NEWSLETTER

INSIDE THIS ISSUE

Christmas Cards will be available soon!

Christmas cards will be available soon. 4 new designs plus 1 from last year, making a pack of 5.
The pack of 5 will be £5 per pack plus postage.
Thank you to Suzy Seel, who helped pick the designs going to print.

Please email lifeafterlary@gmail.com to pre-order your cards.

We will have a maximum of 1000 cards on the one and only print run - first-come, first-served!

Additional Zoom: Thursday 29th October 6.30pm (UK Time)

Further details available in the 'featured' tab on facebook.

Speech Therapist, Alison Smith joins us to discuss all things voicing and caring for a TEP.

Zoom: Thursday 13th November 6.30pm (UK Time)

Further details available in the 'featured' tab on facebook.

Geraldine’s Story

It was late October 1999 I was a month into my 42nd year and it was just an ordinary day but one that changed my life in so many ways. A life that I am so grateful to still have. I felt a lump on the right side of my neck. Four months later in late February 2000, after GP appointments, dental and then Hospital, I was finally diagnosed as having a Squamous Cell Carcinoma.

Things then moved very quickly. I was referred to a local Teaching Hospital where I underwent a radical neck dissection and removal of my right tonsil. The primary cancer was found in my tonsil and had spread into my neck and lymph glands. I was in hospital for 10 days. However, after being discharged I ended up back in hospital with a venous sinus thrombosis. I had felt unwell but now had double vision. This delayed my radiotherapy as my mask couldn’t be made as my face was too swollen from steroids.

I recovered well and finally started radiotherapy, not knowing the impact it was going to have on my life further down the line. Apparently, I was prescribed very aggressive radiotherapy and whether it was the amount prescribed, the fact that it was 25 years ago or just an unlucky reaction, but I was a mess of oozing blisters and skin. Back into Hospital again I went, recovered and home again.

Life then carried on as normal. During the years that followed I started to notice a variety of health issues, and it culminated in me becoming so ill that 15 years later I was off work for quite a while. During that time, I was having increasing problems with breathing, joint pain, swallowing, eating, dizziness, shaking, nerve damage, skin flushing, extreme headaches, anxiety, my blood pressure was extremely labile, extreme fatigue and brain fog. Throughout this time, I had an amazing GP listened to me and who acted upon my requests for help. To cut a long story short, at my request from research I had done she emailed 3 Doctors for advice. A Professor replied suggesting a neurologist at the Autonomic Unit, UCLH Queens Square London. This Neurologist had already replied to her email within 20 minutes! He replied that normally he would have me attend his clinic first to be assessed; however, from all she had told him about my history, he wanted me to go down to London to be tested by the Autonomic Scientists. These tests culminated in me being unequivocally diagnosed as having radiotherapy-induced Afferent Baroreceptor failure and Autonomic Dysfunction.

I then took Medical Retirement from the NHS where I had worked for 20 years. The relief that I felt that I now knew why my health had been worsening over the years and the reasons why I had the problems I did was enormous. I had gastric problems also and because I was getting no answers here in the north, they arranged for one of their gastroenterologists to see me who diagnosed dysmotility and lack of oesophageal peristalsis caused by radiotherapy damage. Also, I had a slight stroke a few years ago and was found to have stenosis in my Carotid Arteries caused by radiotherapy. One was 100% blocked and the other 70%. My BP cannot be controlled with drugs and so I was taught strategies to help as I have constant massive swings in BP throughout the day which is very exhausting and may eventually negatively influence my organs. I cannot praise UCLH highly enough as they keep a constant check on me.

Geraldine’s Story continued..

Four years ago, my Larynx worsened and now both vocal cords were paralysed. I now was fed via peg tube. I made my own blends as I was determined to remain healthy. I was advised that at some point I may require a Tracheostomy or Laryngectomy. The thought terrified me. However, I was constantly having chest infections from aspirating reflux and the bit of food and liquid I chose to swallow. Breathing and speech became increasingly difficult. I was then referred in November last year to a large Teaching Hospital for a Laryngectomy. Due to NHS politics and lists, I had to wait until I finally had it on May 22nd this year. Those 6 months of waiting were difficult; I live alone so choking or being unable to breath was a major fear I had. The potential length of surgery was also a concern due to my comorbidities. I had a wonderful Consultant though, who performed a full Laryngectomy with an SCM flap in under four hours. Other flaps may not have worked for me due to tissue damage. The surgery went well, and I came out of theatre and into recovery feeling ecstatic and so relieved. I was on ICU for 1 day, and then onto the Head and Neck ward. I was able to do all my own self-care by the following day. My swallow test was passed on day ten and home the following day. The staff were amazed at my understanding of a Laryngectomy and how prepared I was. The credit for most of that goes to LAL and I try to promote whenever I can as the group is amazing and a credit to the hard-working Admin team. I am now 4 months post op and having a Laryngectomy has already had a positive impact on my life. Obviously, breathing changes and isn’t always easy but so much better than it was. I’ve had a nasty chest infection (a couple of days after leaving hospital). I am now eating again, with a little difficulty but no more choking and aspirating. I’ve put weight back on, feel healthy and getting out for walks more again. I go out and about and even though I am non-verbal I don’t have problems communicating. However, I am hoping to learn oesophageal speech and use the electrolarynx with family (who have been amazing with their love, support and understanding) when we are all together and I want to be heard. The future now looks brighter, and I am incredibly grateful, so Onwards and Upwards!!

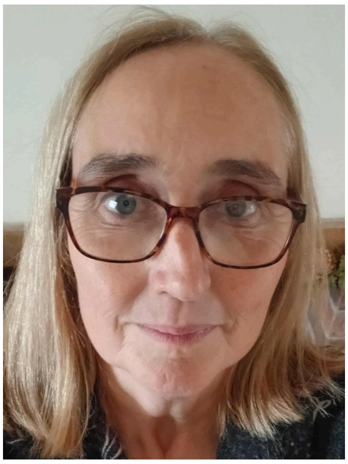
Life After Lary - caregivers, friends and family

Life After Lary has set up a new online support group dedicated to caregivers, family and friends of laryngectomees. As many will be aware loved ones can often be essential when navigating the surgery and treatment process of a laryngectomy. Their role is varied and crucial, from providing aftercare to offering emotional support. It can however be a very difficult role that comes with it's own unique challenges.

This peer led group will provide a safe space to share questions, struggles and advice to those who normally put others first. The group will not permit laryngectomees to ensure a private place where members can be open and discuss topics that may be hard to speak about. Please feel free to join the group if you feel it will be beneficial to you, you can find it on Facebook by searching Life After Lary - Care givers family and friends.

Life After Lary - caregivers, friends and family cont.

The group admins are Lauren Thomson and Louise Mellings, they have each written a short introduction about themselves and their journey with Life After Lary.



Louise - My husband Keith was diagnosed with cancer of the voice box back in November 2022. The day he got his diagnosis, he came to my place of work. I grabbed my stuff and left, returning some months later. Instantly, I became a carer/supporter. Like all of us, we were like a rabbit in headlights for weeks, trying to get our heads around our new normal. After Christmas, Keith had 6 weeks of radiotherapy and 6 sessions of chemotherapy. During the months that followed, we found the Life after Lary Facebook group. The group has meant so much to us both. We have learnt so much, met some amazing people, and love belonging to such a fabulous community. We have been lucky enough to set up our own local Lary Lounge group, which has been brilliant, connecting Larys and the families in our local area. I feel very privileged to be asked to help with the new Facebook group for carers and loved ones. Thanks, Louise.

Lauren - Hi everyone, my partner Steff was diagnosed with laryngeal cancer at age 29 in February 2023. At that time I took it upon myself to do as much research as possible and try to find other people online who have went through the same thing, particularly people around his age as it is so rare to see this in someone so young. I wanted to provide Steff with reassurance that he can live a full life following this surgery. I found quite a few lary's online including Jon Organ who had recently started documenting his laryngectomy journey. I connected with him and found out he was six weeks ahead of Steff in his treatment. His posts were invaluable as Steff followed in his footsteps. We remained in contact whilst he and Steff went through treatment as and we joined Life After Lary as soon as it was set up and now call Jon and the rest of the LaL team friends. We attended the first Scottish LaL meet up in the summer and met both Jane and Carl, we also regularly attend the online Zoom meetings. We have been able to turn this bad situation into a positive one largely due to Life After Lary.

Although I do not currently provide much of a carer role for Steff as he is a young, fit and healthy man who has had very good outcomes from his treatment, I do help him with smaller things such as phone calls, introductions to new people, prescriptions and holding his HME when he needs to cough! When Steff was going through treatment (surgery, radiotherapy and chemotherapy) my care role was more significant. I visited the hospital every day after work while he was in, I brushed his hair, helped him to walk the corridors and learned about stoma care among other things. I also took the role of feeding him through his RIG tube that was put into his stomach as he couldn't eat by mouth during radiotherapy and was often too tired to do it himself. We often attend our local laryngectomy group, help the SLT team by speaking to new patients prior to surgery and contribute regularly to the LaL Facebook group so I hope my experiences can help those who join the new carers family and friends group.

Childhood Cancer Awareness Month

Walking a couple of steps behind the student nurse, we meandered through the corridors of Birmingham Children's hospital towards a section called Waterfall House. Melody was due to be transferred over from intensive care to Ward 18, the cancer ward, so she could continue her treatment. She had already had one lot of chemotherapy on PICU, which wasn't a normal procedure, but not completely unheard of.

As I followed the student nurse into the lifts, I got nervous. It seemed all so overwhelming all of a sudden. What if the treatment didn't work? How much longer would we be here for? Melody had already been in hospital for a month, in an induced coma for 3 weeks' worth of that time. I had been pretty much living at the hospital, spending up to 16 hours a day at her bedside, then, once I had seen her heart rate steady and slow, indicating she had properly drifted off, I would take myself off to the Ronald McDonald house next door to the hospital to attempt some sleep.

The lift doors opened on the 2nd floor and we took a left. We were then let in through a set of double doors.

The playroom was the first thing I saw, open and light, children wheeling stands with their infusions attached, some beeping, alerting the nurses, needing to be changed over. A playhouse, a huge TV, craft area and more. It all seemed weirdly comforting. There were bays and private rooms alike, just off the playroom. We rounded the corner and walked halfway down the long corridor to the nurses station. The student nurse announced us and asked if we could be shown round. I genuinely couldn't believe my eyes when I saw the amount of names on the whiteboard behind the desk. All these children, battling through this horrendous disease. The ward was split, babies and younger children in the first section, and teens up at the top through another set of doors. The first section was to be our home for the next 2 months and I felt more relieved, seeing how welcoming it all was.

Melody struggled to make friends on the ward, despite being more than willing. The kids would come in for their treatment, stay a couple of days and then go home, like an endless conveyor belt. It made my heart ache with how much I wanted to take her home. Some of them we did make friends with and we crossed paths regularly. I often wonder how Daisy, Savannah and Lilly are getting on and we hope the absolute best for them. The hardest part is when you all of a sudden stop seeing the regular ones. There was a family across the way from Melody's room. Their 2 month old daughter was receiving treatment for ALL. Her dad would often pop his head in and offer me a chocolate from his quality street box. One day I realised their room was taken by someone else. It was only when we moved back down to intensive care after Melody's laryngectomy, I saw the dad in the parent's room and found out that she wasn't doing well at all. Soon, family started to arrive and I knew in my heart what that meant. Baby Illyanna grew her wings much too soon.

Melody also made friends with Darcy a 6 year old girl who had lessons at the hospital school with her. Darcy wasn't a patient but her brother, Jayden, who was 10, was. They happened to only live a couple of miles from us. Nothing had worked for Jayden treatment-wise and he was waiting to be accepted onto a trial at Great Ormond Street. If only his blood levels would come down, he would get the go ahead. But they were constantly high, his immune system fighting with every bit of strength it had left. Sadly, he couldn't fight any more and he grew his wings just before Christmas of 2024.

At the end of September 2025, we celebrated Melody's one year lary-versary and her first year being cancer free. We feel very lucky to have been able to bring her home, as so many, like the families above, don't get that opportunity. September is also Childhood Cancer Awareness Month. Approximately 1600 children (0-14 years) are diagnosed with some sort of cancer each year in the UK. This makes up for 1% of all cancer diagnoses, meaning its very rare. Around a quarter of that 1% is taken up by an array of head and neck cancers. The good news is that with how much the understanding, awareness and treatment has progressed, the survival rates of childhood cancer has risen remarkably, more than doubling since the 1970's to well over 80%. During the month of September, if you hear the words "cancer awareness" don't think of just pink ribbons. For our children, our precious little treasures, the colour is gold.

A new chapter

“Our group was born from lived experience, survivor humor, and the belief that no lary should ever feel alone. As we grow, I’m proud to welcome trustees and consultants who share that vision. Together, we honour every voice, every scar, and every story, with clarity, compassion, and courage.”
Jono Organ
Ian Phillipson

Now a New Chapter Begins

As Life After Lary enters its next chapter as a registered charity, we’re proud to introduce the incredible individuals joining us as trustees and consultants. Each brings a wealth of experience, compassion, and commitment to our mission: that no lary will ever feel alone.

To our new trustees, thank you for stepping into this role with courage and care. Your guidance will help shape our future, ensuring our work remains inclusive, transparent, and deeply rooted in survivor truth.

To our consultant Michelle, your insight and support are already helping us navigate this transition with clarity and purpose. We’re grateful for your expertise and your belief in our community.

Together, we honour every voice, every story, and every legacy. Welcome to the team.

An introduction to the trustees:

Michelle

Life after Lary is pleased to be working with Michelle Vickers, an experienced charity leader and consultant, who is guiding the organisation through the process of becoming a registered charity.
Michelle brings over 20 years of experience in the not-for-profit sector, with a career spanning elite sport, head and neck cancer, and animal welfare. For the past nine years she has dedicated her work to the Head and Neck Cancer community, serving as CEO of the Head and Neck Cancer Foundation for eight years, and most recently as Chief Awareness Officer at Oracle Head and Neck Cancer UK, following the charities' merger in May 2024. Alongside this, Michelle has been a trustee of Wycombe Women's Aid for over nine years, where she now serves as Chair.

Michelle says: "Life after laryngectomy is a profound journey of change, and this organisation is already doing extraordinary work to ensure that no one walks that journey alone. My role is to help formalise that vision, so Life after Lary has the structure and recognition it deserves as a registered charity."

Laura

Hi Everyone, my name is Laura. I used to have a tracheostomy and I run "Life After Trachy" which is our sister group, helping people with tracheostomies and their loved ones and carers. I'm a proud member of "Life After Lary" and joined the group after becoming good friends with Jon around a year and a half ago, who supported me very much on my own journey and I couldn't be more honoured and proud to now be a Trustee. Its been amazing to see how far this wonderful group has come and I can't wait to be a part of its future in this exciting new chapter as a charity.

An introduction to the trustees:

David

Hello All, It's a great pleasure to be associated with Life After Lary (LAL). My name is David Frian, and together with my partner Melanie, we run S&J Cleaning Systems Ltd — a national sales, service, and repair company for industrial cleaning equipment. Along with our team, we're proud to be supporters and sponsors of Life After Lary.

I've often been told I'm a bit of a workaholic, so I don't get much time for hobbies! But when I do, I love heading to our special place — Littlestone on the Kent coast — for some relaxation, and a few beers. I love tattoos and have 152 of them (I've even got my own LAL tattoo!).

All our vans proudly display the LAL logo on the rear doors, and from next year, we'll be adding it to all our uniforms as well. We're also dedicating a page on our website to help promote and raise awareness of Life After Lary far and wide.

I am truly proud to support such an incredible cause and look forward to helping Life After Lary continue to grow.

Carl

Hi, I'm Carl Rowell. I'm a proud single dad, a lifelong scout leader, and someone who's always had a passion for helping others, whether through my work as a handyman and decorator or through community service. I've led scout groups for over 13 years, and when I'm not volunteering, you'll likely find me by the water, enjoying a quiet moment with my fishing rod.

In November 2022, I became a laryngectomee following a diagnosis of laryngeal cancer. It was a life altering experience, and like many, I found myself navigating a new reality, one that can feel isolating, even with loved ones around. That's why meeting Jon at a lary meetup in summer 2023 was such a turning point. Joining Life After Lary felt like coming home to a community that truly understands. Its ethos, no lary should feel alone, spoke to something deep in me. It's not just a motto, it's a lifeline.

Becoming a trustee is an honour I carry with pride. It's a chance to give back, to stand alongside others who've walked this path, and to help ensure that no one feels forgotten or unsupported. Sharing stories, swapping tips, and simply being there for each other, these connections are vital to our wellbeing. I'm proud to be part of a team that turns survival into solidarity, and I look forward to helping Life After Lary grow stronger, together.

A lary workstation

Thank you to Doug for sharing his lary station and items he finds useful.

Using these items together allows Doug to keep both hands free while cleaning his stoma and valve, Applying baseplates and making it much easier to gently adjust or manipulate the stoma for a better view. This setup also allows him to work more efficiently, for example, holding tweezers in one hand and a wipe or tissue in the other, which significantly speeds up the whole process.

He has organised the mirror and lamp along with essential supplies on a tray with a stationery caddy, so everything is in one convenient place. This makes it easy to carry from room to room and just as easy to put away when he is done.

Here are three things Doug has recommended:

Flexible Magnifying Mirror

Ideal for changing baseplates with x1 magnification or inspecting the stoma more easily with x10 magnification. It also has the mirror raised so you can adjust it to the perfect height whilst sitting at a table.

IKEA NÄVLINGE LED Desk Lamp (mains-powered)

Provides bright, focused lighting, which is really helpful at home for routine care it also has a gooseneck so adjusting to that perfect angle is easy.

IKEA JANSJÖ USB Lamp (great for travel)

Compact and bendable, it can plug straight into a power bank, perfect for travel.

In Loving Memory

Each month, we say goodbye to cherished members of our community — patients, carers, friends — whose courage and presence shaped us.

To those who have passed recently: Rest In Peace. You mattered. You are missed.

We carry your stories forward—in every laugh, every shared truth, every act of care. Your legacy lives on in the hearts you've touched.

At Atos Care we understand that after your operation, you need more than just products to help you live your life fully. Trust, time and care are more important than ever. The Atos Circle of Care is our comprehensive support service to help you. One of the support services we offer is a community nursing team* who can visit you in your own home to help you on your journey.

Denise Walker

Head and Neck Specialist Nurse

One of our dedicated Head and Neck Specialist Nurses shares how she supports patients who use the Atos Care service.

GET TO KNOW DENISE

Favourite film?
Harry Potter

Favourite holiday destinations?
Italy

What is your greatest strength?
Organisation

When did you start working for Atos?
January 2023

What does a typical day look like?
I start by planning my day as each patient is different and I want to be prepared. Usually, the visits are to assess usage, routines and to give advice when it's needed.

What's your favourite part of working for Atos?
Seeing the progress people make over time. When a patient gets their voice back it's the best!

How do you ensure your patients have a positive experience from start to finish?
I listen to what the patient wants, what their expectations are and manage them if needed, it is important to listen.

From your experience do you have any top tips for laryngectomy patients?
Be open and honest with your nurses, we want to work with you to get the best outcome.

Can you share a success story since working for Atos?
I had a patient who had their laryngectomy 16 years ago, they self-referred and wanted to try adhesives and HME's. They suffered from blackouts due to a dry airway, I was able to start them on a routine of Home and Go HME's during the day and Night HME while asleep to provide the best level of heat and moisture for improved lung health. They have not had any dry airway or blackouts since!

Contact us:

If you are interested in the Atos Care service, you can self-refer by scanning the QR code, alternatively:

0800 783 1659 Option 2
atos.registrations@nhs.net
www.atos-care.co.uk

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* Our nursing teams reach currently doesn't cover all of the UK and Ireland, please reach out to your BestStartNurseorAtosCareRepresentativewhowillbeabletocheckyourlocation.

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.

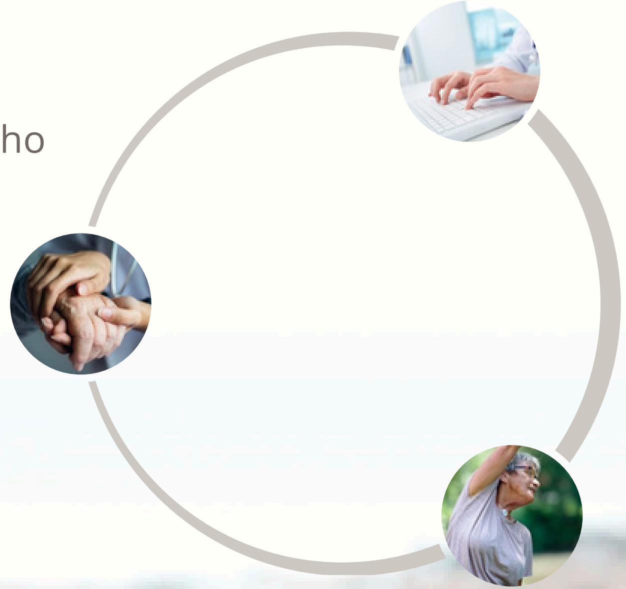
The Atos Circle of Care

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
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Atos Care