



# OESOPHAGEAL PATIENTS ASSOCIATION

## Oesophageal and Gastric Cancer Support

*'former patients helping new patients'*

**Established 1985**

Registered Charity No. 1062461

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Above; Dawn Williams and Mark Reynolds accepting a cheque from Coventry Building Society that was used for the training of Branch Co-ordinators in 2008 (see Chairman's report on page 3)

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Nutrition if you are having radiotherapy or chemotherapy; PAGE 2

Patient Experience on PAGE 4

Advice from the DVLA for returning to driving after your operation; PAGE 5

Regional Branch Meeting dates on PAGE 6

Your letters on PAGE 7

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## NUTRITION

### IF YOU ARE HAVING RADIOTHERAPY OR CHEMOTHERAPY

Radiotherapy for oesophageal problems can affect taste, make the throat feel tender and very dry, and sometimes nausea and tiredness can add to your difficulties and make you a little depressed. All these matters improve when the treatment stops, but taking the best nourishment you can while it lasts will help recovery.

Use the suggestions in the OPA leaflet “SWALLOWING – NUTRITION WHEN IT’S DIFFICULT”<sup>\*</sup> and ask the hospital dietician for help if needed. Medicine can be given to reduce nausea.

Generally, hot spicy foods should be avoided and ask about alcohol if you normally enjoy a drink. Fizzy drinks, fruit drinks (and even beer) may sting, as may very hot drinks, but nevertheless try to take plenty of fluids, including milk.

Chemotherapy can also affect taste and appetite and cause nausea and vomiting for a day or two after being given. Cold food and drinks may be more acceptable at this time as they avoid cooking smells, and tart and salty flavours (e.g. lemon, crackers) may help. Cut down on fat and keep up the fluid intake as some dehydration can occur. Milk is good if you can tolerate it and fruit juice/Ribena to supply vitamin C. Glucose drinks such as Lucozade, fizzy drinks, spring water and herbal teas (if your taste for tea and coffee has changed) are all useful. Fresh pineapple is good for keeping your mouth fresh and moist.

Make use of marinades, strongly flavoured sauces such as sweet and sour, pasta or curry, herbs, spices and seasoning as long as you have not got a sore mouth or mouth ulcers. If you get any cravings go along with them!

Take energy supplements; they are available in liquid or powder form, are an easy way to get extra energy but are not nutritionally complete. They may be obtained on prescription. It may help to suck a boiled sweet or a mint while the chemotherapy is being given. The second and subsequent doses of chemotherapy may be better tolerated but taste may be more affected, particularly if fungal infections occur.

*\*This information has been taken from the OPA booklet “SWALLOWING – NUTRITION WHEN IT’S DIFFICULT” which is available from the Association by telephone or email request.*

*The booklet also contains advice on looking after a stent, achieving a balanced diet, tackling eating problems, advice on food and energy supplements and a comprehensive list of soft nutritious foods as well as several recipes, including some for those times when you are really finding it difficult to face food.*

There are good and bad events to report from the past six months.

We are sorry that Lynne Watson, who has been helpful to many patients and their families for almost eight years as the OPA's Patient Support Manager, has had to take early retirement following her treatment for a brain aneurism.

She will be much missed but we hope she will enjoy leading a less hectic life. We are fortunate that Dawn and Mark have absorbed Lynne's role between them and I am very grateful for their commitment to the Association.

Michael Kerin displayed great organisational skill when he set up the Portsmouth Branch in 2006. He obtained funding for a training course for patient volunteers and inspired his son to run the New York Marathon for us. Sadly, he had a recurrence last year and died in December but the Branch is determined to carry on as he would have wished.

Some better news; several new patient groups have been set up, four of them in the West Midlands. We have enjoyed taking part in their meetings in Wolverhampton, Dudley, Stoke on Trent and Sandwell and hope they continue to flourish. They are well supported by their medical teams and members find them very helpful.

Our first co-ordinators' conference, held in October, was a great success and we will endeavour to make it a regular event. Branch co-ordinators sometimes feel rather isolated, so meeting others and exchanging ideas on the best way to run a branch was very productive.

## Hints, Tips and Answers to Frequently Asked Questions

*"My tip is regarding meals; little and often can be difficult so the freezer becomes invaluable. I use plastic milk cartons for soups. I rinse with hot water to soften the plastic and cut round to make a box. Each box is lined with a freezer bag to contain the soup. They stack well in the freezer and can be labelled with a fine marker pen and used repeatedly. My most useful gadget is the tape bag sealer which I bought from my local market for £10. I use it for all the pureed meals". (CD)*

*A noticeable number of patients mention shoulder problems occurring after surgery. We believe it may be due to the position in which patients are put on the operating table (nobody asks if you are comfortable and you are stuck there for several hours!). Arms have to be out of the way to get at the chest and entry points to the oesophagus and you may have to be moved during the operation. Nerves may be trapped but they usually recover without treatment, but physiotherapy may be helpful in some cases. Let the medical team know if your shoulders do bother you. (OPA)*

*It can be worrying to lose more weight on returning home after surgery but really it should be expected since it's difficult to eat a lot in the early days. Since your stomach is smaller and the digestive process has to adjust to the new arrangements it is best to eat the food you enjoy the most rather than concentrate on foods for weight gain. You may feel full rather quickly (the prokinetic medicines metoclopramide/domperidone may help for a while) but the body needs to do its own thing and will. Exercise will stimulate the appetite and 'little and often' can be a pleasant way of eating. It will get bigger in time though usually not to what it was. After 2 to 3 months the weight loss should stabilise and then gradual gain can occur. (OPA)*

*Firstly, may I thank you (the OPA) for the help and guidance you have given me; I send you my experiences in the hope that it may help others.*

*I am 63, in reasonably good shape and was diagnosed with oesophageal cancer on April 30<sup>th</sup> 2008. It was operable.*

*Eight weeks later I started chemotherapy at the Cancer Centre, Belfast City Hospital. It consisted of three sessions of 3 weeks (9 weeks in total) and was very effective in reducing the tumour. It had few side effects.*

*Three weeks after this I had an operation at the Royal Victoria Hospital, Belfast. The following five days were harrowing; I couldn't sleep; I was uncomfortable with lack of breath and coughing and I needed suction to clear a painful chest. I lost the epidural on day 2. On night six I slept and started to recover. I was discharged after twelve days, at which point I could walk for ten minutes.*

*Twelve weeks later (as at 19<sup>th</sup> January 2009) I have restarted chemotherapy, once again three sessions of 3 weeks. It has not been as easy this time as it is taking a full week to recover from the two drugs given in the hospital. The treatment is bearable however and worthwhile although my digestion is quite disrupted. I find that the sugar content of food, as well as the amount, can affect dumping. I was advised to eat little, often and slowly.*

*I finish all my treatments on Thursday 19<sup>th</sup> February.*

*The medical treatment I have received has been first class. There is a great depth of knowledge, experience and expertise amongst all surgeons, doctors, nurses and ancillary staff at both hospitals.*

*Lastly, I would like to share with the readership my personal measures;*

*I raise my head in bed with a wedge of (32 hard grade) furniture foam; 5'' (125mm) high by 27'' (650mm) [depending on height; I am 6 feet tall] wide (based on the size of the bed). This was cut for me by a local furniture maker for £20. It is okay for me provided that I do not eat too much supper, in which case I increase the height with pillows (another person I know with the same condition uses a 10'' (250mm) high wedge).*

*If necessary, a pillow set across the bed under your thighs stops you sliding down the bed.*

*I have a 75mm thick memory foam topping (60kg/m<sup>3</sup> density) on top of the mattress and the same size. I obtained this from Rhois, Newcastle-on-Tyne for £105 on the internet.*

**(EDITORS NOTE; Memory foam is also available from Dunelm Mill – details in last issue).**

*I have not found keeping my weight up to be a problem. I lost 10kg and now weigh 85kg.*

*Sincerely*

*John Cunningham  
January 2009*

In order to get the most from any consultation it is always wise to aim to build up a good rapport and a great deal of trust between you and the clinicians who are treating you.

Two years ago I was diagnosed with a rare condition, not life threatening but potentially disfiguring. My consultant had rarely treated this condition before, indeed few doctors in the UK have, and my consultant has been in constant contact with those who have experienced this type of infection. He was very open and honest about the treatment I was to receive, for we were embarking upon what would be a very long journey of discovery together. Such is our relationship that we discussed a second opinion, just to cover all of my options. The treatment offered by the second doctor did not seem right for me but during my appointment it was good to hear both clinicians discussing the merits of their own preferred methods of treatment over the 'phone.

My consultant listens to me and we vary drugs and treatments according to the way they affect my body. He believes in treating me holistically to keep both my body and mind healthy. By working together over such a long period he has been able to achieve all this.

One of the great benefits of attending regular hospital appointments is that I have made so many friends; from the friendly receptionist, to the nurse in charge of outpatients, with a wealth of other lovely volunteers and nurses to complement the department. I find that I spend at least twenty minutes just catching up with everyone prior to my appointment! I have no time therefore to have rising anxiety levels. I stay calm and relaxed; just the right frame of mind to be in when I actually see my consultant.

I would not choose to spend my time in a hospital out-patients clinic, but because of my health I currently have to. So, I decided to make the most of that time and get the most out of it.

Make the most of your time there too.

***\*HELP LINE NEWS\****

***PLEASE NOTE THAT DUE TO STAFF CHANGES AT THE SOLIHULL OFFICE THE HELP LINE WILL NOW BE AVAILABLE FROM 9AM UNTIL 3PM EVERY WEEK DAY (WITH AN ANSWERPHONE MESSAGE SERVICE FOR OUT OF HOURS CALLS)***

**DRIVING AFTER AN OESOPHAGECTOMY**

The DVLA advise you to refer to their website, in particular to the section "*At a Glance Guide to the Current Medical Standards of Fitness to Drive*". In the introduction you will find that there is a section entitled "*Driving After Surgery*", which provides general advice and highlights the concerns that should be taken into consideration when returning to driving following surgery.

With regard to specific conditions, in particular surgery related to carcinoma, then as well as the general considerations it would also have to be taken into account whether the underlying condition itself is debilitating to the extent that it could affect safe driving.

Also, the continuing need for medication and its effects should also be taken into account.

**With thanks to the Driver and Vehicle Licensing Agency Medical Adviser  
[www.dvla.gov.uk](http://www.dvla.gov.uk)**

## OPA REGIONAL BRANCH MEETINGS

The following meetings will be held for patients who have had, or are about to have, major surgery for the removal of their oesophagus or stomach. Local specialist surgeons, nurses, dieticians and physiotherapists are always invited to answer your questions so that you can learn more about what has happened to you. The meetings have a friendly format and you will be made very welcome, with former patients making themselves available as hosts for new patients and their families. Patients who have made contact with the OPA to inform us that they have had an oesophagectomy will be automatically invited.

*Please Note: Inevitably, most patients attending our meetings have had, or are going to have, surgery. All oesophageal cancer patients are welcome but this emphasis is to be expected in discussions.*

**If you would like any further information about these meetings, please contact Dawn Williams at Head Office.**

### SPRING 2009 DIARY

Birmingham	Saturday April 25th
Bristol	Monday March 30 <sup>th</sup> and Monday May 18th
Derby/Burton	Saturday March 21st
Poole, Dorset	
Exeter	
Frimley Park	Saturday June 6th
Leeds & Region	
Lincoln	Saturday April 25th
Liverpool/North Wales	Saturday March 28th
Luton & Dunstable	Saturday March 28 <sup>th</sup> and Saturday June 13th
London	Saturday May 30th
Manchester	
Nottingham	
Northern Ireland (Belfast)	
Norwich	Saturday April 25th
Reading	Saturday March 28th
Portsmouth	Saturday April 4 <sup>th</sup> and Saturday July 4th
South Tyneside	
South Wales	

### BRANCH NEWS - LINCOLN “WINTER WARMER”

**On a very cold but sunny Saturday in January, the Lincoln branch of the OPA joined forces with the village of Wragby (where meetings are held) to hold the annual “Winter Warmer”. This event is always well supported with villagers manning stalls offering various goodies along with a raffle, tombola and the ever popular; “Guess the Teddy’s Birthday”.**

**The homemade food was produced by the ladies of the village and, as always, was absolutely delicious. The village hall main function room was used and packed to capacity with every table in use, all beautifully laid out and finished off with colourful floral centre pieces.**

**This continues to be a successful and very enjoyable lunchtime event with everyone giving their time and effort voluntarily. A magnificent sum in excess of £900 was raised.**

**The committee and members of Lincoln Branch offer their grateful thanks to the villagers of Wragby for their generosity and continuing support.**

# YOUR LETTERS

*"Waiting for the News"*

*Yet another appointment looms  
Back to the hospital I must go  
You'll be alright  
You'll be alright  
My inner voice says*

*Into the hospital I bravely go,  
Cleansing hands and booking in  
You'll be alright, you'll be alright  
My inner voice says*

*My name is called.  
Will my legs carry me through?  
You'll be alright, you'll be alright  
My inner voice says*

*We must weigh and test you  
Joy of joys – I've put on weight!  
You'll be alright, you'll be alright  
My inner voice says*

*Through to see the man himself  
"You do look well," he says  
You'll be alright, you'll be alright  
My inner voice says*

*"You've put on weight, you do look well  
But we had better do another scan"  
You'll be alright, you'll be alright  
My inner voice says*

*The horrid liquid I swallow down  
And into the tunnel I duly go  
You'll be alright, you'll be alright  
My inner voice says*

*Ringling 'phone – who can that be?  
The hospital to say -  
You are alright  
You are alright  
My outer voice declares*

*Betty Ward  
January 2009*

*Dear OPA*

*After your departure from the meeting  
yesterday, discussion took place as to the  
allocation of the money received from the  
sale of our recycled greeting cards.*

*The OPA came first on the list and I have  
pleasure in sending the enclosed cheque  
together with our good wishes for the  
continuing success of the work of such a  
worthwhile organisation.*

*Sincerely*

*JE*

*Dear OPA*

*Thank you for coming to our coffee  
morning at the Church Hall last week, it  
really helps when some one from the  
charity we want to support is with us.*

*We all thought that a lot of people came  
because of your organisation and our  
wish to help in a small way. I am glad to  
say that I have enclosed a cheque for  
your funds.*

*Yours sincerely*

*GF*

*We gain a great deal of encouragement from the letters we receive. However, we would also like to receive your questions, constructive criticism and stories for the newsletter please. Your experiences could help and encourage others. Help us to help you via this letters page. We can also answer your queries too. Write to: Mark Reynolds, OPA, 22 Vulcan House, Vulcan Road, Solihull, B91 2JY or email: [enquiries@opa.org.uk](mailto:enquiries@opa.org.uk) (marked 'newsletter')*

At a time of economic gloom I am at least able to let you know about some of the ways in which our funds were raised in 2008. Let me tell you of the major Trust in London who gave us a huge grant amounting to over 15% of our annual running cost and of the other twenty-four Charitable Trusts who supported our work last year and whose combined gifts amounted to around 30% of the funds we needed. For just a few other examples, there were the plucky North Norfolk Beach Runners who plunged into the sea from Cromer Pier on Boxing Day and raised £1,500 for the Association; sponsored runners raised £1,700 and our continuing beneficiary membership of TLC Lottery (see below) brought in a further £1,400 during 2008. As I write this 2009 is still a fairly new year and there is a modest spreadsheet for income. After fourteen years of fundraising I'm used to that feeling of starting out all over again each year but I take heart when I think of the wonderful support we receive annually to find the funds we need to support our members and their families and carers.

*The telephone number for Frances Nott, who has a delightful bed and breakfast near Exeter, was unfortunately misprinted in the last edition. The correct number is 01392 832335 and she can also be contacted by email on francesnott2000@yahoo.co.uk*

## \*TLC LOTTERY NEWS\*

The OPA has been a beneficiary charity of the Midlands based TLC Lottery since July 2005 and in that time over £3,400 has been raised to support the work of the Association. How it works is this; if you play £1 weekly with TLC for the benefit of the OPA, 45p goes directly to the Association (whilst a further portion is shared out between the three owner charities of the Lottery, which are; Birmingham St Mary's Hospice, Acorns Children's Hospice and Birmingham Focus on Blindness).

There is more information, and the opportunity to join the Lottery, at the TLC website; [www.tlc.co.uk](http://www.tlc.co.uk) (don't forget to select OPA as your chosen beneficiary charity if you decide to join) or by requesting a leaflet when returning the coupon below. Membership of TLC is available by direct debit, debit card or sending a cheque by post.

*A new initiative by TLC that starts on April 1<sup>st</sup> 2009 means that the Lottery will donate the cash equivalent of 10% of an OPA players' winnings. So, if someone playing TLC for the benefit of the Association wins the top weekly prize of £1,000, the OPA will receive £100!*

## FUNDRAISING COUPON

I am pleased to send a donation of [£      ]

(Please make cheques payable to OPA and complete your details below)

If you are an income tax payer, ticking this box [   ] will enable the OPA to recover tax on this, and any future donations you may make, under the Gift Aid Scheme, provided you have paid income tax or capital gains tax equal to the tax reclaimed by the OPA on the donation(s) in the tax year.

I would like to organise a Tea Party for OPA, please send me a Tea Party pack [   ]

I would like to play TLC Lottery on behalf of the OPA, please send me a leaflet [   ]

FROM:

Mr/Mrs/Miss/Other .....

NAME .....

ADDRESS .....

.....POST CODE .....

Telephone Number .....Email .....

Oesophageal Patients Association

Registered Charity Number 1062461

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