

Newsletter March 2026

Dear Friends

Welcome to our latest newsletter.

We are pleased to report on very enjoyable Christmas Lunches held in Blackpool, Halifax, Swindon and York and look forward to Summer Lunches and outdoor events currently being arranged.

Of special importance we introduce the Petition on Dental Care for laryngectomees and urge members to support this. See article on page 3.

We are pleased to have been able to provide input to the research project of Team Ora, a group of students at Imperial College, London working to develop a Silent Speech Interface. A member of the team has provided an interim report on their work for us.

Laryngectomee Kyle decided he would like to carry out a skydive as part of his fund-raising efforts for the ENT team at Royal Stoke Hospital and we supported his activity and are pleased to report on his success.

Thank you to members Karen and John for sharing their experiences as the family member of a laryngectomee in Karen's case and for John's amusing account of undergoing surgery on his hand as a laryngectomee.

Thank you to those who supported the charity using the Donation Form in the September newsletter.

We look forward to meeting up with you at summer events.

Best Wishes

Carole Stainton, Trustee



Scan to sign the petition on dental care for laryngectomees

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
sponsored by Atos Care

Coate Water revisited 2025

Trustee Ros Oswald reports:

September can be a wonderful time for a walk with the leaves looking so colourful and the temperature warm without being too overwhelming. We enjoyed the June walk so much that when one of our members suggested a September walk this felt like a good idea. By the time we had found a good date we realised most of September would have gone but the 30 September was the chosen date. We decided to return to Coate Water Country Park. Coate Water is a great place for a walk as it's easy to access being on the outskirts of Swindon. As well as being a Country Park there is a Nature Reserve which means that there is plenty of space for wildlife and interesting trees and plants to enjoy.

We were truly blessed with perfect weather and there were seventeen of us altogether. We saw swans, cormorants and a heron enjoying the autumn sunshine on the lake. It was the perfect opportunity to catch up with the news from everyone within the group and find out about what is happening in other places as we had a visiting speech therapist, Menna, who works in Cardiff. She explained to me about voice banking which was something I had not encountered before. It is particularly helpful for people who have had to have their tongue removed as well as the larynx. If there is time for the voice to be recorded before surgery it can be used to produce a personalised synthetic voice or psv which can be used after the surgery. It is always interesting to hear about new ideas and to think about whether the Charity could be of assistance.

Since attending the ATOS Open Day in June I had been thinking about the possibility of introducing some music into the group. Chatting to Thomas who runs the Shout at Cancer Choir and to some members of the choir had got me thinking. As I am a musician who runs singing workshops at the Bath Festival it seemed a reasonable idea. As our next event in Swindon will be Christmas lunch it would be simple for me to bring along a keyboard and play a couple of popular Christmas Carols. I asked the pub manager if this would be ok and she was very enthusiastic. I also asked our very supportive speech therapist about this and we agreed it made sense to see what our members thought. It was very interesting to speak to everyone about how they felt about the idea. One of our members was a chorister before his surgery and had some wonderful memories about his experiences. He also had a favourite Carol to suggest which got us off to a good start. There was even a short discussion about whether alcohol could be involved! It was very helpful to speak to Menna as she is a singer and

has looked into the value of breathing and singing for people who have had surgery that affects their head and neck. As the idea of Christmas Carols received such an enthusiastic response our Christmas lunch might well have some musical accompaniment!

The drinks and snacks after the walk are always very welcome and chatting over a cup of tea is one of my favourite ways of relaxing. Molly was worn out having tried to carry a very large and impressive log round part of the lake. She was treated to a doggy ice cream as well as a few chips that happened to find their way to her. Two of our members had brought Molly some special doggy treats that she found delicious. The Sun Inn make us feel very welcome and understand how helpful it is to have an area to relax in that does not have high noise levels. They were keen to show us their Christmas menu which looks promising.

As we chatted information was exchanged about new products and ways of dealing with issues that may arise from time to time. I always feel this is such an important part of our time together.

All too soon it was time go our separate ways whilst looking forward to our next event. I will be getting my Christmas Carols book out now in preparation.



Petition: NHS dental care for head and neck cancer survivors

The Swallows Head & Neck Cancer charity, together with other head and neck cancer charities, are currently working on a crucial project to support patients and survivors. The treatment for such cancers, whilst often successful, is brutal and leads to ongoing issues with eating, speaking and oral health.

We are currently helping to raise awareness of an official government petition, launched by the Swallows in November, to try to highlight the problems that arise with oral health and the need for ongoing dental screening to minimise these.

To summarise:

- Between 12,000 and 17,000 new cases of head and neck cancer are diagnosed annually in the UK
- People who have had the radiotherapy on their mouth and neck areas, which is often part of the treatment, are susceptible to ongoing dental problems due to impacted circulation and greatly reduced saliva production
- Dental treatment on the NHS is NOT currently provided in the ongoing treatment pathway for such patients
- Many cannot find an NHS dentist and can't afford private dentistry
- Such patients risk going on to develop problems which are life changing and avoidable - and

which can cost the NHS vast sums

- Inclusion of dentistry in the follow up would reduce these issues and, potentially, save money
- The petition has until the end of April 2026 to reach the target of 10,000 signatures
- Reaching this total will ensure that a key representative will be granted a meeting with a health minister to outline the case
- It is going well so far, but still requires many signatures to achieve the goal
- Signing online takes about thirty seconds and each signature will help
- We are VERY grateful to organisations and individuals who can spread the word and help us to achieve this goal – we hope that you will be willing to do so



The link for the petition is: <https://petition.parliament.uk/petitions/743337>

Trials of a laryngectomee with dupuytren's contracture

John describes his experiences when needing to undergo surgery on his hand:

The nice pre-op ladies were a bit lost and didn't understand all I said. On the day before the op one phoned to enquire about my pipe(I dont smoke) meant my stoma and we gave her the sizes ?? no idea why. She then asked if Pat was my carer well she has been my wife for 55 years so yes; said she must stay with me. Pat was not happy at the thought of watching my operation. However, on the day a special nurse from ICU had been assigned to look after me, so Pat escaped for lunch with a friend.

I had a good laugh with the nurse, showed her the stoma and explained how it worked and I look after it. She then fetched a table, chair and laptop and did her homework.

I had a peripheral nerve block in my shoulder so the right arm was like a rag doll's no control at all.

Afterwards I needed dressing, Pat and the nurse were vying with each other to do so and ended up with a sandal each. Pat saved my favourite shirt from the nurses scissors and luckily they managed to get my hand and pot in the sleeve. Everyone came in to say Goodbye to me and I thanked them and felt like a celebrity.

John



Laryngectomy skydiver Kyle

Kyle reports on his fund-raising skydive experience

This has truly been an incredible experience, not only have I been able to do something I have always wanted to do but me and my sister managed to raise £2,271 for the amazing team that has helped and continues to help me and many others through everything.

The generosity and encouragement from family, friends, and even complete strangers was truly overwhelming and deeply humbling.

I'm so grateful that we have been able to support and help the ENT team at Royal Stoke Hospital to help others and hopefully pass on knowledge to future doctors too.

Early on, my consultant at Royal Stoke Hospital, Mr George, shared his hope that the money would go towards a specialised camera capable of recording procedures. This equipment will play a vital role in teaching future doctors, improving understanding, and ultimately helping even more patients. The experience has been one of the best of my life and I can't wait to do more things in support of such a great cause, especially if it's as fun as jumping out of a plane.

We would just like to say a massive thank you as well because we wouldn't have been able to do it without your support.

In addition to in-air photos I have attached a picture from the cheque presentation.

Kyle



A letter of hope and possibility from Karen

Dear Fellow Family Members,

As a family member of a laryngectomee, I can still remember the sheer fear of what the whole family felt when my dad was diagnosed at the age of 52, with laryngeal cancer and then to be told he would have to undergo a laryngectomy. After 12 years of giving up smoking, he thought he had got away with not getting cancer.

Over the years, I have often looked back at the experience and it's not the doom and gloom of the diagnosis and the surgery, it's what we learned from the experience that I remember - and there was a lot of positives, I can assure you (although you may not think so, as you're reading this).

Whilst my dad was recovering in hospital, post-surgery, he started reading Sydney Norgate's 'Laryngectomy Is Not a Tragedy'. I can't pretend there were no black days, but it did change his outlook on being a laryngectomee. Through this book, he realised he could still have a fulfilling life and more importantly, a voice, even if it sounded unusual to everyone else! Plus, he realised, you don't lose your sense of humour or ambitions because you haven't got your own voice box anymore! The cartoons in the book brightened my dad's spirits and inspired him to make up his own postcard cartoons (referencing two of his hobbies of playing squash and toy train collecting) whilst he was in hospital recovering, to send to friends with progress reports.

My dad set about doing the daily speech exercises. He made game of it and was highly delighted, when our family could correctly identify the words he was practicing and also it lifted our spirits too! Practice, practice, practice does indeed pay off!

Through Sydney's humour in the book, my dad re-found his. He would tell us anecdotes which he found funny as a laryngectomee. Yes, you and your family can still have a laugh.

I remember the sheer joy for my dad and for us, when he proudly blew a whistle for the first time post op, once he had mastered Sydney's tips and advice on how to do so.

Dad became very knowledgeable and efficient regarding the care of his neck stoma, provox and laryngectomy paraphernalia. My mother, Carol, didn't get a look in...and she was a nurse! The second benefit of my dad dealing with his stoma and equipment was that he was often called upon by the nurses on Ward 3 at Preston Royal Hospital, to give support to other patients undergoing laryngectomy and to those laryngectomees being discharged home full of trepidation. It gave him a sense of purpose, as a laryngectomee. He was in a position to help allay their fears and of course, to give them a copy of 'Laryngectomy is Not a Tragedy'.



As well as returning back to work as a factory manager, a goal my dad wanted to achieve was to go swimming. He assumed that a laryngectomee would never be able to go swimming again, until he joined several laryngectomees, a nurse and a physio in a local pool. We were all apprehensive. What if water entered into the neck stoma? My mother told me, it was pure delight, to see the apprehension on all their faces, disappear and be replaced by pure joy and excitement. After that, there was no stopping dad. The next challenge was to go back to playing squash...and to win! And then taking it up a notch, by competing in squash tournaments. Then he took up running. I don't think he had ever been running since school!

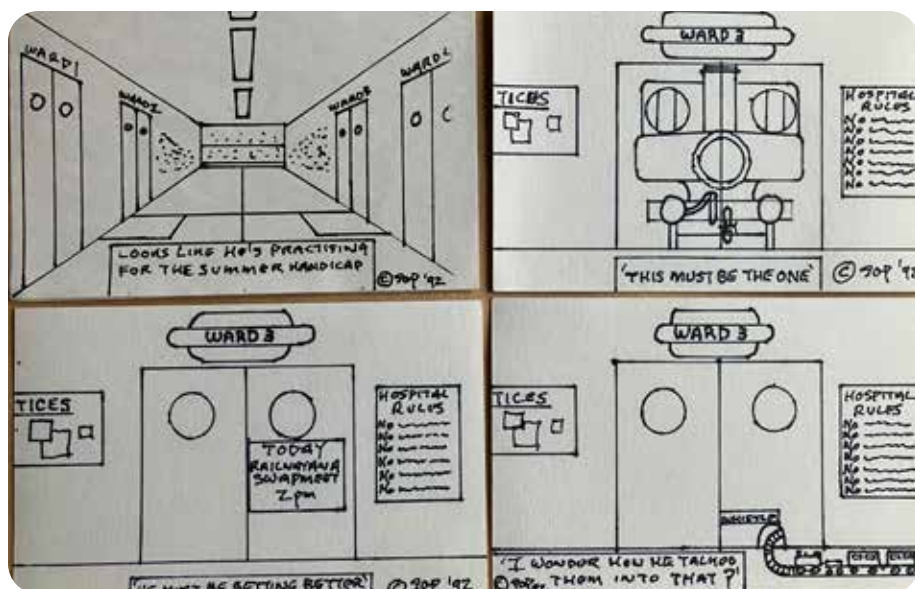
Four years after my dad's operation, my mother died, due to cancer. One of my brother's asked 'What's dad going to do? How's he going to manage?' I had no such worries. As I had lived the closest, I had seen how well he had looked after mum, the house and himself. Thankfully, his work, his hobbies and his family and friends had sustained him. He felt confident to go on a road trip to France with two friends. Once off the ferry, his friends had difficulty being understood whilst speaking French to a Custom's Officer. A hoarse voice from the back of the car piped up 'Bonjour Monsieur. Nous sommes a Paris pour trois jours'. He was beyond jubilant that the Custom's Officer replied 'Merci, Monsieur'. His friends rapidly spun around in their seats with shocked faces 'We didn't know you could speak French!' 'Neither did I! I've not spoken French since I left school!'.
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Sadly, my dad passed away six years after his operation. He was strong until the very end. I kept my dad's copy of Sydney's book 'Laryngectomy is Not a Tragedy' until late last year. I re-read it and decided it was time for it to find a new home; to help and inspire someone else with their recovery post laryngectomy.

Although I have shed a few tears, whilst writing the last two paragraphs, I want you to know, there is life after a laryngectomy. A life of possibility and fulfilment. It is not a tragedy. It can have many positive moments, and you, as a family member, can share in those moments too.

Best Wishes

Karen



Christmas lunches

York

The York area Christmas meal once again took place at Fulford Golf Club on Thursday 18 December 2025. The food and service were as excellent as ever with the traditional turkey meal being a popular choice. I particularly enjoyed the brownie desert which was delicious. It was a very happy occasion and a great opportunity for everyone to catch up with each other. It was well attended and we were lucky enough to have Ruth Wallace join us. Ruth being the speech and language therapist who has treated and helped many of the laryngectomees. Naturally everyone was pleased to see her.

Photographs of the group and individual and couple photos were taken by Jayne Yeates who helpfully provided a festive backdrop. Jayne also gave each of the attendees a 2026 calendar featuring her superb wildlife photographs. What a generous and thoughtful gift for all.

The venue has been booked again for this year and the Christmas meal will be on Thursday 17 December 2026. Please put the date in your diary or on your calendar if you are a lucky enough to have one.

Wishing you all well for 2026. Best wishes

Dawn



Blackpool

We had a fantastic afternoon as always at the Christmas lunch in Blackpool. 20 Oldham Quiet One's made the journey to Blackpool.

The food was delicious and the day was topped off perfectly with a great singer providing entertainment and dancing, see photo!.

On behalf of our group we would like to thank CLT Trustees and the wonderful organising from Sandra and Jean at Blackpool for making the lunches possible and so special.

Please find attached some of the photos I personally took and thanks once again for a wonderful day out xx.

David



Swindon

After our September outing around Coate Water it seemed a very short time before we were gathered for our Christmas lunch. I always enjoy Christmas lunches as they are a very good opportunity to catch up and celebrate a very special time of year. The pub organises a private room for us which is great as it means there isn't any background sound.

We make sure the pub has the orders in advance as that speeds up the service. This year it was complicated because the order for one person had been made by his friend and turned out to be the wrong choice. After some shuffling around we were able to solve the problem and everyone had a meal they could really enjoy.

There was also a transport problem as a car breakdown had put one of our members in a tricky situation but a rented car sorted out the problem. Its great to see the group growing together as they share experiences. Our local speech therapist is also so helpful and often introduces me to a health professional who can attend the lunch and liaise with anyone who may be needing some advice. The relaxed setting definitely helps with encouraging people to share information.

This year I took along my keyboard so we could share a few Christmas carols and wish each other a Merry Christmas. I spent a lot of time playing carols in December with three church services in two days on Christmas Eve and Christmas Day. The lunch was a great opportunity to get the carol season off to a good start.

Ros



Halifax

Members from West Yorkshire enjoyed a traditional turkey Christmas Dinner at Lightcliffe Golf Course near Halifax on 4th December.

Any members in the area would be very welcome to join us on Dec 3rd this year looking forward to seeing you all again.

Carole



Laughing after laryngectomy: An idea in development



Laughter is part of who we are. It helps us connect and feel like ourselves. But after a laryngectomy, laughter can change - in sound, in effort, and sometimes in how it feels socially.

An early-stage idea is beginning to explore an important question:

How does laughter change after laryngectomy, and what does that mean for identity and quality of life?

For many people, our voices are closely tied to identity. When breathing and voice change, confidence and social connection may change too. Laughter is different from speech - it's spontaneous, emotional, and often shared in groups. For some people, their laugh feels unfamiliar following surgery, which may impact their quality of social connection. Others still feel the same joy inside, even if it sounds different.

At the moment, this is not yet a research study, but an idea in its infancy. The goal would be to better understand:

- The lived experience of laughing after laryngectomy, including the impact on identity and social connection
- Do people with laryngectomy experience the same physiological benefits of laughing in the short and longer term?

Laughter is rarely discussed in rehabilitation, yet it plays a powerful role in how we relate to others - and how we see ourselves.

If this idea develops further, the voices and experiences of people living with laryngectomy will be central to shaping it.

Because laughter is more than a sound - it's part of identity.

Your experiences may help shape future work in this area. To express an interest, or share your thoughts please contact me:

Danielle Holbrook
danielle.holbrook2@uhbw.nhs.uk

Lunches 2026

Blackpool

The Blackpool lunch at the Hotel Sheraton on **Sunday 7th June 2026** is being arranged by:
Sandra Waddington
Tel: 01253 899531
Email: waddington46@yahoo.com

Scarborough

The Scarborough lunch will be held at The Crescent Hotel, Scarborough on **Friday 26th June 2026** The event is being arranged by:
Dawn Potts
Tel: 01904 489360
Mobile: 07947624421
Email: dawn.potts@hotmail.co.uk

Plymouth

A summer lunch in Plymouth has been arranged for **Wednesday 8th July 2026** at St Elizabeth's House Hotel, Plympton. Contact Richard Milton for further details:
Mobile: 07480 414277
Email: plymlarysupp@gmail.com

Coate Water 2026

Ros Oswald is planning to arrange a walk at Coate Water, Swindon, followed by lunch, once the weather is suitable.



Christmas Lunches 2026

Christmas lunches are also in the diary on **Thursday 3rd December** in Halifax, **Thursday 17 December** in York and **Sunday 13th December** in Blackpool.

Project Update: Restoring Your Voice with Silent Speech Technology

Imperial College London, Department of Bioengineering, Team Ora

To our friends at the Cancer Laryngectomy Trust:

We are delighted to share an update on our latest research at Imperial College London. Our 3rd Year Bioengineering undergraduate team is developing a Silent Speech Interface, a wearable device designed to help laryngectomy patients communicate clearly and naturally without needing a physical voice.

The Vision

For many who have undergone a laryngectomy, traditional communication aids can be restrictive. Our project uses facial surface electromyography (sEMG) - tiny and (hopefully) inconspicuous sensors placed on the face that detect the electrical signals sent to your muscles when you "mouth" a word. These signals are then "decoded" by a computer. In the future, we envision these words being instantly converted into natural-sounding speech through advanced text-to-speech technology (like ElevenLabs), effectively giving patients their voice back.

Our Progress: Better, More Comfortable Sensors

A major part of our work involves creating the sensors themselves. Standard medical electrodes can be bulky or irritating for long-term use. In the Green/Polymer Bionics Group lab, and in collaboration with the Neuromechanics and Rehabilitation Technology Group, we have been developing a new type of flexible, "dry" electrode made from a conductive polymer called PEDOT:PSS.

Our recent milestones include:

- **Successful Fabrication:** We have successfully created flexible electrode sheets that conform better to the skin.
- **Material Optimization:** We are currently adding glycerol to our next batch of electrodes. This acts as a "doping" agent to lower the electrical resistance between the sensor and the skin, ensuring we capture the clearest possible signal without the need for messy gels.
- **Refining the Vocabulary:** We have selected an initial set of essential words to test, including "Yes," "No," "Wait," "Help," "Pain," and "Bye" .

Next Steps

With the support of the Trust's network, we are moving into the testing phase. We will be comparing our new glycerol-doped electrodes against the "gold-standard" hospital sensors to ensure they are just as accurate, if not more so, for everyday use.

We are incredibly grateful to the Cancer Laryngectomy Trust for providing us with the first-hand patient insights that keep our design focused on what truly matters: user comfort and communication independence.



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



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