (forms 'raft' on top of stomach preventing acid from regurgitating)

Gaviscon
Peptac

Nausea and Vomiting

Prochlorperzine
Promethazine
Domperidone (also helps with gastric emptying)
Cyclizine
Metoclopramide

Diarrhoea

Loperamide
Lomotil
Rehydration sachets

Other Medications

Creon (assists the digestion of starch, fat and protein)
Erythromycin (antibiotic, which also stimulates gastric emptying)

Formulations Available

Tablet – Oral Suspension – Buccal tablet (dissolves under gum) - Capsule Dissolvable - Tablet

*Speak to your local pharmacist to get the best out of your medication.
There are other options than tablets if there is difficulty swallowing.*

With thanks to our friendly local pharmacist for this information

Dave Chuter. Surviving and 'Getting On With It' My Story 2008 - 2012

After struggling with reflux for a few months and a slowly worsening swallowing problem soon after eating I went to my GP. Within a week I had my first appointment to the endoscopy unit at the RSH. After another 2 endoscopy visits, it was carefully and clearly explained that there was a tumour which could be cancerous and I needed surgery to remove it. Again it was clearly explained what the surgery involved and all the possible outcomes and my prospects without surgery. It was clear that surgery would be the best option for the future.

From GP visit to operation day took just 4 weeks, no time to worry about myself, only about Gill my wife, what to tell my 2 daughters and how to organise cover at work. These were the things that seemed most important at the time.

I went into hospital on the afternoon of 25th Sept 2006, dinner was Shepherd's Pie and ice cream for dessert I believe. Surgery was planned for the morning so no breakfast. The surgeons were about very early that day and I was taken down about 8.30am to the theatre, 2 epidurals were placed into my back and that's all I can remember. The surgery took a good 9 and a bit hours I learnt afterwards.

The operation involved removal of most of the oesophagus and in my case three quarters of the stomach, what's left is moved into the chest and joined to the remaining upper part of the oesophagus slightly lower down from my neck. The lower stomach surgery was keyhole surgery with 5 small stab holes but the upper part of the surgery was more invasive and has left an impressive scar to show.

I can vaguely remember waking up now and again in IC during the night and a nurse sitting at the end of the bed talking to me but could not answer back before fading back to sleep. 2 nights were spent in the IC unit, with many visits from the surgeons, nutritionist and physiotherapist who actually managed to get me somehow out of bed and sitting in a chair the next day. Then on to the second stage ward for a couple of nights before on to the main ward. Nil by mouth for the first week or more meant being fed by a tube in to my neck, I think it had 3 or 4 other taps for painkillers and such. There were other tubes and drains attached, the worst was down (and actually stitched to) my nose which was the last to be removed.

No drinks either, just little pink foam lollies to moisten lips and mouth. The first drink was a horrible aniseed solution which was used to show up on the scanner for a swallow test, checking for leaks after surgery, I did get a cup of tea afterwards. The first meal after surgery was battered cod with boiled potato and peas, about a week after surgery, it was an unexpected treat that day and it was good.

I went home after 10 days, spent a lot of time sleeping and resting. After 6 weeks off I went back to work, starting off with a couple hours per day only and slowly building up to full time over a period of 4 months. Eating and drinking has had its own little problems since the operation, it took a while to get into a new routine of small meals more often and drinks between meals instead of with. Over a period of time you do get to know your limits in size of meals, how often and what is likely to cause the dreaded dumping syndrome, it is what it sounds like it should mean and sometimes with painful cramps. My weight did drop quickly after leaving hospital and took 9 months to settle, after 18 months it

started to slowly creep up and the cramps and dumping syndrome slowly becoming less and less. I lost 3 stone to start with and after 24 months I have put back nearly 2 stone again. Fitness levels were very low for the first 6 months or so but do slowly come back and at the moment I do feel fit enough to consider starting jogging again a couple of times a week.

I do consider myself as very lucky person to have survived cancer, without chemotherapy, only surgery. It is all down to my GP in Guildford being aware of what it could be and referring me to the RSH, the endoscopy unit, cancer unit & surgeons, specialists, nurses, nutritionists, physiotherapists and all staff at the Royal Surrey Hospital for their dedicated care, attention and speedy treatment at the early stages, afterwards and ongoing treatment as required.

Being aware and indentifying this increasing form of cancer can only help others by catching and starting treatment at the very early stages.

The above was written soon after the surgery so is accurate as to what seemed important to me at the time. My aim at the time was to get back to work as soon as I could as that would make life normal again.

It took a year or so to consider my life as near as possible normal again and my way of looking at life to start changing again, I'm not sure if this is something others have experienced.

Since then my outlook on life has changed in the sense that rather than just thinking about getting my life back to normal, my thoughts started to turn to thinking of others, how little support was available locally and finding out how I could help and offer support to others with the same pathway, it is the experience of talking to another patient that I felt was missing from the time of my surgery. With this mind and with the hospital Consultants having started up a support group but not always having enough time to organise and run, I offered to take on the role as organiser and chair. We are having monthly meetings for the third year in a row with a varied programme, so patients and carers can pick and choose what they want to attend, and new patient can attend as soon as possible.

We have full support from the OPA and the RSCH Upper GI team in running this local patient support group.

Because of the high commitment of the Royal Surrey County Hospital Upper GI team to their work, patients and carers / family members, when the hospital decided to go for Foundation Trust status, I stood as Patient Governor to be able to support and put across the views and concerns of patients right to the Board of Directors, I am now in my second term having been re-elected.

I am also involved with the SWSH Cancer Partnership Research Group, working on the editing and advising of research study papers and patient info sheets to be easily understood by patients being asked to join cancer studies / trials.

I am now 5 years out from surgery and moved to the south coast for an easier life, but still working full time for a Label Printers in Littlehampton as Operations Coordinator and travelling to Guildford twice a week or more for the volunteer work, which has now taken over my aim in life.



ON A SOFT DIET? STRUGGLING FOR IDEAS?

Breakfast

Pancakes softened with syrup
Melba Toast with butter, marmalade or jam
Softened cereal in milk
Oatmeal and yoghurt
Porridge
Breakfast biscuits
Stewed fruit with yoghurt

Lunch

Crisp bread with paté, soft cheese or smooth peanut butter
Soup (Tinned or homemade with plenty of seasoning) with croutons made with olive oil (many soup recipes are suitable as long as a processor/blender is used)
Jacket potato served with hummus and lots of butter!

Snacks

Crisp Breads/Breadsticks & dips, (melt in the mouth and enjoy the sensation of crunching food plus these have lots of calories!)
Crisps/potato puffs
Melba Toast
Rice Cakes
Fruit smoothie/milk shake

Dinner

Poached or flaked fish in sauce; try hollandaise, lemon sauce, parsley
Spaghetti/pasta with meat sauce
Macaroni cheese
Stew
Shepherds Pie
Moussaka
Curry sauce and poppadoms

Dessert

Lemon meringue pie
Creme caramel
Ice cream
Rice pudding

USEFUL INFORMATION AVAILABLE FROM THE OPA

There are three booklets created and published by the Association for the benefit of members:

The Oesophageal Patients Association (who we are and what we do).

Swallowing - Nutrition When It's Difficult

A Guide to Life after Oesophageal/Gastric Surgery.

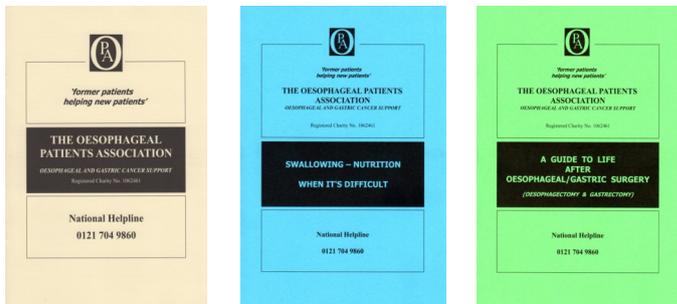
We also have factsheets on advice for relaxation and sleeping available from the Association.

The Association can also provide Restaurant and Toilet cards which are available to use in most European countries.

Please call the helpline on 0121 704 9860 or email enquiries@opa.org.uk

Other Information is also available from:-

www.macmillan.org.uk & www.corecharity.org.uk



JustGiving was started in early 2000 by Zarine Kharas and Anne-Marie Huby, with a simple vision. They wanted to use the power of the internet to enable people to raise far more for charities, easily and cost-effectively.

They created the UK's first online fundraising business. Over the past 11 years, JustGiving has changed the face of charitable giving in the UK:

- charities have raised more through JustGiving than any other site, some £770m in all
- more charities use JustGiving than any other fundraising service; 12,000 charities have benefitted, and in a typical month 220 new ones join up every month, 42,000 people create a new fundraising page on JustGiving.

If you would like to donate to the Oesophageal Patients

Association through JustGiving, please visit:

www.justgiving.com

or alternatively use the Donation Form below. Thank you.

Donation Form

I am pleased to send a donation of £ _____ Date of donation _____ / _____ /2012
(Please make cheques payable to OPA and complete your details below)

If you are an income tax payer, tick here which will enable 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.

FROM:

Mr/Mrs/Miss/Other:

NAME:.....

ADDRESS:.....

POST CODE:

TELEPHONE NUMBER:.....

EMAIL ADDRESS: