



TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

As autumn approaches we hope that you have all enjoyed some summer weather. Carole and I have enjoyed attending Summer Lunches at Blackpool and Bridlington respectively and were pleased to meet so many members there. Several of the "Norgate Clan" have been in Athens attending and in some cases working at Olympics 2004. Our sister who lives there has offered open house to all these visitors at her brand new house. We have welcomed many new members since this time last year and hope that you will be interested to join us in our main fundraising event, Race Night 2004. Best Wishes from all the Trustees.

Regards,
Wendy Thompson

Mini Break in the Lake District

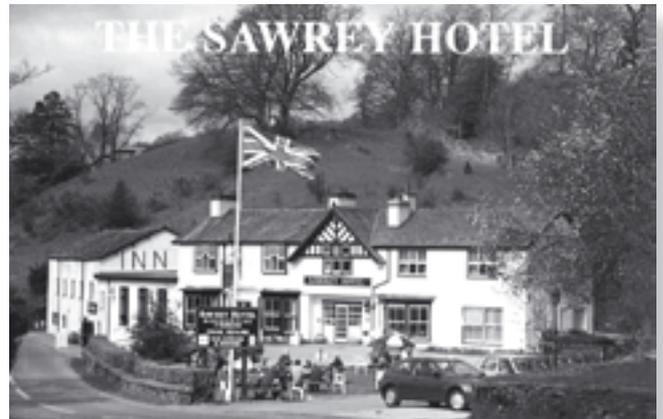
We are very grateful to the proprietors, one of whom is a laryngectomee, of The Sawrey Hotel who have donated the first prize for our raffle as part of Race Night 2004. The prize consists of two nights dinner, bed and breakfast for two people to be taken some time between 31st October 2004 and 17th March 2005, excluding Christmas and New Year. In addition to this splendid first prize there will be dozens of smaller prizes too as usual.

For those of you who have not participated in Race Night before, this is what happens: We offer ownership of imaginary horses as an absent owner at £5 per horse, you can name it yourself or we will invent a name for you. These are then made up into races of 10 horses and an Absent Owners Race Card is printed. We draw out the winners and a prize is sent to the winner of each race. We also have the raffle tickets at 20p each or £1 per book of 5. Alternatively you may wish to make an optional donation rather than taking part in the races or raffle.

We do need all requests for horses and ticket stubs by the 25th October to give us a chance to organise everything.

There is a space on the form for you to request extra books of 5 raffle tickets to sell to others. If you fill this in and send it to me I will be happy to send you the requested number of books. You are under no obligation to sell all of the tickets you request and part books sold are fine. Please remember to order early, as all ticket stubs have to be back to the office by 25th October.

We hope you can participate again this year, a form is enclosed for your reply. I hope you will get some fun out of it and that we can raise a useful sum to continue the work of the trust.



The Sawrey Hotel, Lake District

If you are making a donation and are a taxpayer, please consider signing the declaration on the back of the Race Night form. It would increase your donation at no extra cost to you. I am pleased to tell you that we have been able to reclaim over £700 from the Inland Revenue under the Gift Aid scheme so far.

We must stress however, that if, for whatever reason, you are unable to participate or do not feel that you can sell to others, that you are under **no obligation to do so and need not return the books to us. We fully understand that people's circumstances are different, that they may have moral or religious objections and that some of our members are less mobile than others.**

**Cancer Laryngectomee Trust
National Association of Neck Breathers
PO Box 618
HALIFAX HX3 8WX**

**Telephone/Fax 01422 205522
web site: www.cancerlt.org
email: info@cancerlt.org**

Charity Registration Number: 326653

BBC R4 Appeal

In the April Newsletter we told you about the work going on in preparing for the appeal and we are now delighted to report that it was a resounding success. It was a very exciting experience for Carole and Victoria to meet with Martin Jarvis, who made his own personal touches to Victoria's text, at the recording session. Sitting listening to the broadcast on 9th May brought it all back to life again. The response has been fantastic with over £11,000 donated and a significant raising of awareness of laryngectomees and their problems and of the work of the Cancer Laryngectomy Trust taking place too.

In case you were unable to hear the broadcast this is what Martin Jarvis said on our behalf:

I'm going to speak to you for a couple of minutes. Yes, we all take our voice for granted, with it we can talk, laugh, read aloud, sing, without giving a second thought to what is actually going on in our throats. Like so many of us I'm lucky, but imagine being told you have to trade your voice for your life. Over two thousand people a year in the UK have had to make that choice and one of those is John who was diagnosed with cancer of the larynx, or voicebox. His only option was to have it removed, which meant he would lose his speech he now has to breathe through a hole in his throat.

Writing about his experience John said: "Nothing could have prepared me for the isolation I felt. To be unable to respond when somebody speaks, or to laugh or cry out for help, made me feel helpless and frustrated. Fortunately, I had a great speech therapist who taught me that, with controlled belching, I could speak using air from my stomach, but it was almost a year before I could string a sentence together."

John was able to find comfort and support in the Cancer Laryngectomy Trust, a small charity run by volunteers. It was founded nineteen years ago by someone who had had a laryngectomy.



Victoria Stainton, Martin Jarvis and Carole Stainton at the BBC



Martin Jarvis presenting the Radio4 appeal

He had been shocked to find a lack of support and understanding even by some doctors who had not previously seen the condition. The charity offers a motivating free book 'Laryngectomy is not a Tragedy' to all laryngectomees and health professionals.

It also produces newsletters containing help and vital information for its members, arranges free social functions, promotes awareness and training in organisations such as St Johns Ambulance and gives modest grants to members, usually towards the purchase of medical equipment.

Membership of the charity, which survives solely on donations from the public, is free. I can tell you - Your donation, no matter how small, will make a real difference. Five pounds, for example, will pay for a copy of the book to be sent to a Speech Therapist to assist their work or fifteen pounds will pay for a Welcome Pack for a new member.

Please - use your voice: Make a donation now by telephoning 0800 044 044 that's 0800 044 044 or send a cheque payable to CLT to PO Box 618, Halifax, HX3 8WX, I'll say it again: CLT PO Box 618, Halifax, HX3 8WX. In putting this appeal into words, I'm grateful that I can. Thanks

Help with the Cost of Cancer

As we are all aware there are often financial effects when a member of the family suffers from cancer. Macmillan Cancer Relief have published a very useful guide to benefits and financial help for people affected by cancer. It is available from Macmillan CancerLine 0808 808 2020

Quit Smoking Campaign

There has been some discussion regarding the current Channel 4 Quit Smoking advertisement which features a laryngectomee who also has lung cancer. One of our members has described himself as offended by the use of a laryngectomee in this way. What does anyone else feel about the advert? Please write in or e-mail your comments.

Cancer - My Partner

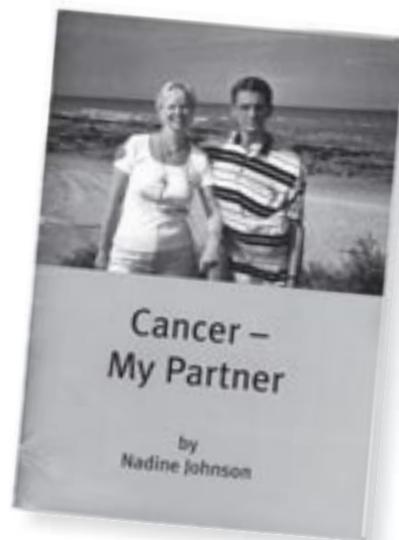
Carole Stainton writes:

This is the title of a very moving book written by Nadine Johnson about her husband Peter's battle with cancer and the effect on her life and their family. Nadine gives a graphic account of all the steps along the journey as new cancer sites appeared and more surgery was needed. She describes their battles for treatment to continue and the move to The Royal Marsden Hospital.

When I received my copy of the book I could not put it down and read the whole moving account in one session with no danger of falling asleep as I usually do. As a carer myself I relate to her comment about feeling a race apart from other people around. I popped into Sainsbury's and saw everyone frantically shopping for Christmas and felt like saying "I'm not doing Christmas, my husband has cancer".

Despite all their setbacks Nadine and Peter are very positive and we wish them both all the very best.

Her book is available from Paul Cave Publications Ltd, 74 Bedford Place, Southampton, SO15 2DF, Tel 023 8022 3591. Price £3.95 (Inc p&p)



Quality of Life Questionnaire

Fiona Duncan of Plymouth University has asked us to publicise their work on quality of life for laryngectomees.

Who are we?

We are a research team led by Dr Paul Farrand from the University of Plymouth interested in a variety of issues affecting patients with problems to their head and neck. Paul is a psychologist who runs clinics for head and neck patients having difficulties coming to terms with their medical condition. The research assistant on the study is Fiona Duncan.

What is the study about?

This research study, funded by Macmillan Cancer Relief, will look at quality of life for patients who have had total laryngectomy and different forms of voice restoration – electrolarynx, oesophageal speech, surgical voice restoration or those who rely upon non-verbal communication. Results will be used to help inform patients and medical staff about the benefits of different forms of voice restoration. Such knowledge will support greater informed choice for patients in the future.

What is involved?

All that is involved is the completion and return of a simple questionnaire. It should take no more than 30 minutes to complete and will ask you very general questions about what you are able to do, how you feel and how you are. All questionnaires are anonymous, so responses cannot be traced.

What to do if you want to take part?

To get hold of a questionnaire, or if you have any questions please do not hesitate to phone Fiona Duncan on: (01392) 475136

Or complete the questionnaire on the internet at: <http://demo.lsa.plymouth.ac.uk/question.asp>

Or e-mail us at: fiona.duncan@plymouth.ac.uk

Or write to us at: Fiona Duncan, Veysey Building, Faculty for Health and Social Work, University of Plymouth, Earl Richards Road North, Exeter, EX2 6AS.

Your participation will be very welcome and will help improve the treatment and care of future patients.

Musical Evening, Line Dancing and Auction of Goose Eggs

These are just three of the methods by which our inventive members have raised money recently. In the photograph you see one of our excellent fundraisers, Sheila Turner, with the walking frame and her Lady Glades friends who arranged the musical evening and also the Line Dancing event. The goose eggs were auctioned by a friend of Carole's husband at their old boys reunion. We are also very grateful to Wath Fundraisers for their generous donation in memory of one of our former members.



A Member Writes

Whilst reading the news letters I was reminded of something I have contemplated doing for some time. I want to recount, briefly, my medical experience for two reasons a) mainly to perhaps assist those who are wondering about the necessity of a laryngectomy and b) to praise our much maligned NHS.

During 1985 I was diagnosed with a throat cancer and was successfully treated with radiotherapy at the Middlesex Hospital, Mortimer Street, London. From December of that year until June of last year I was able to live a completely normal life except that in 1987, because of a slight difficulty in swallowing, I had the misfortune to sustain a perforated gullet as a result of a suggested minor stretching of my gullet.

Then last June I had some discomfort from a sore throat when I decided, rather belatedly I must admit, to visit my doctor. After a treatment of anti-biotic drugs, which were of no avail, he sent me to our local hospital for examination.

After various tests, endoscopy, X rays, blood tests and interviews I was informed that I had another cancer in my throat. My local hospital was unable to treat me so I was sent to one that specialised. After more tests and interviews, understandably there were a few days between

each, the surgeon agreed to operate. I had a total Laryngectomy, a partial pharyngectomy and a right thyroidectomy.

After the operation I was able to eat; at first a soft diet until now when I can by careful mastication enjoy most of the fare I was able to enjoy before December and although it is early days I am coping quite well. I live alone, my wife died some years ago, but I have a son living nearby and am most fortunate in having a very caring family.

Now I wish to pay tribute to our much maligned NHS. Because my local hospital on the Isle of Wight was unable to treat me I had to cross the Solent to two hospitals the Royal South Hants and Southampton General. During that period I made contact with dozens of medical and other staff and would like to record my sincere thanks to them for their kindness, courtesy and patience and I am most grateful for the professionalism of the medical teams. I could not have received better care had I been George W. Bush.

Why have I written this letter? Because I consider the sting is in the tail and it may, I hope, help some folk who are, as I was once, in some fear and trepidation. The "sting"? I am not a youngish man: in a few weeks time I shall be ninety-five years of age.

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