



The Oesophageal Patients Association
Caring for the cancer patient & their family



www.opa.org.uk FIGHTING OESOPHAGEAL & GASTRIC CANCER Spring Issue 2019

Exciting News about our Patron & Emmerdale Star

Emmerdale's Fiona Wade exclusively discusses 'perfect' proposal from co-star Simon Cotton after engagement announcement – and reveals all the details on the big day..



Emmerdale star Fiona Wade announced she's engaged to former co-star Simon Cotton in a romantic Instagram post at the beginning of the year.

Speaking exclusively to OK! magazine, the pair revealed that Simon got down on one knee at her family home in Hertfordshire – the place she feels closest to her father, who passed away 14 years ago.

"We need to move quickly as we're hoping to get married in October. I don't see the point in waiting around, and in my faith people get married quite quickly."

Fiona added: "We're still finalising the guest list, but my on-screen family will definitely all be invited."

Fiona joined ITV's Emmerdale in 2011, and Simon had a part on the show playing an estate agent.

The actor is also known for starring as Ronnie Kray in The Rise of the Krays and the Fall of the Krays.

The pair went public with their romance just six months ago, with an adorable snap of them cuddling in a field.

Article provided by OK Magazine Copy and images © OK Magazine 2019.

We would like to extend our sincere congratulations to Fiona & Simon and thank her for all she does for the OPA!

A few words from Fiona...

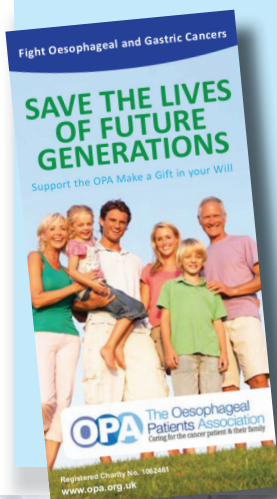
I lost my Father to oesophageal cancer. He was such an amazing person, the best father I could ever wish for and it was so sad and shocking when he was diagnosed. I had never heard of his type of cancer before and I always feel to this day that if we had been more aware of oesophageal cancer or reflux disease then, for sure, earlier diagnosis would have made a huge difference and maybe saved his life.

Early diagnosis by spreading awareness is absolutely

key in saving lives from this cancer. So please help us carry on doing all we can to make people more aware and help us to save lives and to support every single patient who needs our help.

You can support The OPA by making a gift in your Will; one of the most effective ways to help ensure that our fight against oesophageal and gastric cancers continues our mission to save the lives of future generations.

Find out how you can help the OPA by leaving a gift in your will, visit <https://www.opa.org.uk/donations.html>



Charity No. 1062461

National Oesophago-Gastric Cancer Audit: 2018 Patient Report

Publication of the National Oesophago-Gastric Cancer Audit's 2018 Patient Report.

The National Oesophago-Gastric Cancer Audit (NOGCA) evaluates the quality of NHS hospital care in England and Wales for people diagnosed with oesophageal or gastric (OG) cancer.

NOGCA has recently published its annual Patient Report which highlights key findings from the 2018 Annual Report and describes the care that most patients can expect to receive in NHS hospitals. The report is designed to provide patients and their family members with information about the various treatments that patients can receive after being diagnosed with OG cancer.

The Patient Report is available as a pdf via this link: www.nogca.org.uk/reports/2018-patient-report/ Each year, NOGCA publishes an Annual Report to help hospitals to find out what they are doing well and to identify aspects of care that could be improved. For example, the report describes the typical length of



hospital stay and short-term survival after surgery, both of which have improved over the last decade. The 2018 Annual Report also showed regional variation in the use of non-curative treatments such as palliative chemotherapy and radiotherapy.

The audit team welcome your feedback on the 2018 Patient Report and your suggestions for future reports. If you have any comments, ideas or suggestions, please email: og.cancer@nhs.net. The OPA is represented on the Audit Steering Group by Trustee John Taylor.

Bed Wedges - Price Increase



The OPA is continuing to put £12.50 per pillow towards this partnership and Putnams have, on top of that, agreed to a generous discount. The new standard retail price is £59.66, so you pay £31.50 – which is still saving over 48%!

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 <https://www.putnams.co.uk/collections/bed-wedge-pillows/products/bed-wedge>



The OPA Designer Scarf

The new OPA charity scarf was designed by Jolene Guthrie, a Masters knitwear design graduate of Heriot Watt university. The objective was to design a scarf that enhanced the wellbeing of patients suffering from Oesophageal cancer by making them feel special whilst wearing her unisex design and feel comfort from it too. The beautiful scarves have now sold out.

We would like to thank Jolene Guthrie, Jane Robertson and her team at Heriot Watt University, Edinburgh for their support. Funding for the scarves was kindly donated by Celia Murray.

Jolene's details are below:

Website - Jagknitwear.com

Social Media - [Instagram.com/jagknitwear](https://www.instagram.com/jagknitwear)



Keeping it in the family

Part 2 of David Eaves' Story

David Eaves is a member of the Leeds branch of the Oesophageal Patients Association since October 2012. Here he discusses his experiences, his work, and a topic close to his heart: whether there are hereditary factors.

I underwent my surgery in Leeds in June 2012 following diagnosis in February and treatment in April and May. Classic symptoms (difficulty swallowing, having to bring it back up, hiccups, pale appearance due to massive iron loss, fatigue) actually began in the previous October, and I knew then what they were and what it meant. Nonetheless, I didn't want to be undergoing treatment over Christmas, because my mum was coming to visit from Stornoway where I grew up and she still lives. I managed to conceal the symptoms during Christmas dinner, which was quite an achievement. But how did I know, and why would I go to those lengths?

In August 2009, Dad died from Oesophageal cancer. Symptoms first presented earlier in the year but not knowing what it was (and being a Scottish man in his late 50s, not wanting to bother the doctors), he tried to manage the symptoms himself – cut food up smaller, chew more times before swallowing, eat more slowly, change diet. By 2006 it could not be self-managed, prompting a call to NHS24 (the Scottish equivalent of 111), an overnight hospital stay for monitoring, and tests the next day. Diagnosis was essentially immediate with a "terminal" prefix shortly after. But he stubbornly took all the treatment offered to him until two weeks before he died, when he wrote his final diary entry: "No more chemo". The last day of my holiday back home, and the last time I saw him.

Of course, it made no difference what time of year it was when I'd tell Mum that it was my turn. It is still the single hardest thing I've ever had to tell anyone, and because she was 500 miles away it had to be over the phone. A lot less than ideal.

Thoughts invariably turned to what caused it. Random bad luck? Chernobyl, since the fall-out in 1986 affected the North West of Scotland? Lifestyle? Hereditary? I asked at clinic and it was thought then that no, it wasn't. My tumour was right at the oesophago-gastric junction and Dad's

was further up, and if it was hereditary it might have been expected to have been closer.

Since my involvement in the OPA, though, I've come across many more people who have relatives who have been affected. A retired magistrate in London whose father sadly succumbed many years ago, who himself has had successful surgery in the recent past and whose son was at that time facing treatment; a lady from Lincoln whose mother had been ill and whose daughter was suffering from Barrett's; and word just a few hours before beginning to write this of a recent patient in North Yorkshire whose brother was facing surgery too. Are we the unlucky families? My father's uncle died long before I was born. In those days cancer wasn't as openly discussed as now. Was that cancer and what kind was it? My brother was recommended by a GP friend of mine to have a preemptive endoscopy. He hasn't, but his GP knows that if he feels one is needed it will be prioritised. We know that for many cancers there are known and definitive familial links, including breast, ovarian and stomach cancers. Is it the same for oesophageal cancer, so closely related as it is to stomach cancer?

Statistically we have less-than-fantastic survival rates. If you're a patient who's survived surgery and are still going through the mill learning how your new "you" copes with what used to be the most simple of things, you are one of the extremely lucky and successful ones, even if it doesn't feel like it. I know this, all too well, but it isn't always easy to believe.

Because of these survival rates and the poor detection rates for oesophageal cancer, especially historically, there might not be as much information that would help or have helped those of us who have had family members go through this before us. If data were collected when our mothers or fathers or aunts or uncles were diagnosed, it might not be that vast or of good quality. I don't think there's ever been enough of us to be studied. But the data are there now and both quality and quantity have been improving year on year. If a study is done and a familial link found, our sons and daughters, nieces and nephews should be able to benefit from earlier intervention.

Prevention of oesophageal cancer; with aspirin and acid suppression.

AspECT: A PHASE III, RANDOMISED STUDY OF ASPIRIN AND ESOMEPRAZOLE CHEMOPREVENTION IN BARRETT'S METAPLASIA
by Professor J A Z Jankowski. MBChB, MSc, MD, PhD, PGCE, PGCM, SFHEA, FRCR, FACC, AGAF.



The Aspirin Esomeprazole Chemoprevention Trial (AspECT) is to our knowledge one of the largest cancer prevention trials using aspirin and acid suppression in the world. In total 2557 patients with a common precancerous change in their oesophagus, called Barrett's oesophagus, were followed up for an average of 9 years resulting in over 20,000 life-years of follow up. After informed written consent, patients were randomly allocated to four different combinations; Low acid suppression alone, High acid suppression alone, low acid suppression with 300mg aspirin and high acid suppression with 300mg aspirin. We wanted to see if we could prevent progression to local cancer/cancer in-situ (high grade dysplasia), invasive cancer or prevent death by all causes both cancer and non-cancer.

To do this the patients were contacted annually by phone to assess how they were and endoscoped every 2 years to see if there were any changes in their oesophagus.

The main findings of the trial were that

- High dose acid suppression significantly prevented progression to high grade dysplasia, cancer and especially all causes of mortality.
- Aspirin also had an effect on these endpoints but only when patients who received non-steroidal antiinflammatory drugs e.g. brufen were removed from the analysis prior to use.
- The combination of high dose acid suppression and aspirin had a combinatorial effect i.e. worked better than

either alone.

d) The safety of these agents over the 9 years was exceptional as <1% of patients had serious adverse events linked to the medications.

In summary we showed that taking high dose acid suppression significantly benefitted 1 in 34 patients in this way whereas aspirin benefitted 1 in 43 patients. This trial is also unique in that it looked at the combination of cancer prevention agents.

The trial is now being assessed by the National Institute for Health and Care Excellence in the UK to see if National Guidelines need to change.

What does this mean for you if you have the condition 'Barrett's oesophagus'?

Firstly, a higher dose of proton pump inhibitor (PPI) such as Esomeprazole is necessary to improve outcomes - even if on the lowest dose (e.g. 20mg of Esomeprazole) symptoms are effectively relieved. In the AspECT trial we showed that 40mg twice a day of Esomeprazole was more effective than 20mg daily in improving survival - whether due to reducing cancer, or any cause of death at all. This is important, as there have been several reports of PPIs being associated



with an increased risk of cardiovascular and cerebrovascular diseases, such as heart attacks or memory loss respectively, as well as respiratory infections (all of which are commoner among people with Barrett's oesophagus). We did not show this in AspECT, in fact the opposite: all causes of death were less among those on the high dose. We would recommend a minimum of 40mg per day of tablets like Esomeprazole.

Secondly, Aspirin showed a positive effect, particularly on high grade dysplasia (severe pre-cancer) in Barrett's, though the effect was less marked than for high dose PPIs. This is probably because the numbers of participants in the Aspirin/ no Aspirin comparison were fewer, giving the comparison less strength to definitively confirm an effect (though a positive effect seems likely from these results and other published evidence). We don't yet know the best dose of Aspirin (we used 300mg), nor who benefits most, nor how long it should be taken for. We plan to investigate this in further research and



we are asking NICE to consider all the evidence in order to make a recommendation about whether Aspirin should be given to patients with Barrett's oesophagus in combination with a PPI. Certainly the combination was very safe in the AspECT trial.

For those who have been on Aspirin in AspECT, it may be that the effect will last even when Aspirin (given as part of the trial) was stopped at the end of the trial. For those not on Aspirin we are not yet sure what to recommend - NICE may come up with a more definite recommendation.

Finally we are planning to follow up the AspECT patients in the new AspECT EXCEL clinical trial to start in January 2020. We encourage all patients in AspECT to take part just for follow up so we can definitively address the long term risk benefit of combined acid suppression and low dose aspirin cancer prevention.

We plan this to be the first of a number of reports on the progress of current trials. Dave Chuter the Chair of the OPA Trust is a reviewer of the TV3 Marató cancer project. John Taylor is a member of the National Cancer Research Institute oesophago-gastric sub group.

New Look New Logo!



The Oesophageal
Patients Association
Caring for the cancer patient & their family

To complement the amazing work being carried out by the OPA, our supporters, patients, fundraisers and groups, we have re-branded!

The new logo was designed by Expressive Design with the help of Maggie, Drew and consultation with the Trustees, we looked at a number of alternatives but really liked the way the final logo choice reflected our ethos.

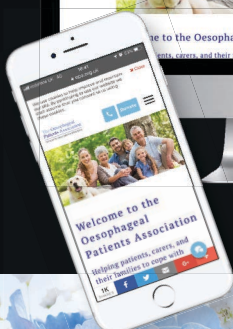
The OPA is all about patients, carers and their families and with the three letters representing our organisation

name it is clear that we are OPA, the circles linked together indicating a close bond with those we help and a nurturing and supportive quality with a modern feel.

We really hope you like our new look and are excited to roll out our new branding in future fundraising packs, activities and communications!

The OPA is a growing support charity working hard to ensure improvement wherever possible, particularly in the information we provide to those we help and support.

Shop online!



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

You can get online at www.opa.org.uk/shop.html

The OPA has now launched an online OPA Shop where you can order all of our literature, merchandise and Fiona Wade wristbands etc. This includes our five booklets, OPA A Guide to Life After Surgery, OPA Swallowing and Nutrition, OPA Recipe Book, OPA Patients Pathway, OPA Notes for a Carer, What can I eat now? DVD and much more.

We produce many thousands of our booklets as a valuable reference to patients, carers and their families, all booklets are supplied free of charge and paid for by the OPA. We would be grateful for any donations you could make so we can continue to help those who need it.

www.opa.org.uk/donations.html

Imperial College London



Exploring patient perception of Quality of Surgery in Clinical trials – Focus Group Research Study St Mary's Hospital, Praed Street, London W2 1NY.

Principle Researcher James Butterworth, MBBS BMedSci MSc (Hons) DIC MRCS (Ed), Clinical Research Fellow, Department of Cancer and Surgery who is based at Imperial College London would like to thank the OPA, John Campolini (London Coordinator) and OPA members for their overwhelming support of the Research Study that took place on Friday 8th February 2019, it was a great success!

Thank you to our supporters and fundraisers



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

Adventure Challenges

www.opa.org.uk/adventure-challenges.html

CAN YOU raise funds for the OPA and at the same time enjoy the fantastic thrill of a hard physical challenge.

By taking part in one of the UK or overseas challenges you will make a huge difference by helping The OPA to support more patients.

Every single pound you raise goes directly towards helping men and women, young and older, who are having to cope with the devastating effects of

oesophageal or gastric cancer.

Check out some of the highlights for 2019 below or check out the Global Challenges website for more information and many more adventures here in the UK and abroad.

SOME OF THE TOP CHALLENGES



Snowdon at Night - UK



The Lapland Husky Trail
Norway / Sweden



Unite and Bike against Cancer
Kerala Cycle - India



The OPA have joined Virgin Money Giving

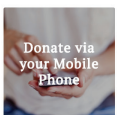
<https://uk.virginmoneygiving.com/charity-web/charity/finalCharityHomepage.action?charityId=1014992>

Virgin Money Giving enables you to fundraise online quickly and simply. With Virgin Money Giving you can raise money for the OPA, via a personal fundraising page which you can share on social media in just minutes.

You can also make a single donation as well as a monthly donation to the OPA via the OPA's Virgin Money Giving page!

Virginija Dainauskiene is our first supporter on Virgin Money Giving, she is competing in the London Marathon 2019!

Other ways you can donate to us:



Please note you can no longer raise funds for the OPA via My Donate. My Donate is closing down on Sunday 30th June 2019.

Forthcoming meetings

Saturday 8th June 2019

Guildford Support Meeting/AGM - 10.30 for 11:00 – 15:00

Holiday Inn Guildford, Egerton Road,
Guildford GU2 7XZ

Saturday 8th June 2019

Derby Support Meeting 10:15 – 12:30

Hilton Village Hall, Peacroft Lane, Derby, DE65 5GH

Saturday 15th June 2019

Portsmouth Support Meeting - 10:00 – 12:00

E Level Education Centre, QA Hospital, Southwick Hill Road,
Cosham, Hampshire, PO6 3LY

Thursday 20th June 2019

Nottingham Support Meeting - 13:00 – 15:00

Maggie's Centre, City Hospital Campus, Gate 3, Hucknall Road,
Nottingham, NG5 1PH

Saturday 6th July 2019

Lincoln Support Meeting - 10:30

Wragby Town Hall, Louth Road, Wragby, Market Rasen,
Lincolnshire, LN8 5PH

Wednesday 10th July 2019

Brighton Support Meeting - 14:00 – 16:00

Charles Neville Room, Peacehaven Town Council Offices,
Meridian Centre, BN10 8BB

Thursday 18th July 2019

Nottingham Support Meeting - 13:00 - 15:00

Maggie's Centre, City Hospital Campus, Gate 3, Hucknall Road,
Nottingham, NG5 1PH

Friday 26th July 2019

Exeter Support Meeting - 13:00 – 15:00

The Force Centre, Corner House, Barrack Road, Exeter, EX2 5DW

For Standing Order Donations

By bank transfer

Recipient bank: HSBC Bank,
34 Poplar Road, Solihull, B91 3AF
Sort Code: 40 - 42 - 12
Account Number: 02301636

To make a donation visit:

<https://www.opa.org.uk/donations.html>

By regular Standing Order payment –

Sort Code: 40-42-12

Account Number: 51354973

I wish to make regular donations to the Oesophageal Patients Association of (tick appropriate box)

£2 £5 £10 £25 £100,

or other amount: _____

Please state amount in words:

every (tick appropriate box) Week Month Year starting on ___ / ___ / ___ until further notice.

Your bank details

To: (insert name and address of your bank) _____

Sort Code: ____ - ____ - ____

Account Number: _____

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:

I want to Gift Aid my donation of £ _____ and any donations I make in the future or have made in the past 4 years to the OPA.

I am a UK taxpayer and understand that if I pay less income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay.

Your Details

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ___ / ___ / ___

Any other Donations

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

Title: (Mr/Mrs/Dr etc.) _____ Name: _____

Address: _____

Tel: _____ Email: _____

Signature: _____ Date: ___ / ___ / ___

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



The Oesophageal
Patients Association
Caring for the cancer patient & their family

Please send this form to:
Fundraising Dept. The OPA,
50 High Street, Henley-in-Arden,
Warwickshire, B95 5AN
Or email to:
enquiries@opa.org.uk

For further information please
contact The OPA on 0121 704 9860
or email charity@opa.org.uk

Registered Charity No 1062461

