

Newsletter September 2024

Dear Friends

We are pleased to report on enjoyable summer events held in Blackpool, Scarborough and Swindon and also look forward to Christmas lunches currently being arranged. Thank you to Sandra Waddington, Dawn Potts and Ros Oswald for arranging these events.

Fundraisers and donors have also been busy on our behalf once again in particular we thank Alexa Davidson and Boston Bowling Club.

We thank Ian Honeysett the editor of CLAN for permission to include the information sheet for health professionals. The information sheet was written by Prof Brendan McGrath, of the National Tracheostomy Safety Project (NTSP) and Malcolm Babb, President of NALC.

In this newsletter Trustee Ros Oswald describes her experience of supporting a member with an application for Personal Independence Payment and there is also information about the cancer charity Look Good Feel Better which might be of interest to members. Also included is an invitation for younger family members to join a research project by Lydia McKeown.

We thank Jayne Yeates for sharing her experiences in her 19 months of adjusting to being a laryngectomee.

Once again we enclose a Donation Form with the newsletter. In the past members have been very generous with donations to our appeal. We are very grateful for your support and look forward to receiving donations once again this year either by cheque to our PO Box or using the on-line banking information on the form.

Best Wishes

Carole Stainton, Trustee

Skydiving by a laryngectomee?

Amy Bainbridge a speech and language therapist in Royal Stoke Hospital has a young laryngectomee patient who would like to carry out a charity skydive. If anyone has any experience or advice please could they contact Amy on Tel: **01782 674113** or Email: **Amy.Bainbridge@uhn.nhs.uk**

Contact us:

Website: **www.cancerlt.org** Email: **info@cancerlt.org**

Address: **CLT, PO Box 618, Halifax, HX3 8WX**

Charity Registration No 326653



This newsletter is
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LATE
NEWS!

Summer Lunch at Blackpool

Photographer David reports on the lunch held at Hotel Sheraton and attended by 60 members from the North West:

Firstly I would like to thank everybody at the Laryngectomee Trust We had a wonderful afternoon at the Cancer Laryngectomee Trust summer lunch at the new venue, the Hotel Sheraton.

The new venue was perfect. The food was lovely and plentiful, the staff were lovely and attentive and the venue itself was very smart and welcoming.

We would just like to thank Sandra and Jean for organising such a wonderful afternoon (again!) and I know I speak on behalf of everyone who attended that their hard work is very much appreciated.



Summer Lunch at Scarborough

Organiser Dawn reports on the Lunch held at The Crescent Hotel:

We had a very successful summer lunch today at The Crescent Hotel Scarborough. The food was delicious and the service as excellent as ever. It was a jolly occasion. 15 of us attended including one lady for the first time. We sat in the Brunswick room. Super light and spacious.



Walk Round Coate Water, Swindon

Trustee Ros Oswald reports:

The 4 July 2024 was a very significant day. In addition to the General Election and our dog Molly's birthday it was the day chosen for a summer event for the Cancer Laryngectomee Trust. Our local speech therapist had suggested a walk followed by drinks and snacks as a suitable idea. Although Christmas lunches are wonderful events they do not suit everyone particularly those who may have some difficulties with eating. We decided to plan a walk around Coate Water which is a lake on the outskirts of Swindon which has a level path around it and a pub nearby.

We were very lucky with the weather as it was sunny but

not too hot and there was a refreshing breeze which made walking very enjoyable. There were seventeen of us in all with a majority having had a laryngectomy. Coate Water is very dog friendly and so we were able to welcome five dogs joining on us on the walk. We had been on the walk before with Molly our Labrador to make sure it was suitable. We allowed one and a half hours for a gentle walk with time for rests and for Molly to fully explore the lake as she is a keen swimmer with an impressive belly flop approach to getting in!

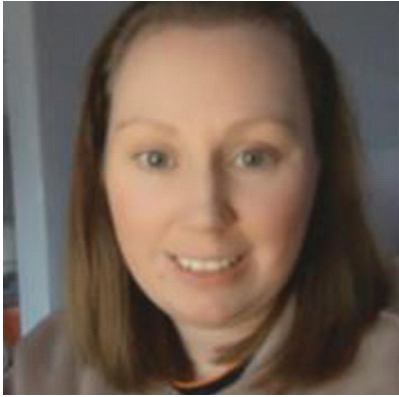
There was plenty of time to chat and enjoy seeing the cygnets and swans that were very entertaining. Some people preferred to have a shorter walk and then relax at the pub. After the walk we were able to sit and

chat whilst enjoying a very welcome drink and snacks. There was even an opportunity to sing Happy Birthday to Molly who was eight years old. She found the combination of walk, swim and good company the perfect way to celebrate.

It was very encouraging to see the way that people who had only recently had surgery or radiotherapy could be helped and supported by more experienced people. There were people using oesophageal speech, valves, phone memos and digital notebooks for communication. It was a very worthwhile way to enjoy some time together and it was clear that this was a good option for a number of people. There were requests for a repeat of the event, I just hope we can organise the weather again!



Fundraiser Alexa



Alexa

Alexa explains why she was inspired to support the charity:

Hi my name is Alexa and I'm a granddaughter of grandparent who has a laryngectomy. My papa is signed up to the trust and when I read the newsletters I thought it was an amazing charity for people who are laryngectomees and their families. I looked into the charity and found out that it was a charity that solely survives on donations from the public. I spoke with my grandparents that I wanted to contribute to the charity by raising funds we decided to hold a raffle. I spoke

with my work colleagues and the people who work in the shop across the road from us about my idea everyone contributed by donating prizes. My work colleagues bought raffle tickets from me and the shop owner allowed staff to sell raffle tickets, family and friends also donated funds to my donation and I managed to raise more than I expected to.

Look Good Feel Better



look good **feel better**

Members might be interested to hear about this national cancer charity:

We understand how emotionally challenging living with cancer can be. That's why Look Good Feel Better run free workshops, virtually and in local communities across the UK, which give

practical advice and support to people living with cancer. Every workshop offers an invaluable opportunity to talk to others in a similar situation, whilst helping support people with their changing appearance. People leave our workshops feeling empowered, motivated and less isolated – allowing them to look good, but feel even better.

Contact Information

Look Good Feel Better, West Hill House 32 West Hill, Epsom, Surrey, KT19 8JD

Tel **0137 747 500**

Web address **www.lgfb.co.uk**

Finding your way through the Benefits System by Trustee Ros Oswald

There are many challenges facing people who have had a laryngectomy. However, there are also some ways in which help may be available including payments made through the benefits system. Many years ago I worked in a Law Centre where we helped people with their benefit applications. A great deal has changed since then but when I was asked to simply talk to a laryngectomee about an application for a Personal Independence Payment (PIP) I felt that at least this was something I could do. It was a very interesting experience which helped me to understand the way the systems work today. I gained some useful information and thought it might be helpful for our members. As a Charity we do not give advice about benefits but simply being a sounding board and giving a helping hand can be very useful. Here are the most important things I took away from my experience.

- ✓ Particularly since COVID it is likely that you may have a telephone interview when applying for a benefit. This can be particularly off putting if you find talking on the telephone difficult. Having someone with you is very helpful. The interview may be long (up to an hour) and some people may find this too tiring for their voice. My experience was that the person working for the benefits agency was a good listener and so it is important not to feel put off by the prospect of a telephone appointment.
- ✓ Honesty is the best policy. This is a very obvious thing to say but I would like to explain exactly what I mean. PIP and Attendance Allowance (AA) are benefits that may be relevant. Eligibility for both these benefits is worked out on the basis of how you are able to cope with every day life. The benefits are there to enable you to pay others to provide help although it is entirely your decision as to how you spend the money. In this situation, honesty means accepting that there are some things which are very difficult and it is natural to be reluctant to say how hard these activities are. Many people find ways to cope or carry out an activity much more slowly than previously. It is important to say so when filling in the form or talking this through on the telephone. The way in which a question is answered may depend on how the question is asked, particularly in a telephone appointment. Even the tone of voice can make a difference.
- ✓ There are a number of different charities who do give advice about claiming benefits. Age UK, Citizens Advice Bureau and Macmillan Cancer are just three of the major charities that can help. Again, telephone help may be the option that is available. Their websites have advice as well.

Contact Information

Age UK Tel **0800 678 1602** <https://www.ageuk.org.uk/>

Citizens Advice Tel **0800 144 8 444** (England) **0800 702 2020** (Wales) <https://www.citizensadvice.org.uk>

Macmillan Cancer Support Tel **0808 808 00 00** <https://www.macmillan.org.uk/>

Message from Jayne

Hello Again

Back into the throws of writing a short piece again for you all to digest.

I trust all fellow Laryngectomees, their Families & Friends are doing well and enjoying the small doses of fine weather we are given periodically.

I'm now 19 months down the line since becoming a member of this Elite club and medically I'm about as good as it's going to get, with a few hiccups along the way. However there's a but ...along the way I've been battered and bruised by life's harsh realities, and although it's not in my nature I'd like to touch upon some of them, if only to let those just coming on board know it's ok to be Frightened, Scared, Desperate, Angry, Wishing you weren't alive and a multitude of other emotions as you try to settle into a new and alien life. However before I enlighten you in a snapshot of my plight, some of my difficulties were obviously apparent and duly noted by one close and dear friend of mine who decided to put pen to paper with a few words which I took and added & embellished upon to try and express the anguish she saw in me and how I feel in my darkest days. I'm sure a few sentiments will ring true with one or two of you. Unfortunately as space in this edition is limited I've given you just a short version with verses taken from the beginning, middle & end it's called "Walk in my Shoes"

Walk in my shoes just for one day
Feel the pain that never goes away
The Physical hard to bare
Added to that the Mental strain
that no one can share

Walk in my shoes for a while
I feel invisible because I have no voice
It's a fact it cannot change I don't have a choice
No one knows the difficulty to make even the slightest noise
So please make an effort when I try
Think yourself lucky you have a voice

Walk in my shoes this way
To hold my head high is such a strain
All in the effort to keep my frame
The scars have gone but the pains remain

Step into my shoes but for a day
When your face doesn't fit
because Lymphodema has taken its hold
What do you do stamp & scream,
have hell to pay
No take a breath and be bold

I'll take my shoes back now
It's not an easy life but its here to stay
This isn't something that's going to go away
I'll have to make my way

I'm sure from those shortened words you'll gather it's not been plain sailing and I've experienced many setbacks from what you would think the simplest of tasks.

I'm sure that you've all experienced the pitfalls of the high street, although I'm reasonably lucky to have developed some Oesophageal Speech there have been numerous occasions people just don't understand but more annoyingly those that once they realise you have a friend & companion with you will from that moment direct their attention to them and not you the customer. Hence there has been more than one occasion I've left the merchandise on the counter and turn tailed out of there before I blew a gasket " not healthy or ladylike".

My biggest hurdle to deal with though was with an insurance company that I needed for them to amend their records to have a nominated person to speak on my behalf, not only did they cancel my policy " potentially ten years premiums down the drain " but were insistent that I needed a power of attorney and they needed Me To Speak Directly to them to action it being reinstated with no loss of premiums and to Personally give the nominated persons details. I thought I'd lost the lot however after many letters to and fro by recorded delivery and at least 50 phone calls on my behalf I finally got an acknowledgement that they accepted it was a spokesperson putting on record and not a power of attorney I wanted. After all I'd only lost my voice not my marbles getting a profuse apology but not before all the frustration, tears "and

I'd probably say blood from
battering my head against a
brick wall"

Which leads me onto after
several months of battling with
these anxieties and Family &
some Friends falling by the
wayside because "They can't
cope with the change" I finally
succumbed to enlisting the help
of a therapist, A Big leap of faith
on my part, and although she
doesn't have a magic wand she
does have some good coping
mechanisms to impart.

"Grant me the serenity to accept
the things I cannot change. The
Courage to change the things I
can, and the Wisdom to know the
difference". Although it's been a
hard lesson to learn this change
and yes there are dark times
but there are positives. I've had
cause to pick myself up, brush
myself down and get out there.
One of which as a keen
photographer I now volunteer
as a photographer to charities
to record their events for them
to be used on their websites
in newsletters and advertising.
Something that's got me out
practising my limited voice on
others and forcing me to face the
world.

It would have been so easy to
recoil into the sofa, pull up the
duvet and shut the world out.

My thoughts are with you all

Jayne Yeates



Tribute to Penny from Jayne

Heartfelt condolences to Trevor White on the loss of his beloved wife Penny. A much loved Wife, Mother, Grandmother and Great Grandma.

After a sudden illness Penny passed away peacefully whilst Trevor held her hand in comfort on June 12th in Pinderfields Hospital.

A well respected member of the community who gave love & affection in abundance. She will be missed by many.

"Those we love don't go away
They walk beside us every day
Unseen, unheard but always near
Still loved, still missed and very dear".

Jayne & All from your Laryngectomee Family

Christmas Lunches

Blackpool

The Blackpool lunch at the Hotel Sheraton on Sunday 8th December is being arranged by
Mrs Sandra Waddington,
76 Rutland Avenue, Poulton-le Fylde,
FY6 7SA
Tel 01253 899531
Email waddington46@yahoo.com

York

The lunch in York at Fulford Golf Club, Heslington Lane, York, YO10 5DY will be held on Thursday 12th December and is being arranged by
Dawn Potts,
The Granary, Hull Road, York, YO19 5LE,
Tel: 01904 489360,
Mobile: 07947624421
Email dawn.potts@hotmail.co.uk

Halifax

The lunch in Halifax which is planned for Wednesday 4th December at Windmill Court is being arranged by Carole Stainton contact at CLT, PO Box 618, Halifax, HX3 8WX
Email: info@cancerlt.org

Swindon

Ros Oswald is planning to arrange a lunch for Swindon area members. For further details contact:
Ros at 17 Kandahar, Aldbourne, Wilts SN8 2EE
Tel: 01672 540619
Email rospiano@yahoo.com

Research project for family members

Have you been diagnosed with cancer, and are you a parent to a young person?

We want to hear from them!

Research suggests that having a parent with cancer can result in feelings of loneliness for young people. I am a PhD student at Queen's University Belfast and I am interested in understanding more about how loneliness is experienced by these young people. This research is needed to ensure young people are best supported by services when their parent has cancer. This study has been approved by the Faculty Research Ethics Committee at Queen's University Belfast.

Can my child take part?

- They are aged 10-19
- They have experienced loneliness and a parent having cancer.
- Your cancer was/is treated with curative intent. Curative intent aims to get rid of cancer.
- You live in the UK.

What does the study involve?

- The young person would take part in an interview on Microsoft Teams about loneliness and a mum/dad having cancer.
- They can also optionally provide three photographs they feel represent or symbolise loneliness or just take part in the interview instead.
- The young person will be thanked for taking part with a £20 Amazon Voucher.



How can I take part?
Email
lmckeown38@qub.ac.uk





Laryngectomy information sheet (for healthcare providers)

This information sheet has been produced to help healthcare professionals who may not be familiar with laryngectomees. More information can be found on the NALC (www.laryngectomy.org.uk) or NTSP websites (www.tracheostomy.org.uk).

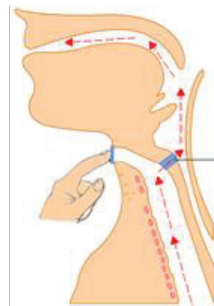
What is a laryngectomy?

A laryngectomy involves surgical removal of the larynx (voice box), usually as treatment for cancer of the larynx. The remaining trachea (wind pipe) is brought to the front of the neck as an end stoma. The mouth, nose and upper airways are no longer connected to the lungs. All breathing, ventilation and oxygen delivery can only occur via the stoma in the neck. Bed-head signs are available to display this information.



Humidification & suction

The humidification normally provided by the upper airways is lost. Laryngectomees need continuous artificial humidification of air or oxygen inspired via the neck stoma. This can be achieved using various stoma covers or protectors. Any oxygen administered *must* be humidified. Cough effort can also be reduced or less effective. Regular suction may be required and should *always* be available.



Communication

Laryngectomees have lost their 'voice box'. Artificial speech is possible via an 'electolarynx' which vibrates the neck externally, oesophageal speech ('burping' swallowed air) or via a Tracheo-oEsophageal Puncture (TEP) valve. The TEP valve allows expired gas to be forced into the oesophagus, facilitating speech.

Anaesthesia

There are no contra-indications to anaesthesia with a laryngectomy. For general anaesthesia, the laryngectomy stoma can be intubated with a tracheostomy tube, specialist laryngectomy tube (eg. Montadon tube shown here) or an endotracheal tube. Supplemental humidified oxygen via an open stoma can be delivered via a 'trachy-mask.' The TEP valve should be left in situ. Emergency management algorithms and further resources are available from NALC and NTSP.



Welcome to Atos Care

The only integrated care and distribution service for people with a laryngectomy and tracheostomy in the UK.

Atos Care is a comprehensive support service, dedicated to making life easier for people living with a neck stoma. We provide a range of services to patients and the clinicians who care for them, including delivery of prescription products and a rich network of care and support services to help them adjust to life after a laryngectomy or tracheostomy.



The Atos Circle of Care

Best Start: Get off to the best start in life after a laryngectomy.

- Enhanced support for your first six months from our Welcome Team of CQC Registered Nurses
- A welcome pack and a welcome call
- Practical tools and equipment to make life easier, including a complimentary care bag containing a range of helpful items
- Regular liaison with clinicians for joined up care



Connection hub: Stay connected to those who know and understand.

- A dedicated Customer Care Representative
- Personalised service - you choose how and when you hear from us
- CQC Registered Nurses to support you in your daily routines, in close partnership and communication with clinicians
- Educational events in the community for people with similar experiences
- Atos MyLife app to provide inspiration and information on living well after a laryngectomy

Care delivered: Bringing the right products and care your way.

- Easy and convenient ordering
- Optional convenient monthly reminders
- Electronic Prescription Service
- Rapid, reliable delivery
- Discreet packaging
- Convenience orders by subscription

Freephone: 0800 783 1659
Text: 0753 7417 928
Email: info@atos-care.co.uk
Web: www.atos-care.co.uk

