



The
New Voice News



New Voice Club of Broward County
Serving the tri-county area
of southeast Florida
www.newvoiceclub.org

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~ Next Meeting Sunday, January 20th, Noon to 2 p.m. ~
Conference Center at Holy Cross Hospital
4725 N. Federal Hwy, Ft. Lauderdale, FL (south of Commercial Blvd)
Noon: Rap Sessions Followed by Light Refreshments 1:15: Meeting and Program

From I-95, east on Commercial Blvd to Federal Hwy (U.S.1) Turn R (south) on Federal Hwy to 47th St. (1st street after the Holy Cross Main Entrance). Turn R onto 47th Street to the Ortho Parking Lot on your right. Park anywhere in the parking lot. Conference Center is the building to the right.
Look for New Voice Club Banner

Explaining How You Breathe ~ a Webwhispers Post December 20, 2007~

I had a request from a member this morning for a way to explain to a new medical person or, in his case, an anesthesiologist, how he now breathes.

Here on the Inhealth site you will find the "before and after" drawings that will show them exactly. You can click on the pictures and enlarge...then print. Take with you. Your new doc will understand immediately that your trachea has been cut and turned to a new opening...the stoma, and you are now a total neckbreather Pictures and explanation are here.

<http://inhealth.com/voicerestorationwhatsalary.htm>

The explanation it gives on that page is: "A laryngectomy is the surgical removal of the larynx. The larynx, also called the voice box, is the organ in the throat that creates speech and, in conjunction with the epiglottis, prevents food from entering the airway during swallowing. It lies between the trachea (windpipe) and the upper part of the airway known as the pharynx, forming part of the tube in the throat that carries air to and from the lungs to create speech, air from the lungs is expelled over the vocal cords in the larynx, resulting in vibrations, which are modified by the tongue, palate and lips. When the larynx is removed, the top of the trachea immediately below the larynx is attached to a permanent opening made in the throat called a stoma. It is through this opening that the laryngectomee breathes." To copy for medical personnel, all you need is the first and last sentence of that. They know the anatomy.

inhealth will furnish you with a set of those pictures and they also have the laryngectomee Needs Chart for your use during a time when you can't speak. You will find pictures of that, an over the bed chart, and decals that say you breathe only through a hole in your neck, along with where to get them. All of this will assist you with your explanations. It's on our site at <http://webwhispers.org/library/FreefortheAsking.asp>

It's a traumatic time, especially for new larys, to have to go for another kind of surgery where they see few of us. If you prepare a folder with this information, it will be ready to show to a new doctor. Sometimes we don't use the same language in trying to explain what happened to us and they don't understand that it is a total laryngectomy. *Pat Sanders*

Editor's note: This post reflects our own mission of educating professionals to our changed anatomy and the needs of laryngectomees. This is the very work we do on a daily basis. Please join us by educating your professional..

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What's Doing Around Town

Warren and Flori Goodman had a great trip to Georgia where they celebrated at a four generation family gathering.... Earl Mogk visited Robert Iglesias, a new laryngectomee, at Cleveland Clinic the day before Thanksgiving....Thanks to Henry Kurainowicz and Elaine Brown for their generous gifts to the club....Mike Rosenkranz is recuperating from a rather nasty fall and will be back among us in January..

Pascale's meeting: Due to an unexpected scheduling conflict, January's HealthSouth meeting was cancelled. There will be no further meetings at HealthSouth. See the article on page four, column one for further details.

Penny's meeting: The NVC was represented by only three long-time laryngectomees, Lenny Weinstein, Gary Morey and Howard Grabowski, but the discussion was still lively at Penny's December 11th gathering. Topics were planned for next year, which will include Dr. Wen describing acupuncture for treating symptoms common to head and neck cancer survivors, and speakers from the Sylvester speech therapy department and Courtelis Center. Ideas were offered to attract Dade County's many new laryngectomees who currently have no local laryngectomee support available, followed by a discussion of the various meetings in Broward county. The meeting ended with the sharing of personal stories in a review of the past year.

Lynn's meeting: A full house in Boca Raton welcomed recent laryngectomee Edward Arndt and his wife Bev staying in Jupiter for the winter from South Carolina. All questions were answered and many topics of interest to new laryngectomees were discussed, including the optimal placement of an EL, stoma attachment as well as humidifying room air to decrease mucus production.

Main Meeting: Despite last minute miscommunication due to building construction in our usual location, a standing room only crowd enjoyed lively discussions and laughter in the beautifully prepared room on the second floor of the Cancer Center which Holy Cross set up for our Holiday Party. Forty-five members and guests were treated to a generous spread of holiday treats and enjoyed outstanding entertainment expertly offered by the dynamic duo, Treble in Paradise. It was heartening to see that so many new members who joined us over the past year were among those attending. Pascale Bourne MS, CCC-SLP was there with her two little angels, and announced her increased participation with our group. She will be in attendance at every main meeting of the club.

Upcoming Events

Main Meeting 3rd Sunday of each month

Next meeting January 20th Noon-2 p.m.

**Rap Sessions at noon
Light refreshments at 12:45 p.m.
Meeting and Program at 1:00 p.m.**

**Conference Center - Holy Cross Hospital
4725 North Federal Highway, Ft. Lauderdale
(U.S. 1 just south of Commercial Blvd.)
More information: Christina at (954) 267-7770**

**This Month's Guest Speaker
Pascale Bourne MA, CCC-SLP
who will speak on
"Safety Issues for Laryngectomees"
Pascale will be available to answer
any questions you may have**

**Support Group Meeting
Boca Raton Community Hospital
Davis Therapy Center
Oaks Plaza, Glades Road at 13th Street**

**Lynn Carrier MS, CCC-SLP
3rd Thursday of each month**

**Next Meeting - January 17th
10:30 - 11:30 a.m.**

More information: (561) 955-2100 Ext 7430

**Veterans Administration Medical Center
7305 N. Military Trail
West Palm Beach, FL 33410**

**Loreen Blumenthal, M.S.P.A., CCC-SLP
Veterans Laryngectomee Group
(Veterans & family members only)**

**2nd Thursday of each month
Next Meeting - January 10th**

11a.m. - 12 noon

More information (561) 422-6237

**UMSylvester/Deerfield
Comprehensive Cancer Center
1192 East Newport Center Drive, Suite 100,
Deerfield Beach**

**Penny Fisher MS, RN, CORLN
Mort Silverblatt SPOHNC Support Group
2nd Tuesday of each month**

**Next Meeting - January 8th
1:30 - 3:00 p.m.**

More information (305) 243-4952

Breaking the Silence on Sexuality

Susan Glaser, LCSW, Janet McKiernan, RN, Page Tolbert, LCSW, Karrie Zampini Robinson, LCSW

Sexuality is a part of our identity and it contributes to who we are as people. Intercourse and reproduction are just two of the many functions of one's sexuality. Our appearance, the way we walk and talk, how we hold ourselves, and how we communicate, all contribute to our sexual identity. Neurological, endocrine, vascular and psychological systems interact to create our sexuality. Family, religion, and society can play important roles in shaping our sexual expression.

Despite the important role sexuality plays throughout our lives, the healthcare team may inadequately address it during the continuum of a head and neck cancer patient's experience. The impact of cancer is multidimensional, affecting some patients in terms of their physical functioning, while affecting others in terms of their body image, self-esteem or self-concept. When confronted with a serious illness, it is often assumed that a person's desire to survive will be a priority over their sexual desires and need for intimacy. While this may be true at times for some people, others may crave the attention of loved ones and struggle with this need while attending to treatment or post-treatment issues. Coming to terms with a new sexual self emerging after treatment seems to be one of the many central tasks of adjusting to living with head and neck cancer.

As one patient remarked, "Cancer just isn't sexy." And it's certainly true that feeling that our life is in danger isn't compatible with sexual feelings or attractiveness. For many patients, fatigue, hot flashes, pain, anxiety and other symptoms can interfere with intimacy. And in some cases, a partner may be anxious or hesitant about pursuing someone who has been ill.

A diagnosis of head and neck cancer and the ensuing treatment can affect one's sexual feelings, as well as one's physical performance. The need for certain equipment, such as PEG tubes for alternative nutrition, or tracheostomy tubes for an altered airway, can physically impede sexual relations. Surgical treatment, chemotherapy, and radiotherapy also affect people in ways that are not conducive to feeling comfortable, let alone sexy. Hair loss, weight changes, gastrointestinal problems, constipation or diarrhea, swallowing issues, can alter functioning as well as self-esteem.

Given the challenges we've mentioned above, it may not be surprising to learn that studies show that head and neck cancer patients have many of the same sexual concerns as patients whose cancer involved a sexual organ. This illustrates that the words "sexual organ" must be thought of more broadly, and should include the mouth, face, and neck, and, of course, the greatest sexual organ of all – the brain. These same studies indicate that twenty-five percent of head and

and neck patients say they do not even fantasize about sexual activity. It's hard to pursue something you don't even think about. Let's examine some of the reasons people with head/neck cancers face such a struggle in the area of sexuality.

People treated for oral, head and neck cancers may have a host of side effects and after-effects particular to their cancer. Serious facial disfigurement may be a concern that is a complex factor. Survivors of other cancers may be able to keep their cancer experience to themselves; however, in most cases this is not an option for head and neck patients. Even when the evidence of surgery or radiation treatment is minor, it is external, and therefore visible as contrasted to other cancer patients who can hide their "scars". This may lead the patient to feel profoundly changed, despite reassurance from others that this is not the case. A poor body image may cause a patient to feel ashamed, self-conscious, or anxious about their body. If a patient has a poor body image or low self-esteem, they may feel unattractive to others. This can lead to a very common phenomenon among those who have had head and neck cancers: isolation. Isolation, of course, can turn to profound loneliness, and from there, to depression. The latter is a risk for any cancer patient, whether or not he actually withdraws from the world. When you've had cancer, it's easy to feel that you are alone with no one to understand what you have been through. In this state of mind, sexual feelings may be the last thing you're likely to experience or to act upon. It's important to know that there are now new medications, which many patients have found helpful in alleviating depression. Some of these medications have some side effects – including dry mouth and lowered libido – which may add to sexual difficulties. Discuss treatments with your doctor or pharmacologist to find which is less likely to cause such problems.

Some patients just assume that sex will not be part of their lives after head and neck cancer. This is particularly true, if someone feels unattractive or disfigured.

For some and head and neck cancer patients, symptoms and side effects are not conducive to reaching and connecting with others. Some patients cannot eat or drink liquids easily. This can make it hard to mingle and meet people in the usual ways, with food being such a central part of many social activities. If one's ability to speak is compromised this may get in the way of meeting new people – or communicating with a current partner. This can make it difficult to have a full discussion of sexual needs, or to convey thoughts and wishes during sex.

Some other physical issues that effect sexual functioning include:

- Dry mouth
- Numbness of the tongue
- Trismus or "lockjaw"
- Pain and stiffness

(cont'd on page four, column two)



January Birthdays

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|----------------------|-----------------------|
| 7th Chrissy Myers | 16th Arthur Schultz |
| 8th Lucy Jamie | 16th Jim Stanton |
| 9th Jim Kimling | 17th Linda Kirschbaum |
| 10th Hy Sherman | 22nd Mollie Rapchik |
| 11th Paul Barber | 23rd Adele Sherman |
| 12th Judith Russo | 24th Leah Ostrander |
| 13th Dorinda Lothert | 26th Doris Shadd |

28th Joe Saliba

Happy Birthday to All

Great News to Start the New Year.

It has been over four years since we have had an SLP in attendance at our Sunday meetings. Effective immediately, Pascale Bourne MA, CCC-SLP will be at every Sunday meeting. Pascale will be our guest speaker for January. "Safety Issues for Laryngectomees" will be her topic. Most of us are well aware of Pascale's credentials, but for those who are not, here is a brief background.

- * Obtained a Master's of Arts degree in Speech/language pathology from the University of Pittsburgh
- * Began working with laryngectomee patients almost ten years ago at the Veteran's Administration Hospital in Pittsburgh
- * Continued working with head and neck cancer patients at H. Lee Moffitt Cancer Center in Tampa, Florida. Co-facilitator of the Chatterbox support group and re-established the laryngectomee visitation program that was started by Penny Fisher.
- * Has facilitated a satellite meeting for the New Voice Club for more than four years.
- * Presently works part-time at Florida Medical Center in Fort Lauderdale and per diem at HealthSouth Rehabilitation Hospital
- * Passionate about ensuring that every person and caregiver affected by a total laryngectomy has access to resources and knowledge to continue living a full life.

The satellite meeting at Health/South Rehabilitation Hospital has been discontinued. Our thanks to Health/South for their courtesy and cooperation during the time these meetings were held. HealthSouth SLPs will attend our Sunday meetings in their ongoing effort to further their knowledge of the needs of laryngectomees. Your Executive Committee is spearheading a search for a site for a first-week-of-the-month satellite meeting.

(cont'd from page three)

Finally, as most patients are well aware, using alcohol can cause major problems for those who have had head and neck cancers. Alcohol use may increase the chances that your disease might return. It can also impair sexual functioning and your sex drive as well.

Sometimes a partner's fears or anxieties may lead him or her to withdraw from the patient. They worry that intimacy may hurt the patient or disturb a surgical flap. Partners may think that they shouldn't be thinking of sex at this time in the patient's life. They may decide to defer physical contact until they feel the patient isn't so vulnerable or until treatment is completed. Naturally, the patient may feel rejected and unwanted if this exchange is not discussed in some clear manner. Sometimes reassurance from a nurse or doctor may help partners to overcome their fears and give them "permission" to reach out. Communication between a patient, sexual partner, and the health care team is imperative if there are sexual issues associated with the changes brought on by cancer and its treatment.

But even in the worst-case scenario, when a partner cannot cope with the changes the patient has undergone, or a new partner cannot be found, it is important for patients to recognize that they need to be comfortable with themselves.

Some suggestions:

Look at yourself, touch yourself, and work to accept your body as it now is. If you have a partner, attempt to involve him or her throughout the treatment process so that both of you can become familiar with the changes that may take place in your body. Try to find professionals you feel comfortable talking to and who can educate you about any changes that can be expected. Ask questions. What is the sexual impact I can expect from my treatment? How long will it last? What can I do about it?

Throughout treatment, simple gestures like cuddling and holding one another can be extremely important. Keep your expectations realistic. Slowly, attempt to explore other options for intimacy. Don't feel that intercourse has to be rushed.

Communication is key. Be courageous and break the silence. Talk about your feelings and ask others about theirs. If this is difficult for you, seek help from staff or outside experts regarding these issues. Look to other patients who may have had similar struggles with body image and sexuality. Attend a support group; try individual counseling, sex therapy (www.aasect.org) if you want an objective sense of support and education.

Use your brain as well as your body. The brain has been referred to as the body's most powerful sex organ. Imagination can work wonders to help one's libido.

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