# NEWSLETTER

## INSIDE THIS ISSUE



### Receive the newsletter by email

Would you like to receive a digital copy of our monthly newsletter? Simply email contact@lifeafterlary.co.uk and we'll add you to our mailing list.

### Share your story

Every journey is unique. If you would like to share your experience, we'd love to hear from you. Your story could help and inspire others in the Life After Lary community.

### Fundraising

Are you taking on a challenge or holding a fundraising event? Let us know so we can help celebrate your achievements and share your fundraising efforts with our community.

### Have an idea?

We're always looking for new features, articles and content. If there's something you'd like to see in a future edition, please get in touch.

## It's our Birthday — 17th July!

A date that began without a plan, without a roadmap, without a team. Just two people chatting, **trying to survive something life-changing**, trying to find answers that didn't exist in one place, trying to make sense of a world that had suddenly become smaller and louder at the same time.

From that moment to this one, everything has grown. Life After Lary is no longer two people. **It is hundreds**. Patients. Partners. Families. Friends. Clinicians. Volunteers.
**People** who know what it means to lose a voice and rebuild a life.
**People** who show up for each other in ways that matter, quietly, consistently, without needing applause.

This birthday is not about celebration.
It is about gratitude.

Gratitude to every member who has joined us. For every person who has raised funds, shared a post, put up a poster, handed out a leaflet, or simply told someone "you are not alone".
For every person who has answered a question in the middle of the night, offered reassurance to a stranger, or shared their own story so someone else could breathe easier.
For every volunteer who gives their valuable time so freely, their care, their lived experience, their heart, without ever asking for anything in return.
For every clinician who has supported our work and helped us reach the people who need us most.
For every family member who stands beside someone through the hardest days and still finds the strength to help someone else. And for the companies that stand with us, the people behind them who choose to support our work, believe in our mission, and help us reach further.
S&J Cleaning Systems, Atos Medical, Severn Health, Sheffmed, Slo Drinks. And many more who give quietly, generously and without expectation.

Life After Lary was born from fear. It grew through courage. It stands today because of you, every single one of you.

This community is built on human connection. On the messages sent when someone is struggling. On the small wins shared that remind us progress is possible. On the honesty, the humour, the resilience, the stubborn hope that carries us all forward.

As we mark another year, we honour every journey, the easy days, the hard days, the days that change everything. We honour the people who have walked with us, the people we have lost and the people still finding their way.

Here's to another year of support, dignity, and community. Another year of showing up for each other. Another year of proving that even after the biggest loss, life continues, and it can still be full.

Life After Lary is more than a charity. It is a lifeline. It is a family. And it is only possible because of you. To every one of you who believes in our purpose, hope and vision, we thank you.

**Jon & Ian**

## Our Mission Statement

Life after laryngectomy is a journey of profound change, physically, emotionally, and socially.

**Our mission is simple:** to make sure no one walks that journey alone. We walk beside every person with compassion, community, and practical support, so that isolation turns into belonging and fear into strength.
At the heart of everything we do is an unshakable belief: no Lary should ever be alone.

Through **HEAL**, we bring our mission to life:
**H – Hope & Healing**
Reminding every survivor that their life, though changed, can still be full of meaning, creativity, and purpose.
**E – Empowerment**
Giving people the confidence, tools, and encouragement to take control of their recovery, their voice, and their future.
**A – Awareness**
Sharing clear information about recovery, speech options, managing complications, and mental health, while raising public awareness to break down stigma and misunderstanding.
**L – Life after Laryngectomy**
Building a safe, supportive community where experiences are shared, strength is found, and every person is celebrated for who they are, not what they have lost. We believe scars are not signs of weakness, but of resilience.
We believe that communication is more than a voice — it is presence, expression, and connection.
And we believe that with the right support, every person can discover strength in their new normal and live fully, with courage and hope.
**This is more than a charity. It is a lifeline, a family, and a movement.**
**Together, we HEAL.**
Life after Laryngectomy is here so no one walks this journey alone. Our mission, captured in **HEAL**, brings **H**ope, **E**mpowerment, **A**wareness, and **L**ife after Laryngectomy together to transform isolation into belonging and struggle into strength.

We believe every scar tells a story of resilience, and that life after surgery can still be full of meaning, creativity, and hope. Together, we **HEAL.**

## Feedback

I feel like I'm part of a family . You can openly express yourself with no judgemental views .. the hints & advice from personal experiences is a great help ... YOU DEFINITELY DO NOT FEEL ALONE

For me, this group, LAL, none of whom I have ever met, is truly awesome, they know everything, they've been where you and I are now and have helped me and my family more than anyone can understand.
Good luck going forward!
Follow my motto -
" if you don't know or you're unsure, post on LAL, sure as eggs is eggs, someone on the group will know "
Keep moving forward, you can absolutely do this!

This group should not be found by chance, it should be promoted and celebrated and encouraged by health professionals, afterall being a Laryngectomee isn't just about the physicalities!

Where do you start!
This group is the equivalent of an extra arm of the NHS, you can post something on here and you will get advice almost straight away, quicker sometimes than getting through to your doctors on the phone and certainly quicker than an appointment
I realise that it's only advice but it's also the reassurance that we all need, well done to us all.

I only found this group recently despite being nearly five years into my journey, oh how I wish it had been earlier, the support and advice is invaluable to both people who have had a Laryngectomy and partners/carers.
Well done to everybody who is involved.

## Claire's Story

When life changes in an instant, you never quite realise how much strength a person can possess until you witness it firsthand. My best friend has shown me a level of courage, resilience and determination that I will admire for the rest of my life.

I still remember the shock of her diagnosis. Before cancer entered our lives, we had spent the week before trying to convince ourselves there must be a simple explanation for her symptoms. In our truly ridiculous fashion, we even joked that perhaps she had somehow managed to get a pen lid stuck in her throat. Looking back now, the absurdity of that conversation makes me smile. We would have given anything for it to have been a pen lid.

Instead, we were confronted with the word cancer. I remember driving home with her after hearing the news, both of us crying, neither of us really knowing what to say. There were no words that could make sense of it. There was just fear, heartbreak and the overwhelming question of what would happen next.

Almost immediately, alongside the fear for her health, came the practical worries. There were endless forms to complete, appointments to arrange and financial concerns that seemed cruelly unfair at a time when all her energy should have been focused on getting well. Cancer doesn't just affect a person's body; it invades every part of life.

Then came the emergency surgery. Everything happened so quickly. Within days, she was facing a tracheostomy and I found myself having to tell her children and her father what had happened. It was one of the hardest things I have ever had to do. Watching the fear and worry on their faces broke my heart. We were all desperately trying to process what was happening while hoping she would come safely through it.

## Claire's Story

Later came the laryngectomy, a life-saving operation that changed her life forever. The voice I had known for so many years, the voice that had shared secrets, offered comfort and laughed alongside me through life's ups and downs, was gone. It felt impossible to imagine at first.

One of the hardest parts of loving someone through serious illness is wanting to be by their side every minute of every day. All I wanted was to sit beside her hospital bed and somehow make everything better. Yet life doesn't stop. The washing still needs doing, bills still need paying, work still demands attention and the everyday chores carry on as though nothing has happened. I remember feeling almost angry at the normality of it all. How could the world continue turning when someone I loved was fighting the biggest battle of her life?

But amid the fear and sadness, there was laughter too. There had to be. Somehow, over the 6 or so weeks between her two operations, her hospital room started to look less like a hospital room and more like a slightly underwhelming holiday apartment. What began as bringing in a few comforts from home soon escalated into what felt like moving house. Bags became suitcases. Suitcases became multiple trips to the car. Cushions, blankets, snacks, toiletries and enough supplies to survive a small apocalypse all found their way into her room.

Then there was the mini fridge. Somehow that little fridge became a symbol of our determination to make the situation feel just a little bit more normal. Looking back, it makes me laugh that while doctors and nurses were focused on life-saving treatment, we were focused on making sure she had cold drinks and her favourite snacks within arm's reach. It was ridiculous, completely unnecessary, and absolutely essential all at the same time.

And if I am honest, alongside the sadness, I have felt anger. Anger that this happened to her. Anger that someone so kind, caring and generous should have to endure so much. It feels unfair because it is unfair. There is no good reason why such a good person should be dealt such a difficult hand.

Yet through every challenge, every hospital appointment, every setback and every difficult day, she has continued to inspire everyone around her. She has faced fear, loss and uncertainty with extraordinary courage. There have been tears, frustrations and moments of grief for the life she once knew, but there has also been laughter, hope and an incredible determination to keep moving forward.

## Claire's Story

Cancer may have changed her voice, but it has never changed who she is. Her kindness, humour, strength and love for her family remain untouched. If anything, her spirit shines even brighter now.

I am endlessly proud of her. Proud of the battles she has fought, the challenges she has overcome and the determination she shows every single day. This journey has changed all of us who love her, but above all it has shown me what true strength looks like. My best friend is not defined by cancer or by the surgeries she endured. Her courage defines her, and I feel incredibly fortunate to walk beside her on this journey and to call her my friend.


## Monthly Zoom: Thursday 2nd July 6.30pm

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***.

**Joining instructions available in the 'featured' tab on Facebook and the Community page on the website. We will also post the link on the day!*

## July — what's happening this month

July will see another important and meaningful month for our community; we have our birthday to celebrate and then we have **World Head & Neck Cancer Day** at the end of the month.

Throughout June, we'll see more Food Fact Friday's, continue our weekly chek-in's and share some lovely feedback from our members. Our birthday week will be a feature you do not want to miss!

We will also cover **Samaritans Talk To Us Month**, **Sarcoma Awareness Month** and towards the end of the month, there is **Self-Care Day** and **International Day of Friendship** to look forward to.

Our Facebok group is a place for us to share, discuss, help and listen and I want to thank you all for your willingness to engae openly, to be vulnerable and to ultimately help others.

To every one of you: **thank you.** You are the beating heart of Life After Lary and we simply could not operate without you.

## Advertise with Life After Lary

**Do you have a business, service, or organisation you'd like to promote?**

Our monthly newsletter reaches over 1,100 members of the Life After Lary community, as well as their families, carers and healthcare professionals.

Whether you're a small local business or a national organisation, we'd love to help you reach an engaged and supportive audience. We offer a range of affordable advertising packages to suit every budget.

By advertising with us, you're not only promoting your business – you're also helping to support the work of Life After Lary.
For advertising rates, package options, or to discuss your requirements, please get in touch at contact@lifeafterlary.co.uk

## Kieron and Tricia:
## Florence: A Memorable Holiday Adventure After Laryngectomy

For many people who have undergone a laryngectomy, travelling abroad can seem daunting. Questions about communication, medical supplies, airport security, and coping in unfamiliar surroundings can make the prospect of a holiday feel overwhelming.

Starting Close to Home

That's exactly how our journey began. My wife and I started with a few breaks in the UK, giving me the chance to rebuild my confidence and get used to travelling again. Think of it as a "practice run" — with the bonus of decent tea and no language barriers. Once that confidence returned, we decided it was time to push the boundaries a little further. Our destination? Florence, Italy. I'm pleased to say it was more than worth it. Florence, the capital of Tuscany, is renowned for its stunning architecture, rich history, and world-famous art. From the magnificent Duomo to the picturesque Ponte Vecchio, every corner of the city offers something special. As a laryngectomee, I was excited by the opportunity to explore this beautiful destination with my wife while also testing my independence. The trip proved that, with a little planning and confidence, travel can still be both enjoyable and rewarding.

Planning Ahead (and Packing... and Packing a Bit More)

Preparation is often the key to a smooth journey. Before travelling, we arranged comprehensive travel insurance and ensured that my medical condition was declared. I also bought a treadmill and used it regularly to build up my fitness and stamina before the trip. We packed more stoma supplies than I expected to need and divided them between my hand luggage and checked baggage. I also took my medication, nebuliser, and a medical information letter explaining my laryngectomy, which our Speech and Language Therapist had provided. We thought this might be useful during airport security checks, but in fact no questions were asked. Simply knowing we had everything in place provided reassurance throughout the journey. We flew from Manchester to Pisa and then travelled by train to Florence. This added an extra element of adventure to our trip. The train journey was comfortable and gave us the opportunity to enjoy the beautiful Tuscan countryside as we travelled through the region.

# Kieron and Tricia:
# Florence: A Memorable Holiday Adventure After Laryngectomy

Communication and Confidence

Communication was much easier than I had anticipated. Everyone we met spoke excellent English, and people were patient, understanding, and willing to help when needed. One example that stands out was during a guided tour of the Accademia Gallery. I needed to clear mucus from my voice prosthesis, and our tour guide immediately came to my assistance. She found us a quiet room away from the crowds where I could deal with the situation comfortably and privately. Her kindness and understanding turned what could have been an awkward moment into a completely stress-free experience. Whether using my voice prosthesis, writing notes, or showing information on my phone, I found people friendly and accommodating. Their warmth helped make every interaction a positive experience.

Discovering Florence

Some of the highlights of our holiday included visiting Florence's historic landmarks. Standing beneath the impressive dome of the Cathedral of Santa Maria del Fiore was breathtaking, the inside was stunning, and exploring the Accademia Gallery to see Michelangelo's David was truly unforgettable. We also visited Piazzale Michelangelo, where the spectacular panoramic views across Florence provided the perfect opportunity to appreciate the beauty of the city. Wandering through the narrow streets revealed charming cafés, artisan shops, and hidden squares, while the relaxed pace of the city allowed plenty of opportunities to stop, rest, and simply enjoy the surroundings. Oh and how can I forget to mention the Gelato bellissimo.

Managing the Practicalities

Of course, travelling with a laryngectomy requires some additional awareness. Staying hydrated, protecting the stoma from dust and heat, and ensuring easy access to supplies were important considerations. There was a great choice of restaurants and I had no problem finding something to eat. In fact I was spoilt for choice. Fortunately, these simple measures allowed me to enjoy each day without significant difficulties. We walked miles every day exploring Florence, and all the preparation on the treadmill certainly paid off.

## Kieron and Tricia:
## Florence: A Memorable Holiday Adventure After Laryngectomy

A New Sense of Freedom

This holiday was a powerful reminder that a laryngectomy does not have to limit life's adventures. While challenges may arise, many can be overcome with preparation, determination, and a positive attitude. Florence offered not only beautiful sights and memorable experiences but also a renewed sense of confidence and achievement. During the flight, I turned to my wife and said, "I never thought I would be doing this again." That moment summed up the whole experience. Before my laryngectomy, international travel was something I took for granted. Afterwards, it felt uncertain. Yet here I was, heading to Italy, ready to create new memories and prove to myself that life could still be full of adventure. For anyone considering their first trip abroad after a laryngectomy, my advice is simple: plan carefully, take the necessary precautions, and don't be afraid to explore. The world remains full of wonderful places waiting to be discovered, and Florence is certainly one of them. Travel is about creating memories, embracing new experiences, and enjoying life to the fullest. This holiday did exactly that, proving that life after laryngectomy can still be filled with exciting journeys and unforgettable moments. A laryngectomy may have altered the route you take, but it does not have to limit the destinations you can reach. Whether your dream is a city break, a beach holiday, a cruise, or a long-haul adventure, careful planning and self-confidence can help make it a reality. The passport is still yours. The opportunities are still there. The journey continues.

## Jon Organ — Throat Cancer Foundation


At the Throat Cancer Foundation, we like Jon Organ.
That is not a difficult sentence to write. Jon is one of those people who has taken something deeply personal, difficult and life-changing, and turned it into something that helps other people.
Through the charity he founded, Life After Lary, he supports people who have had a laryngectomy — people whose lives have been changed by surgery, treatment, recovery and everything that comes afterwards. He offers something that cannot be manufactured in a leaflet or delivered in a clinic appointment: lived experience.
That matters.
A laryngectomy is not simply an operation. It can change how someone breathes, speaks, eats, sleeps, socialises and sees themselves. It can affect confidence, relationships, independence and identity. It can leave people feeling isolated, frightened and unsure what life is supposed to look like now.

## Jon Organ — Throat Cancer Foundation

That is where people like Jon are invaluable.
He can say, "I know." Not as a polite phrase. Not as a well-meaning guess. But because he really does know.
He knows what it means to rebuild life after losing your natural voice. He knows what it means to adapt to a stoma. He knows the practical realities, the frustrations, the dark humour, the awkward public moments, the small victories and the enormous courage it takes to keep going.
So yes, we like Jon.
We like him very much.
But here is the slightly awkward bit.
We hope you never need to meet him.
Not because Jon is not worth meeting. He absolutely is. But because the circumstances that bring people to Life After Lary are circumstances we want fewer people ever to face.
At the Throat Cancer Foundation, our work is centred on prevention, awareness and early diagnosis. Our aim is not only to support people after throat cancer has changed their lives, but to help stop more people reaching that point in the first place.
That is why we talk so much about knowing the signs.
A persistent sore throat. Hoarseness or voice changes that do not go away. Difficulty swallowing. A lump in the neck. Ear pain. Unexplained weight loss. Symptoms that linger, return or do not feel right.
Too often, people wait. They hope it will clear up. They assume it is nothing. They do not want to bother the GP. They explain symptoms away.
And sometimes, by the time they are seen, the cancer has already done more damage than it needed to.
That is what we want to change.
Early diagnosis can change treatment options. It can change outcomes. It can change quality of life. In some cases, it can mean less aggressive treatment and fewer life-changing consequences. Prevention and earlier diagnosis are not abstract ideas. They are the difference between someone keeping more of the life they know and having to rebuild it from the ground up.
That is why Jon's work matters so much — and why our work matters too.
Life After Lary is there when someone has already gone through the storm. It helps people adjust, recover, connect and believe that life can still be meaningful, funny, purposeful and full.
The Throat Cancer Foundation is working further upstream. We want more people to understand throat cancer before diagnosis. We want more people to recognise symptoms earlier. We want HPV and throat cancer discussed more openly. We want better public awareness, better information, and fewer late diagnoses.
This is not a competition between charities.
It is a pathway.

## Jon Organ — Throat Foundation

People need support before diagnosis, during treatment, after treatment and sometimes for the rest of their lives. No one organisation can do all of that alone. But between us, we can make the pathway less lonely, less confusing and, where possible, less brutal.
Jon helps people live after laryngectomy.
We want fewer people to need a laryngectomy.
Both things can be true.
And perhaps that is the whole point.
We are grateful Jon exists. We are grateful Life After Lary exists. We are grateful that people who have had a laryngectomy can find someone who understands the reality of that life from the inside.
But the best outcome is not needing Jon's help at all.
The best outcome is someone recognising symptoms early, speaking to their GP, being referred, being diagnosed sooner and receiving treatment before cancer takes more than it has to.
So yes, we like Jon Organ.
We admire what he is building. We respect the legacy he is creating. We are glad people have him when they need him.
We just hope far fewer people ever do.
**Know the signs. Don't wait. If something does not feel right, get it checked.**

**www.throatcancerfoundation.org**

## Radiotherapy — Practical Tips

A Note About These Tips
The following tips have been kindly shared by members of the Life After Lary community who have experienced radiotherapy themselves. They are based on personal experiences and what individuals found helpful during their treatment. Everyone's experience of radiotherapy is different, so these suggestions may not be suitable for everyone. They are intended to complement, not replace, the advice and guidance provided by your consultant, specialist nurse, radiographer, or wider healthcare team.
**If you have any concerns about your treatment or symptoms, always speak to your medical team.**

**Firstly, Be Kind to Yourself**

- This treatment is tough, none of this is your fault.
- You're doing something incredibly hard, and you're doing it one day at a time.
- Lean on others. No one should go through head & neck radiotherapy alone.

# Radiotherapy — Practical Tips

**Hydration & Mucus Management**

- Sip water constantly; dryness and thick mucus are normal and can be intense.
- Keep a bottle with you at all times; small sips are easier than big gulps.
- Steam or nebulise daily to loosen mucus and make breathing easier.
- Saline nebulisers can help soften crusts and reduce coughing.
- Keep tissues, wipes, and a small bin or bag nearby; mucus can become overwhelming.
- If mucus becomes sticky or stringy, warm drinks or steam can help break it down.
- Sleeping upright can reduce overnight mucus pooling.

**Eating, Swallowing & Nutrition**

- Expect taste changes; metallic, bland, or "everything tastes wrong" is common.
- Eat what you can, when you can; don't wait for mealtimes.
- Soft, moist foods (yoghurt, custard, mashed potato, soups, smoothies) are easier to swallow.
- High-calorie drinks can help maintain weight when eating becomes difficult.
- Avoid spicy, acidic, or crunchy foods once soreness begins.
- Keep food lukewarm; hot or cold can trigger pain.
- If swallowing becomes painful, tell your team early; they can help with pain relief and support.
- Don't feel guilty if your diet becomes repetitive; survival mode is normal.

**Skin Care & Neck Care**

- Use only the creams recommended by your radiotherapy team.
- Apply moisturiser gently; don't rub the treated area.
- Avoid shaving the treated area; use an electric trimmer if needed.
- Keep the neck out of direct sunlight during treatment and for months after.
- Wear soft, loose clothing to avoid friction.
- Expect redness, tightness, and sometimes peeling; this is normal but should be monitored.

**Mouth Care & Oral Comfort**

- Brush gently with a soft toothbrush twice a day.
- Rinse regularly with saltwater or bicarbonate solutions.
- Avoid alcohol-based mouthwashes; they sting and dry the mouth.
- Keep lips moisturised; they can crack easily.
- Ice cubes or cold water can soothe a sore mouth.
- If ulcers appear, tell your team; they can help manage the pain.
- Dental hygiene is crucial; radiotherapy increases long-term dental risks.

# Radiotherapy — Practical Tips

**Breathing & Airway Tips**

- Congestion and mucus can make breathing feel harder; steam helps.
- Gentle coughing or huffing techniques can clear secretions without straining.
- With a tracheostomy or laryngectomy, humidification becomes even more important.
- Keep your airway equipment clean and ready; fatigue makes everything feel harder.
- Clear your trachea before lying down.
- If you need to clear the table, tell the team.

**Fatigue & Energy Management**

- Radiotherapy fatigue is unlike normal tiredness; it's heavy and unpredictable.
- Rest whenever your body asks; don't push through.
- Short naps are better than long ones; they prevent grogginess.
- Gentle movement (short walks, stretching) can help maintain energy.
- Accept help with cooking, cleaning, and errands; this is not the time to be a hero.

**Pain, Medication & Symptom Control**

- Take pain relief regularly, not just when the pain peaks.
- Tell your team early if swallowing becomes painful; they can adjust medication.
- Don't wait until you're struggling; early intervention makes a huge difference.
- If your neck feels tight, gentle stretches (approved by your team) can help.
- Keep a small notebook or phone note to track symptoms; it helps your team support you.

**Mental Health & Emotional Support**

- Treatment can feel overwhelming, that's normal.
- Mood swings, frustration, and tears are common side effects of both treatment and exhaustion.
- Stay connected with people who "get it." Peer support is powerful.
- Let family and friends know what you need (and what you don't).
- Celebrate small wins, finishing a meal, getting through a session, taking a walk.
- Consider a countdown calendar, seeing how far you have come helps.

**Communication With Your Care Team**

- Report changes early, pain, swallowing issues, weight loss, skin reactions.
- If you need help due to the mask and claustrophobia, let the team know.
- Ask questions, no concern is too small.
- If something feels wrong, say so.
- Keep your team updated on what you're eating and drinking.
- If you're struggling emotionally, tell them support exists.

## Radiotherapy — Practical Tips

**Practical Daily Tips**

- Bring water, tissues, and lip balm to every radiotherapy session.
- Wear comfortable clothes, you'll be lying still for a while.
- Keep a small bag with essentials, moisturiser, wipes, pain relief, a soft scarf.
- If you are verbal, expect your voice to change, loss of voicing is normal.
- Plan simple meals for days when you're too tired to cook.
- Keep your phone charged, you'll spend time waiting.
- Bring a reading book or puzzle book.
- If you can, arrange transport help for the tougher weeks.

## We're Proud to Be Registered with the Fundraising Regulator

We're delighted to announce that Life After Lary is now registered with the Fundraising Regulator. This demonstrates our commitment to honest, transparent and accountable fundraising, following the highest standards set out in the Code of Fundraising Practice. We hope this gives our members, supporters and donors continued confidence that every donation is handled with care and integrity as we work to support people living after laryngectomy.


Every donation, no matter the size, helps us continue supporting people living after laryngectomy and their families. Your generosity enables us to provide peer support, resources, events, our monthly newsletter and much more.

If you would like to support the work of Life After Lary, you can make a donation through our website by visiting: **www.lifeafterlary.co.uk/donate**

Thank you for helping us make a difference.

## Time to talk fundraising!
## The Big LaL Dog Walk – Summer 2026

This summer, Life After Lary is inviting supporters from across the UK to take part in The Big LaL Dog Walk 2026 – a fun, flexible fundraising challenge that anyone can join.
Running from 1st June to 31st August 2026, the event is all about getting outdoors, enjoying some fresh air and raising awareness and funds for people living life after a laryngectomy. The best part? You can take part wherever you are and in whatever way suits you. Whether it's a stroll around your local park, a walk along the beach, a hike in the hills, a wander through your neighbourhood, or even laps around your garden, every step counts.

You can walk one mile, 5km, 10km, or simply challenge yourself to complete as many walks as possible throughout the summer.
And despite the name, you don't even need a dog to join in! Bring your dog, borrow a dog, walk with friends and family, or simply head out on your own. The goal is to come together as a community and support a cause that makes a real difference.
Participation is free, although we encourage everyone taking part to raise sponsorship or make a donation to support the work of Life After Lary. Participants will be able to fundraise through our central fundraising page, with the option to create their own linked fundraising pages if they wish.

## Pen Friend Service

A new postal pen friend support service has been launched to help people preparing for, or recovering from, a laryngectomy. To help them feel less isolated and more supported during a life-changing time.
Life After Lary, a registered charity in England and Wales, has introduced **The Pen Friend Support Service** to connect patients, families and carers with volunteer correspondents who understand the laryngectomy journey through lived experience.
Many people facing laryngectomy surgery experience loneliness and anxiety, particularly those who do not use the internet or social media. The new service offers a simple and personal alternative through written letters, providing encouragement, reassurance, and shared understanding.
The service is open to patients preparing for surgery, people adjusting to life after a laryngectomy and family members or carers who would value one to one support. Participants are matched with a suitable pen friend who can offer steady companionship and practical insight through regular correspondence.

A spokesperson for the charity said:
“Recovery and adjustment after a laryngectomy can feel overwhelming, especially when someone feels cut off from others who understand what they are going through. Written letters are personal, private and can be reread whenever support is needed. We want people to know they are not alone and that someone is there to listen.”

The Pen Friend Support Service is confidential and free to access. It is designed especially for people who prefer traditional written communication or who are not comfortable using online support groups.

Anyone interested in joining the service, either to receive support or to volunteer as a pen friend, can write to:

**Life After Lary**
90 Brabazon Avenue
Wallington
Surrey
SM6 9ET
United Kingdom

# Press Release:
# Life After Lary — Built From Adversity, Driven by Lived Experience

Two men who should never have met, did. Not through convenience. Not through circumstance. But through adversity, the kind that rips the floor out from under you and forces you to rebuild from the ground up.

We came from different lives, different families, different stories. But we shared one undeniable truth: laryngectomy doesn't just change a person, it changes everything.

In the quiet after surgery, in the shock, in the endless questions no one prepares you for, we found each other. Not because we were looking for friendship, but because we were looking for someone who finally understood.

And from that meeting, raw, honest, and completely unplanned something began.

What started as two men steadying each other became a support group. What started as a support group became a community. And what started as a community became a registered charity: Life After Lary, built entirely from lived experience, not theory.

**Why We Exist**
We didn't set out to build an organisation. We set out to make sure the next person never had to feel the fear we felt. The fear of not knowing how to breathe, speak, sleep, shower, travel, or simply be in the world again. The fear families feel when they try to be strong, while quietly falling apart inside. The fear that clinicians see, but do not always have the time to sit with and unpack.

We knew that gap.
We lived in it.
And we decided to fill it.

**What Peer Support Really Means**
Peer support is not a leaflet.
It is not a one-off conversation.
It is not a service you tick off a list.

Peer support is lived experience, shared at the exact moment someone needs it most.

# Press Release:
# Life After Lary — Built From Adversity, Driven by Lived Experience

**Understanding**
When someone speaks to us, they are not talking to a textbook or a theory.
They are talking to people who have lived the tubes, the silence, the fear, and the long, hard work of rebuilding.
People who know the questions you are too afraid to ask out loud.

**Calm**
Hospitals are busy places. Clinicians are stretched. Families are overwhelmed.
We step into that space with clarity, truth, and reassurance, the kind of steady, calm presence that helps someone find their feet when everything feels unsteady.

**Practical Guidance**
How to clean. How to speak. How to shower. How to sleep. How to travel. How to live again. These are the things you can only learn from someone who has actually done it. We share that knowledge freely, because no one should have to work it all out for themselves.

**Connection**
Isolation is one of the deepest wounds after laryngectomy. We rebuild community, online, in person, in hospitals, in homes. People quickly realise: I am not alone. I am not broken. I am not the only one.

**Hope**
Hope that comes from someone who has walked the same road carries a different weight. It is believable. It is grounded. It is earned.

**The Lives We Touch**
Every week, we see the real impact of this work:

- A patient who thought their life was over learns they still have a whole life ahead of them.
- A partner who has held everything together finally takes a breath and exhales.
- A family, confused by tubes, silence, and fear, suddenly understands what is happening, and how to help.
- A clinician finds support for a patient they care deeply about, but simply cannot spend an hour sitting with.

We have supported people in hospital beds, in recovery rooms, in their own homes, in moments of crisis, and in moments of quiet triumph.

# Press Release:
# Life After Lary — Built From Adversity, Driven by Lived Experience

We have watched people go from terrified to steady. From isolated to connected. From surviving to truly living.

This is the work. This is the impact. This is exactly why Life After Lary exists.

Two Men, One Mission

We did not choose adversity. But we chose exactly what to do with it.

Two men who met in the hardest chapter of their lives.
Two men who refused to let others walk this road alone.
And a charity that now reaches across the UK, one patient, one family, one moment at a time.

Life After Lary is not built on theory. It is built on truth. On lived experience. On the unwavering belief that no lary should ever feel alone.

And that belief, simple, human, and unbreakable, is what drives us still.

## A long time loving Larys!!!
## Miriam Mitchell
## Speech & Language Therapist

My mum was a health visitor, so I spent school holidays when she was working in the clinic 'helping' (you cant do this now!!) This lady had a great job sitting on the floor and playing with children making silly noises and I thought that's the job for me...a speech & language therapist.I spent some days also observing an 'adult' therapist and liked that too and duly applied. I wasn't bright enough to get in straight away so did a Psychology degree and then did the MSC equivalent then to qualify as a speech therapist in 1990. I know, 36 years as a speechie and I don't look a day over 40!

During my uni course I had a placement at Orsett Hospital with a fabulous therapist and saw my first laryngectomee. An inspiring man with amazing oesophageal speech who had just gotten on with his life post-surgery and was so helpful and supportive of my learning journey. I was hookedI Obviously laryngectomy doesn't fill a whole caseload when you first start working, but after my first year in a joint paeds and adult post I was lucky enough to move to 'adults' full time and began to specialise in Head & Neck cancer patients.

My first experience of SVP was a ENT consultant at the  hospital I was working at ringing me to ask me to come down to ward to 'sort out a patient with one of the new speaking valves'. I had had some lectures about them but not seen any patients so went down to get info before calling the therapist who had given the lectures – Alison Perry at Charing Cross Hospital. She was amazing and invited me to come to London the next day to spend the day with her, experience in-patient laryngectomy and learn about valves including a chance to size and replace one. In those days training was much more flexible and informal – she continued to give me telephone support for many weeks until I could attend a formal course to add to the knowledge she had given me – including recognising that the valve that had been put in had numbers on it and so was a sizer!.

My first 2 laryngectomees became family friends (even coming to my wedding 3 years later) and we all started the Romford Laryngectomy Club together – perversely nicknamed "SHOUT" by them. Bob had been a professional singer and with his 18 piece dance orchestra supporting us, we ran dances twice a year and they donated their raffle monies from other performances monthly – in the first 15 years raising £50,000. Bob continued to sing at every fund raiser using his SVP, songs such as 'Georgia on my Mind', 'Hello Dolly' and my favourite 'Its a Wonderful World'. We took the club members on

## A long time loving Larys!!!
## Miriam Mitchell
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weekends away, days out, and funded equipment for patients and training for staff working with laryngectomy. Sadly Bob died and the dance band eventually stopped supporting us and in the last 15 years we have raised less, through quizzes and sponsored events, but the ethos of larys supporting other larys and a couple of professionals (usually me and our clinical nurse specialist) has continued- 35 years this year! We even had Cheryl Baker from Bucks Fizz as our patron for many years as her cousin was one of my patients.

When I moved jobs to a neighbouring Trust the club came with me and we morphed into the South Essex Laryngectomee Support Club, covering mainly the Basildon, Thurrock, Brentwood and Southend areas, but anyone and everyone is welcome to come along.

I have to say that I love my job, both as a therapist in Head & Neck and helping with generic adult SALT patients, as needed, within my team, and to a lesser extent leading the SALT service at Basildon Hospital and having the chance to influence service development etc. It has given me fabulous opportunities over the years – inc taking SVP equipment and training to Islamabad and Peshawar in Pakistan through sponsorship of Blom Singer then (2006) and the encouragement of my ENT Consultant. And now as I look at retirement, I know that clinically there will be therapists coming behind me to take up the reins of therapy, but more importantly having a wonderful laryngectomee and friend in Doug Sier who is taking up the reins of leading our club into the 21st century and who will push the club to be "for patients, and run by patients", which is what a support group should be.

I have had a wonderful career, worked with wonderful patients, and made many friends across the years, but laryngectomy has been my passion – the strength, resilience, adaptation and 'bloody mindedness' of you all to overcome such a huge life changing operation never fails to surprise and inspire me.

# 100km, Two Walkers, One Voice: Just Keep Moving Forward
## Doug Sier

The London to Brighton 100km Ultra challenge wasn't about finishing fast for me. It wasn't about time at all. It was about facing that moment when every fibre of your body is telling you to stop and choosing to keep going anyway.

People have asked me why I decided to take on something like this.

The truth is, it started with my sister-in-law Gemma. She had completed this challenge before, solo, and wanted to do it again, but this time with someone else. She asked me if I'd join her. At the time, I was very unfit and unhealthy, and I very nearly said no.

Instead, I set a condition. If we could manage a 15 mile walk within a couple of weeks, and build up to completing a third of the total distance before the registration deadline, then I'd commit to it. Needless to say, we hit those milestones without too much trouble, and suddenly this idea became very real.

I think it's important to say that I'm not some ultra-fit athlete. When I first decided to take on this challenge, I was very overweight and hadn't been in the gym since my total laryngectomy over four years ago. Since then, I've lost around 26 pounds and have been back in the gym for about six months. This challenge didn't just test me, it helped change my life.

A big part of my motivation is also showing what's still possible after having a laryngectomy and becoming a neck breather, life changes in many ways, but I'm determined not to let it define or limit what I can do.

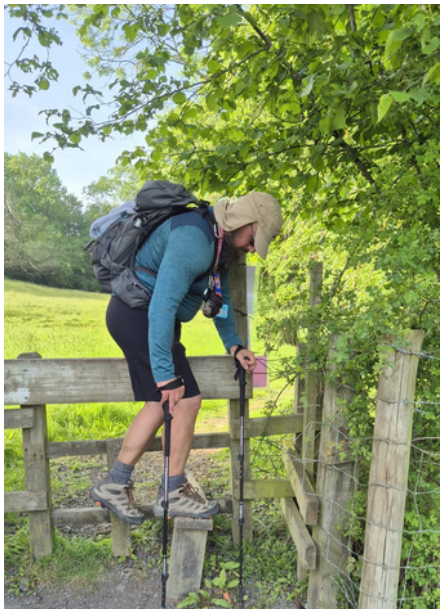
I also wanted to raise much-needed funds for SHOUT, the South Essex Laryngectomee Support Group. They've supported me since my surgery, and I'm now starting to take on more responsibility within the group as we plan for Miriam's retirement after nearly 35 years of running it. This felt like a way of giving something back to a community that has given me so much.

We had trained for this. Consistently.

# 100km, Two Walkers, One Voice: Just Keep Moving Forward
## Doug Sier

Two walks a week at around seven miles, and longer walks whenever we could fit them in. We built up gradually, 14 miles, then 21, then 32, eventually working up to a full return route of 42 miles. A lot of that training followed railway lines, just in case we needed an exit. That safety net helped us push further each time, giving us the confidence to go a little bit further than last time.
But training and reality are two very different things.

Most of our training was done in the colder months. We hadn't prepared for hot weather and certainly not a heatwave. Nothing quite prepares you for what that 30 degree heat does to a challenge like this. It changes everything. Distances feel longer. Energy drains faster. What would normally feel manageable suddenly becomes a real test.
My biggest concern going into it was my feet, what the heat and sweat were going to do to them. All of our training had been in cooler conditions, and I had new boots and specialist socks that I couldn't suddenly change at the last minute.



# Staying Safe in Extreme Heat After a Laryngectomy
# Community Guidance from Life After Lary

Hot weather brings challenges for anyone living with a laryngectomy. Because we breathe directly through the stoma, we lose the natural cooling, filtering, and humidifying system the nose and mouth normally provide. In high heat, the airway can dry out quickly, mucus can thicken, and sweat can cause baseplates to lift. This guide focuses on what matters most: protecting your airway and protecting your skin.

**1. Looking After Your Airway**
Hot, dry or humid air affects your lungs more than you might expect.
**Keep your HME on**
Even when you feel hot, removing it lets unconditioned air hit your lungs. Lower resistance cassettes (like "Go" or "Sport" styles) can make breathing easier in warm weather.
**Prevent crusting and mucus plugs**
Heat thickens mucus fast. Using your nebuliser more often or adding extra sterile saline sprays helps keep things loose.
**Stay well hydrated**
Water is your best tool for keeping secretions thin and easier to clear. Protect against dust, pollen and insects  Summer air carries more irritants. Your HME or a stoma bib acts as your filter — don't leave the stoma uncovered outdoors.

**2. Caring for Your Skin & Baseplate**
Sweat is the biggest enemy of adhesive stability.
Manage sweat to prevent leaks.
Clean and dry the skin fully before applying a new baseplate. Barrier wipes (like Cavilon) can help adhesives cope with perspiration.
Carry spares when you're out
Hot weather often means more frequent changes. A small kit with baseplates, wipes, adhesive and a mirror can save the day.
Give the skin a break when needed
If the skin becomes sore, switching temporarily to a lary tube/button or a fabric stoma bib can help it recover.

**3. Sun & Heat Protection**
If you've had radiotherapy, your neck skin is especially vulnerable. Sunburn in this area can be severe and slow to heal.
**Protect the neck from direct sun.**
A wide-brimmed hat or neck-covering clothing helps. Apply sunscreen carefully around, but not on the stoma.
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# Staying Safe in Extreme Heat After a Laryngectomy Community Guidance from Life After Lary

**Avoid aerosols near the stoma**
Spray sunscreens, deodorants and insect repellents can be inhaled easily. Apply them away from your neck.

**Cool down safely**
Use a cool, damp cloth on your forehead, arms or upper back. Keep moisture away from the stoma area.

**A Final Word**
Heat can make life after laryngectomy feel harder, but with the right habits, you can stay safe, comfortable and confident all summer long. As always, our community is here for you, whether you're managing the heat, navigating recovery, or supporting someone you love.

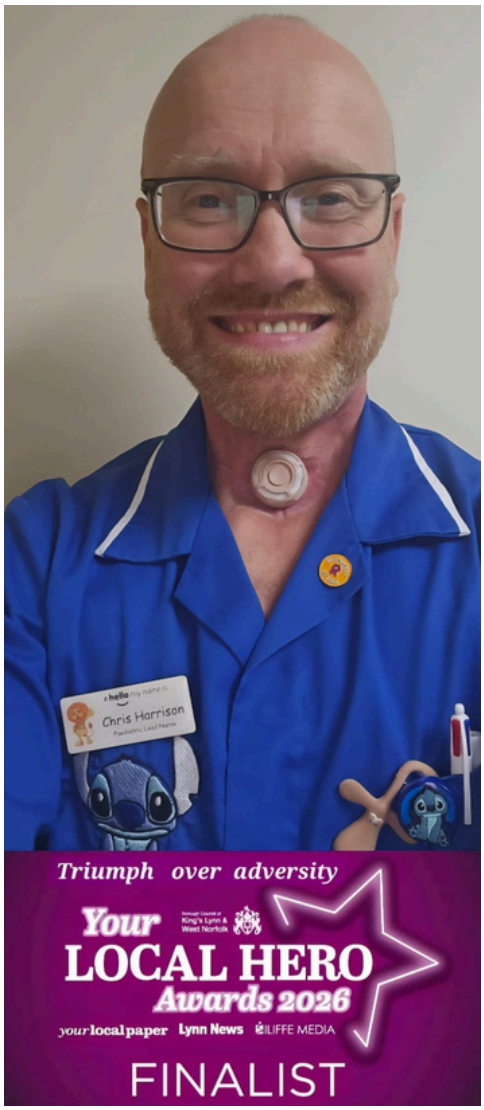
lifeaffterlary.co.uk

# Local Hero Triumph Over Diversity Award 2026

We celebrate life after lary volunteer and Norfolk group leader Chris Harrison on winning a recent award at

**Your Local Paper Local Hero Triumph Over Adversity Awards 2026 ....**

Chris said, "To be nominated was a lovely gesture, shortlisted was an honour and to win was a total shock, but a good one. So many worthy finalists, each and every one. I feel so immensely proud of what I've overcome and continue to deal with, and very happy that I am back at work doing a job I absolutely love. Helping others help care for their children is a blessing and a privilege. The children we help care for are truly the heroes, and I dedicate this award to every single one I've ever helped care for, and continue to help care for. I work with such a great team. Cancer threatened to take my voice, but now I use my voice to help others facing head and neck cancer, helping Lifeafterlary UK. laryngeal cancer is a voice and support for others, both personally and professionally, about living with a laryngectomy. A massive thanks for my nomination, thank you panel for choosing me as your winner, and thank you to all the people, work friends and family who came to support me, including Atos Care UK, who provide the best support service for people with a neck stoma, specifically laryngectomy or tracheostomy."




**So please join us in saying a massive congratulations to Chris and thank you for all you do.**

## 5,000 views and growing

This month, the Life After Lary passed 5000 website views! For a small, new charity built entirely from lived experience, that number means something real. It means people are finding us. It means people are looking for support, for answers, for reassurance and they're landing in a place made for them.

Every visit is someone reaching out. Every click is someone trying to understand what comes next. Every return is someone feeling a little less alone.

And none of this would be possible without Lauren.

Lauren oversees and designs our website with care, clarity, and heart. She makes sure every page is accessible, every update is accurate, and every person who arrives feels welcomed, not overwhelmed. Her work sits quietly in the background, but its impact is huge. We are deeply grateful.

5000 views is a milestone. But it's also a reminder of why we exist and who we're here for. Here's to the next 5000, and to the people who make this community stronger every day.

## Facebook safety

We've recently had a few scammers attempt to join the group and post links to unofficial merchandise, such as t-shirts, or send private messages to members.

Please be vigilant. Be cautious about accepting friend requests from people you don't know, even if they appear to have mutual connections through the group. If you receive a private message from someone you don't recognise, especially if they're trying to sell something, asking for personal information, or encouraging you to click on links, it's best to ignore, block and report them.

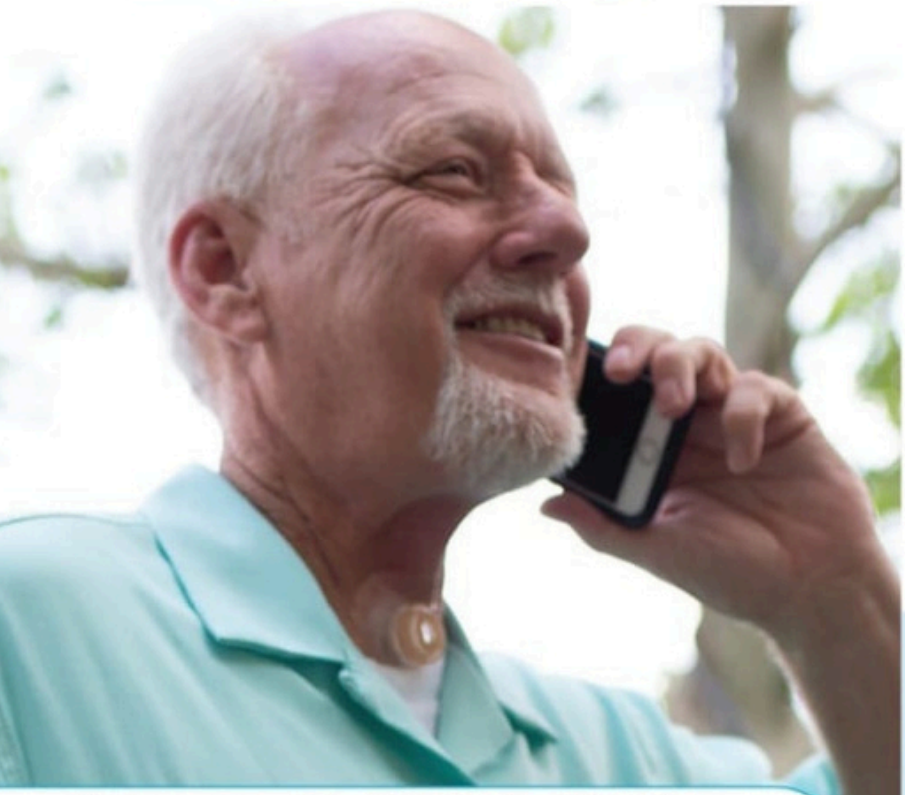
Life After Lary will never ask you for personal or financial information via private message, and any official merchandise or fundraising will always be shared by the admin team in the group.

If you ever see a suspicious post, comment or message, please report it to the admins as soon as possible so we can remove it and help keep our community safe.

Thank you for helping us look out for one another.

INTRODUCING

# Blom-Singer®
# SpeakFree™ HME
## Hands Free Valve



Register on our Laryngectomy SpeakEasy Forum:
www.severnhealthcare.com/community/forum/11-the-speakeasy/
to watch the SpeakFree™ HME video

Whatever your activity or lifestyle. A simple, disposable hands free HME that fits with your active life

AVAILABLE ON PRESCRIPTION

*For more information and to see our extensive range of Blom-Singer® products, please visit our website:*

## It's simple. Your HME and hands free speaking valve, all in one.

The Blom-Singer® SpeakFree™ HME Hands Free Valve is the first heat and moisture exchange (HME) cartridge with a single-use, fully integrated and adjustable hands free valve.

**Features:**

- **Choose your flow and go**
  Two simple choices for airflow resistance:
  ClassicFlow® : BE 1090EZ
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- **Truly innovative**
  One adjustable valve with hands free speech that adjusts from light to extra strong, doing the work of multiple hands free competitor devices
- **Freedom of choice**
  Attaches to Blom-Singer® adhesive housings or a Blom-Singer® StomaSoft® Laryngectomy Tube.

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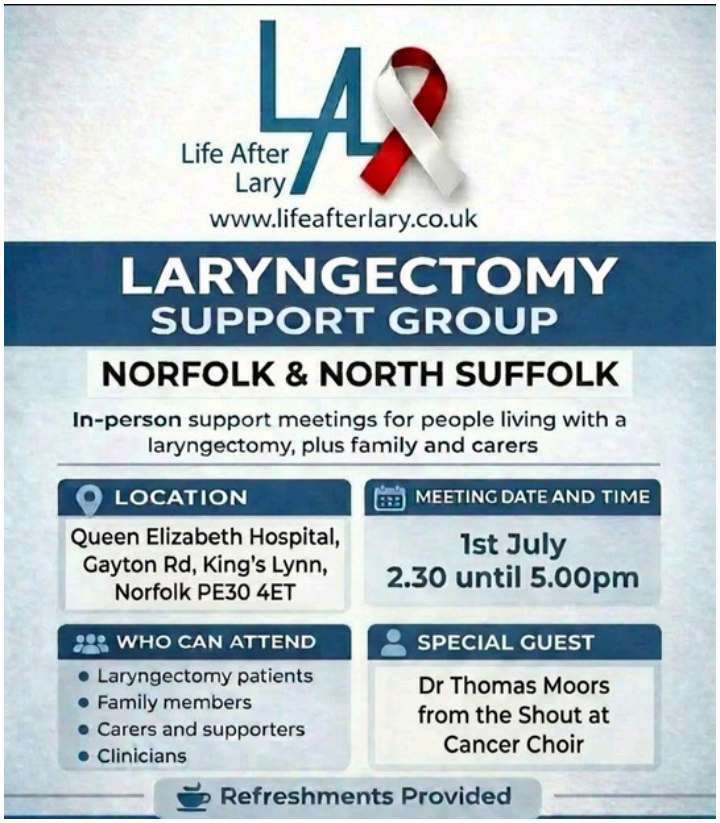
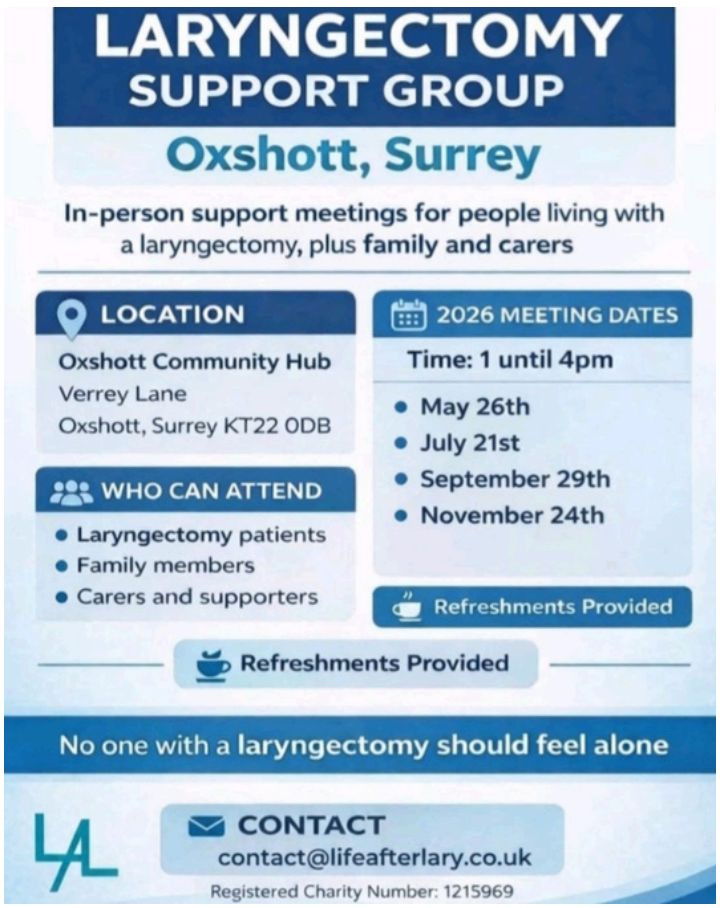
## Dates for the Diary - Future Meet-up's








## Calling all Laryngectomees and supporters

**Severn Healthcare are delighted to invite you to:**

# An audience with Jon Organ Laryngectomee and founder of Life After Lary

**Venue**

**Pontyclun Rugby Club**

Llantrisant Road,
Pontyclun
CF72 9DQ

**Date / Time**

Friday 11th September

10:00am – 12:00pm

If you want to find out more about the charity follow this link:
https://www.lifeafterlary.co.uk/

For further information/to register please contact:
**Menna Payne**
Wales, Clinical Specialist, Speech & Language Therapist
07810 550765 | Menna.Payne@severnhealthcare.com

# Holiday Time!

**Life after Lary** have struck a deal with a holiday park on the **Kent South Coast at New Romney.**

There are 4 beautiful types of accommodation to choose from:

- 2 Lodges with kingsize bedrooms, sleeping 6
- 1 caravan sleeping 8 and
- 1 caravan sleeping 6

The accomodation is dog friendly and the park is across the road from a golden sandy quiet beach. There is a fishing lake and club house which boasts entertainment and an indoor swimming pool.

A perfect relaxing break, ideal as a get away to rest after treatments.

Contact Samantha Gilby — samgilby@hotmail.co.uk / 07949 382819 **quoting Life After Lary for 10% off!**

## With heartfelt thanks

Over the past few months, we have been incredibly touched to receive memorial donations made in honour of loved ones.
Whether through funeral collections or donations in lieu of flowers, these gestures mean so much — not just in support of Life After Lary, but as a lasting tribute to those remembered.

To be chosen as part of someone's legacy is something we do not take lightly.
We are truly grateful for your kindness, trust and generosity during what we know is an incredibly difficult time.

Our thoughts are with you all.

We would like to extend our sincere thanks to our continued sponsor, S&J Cleaning Systems Ltd., who have supported Life After Lary since the very beginning.

Their ongoing willingness to help — through financial support, advertising and generosity — has played a valuable role in helping us continue what we do.

We truly appreciate their continued support — thank you!

S & J Cleaning Systems Limited
Industrial Cleaning Equipment Supplies

# New look
# Same reliable products and services

Atos Care is now part of the Coloplast Group, we are now unveiling our new look that reflects our heritage while embracing our journey ahead.

0800 783 1659
www.atos-care.co.uk

Throughout 2026 you will see our new look appear everywhere, from our packaging to all communications with you. Even as our design evolves, what truly matters remains unchanged.

Atos Care → Atos | Care

Now, as part of the Coloplast Group, we are stepping into a new shared identity.


## Our look is changing, our purpose is not.

We are still Atos, still fully dedicated to supporting you and our mission remains to help make life easier for people living with a neck stoma.

Atos Care will continue to be an integrated care and distribution service for people with a laryngectomy in the UK.

# 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

Inspected and rated Good CareQuality Commission

### **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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