MONTHLY

NEWSLETTER

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Our first in person meet!

A reminder that our first ever meet up is next week. A meeting for patients, family members and carers.
Please let us know if you will attend for numbers for the buffet. There have been offers of transport on the facebook page, if you need assistance please reach out.

We understand not everyone can travel so if you would like to host a meet in your area let us know and LaL will pay for the venue plus refreshments, where possible. ATOS will also attend and have a table of bits and some give aways.

Wednesday 27th November 2024
1pm - 4pm
Tea/Coffee/juice and sandwiches will be provided.
All welcome!
Oxshott Community Hub,
Waverley Road
Surrey
KT22 0RZ

Next Zoom: Thursday 5th December 6.30pm (UK Time)

https://us06web.zoom.us/j/88986898406?pwd=N92OxqDJGdkX6ertpi5luz6wDJfcqF.1

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

Come along and join us for some festive fun and cheer!

Kathy’s Story

My story starts back in 1992 when I was 41 years old. I had a strange virus and I went to the doctor for a checkup. He felt something in my neck and referred me to an endocrinologist. After some tests my diagnosis was thyroid cancer. I was told at the time, that if I had to get cancer, it is the best kind because after they take out your thyroid you are cured and the chances of it returning are very slim. I believed that with all my heart!! I had a young family and I was very busy. I was operated, had radioactive iodine treatment to make sure all the cancer was gone and I was fine for 27 years. Except for the fact that the cancer was close to my vocal chord and one of them was paralyzed during the operation. But I still had the other vocal chord so I was able to speak, a little raspy but acceptable and it didn’t hold me back. I was followed for 27 years every year by an endocrinologist to make sure my medication and everything was fine. 10 months before I was diagnosed with stage 4 laryngeal cancer, I had a scan and the results were perfect. 10 months later on a routine examination my doctor felt something in my neck. I had had a couple of swallowing issues that summer but nothing alarming and I attributed it to my paralyzed vocal chord. Not so! After tests I was told I had stage 4 laryngeal cancer(still considered thyroid cancer) and I needed a laryngectomy. So much for my thyroid cancer being cured!! I had never heard of this operation before and could not believe that I was going to have to breathe through my neck let alone have no vocal chords!! I never smoked or drank !! It didn’t matter. I had a 13 hour laryngectomy with a flap taken from my wrist and thigh. I tried not to look at myself in the hospital as it was frightening and it took me a little while to get used to the idea of looking after my own stoma. I had a feeding tube in my nose that I hated. To communicate I used a paper and pen. During the operation they had put in a TEP. After 2 weeks I went home. Two days later as I woke up, I noticed that blood was coming out of my mouth. I had a bell beside my bed to call my husband and luckily he was still home. I wanted to take a shower and go to the hospital to show my surgeons what was happening and as I got out of bed, I fainted. I was rushed to the hospital by ambulance. My carotid artery burst. A 9 hour operation followed. I am lucky to be alive!! I had to have a feeding tube placed for nourishment as I could not eat by mouth. After 2 more weeks in the hospital I was home again. I had very dark thoughts when I got home. I was on strong painkillers and I was not very rational. Ultimately I wasn’t sure to succeed with my plans and I didn’t want to hurt myself or upset my beloved family so I abandoned the idea and decided to recover. But not before I had another 4 hour operation for a fistula where I asked my surgeon to remove my TEP because it leaked into my trachea and made me cough violently. I couldn’t live like that. I didn’t know how I was going to speak but I didn’t care. So within 2 months I had 3 big operations plus 30 rounds of radiation and 6 sessions of chemotherapy a little later. Needless to say after all those long operations so close together I was deeply fatigued from within. Plus my taste and swallowing were not very good. It took me 2 years for the fatigue to leave my body and for my taste and swallowing to improve. My right shoulder was frozen. I could not lift it. I had physiotherapy for a year until it improved. My scans were showing that I still had small areas of cancer so my oncologist put me on chemo pills. After a month I developed a high fever, stopped my pills immediately and went to emergency room. They told me that I had pneumonia and gave me antibiotics. My oncologist told me NOT to take it. He said the fever was from the medication and I should take Tylenol. I followed his instructions. Five days later I had blood clots coming from my stoma. I went to emergency and sure enough I had pneumonia which was treated with antibiotics during my week stay in hospital. Two days after I got home I noticed I wasn’t seeing well from my right eye. Back to emergency. I had a retinal occlusion caused by a blood clot. Now I am blind in my right eye thanks to my oncologist who told me to take Tylenol and not the antibiotics. I am not on any medication at the moment and I am being followed by another oncologist for a few small spots on my lungs. It has been 5 years since all my operations. I am playing golf, tennis, entertaining, travelling, loving my family and appreciating every moment of my life.

I am an esophageal speaker and I love it. It is as close to speaking the way we spoke before our operation. No device to change or clean and no leaking. I am trying to dispel some of the misinformation about esophageal speech. As laryngectomies we should all be informed about the different ways we can communicate. We are all different, we can all benefit from this knowledge and it should be easily accessible to everyone who has to go through this life changing but life saving operation. I am happy and I feel lucky to be alive. I would like to help as many people as I can through this journey but time is the real healer.

Kathy has made some videos of her speaking on our facebook page search for Kathy Grosvenor to check them out!

Life after laryngectomy: Winter tips

Does the cold affect my stoma?

Before a laryngectomy air is inhaled through the nose, it becomes warm and moist before entering the lungs. After a laryngectomy the air is no longer inhaled through the nose, it enters directly through the stoma. Cold air is dryer than warm air and is therefore more irritating to the trachea. This is because cold air contains less humidity and can dry the trachea and cause sore cracked areas and bleeding. Mucous can also become dry and plug the trachea.

Breathing cold air can also have an irritating effect on the airway causing the smooth muscle that surrounds the airway to contract (bronchospasm). This decreases the size of the airway and can make it harder to get air in and out of the lungs, thus increasing shortness of breath.

When exposed to cold air, consider covering the stoma with a jacket by zipping it up and over the stoma or by wearing a scarf to cover your stoma. It is also highly recommended to always wear a HME where possible. The aim is to create a space for the exhaled and inhaled air to warm up and stay humid. It also allows for air filtration and oxygen and bicarbonate exchange with the environment.

Are you willing to share your story?
If so please email Jane - j4nehogarth@gmail.com to feature in an upcoming issue.

Life after laryngectomy: Mental Health

At our most recent zoom meeting the topic of mental health was raised. This is a very important topic so we felt it should have more coverage than a few lines in the newsletter minutes.

Now that we are into the colder, darker season it can be harder to keep yourself smiling and keep getting out and about. The cold air can affect our stomas making you feel down and unable to get out and do the things you normally manage during the summer months.

How to manage the darker moments:

- Try to keep busy
- Can you go back to work? part-time or work from home?
- Have small targets
- Try a new hobby, knitting, crossword puzzles, jigsaws, painting..
- Set goals and follow through, stay on track
- Snuggle up and watch a good movie
- Try to occupy the mind
- Post on our facebook page
- Take small steps, e.g. get up at the same time every day, make the bed, wash your face, clean out stoma, eat breakfast and so on. Before you know it you have achieved a lot in one day.
- Make a list and mark off everything you have achieved
- Know that if you have an off day that's ok too, it's ok not to be ok!
- Know who to contact for more help if the dark days become too much

Who can I contact:

- Your GP
- Your Clinical Nurse Specialist
- NHS 111
- befrienders.org
- CALM (Campaign Against Living Miserably) thecalmzone.net
- National Suicide Prevention Helpline UK 0800 689 5652
- Samaritans 116123 (freephone) jo@samaritains.org
- SHOUT text 85258 giveusashout.org

You can also contact Jon, Ian and Jane via facebook messenger at any time. I'm sure many others would also be willing to message if someone was feeling low and needed support. Please never feel alone, Jon set this group up to ensure no lary ever felt alone.