



OPA News

FIGHTING OESOPHAGEAL GASTRIC CANCER & RELATED CONDITIONS

www.opa.org.uk

Summer Issue 2017

Help, advice and support delivered by patients and carers for patients and carers

OPA AGM 2017 - Thackeray Museum, Leeds



A big thank you to our speakers Jeremy Hayden - Consultant Upper GI Surgeon - Leeds, Bob Mason - OPA Chairman, Ed Cheong - Consultant Upper GI Surgeon - Norfolk & Norwich, Phil Coverdale - OPA Trustee & Co-Ordinator, John Campolini - OPA patient buddy, John Taylor - OPA Leeds co-ordinator, and our OPA secretary - Haward Soper, Maggie and Drew, the staff at Thackeray Museum, Margaret Nickels for organising the raffle and not forgetting our patients and carers who attended!

We have moved...to a new home

Just a quick note to let you know that we have moved to a new home so please can you update your records.

Our new address is:
50 High St
Henley-in-Arden
Warwickshire
B95 5AN

You can still reach us on the same telephone number: 0121 704 9860

Thanks for all of your help and support!

Special thanks to Pete Hardwick, IT Support and Richard Henrick who helped us with the Office move.



The Oesophageal Patients Association

Caring for the cancer patient and their family

Registered charity No. 1062461



Eli Lilly Video and update

The OPA Guildford Support Group and Elli Lilly have been involved in the production of a DVD entitled 'What can I eat now? – Living with Oesophageal/Stomach Cancer'. This came about when the local dietician Fiona Huddy was approached to give her views about nutrition.



Elli Lilly visited the OPA Guildford Support Group in Feb 2016 to ask patients, family, members and carers what was important from diagnosis, through treatment and after.

It was agreed that the story line would be the patient journey from diagnosis, telling and giving their story and the specialist adding their views, knowledge and expertise in a way that patients will understand.

The intention of Elli Lilly was to make the film available to all patients via patient groups, charities and NHS trusts. The film is now accessible on YouTube. With the endorsement of the OPA we are confident that NHS trusts will take the film on board and be able to give out to patients as diagnosed and put on the surgery pathway.



We must say thank you to Dave Chuter the OPA co-ordinator and all of the Guildford patients and family members who gave their views, knowledge and experience to Elli Lilly during 2016 to help develop the film, without their input it may not have been such a successful film and provided the vital help to support patients.

Aaron Hall - Macmillan Physical Activity Practitioner



Aaron Hall kindly visited the OPA Birmingham Group on 22nd April 2017 to present the benefits of living with cancer and being active.

There are over 60 commissioned programmes across the UK and my role is practitioner of the Lincolnshire Programme. Each programme operates independently in their area but we share the same objectives, which is to offer support, information and gentle motivation to anyone living with and beyond cancer treatment and who is looking to become more active.

There is robust evidence that leading an active lifestyle can have a multitude of health benefits and that being active before, during and after treatment can have a positive effect on physical and mental health. Despite this, only 21% of those living with and beyond cancer treatment are active to the recommended levels and 31% of those living with and beyond cancer treatment show no signs of being physically active at all.

Lincolnshire, along with our partnered programmes from Macmillan, are offering free support and advice to help get more people active. This might be to combat side effects following treatment such as fatigue and tiredness, to get back to an activity such as walking or gardening, or simply to help a person to become healthier and more active.

Move More.
Be a more active you.



If you would like to invite Aaron to present at your patient support group, for further information please email: Aaron.Hall@lincolnshiresport.com or phone: 01522 730 325 Ext: 217 or mobile: 07483 105 222

Fundraising

James Gossage Consultant Surgeon abseiled down St Thomas' Hospital for the OPA. The photos include James in Reflux shirt on the way down and with 2 patients (supporters).



James Gossage



Kevin Ward & Mark Nieman

Thank You
to all of our amazing
fundraisers!

Maggie Haynes

Kharyn McKee

Emma McKee

Eamonn Kelly

Peter Dugmore

Ashleigh Forrester

Cavell Shone

Louise Letman

Antonia Pusey

**Put the
FUN
In FUNdraising**

Phil Coverdale

Ann Danes

Sarah Murray

Nicola Gibbs

Kate Thompson

Linda Robson

The DT Amigo's

Pamela Bonshor

John Chapman
- Patshull Park Golf Club

Shelley Osborn

Sainsbury's Supermarket
Berkshire

Ben Sickelmore

Paul Butcher

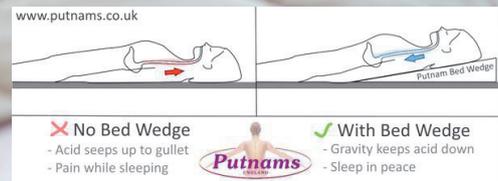
And anyone we may have missed.

Also, thanks for the continued support of our charitable trusts.

Bed Wedges

Goodnight Acid Reflux, Hello Sleep! - Bed Wedge special offer from the OPA and Putnams

More about Bed Wedges



The OPA has teamed up with Putnam Pillows to provide their standard **Bed Wedge - Acid Reflux** at an affordable price of only £26.40.

Both doctors and other practitioners agree a wedge pillow is the best way to relieve the symptoms of Acid Reflux or Gastroesophageal Reflux Disease (GERD) and heartburn by elevating your torso to prevent acid from burning the lining of your oesophagus while you sleep.

Many people with oesophageal disease have to sleep propped up. This can be difficult but some find a wedge pillow helpful. These can be quite expensive.

The Bed Wedge - Acid Reflux can be used in many ways. Place it under your pillow to sleep in a raised comfortable position which is ideal for sufferers of acid reflux and Oesophagitis. Using a bed wedge whilst asleep to elevate your upper half can severely reduce acid reflux. Just adding extra pillows won't work because they elevate your head, not your upper torso. It's also easier to slip off extra pillows as you sleep.

The OPA is putting £12.50 per pillow towards this partnership. Putnams have, on top of that, agreed to a generous discount. The standard retail price is £54.38, you only pay £26.40 - saving over 50%.

Putnams also offer free delivery or you can pay a little extra for next day delivery.

We are very grateful to Hedley Putnam, Director at Putnam Health Co Ltd and to Putnams for their generous discount and postal service.

To take advantage of this offer

1. Please call or email the OPA first and we will give you a Discount Code. Call us on 0121 704 9860 or email enquiries@opa.org.uk
2. With the Discount Code, call Putnams on 01752 345 678. Email info@putnams.co.uk or visit: www.putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge

Note, on the website you will be able to enter the Discount Code on the Check Out page. We are extremely hopeful that this initiative will help many of our members to sleep more comfortably.



OPA Northern Ireland are raising funds for City Hospital in Belfast

Why are we raising this money??

To purchase and provide training for a specialist item of equipment which will make a significant step forward in the treatment of patients with early stomach, oesophageal and colorectal tumours.

What is the Procedure?

It is called Endoscopic Submucosal Dissection (ESD). The new technique, known as ESD (Endoscopic Submucosal Dissection) was developed in Japan and is proving successful as a non-surgical cure for patients with early cancers in the majority of cases.

The new method is to use a suction cap fitted to the end of an endoscope which has a snare at its base. It creates a polyp with the suspected cancerous cells inside and allows for the total removal of the cancerous tissue. This will also give more accurate staging or grading information. The patient can go home within 24/48 hours and invasive surgery will not be required.

Dr Mainie is the Upper Gastroenterology Lead Consultant in the Belfast Trust. To perform this procedure Dr Mainie will require training and this will be delivered by the world experts in Japan. At present no one in Ireland carries out the procedure and following the acquisition of the equipment Dr Mainie will train other gastroenterologists in Ireland.



The overall cost of acquiring the equipment, transporting it to Belfast, paying the consultant's travel and accommodation is estimated at £15,000.

Further information may be obtained from
Helen Setterfield
Email: helensetterfield@opa.org.uk

Medical Alert Assistance Dogs



At a recent Derby meeting a talk was given by Medical Alert Assistance Dogs charity. They train dogs to use their sense of smell to detect a human cancer. They can train a dog to detect a specific cancer from a sample from the suspect patients. They

have been running trials using a limited number of trained dogs and appear to have had very good results in their findings. They have detected a high proportion of patient samples where the relevant cancer is present, while having a low level of false positive indications. Dogs are used in pairs to further reduce false positive results.

The charity continues to investigate other debilitating and potentially fatal conditions which the dogs may have the ability to help. Currently they have not targeted Oesophageal cancer detection. In view of the crucial importance of early diagnosis of oesophageal cancer, who knows where this may lead. If you would like more information, please contact the charity –

Medical Detection Dogs
3 Millfield
Greenway Business Park Winslow Road
Great Horwood
Milton Keynes MK17 0NP

Call 01296 655 888

Email:
operations@medicaldetectiondogs.org.uk

Visit:
www.medicaldetectiondogs.org.uk/



Patient Stories

OPA Nottingham Group - Patient Story



Patricia Massey

Hi my name is Patricia Massey, I'm 78 and live in Sneinton, Nottingham. I help run the Nottingham OPA in the Maggie's centre at the city hospital, every third Thursday of the month.

This is me enjoying a walk round Grasmere.

In 1995 (23 years ago) I was enjoying lunch out with a friend, when my food got stuck, wasn't choking, but could feel it. My friend pointed at me and said "go and see a doctor", I said "why", "just do" she told me. So, as I live next door to the surgery, I went in, the doctor saw me straight away. He sat there looking at me, I thought, he thinks I'm mad. "Take this to the hospital now" he said, "now" I said, "yes now!" he said.

So off we went to the hospital, I was told there was a 6 week wait for tests. But the next day I got a phone call, to come straight in. This was the end of April, they did lots of tests, it was now they told me I had oesophagus cancer, I didn't know I had a oesophagus, to me it was my gullet. I was booked in for 22nd May, had my op on the 26th. It took 11 1/2hrs, was cut from the middle of my shoulder blades, under my left arm and finished under my bust, and down the front, I lost nearly all my oesophagus, 3/4 of my stomach, my spleen, and a rib. Was in intensive care 12 days, then onto a high dependency ward and finally on to a normal ward. Home June 17th.

The only information I was given, was stop eating before you feel full, because 20mins later you will feel full and be ill, and don't drink with food. Also you can't lay flat in bed, try and be propped up. I didn't know when I was feeling ill it was dumping syndrome. I could never gauge when I was full, so had dumping syndrome a lot.

It's now 23 years, and I'm enjoying life. When my husband died 7 years ago, my son who is a landscape photography, said "mum if I go anywhere do you want to come", to which I replied "I'd love to." This year we had two weeks in the Lake District, and two weeks on the Isle of Skye. I met some great people and made many friends, including my special friend Mary, 87, who had her op 18yrs ago.

Maggie Haynes

Can you remember what you were doing 10 years ago in January 2007? Well I certainly can; I was organising my own funeral!



In the previous September, aged 39, I was diagnosed with oesophageal cancer, after having difficulties with swallowing and was given the 3 possible outcomes: do nothing and I would have 9 months to live; if chemotherapy was the only other option, then I could have 18 months; if I were to be a suitable case for surgery...then who knows!!

I ended up having chemotherapy and then lifesaving surgery at Colchester General Hospital. I thank God, I'm still alive albeit with certain limitations regarding energy levels. I've also had to make some quirky little lifestyle adjustments but, in the grand scheme of things, that's nothing compared to what the outcome could have been!

I always knew I'd do a fundraising event to celebrate 10 years post-surgery and came up with the idea of holding an afternoon tea. On the 21st Jan 2017, 100 friends joined us to mark this fantastic occasion. There was a glass of fizz to welcome all our paying guests then I did a little talk about my diagnosis and treatment. My husband spoke about the support we received from the OPA and St Helena's hospice based in Colchester. Our local hospice offers therapeutic intervention which is what I benefitted from. The hospice is also a place for the living as well as ensuring a 'good death'. Attending the hospice empowered me and gave me the confidence to start building a future for myself and my husband, albeit on my long road to recovery.

We also attended the OPA meetings at Guys Hospital where it was beneficial to meet other people in my situation and exchange coping strategies etc. My fundraiser was a way to raise the profile of both these charities because without fundraisers and other forms of giving these charities may well struggle in the future.

Our guests were served a selection of different filled sandwiches accompanied by endless cups of tea using lovely bone china. Numerous homemade cakes were followed by scones with clotted cream and jam accompanied by live background music and lots of chatting and laughter. After an hour or so, the remainder of the afternoon was rounded off with an extensive raffle and an auction.

None of us know what's around the corner health wise and even if you believe you're fit and healthy sometimes a curve ball is thrown and you're trajectory in life changes. As a Christian, I had a lot of prayer and support which got us through a lot of tough times plus I feel my positivity and having had a good wholesome lifestyle helped me come through.

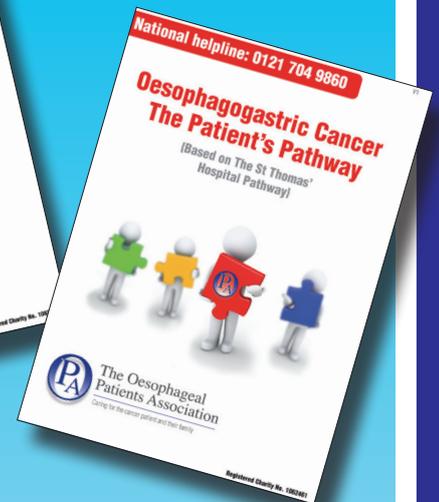
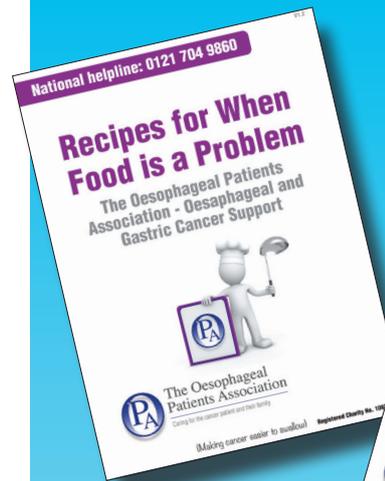
It is with sadness we have to announce that our dear Trustee, Hilary Ryan has passed away. Hilary touched the lives and inspired so many with her courage and ambition. She will be missed by us all!



Watch this space...

Coming
Soon..

New Booklets



Also this year we are having some new Christmas cards which are being designed by partner & carer Christine Muckley



Bite size support groups

The OPA is launching a new initiative – our aim is to help ones create bite-size groups moving away from the larger Hospital Groups for the benefit of ones who do not have the time, energy, resource to attend the much larger Groups set up around the country.

Support groups bring together people who are facing similar issues, whether that’s illness, relationship problems or major life changes. Members of support groups often share experiences and advice. It can be helpful just getting to talk with other people who are in the same boat.

Many patients, their carers and their family members that have had to deal with oesophageal/gastric cancer or related conditions prefer to move on after their surgery. This is a good opportunity for a few people to get together and form a Bite-Size group to help one another. A Bite-Size group may only involve a few persons but the benefits can be very positive.

These groups although small in number can take place in a person’s home, a coffee shop, a church hall, local pub, social club. Smaller groups offer more intimate surroundings and people can feel more at ease.



The OPA would like to encourage people to form much needed groups in the following geographical areas: Plymouth, Barnstaple, Totnes, Devon, Paignton, Bradford, Chester, Crewe, Macclesfield,

If you would like to start a bite-size group, we can help with basic expenses, cost of room, tea, coffee and biscuits. We provide free literature, restaurant cards, leaflets, and access to our helpline. In addition, support can be arranged to help setup, organise, offer advice for your first meeting and continued support afterwards. For further information please call 0121 704 9860 for a chat or email enquiries@opa.org.uk.

Runcorn, Manchester, Sunderland, Newcastle, Wales and Scotland. Feel free to suggest a group in your area if this has not been listed.

Benefits of support groups

Regardless of format, in a support group, you’ll find people with problems similar to yours. Members of a support group typically share their personal experiences and offer one another emotional comfort and moral support. They may also offer practical advice and tip s to help you cope with your situation.

Benefits of participating in support groups may include:

- Feeling less lonely, isolated or judged
- Improving your coping skills and sense of adjustment
- Talking openly and honestly about your feelings
- Developing a clearer understanding of what to expect with your situation
- Getting practical advice or information about treatment options

Getting the most out of a support group

When you join a new support group, you may be nervous about sharing personal issues with people you don’t know. So at first, you may benefit from simply listening. Over time, though, contributing your own ideas and experiences can help you get more out of a support group. From experience the OPA was founded on the ethos that help is provided from patients and carers for patients and carers based on their personal journey with oesophageal and gastric cancer and other related conditions. This has helped them to gain confidence and move on and live a meaningful and purposeful life.



Donation Form

I am pleased to send a donation of £ . Please tick here if this is to be treated as a Gift Aid donation.

Date of donation..... (Please make cheques payable to OPA and complete your details below)

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

For online donations – Account number: 02301636 Sort Code: 40-42-12

NAME:

ADDRESS:

POST CODE:..... TELEPHONE NUMBER:.....

Oesophageal Patients Association, 50 High Street, Henley in Arden, Warwickshire, B95 5AN.

