



OPA News

FIGHTING OESOPHAGEAL, GASTRIC CANCER & RELATED CONDITIONS

www.opa.org.uk

Christmas Issue 2017

Official Office Opening

by our Patron - Fiona Wade



LONG running TV soap Emmerdale was in Henley in Arden, when actress Fiona Wade, who plays Priya Sharma, made a special appearance at the Oesophageal Patients Association's (OPA) head office.

Fiona is patron of the association and was in town to open our new UK base on High Street.

She said: "I was honoured to be asked to open these new offices and to continue to support the work of the Oesophageal Patients Association."

"I lost my father to oesophageal cancer, and I had never heard of this type of cancer before and always feel that if we had been more aware of Oesophageal Cancer and reflux disease then, for sure, earlier diagnosis would have made a huge difference and maybe saved his life."

Around 8,750 people are diagnosed with Oesophageal Cancer each year in the UK. It's become more common over the last 40 years and is now the 13th most common cancer in adults.

The OPA supports patients and carers diagnosed with Oesophageal and Gastric Cancers across the UK.

The new offices will form the base for our helpline and online support system, as well as the co-ordination of early diagnosis awareness campaigns and local support groups across the Midlands and the UK.

Article by the Stratford Herald

Find out about the Fiona Wade Appeal on page 5

OPA Christmas Cards are here!

Find out how you can get yours, see back cover..



Bite-Size Groups update

We can now report the following exciting news!!

Our first couple to hold a bite-size meeting was Ted and Annie Turner who are based in Kent.

Here is their story.

The meeting was held at the Costa Coffee Shop in Dartford, we were surprised at the interest shown & distance they prepared to travel in order to meet. After introducing ourselves, we talked about our conditions and where we are at now. It was interesting how they dealt with the after effects of their treatments. Finally they all said how important this meeting has been and will be in the future.

The OPA will continue this initiative – our aim is to help create bite-size groups, moving away from the larger Hospital Groups for the benefit of those who do not have the time, energy, resource to attend the much larger Groups set up around the country. This is your opportunity to attend smaller more informal groups that you have been asking for! Some great people have expressed an interest in trialling small groups and we have had expressions of interest from many areas that we are currently following up, updates will be provided in due course. Thanks to everyone who has offered their support to the OPA!

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 and can also arrange to visit your first meeting. For further information please call 0121 704 9860 or email enquiries@opa.org.uk

Benefits of support groups

In a support group, you'll find people with problems similar to yours. Members of a support group typically share personal experiences and offer emotional comfort and moral support. They may also offer practical advice and tips 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.

Bob Mason - Retirement as Chairman (14th October 2017).

It has been a great privilege to serve as Chairman of the OPA for the last three years. I have enjoyed meeting members around the country and been extremely impressed by their commitment and support to each other as well as the organization. Starting with the Pearl anniversary we have: -

1. Developed groups in all the constituent parts of the UK.
2. Increased awareness of the disease through REFLUX and our links with AAH.
3. Provided new booklets for many aspects of OG cancer which are free to all.
4. Encouraged mentoring of new patients
5. Provided patient representatives to national bodies such as NICE (Dave Chuter is the OPA

NICE representative).

6. Subsidised foam wedges to prevent reflux

None of this would have been possible without the major contribution of the trustees who give freely of their time and experience. The move to our new offices in Henley in Arden has been a great success and enables Maggie and Drew to improve, if that is possible, the superb personal service they deliver to all our members. Without them there would be no OPA. I wish my successor Dave Chuter all the best in the future and am sure he will guide the OPA forward with great success.

Bob Mason - Chairman OPA

Manchester Royal Infirmary

Great that this Hospital is raising funds for the OPA!

A BIG "thank-you" to Calulla Nulty and all of the Upper GI team: including Consultants, CNS's, Staff on Ward 11&12 who are based at Manchester Royal Infirmary along with previous patients are working together to pedal the distance from Lands End to John O'Groats and back again (approximately 2000 miles). Via static bike on the ward.

Please help us to achieve our goal by donating whatever you can, or even calling up to the ward and working up a sweat to raise funds for wonderful Charity the OPA who work so hard to provide a helpline, patient support information and much more!

If you would like to donate, follow these links
<https://www.justgiving.com/fundraising/upper-gi-team>
<https://www.justgiving.com/fundraising/have-you-the-stomach-for-it>

Put the FUN In FUNdraising

British
Costume
Association

Sean Cole

The Dave Owens & Frank
Goodall Memorial Fund

Vanessa McBain

Karen Edwards

Gerard Mitchell

Wendy Adams

Birmingham
Exhibition
Lions Club

Cavell Shone

Louise Letman

The James Tudor
Foundation

Dogs Home Trust

Peter Robinson &
Sandra Denham

The Wellington Pub

Michael Spacey

Shropshire Past Lady
Captains Society

Our special thanks
to Hilary Ryan for her
legacy donation and
our best wishes
to her family

Heather Doe

Neil Rushton

Daniel Leng

Francesca Jayne

And anyone we may have missed.

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

Castle to Castle challenge in aid of Oesophageal Cancer research



The OPA raised a whopping £15,000 to fund new Oesophageal Cancer treatment at Belfast City Hospital, Northern Ireland. This involved a cycle ride of over 25 cyclists between Carrickfergus Castle and Ballycastle and back. Total funds now raised is over £40,000.00.

Oesopho^ocycle
Supporting Oesophageal and Stomach Cancer Patients in Northern Ireland

**Offer still available!
Over 500 wedges issued**

Bed Wedges

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

Thanks to The James Tudor Foundation we have been able to extend our Bed Wedge 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.

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 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.

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.

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.

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.



Now in stock!

Our great range of informative and helpful booklets and guides



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

Restaurant & Toilet Cards



These restaurant & toilet cards are a must for patients, available in a multitude of languages, this can help when eating out in the UK or abroad, Languages available:

- English
- Dutch
- French
- German
- Greek
- Italian
- Polish
- Portuguese
- Spanish
- Turkish

We can supply these for you, but if you have booked a holiday, dont leave it too late.



We are delighted to announce the launch of the Fiona Wade Appeal for the Oesophageal Patients Association. With wristbands to help raise awareness of Oesophageal Cancer, there will also be a number of videos for you to view/ share.



You can get your wristbands by emailing us at enquiries@opa.org.uk or give us a call on 0121 704 9860. Our thanks to Fiona for helping us to raise the profile of this devastating disease.

Neil swims to raise money for the OPA



Neil, a keen swimmer has raised over £5000 for the OPA already after his wife was diagnosed with an oesophageal cancer. He plans to swim 100km in seas, lakes and pools by December 2017.

Neil says "We've called this cancer Deirdre (Apologies to all human Deirdres!). She has absolutely no place at our wedding in September and we plan to fundraise for OPA to help others." - the wedding took place on 2nd September 2017.

Family and friends have also been extremely generous by donating to the OPA as wedding presents for the couple and this has made a major contribution to the overall sum raised. - The wedding took place on 2nd September 2017.

Here is Ceri's story

At the end of last year, my partner Neil and I, went travelling around S America for over 4 months to celebrate his retirement as a GP. Just before we left, Neil went down on one knee and proposed, so suddenly we were planning a huge wedding as well as our great adventure. It was a wonderful trip which we labelled our 'pre-wedding honeymoon'.

During our travels, I started getting problems swallowing food, and returning back to the UK, this became quite frequent, so we decided I should see my own doctor. She immediately referred me for an endoscopy at our local Exeter RD&E hospital, and the story begins.

Whilst taking the endoscopy examination, the physician also took a small biopsy from the base of my oesophagus which was tested and confirmed that I had oesophageal cancer. It's a funny feeling because, in a way, I'd already guessed. My mother died of throat cancer when I was 20 and I was identifying similar problems, so the diagnosis confirmed my suspicions. I'd suffered from reflux most of my life, so I was aware that my oesophagus was being damaged in some way.



Now!! The wedding? We had 220 people, some of whom had booked flights from as far as Australia, USA, Uruguay and more. We couldn't cancel, and we didn't want to. No matter what state I was in, we decided the wedding would go ahead.

As the wedding day approached, I couldn't believe how well I felt. My medical 'team' were all very happy with my fitness levels at the start of all this which was a great help apparently. I had chemo every Tuesday and radiotherapy 5 days a week, Mondays-Fridays.

The day of the wedding was the happiest day of my life and the most successful wedding. I was marrying this wonderful man I'd lived with for 7 years and we felt the whole world was happy for us.

I feel very lucky to have my new husband Neil holding my hand though all this. My 2 children have been wonderfully supportive, as are all our family and friends. The medical staff all through have been a fantastic and cheerful support and became so excited about our wedding. I've also met some lovely fellow cancer patients who may become friends when all this is over. I hope so.

Life is most definitely for LIVING!!

The OPA wants to say a big thank you to Neil, Ceri and his family and friends!
If you would like to read more about Neil's story and donate too, please visit the BT Donate page:
mydonate.bt.com/fundraisers/neilrushton1
Read my blog at: <https://ceriblogblog.wordpress.com/>

Get Social!

We are raising the profile of the OPA on social media, so why not get involved, you can follow, comment and share! - The more followers we get the higher the OPA's profile and the more patients, carers and their families we can help:



Facebook
opa.org.uk



Twitter
opa.org.uk



YouTube
Oesophageal Patients Association

Edinburgh Meeting

A first meeting has been organised by the OPA & Maggie's Centre Edinburgh which was held on Thursday 28th September 2017.

The meeting was attended by over 60 people and everyone thoroughly enjoyed it. Haward Soper was presented with the finished OPA Scarf which was designed and created by Jolene Guthrie, Heriot Watt University, Galashiels. We have had excellent feedback from the Surgeons Simon Patterson Brown and Peter Lamb, their Upper GI Nurses and the patients, carers who attended. We propose another meeting to take place.

We will update you in due course.



Ref-Lux - BLOWING THE WHISTLE ON CANCER



The aim of this OPA awareness campaign is to educate the public, pharmacists, and GPs about the early signs for oesophageal cancer: heartburn, indigestion and food getting stuck; we know that only 30% of patients get curative treatment. Hence 70% of them are incurable.

Ed Cheong and Sammy Morgan attended a local football match in Norwich. The two teams Mulbarton and Harleston were playing for the Don Frost Memorial trophy. Ed was invited to speak to the spectators and the Swizzel whistles were blown just prior to kickoff to promote the campaign.



Sammy Morgan, former international footballer & Ref-Lux Supporter



Dave Chuter - our new Chairman

As a patient now 11 years post-op who had no access to or knowledge of patient support at my diagnosis which I found so hard as so many questions which the clinical team could not answer. When a meeting was set up by my hospital and hosted by David Kirby of the OPA, a couple of months after my surgery I jumped at the chance to attend and find out how others were living with the complete change of life my treatment caused. This showed how much help was available to patients and their loved ones that I worked with my consultant to set up a support group in Guildford as so many were being diagnosed and treated locally. We celebrated 10 years of support last year.

My passion is to ensure all patient and family members have access to support right from the point of diagnosis, through treatment and afterwards living with the effects of their cancer and treatment.

I have worked with the OPA as a local branch coordinator for the last 10 years and recently became a trustee.

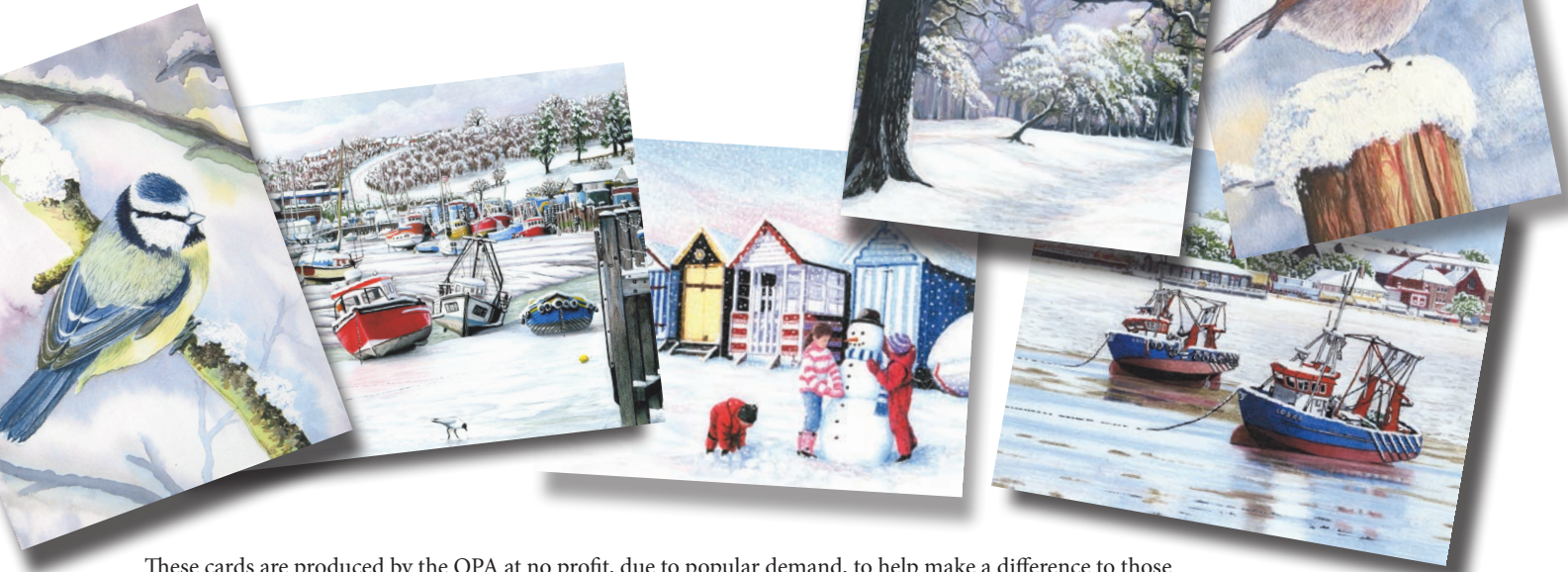
To be nominated and offered the role of Chairperson is an honour, to follow Bob Mason's great work as chairman is going to be hard, but I believe I have the passion and experience of patient support gained by running a local group and by being involved with research.

The OPA aim is pure patient & loved ones/family support, knowledge and experience from diagnosis to survivorship from people who have already travelled this pathway and from the best clinical teams available. Millions are available for research of best treatment and drugs, hardly anything for long term support and care of patients, this is what the OPA are good at and we need to ensure it continues and is funded as much as possible. The OPA can help save lives with involvement to early awareness (RefLux Campaign), reviewing and contributing to NICE treatment guides regarding quality of life from the patient experience and by patient to patient support instead of funding clinical research.

Dave Chuter - Our new Chairman

Christmas Cards

we have 6 wonderful seasonal designs to choose from...



These cards are produced by the OPA at no profit, due to popular demand, to help make a difference to those touched by this devastating disease. We welcome your generosity in giving what you can as a donation, so we can continue to provide help and support for Patients, carers and their families.

Order Form

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.



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

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



'Bluetit', from a painting by Christine Muckley,

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



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

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



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

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



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

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



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

- 5 Cards £7.50
- 10 Cards £15.00
- 20 Cards £30.00
- 50 Cards £60.00



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

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 web-site: www.opa.org.uk/pages/donations.html

Name:.....

Address:.....

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

Amount enclosed for order:.....Donation amount to OPA.....

Total amount enclosed: £.....

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

