"The Laryngectomee Guide" is available in 18 languages (Free eBooks)

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Abstract "The Laryngectomee Guide" contains information about the diagnosis and treatment of laryngeal cancer, side effects of radiation and chemotherapy; methods of speaking; airway, stoma, and voice prosthesis care; eating and swallowing; medical, dental and psychological concerns; respiration; anesthesia; and travelling. The Guide is available now in 18 languages (English, French, Italian, Portuguese, Spanish (4 versions), Bulgarian, Bosnian, Greek, Romanian, Turkish, Arabic, Persian, Simple and traditional Chinese, Korean, Japanese, Filipino, and Russian).

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Laryngectomees face multiple challenges in dealing with the most basic human functions - communication, nutrition, and social interactions. Overcoming these challenges require mastering new techniques in caring for their airways; dealing with life long side effects of radiation and chemotherapy, and surgery: facing uncertainties about their future; and struggling with psychological, social, medical and dental issues.

"The Laryngectomee Guide" can assist laryngectomees, their caregivers and medical professionals in coping with these challenges. It contains information about the diagnosis and treatment of laryngeal cancer, side effects of radiation and chemotherapy; methods of speaking; airway, stoma, and voice prosthesis care; eating and swallowing; medical, dental and psychological concerns; respiration; anesthesia; and travelling.

The Guide contains 18 chapters

Chapter 1: Diagnosis and treatment of laryngeal cancer

Laryngeal cancer affects the voice box. Cancers that start in the larynx are called laryngeal cancers; cancers of the hypopharynx are called hypopharyngeal cancers. Laryngeal
cancer occurs when malignant cells appear in the larynx. The larynx contains the vocal cords which, by vibrating, generate sounds that create audible voice when the vibrations echo through the throat, mouth, and nose.

Laryngeal and hypopharyngeal cancer may spread by direct extension to adjacent structures, by metastasis to regional cervical lymph nodes, or more distantly, through the blood stream to other locations in the body. Distant metastases to the lungs and liver are most common. Squamous cell carcinomas account for 90 to 95 percent of laryngeal and hypopharyngeal cancer.

Smoking and heavy alcohol consumption are the main risk factors for laryngeal cancer.

Symptoms and signs of laryngeal cancer include: abnormal (high-pitched) breathing sounds, chronic cough, difficulty swallowing, sensation of a lump in the throat, persistent hoarseness, neck and ear pain, persistent sore throat, swelling or lumps in the neck, and unintentional weight loss.

The following tests and procedures may be used to help diagnose and stage laryngeal cancer which influences the choice of treatment: physical examination of the throat and neck, endoscopy, laryngoscopy, CT scan (computed tomography), MRI (magnetic resonance imaging), barium swallow, and biopsy. Early or small laryngeal cancer may be treated with surgery or radiation therapy. Advanced laryngeal cancer may require surgery, radiation therapy and chemotherapy. A team of medical specialists generally collaborates in planning the treatment.

Patients should be well informed before making their choice. If necessary, obtaining a second medical and/or surgical opinion is helpful. Having a patient advocate (family member or friend) attend the discussions with the medical team is desirable as they can assist the patient in making the best choice.

Chapter 2: Having surgery: types of laryngectomy, outcome, pain management, getting a second opinion

There are two types of surgery for removal of laryngeal cancer: Removal of part of the larynx or Removal of the entire larynx. Lymph nodes that are close or drain the cancerous site may also be taken out during either type of surgery.

Prior to surgery it is important to thoroughly discuss with the surgeon all-available choices. Because the patient may be anxious and under a lot of stress, it is important to have a patient advocate (such as a family member or friend) also present. It is important to freely ask and discuss any concerns and request clarifications. It is also important to see these medical providers: Internist and/or family physician, Any specialist one sees for a specific medical problem (i.e. cardiologist, pulmonologist, etc.), radiation oncologist, medical oncologist, anesthetist, dentist, speech and language pathologist (SLP), social worker or mental health counselor, and nutritionist.

It is very useful to meet other individuals who have already undergone a laryngectomy. They can guide the patient about future speech options, share some of their experiences, and provide emotional support. Getting a second opinion may also be helpful.

Chapter 3: Side effects of radiation treatment (RT) for head and neck cancer

The side effects of RT for head and neck cancer are divided into early (acute) and long term (chronic). Early side effects occur during the course of therapy and during the immediate post therapy period (approximately 2–3 weeks after the completion of a course of RT). Chronic effects can manifest any time thereafter, from weeks to years later.

Early side effects include inflammation of the oropharyngeal mucosa (mucositis), painful swallowing (odynophagia), difficulty swallowing (dysphagia), hoarseness, lack of saliva (xerostomia), orofacial pain, dermatitis, nausea, vomiting, and weight loss. These complications can interfere with, and delay, treatment. To some degree, these side effects occur in most patients and generally dissipate over time.

Late side effects of RT include permanent loss of saliva (xerostomia), osteoradionecrosis, ototoxicity, fibrosis, lymphedema, hypothyroidism, neurological, ear, and neck structures damage.

Chapter 4: Side effects of chemotherapy for head and neck cancer

Chemotherapy for head and neck cancer is used in conjunction with supportive care for most patients with metastatic or advanced recurrent head and neck cancer. Therapeutic options include treatment with a single agent and combination regimens with conventional cytotoxic chemotherapy and/or molecularly targeted agents, combined with optimal supportive care. Chemotherapy is given in cycles, alternating between periods of treatment and rest. Treatment can last several months, or even longer.

The kind and type of possible side effects of chemotherapy depend on the individual. Some have few side effects, while others have more. Many individuals do not experience side effects until the end of their treatments; for many individuals these side effects do not last long. Chemotherapy can, however, cause several temporary side effects. Although these may be worse with combined radiation therapy, they generally disappear gradually after the treatment has ended.

The more common side effects are nausea, vomiting, diarrhea, sores (mucositis) in the mouth (resulting in problems with swallowing and sensitivity in the mouth and throat), increased susceptibility to infection, anemia, hair loss, general fatigue, numbness in the hands and feet, hearing loss, kidney damage, bleeding problems, malaise, and balance problem. An oncologist and other medical specialist watch for and treat these side effects.

Chapter 5: Lymphedema, neck swelling and numbness after radiation and surgery

Lymphedema is a localized lymphatic fluid retention and tissue swelling caused by a compromised lymphatic system. Lymphedema, a common complication of radiation and surgery for head and neck cancer, is an abnormal
accumulation of protein-rich fluid in the space between cells which causes chronic inflammation and reactive fibrosis of the affected tissues. Radiation creates scarring which interferes with the function of the lymphatics.

There are two types of lymphedema that can develop in patients with head and neck cancer: an external visible swelling of the skin or soft tissue and an internal swelling of the mucosa of the pharynx and larynx. Lymphedema generally starts slowly and is progressive, rarely painful, causes discomfort in the form of a sensation of heaviness and achingness, and may lead to skin changes.

Treatment of lymphedema includes: manual lymph drainage (face and neck, deep lymphatics, trunk, introral), compressive bandages and garments, remedial exercises, skin care, elastic therapeutic tape (Kinesiotape), oncology rehabilitation, diuretics, surgical removal (debulking), liposuction, compression pumps, and elevation of the head alone are ineffective treatments.

Skin numbness after surgery: The cervical lymph nodes, or glands, are generally surgically removed when the cancer is excised. Along with them the sensory nerves that supply the lower facial and neck skin are excised. This creates numbness in the areas supplied by the severed nerves. Some of the numb areas may regain sensation in the months following the surgery, but other areas may remain permanently numb.

Chapter 6: Methods of speaking after laryngectomy

Although total laryngectomy removes the entire larynx (vocal cords/voice box), most laryngectomees can acquire a new way of speaking.

SLPs can assist and guide laryngectomees in the proper use of the methods and/or devices they use to obtain the most understandable speech.

The three main methods of speaking after laryngectomy are:

1. Tracheoesophageal speech where air is exhaled from the trachea into the esophagus through a small silicone voice prosthesis that connects the two, and the vibrations are generated by the lower pharynx.
2. Esophageal speech where vibrations are generated by air that is "belched" out from the esophagus. This method does not require any instrumentation.
3. Electrolarynx or artificial larynx speech where vibrations in this speech method are generated by an external battery operated vibrator (called an electrolarynx or artificial larynx) which is usually placed on the cheek or under the chin.

Chapter 7: Mucus and respiratory care

Mucus production is the body’s way of protecting and maintaining the health of the trachea (windpipe) and lungs. It serves to lubricate these airways and keep them moist. After a laryngectomy, the trachea opens at the stoma and laryngectomees are no longer able to cough up mucus into their mouth and then swallow it, or blow their nose. It is still very important to cough and clear one’s mucus; however, this must be done through the stoma. The best mucus consistency is clear, or almost clear, and watery. Such consistency is, however, not easy to maintain because of changes in the environment and weather.

Steps to achieve better humidification include: wearing an Heat and Moisture Exchangers (HME) 24/7, wetting the stoma cover to breathe moist air (in those who wear a stoma cover), drinking enough fluid, inserting 3–5 cc saline into the tracheostoma at least twice a day, taking a steamy shower or breathing in water vapor, using a humidifier in the house to achieve about 40%–50%, and breathing steam generated by boiling water or a hot shower.

Winter and high altitude can be rough for laryngectomees where the air is dryer and is irritating to 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).

Care for the airway includes: coughing out or suctioning the mucus using a suction machine to clean the airway, avoiding exposure to cold, dry or dusty air.

A suction machine can be used to remove mucus and prevent plugs especially immediately after laryngectomy. Blood in the mucus can originate from traumatic scratch, irritation of the trachea because of dryness.

Chapter 8: Stoma care

It is very important to cover the stoma at all times in order to prevent dirt, dust, smoke, micro-organisms, etc., from getting into the trachea and lungs.

There are various kinds of stoma covers. The most effective ones are called Heat and Moisture Exchangers (HME) because they create a tight seal around the stoma. In addition to filtering dust, HMEs preserve some of the moisture and heat inside the respiratory tract and prevent the person from losing them. The HME therefore assist in restoring the temperature, moisture and cleanliness of the inhaled air to the condition before the laryngectomy.

The skin around the stoma can become irritated because of repeated gluing and removal of the housing. The materials used to remove the old housing and prepare for the new one can irritate the skin. Removal of the old housing can also irritate the skin especially when it is glued.

The buildup of mucus and the rubbing of the tracheostomy tube can irritate the skin around the stoma. The skin around the stoma should be cleaned at least twice a day to prevent odor, irritation and infection. It is important to prevent water from entering the stoma when taking a shower. A small amount of water in the trachea generally does not cause any harm and can be rapidly coughed out. However, inhalation of a large amount of water can be dangerous.

Chapter 9: Heat moisture exchanger (HME) care

HME serve as stoma covers and create a tight seal around the stoma. In addition to filtering dust and other large airborne particles, HMEs preserve some of the moisture and heat inside the respiratory tract and prevent their loss, and adds resistance to the airflow. HME assist in restoring the
temperature, moisture and cleanliness of the inhaled air to the same condition as before laryngectomy.

The HME captures the warm, moistened, and humidified air upon exhalation. It can be impregnated with chlorhexidine (anti-bacterial agent), sodium chloride (NaCl), calcium chloride salts (traps moisture), activated charcoal (absorbs volatile fumes), and is disposable after 24 h of use.

The HME advantages also include: increasing the moisture within the lungs (subsequently leading to less mucus production), decreasing the viscosity of the airway secretions, decreasing risk of mucus plugs, and re-instating the normal airway resistance to the inhaled air which preserves the lung capacity.

In addition, a special HME-combined with an electrostatic filter also reduces the inhalation (and exhalation/transfer) of bacteria, viruses, dust and pollen. Inhaling less pollen can reduce the airway irritation during high allergens season. Wearing an HME with filter may reduce the risk of getting or transferring viral and bacterial infection, especially in crowded or closed places. A new HME filter designed to filter potential respiratory pathogens is available (Provox Micron TM, Atos Medical). There are several types of HME housing; and finding the best HME housing may take trial and error.

The hands free HME allows speaking without the need to manually press on the HME to close it off, thus blocking exhalation through the stoma and directing air to the voice prosthesis. This device frees one’s hand and eases vocational and recreational possibilities.

Chapter 10: Tracheoesophageal voice prosthesis use and care

A voice prosthesis is inserted through a previously created tracheoesophageal puncture (TEP) connecting the trachea and esophagus in those wishing to speak through tracheoesophageal speech. It enables the individual to exhale pulmonary air from the trachea into the esophagus through a silicone prosthesis that connects the two; the vibrations are generated by the lower pharynx.

There are two types of voice prosthesis: an indwelling one that is installed and changed by a SLP or otolaryngologist and a patient-changed one.

There are two patterns of voice prosthesis leak - leak through the prosthesis and leak around it. Leakage through the voice prosthesis is predominantly due to situations in which the valve can no longer close tightly. This may be due to the following: colonization of the valve by fungus; the flap valve may get stuck in the open position; a piece of food, mucus or hair (in those with a fee flap) stuck on the valve; or the device coming in contact with the posterior esophageal wall. Inevitably, all prostheses will fail by leaking through, whether from Candida colonization or simple mechanical failure.

Leakage around the voice prosthesis is less common and is mainly due to trachea-esophageal puncture tract dilation or inability to grip the prosthesis.

It is advisable to clean the voice prosthesis’ inner lumen at least twice a day and after each meal to prevent it from leaking. It is also important to prevent the growth of yeast on the prosthesis.

Chapter 11: Eating, swallowing and smelling

Eating, swallowing, and smelling are not the same after laryngectomy. This is because radiation and surgery create permanent lifelong changes. Radiation therapy can cause fibrosis of the muscles of mastication which can lead to the inability to open one’s mouth (trismus or lockjaw) making eating more difficult. Eating and swallowing difficulties can also be generated by a decrease in saliva production and a narrowing of the esophagus, plus a lack of peristalsis in those with flap reconstruction. Smelling is also affected because inhaled air bypasses the nose.

This chapter describes the manifestations and treatment of the eating and smelling challenges faced by laryngectomees. These include swallowing problem, food reflux, esophageal strictures, and smelling difficulties.

Chapter 12: Medical issues after radiation and surgery: pain, vaccination, cancer spread, hypothyroidism and prevention of medical errors

Many cancer patients and survivors complain of pain. Pain can be one of the important signs of cancer and may even lead to its diagnosis. Thus, it should not be ignored and should be a sign to seek medical care. The pain associated with cancer can vary in intensity and quality. It can be constant, intermittent, mild, moderate or severe. It can also be aching, dull, or sharp.

Cancer pain can be treated by various methods. Eliminating the source of the pain through radiation, chemotherapy, or surgery is best, if possible. However, if not possible, other treatments include oral medication, nerve blocks, acupuncture, acupressure, massage, physical therapy, meditation, relaxation, and even humor. Specialists in pain management can offer these treatments.

Symptoms and signs of recurrent or new head and neck cancer: Most individuals with head and neck cancer receive medical and surgical treatment that removes and eradicates the cancer. However, there is always the possibility that the cancer may recur; vigilance is needed to detect recurrence or possibly new primary tumors. It is therefore very important to be aware of the signs of laryngeal and other types of head and neck cancer so that they can be detected at an early stage.

Low thyroid hormone (hypothyroidism) and its treatment: Most laryngectomees develop low levels of the thyroid hormone (hypothyroidism). This is due to the effects of radiation and the removal of part or all of the thyroid gland during laryngectomy surgery.

The symptoms of hypothyroidism vary; some individuals have no symptoms while others have dramatic or, rarely, life-threatening symptoms. The symptoms of hypothyroidism are nonspecific and mimic many normal changes of aging.

Thyroid deficiency can be corrected by taking synthetic thyroid hormone (Thyroxine). After identification of the proper maintenance dose, the patient should be examined and serum thyroid stimulating hormone (TSH) measured once a year (or more often if there is an abnormal result or a change in the patient’s condition). Dose adjustment may be needed as patients age or have a weight change.
Preventing medical and surgical errors: Medical and surgical mistakes are very common. They increase malpractice lawsuits, the cost of medical care, patients' hospital stays, and morbidity and mortality.

The best way of preventing errors is for the patient to be his or her own advocate or have a family member or friend serve as one's advocate. Medical errors can be reduced by: Being informed and not hesitating to challenge and ask for explanations, becoming an "expert" in one's medical issues, having a family or friends remain in the hospital, getting a second opinion, educating medical providers about one's condition and needs (prior to and after surgery).

Chapter 13: Preventive care: follow-up, avoiding smoking, and vaccination

Preventive medical and dental care is essential for patients with cancer. Many individuals with cancer neglect to attend to other important medical problems and focus exclusively on their cancer. Neglecting other medical issues can lead to serious consequences that may influence well-being and longevity.

The most important preventive measures for laryngectomees and head and neck cancer patients include: proper dental care, routine examinations by family physician, specialists and an otolaryngologist, appropriate vaccinations, stopping smoking, using proper techniques (e.g., using sterile water for stoma irrigation), getting vaccinations, and maintaining adequate nutrition.

Chapter 14: Dental issues and hyperbaric oxygen therapy

Dental issues can be challenging for laryngectomees, mainly because of the long term effects of radiation therapy. Maintenance of good dental hygiene can prevent many problems.

It is advisable that patients receiving radiation therapy to the head and neck visit their dentist for a thorough oral examination several weeks prior to initiation of the treatment and be examined on a regular annual or semiannual basis. Getting regular dental cleaning is also important.

Dental prophylaxis can reduce the risk of dental problems leading to bone necrosis. Special fluoride treatments may help to prevent dental problems, along with brushing, flossing, and having one’s teeth cleaned regularly. Hyperbaric oxygen therapy (HBO) can be used in patients at risk or those who develop osteoradionecrosis of the jaw.

Chapter 15: Psychological issues: depression, suicide, uncertainty, sharing the diagnosis, the care giver and source of support

Head and neck cancer survivors, including laryngectomees face many psychological, social and personal challenges. This is mainly because head and neck cancer and its treatment affect some of the most basic human functions - breathing, eating, communication, and social interaction. Understanding and treating these issues are no less important than dealing with medical concerns.

These issues include: depression, anxiety and fear of recurrence, coping with uncertain future, social isolation, substance abuse, body image, sexuality, suicidal intentions, return to work, interaction with spouse, family, friends, co-workers, and economic impact. All of these can be addressed and treated.

Being a caregiver for a loved one with a serious illness such as head and neck cancer is very difficult and can be physically and emotionally taxing. Caregivers should realize the importance of what they are doing even when they get no or little appreciation.

Sources for support include: Members of the health care team (physicians, nurses, and speech and language pathologists), Social workers, counselors, or members of the clergy, Support groups for laryngectomees and other individuals with head and neck cancer.

Chapter 16: Use of CT, MRI and PET scans in the diagnosis and follow-up of cancer

Computed Tomography (CT), Magnetic resonance imaging (MRI), and Positron Emission Tomography (PET) scans are non-invasive medical imaging procedures that enable the visualization of internal body structures. They are also used to detect cancer and follow up its progression and response to therapy. It is important to realize that these tests are not perfect and can miss a small tumor (less than one inch).

Chapter 17: Urgent care, cardiopulmonary resuscitation (CPR), and care of laryngectomees during anesthesia

Laryngectomees and other neck breathers are at great risk of receiving inadequate acute care when they experience breathing difficulties, when they need cardiopulmonary resuscitation (CPR) and when they get general anaesthesia or sedation. Emergency departments (ED), emergency medical response services (EMS) personnel, as well as hospital personal often do not recognize a patient who is a neck breather, do not know how to administer oxygen in the proper way, and may erroneously give mouth-to-mouth breathing when mouth-to-stoma breathing is indicated. This can lead to devastating consequences, depriving sick people from the oxygen needed to survive.

Neck breathers can prevent a mishap by: Wearing a bracelet that identifies them as neck breathers, Carrying a list describing their medical conditions, their medication, the names of their doctors, and their contact information, placing a sticker on the inside of their car windows identifying them as laryngectomees. The card contains information about caring for them in an emergency, placing a note on their front door identifying them as neck breathers, informing the local emergency services, EMSs and police department that they are neck breathers and may not be able to speak during an emergency, Ensuring that the medical personnel of their local ED can recognize and treat neck breathers.

Chapter 18: Travelling as a laryngectomee

Traveling by car or plane as a laryngectomee can be challenging. The trip may expose the traveler to unfamiliar
places away from their routine and comfortable settings. Laryngectomees may need to care for their airways at unfamiliar locations. Travelling usually requires planning ahead so that essential supplies are available during the trip. It is important to continue to care for one’s airway and other medical issues while travelling.

The Guide is available now in 15 languages (English, French, Italian, Portuguese, Spanish (4 versions), Bulgarian, Romanian, Turkish, Arabic, Persian, Simple and traditional Chinese, Korean, Japanese, and Russian). The E books are free. The Guide is being translated into more languages by medical professionals in the corresponding countries.

The American Academy of Otolaryngology - Head and Neck Surgery and other otolaryngological societies across the world have made the Guide available for free download on their websites.

Links to obtain the Guide in are below. The eBooks and Kindle versions are FREE.

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It is my hope that the Laryngectomee Guide would be helpful to laryngectomees and improve their care across the world.

Credit authors

The manuscript was prepared by a single author.

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