NEWSLETTER

INSIDE THIS ISSUE

Louise’s Story

It was February 2025. A cold, fresh, beautiful night in Rome. We were getting ready to head out for dinner when my tummy turned for what felt like the 10th time that day, a familiar feeling I had only ever felt three years earlier. I couldn't be? Could I? Can wishes in the Trevi Fountain come true that fast? I'd given up testing a few months earlier, sick of the disappointment of seeing negative tests over and over again. But not this time. I stared at the positive pregnancy test in my hand and couldn't believe our luck. Finally. 2025, a year we would complete our little family and a year we'd never forget, although not for the reasons I thought at the time.

I'm not sure how long exactly my voice was hoarse for, but I started to notice it around the time I fell pregnant. It got progressively worse as the weeks went on, along with my morning sickness. I mentioned it at my GP appointments during my pregnancy, and they advised it was probably silent reflux being aggravated by the pregnancy and vomiting irritating my throat. I was prescribed omeprazole and told it could take around 4 weeks to see a difference.

Four weeks later, it was worse than ever. I tried everything...bottles and bottles of Gaviscon, changing my diet, tubs of manuka honey (at a price you'd expect it to cure cancer for), alkaline water, every type of lozenge the chemist sold, you name it - I tried it. I was desperate for any bit of relief. If you've ever spent the day with a lively 3-year-old, you understand how much you need your voice. My GP advised that she would send off a referral to see an ENT to rule out damage to my vocal cords or things like a polyp. In the meantime, my voice came and went, on a good day, barely a whisper.
The breathlessness started around May; I brought it up during maternity appointments but I was always reassured it was just the growing baby putting pressure on my lungs. I also felt a tiredness I never felt before. I hadn't felt this tired on my first but then again, was this normal for a 2nd pregnancy while running around after a toddler?

Louise’s Story — cont..

By July I could barely make it up the stairs without feeling winded, I couldn't sleep for more than an hour at a time and was coughing up more and more blood. I rang A&E as it frightened me but was told not to come in, that it was noted on my chart I had ongoing problems with my throat and it was probably just irritation from vomiting. By this stage I was desperate, I was miserable and I just wanted to feel normal again. I sent a long email to the ENT hospital in my area, outlining my worsening symptoms, the stress it was causing me while pregnant and begging for them to see me earlier. **An email that probably saved our lives.**

Two weeks later I got an appointment and off I went, excited to finally get an answer and sort my 'silent reflux'. What was meant to be a normal day, a routine appointment, changed my life forever. I knew as soon as the doctor put the camera down it was nothing good. His eyes widened and avoided mine, the atmosphere changed in seconds. Before I knew it the room was full of more doctors and nurses, I couldn't hear what they were saying because all I could hear was my own heartbeat in my ears, blood rushing to my head. No one said anything but I knew. I'm no stranger to cancer - I lost my own Mam to breast cancer when she was just 50, 4 years ago. I'd seen those eyes full of pity looking at us before. I didn't get to leave that hospital again for another 6 weeks. There was a large mass on my right vocal cord and it was starting to block my airway. The next few days were a blur. I managed to convince myself while waiting on biopsy results that it couldn't be cancer. Surely it was just a big cyst? I'm only 31, I don't smoke and rarely drink. I'm relatively fit and healthy....but unfortunately, cancer doesn't care.

Cancer doesn't care how old you are, it doesn't care if 'people your age aren't supposed to get this type of cancer'. It doesn't care about your hopes, plans and dreams. It doesn't care if you have small children or a partner who need you. It doesn't care how happy you are and that you finally got everything you wanted. It just doesn't care. It sneaks up when you least expect it and turns an ordinary day into one that will change your life forever.

The biopsy came back and it was confirmed. Stage 4 squamous cell carcinoma. My whole world shattered in seconds. My heart broke for my little family and my baby who wasn't even born yet. I've been there before and I know how hard it is to look at someone with cancer. I didnt want them to go through it. I didnt want my kids to be afraid of me - what would I sound like? Would I even be able to communicate with them anymore?

A word I never even heard of before quickly became one that changed everything - **a laryngectomy**.

Louise’s Story — cont..

My voice.

My laugh.

The way I spoke to, sang to, and soothed my babies.

The stories and whispered “I love yous” before bed.

The jokes me and my fiancé shared every day.

A part of me — my whole larynx and vocal cords — had to be removed and because it was starting to block my airway, it had to happen fast. Doctors said I wouldn't be able to deliver my baby safely if it wasn't removed first because of my breathing and I couldn't lay flat to deliver under general anaesthetic. The pregnancy also made planning more complicated because what was best for me wasn't best for the baby and what was best for the baby wouldn't be best for me. After careful discussions between the ENT consultants and maternity consultants, they agreed the best chance for both of us would be to do the surgery asap (30 weeks), pray the baby stays inside to get a little stronger and then deliver him 5 weeks later so I could start chemotherapy & radiotherapy.

General anaesthetic has a high chance of triggering preterm labour so off we went to surgery, a neonatal team also in theatre with us in case labour started. 12 days from admission to surgery, I hadn't even got my head around it yet, I think I was just in survival mode like a lot of us. That morning was one of the worst mornings of my whole life, going to sleep and not knowing if my baby would be in or out when I woke up. Would we both be ok? Is this definitely the right choice? A 9 hour surgery, how could that not harm him? I was so scared but had to trust that my doctors knew best. **Nothing short of a miracle, my baby stayed put and the surgery was a success**. I'll never forget the relief of waking up and feeling my baby kicking. They monitored us both for a few days in ICU and once it was safe we went back to a normal ward.

I don't remember much of the next few weeks, I just wanted to get home, pack mine and the baby's hospital bag and spend a few days with my first son before I had to go back in again and deliver the baby. The hardest part was staying away from my son while I was still very swollen straight after surgery. I didn't want to frighten him, so I wrote a book to prepare him about how Mammys voice was broken and she had to stay in the hospital for a bit to get a new one. It helped us a lot and I hope it's something that can eventually be available for everyone, for children and grandchildren of laryngectomees. If it makes even one less worry for the next person in our shoes, I'd be happy something good came of it.

Louise’s Story — cont..

After plenty of ups and downs I finally got home and a few days later the highest of highs came when our second son was born - a perfect, healthy, strong, beautiful little boy just like his big brother. I'm surprised I didn't drown myself with the amount of tears of relief that went down my stoma that day. I couldn't believe it, after all the worry, the poking & prodding, scans, an MRI, medications, surgery, stress... nothing had affected him, he was perfect. I'll never forget the happy little bubble I was in that day, nothing else mattered and then how fast it was burst again. I was fitted for a radiotherapy mask before even being discharged from the maternity hospital and treatment started a few days later. The lowest of lows. I thought surgery would be the hardest part, but I struggled a lot during those next 7 weeks. 7 long weeks of chemotherapy and radiotherapy, struggling to keep my energy up, wanting to sleep but not wanting to miss anything with my babies. At least I was able to take stronger pain relief this time as I wasn't pregnant anymore.

Looking back, there were a lot of lows but there were definitely more highs, just proving there is a lot more good in the world than bad. We met the most amazing, nicest people along the way. I thank my lucky stars every day for my amazing surgeons and doctors who were skilled and brave enough to not only save just me, but my baby too. They had never been in this position before either.
All the lovely nurses who felt more like friends towards the end, the SLTs, PTs and nutritionists. The Life After Larry group who are always there to listen and offer advice. Everyone. Even complete strangers who pretend not to be shocked when they hear my new croaky voice. My job, Gas Networks Ireland were amazing. They helped us so much and even deferred my maternity leave so it started later and wasn't wasted during treatment. I have the best family and friends who managed to make me smile every day without fail no matter how sore or tired I was. Who still made me feel beautiful on the days I could barely look at myself in the mirror. Who never gave up on me the days I tried pushing them away and never minded, or at least pretended to not mind, being coughed on while I was still getting used to covering my stoma and not my mouth.

Louise’s Story — cont..

And now, its nearly February 2026. I'm sitting here with my three beautiful boys, with a hole in my neck but it's much better than the alternative, and that's all that matters. I thought I was unlucky to get this type of cancer but really, I'm lucky. Because when you are at your lowest, you realise just how many and how much people care. And that's something cancer can never take from us. Cancer may have taken my natural voice, but it will not take my happiness. It will not stop me from living. I'm still me. There's nothing I can't do now that I didn't do before (besides swimming and singing, but I wasn't great at either anyway).

I breathe differently now. I sound a little different and my new voice has its limits - but it is a voice. And I'll make sure it’s heard loud and clear. For my children. For people not make the same mistake I did and brush off symptoms. For others who have yet to walk this road someday.

And finally, for anyone who needs to know, that even after everything, life can still be amazing, meaningful, and worth fighting for: that there really is Life after Lary. And I'm proud to be part of that.

Life After Lary - Press Release, after press release!

Life after lary becomes a registered UK charity dedicated to supporting people after a laryngectomy

New charity aims to offer long-term support, community and advocacy for people whose lives have been changed by laryngeal cancer

Life After Lary is pleased to announce that it is now officially a registered charity in the UK. The charity will support individuals who have undergone laryngectomy or related treatment, offering peer support, practical guidance and advocacy to improve life after treatment.

Jon Organ, founder and CEO of Life After Lary, said: “Becoming a charity marks a huge step forward for Life After Lary. It gives us the foundations and the legitimacy to reach more people, strengthen our services and ensure that every person living after a laryngectomy has somewhere to turn. Too many people feel isolated after surgery, unsure where to find practical advice or a community that understands what life looks like now. Our aim is to change that. **We are committed to building a supportive, inclusive community where people can share experiences, find guidance and feel less alone**. We also want to be a strong voice on the issues that matter to those living with life after laryngectomy, from better awareness and understanding through to improved services and pathways of care.
For us, this is about more than organisational status. It is about standing alongside people whose lives have changed forever and making sure they have the support, dignity and visibility they deserve.”

If you would like more information, an interview with a trustee, or a case study, please contact:
Name: Jon Organ
Role: Chairperson, Life After Lary
Email: lifeafterlary@gmail.com
Phone: 07557 095909

Notes to editors
- Life After Lary was founded in 2023 initially as a support network and is based in Surrey.
- The charity supports patients after laryngectomy, offering peer support, practical advice, advocacy and community.
- For more information visit lifeafterlary.co.uk or use contact details above.

Life After Lary - Further Press Release

Life after lary are Calling for Greater Understanding of Laryngeal Cancer and the Laryngectomy Community

Life After Lary (Charity No. 1215969) is calling for a national step change in public understanding of laryngeal cancer and the realities of life after a laryngectomy. As diagnoses continue to rise and thousands of people across the UK live with life-altering changes to breathing, speaking, and swallowing, the charity urges the public, healthcare systems, and policymakers to recognise the dignity, resilience, and needs of this often overlooked community.

Laryngeal and throat cancer is frequently misunderstood, and the people who undergo a laryngectomy, a surgery that permanently removes the voice box and reroutes breathing through a neck stoma, face daily barriers that most of society has never been taught to see. These barriers are not inevitable. They are the result of a lack of awareness, outdated assumptions, and the absence of clear, accessible information.

“People living after a laryngectomy are not fragile, tragic, or defined by loss,” said Life After Lary’s leadership team. “They are parents, workers, creatives, advocates, and contributors to every part of society. What they need is not sympathy, they need understanding, visibility, and environments designed with them in mind.”

Life After Lary highlights three urgent priorities:

Public Awareness: Most people have never heard of a laryngectomy until they or a loved one face it. This lack of awareness fuels stigma, fear, and misinformation.
Accessibility and Safety: Simple everyday situations, from airport security to hospital triage, can become dangerous when staff are unaware that laryngectomy patients breathe only through their necks.
Dignity and Representation: Voices after laryngectomy may sound different, but they are no less human. Society must move beyond outdated stereotypes and recognise the full spectrum of communication after surgery.

The charity plans to launch a series of national campaigns, patient-led resources, and collaborative initiatives with healthcare providers to ensure that no one living after a laryngectomy is left to educate the world alone.

Life After Lary - Press Release

“Understanding saves lives. Understanding restores dignity. Understanding allows people to participate fully without having to justify their existence,” the charity added. “throat cancer and laryngectomy are not rare stories, they are simply unheard ones. It’s time to change that. Together, we must do better”

Life After Lary invites journalists, healthcare professionals, policymakers, and the public to join this movement for visibility, equity, and informed compassion.

For media enquiries:

lifeafterlary@gmail.com
www.lifeafterlary.co.uk
Life After Lary Registered Charity in England and Wales (No. 1215969)

Linda Litchfield

Kevin Brooks

*Note: Patients have given full consent to use images.

Life After Lary - Further Press Release - We just can’t stop!

Life After Lary charity chairman Jon Organ Calls for Greater Awareness of HPV-Related Throat Cancer

Rising cases highlight the urgent need for education, vaccination, and early diagnosis.

Life After Lary, a voice for people affected by throat and laryngeal cancers, is calling for increased public awareness of HPV-related throat cancer, as cases continue to rise sharply across the UK.

HPV-related oropharyngeal cancer — affecting the tonsils and base of the tongue — is now the fastest growing head and neck cancer in the UK. Rates have increased by around 30% per decade, with cases doubling over the past 20 years. In men, HPV-related throat cancer now exceeds cervical cancer incidence.

Recent data show a 47% increase in diagnoses in England between 2013 and 2020, underscoring the scale of a disease that remains poorly understood by the public.

“Too many people still believe throat cancer is only linked to smoking or alcohol,” said Jon Organ for Life After Lary. “HPV-related throat cancer often affects people with no traditional risk factors, and symptoms can be subtle. Awareness saves lives.”

Unlike many cancers, most HPV-related cancers are preventable. The HPV vaccine offered to boys and girls, provides strong protection, yet uptake and understanding remain inconsistent. Public knowledge of symptoms such as persistent sore throat, difficulty swallowing, neck lumps, or unexplained ear pain is also low, leading to delayed diagnosis.

Life After Lary - Further Press Release - We just can’t stop!

Life After Lary is urging for:

- Greater public education on HPV-related throat cancer
- Continued support for HPV vaccination programmes
- Increased awareness among men, who are disproportionately affected
- Earlier recognition of symptoms by both the public and healthcare professionals

“HPV-related throat cancer is increasing, but prevention **is possible**,” the spokesperson added. “By improving awareness now, we can reduce future diagnoses and improve survival.”

The organisation is encouraging media outlets, healthcare providers, and policymakers to support awareness campaigns and share accurate information about HPV, vaccination, and early warning signs.

Life After Lary - Further Press Release - Jon's been busy!

Life after Lary is a brand new charity in the UK, created by people who have lived every brutal, frightening, isolating moment of life after a total laryngectomy.

People are discharged into a world that no longer works the way it did the day before. Their voice has gone. Their breathing, eating, sleeping and confidence all shift overnight. And the truth is this. Most are left to cope with that devastation alone. Follow-up support is inconsistent, minimal or completely absent.

Life after Lary steps into that void **because nobody else ever has**.
This is not another neat, well behaved health charity. It is a lifeline built by the people who actually need it. It is powered by lived experience, by scarred necks, by lost voices, by the courage it takes to rebuild a life from the inside out. That authenticity is why people flock to it. For many, it is the first time they have found somewhere they do not have to pretend they are coping. The need has been ignored for decades. Around 700 people in the UK lose their natural voice permanently every year. The physical operation ends in a matter of hours. The emotional recovery takes years. **Isolation, stigma, fear, embarrassment, identity loss, relationship strain and the daily graft of learning how to live again are common, yet almost entirely hidden from public view.** These people have had nowhere to turn. No national support. No voice in the system. **Nothing.**
Life after Lary is breaking that silence. It gives people connection, dignity and proof that they are not the only ones fighting this battle. It helps them reclaim who they are in a world that often stops seeing them the moment their voice changes.

CEO Ian, Trustee Carl and CEO & Chairperson Jon

CEO & Chairperson Jon presenting at a Lary Support Group.

Dates for the Diary - Future Meet-up's

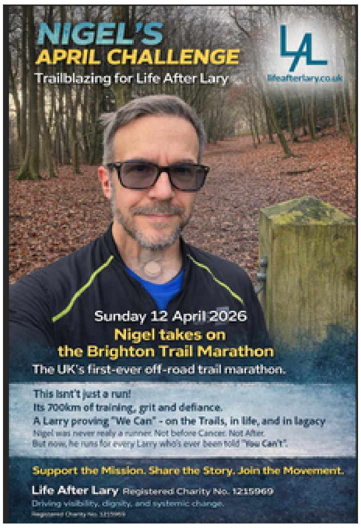
Surrey: 13.00 - 16.00 — Oxshott Community Hub, Verrey Lane, Surrey KT22 0DB.
Jan 27th, March 24th, May 26th, July 21st, September 29th, November 24th.

Shropshire: Lary Lounge 14.30 - 16.00 — The Wakes, Oakengates, Shropshire, TF2 6EP.
27th January, 31st March. Further dates to follow.

Norfolk: 14.00 - 16.00 The Royal Standard public house NR19 1AY.
20th January. Further dates to follow.

To celebrate Life After Lary becoming a charity, Nigel Skilton, a group member, will be undertaking a mammoth challenge. On Sunday 12th April Nigel will take on the Brighton Marathon! The first ever off road trail marathon.

You can sponsor Nigel on Just Giving. We will post the link on Facebook and add it to the Featured Tab, If anyone has any issues, please contact Jane via Facebook Messenger or j4nehogarth@gmail.com



NIGEL'S APRIL CHALLENGE
Trailblazing for Life After Lary
lifeafterlary.co.uk

Sunday 12 April 2026
Nigel takes on
the Brighton Trail Marathon
The UK's first-ever off-road trail marathon.

This isn't just a run!
Its 700km of training, grit and defiance.
A Larry proving "We Can" - on the Trails, in life, and in legacy
Nigel was never really a runner. Not before Cancer. Not After.
But now, he runs for every Larry who's ever been told "You Can't".

Support the Mission. Share the Story. Join the Movement.

Life After Lary Registered Charity No. 1215969
Driving visibility, dignity, and systemic change.
Registered Charity No. 1215969

Monthly Zoom: Thursday 5th February 6.30pm

**Joining instructions available in the 'featured' tab on facebook. We will also post on the day!*

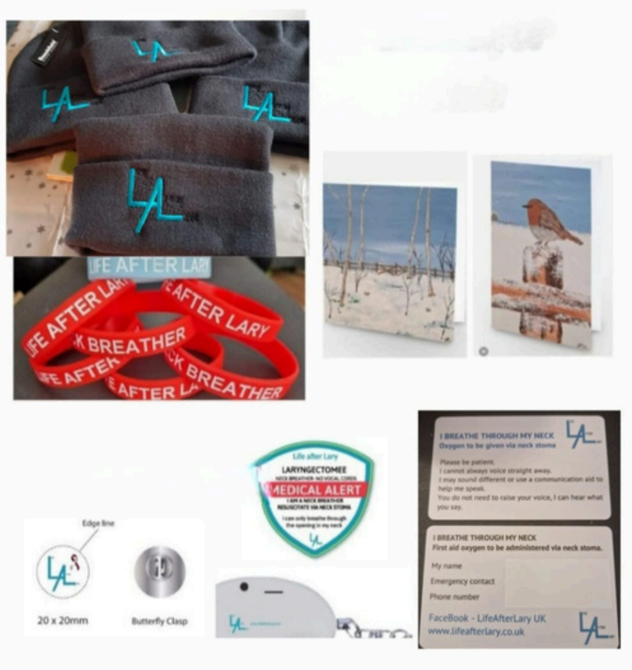
Don't be shy, no need for camera, or talking. You can type if you're nonverbal or you can just sit and listen. Just come along, have a laugh and spend some time with people ***just like you***.

Additional Zoom: Oesophageal Speech Wednesday 18th February 6.30pm

**Joining instructions available in the 'featured' tab on facebook. We will also post on the day!*

We are delighted to have this additonal zoom run by Ian to learn tips, tricks and all things aesophageal speech. All are welcome, non-verbal, those with a speech valve and those who use an electrolarynx. Please join us and give Ian the attendance he deserves!

Available to buy



Available now for sale at a discounted price to group members — **seat belt covers**.
As you may know, we do have a number of items available to buy; hats, car stickers, wristbands, medical alert cards, pin badges alarms and more..

Please contact ***lifeafterlary@gmail.com*** to purchase any merchandise.

We just want to say a huge **thank you** to our continuing sponsor S&J Cleaning Systems Ltd. They have been behind LaL since the beginning and they are always there for us — this time to buy the seat belt covers to allow our members a huge discount!

S & J Cleaning Systems Limited
Industrial Cleaning Equipment Supplies

Shout Out’s

This group continues to be one of the kindest corners of the internet — not because of how many people post, but because of how people show up.

Whether you’re commenting on someone’s first post, answering a question you once asked yourself, quietly reading along on a hard day, or sending support in a private message — **you matter here.**

So many of you offer reassurance, humour, honesty, and hope without even realising the impact it has. A single comment can change the tone of someone’s whole day. A simple “I understand” can make someone feel less alone.

Thank you for holding space for one another. For listening. For encouraging. For staying when things are hard.

This group is what it is because of you — every single one of you 🤍

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.

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

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