NEWSLETTER

INSIDE THIS ISSUE

Call for local laryngectomy group information

We have been collating a list of laryngectomy support groups around the UK to add to the Life After Lary website. You can find the current list here. While our website list is growing, we are aware that many smaller, informal, or local groups might not be on our radar yet. We want to ensure that no matter where someone is in the country, they can find a local community to join.

How You Can Help

If you attend a group that isn't currently listed on our site, please let us know. We have created a simple Google Form to make sharing these details as easy as possible. Find the Google form here.

You can also email contact@lifeafterlary.co.uk if you prefer. Please include the following:
What we need:

- The town or city where the group meet.
- The location, time and how frequently the group meets i.e., once a month.
- A contact person or website, if available.

By taking two minutes to share what you know, **you could be helping a fellow member find a support group in their area**. Thank you for helping us make this resource as comprehensive as possible for the whole community. If you feel you could host a group please email us for more information about how LAL can support this.

Thanks,
Lauren :)

Ian’s Story

Before

My story with, and because of, cancer, occupies most of my adult life. First, my twelve-year-old son contracted Non-Hodgkin’s Lymphoma. I was a young father and far from equipped to deal with it… but my ex-wife and I pulled together, and each of us tag teaming and staying 24 hours on/24 hours off at the bedside, saw him through it.
He endured 8 courses of chemotherapy, a course of radiotherapy and finally surgery to remove the upper lobe of his left lung. He came out the other side and is now a father himself and works as a police officer.

My mother beat breast cancer twice and finally succumbed to liver cancer in 2017.

My good friend Steph also beat breast cancer and another friend, Carol, got through thyroid cancer.

You might say I was prepared!

I have always tried to enjoy life as a reclusive extrovert and a gregarious loner. I avoid playing or watching sports, but enjoy hill walking. I like reading and real ale (the chewy stuff, with twigs in). The last of which lead to me being in the upstairs room of a micro pub in sunny Chesterfield in 2015. I read a few poems and then dressed as a robot I performed Marvin’s Lullaby:

Now the world has gone to bed
Darkness won’t engulf my head
I can see by infrared
How I hate the night

Now I lay me down to sleep
Try to count electric sheep
Sweet dream wishes you can keep
How I hate the night

There are more verses but that is a taster. At the end of the evening, I realised my throat was sore and my voice raspy but the marvellous beer soothed it. It was a lovely solution but in the following days I had to admit that the problem had been growing for a few weeks and that beer was not the answer. I explained my symptoms to the doctor who surprised me by asking “what do you want me to do?” Luckily, I knew the answer, which was: “please refer me to someone with the tools to investigate the problem”.

Ian’s Story — cont..

Two weeks later, I sat in the hospital in front of an impressively bearded gentleman who had a large machine and a referral of “query nodules on vocal cords.” I was asked questions and then, issuing from the large machine was a camera in a bendy straw, which was inserted up my nostril and down my throat to give a view of the offending nodule. After a Hhhmmmm, two Aaahhss and finally an Ah-ha! the camera was withdrawn. When my drool and tears had been wiped away, the impressive beard was divided by a large smile and the words “It is not cancer” were uttered. It was diagnosed as erosion of the vocal cords caused by Silent Gastric Reflux – apparently during sleep the bile rose and being acidic caused the erosion. I was prescribed Esomeprazole and returned each 3 months for more of the same camera malarky. After a year, I was told I now had a malignant growth and that radiotherapy was my best option.

During

Clearly, I was not happy about this, but having reviewed all the options, they were either less beneficial or unacceptable. I travelled to Weston Park hospital in Sheffield and was given a tour, before meeting the consultant who gave the go ahead and I was taken to a side room. There they explained the radiotherapy process, which to minimise damage to the surrounding tissue meant that I would be “shot” at from 30 different angles. This meant I had to be in the same position every time – to the millimetre – to avoid damage to the surrounding tissue. To ensure consistent positioning I was asked to lay, stripped to the waist, on a cold, steel table. A warm plastic airtex blanket in a steel frame was then placed over me, bolted to the table and smoothed into place with damp cloths. It was then unbolted and I sat up to see a perfect, yellow reproduction of my head and torso - scary stuff! Eye holes were cut out and for the following 26 days I drove to Weston Park for a ritualised process of checking Date of Birth, being bolted to the table, moving around in mid-air and 47 seconds later hearing “all done, see you tomorrow”.

The final four days were a little different in that I did not feel physically fit enough to safely drive and was driven there - with the walk from the entrance door to the shooting gallery feeling 3 yards further each day.

The following two weeks were not pleasant, waking as I did each morning having taken part, overnight, in an extended boxing match with three large opponents. My throat constricted painfully and for several days all I could manage to eat was soft boiled eggs and spaghetti hoops. But then I recovered rapidly and after a few weeks was back at work as factotum in one of the best real ale pubs in the county. Work and life continued happily for two years with scheduled check-ups until I found it harder and harder to summon up the energy to last a full day at work. My fears were confirmed in the shape of “a 4mm growth on the left vocal cord”. I was transferred to the care of Mr.O., a big bloke with a ready smile, a straight manner and in whom I had immediate confidence.

Ian’s Story — cont..

After

Home. What a joy. I knew I was well looked after in hospital, but being in my own bed and not being twelve miles away meant I was visited by many more people, which brought huge happiness. I still had the ng tube fitted and as I enjoy cooking (and eating) it was not easy for me watching others eat and having none. So, it was a huge relief when two weeks after discharge I was called in for my swallow test and the ng tube was removed. It wasn’t a burden (it kept me alive), but what a relief to see it go. From that point I was still on Fortisips, but supplemented with soup, yoghurt, custard, and then onto soft boiled eggs and spaghetti hoops (bittersweet memories!), slowly introducing more solid foods into my diet. The biggest pleasure was reintroducing breakfast cereals and toast – as a creature of habit my day starts with a very specific mix of flakes – not for pleasure, but health, topped with nuts, sultanas, seeds and fresh fruit followed by 2 slices of toast, 1 with jam, the other with marmalade and 2 mugs of coffee. When (weeks later) I reached that milestone, I really felt like I was on the path back to me.

Three weeks after discharge I saw my consultant and raised the point that in hospital, I had been doing 20 laps of the ward each day but now couldn’t get from one end of the house to the other without needing to stop. He thought a moment, grinned and said “Ain’t morphine a wonderful thing?”. Five weeks after discharge I was left home alone for the first time as my partner went off to babysit two of the grandkids overnight. The sudden realisation of not being able to easily summon help - if needed – was quite scary. I had been doing quite a lot of research at home ranging from global academic papers to the university of YouTube, so I knew oesophageal speech was a reality. I went to bed and as a starting point I thought – make a noise! I used to quack/talk like Donald Duck to entertain the kids, so I tried that. I failed miserably, but did make a noise. Having made that noise, I kept pushing air around my mouth in different ways making the noise change. It was addictive and I didn’t stop till four hours later when I was able to form recognisable words. In the morning when my partner came home, I went downstairs to greet her and said three little words. We both burst into tears and there was no going back.

From that point on I commentated on washing the pots, I argued constantly with the tv, the radio and at one point with the vacuum cleaner. I discussed moral philosophy with Ari the cat, who had arrived the day after I had the ng tube out when I found him on the back door step yowling. I offered him food and he legged it so I put the food down and went indoors then watched as he wolfed it down. This was repeated for a few days until the day he wandered into the house to demand food. He was a real bruiser and he stayed with me for about 3 months then left as abruptly as he arrived – I don’t know if it was because I sounded like a constipated Dalek, if he didn’t agree with my relativistic ethics, or he just wanted a change. Whichever it was I missed him and having him around did me good.

Ian’s Story — cont..

Over the following year, I went from sounding like a constipated Dalek to speaking through quiet gravel, to a voice that causes people to ask, “do you have a sore throat ?”. As I wear a bandana all the time the laryngectomy comes as a surprise to many.

Now, 6 years on, I have a new cat called Kiki, along with a new family and a new focus on helping build a business in mending teddies and marionettes and making beautiful and useful things. Life can be tiring, but I am happy and have purpose again. I am starting to realise that my objective to be comfortable in my skin, as myself first, and a Lary second, has been achieved. As a result, I am devoting a portion of my time to working for a better deal for Larys.

Monthly Zoom: Thursday 5th March 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. We will also post the link on the day!*

National Disability Card

The National Disability Card is a simple, official-looking ID card designed to help people with disabilities easily show they may need support, concessions or assistance when out and about. Rather than having to explain your needs over and over, the card provides quick visual proof of disability and opens doors to perks like carer tickets, concessions and exclusive discounts at hundreds of venues, shops and attractions across the UK and beyond. It’s pocket-sized, secure and widely accepted at places including theme parks, cinemas and events — saving you time and awkward conversations.
The National Carers Card serves a similar purpose for unpaid carers — people who provide essential support to someone with an illness, disability or frailty.

Together, these cards aim to make everyday life smoother and more inclusive by giving disabled people and carers a practical, trusted way to communicate their needs and access the things they’re entitled to.

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!**

Benefits - Cost of Living

The cost of living in the UK has been steadily rising over recent years, and for many families, it feels like every month brings fresh financial strain. Everyday essentials such as food, energy and transport are more expensive, and even as inflation eases slightly, wage growth hasn't always kept pace, leaving household budgets stretched tighter than ever. As temperatures drop in winter, many people find themselves choosing between heating their homes and covering other basic costs — a situation that charities like Age UK describe as a "crisis hiding in plain sight," with millions cutting back on electricity use or even meals to make ends meet.

If you're feeling the pressure and want to explore what support you might be entitled to, organisations like Age UK offer really helpful guidance. Age UK's website and Advice Line provide information on benefits and entitlements — from Pension Credit and Council Tax Reduction to the Winter Fuel Payment and the Warm Home Discount to help with energy costs — and they even have a free online benefits calculator to check what you might be eligible for. Another great resource is the Citizens Advice service, which can help you check your benefit entitlements, find grants, or check if your local council runs extra support funds to help with essentials like food, heating and rent.

Macmillan's Money Matters team and Maggie's Centres can also offer practical and confidential support. Both organisations understand how overwhelming financial worries can feel during or after a cancer diagnosis, and they are experienced in helping people explore what assistance may be available.
If you would like support accessing any of the services mentioned, please don't hesitate to contact a member of the Admin Team. We will treat your enquiry with complete discretion and will gently guide you towards the help that best suits your circumstances. You are not alone in navigating this.

Disability Awareness & Benefits

Disability awareness is about recognising that barriers — not conditions — are often what limit people. In the UK, disabled people are protected under the Equality Act 2010, which makes it unlawful to discriminate against someone because of a disability and places a duty on employers and service providers to make reasonable adjustments. In Scotland, the same protections apply under the Equality Act, alongside additional devolved social security powers delivered by Social Security Scotland. Disability legislation exists to ensure fairness, dignity and equal access to work, services, housing and public life — but awareness is just as important as the law itself. Understanding your rights can make a real difference.

If you consider yourself disabled and feel your condition affects your daily living or mobility, you may be entitled to financial support. In England, Wales and Northern Ireland, working-age adults usually apply for Personal Independence Payment (PIP), while children may qualify for Disability Living Allowance (DLA). In Scotland, PIP has been replaced by Adult Disability Payment, and DLA for children is being replaced by Child Disability Payment. Applications can usually be started online or by phone through GOV.UK (or mygov.scot in Scotland), and organisations such as Citizens Advice or local welfare rights teams can help you complete forms if needed.

If you receive the higher rate mobility component of PIP or Adult Disability Payment, you may be eligible for the Motability Scheme. A Motability car is a vehicle leased through the scheme using your mobility benefit — it typically includes insurance, servicing, breakdown cover and road tax within the package, offering independence without the upfront cost of buying a car.

You may also qualify for a Blue Badge, which allows you to park closer to your destination, including in designated disabled bays and, in some circumstances, on single or double yellow lines. Blue Badge applications are made through your local council (or via GOV.UK), and in Scotland through your local authority website.

Navigating disability benefits can feel overwhelming, but support is available. Reaching out for advice early can help ensure you receive the assistance and adjustments you are entitled to — and that you're not facing the process alone.

Newly launched - 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

Dates for the Diary - Future Meet-up's

Life After Lary's motto is to ensure no lary is ever alone. In 2026 we are pushing LaL to every corner of the UK to attempt to catch every lary and do just that, ensure no one is alone. Meeting another lary face to face is so important for your mental health.

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

Shropshire: Lary Lounge 14.30 - 16.00 — The Wakes, Oakengates, Shropshire, TF2 6EP.
27th January, 31st March. 26th May, 28th July and 24th November.

Norfolk & North Suffolk: 13.00 - 16.00 The Porters Arms Public House, Red Lion Street, Aylsham, NR11 6ER.
March 10th.

Available to buy

Available now for sale at a discounted price to group members — **seat belt covers**. These have started to arrive on welcome mats across the country, I know I am delighted with mine!
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 ***contact@lifeafterlary.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.**

This month, the Admin Team would like to thank **Lauren** for her help with the website. I’m sure we can all agree it is looking fabulous! We would also like to thank **Ian** (Skip Ari Hunter) for his zoom on oesophageal speech; this was very informative and well attended.

I would also like to thank **Jon** and **Ian** for all they do every month, but even more so now — this group is what it is because of you and we would like to celebrate that! 🤍

Welcome to Atos Care

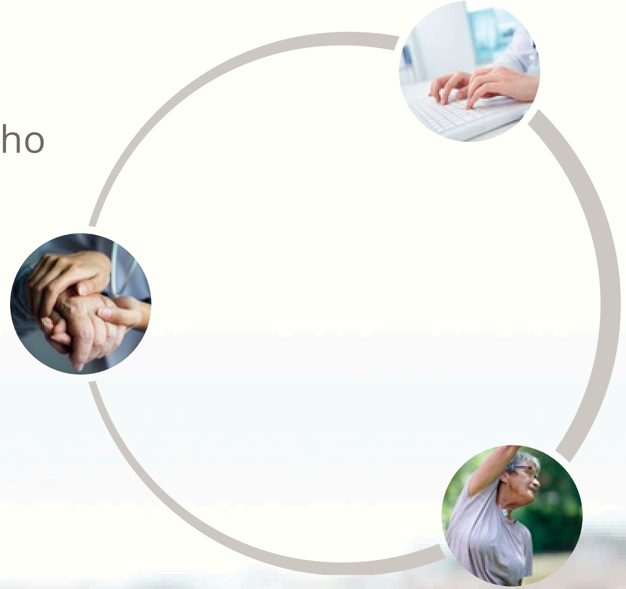
An integrated care and distribution service for people with a laryngectomy in the UK.
Atos Care is a comprehensive support service that includes a team of CQC registered nurses, dedicated to making life easier for people living with a neck stoma.

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

Call us:
0800 783 1659

Email us:
info@atos-care.co.uk

Visit our website:
www.atos-care.co.uk

Atos Care