NEWSLETTER

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World Head & Neck Cancer Day - Sponsored Silence

Sunday 27th July is World Head and Neck Cancer Day! To mark this day, Life after Lary is holding a Sponsored Silence to raise awareness of laryngectomees who no longer have a natural voice or who have no voice at all after surgery. We aim to raise £500 of which some will be spent on LCD writing tablets for those just through surgery. A day or part of the day, include your family and friends to join many patients around the country who no longer have a voice or a natural voice. Pick a time in the day to stay completely silent and think of others. We would also suggest that any monies raised go to LaL but also your favourite H&N charity. Our great friends at The Cancer Laryngectomy Trust or maybe Oracle H&N UK or Throat Cancer Foundation. So get in about it, arrange the day, make it fun, pick your team and your charity! Raise funds and keep quiet!

If you would like a sponsorship form or any further details, please contact Jon at lifeafterlary@gmail.com

Thank you to Slo Drinks and S&J Cleaning Systems for their sponsorship of this event.

Melody’s Story

I want to start this story off by saying how unbelievably proud of my daughter I am, and, through this experience, despite it being one of the worst things a child can go through, let alone a parent, she has made me appreciate the little things in life even more.

Melody started snoring the Christmas before she was 8. She had been asthmatic since she was 4 and I assumed at first it was all part and parcel. All of a sudden in February 2024 the tone of it changed. She started “whooping” on the inhale, “humming” on the exhale. The GP said it was normal and they would reassess during her asthma review in April. I’d managed to record the snoring by that time to show the asthma nurse. They made the decision to change her inhaler from a brown one to a purple one. By the end of May, the snoring had stopped and her asthma seemed to be decently managed by this new inhaler. Melody had no problems competing in her school sport’s day at the end of June, but then a couple of days later she started with a sore throat and it looked like her glands were a little swollen on one side. I got her some strepsils and calpol and thought nothing more. A week later, it still hadn’t gone, so off we toddled to the doctors on Friday 5th July. He said it was hay-fever and I knew that wasn’t right. She had no other symptoms. After work on Saturday I took her to about 3 different pharmacies. They suggested it could be the steroid residue from her inhaler. Sunday, she couldn’t swallow food. Out of hours GP gave her some throat numbing spray. Then Monday she couldn’t swallow water, and the glands on the right seemed a lot more pronounced, so up to A&E we went.

A camera put up her nose and down her throat discovered that, what I thought was her glands, was actually a mass, possibly a cyst, in her throat so they admitted her and booked a CT scan. I remember that she kept asking me for a cold glass of milk and it was breaking my heart that I couldn’t give it to her. At 10:30 that night, the nurses brought me to the desk and showed me the images. The mass on the right hand side of her neck had squished her airway all the way to the back of her neck and her oesophagus was nowhere to be seen. They put her asleep and intubated her. The next morning (Tuesday 9th July) we get told she will be transferred to Birmingham Children’s Hospital.

We were bundled into the ambulance, Melody’s dad and stepmum followed in the car, my partner joined us later in the day as he was tied up at work. She was taken straight into PICU where I was greeted by her name on a board and the word “oncology” underneath. I was devastated. Dr. Hobin, the oncologist soon made an appearance, as did the ENT team. The following day they took Melody for an MRI to get better imaging. They ran into issues when they tried to lie her flat as the breathing tube was getting compressed, cutting off her oxygen. They took her to theatre instead where they re-intubated her with a reinforced breathing tube and they also took a tissue sample for a biopsy. Days went by waiting and waiting for the results to come back. I stupidly googled a lot of the words I overheard during rounds and handovers, much to my detriment and scared myself silly. Finally nearly 2 weeks later we had results. Synovial sarcoma. A soft tissue cancer, usually found round the joints and very rarely in the head or neck. Now the treatment could begin.

Melody’s central line was put in and she had her first batch of chemo over the next 3 days, however, she was still asleep. The ENT specialists came every morning to check on her (and me). 2nd day into chemo, they said “we need to think about waking her up”. All of a sudden, panic struck. How was I supposed to explain all of this to my 8 year old?!

Melody’s Story continued..

Then they dropped that because Melody’s airway was so compromised, a tracheostomy had to be done below her voicebox and a PEG had to be inserted into her tummy so she could eat and get her meds. More drastic changes that I didn’t know how to explain once she was awake, but it needed to be done. They woke her up slowly and she got stronger by the day with the physio team's help. She hated it though.

At the beginning of August, she moved over to the cancer ward where she had another 2 batches of chemo, 3 weeks apart, and we, as a family were training to deal with the tracheostomy care. Regular MRI checks however, found that the treatment was having no effect on the tumour, and in fact, it had grown. At the beginning of September, we were pulled into a meeting with the ENT team and introduced to Neil Sharma and Camilla Dawson, a surgeon and a speech therapist from the QE who had both worked a lot with laryngectomee patients. There is very little info about cases of this sort in children, simply because it rarely occurs in kids. They explained that this was going to be the best option going forward as anything else would mean palliative care. Melody’s dad and myself wasted no time in signing the consent forms. She went to surgery September 30th and was in theatre for 11 hours. It was such a long day but to hear Mr Sharma and Ms Stephenson (the paeds ENT surgeon) say at the end of it all that they were certain that they had got the whole tumour was the best news we could have hoped for.

After 4 weeks of recovery back on PICU (more of the dreaded physio) she moved to Ward 5, a surgical ward. Dr. Hobin came to see us regularly and once the tests were back from the margins, he explained that it was a complete resection and no more treatment was needed. Amazing news! We also learned that caring for her lary was a lot less stressful than the trachy.

As we rolled into November, I got fully signed off with her care by the nurses and I was allowed to take her off the hospital grounds. She also was allowed to spend the nights in the Ronald McDonald house with me.

Finally she was discharged home on 26th November, exactly 20 weeks after being admitted.

Christmas was a quiet affair and then in the new year, I accompanied her into school till the teachers were trained and comfortable. She’s now thriving in her new normality being a sassy 9 year old and we couldn’t be more grateful for the teams that have helped her get to this point. They are truly miracle workers.

Intimacy after Head & Neck Cancer - Karen Liesching-Schroder

OWhen I first received my diagnosis of tongue cancer at the age of 43, I was told by my surgeon that I would have to learn to talk, eat, drink and swallow again, but there was no mention of intimacy during this conversation. At the time, my husband and I were just in shock, denial and then survival mode to get through the next few months of life-changing surgery and treatment. It wasn't until about a year after treatment had finished that it occurred to us this would be an issue. We were sitting together at home and Ian asked if he could kiss me and I said that would be lovely. We tried and I cried, because I couldn't do it. Kissing had always been a big part of our foreplay, kissing and being playful with our tongues. Our kissing had always been so passionate, but I now had no feeling in my partial tongue that hadn't been rebuilt. I knew Ian's tongue was in my mouth but I couldn't cope with much in my mouth anymore. I found I was really concentrating and holding my breath. We both cried. It is something we have tried over and over again, and yes I am one of the lucky ones, because I still have lips whereas there are head and neck cancer patients that I support through the Mouth Cancer Foundation that don't have lips now, or have other issues relating to their head and neck cancers.

The last time we kissed properly, I was 43 which is no age really. Then during my cancer, I went through the menopause; I have had trouble with my smears and I have had had more than my fair share of professionals making me feel horrible, and I am not a horrible person, I have tried with oral sex too but my jaw clicks, grinds and locks, or I am in various amounts of pain with my mouth on a daily basis so this isn't really an option to reciprocate pleasure anymore. My neck has to be at the right angle otherwise I can't cope with the cramps and I can't swallow properly. My way of giving in our intimate relationship is to dress up. Yes I have scars, but my husband sees past those.

I absolutely hate how these cancers impact our relationships and also how many of us are not prepared for this part of the journey. Professionals told me that I would have to learn to eat, drink, talk and swallow again, but no mention of intimacy being a problem. To be fair, in those early days, of discovering this diagnosis, intimacy was the furthest from our thoughts, Initially, it was all about shock, then denial and then survival. However, why is this conversation not bought up at all at any point. I am now 9 years post surgery and treatment, and living with lots of late effects (that I also wasn't told to expect!) Our lives have changed more than I could have possibly imagined. I had to leave my career in education last year and I have suffered quite severe bouts of depression and my husband has been with me throughout. However, many relationships break down because of these cancers because of the lack of knowledge and support in navigating these pathways.

I co-host a weekly zoom support with Joss Harding, dental hygienist and President Elect for the Mouth Cancer Foundation, and during some of our zoom meetings, intimacy issues has been brought up by members. Not everyone wants to or is comfortable to talk about this, but will sit and listen quietly, and others want to talk openly about it and how they feel. Because we have discussed this emotive subject on a few occasions, I decided to put up my own open and honest post first in the group I look, after and then after seeing the response, I decided to share it on other groups too. LifeafterLary also showed that this was a discussion that needed to happen, and then I was asked if I would like to write for your newsletter. We need this to be talked about with our clinicians. Many patients are getting diagnosed younger and even those of us that are creeping up in age, still want intimacy in some form in our lives and why shouldn't we?

Intimacy after Head & Neck Cancer - Karen Liesching-Schroder

Connections are important, we all need some physical touch and we all need emotional love too. It is finding new ways to approach this side of our lives. It isn't a case of being brave, a lot of trust is involved too. Personally, I feel the cancer has taken so much from not only our lives, but the lives of our partners too.

I connected with a psycho sexual therapist in cancer care, who watched me in a previous presentation last year, and we got chatting. We finally got together for a meeting after I asked if she could help support our head and neck patients in some form. We talked for an hour and Lorraine has agreed that she will join us on a zoom support in September, talk about what she does and how she helps patients and partners, bringing to the meeting accessories and ideas to help us navigate a way forward in an area that is completely unmet or looked after by our teams.

I hope by me sharing this, will help others too. Remember, you are not alone.

Meet ups

On Wednesday 11th June Life after Lary held another Surrey meet up. Though numbers were down on last time it was well received and the treats supplied went down well.
Another chance for patients and family members to come together and be as one for an afternoon. For advice, swapping tips or just being together, these events are invaluable. Nicola, best start nurse from atos medical, was on hand to offer advice and we cannot thank her and atos enough for continuing to support our events.

Our Shropshire in person meet is planned for 24th June and we will report on that in our next issue.

Behind the scenes at Life after Lary

– The Work You Don’t Always See, But Always Feel –

While our social media platforms continue to provide connection, education, and daily inspiration, much of Life after Lary’s work happens quietly in the background. It’s this behind-the-scenes effort deeply rooted in advocacy, lived experience, and purpose that shapes real change for patients, clinicians, and policy-makers alike.

This section of the newsletter is our way of keeping you informed about that vital, often unseen work. We believe transparency builds trust, and when you know what we’re doing in clinics, conferences, and committee rooms, you understand how powerfully this community is helping to shape the future of laryngectomy care.

Advocacy, Representation & Education

- We developed and delivered a powerful mental health and laryngectomy presentation to Atos Medical during Mental Health Awareness Month.
- We’re proud to chair discussions on genomic medicine at Great Ormond Street Hospital.
- At The Royal Marsden Cancer Hospital, we’ve contributed to meetings on biomedical cancer research, treatment outcomes, and EDI.
- As Lary Specialists with NICE, we represent Life After Lary at forums exploring robotic-assisted surgery.
- We serve as ambassadors for the Throat Cancer Foundation, Oracle H&N UK, and Radiotherapy UK.
- Delivered a keynote presentation to over 450 members of the Royal College of Speech and Language Therapists at Southwark Cathedral.
- Shared our work with Cancer Research UK at Birmingham University’s Clinical Trials Unit.
- Spoke at the UKIO Oncology Conference in Liverpool on the mental health challenges post-laryngectomy.
- Delivered talks to students in the UK and at Michigan State University.

Community at the Core

- We continue to host in-person meetups across the UK—in Scotland, Surrey, and Shropshire.
- Our monthly Zoom meetings remain a highlight, offering support, education, and connection.

UKIO Oncology conference 2025

Behind the scenes cont.

Why It Matters

All of this work, every meeting, every presentation, every conversation, feeds into a bigger purpose; to ensure that no laryngectomy patient is left behind, that lived experience is heard, and that support is not a postcode lottery, but a national standard. By raising our profile and showing NHS staff, clinicians, researchers, and charities what we do, we open doors for new patients to be referred to us at the right time—when they most need a listening ear, a friendly face, or proof that there really is Life after Lary.

Our Promise

This group was started almost two years ago by Ian and myself, built on one promise; No Lary Should Ever Be Alone.
And with all of you by our side, we'll continue to keep that promise. On social media. Behind the scenes. In every hospital and every heart.

Thank you for standing with us—and for helping us prove, every single day, that we are stronger together.

LaL presented to students at Michigan state university for the second year

Life after Lary presenting to SALT at southwark cathedral London

How Life after Lary can help

When Peter's electrolarynx failed in early May he contacted his speech and language therapists. He was told that as he had his for 10 years they could not do anything. Peter was looking at around £1000 to give him back the ability to communicate and sing in the laryngectomy choir again.
This was more than a voice to Peter; this was his whole life, his hobbies, his pastime in singing - just everything.

Peter turned to Life after Lary and we are glad he did. Within a week we had supplied Peter with a new electro larynx and the ability to talk and sing again.

With the help of this group and others, we are able to continue to support laryngectomees. Whether it is an electrolarynx, a nebuliser, a care pack, cash grants, a hand held fan or just a bouquet of flowers or a voucher to cheer up a patient.

Thank you all for continuing to donate to Life after Lary to help us support others.

A holiday deal!

Life after Lary have struck a deal with a holiday park on the Kent south coast at New Romney. There are 4 beautiful accommodations to choose from.
X2 lodges king-size bedrooms that both sleep 6
X1 Caravan sleeps 8
X1 Caravan sleeps 6
If you book and quote Life after Lary you will receive a 10% discount on any holiday. Weekends or weeks. The park is located across the road from a golden, sandy, and quiet beach. And the accommodation is dog-friendly. There is a fishing lake and clubhouse with entertainment and an indoor swimming pool is also on site.
Contact Samantha Gilby at samgilby@hotmail.co.uk or phone
07949 382819 and dont forget to quote Life After Lary when booking.

Next Zoom: Thursday 3rd July 6.30pm (UK Time)

Further details available in the ‘featured’ tab on facebook.

If anyone would like to join but is unsure of zoom and how it works please contact Jane who would love to help to ensure you can join in.

Some sad news

Sadly we report the recent passing of Jamie Rae, founder and CEO of The Throat Cancer Foundation, where Jon Organ is an ambassador, marks the end of an extraordinary life.
Jamie led the charge to change the government's mind and secure the inclusion of boys in the UK's HPV vaccination programme. In 2010, Jamie was diagnosed with HPV related oropharyngeal cancer and established the Throat Cancer Foundation 2 years later. Jamie launched the HPV Action coalition in 2013 and the rest is history.
Jamie's legacy is monumental and he will be sadly missed by so many.

His work lives on and ensures that future generations of boys and girls alike will be protected from one of the world's most common and dangerous viruses.

May he rest in peace.

JUL
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Patient open day invitation

Come and meet other laryngectomees

At Atos, our mission is to help make life easier for people living with a neck stoma. We understand that having a laryngectomy can be life changing. To help support you every step of the way we are holding an Atos Patient Open Day where you can come and meet the Atos Care team and other laryngectomy patients.

We will have experts available on the day to help with any queries you may have.

We will have special guests on the day including Life after Lary and a private screening of the film 'Can you hear my voice' featuring the Shout at Cancer choir.

Come at your leisure to mix and mingle from 3pm – 5pm
Can you Hear my Voice film screening 5pm – 7pm

Date: 9th July 2025
Venue: Epsom Downs Racecourse,
Epsom, KT18 5LQ

Two ways to register (please choose one):

1. Scan the QR code below and go to the website to complete the form
2. Go to the following website and complete the form:
www.atos-care.co.uk/events/atos-medical-patient-open-day


Meet our Atos Care experts


Refreshments provided


Can You Hear My Voice

Special guests Life After Lary

If you have any questions, please contact eventsuk@atosmedical.com

More details overleaf on how to register

Scan to register

Welcome to Atos Care

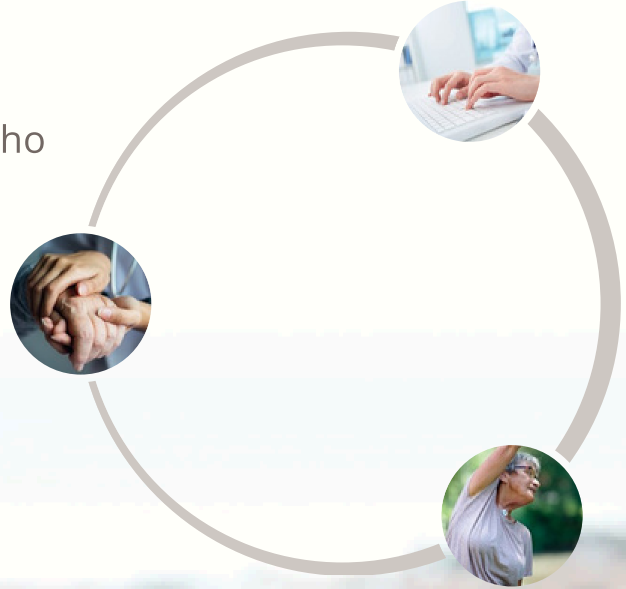
An integrated care and distribution service for people with a laryngectomy in the UK.
Atos Care is a comprehensive support service that includes a team of CQC registered nurses, dedicated to making life easier for people living with a neck stoma.

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

Inspected and rated
Good
Care Quality Commission



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

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

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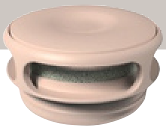
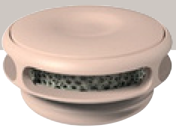
- Better pulmonary performance
- Enables 24/7 HME use
- Reduction of mucus
- Reduced coughing


Home HME

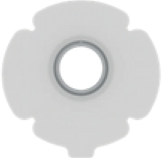

Go HME

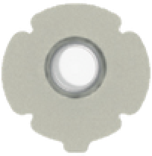

Night HME

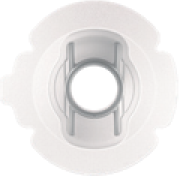

Energy HME

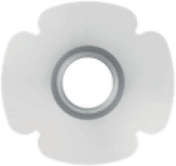

Protect HME

FreeHands HME


Standard Adhesive


Sensitive Adhesive


Stability Adhesive


Night Adhesive

Breathe better, whatever you do

The Provox Life™ system was developed on the basis of thorough research, and is designed to address the challenges that you experience with HMEs and attachments.

Designed for people with a laryngectomy, the system offers a complete, flexible solution that allows you to experience a personalised routine, no matter where you are on your recovery journey.

Please visit our website at **www.atos-care.co.uk** or call us on **0800 783 1659** for more information on how Provox LifeTM can improve your quality of life.

The next generation solution consists of:

- **Six high performing HMEs that offer improved humidification and breathability**
- **Four newly designed adhesives for a wider range of skin types and stoma contours with improved materials and new SecureFitTM coupling**
- **HMEs that are compatible with all adhesives in the Provox LifeTM range to offer you a personalised routine**

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