

NEWSLETTER

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World Head & Neck Cancer Day – Sponsored Silence

On Sunday 27th July our members and their family and friends took part in a Sponsored Silence, staying quiet for hours to raise awareness of the daily realities faced by those living without a voice after a laryngectomy.

It was a powerful and humbling experience for everyone involved. While silence can feel uncomfortable, it offers a small glimpse into the communication challenges our community faces every day.

Thanks to the dedication of our participants and the generosity of their sponsors, we not only raised vital funds for support services but also helped spark important conversations about life after a laryngectomy.

A heartfelt thank you to everyone who took part or donated. You've helped give a voice to those who often go unheard.

Funds will be used to purchase LCD writing tablets and hospital care packs to complement our radiotherapy packs. Do you know anyone who would benefit from our packs? If so, please email lifeafterlary@gmail.com

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



Zoe's Story

The Effect on Wifey

'It is what it is.'

That was all Graham said in the car on the way back from the hospital. The diagnosis of a cancerous tumour in his voice box wasn't all together unexpected. All his symptoms were exactly the same as his brother 15 years previously. The treatment was going to be the same too. A total laryngectomy followed by 31 shots of radiotherapy.

I had no idea how he felt at that moment. My brain was pin balling about all over the place wondering how I would find the hospital he was booked into. Where would I park the car? Where were the doors? This is how my autistic mind behaves when faced with unexpected and, most likely, negative challenges. When I discovered the road to the hospital was one I had travelled a few times before that really helped, although I was still very anxious. Covid restrictions prevented me going in with him and as I stopped at the main entrance he opened the car door and said, 'Bye doll, love you.' I knew I would never hear his voice again. I drove home sobbing and wailing loudly not knowing what the future held for us. I'm not a natural carer and worried I wouldn't look after him properly. We began daily video calls whenever he felt up to staring at a screen. I would babble on about all sorts until I could see him getting tired. Before I put the light out at night I would send a gif, usually a cartoon animal offering hearts or some such like. Anything to keep his moral up.

When he came home I worried continuously about how I was going to get him to his radiotherapy appointments. It was across the other side of Glasgow and I knew there was no way I would be able to find the place once let alone go every day for 6 weeks! The relief when I heard about a charity that offered transport for cancer treatment was huge. I was so grateful I kept sending them donations.

Jump 6 weeks and Graham finished radiotherapy on the Friday. His swallow was practically non-existent and he'd lost 3st. He looked so frail, I could see his spine and also ribs from the back, and his denture looked too big for his face. By Monday I knew I had to face another anxiety of finding someone in authority to phone, and actually call them and talk to them. I plucked up the courage, managed to get some success and he was hospitalised for 10 days with a feeding tube fitted. That feeding tube was a guest in our house for more than a year. It was a reassuring gadget in that I had the comfort of knowing Graham was getting all the nutrients he needed. It did have a nasty habit however, of thinking it was blocked usually around 4am and it would scream its little electronic alarm until I woke and worked out which buttons to press to shut it up!



Zoe's Story continued..

The weight went back on though and the feeding tube was redundant at last. Graham now has an eating routine and TV timetable for things he has recorded. I work from home as a piano teacher so I'm always there buzzing about and available for anything needed sorted out. I think things are as good as they are going to be. We have a form of sign language we use as Graham doesn't always get too much success with his speaking valve. I design what I say for him to be able to answer with a thumbs up or down.

This is our story from my perspective. It seems a bit condensed but I thought I would spare you the yuckier bits, and there was a lot of that to be missed out! I tell Graham that whatever curveballs come along then we will just deal with them together. I am convinced I can always find a solution one way or another, I just have to recognise when my autistic traits start getting in the way and overcome them. Keeping him alive is far more important than me having a meltdown. It's exhausting, but that's what you do when you love someone.

In sickness and in health.

Next Zoom: Thursday 4th September 6.30pm (UK Time)

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

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

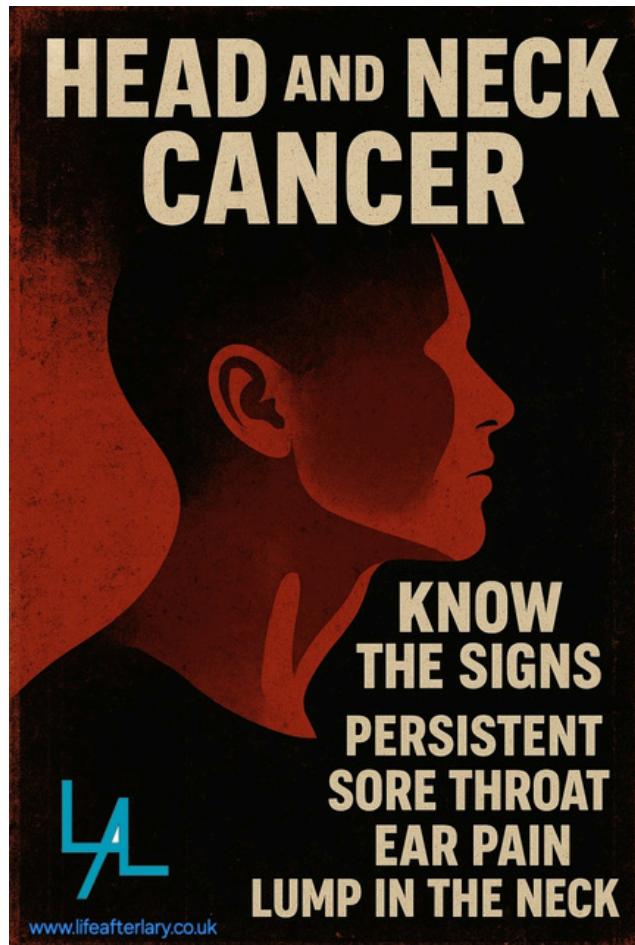
World Head and Neck Cancer Day: Raising Awareness, Inspiring Action

On World Head and Neck Cancer Day, Life After Lary proudly joined the global effort to raise awareness, educate the public, and stand in solidarity with those affected by head and neck cancers.

Through a series of local events, online campaigns, and powerful personal stories shared by our members, we helped shine a light on the importance of early detection, the impact of treatment, and the life-changing journey many face after a diagnosis, especially those living with the effects of a laryngectomy.

Our awareness efforts reached far beyond our usual circles, sparking conversations that matter. Whether it was engaging with the public on social media or simply talking with someone who hadn't heard of a laryngectomy before, every action made a difference. We're incredibly proud of our community for coming together with such passion and purpose. Awareness is the first step toward change, and thanks to your efforts, more people now understand the signs, risks, and long-term realities of head and neck cancers.

Let's continue to raise our collective voice, for prevention, for support, and for hope.





Life After Lary at Atos Medical Awareness Day Epsom Racecourse

On 9th July, Atos Medical hosted a special Awareness Day at the beautiful Epsom Racecourse, bringing together patients, healthcare professionals, and support organisations to share knowledge, experiences, and encouragement.

Life After Lary was honoured to be invited to host a stand at this inspiring event. It was a wonderful opportunity to meet attendees from across the region, raise awareness about life after laryngectomy, and share the support and resources we offer.

Throughout the day, we had many heartfelt conversations with individuals at different stages of their recovery, as well as their families and carers. We were able to connect people to our community, answer questions, and offer practical information all while enjoying the warm, welcoming atmosphere Atos Medical created.

A huge thank you to Atos Medical for organising such a valuable event and for including *Life After Lary* in their programme and a massive thanks to Carl and Tom for manning our stand. We look forward to future opportunities to work together in supporting and empowering the laryngectomy community.





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



Running with Heart: A Marathon in Memory and Support

On the 20th July, our community was deeply moved by the dedication and strength of two incredible women who ran the Liverpool half marathon in support of Life After Lary.

They ran every mile in memory of their beloved father Keith, a laryngectomy who sadly passed away in May and whose journey continues to inspire all of us.

Their commitment was more than athletic, it was deeply personal, turning grief into purpose and honoring his legacy through action.

With every step, they raised awareness and vital funds to help others facing life after laryngectomy, ensuring that no one walks that road alone. Their run wasn't just about crossing a finish line, it was about carrying forward love, resilience, and hope.

We are so proud and grateful to have them as part of our extended Life After Lary family. Thank you for turning pain into purpose and for reminding us all what strength truly looks like.

"Throughout this journey, we took great comfort in a truly special laryngectomy support group.

This group not only provided practical advice but also gave us a sense of community and hope when we needed it most. Thank you, Life after Lary"



How Life after Lary can help

Did you know?

Because of amazing donations we can provide care packs for surgery and or radiotherapy. Red wrist bands, laryngectomy window stickers, pin badges, personal alarms plus many other items.

Christmas cards will be available again this year designed by our very own artist Jon and printed by Atos. If you would like to pre-order cards or purchase any of the above items, please contact lifeafterlary@gmail.com

For anyone without online access, please feel free to pass along our registered address
 Life after Lary
 90 Brabazon Avenue
 SM6 9ET

Dysphagia friendly drinks

Safer ~ Simple ~ Enjoyable

Use Code:
LAYRS15 for
15% OFF
 your first
 order



Slō Milkshakes+ Oral Nutritional Supplements

Flavoured with real powdered fruit and cocoa and mixed with cold whole milk they are fresh, rich and creamy to drink.

Slō Syrup Concentrated liquid thickener

Replaces tins of thickener.
 Makes smooth lump free drinks that satisfy the taste craved.

Pill-Eze Makes Pills easy to swallow



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

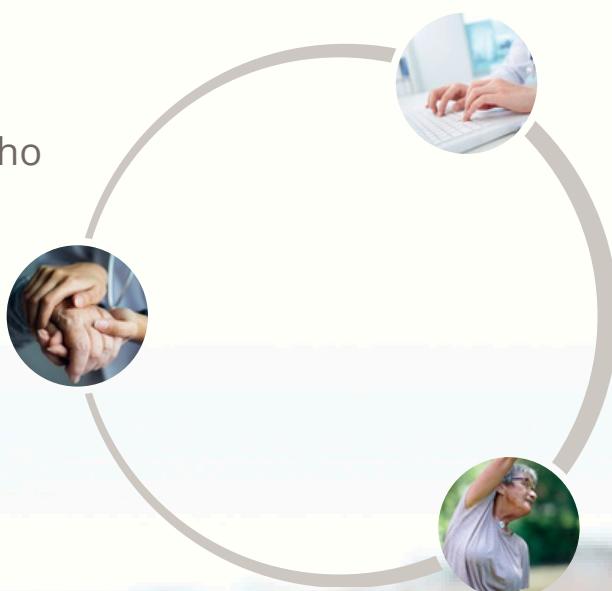
Best Start: Get off to the best start in life after a laryngectomy.

- 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



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

