

THE

NEWSLETTER

OESOPHAGEAL PATIENTS ASSOCIATION

Gullet & Stomach Cancer Support

Issue 21

Autumn 2013

Registered Charity No. 1062461



Introducing Maggie

Increasingly, you may find our telephones being answered by Maggie Robinson. She started work at the OPA's Solihull office in March 2013. Following redundancy after 15 years at the Independent Regulatory body of the Law Society, she knew immediately she saw our advert for 'Patient Support & Branch Development Officer' that the OPA was the type of organisation she wanted to be part of. So here she is!

She says she finds the work very fulfilling. "I have seen how the OPA can really make a difference to patients' lives and I am pleased to play a part in this. HQ is undergoing a lot of change and I am bringing my ideas on board, so it is an exciting time all round. There is a huge amount to be done!"

She is married with two daughters; she spends her spare time writing children's stories, reading and walking her Chorkie dog, Tommy.

Our general manager Dawn was taken seriously ill whilst on holiday in France in August. We all send her our love and hope for her speedy return to good health and full strength.

Do you have a story to tell?



Anything you think other patients and carers would like to hear about? Your cancer story, innovations at your local hospital, or a successful fund raising adventure, for example?

LET US KNOW ON News@opa.org.uk or phone 0121 704 9860.

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HSBC runs for the OPA!!

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OPA - Experienced patients helping new patients

FATIGUE— A FORGOTTEN SYMPTOM

In a recent research project by Beverley Gambles of Macmillan, Lincoln, into cancer related fatigue, her most significant finding was that fatigue, which can affect patients before diagnosis, during and after treatments, and in survivorship and palliative care, is a forgotten symptom.

The conclusions from her study are that fatigue :

- has an absolutely HUGE impact on patients,
- is complex in its causes,
- can be managed through a variety of approaches, and
- is often under-reported, under-recognised and under-treated.

Significantly it was found that there is often a considerable difference between clinicians' and patients' views on fatigue, which can be to the patients' considerable detriment.

Her recommendations were fourfold:

- Further education for patients and health professionals alike
- Health care professionals should be encouraged to question patients on fatigue more often through the treatment pathway and to recognise the appropriate words used by patients to describe their fatigue
- Patients need to be encouraged to report fatigue without fear of feeling labelled as "being a nuisance"
- Patients need to be reassured more often that fatigue does not automatically mean that cancer is progressing.

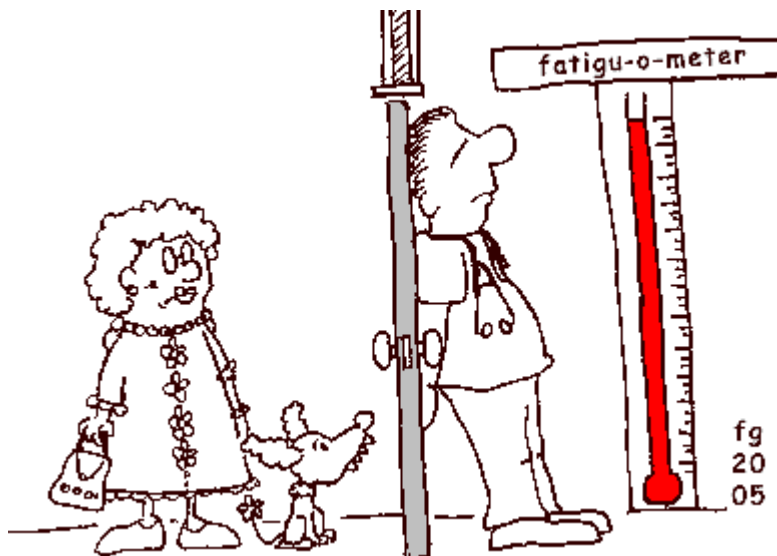
Macmillan tells us that fatigue affects everyone differently. Even just talking about your fatigue can help you manage its effects. So can making even small changes to your diet, exercise and sleep habits.

It is important to tell your health professionals about your symptoms of fatigue, without playing them down.

Symptoms can be as simple as feelings of no energy or strength, difficulty in concentrating and making decisions, breathlessness, light headedness, insomnia and feeling more emotional.

Fatigue is not the same as tiredness. If you're tired and have a midday nap, you wake up feeling refreshed; that's often not the case with fatigue.

Fatigue is recognised as a side effect of chemotherapy, radiotherapy and surgery. Fatigue is also a side effect of the pain and eating problems that can both be caused by any of the above. But it is sometimes overlooked that fatigue can be a long term side effect of surgery on the digestive system, when this leads to problems in absorption or anaemia or other deficiencies. If the OPA were in a financial position to commission



research, this would probably be the first area we would choose!

Macmillan publish some very helpful guides on fatigue, which in particular outline how changes to diet, exercise (including relaxation exercises) and sleep habits can improve the situation. There is good evidence that even a little exercise, taken after medical guidance, can reduce the symptoms of fatigue.

One good idea to help manage symptoms is a "Fatigue Diary". Its use will help sufferers - and, importantly, their carers - plan their days to be able to take best advantage of the identified times of day when symptoms are at their least and cope more effectively at the worst times of day.

More information available from:

OPA Helpline - MacMillan - Your Health Professionals

BREAKING NEWS:

RECOVERY TIMES AFTER SURGERY

A recent European research study of 455 patients has established that 3 months after oesophagectomy is the lowest point for most patients, in terms of subsequent health related Quality of Life.

Most patients returned to some form of "normal" quality of life by one year post surgery - except, interestingly, in cases of patients who spent greater than ten days in hospital, when it took longer.

Jane Darnton

THE NORWICH EXPERIENCE

The Norfolk and Norwich branch has one of the biggest attendances of all OPA support groups, and even offers 24 hour advice to all its local patients and carers. Here, Loraine Ruddle, one of the branch leaders, explains how they achieve what they do.



The Norfolk & Norwich Branch Leaders, with (front) Upper GI Nurse Specialist Jane Tallett and Dr Richard Tighe, Consultant Gastroenterologist, beside one of their awareness campaign messages.

It has taken time to achieve how we now operate. Jane Tallett and Angela Longe, our two main upper GI nurses, have been extremely supportive and they will now email us details of any patient who would like some support prior to the op.

Mike or Sue will arrange a meeting or speak to them on the telephone; there have been occasions when Mike will sit with a patient undergoing Chemotherapy or meet with them during their pre-op appointments, or during subsequent treatment.

We now contact the ward directly on a weekly basis, and the two receptionists,

David Kirby initiated the first OPA meeting at Norfolk & Norwich Hospital (N & N) on August 2, 1996. Over the next few years Rodney White, a former patient, and his partner Pat Williams, hosted bi-annual meetings and visited many patients in the hospital.

Unfortunately Pat became very ill and she and Rodney made the decision that they were no longer able to continue running the branch.

Following my husband Mike's surgery, we had attended one of their meetings and were very impressed. Mike felt he wanted to "give something back" and Rodney suggested that he might help with the OPA. The necessary training was given and we co-hosted our first meeting in November 2009. Mike was also introduced to a fellow patient, Sue Hales, who wanted to help and she had also undergone the volunteer training.

We asked if it would be possible to obtain details of **all** patients undergoing surgery so we could make sure they **all** had details of the OPA. In the first twelve months we would call the surgeons secretaries and obtain the relevant details; once we had the date of operation we could then estimate how long it would be before the patient was on the ward. Then, a quick phone call to the ward would determine whether the patient wished to be seen.

Trish & Mel, will update us with patients that are in HDU and the ones that are on the ward. They also make sure that each patient does want to be seen before Mike and Sue visit. We even receive an email when any patient leaves HDU for the ward, so we can make sure we visit with them in good time. Should any of the patients not wish to be seen we post out the three OPA leaflets along with a covering letter and contact details.

The support meetings are held twice a year, on the last Saturdays of April and October, in the Benjamin Gooch Lecture Suite in the N & N. We send the invitations out six weeks prior to the meeting and always include the surgeons and medical staff. If we receive no response from any patient on three consecutive occasions we remove their name from our mailing list, as we feel they obviously do not want further support.

At the meeting we will always try to have a speaker. This is normally one of the medical team and up to now we have had talks about diet, exercise, changes in treatment and many more subjects.

We are fortunate in the fact that we do not have to pay for the hire of our venue. We also arrange free parking for attendees. Some people are unable to attend because they are unable to afford the fuel or do not have transportation. We have looked at ways of addressing this prob-

lem, car sharing or community transport, but unfortunately this has not yet proved possible as we have such a large catchment area with many patients living in very rural areas.

We have two people who make hand-made cards and they attend every meeting and sell cards. They also sell their cards at local fetes etc. Each December we benefit from some of the money that has been raised.

We also have a raffle at each meeting, and rely heavily on the generosity of patients and local businesses for the success of this. The last first prize was a meal and drinks up to the value of £60 at a local restaurant. We have found a good first prize will prompt better raffle ticket sales. We rely on our raffle ticket monies to pay for the meeting expenses along with the rising cost of postage.

Over the last few years there have been a variety of fund raising events from sponsored parachute jumps to the strongest man competition. We are always looking for new ideas and are currently negotiating a few quiz nights and perhaps a disco to swell the coffers. On a smaller scale a book exchange club – perhaps 50p for swapping a book—would also help.

Mike, Sue and I realise how fortunate we are in having a well supported group but do not take this for granted and continue to look at ways we can improve. We feel that it is of paramount importance to form good working relationships with both the medical team and patients and this can only be done over time.

We always tell all new patients and their carers that they are able to contact either Sue or us 24/7. Often they need support or advice or just a friendly chat out of “business hours” and we have received very favourable feedback regarding this.

Without the constant support of the surgeons and nurses and clerical staff of the N & N we couldn’t do what we do and they know that we will do everything we can to help them. The N & N have recently promoted a DVD which will be given to each patient that has been diagnosed with Oesophageal cancer. It explains the treatment etc and we were asked if we could promote the OPA, which we happily did.

The recent Awareness programme for Oesophageal Cancer was run last year with East Anglia being part of the pilot scheme and again we were asked to promote the OPA. We also help at information days held by the hospital and hope to roll these out to local surgeries.

The one thing we have learnt is the wheels of the NHS can be very slow, so you have learn to be patient and move at the speed dictated by the hospital.

Slow and steady definitely wins the race.



We, the OPA Committee, would like to thank Mike and Loraine (pictured) and Sue for all their sterling efforts. They are lucky to have such enthusiastic help from their NHS staff and we are working to encourage this in other parts of the country where it is less apparent.

BREAKING NEWS:

The recent local ‘Be Clear on Cancer’ pilot awareness scheme (mentioned above) resulted in 35 extra cases of oesophageal cancer being diagnosed.

Meanwhile.... We have literally just heard that the Department of Health is provisionally making plans for oesophago-gastric cancer to be elevated to a regional awareness campaign in 2014, with TV advertising. We are being asked for our thoughts on the messages they have prepared so far for this campaign, a REAL chance to contribute and make a difference in our quest to save lives by earlier diagnosis.

Leeds OPA eat out in style at the Waterfront Restaurant, Doncaster College



Margaret and Derek Barnett (left), members of the Leeds Regional Branch of the OPA, are served a Yorkshire Tea Sorbet, one of six courses of a sumptuous meal prepared and served by students of Doncaster College.

John Taylor, member of the Leeds OPA Committee, who was a former Principal of the College, conceived the idea of the event. John was diagnosed with oesophageal cancer shortly after his retirement and underwent an oesophagectomy in October 2010.

John briefed the student chefs and front of house staff beforehand on the nature of our cancers and the dietary implications of the surgery and they responded magnificently to the challenge producing a high quality imaginative taster menu with a Yorkshire theme. Each course was delicious and the sympathetic pace of service was much appreciated by the 24 members present. Menu items included Just Cooked Hake with sautéed spinach, samphire, broccoli puree and foam; and Rhubarb Mousse with clotted cream.

Some of the students had just returned from Spain working in Michelin star restaurants and this was reflected in the quality and success of the event.



This event may be of interest to other branches. John Taylor (email: leeds@opa.org.uk) is available to give advice to anyone who wishes to arrange a similar event in their area.

Research and You

Cancer of the oesophagus is a difficult disease to treat. Basic scientific research is urgently needed and genetic studies of cancers are becoming ever more important. Some cancers have faults in a few very important genes: you may have read about the steps taken by breast cancer sufferers when they know a gene is 'wrong' in their family. Unfortunately cancer of the oesophagus is a more complex genetic problem. Detailed scientific research searches out the faulty genes, hoping to improve diagnosis and to tailor individual treatment. If you have had surgery then you might have been asked if little bits of your tumour could be retained and used for ethically permitted research. Looking at the genes in the DNA of tumour cells is getting ever more sophisticated. There are also 'ever-lasting' tumour cell lines, sourced from tumours and kept frozen. These are grown again in the lab to test genetic faults and new chemotherapy drugs. If you gave permission for a sample of your tumour to be used, or to be included in a clinical trial, give yourself a pat on the back!

Jane Darnton

Edinburgh Half Marathon 26th May 2013

After 6 months of sweat and tears the day had finally arrived and, with some trepidation, a short, bald, angry man (Iain Sharpe) and a skinny man with big hair (Neil Pearce), both from HSBC in Edinburgh, approached the start line of the longest run that either man had ever attempted. Why, you might ask?

“No matter how much pain and suffering we may endure running, it is nothing compared to the journey that any cancer patient experiences”, said Neil Pearce. The OPA is a charity that is extremely close to both our hearts as our mothers suffered from oesophageal cancer about a year apart. We are happy to say we kicked its dirty little back side. We wanted to raise awareness of the illness and help support the charity that helped our mums at an extremely difficult time in their lives.

Back to the big day and for Scotland a very uncharacteristic hot and sunny one. Not ideal for running long distances, especially when we've been training in traditional Scottish Spring weather of wind, rain, freezing temperatures, sleet and snow.

After a short walk to the start line we begin the race, ducking and diving our way to find a space where we can keep a steady pace. We go through Holyrood Park, past the Parliament and Palace (I am convinced I saw the Queen) then we headed out of town towards the coast hoping a sea breeze will help cool us down. Then the historic town of Musselburgh, where we knew the final stretch was in sight, giving us the boost we needed to keep our blistered feet going.

The race finished in the Pinkie Sports ground where we were cheered home by an enthusiastic audience and the local radio station shouting out

people's names as they crossed the line.

The run itself seemed to pass really quickly and both of us enjoyed the overall experience and the sense of achievement in not only finishing the race without any injury but also raising a significant amount of money for the OPA.

We should like to thank all our supporters who gave so generously. It kept us going and motivated in the dark days of February and March when we were pounding the streets, training, when we would've rather been in bed.



The OPA's Jane Darnton thanking Neil Pearce at Holyrood Palace

We'd also like to thank HSBC, who generously gave us £1000 towards our total."

Iain did the 13 miles in 1 hour 45 minutes. Neil took ten minutes longer, pipped to the post by a man dressed as Peppa Pig!

Overall, they raised £2072. To quote Neil, "this was for a great cause and we both hope that it will make a difference to the charity and the people it helps."

Note from Chairman: Indeed it will, Neil and Iain, indeed it will, thank you!

Branch Meetings Around The Country in Forthcoming Months

October 2013:

5th: Frimley

9th: Brighton

12th: Leeds

25th: Exeter

26th: Norwich, Birmingham,

London

31st: Guildford, Liverpool

November 2013:

9th: Exeter, Stevenage

28th: Guildford, Liverpool

29th: Exeter

30th: Grantham

December 2013:

5th: Brighton

7th: Derby

See the OPA website, or contact Head Office or local branch leaders to confirm details and for more information.

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

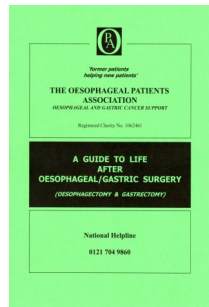
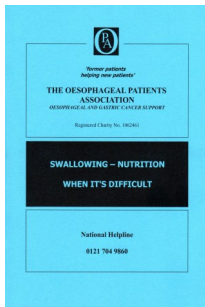
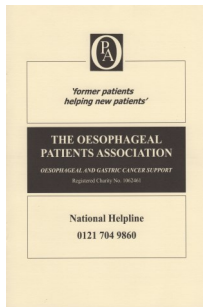
A Guide to Life after Oesophageal/Gastric Surgery.

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



Please forgive us if this newsletter's arrival finds you at a difficult time or is distressing in any way. If you want us to remove your details from the mailing list for whatever reason please let us know by 'phone, letter or email.
The Committee

HEALTHUNLOCKED



Our HealthUnlocked website now has over 400 members!

If you have access to the internet this can be an invaluable source of advice and discussion separate from meetings or the helpline.

Firstly, there is a section for Questions. Recently, these have been about experiences of radiotherapy and chemotherapy, the cost of small-sized meals when eating out, and hiatus hernia. Much like a support group meeting, people pitch in and share their wisdom, and it is a way of helping newer patients get through where others have travelled before.

Then we have 'Posts', where people can compose their own reflections and experiences without the content actually being a question. Recent contributions have been about digestion problems after surgery, 'Good News at Last!', and wedge pillows.

There are also 'Polls' - most recently about digestion problems after surgery, but in the past about diabetes, hiatus hernia, and foods that give trouble. You can look up the results of each one. The more people who take part, the more meaningful it becomes.

Visit <https://healthunlocked.com/oesophagus> think of a nickname to use (it is anonymous), and join in.

We also have OPA Charlie's Circle for those receiving palliative care <https://healthunlocked.com/opachariescircle>.

Alan Moss

Donation Form

I am pleased to send a donation of £ _____ Date of donation / /
(Please make cheques payable to OPA and complete your details below)

If you are an income tax payer, tick here which will enable 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.

FROM:

Mr/Mrs/Miss/Other:

NAME:.....

ADDRESS:.....

POST CODE:

TELEPHONE NUMBER:.....

EMAIL ADDRESS: