



# Newsletter March 2025

## Dear Friends

Once again we have been very pleased to welcome members to Christmas Lunches in Blackpool, Swindon, York and Halifax. Please see photos of members enjoying these events many of which have been taken by amateur photographer our member Jayne.

We are now planning Summer Lunches in Blackpool and Scarborough and another outing to Coate Water, Swindon.

Thank you to everyone who supported our Donation Form appeal in September. A total of £1 620 plus Gift Aid was raised.

We hope you enjoy reading about the personal experiences of members Hazel and George and are pleased to introduce Life after Lary and to catch up with Joy's Caregivers group.

Thank you to Mickleover Walking Group for their support in Memory of Doreen Ward.

We are hoping to include a newsletter item of travel advice for laryngectomees in a future edition and would welcome any advice and suggestions which members can send in please.

Best Wishes

**Carole Stainton, Trustee**

### Contact us:

Website: [www.cancerlt.org](http://www.cancerlt.org) Email: [info@cancerlt.org](mailto:info@cancerlt.org)

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

Charity Registration No 326653



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## Caregivers for Laryngectomees Update

In our September 2021 newsletter (Available to download from our website) Joy Shaw introduced her Facebook group exclusively for the caregivers of laryngectomees. Joy now updates their activities:

The group is still going strong in it's 9th year, and sadly still getting new members. I know it's the tip of the iceberg but a cure for cancer would mean the group would dwindle and that is what I'd hope for!

I also now run a group called "lary's remembered". It's a private group only for those from the caregivers group who have lost their lary. I have 33 members and a few more "thinking about it". Sadly we still get a few deaths and larys on end of life. Some members just leave after their lary dies but it's good that some stay and support the others.

If you would like to join the caregivers group 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](mailto:Murphyjoy69@googlemail.com) and we'll sort out your membership to our fantastic support group. You won't be sorry.



## George's experience of Oesophageal Speech

In the September 2023 magazine Jayne provided an insight into her journey so far as a Laryngectomee. Being a member of this elite club since 2007 much of her concern and frustration I completely understand. As much of the frustration is generated by the ability to communicate effectively. I have been an Oesophageal from the outset and have perfected my skill over the years and often forget how difficult it was to learn and perfect.

I became a member of this elite group of Laryngectomies in October 2007. During my surgery I was not made ready for a valve as radiotherapy had made it difficult to find a suitable site. I was left with the choice of an Electro larynx or learn Oesophageal speech. I was fortunate to have a Speech therapist Denise Bradshaw who was understanding and bit by bit together we got there. I also made use of the book Laryngectomy is not a tragedy. I returned to my job as a trainer/ lecturer at Blackburn College supported by my workmates I became quite proficient, alas though not able to go back on the Karaoke circuit with any success.

As we welcome 2025 it is now 18 years since I became a Lary and enter the year of my 80th birthday, I am still able to hold a conversation however my voice now is not used and I am aware that the volume is not what it was. To this end I decided to find a way in which I could use my voice more regularly and now work on Tuesday and Fridays as a volunteer at my local Hospice. Skills I learnt over 40 years in the Gas Industry put to good use on the everyday mishaps and breakages that occur on a busy unit providing a vital service to those at the end of life. The benefit to me is that I get to talk using my voice to communicate or offer advice.

On reflection it has been a journey into the unknown and I suspect much of the travelling my wife and I have done may not have taken place had I not become a Lary.



# Trustees Report

## Year end January 2025

In the Annual Report for 2024 I referred to different methods of communication including Facebook. During 2024 I have been looking out for different ways in which people who have had a laryngectomy choose to communicate. It has been a fascinating process which has taught me a great deal about human ingenuity and determination. I often feel that people who have had this surgery seem to become a very special kind of person. They endure a great deal and go on to find out what they are truly capable of. They demonstrate courage, compassion, kindness and hope in a way which is inspiring.

In the summer of 2024 I organised a walk for a group which enabled everyone to bring a dog with them in if they wanted to. We took along our Labrador Molly and as the walk went around a lake she took the opportunity to demonstrate her rather energetic diving and swimming skills. We were joined by a selection of different breeds and sizes of dog all of which enjoyed meeting up, getting to know each other and exploring the route. The presence of the dogs enabled people to communicate through their dogs. Speech became unnecessary when throwing a ball or stick was just as meaningful. It was a very relaxing and enjoyable walk which I am planning to repeat. Molly is looking forward to it already.

Our Christmas lunch was a 'no dogs' event but this time it was obvious that technology is able to facilitate communication with various apps being used to interpret speech, pass along messages and access the Facebook page Lifeafterlary UK. It will be interesting to see the extent to which artificial intelligence will enable communication to become simpler in ways that we cannot even imagine. When my father set up the Cancer Laryngectomy Trust in 1985 he did so as an act of hope and courage. Without knowing what would become possible he took the steps to enable the Charity to help people he would never know or have the chance to meet. The events of 2024 enabled me to see the results of his actions. I am looking forward to seeing more innovations in 2025.

We do hope that 2025 will be a peaceful and healthy year for you and your family.

Ros Oswald  
Trustee

# Into the future

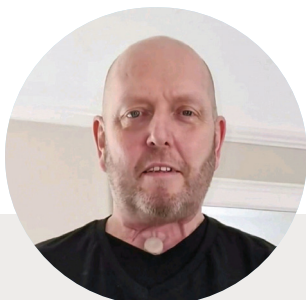
When this Charity was set up in 1985 the Internet barely existed for most people. It was nearly 20 years before Facebook was invented and it was 2010 before Instagram arrived. Since then social media has become the normal way of communicating for many people. As a Charity wanting to find as many people as possible we were aware that this method of reaching out was important but the reality was that we did not have the skills or time to make it happen.

Although social media sometimes attracts negative attention this group is a shining example of how to give positive, helpful, constructive, compassionate help to as many people as possible. Laryngeal cancer is not a common cancer and can lead patients to feel isolated and alone. By setting up accessible informative social media pages and being highly responsive this group has significantly helped many people. In addition zoom and in person events are being held.

In 2022 Life after Lary came into existence and is doing an excellent job at making contact with many people who have had a laryngectomy. Jon Organ runs the Instagram page, Ian Phillipson runs the Facebook page, Marc Valentine-Morton hosts the web meetings and Jane Hogarth runs admin and design. We are very pleased to be in touch with them and we are planning to support each other in our goals to help as many people as possible. The group has:

It is inspiring to see how positively the members reach out to each other. At the same time it is interesting to see how even medical qualified people may have only a limited understanding of what it really means to have had a laryngectomy. We are looking forward to working with this important group in the future and wish them well in their endeavours. It is definitely worth checking out the group and finding out more about all the good work that they are doing.

- **Website**  
[www.lifeafterlary.co.uk/](http://www.lifeafterlary.co.uk/)
- **Facebook**  
[www.facebook.com/groups/809357200892816](https://www.facebook.com/groups/809357200892816)
- **Instagram**  
[www.instagram.com/lifeafterlary/](https://www.instagram.com/lifeafterlary/)



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🌐 [www.lifeafterlary.co.uk](http://www.lifeafterlary.co.uk)

📷 [www.instagram.com/lifeafterlary/](https://www.instagram.com/lifeafterlary/)

📘 [www.facebook.com/groups/809357200892816](https://www.facebook.com/groups/809357200892816)





# Thank you Mr Norgate



Last summer I received an email from Hazel about how she had used the book *Laryngectomy is not a tragedy* written by our late founder Sydney Norgate to learn to speak again after her laryngectomy

Hazel has kindly agreed to share her experiences:

2017 was a challenging time for me and learning to adapt to massive life changes following long surgery for Laryngectomy because of misdiagnosis.

Months later, I had a valve fitted: great at the time to have some semblance of voice but along with that were constant leaks, valve changes, constant coughing and clearing and a generally uncomfortable time. I had never heard of Oesophageal speech (ES) until much later having Googled alternative ways of speaking for people who had had laryngectomy, and up came Mr Norgate's book, *Laryngectomy is not a Tragedy*.

I gave myself a two year goal. It was during Lockdown 2020.

I recited one word and kept repeating it....or my way of saying it.

Recorded each session on my phone, which I still have, so if I was having set backs and some not very good

sessions I could listen to those to see how far I'd come. It was really hard, especially at the start. I used to sing the words too. Or my version of singing. I started to learn the ukulele around that time so if I strummed a chord then would say the words to the chords. That really helped. I had years before, decided to learn the drums; which was my way of shouting - banging a drum ! I am in the Shout at Cancer Choir, and enjoy performing with them. The bit about trying to blow a balloon or blow out a candle was often funny because I couldn't do it: I can now no problem.

Encouraging myself really. I nearly gave up, lots! But pressed on with it.

Using single words, lists of them from the book, I used to ask people to listen to me and repeat back what they heard. My granddaughter Lily, then 13 used to help me with this.

I took the decision to have my valve blocked off and could only use ES. That was scary!!! But I did it and have since had my valve removed.

I have not looked back. Although I can't produce as much volume when speaking with the valve it's miles better. I haven't looked back. Thank you Mr Norgate

Hazel



## Contact Information

*Laryngectomy is not a tragedy* can be downloaded from the website [www.cancerlt.org](http://www.cancerlt.org) or to receive a paper copy apply by email to [info@cancerlt.org](mailto:info@cancerlt.org) or by post to CLT, PO Box 618, Halifax HX3 8WX



# Christmas Lunches

## York

Dawn Potts arranged the lunch at Fulford Golf Club and reports:

The room was lovely, table beautifully set, service excellent and food delicious. Everyone really enjoyed it including those attending for the first time.



## Blackpool

David reports on the lunch in Blackpool:

Thanking you for yet another wonderful lunch we all had at Sheraton Hotel in Blackpool before Christmas.

Sandra and Jean once again organised a terrific afternoon for us all. The venue was lovely and decorative beautifully for Christmas. The food was delicious and the staff looked after us all brilliantly. We also enjoyed entertainment with a singer to round off a wonderful afternoon which everyone seemed to thoroughly enjoy.

So once again thank you for another wonderful afternoon. We all appreciate it so much.





## Halifax

After over thirty years we had to move to a new venue which proved to be very successful. Lightcliffe Golf Club created a very enjoyable day with an excellent Christmas meal. We were pleased to welcome a new member and spouse to join us too who enjoyed meeting fellow larrys.



## Swindon

The Swindon lunch held at the Sun Inn was arranged by Ros Oswald who reports.

The Christmas lunch was very successful with 13 laryngectomees and 9 supporters and carers. A lot of people there were sharing information about new valves and techniques that are available. It was a very good natured event.

It's so encouraging to see more and more larys and their friends and partners coming along to the social get togethers.

Member Ralph's appreciation of the lunch: Not only do Helen and I enjoy it immensely (the clock from 12.00 to 3.00pm just flies!) but I always seem to learn of some new product (and dare I say get the chance myself to pass on some ideas, information and encouragement to others)

It's so incredible what you and your sisters have done for us larys!

Your Dad was a true pioneer and ambassador getting out there and showing there can be a good life after having neck cancer and a laryngectomy operation.

He would be so proud of you.  
Ralph





# Events 2025

## Blackpool

The Blackpool lunch, arranged by Sandra Waddington, will be held on Sunday 8th June 2025 at Hotel Sheraton, Blackpool. Sandra Waddington, 76 Rutland Avenue, Poulton-le Fylde, FY6 7SA Tel 01253 899531 email waddington46@yahoo.com

## Scarborough

The Scarborough lunch will be held at The Crescent Hotel, Scarborough on Friday 27th June 2025. The event is being arranged by Dawn Potts, The Granary, Hull Road, York, YO19 5LE, Tel: 01904 489360, Mobile: 07947624421, email dawn.potts@hotmail.co.uk





### **Swindon**

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

### **Christmas Lunches**

Christmas lunches are also in the diary on Thursday 4th December in Halifax and Thursday 18th December in York.



# Mickleover Walking Group Xmas Charity

A walking group from Mickleover in Derby recently raised £350 (plus gift aid) for the charity in memory of Doreen Ward. Doreen passed away almost 40 years ago but as a laryngectomee she was helped at the time by the charity's founder Sydney Norgate and his wife Lucy. After she passed away, Sydney wrote a lovely letter to her family saying that he and his wife had formed a deep rapport with her. She was only 54 years old and didn't get to see her granddaughter born - like many others, she was taken too soon.

Trustee Carole Stainton remembers Doreen from those early days when her parents spent many hours working to support fellow patients and raising money to continue the work.

Mickleover was formerly a village but has now been incorporated into the City of Derby. The Mickleover Community Walk was set up by Sandra Ward (Doreen's daughter-in-law), some nine years ago and has grown from strength to strength since then. The first walk was on Monday 11th January 2016 and there were 13 walkers, mainly friends and neighbours. Since that time the group has grown and a walk of about 3 miles is led almost every Monday morning. This year (2024) we have had 126 different people who have walked with us at least once, a maximum of 55 people and an average in excess of 43 people. The group is one of a number of walks that are arranged at different times in the

week around Derby, which are supported by Livewell Derby.

The Mickleover Community Walk has seven volunteer walk leaders (see photo below) led by Doreen's Daughter in law Sandra (centre) and her husband Andy (Doreen's son, far left).

Sandra organises a Christmas lunch immediately following one of the walks late in the year and this year it was on Monday 9th December and the opportunity is taken to raise money for a worthy charity. On this occasion, the Cancer Laryngectomee Trust was chosen, to remember Doreen as the 40-year anniversary of her passing approaches.

Forty-nine people enjoyed the walk itself and although it was cool, the sun did shine on us; see photo (right) with Sandra in the centre. We then had a buffet lunch at the Mickleover Country Park Social Club known locally as the Pastures Social Club.



Following the walk a number of presentations were made, including presentation of the trophy for the person who had done the most walks this year.

Statistics of the groups walking over the year were presented and it was reported. This included the fact that between us we had walked more than 5300 miles; equivalent to one person walking from Mickleover to Sri Lanka!

This was followed by a buffet lunch and then the fun continued, which presented more money raising opportunities.



A general knowledge quiz (£1 per person to enter) was held with questions having been prepared by Andy and Sandra – the photo shows Andy asking one of the questions. There were 15 questions and a couple of tie breaker questions. It was a very close result with the winning team scoring 11.5 but two other teams scoring 11 each, so the tie breaker questions weren't actually required. The winning team were then asked to randomly select one of two envelopes to determine whether they would win the cash (£59) or a box of Celebrations. When they opened the envelope, they discovered that they had won the chocolates so the £59 went to the charity instead

Next was a game of bingo. The cost was £2 per strip of six sheets. Two of the other volunteers called the numbers with prizes of £5 for one line, £7.50 for two lines and £10 for a full house.

This was followed by a raffle; another of the volunteers had been selling raffle tickets for a number of weeks prior to the event. The prizes had all been donated by the walkers themselves and included bottles of wine, boxes of chocolates, perfumes, and even a voucher to spend at Tesco, kindly donated by another of the walk leaders.





Throughout the whole event, there was a table with a sale of second-hand books and jigsaws and an honesty box and again these had all been donated by the walkers themselves.

So small costs and lots of people can really raise a significant amount of money.

A word about Doreen who passed away from this cancer on 18 April 1985. About a year earlier she endured much suffering to have her larynx removed and so became a laryngectomee, subsequently breathing through a hole in the neck. She tried very hard to talk but didn't manage to. Unfortunately, the cancer returned.

She was brought up to be hard-working – her parents had a guest house and later a hotel and she was kept busy helping out. She married at the age of 19 and went on to have three children and also looked after her elderly parents. She had a number of jobs over the years including running a grocer's shop in the 1960s and a Guest House in the 1970s. She was an intelligent lady and was well liked and respected by all who knew her and has been sadly missed over the last forty years.

RIP

**Doreen in happier times  
in the 1970s.**





# 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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