

OPA News

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FIGHTING OESOPHAGEAL & GASTRIC CANCER

Christmas Issue 2018

Order your OPA Christmas Cards!

MAKE A DONATION



With six fantastic designs to choose from, we have limited stocks of these beautiful cards

See back cover to order.

or shop online: <https://www.opa.org.uk/sections/christmas-cards.html>

Get online!

We are delighted to announce the launch of our new website.

You can get online at www.opa.org.uk.

With technology and availability of information to patients, carers and their families becoming even more important, we have a brand new website. Our new site is fully mobile compatible and is responsive for mobile and tablet devices to keep up to date with the latest news and advice from the OPA on the move, so you don't have to miss a thing. Don't forget to take a look at our new shop online!



You can also donate via your phone, to help us keep up the valuable support work we do to help patients, carers and their families.

Welcome back John Taylor - New Trustee



John became aware of the need to consult his GP when he experienced difficulty in swallowing whilst on holiday in Seville in 2010, shortly after his retirement as a Chief Executive and Principal of the Sheffield College. He had an oesophagectomy

in October 2010 after a course of chemotherapy. The CT scan also revealed an enlarged polyp in the colon that was removed surgically at the same time. There were subsequent complications from the removal of the polyp that led to emergency surgery for an infarction of the bowel, a temporary stoma and a subsequent

reversal in 2013.

John and his wife Marisol are very grateful for the support they received from the OPA and became active members of the local group. John is now the chair and Sol the secretary of the Leeds Regional group. He is the OPA representative on the NOGCA the National Oesophago-Gastric Cancer Audit and the Oesphago-Gastric Working Group (Cancer Surgery Service Review).

They have three children and seven grandchildren. He was a keen sportsman retiring from playing cricket just before his operation and is now an avid spectator following Hull City and Yorkshire CC. He enjoys walking in the Yorkshire Moors and spending time with his grandchildren who live in Epsom, Aboyne, and Leeds.



Volunteer Corporate and Community Group Fundraisers Wanted!

Can you help?

More and more people of all ages are developing oesophageal and gastric cancers. Help the OPA to continue the fight.

Are you a retired fundraiser? Do you have a natural flair for fundraising?

The OPA currently gets very little money from community groups or corporates and is looking to expand its fundraising activities in these areas. Could you help with this?

You will need

- Excellent written and spoken communication skills
- Presentation skills
- The ability to motivate and manage others
- Excellent organisation skills
- Budget management skills
- Good time management skills



All of this will contribute to YOU helping a very important cause!

If you feel you can help the OPA, then please contact us at charity@opa.org.uk or for a chat call 0121 704 9860



Dressed to Kill Cancer

a Charity Fundraising Fashion Event

We had a beautiful sunny day in Henley in Arden on 30th June 2018 for the Fiona Wade 'Dressed to Kill Cancer' Fashion Show and what an amazing time we all had! Thank you to our sponsors:

- Expressive Design
- Invictus at Home
- Ppetrade.com
- Furniture Maxi
- Air Aesthetics
- Taylor Herrick Recruitment
- Cheals Restaurant of Henley
- Henley House and Alfred Cross Tailoring
- Studio 34 Boutique
- The White Swan/Stoneaged Steakhouse
- Henley Ice Cream
- Henley Sandwich Bar



We are grateful to Henley House and Studio 34 Boutique for supplying all the gorgeous models. Special thanks to The Stratford Herald, Laurence Marshall from The Guildhall, our Trustees, Maggie, Drew & Phoebe and everyone who attended.



ALFRED CROSS



Thank you to our fundraisers...

- Matthew Doyle
- Christina Lomers
- Cavell Shone
- Laura Diana Terry
- Corin Millward
- Jenna Swift
- Tracy Salt
- Mia Hillyard
- Ptarmigan Media
- Hannorah Lee
- Eamonn Kelly
- David Gibbs
- Jodi Martin
- Richard Barr
- Kharyn Mckee
- Paul Creed
- Faye Caroll
- Mia Hillyard
- Delyth & Geraint Eickerman
- Charlotte Koncar
- Callula Nulty
- Richard Hoare
- Jess Walker
- Fiona Jeffries
- Ray Clark
- Ronald Hotchkis
- Alisa Morrison
- Kate Thompson

Put the FUN In FUNdraising

And anyone we may have missed.

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



Band Appeal with thanks to Ray Clark



On Saturday 6th October, Ray Clark held an event at the Junction Theatre, Goole which raised an amazing £1089.38 for the OPA and the Fiona Wade Appeal. The night consisted of six acts together for one-night only including Daniel Defoe "Memories from "The Musicals"", Mr Chris Field "International Female Impersonator", Jessica Sharp "Stunning Female Vocalist", The Alcatraz Swim Team "Live Lounge Acoustic Duo", William Knight "Dazzling Comedy Magician" and Ray Clark "Voice of the 60's". Thank you to the sponsors; Glews Garage, Elite Office Furniture, KSP Tooling, Clan Shots Photography, Abacus Accountancy and Steve Walker Motor Engineer.

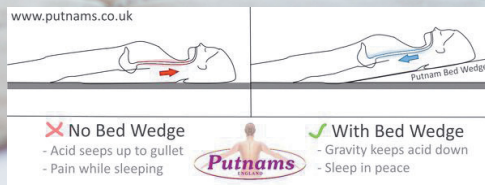


Bed Wedges

Offer Still available!
Over 1000 wedges issued

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 £29.94.

Many people with oesophageal disease pre and post-surgery find it uncomfortable to sleep lying flat - they need to be propped up to keep gastric acid where it should be.

If you suffer from this problem you can prop your bed up on books or purpose-made blocks, or you can prop yourself up with three or four pillows, but many people find a bed wedge under their ordinary pillow to be the best solution. It's not as awkward as raising your bed and you don't slip down so much,

and it's not as uncomfortable as lots of pillows.

There are many different versions of bed wedges on the market - just type 'bed wedge' into your internet search engine and you'll find dozens of them. They come in different shapes, sizes and prices, and you may need to try several before you find the one that suits you best. But like many other people, you may find the cost and effort worthwhile.

One of the best bed wedges is available from health and comfort specialists Putnams, which is why the OPA is continuing with its collaboration with Putnams to offer its members an exceptional deal on their wedge. The list price of this premium product is £57.92, but with a code from the OPA you can buy it for £29.94 including postage - a saving of nearly 50%.

To take advantage of this offer

If you want to take advantage of this offer, call the OPA on 0121 704 9860 or e-mail: enquiries@opa.org.uk. This is a members-only offer, but don't worry if you're not a member - joining the OPA is free and we just need a few details from you.

Once you've been given your discount code, you just call Putnams on 01752 345 678, e-mail them on info@putnams.co.uk or visit their website

<https://putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge>. If you're buying on-line you'll be able to enter the discount code on the Check Out page.

The discount code is valid for the ordinary wedge, which is 24" wide, but Putnams also offer a wider one - 36" - and a memory foam version in both widths. To check the price for these, contact Putnams by phone or e-mail, quoting your OPA discount code.



Keeping it in the family

David Eaves' Story



In the first of two articles, David Eaves explains how the collection and study of data may lead to an improvement of outcomes for oesophageal patients. David represents the Oesophageal Patients Association on the National Oesophago-Gastric Cancer Audit and is a member of the Leeds Region.

Every visit to an NHS or NHS-funded service results in vast amounts of data that are collected and collated by NHS Digital[1], the part of the NHS where I now work. The data are used for many reports and statistics, never attempting or needing to know who any of the individuals are. But research organisations and charities and other organisations can apply to have data sent to them for specifically agreed purposes and under strict conditions, including length of time the data may be used and stored. Under certain restricted conditions, where individuals in studies have consented[2], data for these patients can be sent encoded in such a way to allow these organisations (and only those individual organisations for those specific purposes) to identify those patients (and only those patients). Hospital data, in-patient, out-patient, emergency care, maternity care, mental health data, prescribing data, births data, mortality data, a patient's entire journey through the NHS, and only ever those who absolutely need to know, and are legally permitted, being able to determine who those people actually are. The possibilities are vast.

One important use of these data, and most relevant to us, is Clinical Audit. Every year CARMS, the Clinical Audit and Registries Management Service in NHS Digital, collects and collates data from many sources for audits for many different areas: the National Diabetes Audit, the National Bowel Cancer Audit, Pulmonary Hypertension, Out-of-Area mental health Placements, and of course the National Oesophago-gastric Cancers Audit (NOGCA). Because of the similarities of stomach cancer and oesophageal cancer and their treatment regimes, these two are studied together.

NOGCA collects data from all patients diagnosed with OG cancer and links it to other data, such as mortality and

chemotherapy data. This rich data source is analysed and report published each year. The audit is able to identify: the outcomes of care; whether care meets national guidelines; and variations in practice, for example chemotherapy regimens. By identifying variations, the audit prompts national clinical discussion and facilitates the sharing of best practice.

The latest annual report was published recently and is available, along with previous reports and other resources, on the NOGCA website[3]. Some key findings in the latest audit include:

There is a need to investigate how to improve early diagnosis and investigate the reasons for high rates of diagnosis after emergency admission.

There is still a need to improve waiting times between referral and treatment

In line with clinical recommendations, the use of CT scans for initial assessment has increased, as has the use of PET-CT scans for patients being considered for curative treatment, though with some regional variation

There are regional differences in the proportion of patients managed with curative intent and in the types of palliative treatment used

There is still a high standard of surgical care in England and Wales[4] with low mortality rates after curative surgery.

By examining previous reports and data it's possible to see how the improvements in practice recommended by these audits are improving patient outcomes. These reports are, of course, generally aimed at the clinical community and for nearly everyone reading this (apologies for the sweeping assumptions) they will be difficult to understand. The charts are also unhelpful if you don't understand the specific data behind it and what they mean, so please don't start looking at them and start panicking.

A welcome innovation for the 2017 report was input from patients and a dedicated patient-focused supplement. This report is available on the NOGCA website.

The latest at the time of writing is still the 2017 one; the 2018 patient report is not yet complete but will be released in due

course. The OPA are developing stronger links with the audit and hope to be able to influence additional areas to study through increased patient experience feedback. You can begin to take part now by discussing this in your regional meetings and emailing OPA.AuditFeedback@icloud.com. CARMS have indicated they'd be willing to talk to other regional meetings about the audit, and I would be happy to discuss how we as patients can help

The photograph is of David with his father. His father died in August 2009 of oesophageal cancer. Three years later in 2012 David was diagnosed with oesophageal cancer and had an oesophagectomy. In the second article to be published in the newsletter in the Spring he will outline his experiences of oesophageal cancer and query whether hereditary factors may be of relevance.

Links:

NOGCA main website [<https://www.nogca.org.uk/>]

NOGCA 2018 Audit Report [<https://www.nogca.org.uk/reports/2018-annual-report/>]

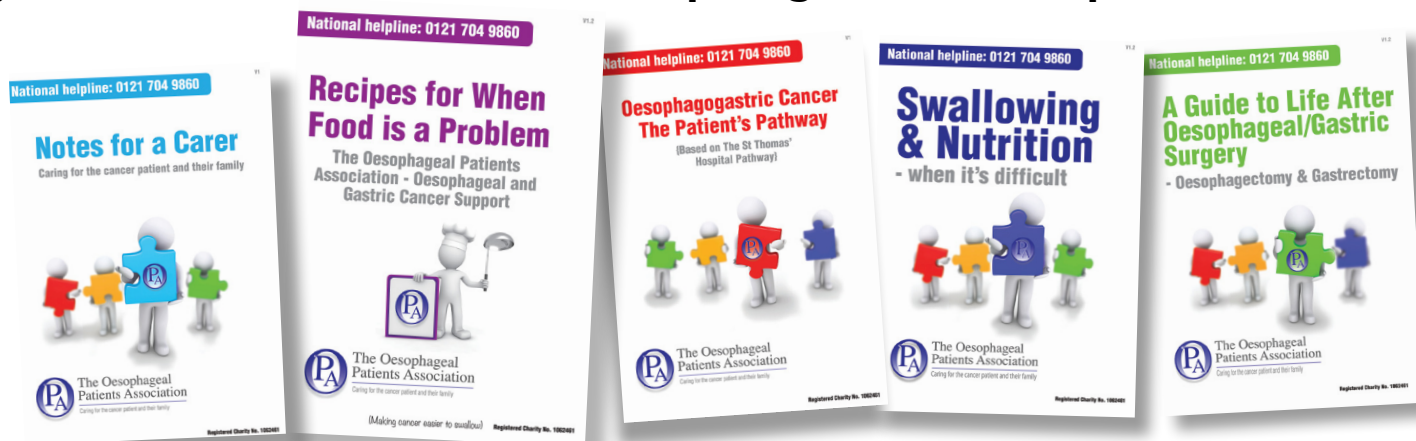
NOGCA 2017 Audit Report [<https://www.nogca.org.uk/reports/2017-annual-report/>]

NOGCA 2017 Patient Report [<https://www.nogca.org.uk/reports/2017-patient-report/>]

- (1) in full compliance with all laws and guidelines; primarily for patient care but also for payments, costings and performance
- (2) Patient Objections. For more information, please see <http://nhs.uk/your-nhs-data-matters>
- (3) Relevant weblinks are available on the OPA website.
- (4) NOGCA 2018 p39, Key Finding 2 and recommendation

Helpful guides from the OPA

Our great range of informative and helpful booklets and guides, you can also order online at: www.opa.org.uk/sections/opa-literature.html



Our booklets are widely distributed free of charge to the NHS Hospitals, Maggie's Centres, Health Care Professionals, Macmillan, patients carers and their families.

Forthcoming meetings

3rd November 2018 - Exeter (Regional Meeting) - 10:00
Dave Chuter OPA Chairman visit
The Kenn Centre, Kennford, EX6 7UE

15th November 2018 - Nottingham - 13:00 - 15:00
Maggie's Centre, City Hospital Campus, Gate 3, Hucknall Road, Nottingham, NG5 1PH

30th November 2018 - Exeter - 13:00
The Force Centre, Exeter, EX2 5DW

1st December 2018 - Derby - 09:45 - 12:00
Hilton Village Hall, Peacroft Lane Hill, Derby, DE65 5GH

1st December 2018 - Portsmouth and South Hampshire - 10:00 - 12:00
E Level Education Centre, QA Hospital, Southwick Hill Road, Cosham, Hampshire, PO6 3LY

5th December 2018 - Brighton - 14:00 - 16:00
Charles Neville Room, Peacehaven Town Council Offices, Meridian Centre, BN10 8BB



Place your Christmas Card Order Here...

You can order your OPA Christmas Cards by calling 0121 704 9860, posting this order form and sending with a cheque to: OPA, 50 High St, Henley-in-Arden, Warwickshire, B95 5AN or email the order to us: enquiries@opa.org.uk or via the shop online.



'Snowfall, Hockley Woods, Essex' from a painting by Christine Muckley,

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- 20 Cards £30.00
- 50 Cards £60.00



'Bluetit', from a painting by Christine Muckley,

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'Snowfall, Southend-on-sea, Essex' from a painting by Christine Muckley,

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'Winter Scene, Leigh-on-Sea, Essex' from a painting by Christine Muckley,

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'Winter Robin', from a painting by Christine Muckley,

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'Snowfall, Thorpe Bay, Essex', from a painting by Christine Muckley,

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- 20 Cards £30.00
- 50 Cards £60.00

Please send your payment together with a tick against the card(s) you wish to order to: OPA, 50 High St, Henley-in-Arden, Warwickshire B95 5AN or email the order to us: enquiries@opa.org.uk

Please make all cheques payable to the OPA, or pay online:
Account number: 02301636
Sort Code: 40-42-12,
or via our website:
www.opa.org.uk/sections/christmas-cards.html



Full set of designs

- 6 Cards (one of each Design) £9.00
- 12 Cards (two of each Design) £18.00
- 24 Cards (four of each Design) £36.00
- 48 Cards (eight of each Design) £58.00

Christmas Card Order Form

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Amount enclosed for order:.....



Donation Form

I would like to make a donation of £

For online donations: Account number: 02301636. Sort Code: 40-42-12. For standing orders: Account number: 51354973. Sort Code: 40-42-12

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Tel:..... Email:.....

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