The Oesophageal Patients Association
Making cancer easier to swallow

January 2014

Support for Gullet & Stomach Cancer and Related Conditions

NEWSLETTER

A Date For Your Diary:

Would you come to a meeting entitled: "The Future of Treatment for Oesophageal and Gastric Cancer"?

THEN COME TO OUR AGM!!
June 21

Details on page 8!

Local Support Group Meetings: See Page 2

Inside this issue:

An Interview With........

As patients we tend to be in awe of the clinicians we encounter during our treatment, be they surgeons, oncologists, gastroenterologists, specialist nurses or dieticians.

In this Newsletter, we are launching a new occasional series of articles, entitled "An Interview With", designed to provide some insight into the background and philosophy of leading clinicians. We hope we can uncover the underlying motivations of these extraordinary people and understand what drives them to dedicate their lives to saving ours!

In this first article in the series, OPA Trustee Larry Rees met and interviewed Professor George Hanna, head of surgery at Imperial College, London, pictured here at work.

TIME FOR A STRETCH?

One of the scariest moments for any patient post oesophagectomy or total gastrectomy is the discovery of not being able to swallow properly again. **DON'T PANIC!!** It's more common than you might think and can be caused by several issues other than the return of cancer. Here's how it can happen and what can be done to deal with it.

After surgery, it is not uncommon for a new join between oesophagus and stomach to over-heal and tighten down causing a blockage or sticking sensation when you swallow food. It particularly commonly occurs within the first nine months after surgery. It is easily treated by having an endoscopy, during which the narrowing is gently stretched, either under sedation or general anaesthetic. Sometimes it works first time, but occasionally several stretches are required to open up the narrowing permanently.

It is IMPORTANT not to put up with swallowing difficulties. Contact your consultant via his or her secretary, or your Specialist Nurse. Don't be hesitant about this; you absolutely need to be eating normally after treatment.

If you've had the experience of needing stretches, would you like to tell others about it? We'd welcome a Patient Story on this (or indeed any other) subject from any members for a future newsletter. Contact news@opa.org.uk or the helpline.

Chairman's Corner

JOHN TALBOT

This edition, I sadly have to start with news of the departure of two of the OPA's stalwarts. John Seston, a Trustee for the last seven years, and the organiser of many a Birmingham Support Group meeting, has found that the pressure on his time has become so great that something had to give. He resigned in November to devote more time to his family, work and many other commitments. We wish him well.

Then, Rick Martin, our treasurer for the last twelve years, has asked that someone else take over that task in 2014. He too has had enormous pressure on his time, as so many other Head Office duties—particular Institutional Trust Fundraising—fell to him, by design or default, and he never shied away from trying to fit them all in! But he is remaining as Trustee and hopes, after a break, to return to duties more directly involved in helping patients. We hope that in 2015 he will spearhead a new initiative in local support groups, overseeing growth in the whole of the West Midlands area.

David Holden, a Trustee in London, will act as temporary Treasurer, and so it is perhaps no surprise that the remainder of this column is an

APPEAL FOR HELP!!!!

If you have skills as a charity Trustee or Treasurer and the time to donate to the OPA, please do get in touch. If you have other skills you think that the OPA might benefit from, regularly or occasionally, again, please do get in touch. That might be in Law or Finance, Fund Raising or PR, to suggest just four examples.

We'd also specifically welcome help in areas such as Scotland, the South West, the North East and Wales, areas where currently the OPA is very thin on the ground.

Just give me a call on 01476 571599 or drop me a line at johntalbot@opa.org.uk and let's talk about it. No obligation!!

Meanwhile, THANK YOU to all those who so generously completed standing order donations last newsletter, helping us tackle this year's shortfall of £20,000. There is another form enclosed, in case you wanted to ask any other friends or family. And we've given you some early fun fund raising ideas, in advance of the launch of a more thorough Fund Raising initiative, soon….

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Email: enquiries@opa.org.uk

ACHALASIA

Achalasia is a disorder of the oesophagus that causes difficulty in swallowing and choking over even soft foods and liquids. We now have a website page for achalasia patients on the OPA website.

Achalasia patients typically suffer long periods of distressing symptoms before being diagnosed. The prospect of surgery worries them, not least because it is more of an elective process than it is for cancer. Their condition is related to nerve endings and muscles affecting peristalsis, so it is likely to be a life-long condition to some extent. They have some things in common with OPA members (eg diet problems, dilatations, myotomies and regurgitation) and there are even a few patients who have had achalasia-related oesophagectomies.

A first meeting of a new support group was held at St John's Wood, London on 12 December. 44 people attended, from as far as Chester, Eastbourne and Peterborough. Talks by surgeon Majid Hashemi and gastroenterologist Rehan Haidry were extremely well received. The meeting opened up a great well of gratitude that they had been brought together to hear about the medical aspects of their condition, and it was much like any OPA patient support meeting in that they appreciated mutual support.

See http://www.opa.org.uk/pages/achalasia.html for more information.

PATIENT EXPERIENCE
IAN ANDERSON of Luton

CURATIVE TREATMENT WITHOUT SURGERY

I first experienced difficulty swallowing around April 2012 but after a couple of visits to the GP Gastro Reflux was thought to be the issue. Being just 39 years of age at the time meant I was not deemed to be in the high risk group for Oesophageal Cancer. After no improvement was detected following a month on Omeprazole and Domperidone tablets I was referred for a Gastroscopy.

That took place on the 14th December 2012 and they soon found that I had a tumour. It certainly wasn't the diagnosis I was expecting, especially given my GP's recent confidence that it was just Gastro Reflux. Hearing from the medics that it was big—the doctor almost couldn't get his camera past the tumour - did not give me much reassurance and so I went home and started to Google. Big mistake! Anyone who has tried to view some of the stats available on the internet could be forgiven for giving up straight away. My future looked bleak, and I didn't know where to turn.

My local Upper GI nurses Wendy and Heather were fantastic and swung into action to ensure I had a CT scan and a meeting with my consultant Mr Jambulingam before Christmas. So while others might have been wrapping presents on Christmas Eve I was in a small office being told that I had a 12cm tumour in my oesophagus and that I was considered "borderline" for curative treatment, subject to further scans. One was an endoscopic ultrasound (EUS) at Hammersmith Hospital and the other was a CT/PET scan at Mount Vernon. It was also suggested that I should have a staging laparoscopy which is where the surgeon goes in using keyhole cameras to get a visual look at the tumour.

In January 2013 the decision was finally taken to treat me with a view to cure. I had been diagnosed with the Squamous Cell Carcinoma variant of Oesophageal Cancer and recent studies showed that the success achieved by treating the patient with radical chemoradiation was delivering similar results to surgery. This type of approach has not been seen to work for Adenocarcinoma tumours which are still primarily treated by surgery. So while I had started my discussions with a surgeon, it was now the Oncologist who was determining my treatment.

I was admitted to Mount Vernon Hospital for three cycles of chemotherapy starting on 18th February. The first week of each three week cycle saw me receiving 5FU and Cisplatin drugs as an inpatient while the following two weeks were to recuperate ahead of the next cycle. My final cycle concluded in early April, and a scan soon followed to check on progress. I was amazed and delighted to discover that the tumour had shrunk from 12cm to a size no longer detectable by the CT/PET scan.

However there was a chance that some cancerous cells remained in the wall of the oesophagus so the decision was taken to proceed with a course of Radiotherapy (26 consecutive week days) along with further Chemotherapy which would help to enhance the response achieved by the Radiotherapy. My final Radiotherapy session took place on 26th June, and while my oesophagus was battered and sore, that was a small price to pay if the cancer was beaten.

Getting back to normal eating has been a long process. On the days after Radiotherapy I was restricted to soup, yogurt and possibly some soggy breakfast cereal. Slowly solids returned to my diet, although things would still periodically get stuck. I was monitored closely by Dr Mawdsley and her team, with regular visits to clinic to discuss my progress and any side effects I was experiencing.

A further CT scan in early September was clear, while an endoscopy in early October found a stricture (narrowing) which was preventing me from having a complete return to normal eating. I had a dilatation (stretching) of the oesophagus, and I may need further such procedures before it is back to its normal width. However my diet has almost returned to normal with only a small number of foods now out of bounds.

When I was told that I was going to receive Chemoradiation with a view to cure, I desperately searched the internet for success stories. Or in fact any stories of this kind of treatment. I could find very little, and so I hope by me publishing my story it will show that it can work as a treatment. My only minor complaint is some neuropathy (pins and needles below my knee) but I can live with that. Given where I was in December last year, life is pretty good and I am looking forward to returning to work and getting my life back on track.

LARRY REES

An Interview with Professor George Hanna Head of Division of Surgery - Imperial College London

By Larry Rees

I first met George Hanna in February 2006 after my own diagnosis of oesophageal cancer.
I was immediately impressed by his depth of knowledge and calm commitment to help me beat it. When I asked him what I could do to help he said “get fit and fat”. Little did I know how that advice would help save my life as I battled for 3 months to recover from a post-operative leak.
Over the subsequent months I came to know him very well and of course had regular follow ups over the next 5 years.

Studying in Cairo

LR - Where did you originally study for your medical degree?

GH - I started my medical studies at Cairo University and graduated in 1988. Subsequently my parents supported me to get the best possible education so they encouraged me to apply to the UK to get a post graduate opportunity. I chose to study in Dundee as it was the global centre of excellence for keyhole surgery. I was attracted to study keyhole surgery as it seemed to me that it was the most important area of surgical development that could have a real impact on patient outcomes for the future.

Training with Sir Alfred Cuschieri

LR - Tell me a bit about your early surgical background in Dundee?
GH - When I started my post graduate training in Dundee they were pioneering keyhole surgery and laparoscopic surgery under the leadership of Sir Alfred Cuschieri. This field has a huge impact on patient recovery and surgery. As an evolving promising technology it was absolutely the right training opportunity for me. The broad application of it to surgery in general is really important.

As it turns out, even though I have a passion for keyhole and specialised in it, it is not necessarily the best solution for advanced upper GI cancer procedures. As a clinician you have to do what is best for the patient not what your personal passion is.

Currently there are a number of trials that are looking at the value of keyhole in upper GI cancers and hopefully we will get more insights into its application for the future in due course.

LR - And how did you come to specialise in upper GI surgery?
GH - As well as being a pioneer in keyhole and laparoscopic surgery, Sir Alfred Cuscheiri is also an upper GI specialist, so naturally I started to learn more about it.

Sir Alfred Cuscheiri is a superb clinician, outstanding academic and above all a good human being. And this was a huge influence on me.

During my time with him I came to realise that Upper GI surgery is the ultimate challenge as it requires technical skills, intellectual ability and good clinical judgement. In the end it requires your entire mental and physical skill to achieve success in this field.

Couple this with the fact that the disease itself has poor clinical outcomes and it was clear to me that this was a real challenge for a surgeon to have a major impact on the future.

The move to Imperial College

PROF GEORGE HANNA

LR - What was it that attracted you to move to join Imperial College?
GH - After completing my post graduate training, from basic surgical skills to advanced upper GI surgery, including clinical and academic training, I was fortunate enough to get the opportunity to work with Imperial.

What particularly attracted me was that Imperial College encourages the pioneering of technology and integrating the research into clinical practice.

I joined as a senior lecturer in surgery and consultant upper GI surgeon and have since been promoted to reader and subsequently professor. Currently I am the head of division of surgery for Imperial College London. I also have to say that the department of surgery has been very supportive of my career progression.

LR - Approximately how many patients do you deal with per annum?
GH - I see around 120-150 new patients a year and operate on about 40. As you know many patients are not candidates for curative resection. This is why I have such a big interest in researching early diagnosis.

LR - How do your patients split between oesophagectomies and gastrectomies?
GH - It is around 60:40

How treatment has changed in recent years

LR - What would you say have been the biggest changes you have seen in treatment over the last 10 years?

GH – Neo-adjuvant chemotherapy has had the biggest effect in becoming the standard practice in the last 10 years. It improves patient long term survival but of course it cannot work on its own. Surgery remains the curative option.

Another important change in treatment has been the use of endoscopic therapy for high grade dysplasia and very early tumours. This includes endoscopic resections and ablations.

And then I would say that surgeons are now much more aware of the value of radical clinical procedures. This means the role of systematic removal of regional lymph nodes around the tumour. This is the standard practice in Japan but has had doubters in the west because of the perception that it has a high impact on the patient and risk of complications. Currently more surgeons are practicing this approach with very good outcomes.

Causes of upper GI cancers

LR - Naturally patients are curious to know what causes upper GI cancers – have there been any new insights into this in recent years?

GH - First of all it is important to understand that there are some associations with upper GI cancers but no real absolutes. In that regard we have not made any significant breakthrough in our knowledge.

One association is the presence of Barrett's and its progression from reflux disease. In the case of adenocarcinoma tumours there is an association with obesity and reflux. And in the case of squamous cell tumours there is an association with alcohol consumption and smoking.

But I really must stress that whilst associations are of course important they do not in themselves give us the clear answers we would like to have with regard to causation.

Long term quality of life

LR - What are your thoughts on improving the long term quality of life of upper GI patients?

GH - The good news is that upper GI cancer patients are generally enjoying a much long life expectancy after surgery than ever before, which, as a specialist in this field, is a wonderful thing to be part of. And of course with that longer expectancy we have become increasingly aware of a number of post operative challenges which are directly related to and are therefore side effects of the surgery.

So our first challenge is to understand them more fully and that includes their interaction. Then we must develop clear strategies for dealing with them and assisting patients to understand and cope with them.

In particular I would say that we are getting better at recognising and working with patients to understand them.

Side effects such as Dumping syndrome, steatorrhea (which is due to malabsorbtion), and SIBO (small intestinal bacterial overgrowth) are commonly identified in patients.

Additionally there are psychological impacts of this type of surgery which patients have to deal with.

It is through the excellence of our clinical nurse specialists and I might say the voluntary work done by members of the OPA support groups such as your own, that are playing a significant part in identifying, researching and educating on these matter.

George Hanna's Research

LR - So where do you focus your personal research efforts?

GH - I am currently leading a research group that is working on the identification of compounds in exhaled breath to diagnose cancer. We have already had very promising results and this has potential to be a non-invasive bedside test to diagnose and monitor patients with Upper GI cancers. It can act as a risk assessment tool to direct patients who need endoscopy and biopsies.

You might be aware that there is scientific evidence that dogs can smell cancer? Essentially we have taken this idea and found a technological strategy to assess breath for cancer diagnosis. I think that this is a very exciting opportunity for the future.

I'm also the director of the Imperial National Institute of Health Research diagnostic evidence co-operative, which is responsible for studying and generating evidence for different technologies which will be used for point of care testing in the future.

George Hanna's CV

Age - 49, Married to Therese with two daughters, Julia and Catherine

CURRENT APPOINTMENTS

Head of Division of Surgery - Imperial College London

Chair of oesophago-gastric cancer pathway - London Cancer Alliance (LCA)

Chair of oesophago-gastric cancer multidisciplinary team - Imperial College NHS Healthcare Trust
QUALIFICATIONS

MB BCh, Faculty of Medicine, Cairo University, Egypt 1988

FRCS (Edinburgh) 1993

PhD (Dundee) 1997

FRCS (Gen. Surg), special interest in upper gastrointestinal surgery 2002

MErgS (Ergonomic Society, UK) 2004

FRCS (England) ad eundem 2006

Professor Hanna is widely published and has contributed to over 140 clinical papers, reviews and book chapters to date.

Continued, page 6.....

An Interview with Professor George Hanna
A glimpse into the future

LR - What would you say are the most promising changes that you think will emerge for the future?

GH – there are a number of very promising concepts that I believe will play a significant role in the future.

Non invasive diagnosis which enables higher pick up rates with non-specific symptoms such as dyspepsia in younger people, heartburn and non-specific abdominal pain. This is really important as in the UK the prevalence of the disease just does not warrant routine endoscopy investigations for those symptoms.

There are some excellent developments with nano technology for targeted chemo delivery at high concentrations to the tumour which results in minimal systemic toxicity.

Personalised care which entails appropriate chemo therapy to specific types of tumours is another promising research area. This is relevant as upper GI cancers are often of mixed genetic sub types even in a single patient.

This means that they are complex and often patients have more than one sub type present. Personalisation could address this more effectively in the future.

And finally as I alluded to earlier in the interview the standardisation of surgical procedures should be the norm as we learn more about the most effective techniques.

LR - Professor Hanna, I would like to thank you for a most illuminating and frank interview. On behalf of the OPA and its entire membership we thank you for your dedication to our cause.

PROF GEORGE HANNA

MEETING DATES

The highest priority for the OPA is summed up by our slogan "Experienced Patients Helping New Patients" and one of the most successful ways for this to come about is through our local support groups. Anyone who has been touched by oesophageal or gastric cancer or related conditions is warmly welcome at any of these meetings.

These are only some of the forthcoming meetings. Others are planned in Leeds, Lincoln, Liverpool, Manchester, Luton, Preston and elsewhere. Please check on the OPA website, contact your local organisers or seek information from the OPA on 0121 704 9860. And please verify the meeting details before you attend, in case of last minute changes.

8 Feb	10:30	Lakeside International Hotel	**Frimley**
13 Feb	14:00	Cancer Care Slyndales	**Lancaster**
15 Feb	10:30	Friends Meeting House, Euston	**London**
22 Feb	10:30	St Barnabas	**Grantham**
27 Feb	18:00	Holiday Inn	**Guildford**
28 Feb	13:00	The Force Centre	**Exeter**
28 Feb	11:00	Royal Marsden	**London**
8 March	10:30	Wyberton Parish Hall	**Boston**
8 March	10:00	Hilton Scout Hall	**Derby**
13 March	14:00	Cancer Care Slyndales	**Lancaster**
27 March	18:00	Holiday Inn	**Guildford**
28 March	13:00	The Force Centre	**Exeter**
29 March	10:00	Queen Alexandra Hospital	**Portsmouth**
5 April	10:30	Beechlawn Hotel	**Belfast**
9 April	14:00	The White Horse, Rottingdean	**Brighton**
10 April	14:00	Cancer Care Slyndales	**Lancaster**
25 April	13:00	The Force Centre	**Exeter**
26 April	11:00	Holiday Inn	**Guildford**
26 April	10:00	Edgbaston Cricket Ground	**Birmingham**
26 April	10:00	Norfolk & Norwich University Hospital	**Norwich**

David Kirby

A man who truly cares - a tribute by retiring trustee John Seston

"I know just how you feel – I know what you are going through".

These words can seem very empty especially when you know the person who uttered them is just being sympathetic but has never had any personal experience of your illness.

I would like to think that we are different at the OPA, because we know what we are talking about. Our slogan for many years has been "Experienced patients helping new patients". Most of us have had oesophageal cancer or similar illnesses and subsequent surgery or treatment, or are carers who have been there for those who have been ill.

David and Daphne Kirby at the Norwich AGM, April 2013

I had surgery on the 26th October 2001 and when I closed my eyes in pre-op I really didn't know what the future would hold, or indeed if there would be any future. The next few days were very "fuzzy". I remember my bed crashing against a doorframe as I was being transferred from Intensive Care to a ward and then gradually, after a couple of days, started to recognise and appreciate the people around my bed – my dear wife Barbara, my family and a stranger.

The stranger was David Kirby, who had spent many years visiting patients and their carers in Birmingham's hospitals offering advice, encouragement, sympathy when appropriate, and, most importantly, empathy.

David could honestly say "I know how you feel - I know what you are going through" because he had been through it, back in 1980. Five years later he had founded the OPA. He had found that "there was an immediate affinity" with other patients, "with a feeling of mutual reassurance" - and that is what the OPA is all about.

Over the years David has, of course, had the loyal and enthusiastic support of his wife Daphne, who has taken on many invaluable responsibilities within the OPA. David has always kept abreast of research and development, clinical trials, new technology, techniques and treatments. He has attended many conferences and seminars that have allowed him to advise and help both patients and clinicians. David asked me to become a Trustee of the OPA about 7 years ago and since then we have seen many changes. In recent times David has experienced more health challenges and realised it was time to 'slow down', but not without first securing the future of the OPA. He has left it in the capable hands of a new group of Trustees who bring much needed skills and experience to the table, working along with our great Head Office staff, Dawn and Maggie.

May I add at this juncture, that we all really look forward to Dawn, who has so ably assisted David, recovering to full health very soon. Richard Martin, who has been an indispensible stalwart supporter of David and the OPA over the years, will continue to be, with his many years of experience, a vital source of advice for the new management team.

David has been very pleased and encouraged to observe the growth and strength of our branches up and down the country. It was at the AGM, at one such strong branch – Norwich – that the OPA recognised David and Daphne's wonderful service to the OPA with a presentation (see left) and by asking David to be our Life President.

Our new Trustees have brought along many fresh ideas on how to take the OPA forward, with particular emphasis on fundraising in a very difficult economic climate, an awareness campaign and other projects.

Our branches also do a sterling job. Some, whilst prioritising their support for the OPA, also have commendable projects such as supporting their local hospital. None ever lose sight of our utmost priority, to provide support for patients.

I am sure that all this warms David's heart, and gives him confidence that the OPA has a rosy future and will continue to support those that need us. We must always, though, maintain the fine legacy of care that David has bequeathed us and be determined to pursue that mission statement that "Experienced patients will always be there to help new patients"!

USEFUL INFORMATION AVAILABLE FROM THE OPA

There are three booklets created and published by the Association for the benefit of members:

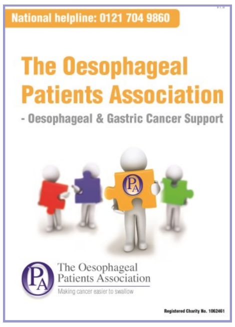
- The Oesophageal Patients Association (who we are and what we do).
- Swallowing – Nutrition When It's Difficult
- A Guide to Life after Oesophageal/Gastric Surgery.

We also have factsheets on advice for relaxation and sleeping and we can provide Restaurant and Toilet cards for use in most European countries.

Please call the helpline on 0121 704 9860 or email enquiries@opa.org.uk

Other Information is also available from:-

www.macmillan.org.uk & www.corecharity.org.uk

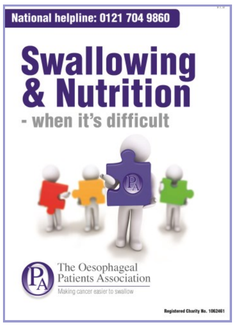


National helpline: 0121 704 9860

The Oesophageal Patients Association

- Oesophageal & Gastric Cancer Support

The Oesophageal Patients Association

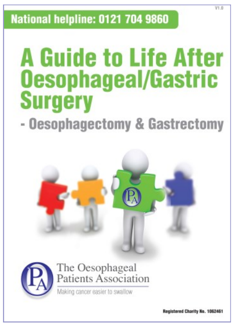


National helpline: 0121 704 9860

Swallowing & Nutrition

- when it's difficult

The Oesophageal Patients Association



National helpline: 0121 704 9860

A Guide to Life After Oesophageal/Gastric Surgery

- Oesophagectomy & Gastrectomy

The Oesophageal Patients Association

OPA ANNUAL GENERAL MEETING

The Annual General Meeting has been arranged for Saturday 21 June 2014 at 10.30am at Friends Meeting House, 173-177 Euston Road, London, NW1 2BJ.

The theme of the meeting will be "The Future of Treatment for Oesophageal and Gastric Cancer" and we are planning to have speakers talking about future developments in diagnosis, treatments and after care. We hope that this will attract as many members as possible.

The venue is directly opposite Euston station in London to make it easier for those who will be travelling to London by train.

The AGM will also vote on some changes to the constitution that have been agreed by the Charity Commission.

The changes are primarily as follows:

- widening our scope so that we offer support to patients with any related Upper GI condition rather than being confined to oesophageal and gastric cancer (eg achalasia)
- making it possible to promote relevant research (eg digestive disorders after surgery)
- clarifying that we can collaborate with other charities for relevant purposes (eg the Awareness Campaign)
- clarifying that we can appoint people to special positions (eg Life President, Patron)
- clarifying that members of the national committee act as Trustees, and
- clarifying that carers are members of the OPA.

The details of the constitution and proposed changes can be seen on our website at http://www.opa.org.uk/news.html

If anybody has any queries about the proposed changes, please contact our Vice Chairman at alan@alanmoss.demon.co.uk.

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.

NAME:...

ADDRESS:…………………………………………………………………………………………...

POST CODE: .... **TELEPHONE NUMBER:**…................……………………………

EMAIL ADDRESS: ....

Oesophageal Patients Association, 22 Vulcan House, Vulcan Road, Solihull, West Midlands B91 2JY.