

Newsletter September 2021

A personal note from Carole Stainton, Trustee

Dear Friends

We hope you have all been keeping well over the difficult months we have been living through. Let us hope things are beginning to slowly improve and that we can plan to meet up for Christmas lunches.

Trustee Ros Oswald has created a fitting tribute to Wendy Thompson and I have enjoyed going through photos of past charity events to select for the article. It makes us all very proud to see what we have achieved over the past 35 years in our work to support laryngectomees.

It has been very difficult for all charities to carry out fund-raising activities during lockdown so we are very grateful to Jodie Williams and her colleagues at Aviva for their charity walk for us. Her account of the event appears later in the newsletter.

We are also pleased to introduce Joy Shaw who has created a Facebook group to support caregivers for laryngectomees.

Once again we enclose a Donation Form with the newsletter. We are very grateful to members for donations received in the past.

We hope you enjoy reading the articles from members.

Best Wishes

Carole Stainton, Trustee

Donation Form 2021

As mentioned, we have enclosed a Donation Form within this newsletter. We are very grateful to all our members and supporters for their continuing support for CLT.

These donations will help us to provide support to laryngectomees throughout the UK. Thank you all.

A TRIBUTE TO WENDY THOMPSON

TRUSTEE 1985 - 2020

On the 15th February, our sister Wendy passed away peacefully. Although she had been experiencing some health problems, her death was sudden and unexpected. The last time I spoke to her, less than a week before her death, we were chatting about the Charity and looking forward to being able to arrange some Charity lunches again, having had to cancel our 2020 events. She was as positive as ever and keen to see her laryngectomee friends again. It is a tribute to her character and love of the Charity and its members that her thoughts were for others at this time.

Wendy was appointed as a trustee in 1985 when the Charity was set up by our father Sydney. His diagnosis of throat cancer had come as a shock but Wendy was very proud of how he coped with the diagnosis by writing his book "Laryngectomy is not a tragedy" and by setting up the Charity. It was always an important part of her life. She organised and attended lunches, attended support group meetings, wrote a column for the Newsletter, sent out the Newsletters, carried out the practicalities for Race Night and took an active part in the ongoing work of the Charity including making decisions about grants and representing the charity at Information Days. She enjoyed meeting people and getting to know them and their friends and relatives. Having seen Sydney come to terms with his diagnosis and surgery, she was able to empathise and support our members. Ruth Wallace, the Principal Speech and Language Therapist at York Hospital, knew Wendy and saw the support and encouragement that she provided. Ruth described Wendy as making a real difference to the lives of many laryngectomy patients and their partners and carers. She was fully supported in her work for the Charity by her devoted husband, Bill and her daughters, Sarah and Helen.

She is sadly missed by her family and friends including the friends she made from her work with the Charity.

Ros Oswald
Trustee



A TRIBUTE TO WENDY THOMPSON



The photos show Wendy in her role as Trustee over a number of years: With fellow trustees Ros Oswald and Carole Stainton and the Mayor of Calderdale, At the launch of 2nd edition of Laryngectomy not a tragedy, Representing CLT at an Information Day and hosting and attending various lunches.

Presentation to Royal Preston Hospital

The members of The Preston and Chorley Districts Laryngectomee Association recently presented a further set of Boogie Boards to the Speech and Language Therapy Department at the Royal Preston Hospital for distribution to new laryngectomees. Kim Winterton says how much the boards are appreciated by patients when they undergo their surgery. The funding for the donation came from a grant from Macmillan. The group also make up packs of information for new patients which include items from CLT to help the patients, where to go for help, emergency cards, pot in the fridge, a message to go in a wallet or purse, it all helps.



Do you C Us?

A national campaign has been set up by Cancer52 which is an umbrella group for charities who support people with rarer cancers. Cancer of the larynx is a rarer cancer. The purpose of the campaign, which is called “Do You C Us?” is to encourage people to come forward to seek medical advice if they are experiencing symptoms and to keep the pressure on the Government to make sure there is adequate funding for cancer care.

The campaign was launched by Paul Bristol MP at a Parliamentary Zoom Meeting on the 29th June. Details of the campaign can be found at <https://www.doyoucus.org.uk/>. The website includes the stories of people who are living with one of the rarer cancers and include the details for George who has had a laryngectomy.

During the launch meeting Dr Ellie Cannon who is the GP for the Mail on Sunday explained the difficulties GPs face in deciding which patients need further investigations as some of the symptoms are so common. It was very clear that the role of charities who support people with the rarer cancers is vital and can make all the difference when someone is coming to terms with a diagnosis.

Shout At Cancer - The Laryngectomy Choir

Singing in a choir might not be the first choice as a suitable activity for someone who has had a laryngectomy. When we think about singers we tend to think about the sound we hear as they sing. However, singing in a choir is about so much more. It is about breathing, confidence, friendship, camaraderie, support, memory and having fun. Shout at Cancer is a Charity set up by a team of patients, doctors, speech and language therapists, researchers, singers and actors that work closely together. They are dedicated to helping people rebuild their lives after laryngectomy. They use workshops incorporating breathing, singing and acting techniques, with public performances and collaboration with musicians, singers and actors. They have set up the Laryngectomy Choir which has appeared in a number of different settings and won awards for its work.

Can You Hear My Voice is a film made about the setting up of the choir which had its premier on the 28 February 2020. Songs the choir sing include Silent Night, Joy to the World and Somewhere Over the Rainbow. CLT members Alan Wells and Spyros Koskinas are members of the choir and have told us how they benefit from being involved. Alan Wells has found that learning breathing techniques used by professional singers has helped him improve the range and quality of his voices. He has performed with the choir in Britain and Belgium receiving a standing ovation which has been a real boost to him. For Spyros Koskinas the choir has given him something to be proud of and encouraged him to mix with other people who have had a laryngectomy. The sense of camaraderie with other choir members has also helped with boosting confidence and self esteem. The choir can be seen and heard on Youtube at <https://www.youtube.com/watch?v=vjGRUd0OUow> and on BBC Radio at <https://www.bbc.co.uk/sounds/play/w3csz38r>. If you are interested in finding out more about improving your breathing technique it is worth finding a singing teacher who is willing to help. Who knows, it may be the start of a completely new interest or the revival of an old passion.

Christmas Lunches

Provisional arrangements are being made for Christmas Events to be held if circumstances allow.

The lunch in Halifax is planned for Wednesday 15th December at Windmill Court is being arranged by Carole Stainton [contact at CLT, PO Box 618, Halifax, HX3 8WX email: info@cancerlt.org](mailto:info@cancerlt.org)

The Blackpool lunch at the Imperial Hotel on Sunday 5th December is being arranged by Mrs Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA [Tel 01253 899531](tel:01253899531) [email waddington46@btinternet.com](mailto:waddington46@btinternet.com)

The lunch in York at Novotel. York YO10 4FD will be held on Wednesday 8 December 2021 and is being arranged by Dawn Potts, The Granary, Hull Road, York, YO19 5LE, [Tel: 01904 489360](tel:01904489360), [Mobile: 07947624421](tel:07947624421), [email dawn.potts@hotmail.co.uk](mailto:dawn.potts@hotmail.co.uk)



For any queries, please contact CLT on: 0142205522.



This newsletter is sponsored by Atos Care

Aviva Quotes Rother Valley (Sheffield) Walk 2021

During the pandemic some of our Aviva colleagues' parents have sadly lost their brave battle against cancer. One of these colleagues was Sioned and her partner Luke who unfortunately lost their lovely dad and father in law Andrew a few months ago. He was a fantastic family man at the heart of his small community in North Wales when he was sadly diagnosed with cancer of the Larynx two years ago, with the support of his wife, Eirwen, his daughters Sioned & Emma and their families he fought bravely & courageously throughout his treatment.

Our Aviva team wanted to raise money for three great cancer charities by doing a charity walk round Rother Valley on 10th July in Sheffield. In memory of Andrew and his family a quarter of the money raised will go towards The Cancer Laryngectomee Trust who help and support families in similar circumstances, currently at £566 with a Virgin fundraising page and our employer Aviva who match anything we raise. Fifteen of us undertook the walk including our youngest walker Andrew's grand daughter Aurora who was two years old! We completed it in just 3 & half hours, with the weather staying dry and all doing a fantastic job! We hope the money we raised will help families similar to Andrews and Sioned's during these difficult times where extra support can mean so much! We'd also like to say a big thank you to Carole for all her support in helping us with fundraising & T-shirts.



Caregivers for Laryngectomees

Joy introduces the Facebook group she has created to support caregivers for laryngectomees:

In 2015, after a year of losing his voice to a whisper and various treatments even voice therapy, my lovely husband Ash was rushed into hospital for a debulking of the tumour that had suddenly grown and was choking him. I saw it on the screen and I swore it had a little face like a monster. 5 days later he had his laryngectomy and with little time to prepare or understand fully what was happening it was done, and there he was in ICU with a tube in his throat, no voice and what seemed like the starship enterprise attached to his body by leads and tubes.

The senior speech therapist had said to us at the consultation to explain they would remove his voice box that they would "give him a much better voice than that", a voice which, by that time, was barely a whisper. I imagined a mechanical voicebox of some kind inserted into his throat?

The first few weeks were a blur of hospital visits, snatched conversations about his progress, some good, some bad, sleepless nights, no appetite and driving in the cold wet dark January traffic twice a day. Terrified I might not understand him, might not understand what the doctors told me. Usually he slept, full of morphine, and I watched and sometimes I cried. Every drive home I cried. I spiralled into an abyss. People asked if we were ok, and I said with a smile "yes, great thanks". I lied. I couldn't put it into words.

I asked a question late one night on a facebook support group, and a woman called Lizzie replied straight away. She became my lifeline, my angel, my saviour and now she is my long distance facebook friend, although she plays it down and says it was just right place right time. It wasn't and I cannot think how I'd have coped without her. Her husband was 20+ years in to his laryngectomy life. That gave me hope past tomorrow.

Ash came out, time went on, he became "ok" but I still struggled. Luckily I worked from home and at weekends as a wedding singer, so I could devote time to him, but I didn't know how much I needed to do, and with so many things being checked, appointments, new medication, blood tests, I was very stressed. People asked how we were doing and I said "we are doing great" but again I lied.

I spoke to a friend who had terminal cancer about whether I should start a group just for carers/caregivers. I didn't want medical people involved or the person who had had the operation but to find somewhere to speak to people like Lizzie in a "safe place". She said "go for it but don't let it become cancer led". She knew from her family how much they were affected and she suggested a place that also had fun topics, self help discussions etc. So a couple of months after I started up our group called "Caregivers for Laryngectomees". Fast forward and today we have over 450 members from all over the world. Different time zones, life styles, families and even languages, but we all share a common bond - we love and care for a Laryngectomee.

Caregivers for Laryngectomees

We have members just starting out on this crazy laryngectomy life, some who are settled and doing ok, some struggling, some dealing with end of life care, but we all support each other. It's like a little community. We have topics for each day - Moany Monday to get issues off our chests, "tell me Tuesday" - today is what is the role of a caregiver?, "what is it Wednesday?" with a picture quiz, Pet Therapy / Thursday where we post pictures of our beloved pets, and Friday (the one I love best) is Fun Friday. A day not to speak of the "C" world but to post funny things to make each others laugh. "Song for Saturday" when we post what we are listening to, and "serene Sunday" when we tell each other if it is serene or not, sometimes with pictures from all over the world

In between there are many conversations about forthcoming scans or appointments and each post will receive good luck posts, hugs, tips, and some send prayers, and when we find out the good or bad news we all share it. There are some members who have lost their loved one since I formed the group. Some have left but the majority have stayed, feeling that in our group people truly understand their highs and lows, and they also give hope and advice to newly bereaved members. It's amazing to see how much love and care there is for each other. We see each other's gardens, families, pets, and of course we see their beloved Laryngectomee now and again!

Last year with the madness of Covid we had a virtual tour of route 66 with people using imagination and a lot of fun along the way. It took us out of our lockdown lives which made caring for another person so very hard. At the moment we are nearly at the end of our virtual tour of the UK, Lands End to John O Groats, with stops along the way where members live, and they posted their local history and places of interest. Our members in the USA and Australia and India and Malaysia love it since some have relatives here in the UK.

So if this sounds good to you please feel free to send a membership request. You'll be asked a couple of simple questions (we guard our group very carefully because it's so important that it is private and safe for the members) and when you join just see how many "welcome" messages you get!! [Search for "Caregivers for Laryngectomees"](#) or get in touch with me - Joy Shaw (Manchester) or contact me at Murphyjoy69@googlemail.com and we'll sort out your membership to our fantastic support group. You won't be sorry.

Joy Shaw



Geoff's News from Chelsea

After visiting family in the south west Geoff was back at the Royal Hospital in June and provided this update for us:

We're still not open to the public here at the Royal Hospital and we were all gearing up for the return of normality on Monday, 21st June 2021 but as we all now know, things have been pushed back until Monday, 19th July 2021. Consequently, our Founders Day, the most important date in our calendar, has been pushed back again. For further information see www.chelsea-pensioners.co.uk/foundersday

I had to don my best Blues for a visiting Colonel and Warrant Officer from the Regular Army the other day. Had to pretend to listen intensely to what they had to say!

On Thursday 3rd Jun 2021 we had a Commemorative Ceremony held on the Figure Court of the Royal Hospital Chelsea. This involved a parade and service for the 14 we lost during the pandemic. We also issued our civilian staff with a commemorative pin by way of a Thank You, which I thought was rather a nice touch. This was the first time I had worn my Scarlets and Tricorn for a ceremonial event as you can see in the photographs!

I finally have my first Smartphone which I've managed to sync with my desktop and laptop after a few fraught hours!

I've now had three speech valve changes in as many weeks. Last Wednesday, they changed my speech valve for a longer one and it seems to be working fine... and it's not leaking. I'm scheduled for a Barium X-ray on Tuesday morning next week at the Imperial College, Charing Cross Hospital. The results of a test on an earlier valve at the Microbiological Laboratory show there's something nasty going on there which the strong antibiotics I've been taking simply aren't touching. So initial analysis is producing results. The question now is... what will they do about it all?

Please take care and stay safe!
And wish all your readers the same.

Best wishes,

Geoff
Geoffrey N. READ



What's On in September



Hands-free speech with Provox Life™ FreeHands HME

- ✓ Reduces mucus production and coughing
- ✓ Easy removal of HME from Provox Life™ FreeHands FlexiVoice without the need for a removal aid
- ✓ Compatible across the range of Provox Life™ Adhesives



The freedom to speak hands-free,
whenever you need it, and by
occluding your stoma.



What's On in September

Different ways to voice after a laryngectomy

Thursday 16th September
Tuesday 21st September



Special guest speaker
Malcolm Babb
President of NALC



Practising voicing with Dr Thomas Moors

Wednesday 29th September



Hosted by
Dr Thomas Moors
Director of Shout At
Cancer



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