

A close-up photograph of lavender flowers in shades of purple and blue. A honeybee is perched on one of the flower spikes, facing right. The background is a soft-focus field of more lavender plants.

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

May 2023



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From The Editor's Desk Community

Hello Friends!

If you need an online laryngectomy club to be a part of or are interested in starting one in your area, Tom Olsavicky of Yorktown, VA, tells us how it's done. Read about the Peninsula Lost Cord Club, its success, and the importance of patience and perseverance when things get challenging.

Brooke Moore of New Windsor, New York, shares about her dreams. In "Sci-Fi or Real Life?", Brooke envisions a world in which laryngectomees are normalized and everyone else is the exception. This world of hers is fun for laryngectomees to dream about!

Got a sweet tooth? Jeanine Milano, MS, RDN, CSO, Senior Clinical Dietician of Moffitt Cancer Center in Tampa, FL, tells us all about the use of dietary sweeteners. She stresses the importance of good nutrition and weight control during and after cancer treatment and that moderation is the key.

We are still collecting replies to our "What Do YOU Say?" question and will share these when we have a few more of them. The question is: How have your life experiences equipped you to help others? So, what do YOU say?

We are always grateful for your comments and suggestions and for your support of Whispers on the Web.

Enjoy the issue!

Tom Whitworth
WebWhispers President

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Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S, CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at Kalmand@uthsc.edu or Erin.Guidera@moffitt.org

Understanding Artificial Sweeteners and Sugar Substitutes

It is important to be mindful of what you eat during and after treatment for head and neck cancer. Maintaining good nutrition and weight management are a crucial part of cancer treatment and recovery. Although sugar substitutes can lower caloric intake, these options and their terminology can be confusing. The following is an explanation of some of the common types of sweeteners and sugar substitutes, with a reminder that moderation is key!

Natural Sweeteners

Natural sweeteners are promoted as healthier options than sugar and other sugar substitutes. But even these “natural sweeteners” often undergo processing. Natural sweeteners that the FDA recognizes as generally safe include:

- Fruit juices and nectars
- Honey
- Molasses
- Maple syrup

Natural sugar substitutes may seem healthier than sugar. That said, consuming too much added sugar (even natural sweeteners) can lead to health problems such as tooth decay, weight gain and increased triglycerides.

Artificial Sweeteners

Artificial sweeteners are synthetic sugar substitutes. They can be derived from chemicals or from naturally occurring substances, such as herbs or sugar itself. Artificial sweeteners can be attractive alternatives to sugar because they add virtually no calories to your diet. Additionally, you need only a fraction of artificial sweetener compared with the amount of sugar you would normally use for sweetness.

Possible health benefits of artificial sweeteners:

Weight control. Artificial sweeteners have practically no calories. If you are trying to lose weight or are trying to prevent weight gain, products sweetened with artificial sweeteners may be an attractive option, although their effectiveness for long-term weight loss isn't clear.

Diabetes. Artificial sweeteners aren't carbohydrates. So unlike sugar, artificial sweeteners generally don't raise blood sugar levels.

There are possible health concerns with artificial sweeteners. Critics of artificial sweeteners say that they cause a variety of health problems, including cancer. In the 1970s, studies linked the

artificial sweetener saccharin to bladder cancer in laboratory rats. Because of those studies, saccharin once carried a label warning that it may be hazardous to your health.

According to the National Cancer Institute and other health agencies, there's no definitive scientific evidence that any of the artificial sweeteners approved for use in the United States cause cancer or other serious health problems. As a result, the warning label for saccharin was dropped.

Novel sweeteners

Novel sweeteners are hard to fit into a particular category because of what they're made from. Stevia is an example. The FDA has approved highly refined stevia preparations as novel sweeteners but hasn't approved whole-leaf stevia or crude stevia extracts for this use.

Sugar alcohols

Sugar alcohols (polyols) are carbohydrates that occur naturally in certain fruits and vegetables — although they can also be manufactured. Despite their name, sugar alcohols aren't alcoholic because they don't contain ethanol, which is found in alcoholic beverages. Sugar alcohols contain calories. But they're lower in calories than sugar, making them an attractive alternative. When eaten in large amounts, sugar alcohols can have a laxative effect, causing bloating, intestinal gas and diarrhea. Product labels may carry a warning about this potential laxative effect.

Moderation is key!

Artificial sweeteners and sugar substitutes may help with weight management, but they should be used only in moderation. Food marketed as sugar-free isn't calorie-free, so it can still cause weight gain. Keep in mind that processed foods -

which often contain sugar substitutes - generally don't offer the same health benefits as whole foods such as fruits and vegetables.

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Jeanine Milano, a Registered Dietitian-Nutritionist, has been working at H. Lee Moffitt Cancer Center in Tampa, Florida for almost 4 years. Last summer she became a board-certified specialist in oncology nutrition and is now the subject matter expert for Head and Neck Cancer within the nutrition department here at Moffitt. You can find Jeanine in the outpatient nutrition clinic in the rehab department, where she helps keep patients healthy before, during and after treatment.

References:

Mayo Foundation for Medical Education and Research. (2020, October 8). Pros and cons of artificial sweeteners. Mayo Clinic. Retrieved August 31, 2022, from <https://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/artificial-sweeteners/art-20046936>





Forming a Support Group

Tom Olsavicky

It was 2008 when I was told that I would need to have a total laryngectomy and I thought my life would be forever changed. I can remember thinking that I would be writing everything I had to say because I didn't know any other way of speaking without a voice box. However, I picked up a flier in the doctors waiting room that had information on the Tidewater Lost Chord Club (LCC) in Virginia Beach which was 40 miles from my home.

I was eager to find out what they did and how they coped with this surgery. I thought it would be a quiet meeting, but I was very wrong. As soon as I entered the room, I heard everyone "talking" but sounding a bit different than normal. That's when I realized I would be okay!

Throughout the meeting I listened to the different voices and on the way home I told my wife what I would be choosing for my voice. I wanted to be understood and if I could use an electrolarynx to accomplish that, then that is how I would sound after surgery. It was a very emotional first meeting, but I saw that there was a good life ahead.

The more meetings I attended, the more I felt that I needed to be able to somehow pass along what I was about to experience. I learned of 60 other folks within a 50-mile radius from me that were not attending these club meetings.

About a year after surgery, my speech-language pathologist (SLP) strongly suggested starting my

own support group and possibly getting those 60 laryngectomees involved. I thought it was worth a try and it would be a way for me to pass along what the Tidewater club did for me. My SLP helped secure a meeting location and we came up with a name, the Peninsula Lost Chord Club.

I had heard the words "support group" should not be used because it should imply more than that since many larys were not new and did not need support. I wanted to get as many of us involved so that we could learn from one another. I now had to get the word out about the new club and to let the surgeons in the area know what we wanted to do.

I wrote a letter and with the help of the American Cancer Society was able to send it to many larys and doctors in the area. We picked a date, and that first meeting's attendees included me, my wife, my SLP and one other lary.

Since I was determined to hang in there, I was not discouraged and proceeded to send out a recap of that meeting. Well, the recap did the trick and got more interest in our club. Before long, I had more larys, caregivers and friends of larys getting involved.

I started to invite guest speakers to increase interest and to further get the word out as to what could be accomplished. The local surgeons were seeing new patients who had been to club meetings respond better to treatments and accept

their new life more quickly. Surgeons then started recommending all newly diagnosed individuals attend our club meetings prior to having surgery. That alone gave us a huge boost to what we were trying to accomplish and fueled the fire in me to continue the effort for as long as I could.

I attended a visitation training session provided by the Tidewater LCC so that I could begin hospital and home visits to reach beyond the club meetings. By providing club flyers, vendor information brochures, and helpful internet information, I began to see attendance growing to 20 or more. Then COVID set us back because we were unable to meet in person.

That is when I heard of something called Zoom that could be used to safely meet and share stories and provide guidance. I have had such good attendance with that platform and members can attend regardless of the weather, traffic, or their location, so I now conduct two Zoom meetings per week plus have one in-person meeting per

month. The Zoom meetings have allowed me to reach patients in other states which gives us a much broader perspective and shows us how the larynx all over our country are adjusting to their locales and changing weather conditions. I still belong to the Tidewater LCC and will be forever indebted to them for how they helped me accept this “new normal” and the support they still offer to my own club.

I am more determined than ever to continue to provide encouragement, information, guidance and help to all newly diagnosed throat cancer patients no matter how large or how small my club numbers tend to be. My in-person meetings have gone down to just two of us at times but seem to be bouncing back since mask mandates have been lifted. I want folks to know there is a place to come to get answers to their questions and to learn from our experiences in this journey. I hope that this article will encourage you to start a club of your own and enjoy the satisfaction of helping those who come after us.



Sci-Fi or Real Life?

Thoughts on Life as a Laryngectomee Brooke Elkan-Moore

I have never been a fan of science fiction, not even after years of watching Dr. Who with my husband who loved all types of sci-fi. But in the last few weeks, I have had several interesting dreams that can only be put in the category of strange and unusual.

Each one had an element of medical mystery, surprising results, and odd context. In all of them, laryngectomees were the normal, most populous of the characters, and generally the rock stars of the situation. (Prelude to the IAL meeting, for sure.)

What was central to all of them was the normalization of neck breathing. Those who were nose and mouth breathers were thought to be odd and pitied as they were forced to endure horrible odors, lingering allergies, and sneezing attacks. Not that we as larys are totally without those moments.

Complicated and beautiful stoma covers prevailed and HMEs were in bright colors, blinged out and beautiful. One wearer had a base plate that was customized for the neck shape and stoma position, providing a dramatic place of honor for the HME. Atos and InHealth, consider what that could be like!

Hands free speaking was simple and clear, no blown base plates and lots of volume. (Perhaps wishful thinking gone wild.) Voicing was filled with intonation, loud and soft as needed, and appeared effortless. There were artificial larynx devices (ELs) that were beautiful to look at, ergonomic in design, made for different hand and neck sizes, providing sound quality that was ethereal and compelling.

Some ELs were designed to lay along the neck, rising as needed to make contact as speech was initiated with minimal effort. One character had an implanted EL device which was a smart



device responding to breathing and movement to provide contact and sound. Very cool indeed.

The neck breathing was so natural, so ordinary that no one was taking notice. In one of the dreams, swimming freely underwater was possible with no complex apparatus. The feel of the water and the surge of energy from gliding along was so real that I did not want to awaken. If anyone asks me if I miss anything from before, it would be the freedom to be in the water with no concerns other than stretching, taking off and gliding along. My earliest memories are of swimming and of diving off of the highest platform at the pool at 3. I thought that since I was so far from the bottom, I would not hit it! Needless to say, my mother almost had a heart attack when I launched off!

Daily life as a lary does involve some sci-fi elements for most of us, from the way we communicate to how we breathe. Finding our best path to health and happiness involves embracing those elements and pushing the limits of what is offered to us while imagining a wide world of neck breathers moving through life with grace and joy.

