

Laryngectomy Support: BCL Meeting Follow-Up, Part 2 of 2

Andre Charpentier, Virginia Charpentier
Wed, Jan 15 at 1:54 PM

Hello Dear Folks,

We are passing these links and attachments below around again for our new members as well as for anyone who may have missed them.

Knowledge is powerful...and anything that will facilitate living as a laryngectomee can be worthwhile. Please note, this email is 'Part 2 of 2'. You should have also received an email (Part 1 of 2) with our notes and links from topics discussed during our meeting on this past Tuesday, January 14th.

Topic #1

Len worked with the Head and Neck Cancer Alliance (HNCA) to put together a Webinar on August 19th for Laryngectomees. That wonderful webinar, **“Thriving as a Laryngectomee: Finding Joy and Embracing Hobbies”** is now available on YouTube!

The first link below is a video, featuring Len as one of three 'thrivers' in the aftermath of having had a total laryngectomy. Great Job, Len!!! We so appreciate all the positive energy you bring to the laryngectomee community!

<https://www.youtube.com/watch?v=TYe0NivlYng> Video

This second link is for the informational slides shared during the webinar.
<https://www.headandneck.org/wp-content/uploads/2024/08/August-Webinar-Draft-Slides-1.pdf> Slides and info

This third link is to the main page of the Head and Neck Cancer Alliance (HNCA) website which is a terrific resource for laryngectomees.
<https://www.headandneck.org/>

Topic #2

Tom shared that the September, 2024 newsletter from Web Whispers includes a great article on TEPs. You can access the newsletter with this link:

<https://webwhispers.org/wp-content/uploads/2024/09/WotW-September-2024.pdf>

In a discussion regarding speaking volume, Tom also shared that he periodically will use a voice speech amplifier to increase his voice volume. There are many different kinds available. His device is the *Chatter Vox Model 100*.

Topic #3

Tony has been a total laryngectomy since 1990 and uses an electrolarynx and esophageal speech to communicate. He is happy to talk with anyone with regard to suggestions to support communication and maximize voice quality.

Tony has worked successfully with many people in person and in online formats. He can be reached through his cell phone or through his email. Tony **prefers** folks reach out to him through his **cell phone**, by either texting or calling him.

For his information please send me an email at: Acharpen@umich.edu

Topic #4

We also had a discussion concerning the possibility of extending the life of one's TEP voice prosthesis. Some members use nystatin, which is a prescription antifungal agent. Another member commented on her use of apple cider vinegar in water. If you are interested in learning more about this topic, your speech and language pathologist (SLP) could help you.

Topic #5

During a discussion with regard to a member's question about when a laryngectomy is to be hospitalized for an unrelated procedure or surgery involving anesthesia, Chloe Thorburn, SLP shared attachments of diagrams, photos and a sign clarifying the needs of a total neck breather.

For your peace of mind and your well-being, we recommend printing these out and bringing them with you, in the event that the medical personnel are unfamiliar with the needs of a total laryngectomy.

One of the attachments explains the anatomy with a TEP and the other explains the anatomy without a TEP.

Both attachments can be found at the *very* end of this message in pdf form.

Topic #6

We have also discussed the sometimes frustrating process of getting supplies and where to get those supplies.

Many folks get their supplies directly from Atos Medical or From InHealth.

Tom shared a wonderful compilation of companies where laryngectomee supplies can be found. That list is also in a pdf attachment at the very end of this message.

Topic #7

A while back, we shared some wonderful informative resources that we had received. We'd like to share two diagrams again in the **blue links at the very end** of this email for those who may not have seen them. You will need to click on the attachments and download them to your device.

The **"Dual Doctor"** diagrams are patient-created handouts for total laryngectomees to bring with them to the hospital if they require surgery or admission for something else, to help the medical staff understand their needs. One of the diagrams explains a laryngectomee's anatomy including a TEP and voice prosthesis and the other is the laryngectomee's anatomy without a TEP. While these links are very similar to the attachments, they are not duplicates.

Topic #8

Itzhak Brook MD, a world renowned doctor and author as well as a total laryngectomee, has a blog that addresses all aspects of head and neck cancer and life as a laryngectomee.
<https://dribrook.blogspot.com/>

Dr. Brook has also written books on the subject.

Itzhak Brook MD has recently announced the publication of the 6th Edition of his Laryngectomee Guide. He has shared the following information:

"I am happy to announce the publication of the 6th edition of the Expanded Laryngectomee Guide, now spanning 379 pages. This updated and revised edition offers valuable information to assist laryngectomees and their caregivers with a wide range of concerns, including medical, dental, and psychological issues.

The guide includes comprehensive details on head and neck cancer and its surgical treatments, side effects of radiation and chemotherapy, various speaking methods, and care for the airway, stoma, and voice prosthesis. It also addresses eating and swallowing challenges, and provides guidance on respiration, preventive medicine, urgent care, anesthesia, and traveling. Additionally, the guide offers helpful resources specifically for laryngectomees and head and neck cancer patients."

The E Book is free for download <https://bit.ly/3xvA49f>

Paperback and Kindle are available at <https://www.amazon.com/dp/B0D7SHQN4>

We also highly recommend Dr. Brook's book, *My Voice: A Physician's Personal Experience With Throat Cancer*. Dr. Brook, being a physician as well as a total laryngectomee, brings a very interesting perspective to life as a laryngectomee with attention given to the social emotional effects of such a surgery. This can also be found on Amazon. [My Voice: A Physician's Personal Experience With Throat Cance](#)

Topic #9

The International Association of Laryngectomees (The IAL) Website offers a wealth of information pertaining to laryngectomees. When you go to the website, click on the triple bars on the top left to see all of the available resources...Publications, videos, Facebook groups...just to name a few. It's definitely an amazing compilation of beneficial resources.
website : <https://www.theialvoice.org/> This is definitely a helpful resource.

Web Whispers is another organization with lots of information. <https://webwhispers.org/>

Topic #10

Shower Stoma Covers

Many people are very happy with a small, plastic clip on to cover their stoma while showering.

Andre found these two and prefers them over the small, plastic clip on. The two shower stoma covers can be found at [Shower Protection](#)

Topic #11

Ann Marie has shared information with us regarding free publications which she highly recommends, *Living Well After Cancer: Cure* and *Living Well After Cancer: Heal*. **To subscribe for this free and very worthwhile publication, visit: curetoday.com/heal-subscribe** Thank you, Ann Marie...You are a powerful testimony to 'living well after cancer' and with cancer...and we are so grateful to you for all the information, the strength and the positivity you bring to our group.

Topic #12

Len, who is marked his 4th anniversary in 2024 as a laryngectomee in March, shared a fantastic article which he wrote for Lary's Speakeasy Website. Len, who is an avid skier also teaches children how to ski!

Len, thank you for sharing your positive energy with us and for sharing this beautiful article. Carpe Diem, dear Len!

The link is below.

<https://laryspeakeasy.org/ski-more-talk-less/>

Topic #13

Tom shared information on a group which meets online every Monday afternoon providing support for those learning and using esophageal speech as well as the electrolarynx. Please see below for more information and the link.

From: The International Association of Laryngectomees
<jennifer.malkiewicz-theialvoice.org@shared1.ccsend.com>
Subject: Join our ES AL Support Group Live Zoom

For more information contact:

Reply-To: jennifer.malkiewicz@theialvoice.org

Topic #14

Topic 15

Tom Olsavicky also shared a link to a peer support online group which he leads. He holds several meetings regularly and all are welcome to attend! For more information, Tom can be reached at his email, tolsavicky@cox.net

<https://us02web.zoom.us/j/79864272556?pwd=MHRFRXBVSkIwblo2d1V6MEFiWXBtZz09>

Topic #16

Enhancing Your Sense of Smell and Blowing Your Nose

During a discussion on diminished sense of smell, Ron, who joins us from California, shared this video.

Thank you, Ron...We very much appreciate all your positivity and learned experience!

Here is Ron's video.

Hi Guys,

Here is the video regarding enhancing sense of smell and enhancing the ability to blow your nose.

[Helpful hints for laryngectomees regarding enhancing the ability to smell and fix a runny nose.](#)

Topic #17

Topic #17

In a discussion on keeping active, Ann Marie shared the benefits of Urban Poling. A link for purchase as well as an article outlining **8 Benefits of Urban Poling** follows:

https://www.amazon.com/Urban-Poling-ACTIVATOR%C2%AE-Silver-Gray/dp/B01JQDFLKK/ref=mp_s_a_1_3?crd=2DUG4CFOJPOOE&dib=eyJ2ljojMSJ9.QOD0DkcUc32V3U4nsMmKS9UAsi5xniOOQhLUik21PeN_LyI3NvPAYEIMeyweaB_itvbWKBbwT_MEO_10Sc7hJiyPpCzsau1vsEacT_2b88btR3ok9KP-1ccsVpj1kOTi4aw_c_ULRWcg86C89GK-ZkwRBu3Knb7Lmny-SKlw2Xv5UAkhwPK7SovJkeraw6ZUiGCIJgBNuyqzaNVeWsWBjw.4IMRTqBteGL_jkzvegPh9SWgxWBZY2rXM-iBSEm67w4&dib_tag=se&keywords=urban+poles+for+walking&qid=1727826506&srefix=%2Caps%2C75&sr=8-3

<https://urbanpoling.com/8-benefits/>

Topic #7 Attachments

These are the diagrams mentioned in our message as part of Topic #7. Click on each and download to your device.

[Download all attachments as a zip file](#)

[Dual Doctor and PostOp LaryInfo-Generic TEP.pdf](#)

[Dual Doctor and PostOp LaryInfo-Generic Non-TEP \(1\).pdf](#)

The following attachments correlate with Topic #5

[Download all attachments as a zip file](#)

[Laryngectomy alert signs - TEP.pdf](#)

[Laryngectomy alert signs - no TEP.pdf](#)

[Suppliers.pdf](#)