

TO HELP IMPROVE THE QUALITY OF LIFE FOR ALL NECK BREATHERS

Dear Friends

I am looking out at a lovely blue sky listening to the birds and the wind chimes which Carole bought for us last Christmas. The poor flowers in the garden don't know whether to flower or not as we have had a mild winter and then a really cold snap. Just when I had to go to Halifax for the AGM it was one of the worst mornings of the winter.

As you know my husband Bill and I enjoy our winter holiday and we know that laryngectomees often have concerns about travelling away from home. Therefore we are very pleased to be able to offer you a copy of the Laryngectomee's Travel Guide which you will find described later in the newsletter.

Most of our recent travels have involved family events, Lucy and Sydney's fourth grand-daughter Victoria was married recently at a very moving ceremony in a hotel on Windermere. She carried a bouquet of cream canna lilies and anemones which were Lucy's favourite flowers. Then the following weekend we all joined them for a second reception in their home village in Oxfordshire. Once again we were able to meet up with baby Marcus looking very smart in his gold waistcoat made by Grandma Carole. While there we also took the opportunity to hold a Trustees Meeting. We rounded off our trip with a visit to Ipswich to see our sister over from Greece visiting her son in his new house.

The Summer Lunches are being arranged and Bill and I will be meeting some of you in Bridlington.

Hoping you all have a nice summer

Best Wishes

Wendy Thompson on behalf of the Trustees



*The happy couple on their wedding day*

### **A Laryngectomee's Travel Guide to the British Isles**

The guide has been prepared by Paul Cantlie who lives in Hampshire and had a laryngectomy in 2001. After his car was wrecked under him 100 miles from home, he realised that while neither hurt nor unvoiced on that occasion and able to get home by train, he might not always be so lucky and it would be as well to think about how a hospital would deal with a voiceless laryngectomee.

From this developed the idea of this guide as a means of allowing neck-breathers to travel with more confidence than in the past. Paul had expected that a list of hospitals able to help a laryngectomee would be readily available from the Department of Health but none was available so he set about compiling a list himself using the NHS website. The Patient Advice and Liaison Services assisted with providing the information.

The booklet provides locations and lists of all hospitals believed to handle emergencies of the type that laryngectomees may suffer. Small maps show the spread of towns with suitable hospitals. There is an Emergency notice for the reception staff or A&E and the next page gives a list of the usual conditions to help a voiceless laryngectomee indicate what the problem is. The rest of the section lists the different hospitals, their addresses and main details.

The booklet can be down-loaded from our Web Site [www.cancerlt.org](http://www.cancerlt.org). If you would like a printed copy please send a stamped self addressed envelope at least 7.5" by 5.5" (18.5cm X 13cm) bearing a 1st or 2nd class stamp to CLT, PO Box 618, Halifax HX3 8WX marking your envelope Travel Guide.



## Quality of Life Research

Recently some researchers at the University of Plymouth carried out a national study funded by Macmillan Cancer Relief which looked at aspects of quality of life after total laryngectomy.

The specific aim of the project was to examine the effect that the different methods of voice "restoration" following total laryngectomy have upon quality of life.

### How the Research was Done

The researchers sent out a questionnaire to laryngectomy clubs all over the UK and were delighted to receive over 260 completed responses, many of which were from members of the Cancer Laryngectomy Trust.

The questionnaire asked participants to tell us about:

- What voice restoration method they currently used
- What they thought about the quality of their new voice
- What they thought about the amount and quality of support from family and friends that they were receiving
- How they viewed their general health now as compared to a year ago
- How they viewed their ability to carry out physical tasks such as climbing stairs or carrying groceries
- How their physical or emotional health has affected their work role or other daily activities. For example have they had to cut down the amount of time they spent at work or doing hobbies.
- How much physical pain they felt they had been in during the past few weeks
- How they viewed their emotional wellbeing such as did they feel full of life, did they feel calm and peaceful, did they feel worn out.

### What was Found and What Does it Mean?

A couple of the findings were not surprising. Firstly, laryngectomees that used the TEP method of voice restoration were much happier with their new voice

than users of the other two methods. Secondly the questionnaire showed that regardless of voice restoration method, quality of life is worse for laryngectomees than for a group of people the same age but with no history of the operation.

It was also found that overall men tended to have a better quality of life than women. This could be because women are more affected by the disfigurement that the operation causes and by the masculine sound that all methods of voice restoration produce. Perhaps this means that the counselling needs of women after their treatment need to be further developed.

Another finding was that participants who perceived their support from family and friends to be better had a better quality of life especially if they perceived that their family and friends could be relied upon to help out with chores and errands.

An interesting finding is that the oesophageal speech users that took part in the study had significantly worse scores on the questions that asked about physical pain. The researchers have not yet been able to find a satisfactory explanation for this.

One particular finding was quite controversial and caused some debate amongst speech and language therapists when they were presented with the results. This finding was that across the three methods of voice restoration there were very few differences in quality of life. In fact electrolarynx users tended to have slightly better quality of life scores. This challenges the widespread opinion that TEP users who have a better quality of voice must also have a better quality of life.

However those who did not use any of the methods of voice restoration had a worse quality of life than those that used at least one method. This indicates that whilst improved voice perception does not dictate quality of life, it is important to have a voice to at least a minimal standard.

If anyone would like to receive a more detailed summary of the results or would like to tell us what you think please do not hesitate to contact me at fiona.duncan@plymouth.ac.uk

## Texting the Emergency Services

Anyone with speech or hearing impairment who lives in West Yorkshire can make use of a texting service to contact the police for the equivalent of a 999 call. The text number is 07786 200200 and the message must start with 999. The text is conveyed to the police communications centre as an e-mail and the caller should receive a confirmation text within 20 seconds. There may be a delay in a message reaching the police depending on the demands on the mobile phone networks and the lack of prioritisation of messages. If a response has not been received within two minutes users are advised to try again or seek an alternative method of contact.

Members living in other parts of the country might wish to contact their local police force to enquire whether a similar service exists there.

### **Border Lost Chord Club Outing**

Ivor Smith, Secretary of the Border Lost Chord Club, reports on the club's outing last summer

As usual June has become our month for our summer trip, so there was no meeting this month and instead our destination was Scotland so with passports at the ready off we went on the 6th of the month.

With funding obtained from the Cancer Laryngectomy Trust we were able to pay for the bus, the entry cost and also everyone received £5 towards their midday meal.

Almost 30 members and carers enjoyed an excellent day out at New Lanark, this is an old mill that has been renovated and is again in working order. There are also mill workers cottages, a shop and school room, all restored to the period.

With the weather so kind to us a lot took the opportunity to walk along the banks of the Clyde to see the Falls of Clyde. With such good weather I am pleased to say the falls had very little water in them but were still quite spectacular.

I think there was something for everyone at the café for lunch and a hotel for anyone to have a drink and plenty to see. We arrived at 12 noon and left at 4 pm I think that just about worked out right for everyone, not too long but long enough to see everything.

As usual after a successful day out on the way home conversation turned to where to go next year. One possibility under consideration is Beamish.

Thanks to you for our funding. Ivor Smith Secretary BLCC

Trustees Note If any other groups would like to request financial support for a similar outing please contact the office for a Grant Request Form.



*Border Lost Chord Club Members*



*The Falls of Clyde*



### **Sovereign Healthcare Presentation**

Once again we are very grateful to Sovereign Healthcare for their generous support in the form of a cheque for £1000. Mr Leslie Morgan represented Sovereign when he presented the cheque to the Mayor of Calderdale Councillor Colin Stout as Vice President of the Cancer Laryngectomee Trust. Also present were laryngectomees John Bramall and Donald Owrid accompanied by his wife Maureen. The money will be used to finance the printing of the Travellers Guide for Laryngectomees referred to elsewhere in this newsletter.



*The Mayor of Calderdale receives the cheque from Mr Leslie Morgan*

### **Summer Lunches in B, B and B**

B as in Blackpool is already planned on Saturday 16th of June at the Hackett York House Hotel. Please contact Malcolm Rothwell, 23 Dorset Road, Atherton, Manchester, M46 9PP Tel 01942 892403

B as in Bridlington the second event there this year is to be held at The Expanse Hotel on Sunday 15 July. Please contact Mrs Ann Smith, 47 Bonser Gardens, Sutton-in Ashfield, Notts, NG17 1DT Tel 01623 432588

B as in Birmingham is still in the planning stages and we need your help, please. We are thinking of holding a lunch one Saturday in July or August somewhere in the Midlands and thought Birmingham being central for travel might be a good location. If anyone knows of a suitable restaurant/hotel not too pricey but good value for money and with free parking in or around that area please let us know. Expressions of interest in attending the lunch would also help us to assess the numbers likely to attend.

### **The Bridlington Summer Lunch 2006**



web site: [www.cancerlt.org](http://www.cancerlt.org)  
email: [info@cancerlt.org](mailto:info@cancerlt.org)



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