How You Can Help a Loved One Before and After a Laryngectomy

1) Before the surgery, record your loved one's voice.
2) Contact your local Emergency Medical Service (EMS) and/or Fire Department. Inform them that a laryngectomee is a total neck breather and:
   a) He/She ONLY breathes through an opening in their neck called a stoma. They are a Total Neck Breather
   b) Their Voice Box was removed and may have trouble speaking
   c) If oxygen and/or resuscitation are needed, it can only be provided through the stoma. NOT THROUGH THE MOUTH AND NOSE!
   d) Take the DVD: Rescue Breathing for Laryngectomees and Other Neck Breathers by Itzhak Brook, MD, MSc. to the EMS to review in case of an emergency (available through Atos Medical).
   You can also go to the following website to download a written booklet:
   e) Communicate any other important medical information
3) Find a way to communicate before coming back home from the hospital, such as:
   a) gestures c) lip reading e) speech menu
   b) writing d) artificial larynx (AL)
4) If an artificial larynx is being used, be patient. It takes time and training from both of you to understand one another. Some things that you can do, to help train your ear are the following:
   a) Pick a category (For example: days of the week, months of the year, colors, animals, places)
   b) Have your significant other say a member of the category using the artificial larynx
   c) Then, you try and guess what he/she said
   d) Practice this until you can understand about 75-80% of what he/she said
   e) Encourage your significant other to use the AL as much as possible
   f) See Care Tips 9 for more training tips on using the AL

Helpful Links:

- International Association of Laryngectomees: http://www.theial.com/ial/
- Web Whispers online support group: http://webwhispers.org/
- Head and Neck Cancer Alliance: http://www.headandneck.org/
- Support for People with Oral and Head and Neck Cancer: http://www.spohnc.org/
- Cancer Forward: http://www.cancerforward.org/
- Kansas University Medical Center's YouTube video: http://www.youtube.com/watch?v=LYrIVn4elQY
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5) If your significant other uses a smartphone (i.e. iPhone, Blackberry®, Droid), tablet pc and/or laptop computer, the following programs speak what you type:
   a) Speak It!  Text to Speech   c) Verbally for iPad
   b) Go Talk Now for iPad   d) Predictable

6) Set up your In Case of Emergency (ICE) contact information on your loved one's cellphone.

7) Purchase a medical alert bracelet with “Total Neck Breather” engraved on it. You can also include other important medical information (For example: high blood pressure, diabetes). Carry a medical alert card on your person.

8) Call your medical insurance company to ask the following questions:
   a) What are your Durable Medical Equipment (DME) benefits?
   b) Who are the approved DME providers in your area? These are suppliers that can bill your insurance for medical supplies like heat and moisture exchangers (HMEs), saline solution, suction catheters, and baseplates
   c) Will they cover medical supplies from out of network DME companies?

9) If your speech pathologist and/or doctor tell you that you will need to order special supplies after your surgery, call the supplier and set up an account ahead of time. This will make shipping process faster when you are ready to order.

10) During showers, a Provox® Shower Aid should be worn to prevent water from going into the stoma.

11) Have your speech pathologist, nurse and/or doctor tell you if there is a local support group in your area. These groups can be very helpful as they typically have guest speakers talk about various topics that can help your quality of life.

Check With Your Doctor, Nurse and/or Speech Pathologist regarding a list of supplies you may need upon discharge:

- Dry Erase Board or Pad of Paper
- Provox® Shower Aid
- Lint Free Facial Tissues and/or 4x4 gauze pads
- Saline
- Aquaphor® Healing Ointment for dry, irritated skin
- Long handled cotton swabs
- Compact Mirror
- Flashlight
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