



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

SPRING NEWSLETTER

MARCH 2016



David and Barbara Shreeve organise a monthly drop in session for members of the Leeds Regional OPA at the Sir Robert Ogden Macmillan Centre at Harrogate Hospital. It is an Informal occasion and gives members the opportunity to discuss issues in a relaxed and friendly environment. Part of the session is to enjoy light refreshments home baking, local cheeses and pies. At the drop in session on Thursday 18 February members were delighted to welcome HRH Prince Charles and Camilla Duchess of Cornwall. Prince Charles is the Patron of Macmillan Cancer Care, a key partner of the OPA, that provides assistance in awareness campaigns, accommodation for meetings, literature, training and online information for oesophageal cancer patients. The Royal visitors were very interested in the work of the

OPA and particularly in how patients and carers support one another. John Taylor, Chairman of the Leeds Regional Group had the opportunity to speak at length to Prince Charles on the nature of the disease and the effects of the treatment. Prince Charles was also interested in the impact on the carer and questioned carers on their experiences. Camilla talked with David Shreeve about the problems being encountered by survivors of oesophageal cancer, and those still undergoing treatment, particularly in regard to eating. She also recognised the value to both patients and carers of belonging to a support group. Joan Bardsey, who had her surgery over 10 years ago, brings local pork pies to every session and was delighted when Prince Charles accepted her last pie!





'Undergoing Oesophagectomy from the Patient's Perspective'

Les Viner



Les Viner is a volunteer for the OPA acting as Co-Ordinator for our Grimsby Branch. He has always been an extremely fit man, excelling at road cycling, climbing and skiing. However, three years ago Les was diagnosed with oesophageal cancer.

Seventy year old Les had no previous history of illness, when he suddenly started suffering stomach pains, vomiting freshly chewed food and losing weight. Initially his GP prescribed Lansoprazole to no effect. He was referred for gastroscopy and subsequent biopsies showed a poorly differential Squamous Cell CA oesophagus. Les was transferred to the care of Princess of Wales Hospital, Grimsby when he was suffering significant weight loss caused by the fast cancer growth, was unable to eat

and could only drink fluids via a straw. After a further gastroscopy and argon laser treatment to widen the oesophagus, he started chemotherapy which reduced the size of the cancer and within ten days was able to eat some solid foods.

Married to an experienced community nurse, Les had led a full and rewarding life surrounded by a close family with six grand-children. He had experienced life and death situations on high mountains and in two armed conflicts, including the Falklands campaign where he survived the bombing of the Sir Galahad. His attitude was as the old military analogy 'if the bullet's got your number on it, it will get you, it will either kill you outright or injure you, in which case you put your life in the hands of the medics.' He didn't know if his condition was treatable and had to wait 9 weeks for the chemo to end when he could have a further CT scan to find out whether it was operable or not.

When the final CT scan was done, his consultant offered 'surgery to cure'. If he had refused the surgery, Les would not have survived for more than a few weeks, so the choice to proceed was a 'no brainer'. The risk factors were explained to him and it became clear that as the patient he had an important role to play in the team effort that was needed for a successful outcome. So regaining a high degree of fitness, after nine week of chemotherapy, was a priority. Les rode his bike for up to a hundred and fifty miles a week and his lung function test prior to general anaesthesia showed excellent results.

Les had done all he could to prepare for the operation as was now in the hands of the surgical team.

He summarises by saying:

"My stress levels in the anaesthetic room prior to the operation on a scale of 1 – 10 were 2. I had done all I could to prepare for the operation and was in the hands of the surgical team and God. So no point in wasting energy and getting stressed about it. In my experience it is essential for any patient to find a coping mechanism. So, succinctly:

- Put your family affairs in order
- Talk about your condition with family and friends
- Share the operative risks with them
- Listen to advice given to you by your surgeon, anaesthetist and other health professionals and act up on it

Continued on page 3



- Read the information packs and do not be afraid to ask questions no matter how trivial they might appear
- Work hard at developing a close relationship with your consultant and specialist nurse
- Finally, as a key member of the team, play your part by heading the advice of the professionals and keep a positive mind set even during the dark moments. There is a light at the end of the tunnel and you will get through the biggest challenge of your life.”

Following his eleven and a half hour life- saving operation, Les was told to expect that it would take 6 months to a year to get back to any sort of normal fitness levels. Although the operation was a complete success and the prognosis good, Les still needed 3 more sessions of chemotherapy. He then concentrated on becoming fit again, with a simple strategy, planning daily activity and then did a small percentage more than the plan, knowing that his body would tell if he had done too much. After several months of hard work Les was able to walk 3 miles a day and he could ride his bike for up to 15 miles on the flat.

Les comments on his operation:

“Cycling, the skills of the surgeon, the nursing team and a positive mental attitude saved my life”. He goes on to say: “ I believe that the key to recovery is a positive attitude, sense of humour is critical and support from your spouse/carer, family and friends is vital and a determination to get your life back. There will be good days and not so good days and maybe occasionally a bad day, but you are still alive with a chance for many active years ahead, your future is in your hands. Enjoy every minute.”

Precis from Les Viner

OPA Scarves

The South Coast branch has kindly donated £1600 to the OPA to design and produce a scarf. Ron Haines the South Coast co-ordinator suggested a scarf as patients are more prone to feel the cold after there operation. Thank you to the South Coast branch and to Ron for their excellent idea and for their kind donation. The scarves are now on the website and can be purchased.

Made of acrylic, our high-quality luxurious feel scarf is thick and warm. Multiple colours on light blue. £10.00 plus £1.00 P&P



Restaurant/Toilet Cards

We now have new Restaurant Cards in different languages; English, Spanish and French, Dutch, German, Greek, Italian, Polish, Portuguese and Turkish.





Fundraising

In Memoriam' and 'Making a gift in your Will'

The OPA has traditionally received generous donations in memory of loved ones and friends who have had to cope with the devastating effects of oesophageal and gastric cancers. Such donations are enormously important to the charity and will always provide valuable assistance to the continuity of the OPA's work.

Nowadays, we are working to raise funds in a difficult and competitive climate and need to make people more aware of how they can make all the difference to helping to support patients through raising funds for The OPA. The funds are needed not only to continue the work of the charity, but also to expand the services to support many more patients. We must establish support groups in areas where there are currently none available, to provide access to meetings for the many patients who are unable to travel long distances to their nearest support group.



So, one of the ways in which our fundraising efforts will become more proactive is to publicise the valuable contribution that legacies and In Memoriam donations can make. Our new 'Leave a Gift in your Will' leaflet can either be downloaded from the 'How you can Help' pages on the website or the printed version is available from Head Office. We are seeking help in distributing the leaflets and will be pleased to send supplies to you. You can assist our campaign by approaching your local solicitors to ask them to consider having them available for clients who would like to support a charity in their Will.

We have also registered with 'MuchLoved' an online method of making donations and setting up special tribute pages in memory of loved ones. To find out more, please have a look at the In Memoriam page on our website, under the heading of 'How you can Help'.

Thank you to all our supporters for their donations and fundraising efforts on our behalf.

You are making a difference!

Amongst the many donors who have organ-

An evening full of fantastic entertainment and fundraising for the OPA. The night included a Michael Bublé tribute act



(James Williams- As seen on X-Factor), a buffet, strip of raffle tickets and dancing to 60's & 70's Rock'n'Roll. Mo held the concert in memory of her brother, Brian Chapman, a former Solihull Police Officer, well known locally who died of oesophageal cancer eleven years ago. Mo raised over £2000 for the OPA.

Mo is also organising a floristry business seminar at the Holiday Inn, Solihull on Sunday 24th April. There will be a floral competition

If you would like to organise an event or help to raise funds for the OPA then please email us at charity@opa.org.uk or call 0121 704 9860 for a chat.



New Trustee

John Taylor



John became aware of the need to consult his GP when he experienced difficulty in swallowing whilst on holiday in Seville in 2010, shortly after his retirement. He had an oesophagectomy in October 2010 after a course of chemotherapy.

John and his wife Marisol are very grateful for the support they received from the OPA and became active members of the local group. John is now the chair and Sol the secretary of the Leeds Regional group.

He spent most of his working life in further education and was principal and chief executive of colleges in Sheffield, Leeds, Doncaster and Preston. He also lectured in colleges in Staffordshire, West Sussex and Cheshire. He is a governor of Leeds Trinity University, chair of St Monica's Trust and a trustee of the Charles Plater Trust. He was previously a member of the Learning and Skills Council and chaired the British Education Communications and Technology agency and Wheatfields Hospice in Leeds.

He is married to Sol and they have three children and five grandchildren. He was a keen sportsman retiring from playing cricket just before his operation and is now an avid spectator following Hull City and Yorkshire CC. He enjoys walking in the Yorkshire Moors and spending time with his grandchildren who live in Epsom and Aboyne, Aberdeenshire.

Welcome back

Professor Anthony Ingold



Tony began his career as a Medical Laboratory Technician, including working for several years for Imperial Cancer Research Fund in London. He gained his first degree and doctorate both by part-time study at Birkbeck, University of London, whilst working full time and bringing up his young family. He worked for several years as a Senior Research Medical Microbiologist at the Brompton Hospital in London, where he carried out many of the early clinical studies on the use of Amoxycillin in treating chronic non-tubercular respiratory infections. He continued his research career as a university reader moving to the fields of management and business. He has published widely, including both academic books and articles in referred journals such as Lancet and the BMJ.

Tony is now retired and is a volunteer at the Queen Elizabeth Hospital NHS Trust, working half day per week in the Clinical Decisions Unit. He is also a lay member of the Pan Birmingham Cancer Research Network and the Pan Birmingham Cancer Network User Partnership Group. Having had cancer himself, now thankfully cured by skillful surgery at the QE hospital, he is also a member of the Network Site Specific Group for Upper Gastrointestinal Cancer.



John & Candy Talbot

John and Candy who ran the OPA Grantham Group and also the Nottingham Group at Maggie's Centre, have now moved on.

John & Candy Talbot have sadly said goodbye to the many friends they have made through the running of Grantham and Nottingham support groups over the last five years. They have moved up to "God's own country", not just to be closer to ever more ailing mothers and other family members, but also to take on another house project, converting a tired semi with a paddock and spectacular Ilkley Moor views into a Wow home for the next phase of their lives.

But they are not saying goodbye to the OPA. They intend to join the Leeds group and lend a hand if ever needed. Meanwhile, the Nottingham group continues on its now well established drop-in basis, the third Thursday of every month at Maggie's Centre in the City Hospital campus.

One of the innovations that John introduced in his two groups was to hold occasional walks with a light lunch to follow, in locations such as Burleigh House, Wollaton Park, Southwell and Grimsthorpe Castle. But the highlight of his times at this group must remain the talk he arranged at Trent Bridge given by Geoffrey Boycott on positivity through cancer.



Goodbye & Good Luck!



Recipe

Sweet Potato

Ingredients

- 2 large sweet potatoes
- 1 large potatoes
- 1 onion
- 1 carrot
- 60g butter
- 1 tablespoon olive oil
- 850mls vegetable or chicken stock
- Crème fraiche

Method

Peel and roughly chop the onion. Sauté for a few minutes in the butter and olive oil over a medium heat until the onion is translucent.

Meanwhile peel and roughly chop the potato, sweet potato and carrot and add to the onions. Stir for a few minutes before adding the stock. Simmer for approximately 10-15 minutes or until the vegetables are tender.

Liquidise to form a smooth consistency. Season to taste and serve with a dollop of crème fraiche.

Recipe courtesy of Mhairi Donald. (Whizz it up recipes)

The Association Excellence Awards 2016

The Christmas issue of OPA News, in its newly designed format, has received an accolade by being shortlisted by The Association Excellence Awards 2016 under the best association newsletter category.

The Association Excellence Awards are important because they recognize best practice, excellence and innovation in professional associations. The publicity surrounding the event was extensive and all helped to strengthen the public profile of The OPA.



Maggie & Jacqui
at the Newsletter Awards 2016



The Association Excellence Awards 2016

FINALIST
Best Association Newsletter



Forthcoming Meetings

- 23rd April 2016 - Leeds
- 3rd May 2016 - South Coast
- 5th May 2016 - Birmingham (QE Hospital), Isle of Wight (**Bob Mason OPA Chairman visiting**)
- 6th May 2016 - Essex
- 12th May 2016 - Lancaster (**Bob Mason OPA Chairman visiting**)
- 14th May 2016 - Exeter (Regional Meeting)
- 19th May 2016 - Nottingham, Colchester
- 20th May 2016 - Royal Marsden
- 21st May 2016 - Grimsby
- 24th May 2016 - Bristol
- 25th May 2016 - Preston
- 27th May 2016 - Manchester (Trafford), Exeter
- 28th May 2016 - Guildford, Scotland (Oesophagull)

OPA AGM

Hosted by Birmingham

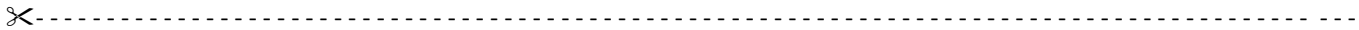
Old Joint Stock

4 Temple Row West, Birmingham B2 5NY

**25th June
2016**

10:00 for 10:30

A buffet lunch will be provided



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:



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