A lary was scheduled for spinal surgery. Hospital records clearly stated: “total neck breather.” The surgeon, nurse anesthetist and anesthesiologist either hadn’t read the record, or had not understood it. They tried to give her oxygen and anesthesia down her throat. Things went south and they called an emergency code with doctors racing to the operating room. Some doctor removed her TEP prosthesis, and then another thought the TEP puncture was a tear in the trachea and tried to repair it. She could have suffered brain damage or died. She survived when she was transferred to a hospital that knew how to treat larys. It is not known if she sued the first hospital. (Reported by a medical doctor.)

Biggest Threat to Lary Health and Safety


Part 1 can be read at TheIAL.com under Publications-The IAL News. If you have not read it, please do. Part 1 reported on a survey of over 45 speech therapists and a half dozen MDs. The threat to laryngectomees health mentioned by the majority was: “A lack of basic knowledge of laryngectomees and their changed anatomies and their breathing by medical professionals (such as confusing tracheostomy vs. laryngectomy), and subsequent inability to provide appropriate treatment. These professionals include pulmonologists, respiratory therapists, primary care physicians, nurses, anesthesiologists, SLPs, and ENT MDs.”

Part 1 stated that laryngectomees can minimize the chances that medical professionals will injure them and even cause their deaths. Several things were recommended:

1. Identify yourself through bracelets and necklaces, cards carried in wallets or purses, notifying first responders ahead of time, use car window stickers, and others.
2. Learn how your breathing worked before you became a laryngectompee and how it now works. Know that you are a total neck breather. The article also stated that the air reaching our lungs is now dirtier, drier, and cooler.

It described ways to improve our breathing by urging us to wear a stoma cover 24/7, maintain an indoor humidity level of between 40-55%, and listed ways to maintain a good flow of mucus (which is essential for healthy lungs and windpipe.) It concluded with a quote and the advice to never allow medical personnel to put an oxygen or anesthesia mask over your mouth and nose, or a tube down your throat, without questioning them on whether they understand you are a laryngectompee and total neck breather.

It is a sad fact, but laryngectomees (and their loved ones/caregivers) must stand guard and advocate for themselves until they are certain that medical personnel who will provide treatment understand our changed breathing systems.

Like anyone else, we would like to fully trust a doctor, nurse or other medical provider we have gone to for treatment. It really seems an unfair burden on us to possibly have to educate these professionals about how we breathe. Unfortunately, the facts tell us that we should ask questions and make sure they understand what a total neck breather is.

“Never assume that medical staff understand how you breathe.” Brian Shute, Ph.D., CCC-SLP

A Laryngectompee’s Nightmare

A lary was scheduled for spinal surgery. Hospital records clearly stated: “total neck breather.” The surgeon, nurse anesthetist and anesthesiologist either hadn’t read the record, or had not understood it. They tried to give her oxygen and anesthesia down her throat. Things went south and they called an emergency code with doctors racing to the operating room. Some doctor removed her TEP prosthesis, and then another thought the TEP puncture was a tear in the trachea and tried to repair it. She could have suffered brain damage or died. She survived when she was transferred to a hospital that knew how to treat larys. It is not known if she sued the first hospital. (Reported by a medical doctor.)

On His Deathbed

A Speech Therapist (SLP) stopped to visit a hospitalized laryngectompee friend who was dying. When she came into the room she saw that an oxygen mask had been placed over his nose and mouth. She asked a nurse why, and she replied, “To make him comfortable.” She explained that he was a laryngectompee and total neck breather and that oxygen going into his stomach was not “making him comfortable.” She refused to leave until the oxygen was provided through his stoma. (Reported by an SLP [speech therapist.])
Why?

How is it possible that a doctor, nurse, anesthesiologist, respiratory therapist, speech therapist, or nurse anesthetist does not know how we breathe? How can so many make terrible mistakes that injure us or worse?

The answer has a number of parts:

1. There are very few laryngectomees. Most sources estimate that there are 50,000 to 60,000 total in the U.S. It is a tiny percentage of the total adult population; a tiny fraction of one percent. The number of laryngectomy surgeries is estimated at about 10,000 per year. But the number of laryngectomees who died in that year is not known. Death certificates list the cause of death such as heart or respiratory failure and not that the person was a laryngectomee.

2. A medical professional, even one who has had some explanation of our breathing at some point in their training, can go through an entire career and never treat one of us. “Use it or lose it.” Like everyone else, medical people can forget.

3. Medical personnel may not know that they do not know that our anatomy is different, and therefore how to treat us.

So they may fall back on patients they have seen before who have holes in their necks, “trachs.” But the mouths and noses of trach patients are still connected to their lungs. Their neck hole typically helps them get a little more oxygen when something in the upper respiratory tract is partly blocked. But if they are having surgery, a tube can be put down their throats (intubated) and oxygen and anesthesia provided. If they try to intubate a lary that way no oxygen or anesthesia can reach the lungs.

4. It would not be unusual for a description of a laryngectomee’s changed anatomies to never be discussed in the initial programs of SLPs, MDs (until they specialize in ENT), anesthesiologists, respiratory therapists, etc. The educational programs are simply full of information which applies to the other 99.999% of the population.

But as the first article which appeared in the May issue of the IAL News explained, there are things we can do to minimize the chances that medical personnel make mistakes in our treatment.

In the survey of 45 SLPs and several MDs, the second most mentioned threat to laryngectomee health and safety was depression.

Dealing with Depression

“Sir, I’m sorry to tell you that it IS cancer and at an advanced stage, and the only option is to surgically remove your larynx, your voice box.”

That statement is terrifying and overwhelming to many. It rattles their world and raises questions about survival, jobs and income, loss of a sense of who they are, impact on loved ones, loss of friends and hobbies, and many other fears. It is so world shaking that a few people refuse to have the surgery. If they were afraid of losing their voices and having a hole in their necks, they often end up with both as the cancer grows. A few take their own lives.

But if they agree to the surgery, they face an extremely long physical recovery along with what can be severe and long-lasting communications and other problems. It’s said that recovery from laryngectomy is not a matter of days and weeks, but months and even years.

There is a great deal of information laryngectomees need to learn, and the cancer may come at a time in their lives when dealing with many changes and learning a lot of new things is far from easy. For those without a support system of spouse, other family, caregiver or friend it can be especially overwhelming.

There is a growing reluctance of many medical personnel to ask a fully recovered laryngectomee to visit with the patient before and after surgery. There is a decrease in the number of laryngectomee support groups, and an inability of some larys to have the tools and knowledge to find support.
Anxiety and depression are common in laryngectomees as it is in other cancer patients. But depression frequently goes undiagnosed and untreated (studies have shown that primary care physicians fail to diagnose at least half of their depressed patients, particularly the elderly). A diagnosis of “clinical depression” is made based on how long the symptoms are lasting and how much they interfere with normal life activities.

Written questionnaires are often used to screen for depression. An example is one which asks for a yes or no answer to ten questions: “Over the past two weeks have you experienced:
- feelings of sadness and/or irritability?
- loss of interest or pleasure in activities once enjoyed?
- changes in weight or appetite?
- changes in sleeping patterns (not enough or too much)?
- feeling guilty?
- inability to concentrate, remember things, or make decisions?
- fatigue or loss of energy?
- noticeable restlessness or decreased activity?
- feeling hopeless or worthless?
- thoughts of suicide or death?”

With this questionnaire from the National Mental Health Association answering “yes” to five or more questions, or “yes” to the last one (for which you need to seek immediate professional help) are strongly suggestive of “clinical depression.” However, this diagnosis must be made by a psychiatric professional. Since depression is a symptom of thyroid gland problems, thyroid function needs to be ruled out.

Clinical depression is readily treatable with medications, counseling, or a combination of both. A number of very effective and non-habit forming medications are available. There are a number of approaches used in counseling. Self-help groups are beneficial. “Talking” therapies, such as cognitive-behavioral therapy provided by psychologist, psychiatrists or others, has been proven effective. See your primary care physician, psychologist or psychiatrist for diagnosis, referral, and/or treatment.

But the isolation and depression most laryngectomees experience is not “clinical depression” requiring professional help. Instead, there are many things laryngectomees can do to improve their isolation, anxiety and feelings of loneliness.

Communicate

Communicating is very important, especially for laryngectomees, and by whatever method or methods they have. Communication has been described as the most important of all life skills. It is what enables us to pass information to other people and to understand what is said to us.

But communication is also the means of establishing and maintaining relationships with others. Communication is essential to mental health. By expressing ourselves we can free the thoughts and feelings bottled up inside. It is a release.

Connecting with people including other laryngectomees is very helpful. Attend local support club meetings in person or via Zoom. For those without a computer or smart phone, public libraries have computers and people who can help with connecting them with support groups including the Internet’s WebWhispers, the largest laryngectomee support group. It is a great source of information and people who care.

Stay Healthy

Exercise: a minimum of 30 minutes most days. Even just walking can be very beneficial. Get outside, just that can be uplifting. Maintain a healthy diet and weight. Take multivitamin supplements. Get enough, but not too much, sleep. Keep to the schedule for follow-up and standard medical visits. Keep well hydrated. Coffee and tea do not count. Drink water and reduce drinking sugared beverages. Reduce sitting and screen time. Avoid using alcohol or drugs to self treat your feeling down.

Etc.

Volunteer. Visit a local, state or national park; botanical garden or zoo. Treat yourself. Join a church or become more involved in yours. Listen to music you like. Meditate. Do gardening. Help someone. Give to charity. Try and fill your hours and days with anything which makes you feel good about yourself.

Part Three, and the last in the series, will appear in the November issue of the IAL News.

Compiled by David Blevins