

To help shed a little light...



Answers to your questions

Helpful information
for recent laryngectomees

The quebec federation of laryngectomees

Revised: september 2005

Acknowledgement

In the early 1960's the "Florida Laryngectomee Association" published a brochure of questions and answers aimed at clarifying some of the main concerns of people having undergone a laryngectomy (laryngectomees). The same model has been maintained in the present booklet.

We would like to thank Mr. August G. Hodak, President of the Florida Laryngectomee Association who allowed us to translate and adapt pertinent passages from the Association's brochure.

Special thanks to Mr. Marc-E. Thivierge, a laryngectomee and retired journalist from the press galleries of the Quebec National Assembly, who translated the Florida Association's brochure for our French-speaking laryngectomees.

We would like to express our gratitude to Dr. Daniel Larochelle, Director of the Department of Otolaryngology at Notre-Dame Hospital in Montreal, to Mrs. Doris St-Pierre-Lafond, Director of the Speech Therapy Department in the same hospital, as well as to her assistants Mrs. Louise Prud'homme and Mr. Clément Bolduc, who edited the responses so that they are clear, truthful and easy to read.

Members of the board of governors of the Montreal Association of Laryngectomees were asked to evaluate the pertinence of the questions and the precise answers of the first document. Who, better than experienced laryngectomees, to pass such a judgement? We wish to thank them for their indispensable collaboration.

For the second time since 1984, the Quebec Federation of Laryngectomees has revised its Question! Answer booklet. We hope that you shall find as much satisfaction in reading this booklet as we have revising it for you.

The Quebec Federation of Laryngectomees

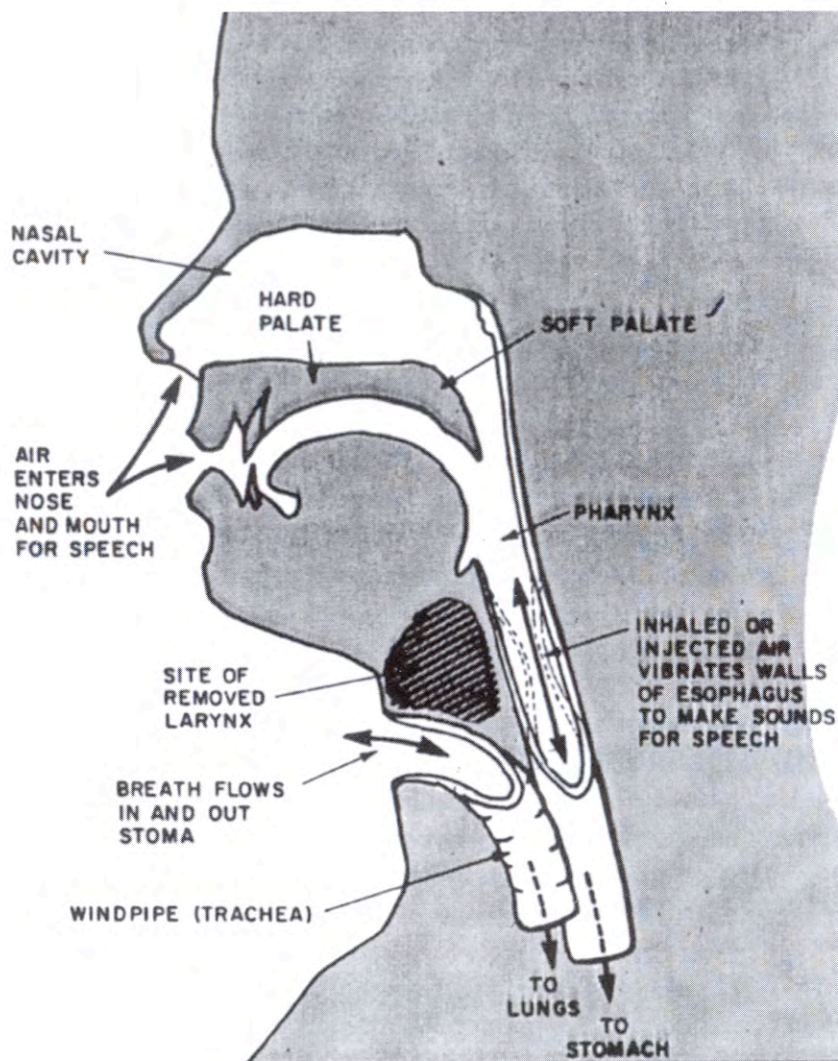


Figure 2 - After laryngectomy

10. Q. Is it really necessary to protect my stoma from dust?

- A. Yes, it is very important. Don't forget you can no longer depend upon your nose to filter, warm and moisten the air you breathe. Consequently, you are more sensitive to various irritants. If you are allergic to certain types of dust or if you are usually affected by certain chemicals (gasses, vapors, etc.), it is very important for you to cover your stoma. Remember that you must avoid alkaline dust (emitted during demolition work) which is particularly corrosive. Some people are even affected by "normal house dust" when they don't wear filters. In short, there are a thousand and one reasons for protecting your stoma with a filter.

11. Q. How can I tell if I have breathed in some harmful dust? What can I do about it?

- A. Normally, after breathing in some harmful dust, you will feel like coughing up heavier secretions than usual. Quickly cover your stoma and move to a place where the air is cleaner. Some types of irritating and corrosive dust particles take effect after a few hours. You will see a change in the colour of the secretions which will also become more gluey and sticky. To avoid being inconvenienced by dust particles of all kinds you are strongly advised to cover your stoma with an appropriate protector at all times.

12. Q. What kind of filter should I use to cover my stoma?

- A. The type of filter is irrelevant; it is the use of one that is important. There are very many types of filters. Some are free while others are sold by private companies. Here, in Quebec, the centers of Service to Laryngectomees distribute, free of charge a variety of filters. The Canadian Cancer Society offers some filters that are fabricated by its volunteers. Some "throw away" types of filters can be found on the market; but one must consider the long term expense of these. Finally, you can choose to fabricate your own to your taste and need. The ultimate goal is always to filter the air one breathes and to guard against the intrusion of any foreign object.

13. Q. Are there any important precautions to take?

- A. When you take a bath or a shower, be sure that the water does not enter your stoma. When boating, take a life preserver which allows you to keep your head and shoulders out of the water in case of an accident. As well, do not risk eating any food when you are lying on your back, especially if your stoma is not covered.

14. Q. Why does so much secretion accumulate in my stoma in the morning?

- A. Have you ever counted how many times you have to clean your stoma during the day? Surely many times. What happens while you sleep? Except on rare occasions, you don't feel the same need to clean your stoma. Yet, secretions do form in your trachea 24 hours a day, even during the night. As a result it is not surprising that there is a certain accumulation after 8 hours of sleep. Remember that before your operation this buildup was taking place in your trachea during the night. In the morning, you cleared your throat by spitting up or by swallowing these secretions. After your operation, this buildup does not reach your throat anymore; it stops at your stoma and you must clean it with a handkerchief.

15. Q. How can I best clear my stoma?

- A. Usually, it is enough to cough while placing a handkerchief in front of your stoma. The coughing brings up the secretions that have accumulated in the respiratory canal. If you notice a slight trace of blood in the secretions, don't be alarmed; this is rather frequent and not serious. However, if there is a large amount of blood, consult your doctor.

16. Q. How can I take care of my secretions without attracting attention when I am in a group?

- A. If you wear a filter, as we strongly recommend, this problem is easily solved. When you feel like coughing or sneezing, place your hand over your stoma and bow your head. This movement will have the following effects:

- a) It will greatly reduce the noise made by your cough or sneeze;
- b) It will make your secretions adhere to the filter and facilitate a return to normal breathing.

You will then have all the time you need to reach a lavatory where you will be able to clean your stoma and filter. Many laryngectomees are so discreet about it that they give the impression of not having secretions "like other people".

17. Q. Can cold weather irritate my stoma?

- A. If the stoma has healed well, cold weather will not irritate it. However, cold air entering your trachea through your stoma could irritate your wind-pipe and lungs. Don't forget that the air you breathe in now is no longer warmed by first passing through your nose. In cold weather, it is a good idea to create a kind of warm air space in front of your stoma by wearing a filter and even a scarf when it is very cold.

18. Q. Can I blow my nose?

- A. Yes, but not with the same force as before. Before the operation, the air was propelled from your nose by your lungs. After the operation, this air pressure is much less as it comes only from the mouth and the back of the throat. To blow your nose, place your handkerchief under your nose and close your mouth while keeping your jaws apart. Then, bring your jaws together as you force the air through your nose. For better results, free one nostril at a time while closing the other. Practice these steps and you will become more skilful.

19. Q. Can I take a shower? Wash my hair?

- A. Certainly. To guard your stoma, buy or make an appropriate protector. Your association will give you the necessary information. Should you take a shower without using a protector, make sure the water sprays in such a way so as not to get into the stoma. If you are afraid of the shower, wash your hair in the kitchen sink. Remember that: whenever there is a risk that water might enter your stoma, just place your hand or a wash cloth in front of the opening. This basic rule will help you to adapt to any situation.

20. Q. Is it true that laryngectomees require more humidity?

A. Warmth and humidity are helpful to laryngectomees; cold, dust and dry air are harmful. Many feel the need of extra humidity in their homes. A humidifier can be installed in the house and an extra one in the bedroom if necessary.

After being exposed to dust after a day when the air was very dry, nothing is more invigorating to a laryngectomee than a good hot water shower or bath.

21. Q. Q. If I am in an accident or if I pass out on the street, what will happen to me?

A. We suggest that you keep an identity card which contains information on your condition in your wallet. Moreover, it would be wise to wear a MEDIC-ALERT type bracelet on your wrist. Your regional office of l'Association des Laryngectomisés provides its members with an identity card containing advice for those who come to your aid. It would also be good for your family to know the mouth-to-stoma method of artificial respiration.

Part three

Some restrictions...but bearable ones

22. Q. Can I smoke?

A. Most medical advisors would answer, "You should not smoke". According to a specialist in Otolaryngology, 98% of his laryngectomy patients were "heavy smokers". It is said that lung cancer was nonexistent in Iceland until American soldiers introduced cigarettes there in 1917. Today, Iceland has the same percentage of victims of lung cancer as other western countries.

23. Q. Can I take a little drink from time to time?

A. That depends on you. If you found it difficult to "stop in time" before the operation, you will have the same problem afterwards;

it might even get worse. So you are the only one who can judge what decision to take.

24. Q. Will my sense of taste return?

- A. This varies from person to person. In time, you will probably taste all kinds of food; perhaps not with all the nuance and subtleties you had before, but sufficiently to appreciate the pleasure of dining.

25. Q. Will my sense of smell return?

- A. After a time (which varies from person to person), most laryngectomees are able to distinguish a good number of smells. Smells which spread quickly (kitchen odors, gasoline vapors, etc.) are more easily perceived. It requires only a minimum of attention and skill to take air into the nose. You just do the opposite of what you do to blow your nose. First, close your mouth while bringing your jaws together. Then, keeping your mouth shut, open your jaws while breathing in through the nose. You feel the cool air entering your nostrils?

Part four

Back to work

26. Q. Do you think I will be able to return to my work?

How soon?

- A. A good number of laryngectomees are able to return to work after the operation. As far as we know, most of them keep the same occupation as before. There are exceptions, of course. We know doctors, dentists, lawyers, salesmen, administrators, policemen, carpenters, truck and taxi drivers, etc. who have gone back to their work with no major problem. The exact time when you will be able to do so, is a question only your doctor can answer. If your employer hesitates to take you back, consult your Association.

- 27. Q. Are there special precautions I should take when returning to work?**
- A. Yes. Take care to cover your stoma so that no dust or foreign particles get in. By proceeding slowly, you will increase your stamina and not feel overtaxed.
- 28. Q. Is it true that I will no longer be able to lift heavy loads?**
- A. You no longer have your larynx to lock in the reserve of air required by your lungs while making that effort; but you still have your arms and your muscles. If you are not as good a “piano-mover” as before, you are still capable of making the efforts required by a normal active person. We know some laryngectomees who, without being supermen, still move crates of goods in warehouses the whole day long.
- 29. Q. What can I do if I have financial problems?**
- A. Should financial difficulties exist, consult the social worker attached to your hospital centre. If you don't know her, your nurse or doctor will provide you with the necessary referral. Your Association will also guide you if you wish.

Part five

Rehabilitation, Speech Therapy, Communication

- 30. Q. I have heard of rehabilitation and speech therapy. Would you tell me something about these programs?**
- A. The first part of the program teaches you to look after yourself. This means taking care of your stoma yourself. This will increase your self-confidence and make you feel more secure. Follow your nurse's advice. At home, arrange your bathroom (mirror, lights, toilet articles, etc.) in such a way that you can take care of yourself without help.
- The second part of the program helps you to establish communication. Presently, there are three main ways of doing this:

- a) by the esophageal speech which enables the laryngectomee to speak without any special apparatus;
- b) by an artificial voice source which uses an external artificial larynx;
- c) by the tracheo-esophageal speech which is produced with the use of a T.E.P. (tracheo-esophageal prosthesis).

Your doctor or your speech therapist will provide you additional information and encourage you to participate in a free speech therapy program.

The third part of the program aims to help you to get back to a normal life within society, in your family circle and, if it applies, in your work milieu. To obtain the best possible programs of rehabilitation and speech therapy, laryngectomees, in most countries of the world, get together to form associations.

31. Q. How can I communicate while learning to speak again?

- A. You can write down what you want to say (paper and pencil or magic pad). You can also try to communicate by forming words with your lips and mouth (without making sounds). Articulate your words carefully so that those looking at you can “read” your lips correctly. Remember that others want to communicate with you and that they become upset when they don’t understand what you want to tell them. Be natural and understanding with others; ask them if they understand you. Your attitude will greatly reduce their anxiety.

32. Q. What is esophageal speech?

- A. In a laryngectomee, the esophagus (alimentary canal) assumes the role of the removed larynx and vocal cords, hence the name, esophageal speech. The upper esophagus contains a muscle which expands and contracts just like the vocal cords did. Someone using the esophageal voice first pushes the air from his mouth back into his esophagus. He then pushes this air out by contracting the upper esophageal muscle while pronouncing the words he wants to say. Your speech therapist or your physician will give you more information on this subject if you ask.

33. Q. What is an artificial larynx?

- A. It is an apparatus which produces vibrations like those of a small electric motor. These vibrations replace the sounds you make with your vocal cords before your operation. They are transmitted to the mouth and become words and sentences when the syllables are well pronounced. There are many models of artificial larynxes. Your speech therapist will demonstrate various models for you.

34. Q. What does the following phrase mean?

“To speak with a T.E.P.” (tracheo-esophageal prosthesis)

- A. Before losing your larynx and vocal cords, you used the air exhaled from your lungs to speak. Since the operation, the air exhaled from your lungs no longer reaches your mouth; it now comes out through your stoma.

The T.E.P. resembles a small plastic cannula that the doctor inserts through the wall that separates your trachea and your esophagus in order to let the air exhaled from your lungs to get to your mouth.

As the air is exhaled, the laryngectomee blocks off his stoma with his finger or a valve to force the air to go through the prosthesis and hence to the mouth. Thus, a vibration is created, a sound that one must only articulate to obtain words.

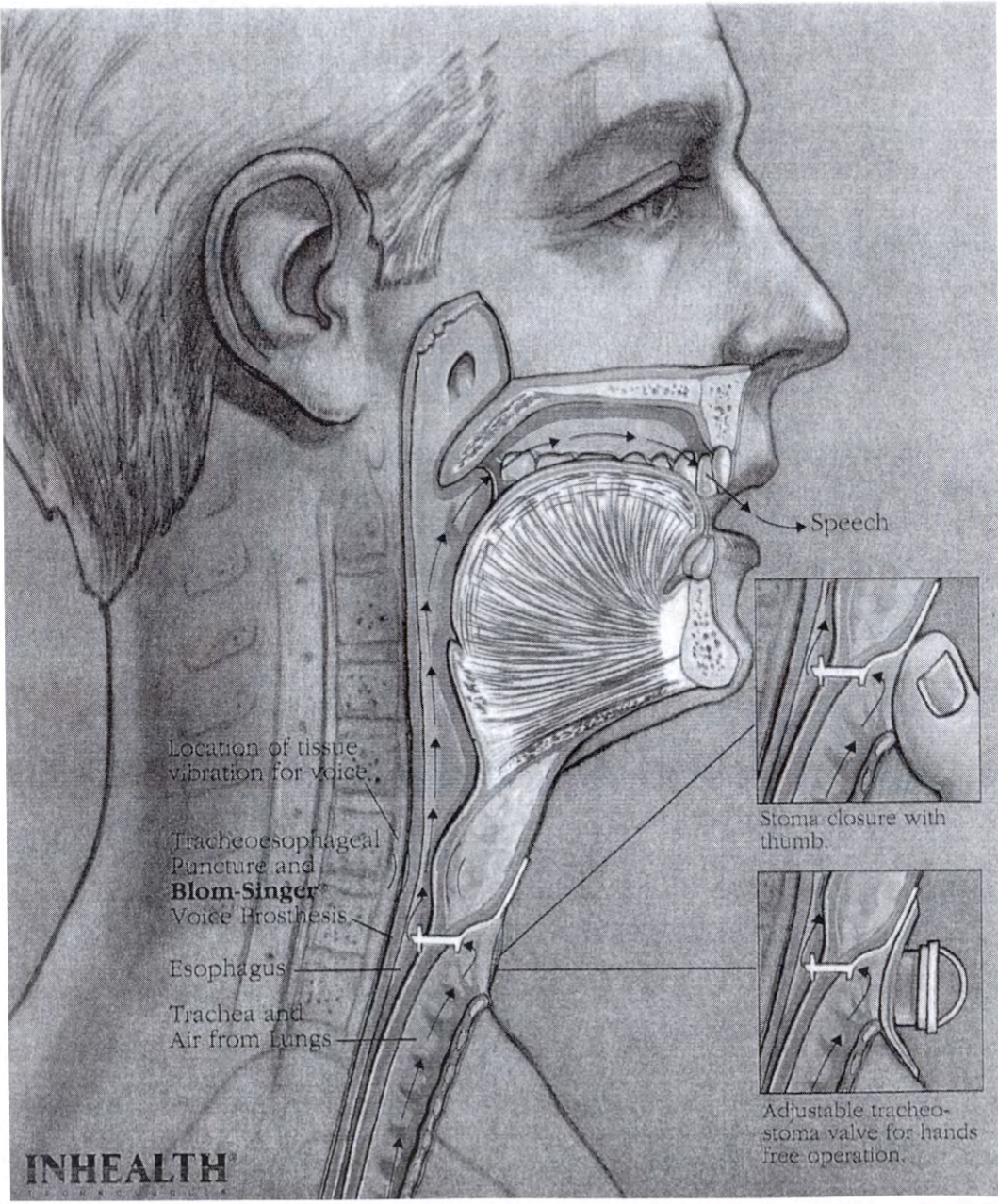
35. Q. Do you think I will be able to learn to talk?

- A. A great majority of laryngectomees today learn to speak using either esophageal speech, an artificial larynx or a T.E.P. Follow the advice of your speech therapist, observe your fellow laryngectomees and you will find a way of communicating which corresponds to your abilities.

36. Q. If I want to learn to speak, when can I start?

- A. As soon as your doctor judges that you have recovered sufficiently, he will tell you to start speech therapy. In some cases this permission may be held back or suspended temporarily due to complications or the need for further treatment.

Tracheoesophageal Voice Prosthesis



Forward

To speak and express one's thoughts and needs through speech is such a natural and normal process that it is hard to imagine what life would be like without speech. It is astonishing to learn that life can go on after the loss of one's larynx and vocal cords.

Laryngectomy surgery is a type of operation not much talked about in the media. Therefore it is not surprising that little is known about it.

If you yourself have recently undergone a laryngectomy, your doctor undoubtedly explained to you all the reasons why it was necessary to remove your larynx and vocal cords.

The Fédération québécoise des Laryngectomisés offers this booklet to help you better understand what has happened to you. Here you will find answers to the main questions you may be asking yourself or that you will find yourself asking during the first months of your convalescence.

This booklet is not meant to take the place of information and advice given to you by your physician, your speech therapist or your nurse. Its aim is to draw on the experiences of others who have undergone a laryngectomy in order to help you overcome the difficulties you encounter and so that you may continue to live a rewarding life.



37. Q. How long will it take me to learn to talk?

- A. Many factors can influence the length of the duration. If you choose to use an electro-larynx, the formation is very short; you may be able to speak within a week of your surgery, if everything goes well.

If you choose to go for the T.E.P. you will be speaking very shortly after the implant of the prosthesis.

If you intend to learn esophageal speech, the learning time may vary from a few weeks to a few months depending on different factors. Your speech therapist will explain the different factors that may influence the length of your “schooling”

38. Q. Do I have to find my own speech therapist?

- A. That will not be necessary. In almost all Quebec hospitals where laryngectomies are performed, there is a speech therapy department. Speech therapists are professionals qualified to teach you how to speak. One of them will visit you before you leave the hospital. Your doctor will inform the speech therapist as soon as you are able to begin treatment. Even if there is no such department in the hospital where you had your surgery, you still have the right to free speech therapy services. Your doctor will direct you to the nearest speech centre.

39. Q. Will I be able to speak on the telephone?

- A. Yes. Whether you use esophageal speech or an artificial larynx, you will be able to speak on the telephone. The telephone automatically increases the volume of your voice. The important thing is to pronounce each word very distinctly, to speak slowly and clearly without forcing your voice and to be sure to place the phone directly in front of your mouth. But watch out! If you can only whisper, you won't be heard over the phone. Certain adaptations are available to help you overcome this problem. Ask your Association for information.

- 40. Q. Should I participate in get together with family and friends? How will people react when I must write to make myself understood?**
- A. Do not isolate yourself. Go to your friends and to your relatives. They are waiting for this gesture on your part so they, in turn, can visit you. Don't worry about how they will react; they are interested in knowing your thoughts, your reflections, no matter what means you use to communicate. When you can finally talk, they will be just as happy as you.
- 41. Q. Is it true that esophageal speech fails in times of emotion and anger?**
- A. When we are either emotionally moved or angry, all the muscles of our body become tense. This is especially true of the throat muscles. Before your operation, did you ever try to swallow a mouthful of food when you were upset? Well, it is these same throat muscles which have to expand and contract for esophageal speech. If, for some reason, these muscles cannot relax, esophageal speech is not possible.

Part six

Social Life

- 42. Q. When people see the hole in my neck, won't they turn away from me?**
- A. First of all, it is neither prudent nor hygienic to leave your stoma uncovered. You can get free filters; so you have no reason not to protect yourself nor to leave your stoma uncovered for people to see. Nothing else need be changed in your way of dressing. It is a question of personal taste and respect for others. You will see many laryngectomees wearing shirts and ties, ascot ties, scarves or turtle-necks. You have probably been among laryngectomees, men and women, on the street, in the subway, at the theatre, without even suspecting that these persons breathed through an opening in the neck. Why didn't you notice anything? Because

these people were dressed like everyone else. Is it necessary to say more to convince you that your appearance is something that depends uniquely on you and your good taste?

43. Q. Is it normal for me to feel embarrassed about my condition?

- A. Anyone can become anxious when there is a change in the way he looks or acts. Think of those who have all their teeth taken out, of a woman who has had a breast removed, of someone who loses all his hair, etc. Instead of feeling sorry for yourself, think about how you are one of the privileged whom modern medicine has saved from a quick and sure death. Come meet other laryngectomees and learn how to overcome your embarrassment.

44. Q. Will my wife (husband) and I find it difficult to get along?

- A. Living together demands constant adjustment. This is even more so when one of the two has had his appearance or his way of functioning altered by surgery. The fact of not being able to talk might increase the chances of being misunderstood. Both parties must exercise great patience, especially during the first year of readjustment. As part of your readjustment, attempt to clear up any misunderstandings of the day before going to sleep.

45. Q. Will meetings with other laryngectomees be helpful?

- A. You will feel much more at ease if you make your first steps in conversation with people who have faced the same problems or with volunteers who are used to speaking with laryngectomees. These meetings will also give you the chance to meet people with a lot of experience in rehabilitation who are ready to share the fruits of their experience and to respond to your concerns. At these meetings, the spouses of laryngectomees can meet other spouses as well as volunteers who will help them cope more easily with the period of readjustment.

Part seven

Centers Offering Information and/or Services

46. Q. If my family or myself wish to get more information, where can we obtain it?

- A. First of all, you may call or come to the:
Quebec Federation of Laryngectomees
5565 Sherbrooke st. east, 5th floor
Montreal, Quebec H1N 1A2
Phone: (514) 259-5113
Fax: (514) 259-8946
E-mail: fqlar@fqlar.qc.ca

You should also know that the Quebec's Ministry of Health and Social Affairs (MSSS) subsidizes two laryngectomee Centers:

For Eastern Quebec residents:

Le service aux laryngectomisés du CHUQ
Hôpital Hôtel-Dieu de Québec
11 Côte du Palais
Québec, Québec G1R 2J6
Phone : (418) 691-5095
Fax : (418) 691-5377

For Western Quebec residents :

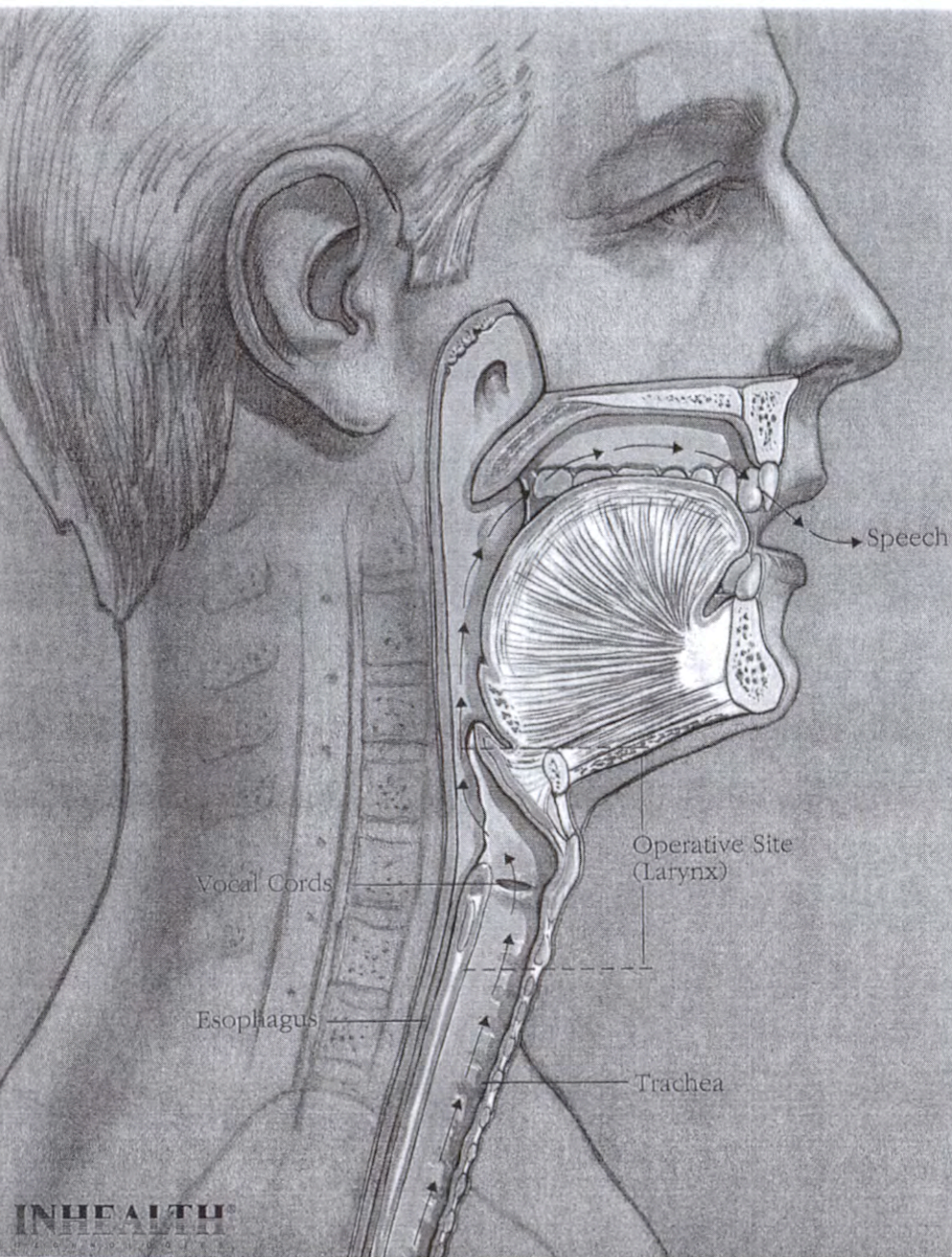
Le service aux laryngectomisés du CHUM
Hôpital Notre-Dame de Montréal
1560 Sherbrooke st. east
Montreal, Quebec H2L 4M1
Phone: (514) 890-8000, poste 25585

You may also call the Canadian Cancer Society of your area (you will find their address and phone number in your local telephone book).

If you wish to reach the nearest laryngectomee's association, please call the Federation.

Notes

Before Laryngectomy



After Laryngectomy

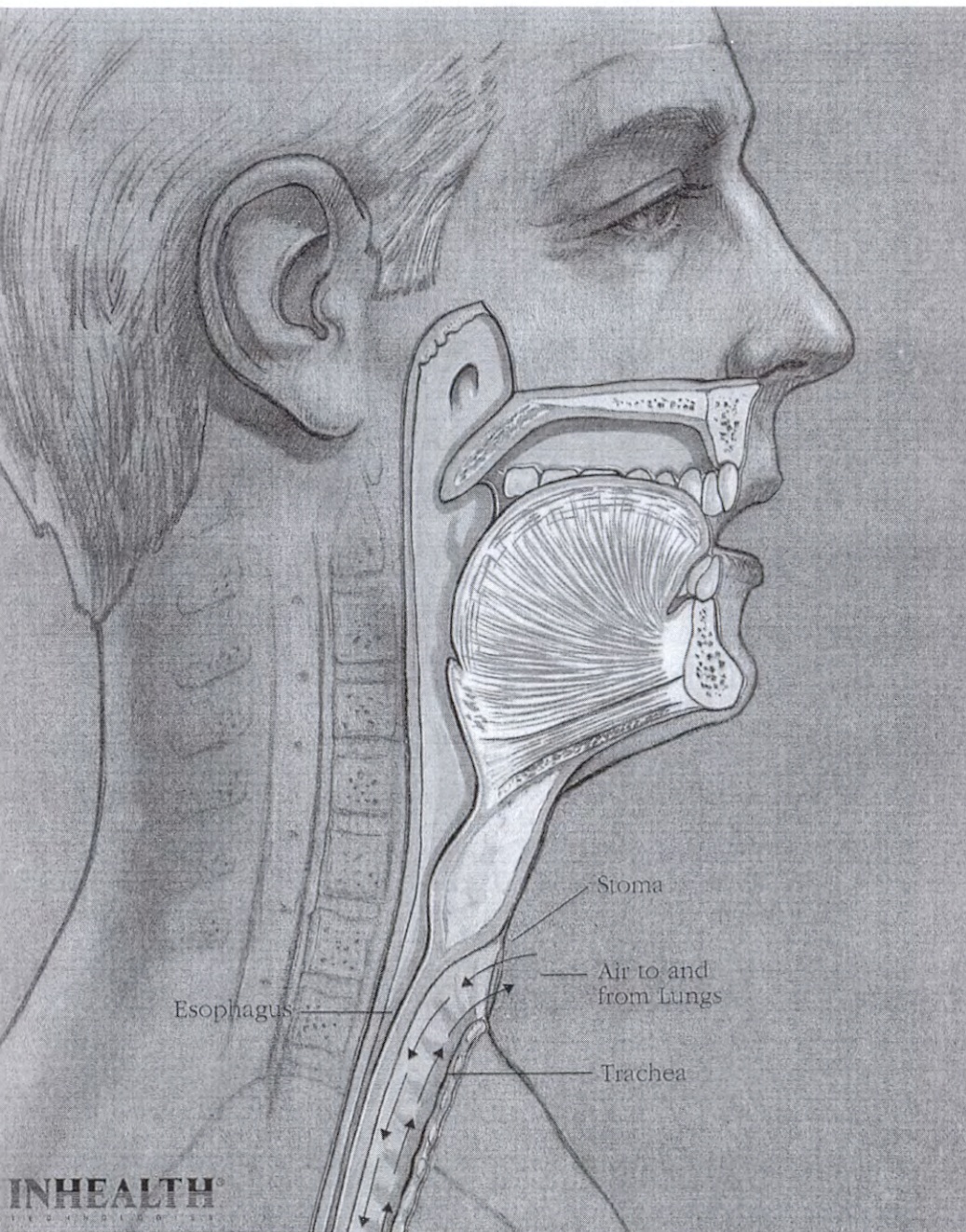


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Part one

The operation and its main effects

1. Q. What is a total laryngectomy?

A. It is a surgical operation which removes the entire larynx. The larynx is called the “organ of speech”. It is situated in the throat at the end of the trachea (respiratory canal) in front of the esophagus (alimentary canal). It contains the vocal cords.

2. Q. Why is a laryngectomy performed?

A. Most often, the surgeon removes the larynx because he has discovered a malignant tumor on the vocal cords or in the throat and neck.

3. Q. Why must there be an opening in the neck?

A. This opening is necessary to allow the air you breathe to enter and leave the lungs. When the larynx is removed, the trachea (respiratory canal) is too short to reach the back of the mouth, making it impossible to breathe either through the mouth or the nose. The doctor then has to bend the top of the trachea toward the front of the neck where he makes an opening to enable you to breathe (*see illustration*).

4. Q. Will I always have to breathe through this opening?

A. If you have lost both your vocal cords (total laryngectomy), the answer is yes. If the surgeon has removed only one cord (partial laryngectomy), the opening is probably only temporary. Medical researchers have been working for the last 20 years to perfect a reconstruction of the throat to close the opening for total laryngectomees. The research is still continuing.

5. Q. What is the name of this opening in my neck?

A. The surgical procedure for the opening is called a tracheotomy, this means “mouth of the trachea”. However, the common way of referring to this opening is a stoma.

6. Q. How long shall I have to wear the cannula in my stoma?

A. Your doctor will tell you what is best in your case. You will find out, by talking with other laryngectomees that some of them wear it all the time; others only at night and most of them stop wearing it after a time. If you follow your doctor's advice, you won't have any problems.

7. Q. Will I have trouble swallowing?

A. During the operation, the doctor has to reconstruct a part of the alimentary canal. It sometimes happens that the part which has been reconstructed is slow to recover its flexibility. If this is your case, you must follow your prescribed diet carefully and modify your eating habits. It is suggested that you chew and swallow small mouthfuls of food. On this particular point, patience will be your best ally. Many laryngectomees have no difficulty in swallowing after leaving the hospital.

8. Q. Is it really necessary to see my doctor again for periodic checkups?

A. Your doctor has surely informed you about its importance. You must follow the checkup visits he has set up for you. You will feel better and be less worried about your health in the months and years ahead if you accept these periodic examinations which can detect possible complications.

Part two

Basic care and precautionary measures

9. Q. Is it important to clean the cannula? How is this done?

A. It is important to keep your cannula clean. How often you clean it depends mostly on the amount of secretion that builds up inside the cannula and on other possible causes of clogging: smoke, dust of all kinds, etc. To clean your cannula, soak the two pieces in hot, soapy water; use a cylindrical brush to clean the inside. Rinse under hot water and dry the pieces by shaking them. Don't use a towel.

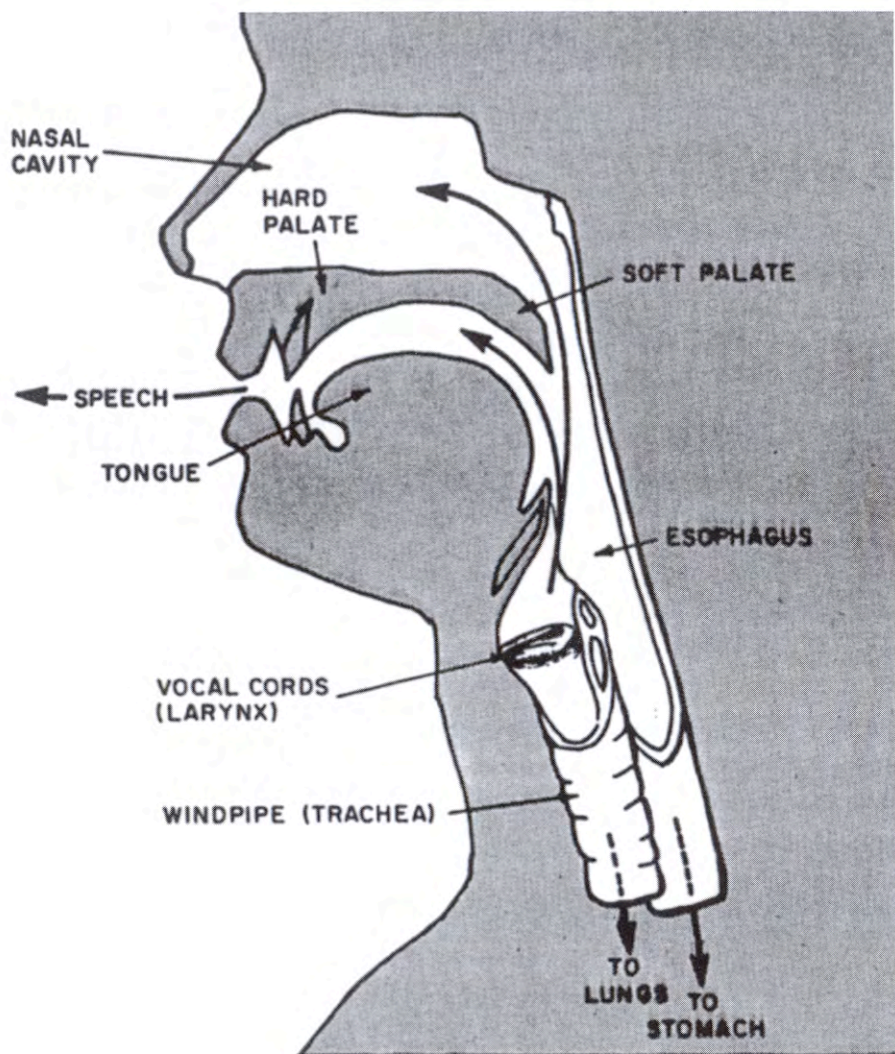


Figure 1 - Before laryngectomy