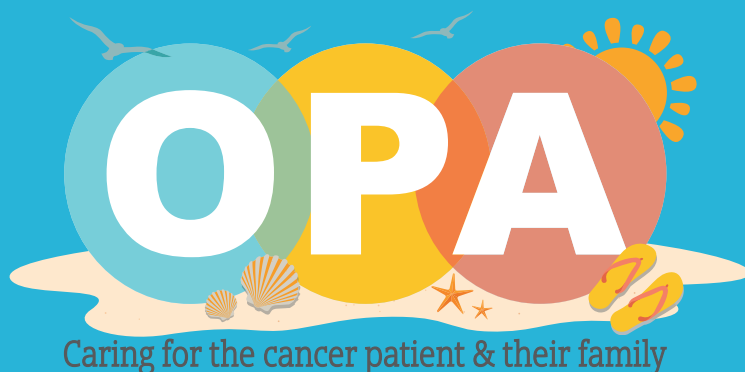


# Hello Summer







Oesophageal and Gastric Support



## OPA Summer Newsletter 2022

Welcome to the Summer Issue of the OPA Newsletter!

.....  
In this issue, you can catch up on all things new...

-  **New Trustee**
-  **OPA Teddy Bears**
-  **Fundraiser Stories**
-  **OPA Carer's Meetings**
-  **GORD Awareness Week Report**
-  **Could it be Cancer? –  
Article by John Campolini, OPA Chairman**

**And much more... happy reading!**



**Look who's come to  
visit the OPA!**

"The Jubilee Central Weekend took place from **2<sup>nd</sup> to 5<sup>th</sup> June** and the OPA saw some very special visitors! We hope that everyone had a great time!"

Scan the  
**QR Code:**  
To visit our  
website



# Welcoming Our New Trustee

In 2004, I was struggling to swallow so I decided to get checked out at our local hospital, following a trip to my GP. I then had chemo and a oesophagectomy in the same year. Less than a year later, I was told I had secondaries in my liver. Chemo re-started and the specialists decided on a dissection of the left lobe. After a long road to recovery, I am here to tell my tale and provide support, advice and hope to those going through the same.

The reason I offered my help to the OPA was to encourage people to speak about their diagnoses, prospects and to help, as well as give advice, hope and support as there is very little in the way of after care for oesophageal patients. For me, it has been a process of trial and error; therefore, it's about finding out what works best for people individually and offering them options that are not otherwise available.



Ron Lumb

## OPA Teddies

***We have a range of teddies with personalised OPA knitted jumpers and scarves, all of which were donated by Annie Brinkworth.***

New In  
Stock!

This love affair we have with teddy bears does not stop when we leave our childhood behind. Brits, it seems, are particularly fond of their bears and in one survey, it was found that up to 35% of British adults still take their bears to bed with them.

The study showed that these were primarily women who had kept their bears from childhood, treated them like friends, shared their problems with them and cuddled them during tough times. Interestingly, up to 25% of British businessmen admitted that they take their teddy bears with them on business trips.

***You can browse our range of teddies on the OPA Online Shop here:  
<https://opa.org.uk/product-category/opa-teddy-bears/>***



# Stories from our amazing Fundraisers!

## Let's eat pancakes!

"Here are a few photos from the fundraiser held on pancake day - the theme was butterflies. We had a lovely day and the money was raised from the residents and their families here at Derwent Grange sheltered housing.



I wanted to give back as the OPA had helped me with information about my operation for Oesophageal Cancer. It was totally out of the blue that I found out I had cancer but was lucky to have it be caught in time. I had my oesophagus removed three years ago and I really needed the help and support I got from you; my husband and I are extremely grateful.

I am recovering but life is a little different. Thank you." **Valerie Burgess**



## Virtual Charity Stream

This virtual gaming stream took place on Saturday 7th May 2022 to raise money and awareness for the OPA, in memory of Bectorious' father.

They smashed their target which was set at £250!

Three streamers took part in this amazing charity event with one goal - to raise as much money and awareness as possible for the OPA Cancer Charity.

The Twitch stream lasted 12 hours and included a pirate quest in an OPA custom ship, an online rescue mission and, what we think is the first ever Charity Triathlon held in the meta verse with the support of The British Enforcement GTA server.

### Names of the participant streamers:

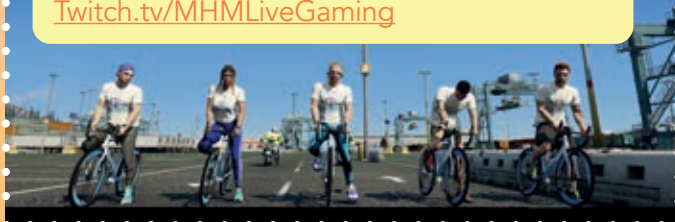
Bectorius, Mag the Duck, MHM Live Gaming.

**If you wish to follow them on their charity adventures, you can do so here:**

[Twitch.tv/bectorious](https://www.twitch.tv/bectorious)

[Twitch.tv/magtheduck](https://www.twitch.tv/magtheduck)

[Twitch.tv/MHMLiveGaming](https://www.twitch.tv/MHMLiveGaming)





# Ray Clark's Band Appeal 3

Saturday 14th June 2022 saw the Junction Theatre in Goole host the very special band Appeal 3 for the OPA fundraising evening

Composed of local lady Sally Mollan, the night featured several live acts including a series of acoustic covers by The Alcatraz Swim Team, two very talented musicians who had travelled from Leeds From York came Irish singer/songwriter Paula Ryan; a pop/rock trio called

Stagefright performed a number of 60/70's covers and had reunited specifically for the evening. Finally, following a twelve-year rest, sixties rock 'n' roll singer Ray Clark graced the stage.

Thank you so much to Ray Clark and everyone who took part and attended this amazing event.



# Thank you to all of our Fundraisers

Valerie  
Burgess

Natasha  
Carroll

Jade  
Hunt

Ellie  
Steers

Pat  
Lilleystone

Mag  
the  
Duck

Claire  
Green

Christian  
Von  
Schudnat

Bectorius

MHM  
Live  
Gaming

Rachel  
McKenna

Ray  
Clark

Jose  
Inacio

Jennifer  
Owen

Sunderland  
Benefit  
Centre

Sue  
Harrigan  
& Friends

Gary  
Mutimer

Louise  
R

Nick  
Wright

Teresa  
Jones

Thank you  
to all of  
our regular  
donors

Thanks for  
the continued  
support of our  
charitable trusts  
and foundations.



# Legacy Leaflet

**A message from our Patron - Fiona Wade:**

"Your legacy will help save the lives of future generations. Please consider making a gift in your Will to The OPA and help us continue our fight against oesophageal and gastric cancers.

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 to this day I feel 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 the key in saving the lives of people suffering from this cancer.

So please, help us carry on doing all we can to make people more aware and save lives and support every single patient who needs our help.

Thank you."



**Scan the QR Code:**  
To view the Legacy Leaflet



# Could it be Cancer?

**Heartburn can be a sign of something more serious**

*Are you suffering from heartburn, acid reflux or indigestion? If the answer is yes, please read on because taking action now could save your life!*

Let me start from the beginning. My name is John Campolini. I come from an Italian background and started my early life with my parents and sister in South London before eventually moving to Beckenham. As an Italian family, we did what most Italians did after the Second World War, and we made ice cream – gallons of it-which was sold to the general public from various outlets.

In 2013, I started to suffer from heartburn or acid reflux, especially at night and I bought some over-the-counter medication which had little to no effect. After a visit to my GP who prescribed a month's supply of medication with the words that if it did not improve, I was to return for further investigations. Well, I returned to my GP who ordered an endoscopy which although unpleasant, eventually helped save my life! After the first endoscopy, my consultant said that he had found nothing but wanted to bring me back in a year's time for a second endoscopy.

A year later, during that endoscopy, attended by my consultant who was watching his registrar examining me, my consultant took over and after looking at the scans on screen and ordered some biopsies. This was when I realised that I might have a problem. After having the medical equipment removed from my mouth, I asked my consultant, "Do we have a problem," to which his reply was a very short, "Yep"! He suggested waiting for the results of the biopsies and seeing him again in three days time, which I did. After exchanging pleasantries, he asked me if I had any ideas about what might be wrong.

**John Campolini**  
OPA Chairman  
since 2018



I told him that I thought I had cancer to which he responded that I was correct but also very lucky! Just being told I had cancer and then being told I was lucky was difficult to take in all at once.

He went on to say that the plan was not to treat me but to cure me and that my case had already been transferred to St Thomas' Hospital, London and my first appointment was in three days. I duly presented myself to St Thomas', was talking to a cancer specialist nurse when the door opened and in came a man who was ultimately to save my life, Bob Mason, one of England's authority on Oesophageal Cancer. We had a full and frank discussion regarding my position and he explained what he proposed to do surgically. So, a fair bit of plumbing had to be done! We spoke about timing for the operation we agreed on 11<sup>th</sup> of November 2014, which was Armistice Day. I presented myself at St Thomas' on the 10<sup>th</sup>, was prepared for surgery on the 11<sup>th</sup> and as I was about to be anaesthetised, I remembered that I might not wake up from the operation and said my prayers and asked the Good Lord to look after me which I am glad to say he did. The operation was a lengthy one and I was then put on life support, then transferred to the Intensive Care, then high dependency and then a general ward. After 4 weeks, I was finally home for Christmas complete with a feeding tube. Thankfully, the tube was removed 2 days before Christmas and I was able to have Christmas Dinner with my long-suffering family, even if it was a small portion.

**Continued on the next page...**

I then made a major mistake by having a small piece of Christmas Pudding which caused me no end of problems, stomach wise!

I had been told that I was to take some time off from work and that it would take at least 12 months to fully recover. I appealed for and received a 6-month leave from the Criminal Justice System ( I was a Presiding Justice at Camberwell Green Court) but returned after just 2 months, much to everyone's surprise, and a few years later, at the age of 70, I retired after 36 years of sitting in Courts.

Some time during this period, and during a routine check up at St Thomas' after Bob Mason had retired and his position had been taken over by James Gossage. One of the 4-man surgical team that operated on me, I was asked by James if I would consider joining the Oesophageal Patients Association as a Trustee. He explained what the OPA was and I remember my response exactly, " After all you have done for me, I can't refuse" and I became a Trustee and am now in my fourth year as Chair. At every opportunity, I do my best to make Oesophageal Cancer more well- known as early diagnosis and treatment can save lives. It is one of the most serious forms of cancer, because when the symptoms finally appear, it is often too late. Anyone who is taking medicine for reflux etc, should make sure they receive an endoscopy which at present is the best

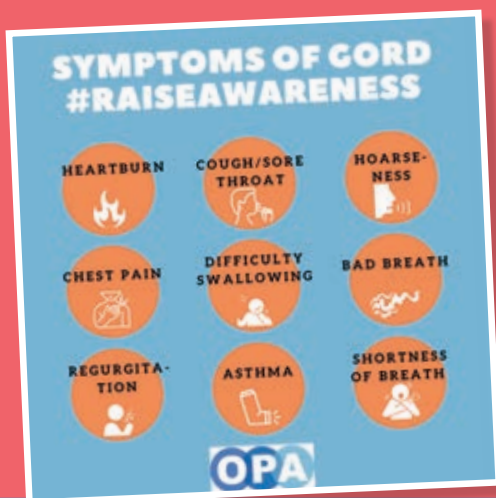
way of finding out if there is a problem.

Who or what is the OPA? The Oesophageal Patients Association is the largest national cancer charity support group for Oesophageal and Gastric Cancer.

Its website offers advice, booklets and more, free of charge to anyone asking for them. We have support groups up and down the country. Have a look at our website, the Oesophageal Patients Association - Cancer Charity (<https://opa.org.uk>) for plenty of useful details and contacts.

In the past year, we have handled thousands of emails from patients, carers and family members, hosted a number of Zoom meetings because of the lockdown and are about to restart face-to-face meetings in 2022, now that we have hopefully seen the end of lockdowns and can return to some normality.

My hope is that we can support each other in various ways such as meetings, having discussion groups, inviting specialist speakers to our meetings, making GP's more aware and asking for further investigations to be carried out for patients.



#### **\*Symptoms of Acid Reflux include:**

*Heartburn, indigestion, sour taste in the back of the mouth, regurgitation, chest pain or discomfort, chronic cough, sore throat and/or hoarseness, belching gas and bloating, trouble sleeping, intolerance to certain foods and nausea.*



**So, please visit the OPA website.**

Make sure you are referred if you have symptoms as described above and ensure that you seek medical advice asap – it really could save your life!



# OPA Carer's Meetings 2022

**Hosted by Liz (Carer) & Dave (Patient) Hair**

'We all have the same issues both as carers and patients and what was apparent was that the chance to talk to others in the same situation is very important. This cancer is not as well-known as others and the understanding from others is even less than those of us who have been through it.

Common issues are anxiety, diet, eating and digestion, worry and depression. Now that COVID-19 is somewhat under control, the anxiety about undertaking a journey, how to eat, sleep and deal with problems that come with surgery are at the forefront of the minds of the patients. However, it is reassuring to see that both long-term survivors and those who have recently undergone surgery are optimistic about survival.

To quote one patient, "We deal with what is in front of us and do the best we can". For carers it is about understanding and patience.

One of our carers deal with teenagers and finds they are more receptive to talking about cancer and issues around it than our friends and work colleagues. This raises the thought that talking to secondary schoolchildren about this issue could be quite productive in raising awareness.

Life does go on, and Dave and I keep as fit as we can, walking and enjoying our surroundings and our family. It is important to keep talking, spread awareness and focus on what is important in life. Cancer is a disease not a product of a way of life and can affect anyone.

*We will keep meeting, talking, and raising awareness'*



## **\*The OPA are looking for:**

Additional Carers/Dietitians who can host Zoom meetings, please contact us for further information.

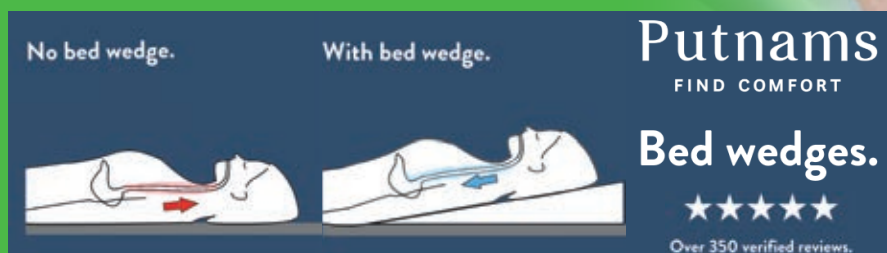
## Putnams Bed Wedge Pillow Special Offer

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

**The standard retail price is £72.67. So, the OPA has teamed up with Putnam Pillows to provide their standard Bed Wedge - Acid Reflux at an affordable price with a £24.01 discount, so you only pay £48.66.**

For more information, please visit:

<https://opa.org.uk/bed-wedge-special-offer/>



**ONLY  
£48.66**

# Acid Reflux Awareness Week 2021 Update

In November 2021, we launched the second successful UK Acid Reflux Awareness Week! With over 13% of the UK population suffering from Gastro-Oesophageal Reflux disease, we believe that raising awareness of the symptoms, how to get tested and what the various treatment options are is critical to maintaining a healthy oesophagus.

## Our key messages of the campaign were:

1. **Get Educated - Reflux is so much more than just heartburn. There are various symptoms that are associated with this disease and we wanted to make as many people as possible aware of this.**
2. **Get Evaluated - For some patients, diet and lifestyle changes are not enough to alleviate the symptoms and for these patients, we wanted to raise awareness of the different tests that patients can undertake to determine the exact extent of their disease so that the appropriate treatment plans can be offered.**
3. **Get Treated - We wanted to make sure patients were educated about all the different treatment options available to them in order to have an informed conversation with their GP or Reflux Centre.**

We partnered closely with Reflux UK, Functional GUT and Johnson & Johnson to raise awareness about this disease.

A designated space on our website was dedicated to the awareness week, and we delivered a comprehensive social media campaign that reached people across the country. Alongside social media, a free patient event was set up by the Functional Gut Clinic where patients could learn more about reflux from a Reflux Team that included a Clinical GI Physiologist, Jordan Haworth. Over 100 patients accessed this free virtual event and the feedback following the event was incredible.

We were able to increase our following on our social media channels and deliver our best website performances. In addition, we also sent materials to patients and healthcare professionals via Posters, awareness packs, newsletters and Mailshots.

We are looking forward to this year's GORD Awareness week where we will build on the success and learnings from 2021.



**Scan the QR Code:**  
To view the GORD Booklet



**ACID REFLUX IS A DISEASE, NOT A BAD MEAL CHOICE!**

- GET EDUCATED
- GET EVALUATED
- GET TREATED

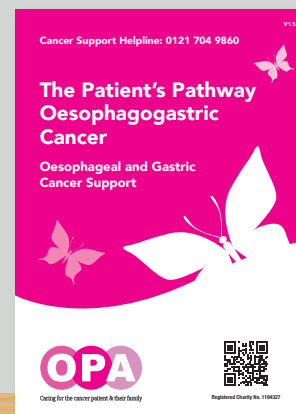
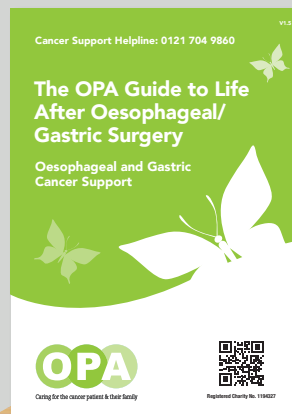


**GORD: A Primary Risk Factor**

While having GORD does not automatically lead to Oesophageal Cancer, it can increase your chances in several ways: Adenocarcinoma and Barrett's Oesophagus.

## Publications from the OPA.

We are here to help those with or affected by Oesophageal and Gastric Cancer. Thus, here are some of our helpful booklets, they are free and can be posted or downloaded from our website.

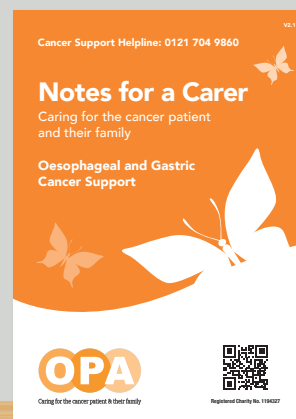
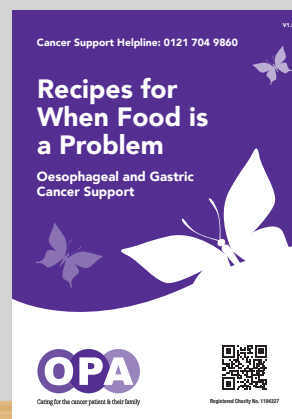
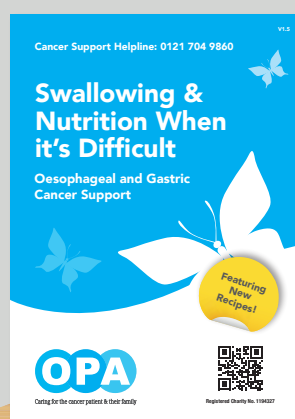


### A Guide to Life after Surgery

This is the OPA's most comprehensive overview of the surgical operation and the consequent life-altering pathway to the fullest possible recovery.

### The Patient's Pathway

This provides a brief overview of the stages of pre-operative preparations following a diagnosis of oesophageal or gastric cancer, the surgery itself and of recovery and post-recovery follow-ups.



### Swallowing & Nutrition

Possibly the greatest change to the lifestyle of the post-oesophagogastric surgery patient occurs with eating and digesting food.

### OPA Recipes for When Food is a Problem

This is a book of recipes and food ideas for people who may need to put on weight, have difficulty in swallowing, or who are living with the after-effects of surgery on their stomach.

### Notes for a Carer

Caring for a cancer sufferer or survivor is not a time-limited commitment, for which patience, understanding, empathy and warmth are indispensable qualities that can enhance the sufferer or survivor's quality of life.



### Dual Purpose Card

Recognising that after surgery for oesophageal or gastric cancer, patients often cannot eat full restaurant portions.

### OPA Leaflet

This foldout leaflet introduces the work of the OPA, to which one can donate and suggests ways to contact us by phone, email, ZOOM (by prior arrangement).

### Reflux Disease and your Treatment Options

The OPA has produced, in collaboration with the makers of the LINX Reflux Management System, a booklet and leaflets to explain reflux disease and its treatment options.

These publications are available to patients and medical staff on request. There is no charge to individuals and no membership subscription.



# I would love to make a donation



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: 51354981 Sort Code: 40-42-12

## For Standing Order Donations

### By bank transfer

Recipient bank: HSBC Bank

Sort Code: 40 - 42 - 12

Account Number: 02301636

### To make an online donation visit:

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

### By regular Standing Order payment –

Sort Code: 40-42-12

Account Number: 51354981

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: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

Please send this form to: Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF. Or email to: [enquiries@opa.org.uk](mailto:enquiries@opa.org.uk)

For further information please contact The OPA on 0121 704 9860 or email [charity@opa.org.uk](mailto:charity@opa.org.uk).



## Make a donation today!

### Scan the QR code

