



The Oesophageal Patients Association  
Making cancer easier to swallow

November 2014

## Support for Gullet & Stomach Cancer and Related Conditions

# NEWSLETTER

## Message from the Chairman



"I am sad to have to tell you that I have decided that I cannot continue as Chairman of the OPA. I have made my decision for personal reasons, with a change in family circumstances now demanding a significant proportion of my time. I will remain in position until early next year, but with Trustees taking on the majority of my workload. It is my intention to continue running my two local support groups, in Nottingham and Grantham, and I will also remain as a Trustee.

The OPA has gone through a difficult period but we have stabilised finances and Head Office, we have a committed team who are there for the long term. It is my hope that we can have a new Chairman in place well before our next AGM, and particularly well before next year's landmark "pearl anniversary" celebrations and fund raising initiatives".



Life with Dysphagia is difficult enough without the worry that mealtimes can bring along with the chore of preparing food. With our textured and reshaped pureed range, we offer a visually attractive, delicious and nutritionally balanced meal bringing a sense of normality back to your loved ones.

[www.simplypuree.co.uk](http://www.simplypuree.co.uk)

**Local Support Group Meetings:  
See Page 8**

## OESOPHAGEAL CANCER WESTMINSTER CAMPAIGN

The Oesophageal Cancer Westminster Campaign is a group comprising of several patient groups, including the OPA, in collaboration with clinical experts, industry and families bereaved by Oesophageal Cancer, campaigning at Westminster, through the NHS and the media.



The inaugural reception, which took place on Monday 13th October at the House of Commons, drew attention to the fact that more than 70% of the oesophageal cancer cases in the UK are associated with Barrett's Oesophagus. That awareness of this amongst the public and health professionals is low, and that access to early diagnosis and treatment for Barrett's Oesophagus reduces the likelihood of developing cancer which saves lives and is cost-effective for the NHS.

Speakers included Tim Underwood BSc (Hons), MBBS, PhD, FRCS, temporary chairman of OCWC, Professor Mike Griffin from Newcastle and Professor Pradeep Bhandari, Gastroenterology consultant. With Andrew Gwynne MP, Norman Lamb MP and Jane Ellison MP, all attending, we secured three of the most high profile and influential speakers on health in the UK and promoted the conversation on Oesophageal Cancer to the highest level.

It was a hugely successful day with thirty MP's signing the campaign and pledging their support.

We were also delighted to be informed that the next "Be Clear On Cancer Campaign" will be on Oesophago-gastric Cancer and will run from 26th January to 28th February 2015.

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## A WARM WELCOME TO.....



Our new trustee Mr Edward Cheong BSc (hons), MD, FRCS is a consultant oesophagogastric and laparoscopic surgeon at the Norfolk & Norwich University Foundation Trust, who specialises in minimally invasive oesophagectomy (MIO) for cancer. He graduated from the University College Cork in Ireland, did his specialist registrar surgical training in the Eastern region in England, and then completed a year fellowship in minimally invasive oesophagectomy in Pittsburgh, USA with Professor J. Luketich. He is also the Upper GI Cancer Lead at the Norfolk & Norwich University Foundation Trust. For the last four years, Ed and the rest of the team have changed the way things were done for oesophageal and gastric cancer surgery; and today they have one of the best outcomes after oesophageal and gastric cancer surgery in UK. Outside work he enjoys sport and does long distance running as well as taking an interest in football and rugby.

Mr Damien Cassidy has taken up the important role of treasurer. Damien joined British Gas Eastern in October 1988 as an Assistant Auditor, in 1990 he was promoted to the role of Auditor reviewing financial and operational business processes in the UK. He continued to work in this role during the re-organisation of the company working in the Lattice Group, BG Group and then National Grid Transco following the merger with National Grid. He was promoted to the role of Senior Internal Auditor and continued at this level in National Grid until February 2014 when he set up a cloud bookkeeping practice. Damien will be a very valuable member to the team and he is already looking at ways to improve our accounting procedures.



### From the News Media .....

The UK tops the international league table for a type of gullet (oesophageal) cancer, known as adenocarcinoma, in men, reveals a comprehensive estimate of the total number of new cases around the globe in 2012. Worldwide, men are around four times as likely as women to develop the disease, the findings show. *Published by the British Medical Journal Oct 2014*

A £110m cancer research centre is planned for Headington to study pioneering treatment with hundreds of county sufferers. Oxford University today, 23rd October 2014, announced The Precision Cancer Medicine Institute, planned for a 2017 or 2018 opening.

It will study drug, surgery and radiation therapy and will be aided by 400 to 450 Churchill patients a year with hard-to-treat early stage diseases like lung and oesophageal cancer.

Despite previous indications to the contrary, the oesophagus does have its own pool of stem cells, said researchers from the University of Pittsburgh School of Medicine in an animal study published online in Cell Reports. The findings could lead to new insights into the development and treatment of oesophageal cancer and the precancerous condition known as Barrett's oesophagus.

Dr Sean Duffy, NHS England's national clinical director for cancer, said: "We are working closely with Cancer Research UK to support the NHS to improve outcomes for patients through earlier stage diagnosis.

"The NHS is successfully seeing 50% more patients than four years ago and survival rates have never been higher. Almost nine out of 10 patients say their care is excellent or very good." *Published by The Guardian September 2014*

## JILLY'S JUMPING BEANS

The day of 'THE JUMP' had finally arrived. The three of us were not yet looking outwardly nervous but rather animated and excited, although we were pretty sure those feelings might change once we were 'suited and booted'.

It was a fantastic sunny day on Monday July 28th 2014 with only a little fluffy cloud in the beautiful blue sky. Mum Had been up since 7am baking and making a picnic. 30-40 lovely family and Friends also came to support the three of us who would be jumping.

We went into a room to do all of the formal bits and pieces and then the briefing which consisted of advice on breathing (as in "don't forget to"), the positions we needed to adopt as we fell from the plane and how to land. We then got into our fabulously fashionable flying suits (one size fits all) and our harnesses, then walked out to the aeroplane to calls of good luck from our supporters.

Unlike conventional small aircraft there were no seats and we sat on the floor. The door to the aircraft was a roll of see clear plastic so we could see the landscape rushing past and then down and away as we took off. The views from the air were breathtakingly beautiful as the plane banked and climbed higher and higher, circling back over Langer Airfield, never

to far from the orange wind-sock that marked our (hoped for) landing site. When we had nearly reached the required 13,500 feet our instructors told us to sit on their legs, (I say!), whilst they made sure we were firmly attached to them with our harnesses. We donned our helmets and goggles, and then moved towards the now open door. With the instructor sitting on the edge of the opening, we had to bend our legs back so that the soles of our feet were touching the belly of the plane, our heads back so that they were resting on our instructors shoulder and our arms crossed over our chest and our bottoms outside of the plane.

Then ... GERONIMO!

We went face down into free fall for about 45 seconds. It was amazing. We could see green fields and then fell

through some of the clouds that had gathered since morning. My niece wanted to know what clouds taste of

but, I am sad to say Molly, they tasted only of water. My instructor tugged the release cord, the parachute unfurled instantly and we lurched up ... then, almost silently, began a more gentle descent, floating. Lovely.

Well, lovely until the instructor pulled left and swiftly right so that it felt as though we were riding a rollercoaster. Urrgghh, I don't like rollercoasters very much!

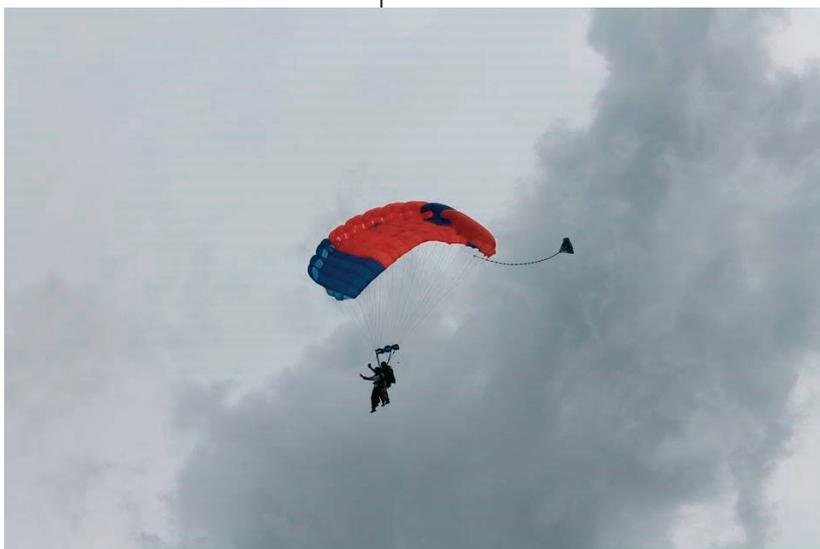
Did you know that you can get air sick during a parachute jump? Well, you can and Sophie can testify to that after she decorated her flying suit on the way down. We were all given an opportunity to have a go at steering our parachutes too, which was much more fun than feeling air sick.

As we got closer to the ground we could clearly see our huge support er's picnic party and waved and cheered to them. However, the ground seemed to be getting closer very quickly and we were told to assume our landing positions. We all landed in fairly elegant style accompanied by massive cheers from our supporters.

It was awesome, in the true sense of the word (dictionary definition of 'awe' is 'wonder and respect mixed with dread'). We could not actually believe we did it and it was over.

Hopefully we have made more people aware of this type of cancer and raised a fair amount of money too. For us personally, we had Mum very much in mind,

(Auntie to Sophie), and are immensely proud of Jillian Chatfield and her personal battle against this cancer.



Jilly's Jumping Beans by  
Pamela Daniel, Paula Thorpe, Sophie Underwood

### PATIENT EXPERIENCE

#### Bryan Woolnough

I turned 40 in May 2011 and when I started to have some slight problems with swallowing at breakfast time later that year, I initially put it down to heartburn and just getting older. It was really mild and only happened with the first meal of the day. Around February 2012 I experienced a few days of going to the toilet and it being black and only then did I feel that maybe I should go and see a doctor. My GP referred me on for an endoscopy and, following three procedures and a couple of scans, I was given the news that I had stage 3 oesophageal cancer. Lucky for me at the time I was still pretty sedated from the most recent endoscopy. For my family, who were with me, it was the worst news possible.

I strongly believe that when you are given such life changing news it really can go two ways. For me I decided there and then that I wasn't giving in to this. I was incredibly lucky with the support of both family and friends although telling people was probably the hardest part of the whole process. You are suddenly telling people you love something that you know is going to upset them and over which neither you nor they have any control.

The next two months seemed like a whirlwind of appointments, further scans and Multi Discipline Team meetings. Initially it was thought that radiotherapy would be the best way forward but the size and position of the tumour (adenocarcinoma at the join of the stomach and oesophagus) meant that this wasn't the best option. The consensus of opinion was that the best option would be, for me, the most drastic; chemotherapy followed by a cardio-oesophagectomy removing both my oesophagus and part of my stomach and, just for full measure, chemotherapy afterwards. A major-operation chemotherapy sandwich!

I was given all the statistics and yes there were times when it felt totally overwhelming. But the important thing for me was that these are just numbers; everyone's journey through cancer is unique and no-one knows for sure what the outcome will be. So I decided early on to focus on the positive as much as possible. If I was told that, statistically I had a 14% chance of surviving 5 years, then I focused on being part of that 14%. I also had youth on my side; my consultant had only dealt with one person younger than myself.

The day that I started chemotherapy I felt an enormous sense of relief. At last it felt like we were fighting back. I live very close to The Christie Hospital in Manchester and the care and support that I received there was second to none. As a world leading cancer centre there couldn't be a better place to receive treatment. Chemotherapy

gave me few side effects and although the nurses had prepared me for the worst, for me, it never happened. I know that this is not the case for most people. But again everyone's journey is different and you should never lose heart.

I learnt an entirely different set of vocabulary and skills – neutrophils, patience, how to inject myself, super conscious hygiene, alternative recipes, wet wipes all become part of my daily routine.

So D-Day arrived in September 2012. The chemotherapy had reduced the tumour slightly and the operation was to go ahead. After 11 hours of surgery I awoke and was just so glad to be alive. I then spent a week in a virtual state; heavily dosed with a morphine epidural I found it difficult to separate what was real and what was imaginary. That said, due to the nature of the operation, this was probably the best state to be in. My road to recovery had begun and I slowly started to take back control, doing everything the physio said and steeling myself for the day I could drink and eat again. The body and mind are truly amazing things. Looking back there's certain things, probably the worst moments, that I simply can't recall and I think that's the body's way of protecting itself and you.

After a week I was able to drink and eat very small amounts. I always knew my will to eat would win out and each day I went from strength to strength. After another week I was discharged from hospital and spent several weeks slowly recuperating and getting back up to speed through the care of my family. On New Year's Eve 2012 I had my final in-patient chemotherapy treatment. To be honest I'm not sure if I could have carried on for more and it felt so symbolic that this date was the last time.

There's been ups and downs; getting used to my 'new plumbing', constipation followed by diarrhoea, nausea, dumping syndrome, learning what things and what amounts I can eat. But in reality, and compared to the alternative, these are such small issues and I have just learnt my own coping mechanisms. It's a fine line between not giving in to the issue but being able to recognise any real limitations. I think it's a work in progress but I'm getting there.

Each anniversary now is a milestone; one year after the operation, 2 years since diagnosis. I have now almost made it to the half way stage in the 5 year survival race and am about to go on holiday to New York - a long held dream which I am now making reality.

I once read that cancer means that the door to death is opened and never quite shut again. I prefer to think of it as giving you an awareness of what is important, a sense of urgency to do things now rather than put them off and an appreciation of people and the way time is spent. And that can't be all bad.

## USEFUL INFORMATION AVAILABLE FROM THE OPA

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

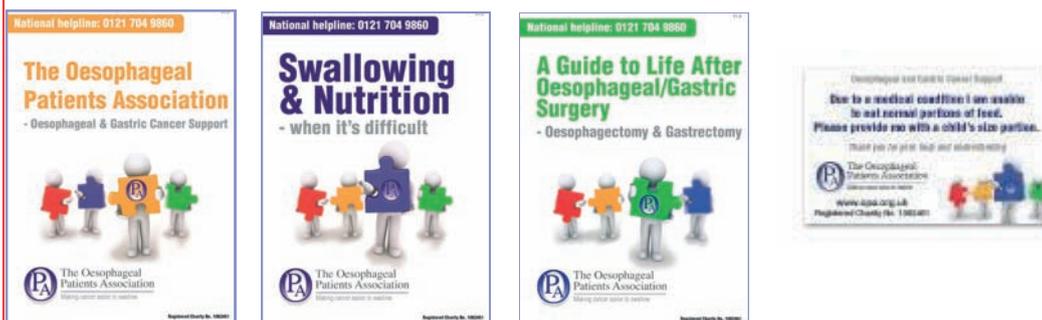
- The Oesophageal Patients Association (who we are and what we do).
- Swallowing – Nutrition When It's Difficult
- A Guide to Life after Oesophageal/Gastric Surgery.

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](mailto:enquiries@opa.org.uk)

Other Information is also available from:-

[www.macmillan.org.uk](http://www.macmillan.org.uk) & [www.corecharity.org.uk](http://www.corecharity.org.uk)



## LETTERS COLUMN

Your views are always welcome, write to [news@opa.org.uk](mailto:news@opa.org.uk)

Dad was diagnosed with oesophageal cancer the day before his birthday in April 2011, his cancer was stage two/three. He then underwent chemotherapy and an operation. His chances were not great but he rallied and is an example to us all. I was due to get married in September 2012 and was afraid my dad would not be around to see it and give me away but thankfully he was! He still struggles a bit with swallowing and has had numerous stretches but 3 years on from his diagnosis he is doing really well and has a great quality of life. This is largely thanks to the fantastic team at Aberdeen Royal Infirmary and community health teams in our local area. I too found great support in the OPA and spoke with Dawn on numerous occasions.

Dad and our wider family have since raised more than £5,000 for research into this, sadly, growing cancer.

Lisa Barclay

My oesophagectomy operation was early March 2013 when I was 71 years.

In I.C.U and H.D.U my experiences were.....

I thought I was in a military field hospital with injured military everywhere. Other things were the ceiling panels changing shape and colour also curtain runners and poles were wrapped with barbed wire.

My wife and visitors must have thought I was loopy! All seems okay now thank goodness.

My operation was done at the James Cook University Hospital, Middlesboro. All treatment and after care was excellent from pre-op specialist nurses, who described what was going to be carried out, to the superb medical team.

If there had to be a downside it was the chemo, which made me suffer, but it worked. ADVT was noticed in my calf and cured with 6 months of Warfarin.

I have just had a CT scan and am seeing the surgeon soon for the results.

Peter Briggins

## THANK-YOU to



The fantastic Hough family for all of your fundraising events in memory of Julian Hough.  
 Thank-you to Emma & George who ran the Edinburgh Marathon & Kirsty & Rich- who ran the Midnight Sun Marathon in Tromso, Norway.  
 Also a special thank-you to Gillian for arranging the Beer festivals.  
 The O.P.A have received a magnificent cheque for £6266.81 from all of their hard work.  
 Well done!

Margaret Farrell, Coral Jenkinson & Jo Belfield held a traditional afternoon tea on the 4th & 11th of August 2014 raising an amazing £1,052.

Mrs Margaret Farrell said her and her family will also be having a “ Christmas open house” on Monday 8th December in Derbyshire. She will be holding a raffle, serving refreshments & selling cakes with all proceeds going to the OPA.



Ann Sumner’s daughters have been rallying their friends to help out with raising funds.  
 They have completed a gruelling challenge in the Lake District comprising of Kayaking the longest lake, Trekking the highest mountain and Cycling the toughest pass. They have raised approximately £500.  
 Well done girls for all of your hard work .

## WINTER 2014 & SPRING 2015 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, Liverpool, Manchester 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.

Dec 2	Dudley	Dec 3	Brighton	Dec 5	Royal Marsden
Dec 6	Boston	Dec 11	Lancaster	Dec 13	Portsmouth
Dec 18	Preston	Dec 18	Colchester	Dec 18	Nottingham
Feb 7	Frimley	Feb 28	Grantham	Apr 25	Norfolk
Mch 7	Derby	Apr 25	Norfolk	May 30	Grantham

## PORTSMOUTH NEWS

Sitting in his car at a service station, unable to move, Mike Cotton thought he was about to die.

He was in excruciating pain and all the colour had gone from his vision. Feebly, he tried to explain to the 999 operator where he was

Mike recalls: 'I said "I'm dying".'

After that I don't remember a thing.' His heart stopped twice on the way to hospital.

Mike's children, who live in Canada, were asked to fly home immediately.

'My wife was terribly upset,' says Mike. 'They told her they didn't think I would survive the evening.'

'My children thought they were coming home for my funeral.'

That was just three months ago. Mike 71, from Rowlands Castle, is now a picture of health following the burst diaphragm.

But the story starts much earlier than that – because he ignored signs that would eventually lead to oesophageal cancers.

'Throughout my life I'd always had problems with acid reflux, indigestion and heartburn,' says Mike. 'But I'd ignored it. Then,

four years ago, I experienced great difficulty swallowing. One night, in the pub, I couldn't swallow at all.' In a lot of discomfort,

Mike eventually went to the doctors but was sent away with tablets. It didn't improve so he went back and was sent for an

endoscopy – and a tumour was spotted on his gullet. He says: 'From that point on my feet never touched the ground. The NHS was simply fantastic.'

'Being told you have a tumour is a traumatic experience. It's mind-blowing. But fortunately my consultant said "I can tell you it's operable". And those are the words you want to hear.'

Because the cancer had not spread further than the gullet, Mike was eligible for a rare

operation called an Ivor Lewis. It is so complex, and risky, that patients have to spend months getting in shape. After several rounds of chemotherapy, six months of walking two miles a day and piling on the pounds, Mike was ready for the operation. He says: 'That time marching towards an operation like that is quite something. I had to keep myself physically fit. The operation is extremely intense and weakens you terribly.'

'They made an incision through my tummy using keyhole surgery and disconnected the tummy from the bowel. They also went in through my right shoulder and broke a rib to get into the gullet.'

'It is a very difficult operation because it's so near to the major organs. They cut a margin around the gullet to be safe and bring the stomach up into your chest. They then reconnect it to your gullet and reduce the stomach size.'

Mike spent an entire day in surgery and eight days in hospital

'I was very, very weak. It really takes it out of you. I could not even stand up to shave. But I was so pleased to have survived. Some don't.'

'It was a tremendous, traumatic operation. I went from 16st to 11st.'

Over the next few months, with the help of wife Mary, Mike got back to full health.

But, although the operation was a success, it had weakened his diaphragm and that is what caused the rupture in July this year.

He began to feel unwell while driving and managed to pull over at Rownhams service station on the M27.

Mike says, 'I was in considerable discomfort and feeling very nauseous. I couldn't breathe – I knew I was dying.'

'My eyesight went and I could only see in negative, no colours. I could hardly see my phone and at first I dialled 888 instead of 999.'

'I was so disorientated that I couldn't tell them where I was at first. All I knew was I was

dying.

'The operator was saying, "stay with us" but I was in so much pain it was unbelievable. I knew if they didn't get there very quickly I would die. It felt like they were taking an age.'

'And suddenly the door was wrenched open by the ambulance crew. A very nice paramedic said to me, "what's the matter mate?"'

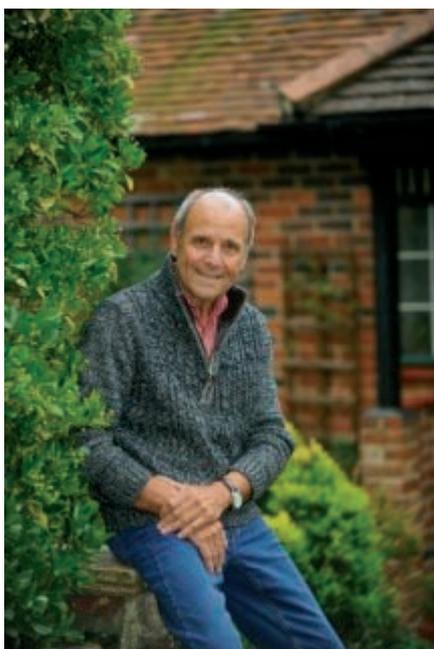
Mike was put in an induced coma and an operation was performed to bring his bowels down to the correct area. They took one third of it away.

His family played his favourite Spanish music to him while he was unconscious.

He says: 'The first thing I saw when I woke up was my daughter and son walking towards me, but I couldn't talk to them because I had a breathing tube in my throat.'

'The emotion was incredible. I thought, "where am I?" and burst into tears.'

Mike has now fully recovered and is working hard to encourage people to visit their GP at the first signs of oesophageal cancer.



# JOIN THE BLOG.....

<https://healthunblocked.com>

- Q “ I'm currently experiencing dumping syndrome it comes on after I have eaten.... Can anyone tell me why this happens?  
I get symptoms of dizziness fatigue nausea trembling and sweating”
- A Dumping is literally a real pain but it can be controlled. I found the best advice was from the OPA - but there are also lots of useful tips on their website. If it does cause you pain -I found a hot water bottle helps to relieve the symptoms too! It will get better as you get to know what is causing it for you but it does seem to be something we all have to get under control and continue to monitor.
- A. Have you kept a food diary? Is there any pattern to the dumping? Is this late or early dumping? If the effect is fatigue sometimes a boiled sweet will help as will a dextrose tablet.
- Q Milkshake froth in your throat?
- A. I thought it might be helpful for others to share some advice about the problem that some people have when you keep accumulating foamy stuff in your throat that you cannot swallow, and have to spend time spitting out after eating, perhaps for an hour or so to clear it.
- It may not be that everyone is the same, but what seems to happen is that saliva and gastric juices are accumulating in what is left of the stomach. With the absence of the valve at the top with the junction of the oesophagus, air mixes with this cocktail and it becomes like a milkshake froth. Domperidone is seen as the normal solution to this problem, but it has to be used in a certain way. One needs to take Domperidone 30 – 40 minutes before eating. Domperidone as well as being an anti-sickness drug is also a muscle relaxant so it relaxes the muscles of the digestive system so that everything moves downhill a little more quickly and moves this gunk out of the chest area. Taking it 30 -40 minutes before eating can be the most important bit.’
- So if you have this problem, and find that domperidone is not working, it might be worth thinking about when you take the medication as that can make a difference.
- The other thing to think about is whether you swallow a lot more air than normal with food. This can sometimes result in smelly wind. So eating fairly slowly, and chewing everything well can also make a difference.
- Q Just want ask anybody please only now and again I suffer from that horrible bile that comes up during the night when your a sleep !! is it because I have slept on my left side or is because I have eaten late just before going to bed or is it both ??? the bile that comes up eventually is a yellow colour and once you have clear your chest or throat all is fine again but its not a nice experience, I wait for some people's views on this subject I am nearly 3 years post op.
- A. I take two 5ml spoonfuls of Peptac Liquid before going to bed, as prescribed by my GP. The last time I forgot, I had a severe acid reflux during the night.

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[https://twitter.com/OPA\\_UK](https://twitter.com/OPA_UK)



## OPA MERCHANDISE



When ordering, don't forget to state your preference of gold or chrome finish, or shape, where appropriate.

An Introductory Range of OPA Branded Items are now available for purchase. Help support the OPA by buying these products. Not only do the funds help us function, but using these items helps raise the profile of the charity and the work we all do.

Just send us your name and address **and telephone number** with details of what you would like to order, together with your cheque or postal order, to The OPA, 22 Vulcan House, Vulcan Road, Solihull, B91 2JY. All our prices INCLUDE P&P by 2nd Class Royal Mail.



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Registered Charity No 1062461

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# Standing order form

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sort code: ...../...../..... account No: .....

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)                                                                 

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Recipient Bank: HSBC Bank, 34 Poplar Road, Solihull, B91 3AF.  
Sort Code: 40/42/12 Account Number: 51354981

Details of person setting up Standing Order:

Title (Mr,Mrs Dr etc)..... Name.....  
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*giftaid it*  Tick the box to add an extra 25p to every £1 you give at no extra cost to you.

Yes, I pay tax in the UK. Please treat all donations I make or have made to the Oesophageal Patients Association for the past 4 years and in the future as gift aid donations until further notice.

(You must pay income tax/capital gains tax at least equal to the amount of tax reclaimed on your donations)



**Please send this form to the OPA,  
22 Vulcan House, Vulcan Road, Solihull,  
B91 2JY.**

Registered Charity Number 1062461, Chairman: John Talbot.  
www.opa.org.uk. Tel: 0121 704 9860

## The Day in the life of an.....

Oesophago-Gastric Clinical Nurse Specialist (Upper GI CNS)

Dear readers of the National OPA Association, my name is Lorraine Sutton and I am an upper GI Clinical Nurse Specialist at Portsmouth NHS Trust on the sunny south coast.

It is a real privilege to work as the Clinical Nurse Specialist at the Queen Alexandra Hospital. Every day I am in direct communication with patients and their families to ensure seamless continuity of care within our multi-disciplinary team. Working alongside my fantastic colleagues that make up the upper gastro-intestinal team within our Trust, we provide the support and advice for our patients and their families and provide guidance during their treatment journey.



Diary in the typical day of a clinical nurse specialist:

Arrive in the office about 7:30 am to pick up emails and new referrals.

Visit patients who are about to undergo a staging laparoscopy and endoscopy. This is a key staging procedure and helps the surgeon plan future surgery. It is done under a general anaesthetic.

I will then go on to meet patients with their families prior to surgery for an oesophagectomy or gastrectomy. This can understandably be a very emotional time for the family, so we discuss the events of the day and how we will communicate throughout the day and at what stages. Once the patient has gone to theatre, I then take the family to the intensive care unit (ICU) so they are familiar with layout, visiting hours and contact numbers.

Return to the office to pick up the telephone messages that have been left over the weekend and action them. I have a lot of calls to deal with, from both surgical and oncological patients, many are queries relating to treatment and issues that have occurred since the start of their treatment. My work mobile has made me much more accessible to my patients and has given peace of mind to their families knowing there is always an answer just a phone call away. The work mobile has also improved my direct contact with the other health professionals, enabling them to keep me informed of patient admissions to oncology or gastro units, and also any changes or interventions in patients treatment pathways.

The surgical clinic takes place on a Friday afternoon, at which action plans are put in place ready for Monday; this is for patients coming in for surgery, patients being booked for investigative procedures, arranging patients for pre-clerking, at all times trying to minimise the number of visits the patient has to make to the hospital.

The part of the day I look forward to the most is the post-op visits on ICU, surgical high care (SHC) and E2, our specialist upper GI ward. There is no greater sense of job satisfaction than chatting to patients who have undergone pre-operative chemotherapy and then major surgery who are now sitting up in bed on the road to recovery and asking when they'll be able to have a cup of tea!

I tend to start my visit in ICU. Loved ones are often surprised at how quickly our patients are out of bed and sitting up in a chair which is testament to our early physiotherapy interventions and the care of the ICU team under the direction of our consultant surgeons – Mr Mercer, Mr Toh, Mr Knight, Mr Carter and Mr Somers.

My next visit takes me to Surgical High Care where most patients are now making great strides towards eating and drinking, losing some of their attachments, ie, drains which have been inserted during surgery, and are under the careful watch of our UGI surgeons and our specialist UGI dietician (Briony Robinson), together with other professionals such as the pain team, the ICU team and physiotherapists.

Cont.....

## The Day in the life of an.....

I then continue on to the UGI specialist ward E2. Patients here are usually in the final stages of treatment and planning for home. The team on E2 work tirelessly to assess the requirements of every individual patient in order to promote a positive recovery and discharge into primary care (community). I enjoy the communication with patients, their family and friends, gaining a picture of how the discharge into the community setting will impact their lives. There is plenty of psychological support offered as the adjustments for this group of patients is huge. I work closely with my colleague Carole Harris the UGI Nurse Practitioner, and the team on E2, for patient centered care to provide a positive patient experience. I can be on the ward for 1-2 hours depending on the amount of support required by a group of patients.

Despite my best plans - lunch is usually on the hoof and I rarely get to savour our excellent hospital dining facilities!

Afternoons are spent with follow up visits to theatres with a surgeon, discussing the outcome of the laparoscopy with the patient and their family. Patients generally tell me that being told you have cancer is a bombshell. However waiting for appointments and outcomes is also extremely stressful and therefore we try to keep the family in the picture letting them know as soon as possible any further news and appointments - usually on the day.

Other visits I may make during the day will be to oncology wards, attending outpatient appointments, meeting patients after they've had an endoscopy or other procedure or test, all with the aim of supporting the patient.

Back at the office – discharge packs for patients going home are prepared with supportive literature, contact details, a follow up clinic letter and invitation to our support group 'SPLASH' which runs quarterly at QA Hospital Portsmouth NHS Trust (this can be accessed via the national OPA website). The support group has grown rapidly and a proportion of time is given to facilitating the agenda for the next meeting in communication with a patient led committee.

The latter part of the day is spent telephoning discharged patients to see how they are adjusting at home since leaving the hospital environment. I try to do this 24-48hrs from leaving the hospital, one week later and one month later. This is a really important part of my job to maintain the ongoing supportive network and liaising with the community services. Patients are encouraged to contact me with any issues they may have, as this can prevent a hospital admission if monitored effectively.

My day usually finishes at 17.00 and there is always plenty to carry on for another day.

My role is to support patients and their families through a time in their lives when having a key worker as a point of contact is paramount. We as a team, surgeons, consultants and oncologists - all members of the upper gastro-intestinal multi-disciplinary team - cannot take the diagnosis of cancer away but we can work together to empower, treat and facilitate the

## Media News

### **PLOS Medicine Sept 2014**

Patients prescribed proton pump inhibitors in combination with diuretics face increased risk of hospitalization for low blood magnesium.

Taller individuals are less likely to develop oesophageal cancer and it's precursor, Barrett's oesophagus, according to a new study<sup>1</sup> in Clinical Gastroenterology and Hepatology, the official clinical practice journal of the American Gastroenterological Association.

### **BBC Nov 2014**

Cancer of the gullet could be diagnosed with a cheap and simple sponge-on-a-string test, latest trial results show.

In tests on more than 1,000 UK patients, it was found to be well tolerated, safe and accurate at diagnosing Barrett's oesophagus.