

Laryngectomized Speakers

Source Book



INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES

Preliminary Update

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TABLE OF CONTENTS

INTRODUCTION	4
POTENTIAL AUDIENCES FOR LARYNGECTOMIZED SPEAKERS.....	5
SPEAKING TIPS FOR LARYNGECTOMEES.....	7
CANCER OF THE LARYNX.....	9
LARYNGECTOMEES	11
SPEECH AFTER LARYNGECTOMY.....	15
AVAILABILITY OF INSTRUCTION.....	20
REHABILITATION	23
INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES	26
LOCAL LOST CORD CLUBS.....	31

INTRODUCTION

Thirty years ago, a laryngectomee speaking before a public group caused a great stir of excitement because not too many people knew anything about cancer of the larynx, (pronounced “larin(k)s”), laryngectomees, or their manner of speaking.

All that has changed - and for the better. Since the American Cancer Society started sponsoring the activities of the International Association of Laryngectomees (IAL), constant publicity about laryngectomees has been issued. The general public is now aware that such cured cancer patients can speak again. Therefore, laryngectomees speaking are no longer a miracle, and they must have a message to deliver, or they might lose their audience. Some laryngectomees may run into trouble for the simple reason that they were not public speakers before their operations, and have not the slightest idea of how to prepare or present a speech.

The purpose of this handbook is to provide facts, figures, information and ideas for formulating a speech on most subjects relating to laryngectomees and their rehabilitation. The handbook does not pretend to be the source of all authoritative information, but it does give ideas to assist laryngectomized speakers in their presentations. So, SPEAK UP, and enjoy yourself in doing so.

POTENTIAL AUDIENCES FOR LARYNGECTOMIZED SPEAKERS

The following list is by no means complete, but it will give you an idea of the kinds of organizations which are always looking for speakers for their programs, as well as those specialized groups who are directly and indirectly concerned with cancer, laryngectomees, alaryngeal speech, rehabilitation, and first aid. Don't wait for them "to call you." "You call them." Contact the program chairman of the clubs and offer to provide an interesting program.

American Cancer Society:

Divisions, Local Units, Volunteer groups within a Unit

Educational Institutions:

Universities, Colleges High Schools, *Grade Schools
(* for smoking and health speeches only)

Service Clubs (civic):

Lions Rotary, Kiwanis, etc.

Fraternal Organizations:

Masons, Elks, Moose, Eagles, etc.

Religious Organizations:

Church groups, Associations of churches

Patriotic Groups:

American Legion, V.F.W., Am-Vets, D.A.V., etc.

Medical Groups:

City, County, and State Medical Associations
Hospitals, Nursing Homes, Clinics
Medical Schools, Nursing Schools
Rehabilitation Centers, Practical Nursing organizations

General Organizations:

Y.M.C.A., Y.W.C.A., Y.M.H.A., Y.W.H.A., C.Y.O., etc.

Business and Industrial Groups

Elderly Citizens Centers, Personnel Administrators

Local, County, and State Government Administrators

Women's Clubs, Civic Clubs

Social Security Workers, Welfare Workers

Vocational Rehabilitation Counselors

Public Safety organizations:

Local Police, County Sheriffs, State Troopers

Local Firemen, Voluntary Fire Companies

Ambulance Drivers, Voluntary First Aid Squads

Hospital Receiving Room Personnel

Firemen's and Policemen's Training Schools, Industrial Medical Personnel

(*these groups for first aid talks in particular)

New clubs or groups of laryngectomees

SPEAKING TIPS FOR LARYNGECTOMEES

Laryngectomees cannot speak well, if at all, when they are upset or nervous. If you are physically or emotionally upset, don't try it. It might do more harm than good. Get someone to "pinch hit" for you.

Relax! Remember when you were learning how to speak? The instructor said "relax". Take a deep breath - or two. It will help you collect your thoughts as well as relax.

A glass of water handy does help at times.

Don't try to force yourself - or your voice. Most public places will have a public address system. (Find out in advance.) Just speak normally. You'll find that your voice carries better than you think.

Don't try to speak longer than usual, or what you consider your length capacity. Keep it as short as possible, but "load" what you say with solid facts. Then go back some day for another speech on different subjects.

Make a good appearance, and always cover the stoma and wear a necktie. For the ladies, your best piece of jewelry or scarf is called for.

Start out by addressing the chairman of the meeting by name. Then greet the audience. Thank them for the opportunity of speaking before the group.

Know your audience. Find out something about them in advance. Then lay out your talk so that you can tell them something they might not know. If you're talking to doctors, skip the facts about your surgery and the results. They practice it every day. Tell them about rehabilitation.

Prepare your talk in advance. Make a set of notes you can read, and know what the notes mean. Try to keep in mind the sequence of subjects you will mention.

Stick to the facts. Don't get involved in a subject on which your knowledge is shaky.

Try to give the hopeful side of cancer of the larynx and total rehabilitation. Don't dwell on the unpleasant aspects.

Look directly at the audience, not at some far corner of the room. Make each person think you are speaking directly to them.

Upon closing your speech, always thank the group again for its kindness, and try to leave them a message in a few well-selected words. The audience is likely to remember what you said last, rather than what you said first.

And, SMILE.

CANCER OF THE LARYNX

WHAT IT IS

Cancer of the larynx is one of the most curable of all cancers. It, like other cancers, is the uncontrolled growth of cells which, if not treated properly and in time, will continue to multiply into a large growth. In larynx cancer the growth on the vocal cords or surrounding tissue makes it difficult for a person to speak, eat, and breathe. The two most accepted methods of treatment are radiation and surgery. The reasons that cancer of the larynx is one of the most curable is that it is located in an accessible part of the body where it may be treated easily, and it usually gives early warning signals of its presence.

DEGREE OF SEVERITY

If detected in time, surgery may be avoided. Radiation very often results in complete cure without loss of the voice. Sometimes, if the cancer is localized on only one of the two vocal cords, and other factors being favorable, the surgeon may remove only a part of the cords while saving the remainder. This is called a “partial laryngectomy” and preserves the voice. If the cancer has advanced past that stage, the surgeon will remove the entire larynx containing both vocal cords, o a “total laryngectomy.”

WARNING SIGNALS

The important thing to remember is that doctors estimate cancer of the larynx is better than 90% curable if detected in time. The warning signals are hoarseness, shortness of breath or difficulty in swallowing. These signals do not necessarily mean that a person has cancer of the larynx, but if any one of them persists more than two weeks, a doctor should be consulted.

STATISTICS

Although the incidence of cancer of the larynx is relatively infrequent from the standpoint of the total number of cases of cancer discovered each year; it is a serious problem.

The American Cancer Society estimates that there are over 30,000 laryngectomized individuals living in the United States.

Approximately 12,100 new cases are diagnosed each year. The ratio of men to women is presently approximately 4 to 1. The average age of those individuals is about 63 years. The combined habits of increased alcohol intake and smoking have been identified as high risk factors in the cause of this disease. Industrial exposure, genetic predisposition and viruses may also play a role.

LARYNGECTOMEES

WHAT IS A LARYNGECTOMEEE

A laryngectomee is a person who, usually because of cancer, has had the larynx, or voice box, removed surgically -- thus permanently losing the ability to speak normally. It should be noted that a few laryngectomees have not had cancer. Automobile accidents, hunting accidents, burns and war injuries are other causes. In Europe there are many laryngectomees as a result of wounds received during World Wars I and II.

PHYSICAL CHANGE

The larynx, which is located in the front part of the neck and connects the throat to the windpipe, is removed and therefore no connection between the mouth and the lungs remains. The surgeon creates a hole (stoma) in the lower front part of the neck and joins the trachea to it. However, the laryngectomee eats and drinks by mouth as usual.

PERSONAL HABITS

As a result of the lungs having their outlet in the neck, laryngectomees must become accustomed to the unusual sensation of breathing through the neck opening rather than through the mouth or nose. They will learn new methods of nasal and oral hygiene. They must also learn to cough, sneeze through the opening in the neck, and will learn to take care of the opening as well as what to do when temperature and humidity change.

Usually, new laryngectomees lose their senses of taste and smell, but as time goes by, and with practice, these two senses return to a variable degree. Naturally, there are exceptions to all rules, but a great many laryngectomees find that they can no longer lift or strain as hard as before the operation. The reason is that there is no way of closing the stoma to build up internal pressure as a normal breather does when he/she lifts a heavy load by compressing the lips and holding their breath. Other laryngectomees do not seem to be affected, and work just as strenuously as ever.

The fact that a laryngectomee cannot close off or prevent water from entering the stoma, as normal breathers do with mouth and nose, they

cannot engage in swimming. It is possible for a laryngectomee to drown without ever getting the face wet. A few laryngectomees do attempt to swim and some have even developed a snorkel which fits closely over the stoma. Likewise, the patient must be extremely careful in taking a shower, to keep water from entering the stoma. A shower collar is available which has solved this problem.

STATISTICS

As mentioned under the topic “Cancer of the Larynx”, there are over 30,000 laryngectomees living in the United States (as of 1987). The average age of laryngectomees known to the IAL is about 63 years, although we have heard of persons as young as 4 years and as old as 105 years at the time of their operations. The IAL knows of several persons who had their operations more than 50 years ago. Many are well 30 or more years after surgery. Cures of 10 or 15 years are very common, and these will increase as time goes on, thanks to modern methods of treatment.

PSYCHOLOGICAL ASPECTS

The rehabilitation of laryngectomees is discussed in a separate section, but the problem is so involved that the various items of concern are collected in this one section for quick reference.

- Fear of Cancer — In spite of the fact that hushed whisper attitudes about cancer have been largely overcome, most patients fear “cancer” more than any other disease. To some, it is like facing certain death. They are not aware that this particular type of cancer has a high rate of cure, compared to other cancer sites.
- Fear of the Operation - Some surgeons feel that this fear has little impact upon the patient’s total mental attitude, but a new patient who has not been operated upon before, and who has enjoyed good health, does have certain fears about the operation. These include taking anesthetic, the operation, extreme pain upon recovery, mutilation, and subsequent silence. Volumes have been written on this subject, and the items are familiar to all medical personnel.

- Fear of the Present - When patients regain their faculties after the operation, they find that they have a great amount of time to contemplate what has happened to them. Some of their concerns are: “Will I live; did they get all the cancer; will I talk again; will I work again; how will I ever pay for all this; how will my family act towards me?” Any one of these fears taken separately might be enough to cause mental instability. So it is easy to understand the precarious mental attitude of patients immediately after the operation. Nevertheless, these fears are genuine.
- The “Whole Person Concept” comes into play without patients even knowing about it. In other words, patients feel that they might be something less than a “whole person” after it is all over. They may feel that they will be “freaks”, and that they are no longer potent or sexually attractive, or that they will be classed as “deaf and dumb”. Doctors and nurses are aware of these problems and do a tremendous job in helping to overcome them while patients are hospitalized.
- Fear of the Future - As time passes, patients will have overcome most of the previously mentioned fears, and will have replaced them with another group of fears related to the future. They will then wonder about such things as “How long are they going to feed me through a tube; must I wear something permanently in the stoma; will I be able to taste or smell anything; how will I blow my nose; and, will I be able to eat and drink normally?”
- Obviously, any departure from normal habits will cause great concern to any individual, and when they are present at the same time, they do develop into fears. There are, of course, many subsequent fears and consternation that will keep ‘nagging’ patients, such as, items related to speech, social activities, recreation, and so on, and these are mentioned in the section on “Rehabilitation”.

- Visiting the New Patient - The greatest single contribution to the rehabilitation of new patients is a visit either pre-operatively or post-operatively, while patients are still hospitalized, by well-rehabilitated laryngectomees who speak well. Just being present in the patient's room, well dressed, well-mannered, and speaking easily with the doctor, nurse, or other persons present, gives patients hope and determination to try to emulate the visitors. It also answers many of the questions and fears that have been worrying the patients. Many surgeons request visits by laryngectomees at a specific time, for the specific purpose of easing patients' tense state of mind, which in turn, improves their medical recovery and convalescence.

SPEECH AFTER LARYNGECTOMY

KINDS OF SPEECH

A laryngectomee can definitely speak after the operation. There are three different methods of acquiring speech available to the new patient: 1) esophageal speech, which is produced without external devices of any kind, 2) artificial electronic and pneumatic devices, and 3) tracheoesophageal shunt procedure. Many doctors and speech pathologists recommend the use of an artificial device immediately after the operation, and until the patient is able to develop esophageal voice. In instances where the patient is illiterate, the use of a device from the beginning is a necessity, otherwise the patient cannot make known his/her needs and wants.

1) ESOPHAGEAL SPEECH

WHAT IS ESOPHAGEAL SPEECH

Since the lungs can no longer expel air into the mouth, the laryngectomee must learn an entirely new method of speech. The patient is taught to take air into the mouth and force the air into the esophagus by locking the tongue to the roof of the mouth. When the air is forced back up, it causes the walls of the esophagus and pharynx to vibrate. This action vibrates the column of air in the passages, causing a low-pitched sound. This sound is the laryngectomee's voice. (It is produced by a controlled belch or burp.) The patient then articulates this sound into words with the tongue, lips, teeth and palate, as do normal speakers.

EFFECT ON FAMILY

Admittedly, even at best, esophageal voice is not exactly melodious, although some laryngectomees achieve a remarkable smoothness in their voices. At the beginning, the new voice will be quite rough or guttural. Time and practice improve the quality of the voice. To the laryngectomee who has been silent for probably a month or more, and to his family, the new voice will be beautiful in spite of its roughness or tone. They had believed that it would be next to impossible for the patient ever to make a sound again, until they actually heard the new voice. After the patient makes his/her first sounds and a few words, the family realizes that he/she will again speak fairly well, and so it is up

to them to encourage the patient and assist him/her in practicing in any manner possible. The support of families and friends is essential in the rehabilitation of laryngectomees.

FACTORS AFFECTING ESOPHAGEAL VOICE

In addition to those factors mentioned above, other factors affect the ability of the patient to speak again. The physical condition of the patient is often a prime factor. The surgeon should be the one to decide when the new patient might start lessons in esophageal speech, since the healing process in the throat and neck must be well advanced in order to prevent damage to muscles and tissues. If the patient has other physical problems, he/she cannot pay strict attention to lessons in esophageal speech. The severity of the operation often affects the ability of a laryngectomee to develop an esophageal voice. The amount of tissue removed and the shortening of muscles, etc., affect the elasticity of the remaining portions of the esophagus.

MOTIVATION

Well-motivated patients are usually able to develop an esophageal voice without too much trouble and within a relatively short period of time. By well motivated we mean patients who have “everything” to gain. In other words, they may have determination because of a fine family relationship, a fairly good job with future potential, or, they may be financially able to take care of their future. If patients have been promised their old jobs back after they learn to speak, this in itself creates enough motivation for them to really work at developing their esophageal voice. A new laryngectomee who is not well motivated will probably have difficulty in developing a new voice. If a person lives alone, he/she is handicapped right from the start because of lack of pushing, helping, and encouraging him/her onward. If a person is of a tense, nervous or emotional make-up, he/she will find it hard to relax sufficiently in order to develop their new voice. If patients look upon the entire situation with disdain, they decrease their chances of developing a voice.

The main thing to remember in developing esophageal voice is that it takes perseverance, practice, and patience.

HOW LONG TO LEARN

The first question asked is usually “How long does it take to learn to speak?” No speech pathologist or instructor will answer that question definitely. It may take as little as a week or as long as a year for a person to develop understandable esophageal speech. There are some persons who are called “naturals”, or those who learn to speak again almost spontaneously. Others just cannot seem to grasp the method of trapping air in the throat and making a noise with it when expelled. After several months of complete lack of progress, a laryngectomee is often advised to investigate the use of an artificial larynx.

STATISTICS

Laryngectomees communicate using various methods. It is estimated that approximately 50% use esophageal speech; 30% use various electronic devices (some use a combination of both methods); 5% to 10% use the tracheoesophageal shunt; and 5% to 10% do not speak at all.

2) ARTIFICIAL DEVICES

ELECTRONIC LARYNGES

There are two types of devices to assist laryngectomees in speaking or in speaking better. The first type is an artificial electronic larynx which creates a voice for a laryngectomee who is absolutely unable to speak understandably with an esophageal voice. The other type of instrument is an electronic amplifier, which is used to increase the volume of speech of a person who uses esophageal voice.

EXTRA-ORAL LARYNX

Two different types of the artificial larynx are available-- extra-oral and intra-oral. The extra-oral type of instrument looks like a flashlight with batteries in the handle, and has a vibrating disc on the end, which is pressed against the outside of the neck. When a switch is pressed, the disc vibrates, causing a sound to be emitted which travels through the soft tissues of the neck into the oral cavity. Adapters can be fitted to make them into intra-oral devices. This sound becomes the laryngectomee’s voice.

INTRA-ORAL LARYNX

The intra-oral type of artificial larynx consists of a shirt pocket transistorized battery pack, which is connected to a sound emitter by a small wire. The sound emitter is the size of a silver half-dollar and about a half inch in thickness. It is held in the palm of the hand, and when a switch is pressed, it emits a vibrating sound, which is transferred directly into the oral cavity through the mouth by means of a small hollow plastic tube which is attached to the sound emitter. The sound becomes the laryngectomee's voice.

AMPLIFIER

A number of amplifiers are presently on the market to assist laryngectomees with weak or soft voices to increase their volume. Some amplifiers are small enough to be carried in the shirt pocket or purse.

3) TRACHEOESOPHAGEAL SHUNT PROCEDURE

VOICE RESTORATION WITH A PROSTHESIS

Prosthetic devices are fast becoming alternative solutions in the development of esophageal voice.

A small opening is made in the rear wall of the trachea and the front wall of the esophagus. The entrance to the opening is just behind the stoma. This opening is called a tracheoesophageal "puncture" or "fistula" or "shunt". A small silicone tube or prosthesis is kept in the opening in order to: 1) keep the opening from closing; 2) allow lung air to pass into the esophagus; and 3) prevent food and liquid from entering the airway. When the stoma is covered and the person exhales, lung air passes through the prosthesis and into the esophagus supplying the necessary air for the production of esophageal speech.

It is a relatively simple and safe procedure. An assessment must be made to determine if the individual is a good candidate for the prosthesis. This assessment takes into consideration anatomical factors, functional limitations, surgical complications, physical problems, dexterity, and motivation. The first surgery of this type was called the Singer-Blom Tracheoesophageal Puncture Procedure. Since it was first reported in 1979, variations of this surgical procedure have

been developed, and many different designs of silicone tubes or prostheses are available. Patients should discuss surgical-prosthetic voice restoration with their physician as well as their speech pathologist. They can offer a greater depth of information about it.

AVAILABILITY OF INSTRUCTIONS

TYPE OF INSTRUCTION

Two different methods are available for teaching new patients alaryngeal speech -- group and individual. The type of instruction chosen by patients will depend upon their psychological makeup, and in some few cases where fees are involved, their ability to pay. This problem can usually be solved.

GROUP INSTRUCTION

Group instructions have proven to be advantageous to both the instructor and the patient in most cases. Usually a group consists of from 3 to 10 or even 15 new patients all learning post-laryngectomy voice at the same time. The instructor is careful to group together those patients who are at about the same stage of voice development. The instructor tries to avoid putting beginning pupil-patients together with advanced pupil-patients. The psychological advantage involved is the comparison of progress. When a patient sees other patients getting sound or even words, it has a competitive reaction with the patient. In other words, the patient may feel "if they can do it, I can too. The instructor is careful to observe the group in order to detect any patient who becomes depressed because of apparent lack of progress in comparison to other patients.

INDIVIDUAL INSTRUCTION

The psychological advantage in individual instruction is that the patient feels that he/she is receiving the exclusive attention and assistance of the instructor. Usually, there are not enough patients in most areas around the country to conduct group classes and therefore individual instruction is the logical alternate. The patient is not bothered with conflicting personalities or the progress of other patients, and the instructor can observe the individual patient much more closely. Far more laryngectomees learn esophageal voice by the individual method than by the group method.

Some persons feel that a professional person is best qualified to teach new patients because of their educational training. Others feel that a lay laryngectomized instructor can do better because he/she has been through a similar experience. In either case the teacher must be well

qualified to teach laryngectomees. A poor teacher can result in failure that may be difficult to overcome.

**PROFESSIONAL
SPEECH PATHOLOGISTS**

Professional speech pathologists have one great advantage over the lay laryngectomized instructor in having the educational background for dealing with such patients. The professional has studied psychology, methods of teaching, -etc., and therefore is able to diagnose and anticipate potential problems. Most professional instructors who are actively engaged in teaching alaryngeal speech have done some graduate work in the field, and are well aware of speech mechanisms and the production of alaryngeal speech. Once the patient has developed a tone or voice, the professional person can develop speech more rapidly than most laryngectomized instructors.

**LAY LARYNGECTOMIZED
INSTRUCTORS**

Some laryngectomized instructors have attended IAL Voice Rehabilitation Institutes and have gained a great deal of professional knowledge about instructing new patients, but there are fewer than 300 of these persons in the entire United States. Therefore, we must speak of the average lay man -- who has not studied the actual teaching of esophageal voice. The one great advantage, as mentioned before, is that the laryngectomee is actually speaking with an esophageal voice and has undergone the same trauma and experiences as the new patient. In other words, the fact that he/she has had similar experience instills a great deal of confidence in the new patient. However, after voice has been achieved, the average laryngectomized instructor, lacking the professional knowledge, usually cannot bring the patient along as fast in developing understandable speech.

**WHERE CAN I GO
TO LEARN**

“Where Can I Go To Learn?” is the most prevalent question asked among all new patients. It is not unusual for a patient to be discharged from the hospital without having been told what to do next. However, by various means, the IAL is trying to correct that situation.

INSTITUTIONS

Speech instructions are available at colleges, university speech and hearing departments, hospitals, private speech and hearing clinics, American Cancer Society offices, and lost chord clubs. Some of these institutions offer only individual instruction, but those located in larger cities offer group instruction as well.

The IAL publishes a Directory of Instructors of Alaryngeal Speech which includes the names of those laryngectomees who have successfully completed an IAL Voice Rehabilitation Institute course or who have had long experience in the field of teaching alaryngeal speech.

FREQUENCY OF LESSONS

Instructions, whether individual or group, usually last about one hour. Because most laryngectomized instructors teach voluntarily, they cannot spare the time to teach a new patient every day as can a professional person who might make such arrangements. When a patient starts, he/she should try to make arrangements to take a lesson every day for a week or two. It naturally takes much longer when lessons are given only once a week. Perseverance, patience, and practice are all important to the new patient.

REHABILITATION

REHABILITATION

The IAL's chief aim is not just vocal rehabilitation of the laryngectomized patient, but rather TOTAL rehabilitation. There are a number of factors involved in becoming totally rehabilitated, and of course, speech is the first and most important of these factors. We talk about speech rehabilitation in another section. Other factors are family relationships, financial situation, social, religious, civic, and recreational activities.

FAMILY

The spouse of the laryngectomee, as well as other members of the immediate family, undergo almost as much of a shock as a result of the operation as does the laryngectomee. Therefore, they also must have a certain amount of rehabilitation. This is mentioned in the section on "Local Lost Chord Clubs" (consulting families). However, the family does recover its emotional stability faster than the patient, and must then act as a stabilizing influence upon the patient. All members of the family should encourage the patient to look to the future with optimism and should assist him/her with his/her speech lessons. The post-operative period is most important to the mental stability of the patient, and the cooperation, love and encouragement of the family will be the greatest single factor in eventual recovery.

SPEECH

Speech is explained in a separate section, but it is well to mention here that patients must be convinced of the fact that they will speak again either by esophageal voice or by means of an artificial electronic larynx, or by means of the tracheoesophageal shunt procedure.

FINANCIAL

This general subject is quite often the most pressing for a laryngectomee, and sometimes takes a great deal of effort on the part of the patient, the family, friends, employer, and even public agencies to solve the immediate financial worries. Employment is of course the greatest single worry to the patient if he/she was employed before the operation, or, is of an employable age. This subject is discussed in a separate section. Generally speaking, if the patient does not have immediate, overwhelming financial worries, he/she should be able to

concentrate on other areas of rehabilitation.

RELIGIOUS

The religious aspect of rehabilitation is probably the next important, and steps should be taken on behalf of the patient to obtain consultation with his/her pastor, priest, or rabbi, that he/she may lend a degree of peace of mind. After physical recovery has been achieved, patients should once again join their family and friends in church affairs -- even before they can speak again.

RECREATION

Laryngectomees should engage in the recreational activities they enjoyed before their operation, just as soon as they are physically able. Doing familiar things gives the individual the confidence that is necessary for his/her efforts in other phases of rehabilitation. They realize that they are just as good a person as they were before -- that they can still swing a golf club or fish, or whatever their favorite sport. Here again, the family should join in the recreational activity if at all possible, without seeming to be pampering the patient.

SOCIAL

At this stage, laryngectomees should have regained sufficient confidence to rejoin their social activities. They should get back into socializing with neighbors, going to bridge or country clubs, or whatever their activities may have been before. If they enjoyed cook-outs, by all means let them have a "block party" in order to demonstrate that they are still the best cooks in the world.

CIVIC

After the other phases of rehabilitation have received some attention, new laryngectomees should broaden their scope and rejoin any civic activities such as civic clubs, religious organizations, patriotic groups, fraternal orders, and actual civic groups, such as school boards or local government.

GENERAL

As you can see, TOTAL rehabilitation is just that -- a continuation of life as it was before the operation. By this we mean "as nearly as possible". Time does take its toll, and no tomorrow is exactly the same as today. This is sometimes more difficult than it sounds, because of the mental attitude of the patient. This is the reason the patient must

have the cooperation of family and friends. Sometimes new laryngectomees do not want to face friends, but would rather meet a stranger, so that they do not have to discuss “what happened to them”. During all phases of rehabilitation, speech lessons should be continued. If necessary, professional advice should be sought in order to convince the patient that he/she is still just as good a person as before.

EMPLOYMENT

A laryngectomee can do almost anything after the operation as before. This includes work. Laryngectomees have learned the hard way to try harder. Most of them are back at their old jobs, using their ability, experience, and loyalty. There is no reason, in most cases, why laryngectomees should not be continued on the job. They are anxious to show that they are just as good now as before the surgery. They can continue to meet the public and can talk on the telephone if that is part of the job. There are only a few jobs with which laryngectomees have difficulty, such as those with an environment of extreme heat, cold, gases, dusts and fumes. Laryngectomees work in almost every type of business you can imagine. They are working in all levels of manufacturing, industry, business, government, farming, the professions and public service industries.

Unfortunately, in a minority of cases, some laryngectomees have not been retained in their jobs after physical recovery. Attitudes toward these former patients have improved immensely, but some people are still prejudiced. Employers should assure their other employees that cancer is neither contagious nor infectious. Cancer is no more contagious than a heart attack or a broken leg. Superstition and “hushed whisper” attitudes toward cancer have been largely erased.

THE INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES

WHAT IT IS

The International Association of Laryngectomees is a coordinating organization composed of over 300 member clubs which are variously called “Laryngectomee Clubs”, “Lost Chord Clubs”, New Voice Clubs”, and other names deemed appropriate to denote their purposes. The IAL is a voluntary, non-profit association dedicated to the total rehabilitation of laryngectomees.

WHERE ARE THE CLUBS

The member clubs are located throughout the United States, Canada, Europe, South America, Asia, and Africa.

WHEN WAS IAL FORMED

The IAL was founded in 1952 during a speech pathology institute held at Cleveland, Ohio. Thirteen clubs were represented at the founding which was sponsored jointly by the Cuyahoga Unit of the American Cancer Society, Western Reserve University, the Vocational Rehabilitation Administration of the Department of Health, Education and Welfare at Washington.

AIMS AND PURPOSES

To encourage and maintain an exchange of ideas and methods for the training and teaching of alaryngeal methods of communication so that all laryngectomized person, regardless of where they may be located, might have the opportunity to learn to speak again; and to foster and support recognized standards for the rehabilitation of laryngectomees.

To publish and disseminate helpful information for the better rehabilitation of its members and others who have undergone a laryngectomy.

To cooperate with the American Cancer Society, its Divisions and affiliates, and all other recognized societies and organizations whose purposes are to combat cancer in all forms.

To improve the understanding of employers about cancer in general and cancer of the larynx in particular, so that laryngectomized persons

may retain or obtain employment after their operations.

**WHO MAY BELONG
TO THE IAL**

Any laryngectomee (or partial laryngectomee) may join one of the IAL member clubs and thus automatically become a member of the IAL. All laryngectomees living within a club area are considered members of the club, whether they pay dues to the club or not.

**THE BOARD OF
DIRECTORS**

The IAL Board of Directors is composed of 16 persons, 14 of whom are laryngectomized members of the various clubs, and six directors-at-large who need not be laryngectomees or members of IAL clubs. All Directors are elected for two-year terms, and all serve voluntarily without pay. The Directors are elected by the delegates of the clubs at the annual meetings.

**OFFICERS AND
EXECUTIVE COMMITTEE**

The Executive Committee is composed of the President, Vice President, Secretary, Treasurer, and two other members of the Board of Directors. The Board of Directors elects the two general members of the Executive Committee. The officers are elected from the clubs by delegates at the annual meeting and serve a two-year term.

ANNUAL MEETINGS

Annual meetings of the Association are held at various cities in the United States, usually during the last few days of July and/or the first few days of August. The location of the Host City is determined by the Annual Meeting Committee with approval of the Executive Committee. Any club that is qualified by membership and activities is eligible to submit an invitation to the IAL for being host at a future annual meeting.

**BOARD OF DIRECTORS
MEETING**

The stated annual meeting of the Board of Directors must be held during the months of July or August, and is therefore usually held on the last day of each annual meeting. An interim workshop of the Board of Directors is held usually during the month of March or April at a city selected by the Executive Director. The interim workshop is attended only by chairmen and vice chairmen of

all standing committees as well as the complete membership of the Nominating and Annual Meeting committees.

DELEGATES OF MEMBER CLUBS

Each member club chooses its own delegates to the annual meeting of the IAL. Each club is allowed a set number of delegates according to a sliding scale of dues paid by the member club to the IAL. It figures out to one delegate per each \$13.00 in dues paid to the IAL. The delegates are the final body of authority in the organization.

COMMITTEES

In the absence of specific directions from the Board of Directors, the President shall appoint the members and chairmen of standing and ad hoc committees.

The terms of committee members expire with the expiration of the term of the appointing officer, unless the committee is dissolved at a previous date. The committees are as follows:

Standing Committees -- Nominating; Bylaws and Procedures; Finance; Speech Standards; Rehabilitation and Public Affairs; Medical Affairs; and Annual Meeting. The President may appoint persons to the committees who are not members of the Board of Directors or delegates.

PROGRAMS AND PROJECTS

IAL NEWS

The IAL NEWS is a newsletter published by the organization which goes to nearly 30,000 persons in the United States and 55 foreign countries. It is mailed free of charge to all known laryngectomees, doctors, nurses, speech therapists, rehabilitation specialists, cancer workers, and other interested persons. The newsletter may be the only means of communication for some laryngectomees, about other laryngectomees, because they do not live close to population centers, and therefore, have no contact with other such persons. It is an inspirational and “newsy” letter regarding activities of individual laryngectomees, member clubs and subjects of interest to

laryngectomees such as the latest in the state of the art in the management of cancer of the larynx, communications and resources.

ANNUAL MEETINGS

The IAL has conducted an annual meeting every year since its founding. The annual meetings are usually three or four days long and are held during the month of July or August in the larger cities around the United States. The locations are shifted geographically in order to enable laryngectomees from all over the country to attend an IAL meeting at least once every three or four years.

The purpose of the meetings is to conduct the business of the Association, present various workshops, discussions, lectures and panels regarding alaryngeal speech and the rehabilitation of laryngectomees, and to engage in the usual social activities which are a definite part of total rehabilitation. Attendance runs between 400 and 500. As many as 85 local clubs have been represented by delegates at one single annual meeting.

VOICE REHABILITATION INSTITUTE

The annual Voice Rehabilitation Institute is one of the major projects of the IAL. It is designed for the purpose of training teachers in the various methods of alaryngeal speech and to provide attendees with an intensive program including lectures, daily therapy, and rap sessions.

Distinguished guest faculty serve as clinical supervisors and demonstrate current therapeutic techniques. The Institute is sponsored financially by the IAL and the American Cancer Society. The Institute is presented at a speech and hearing department of one of the larger universities located in the city of the Annual Meeting.

FIRST AID FOR LARYNGECTOMEES

Laryngectomees have a special risk of losing their life because of what might ordinarily be a minor mishap or accident. The reason is that they have an altered anatomy as a result of the operation, and the vast majority of public safety officials and rescue personnel do not know these facts.

One of the main projects of the IAL is safety and first aid for laryngectomees. The IAL has published a booklet “First Aid for Neck Breathers”, for all kinds of first aid personnel explaining the anatomy of a “neck-breather”, and the proper methods of administering first aid procedures. Most laryngectomees now carry emergency identification cards that are readily discernible in case of emergency.

Most of the member Lost Chord Clubs have formed teams who go out and give demonstrations and lecture on proper first aid procedure. They speak to such groups as policemen, firemen, sheriffs, state police, and ambulance crews; people who are most likely to be called in case of distress. Nearly a third of a million of the first aid booklets have been distributed throughout the United States.

IAL CORRESPONDENCE

The IAL maintains correspondence with professional medical groups, speech therapy groups, and governmental agencies, and of course, tries to assist in the forming of new clubs, both in the United States and abroad. A large amount of the daily correspondence in the IAL office is answering individual requests for assistance and information from laryngectomized persons. All letters are answered individually and assistance provided in whatever manner available.

LOCAL LOST CHORD CLUB

Whenever a local laryngectomee gives a talk to a local group, it is wise to tell the audience something about his/her own lost chord club. People are interested in what is going on right around them and therefore it is always best to name names and locations, so that the audience can draw a direct picture of the local situation. Most people in the audience will be proud to know that such activities are going on for the benefit of the local population. Listed below are a number of items that may be of interest to the audience about your club. Fill in the space provided so that you may have a ready reference regarding your club.

DATE FORMED _____

BY WHOM _____

SPONSOR-BACKING _____

MEETING PLACE AND WHEN _____

GROWTH (NO. OF MEMBERS) _____

DUES-ASSOCIATES & MEMBERS _____

PURPOSES (GENERAL) _____

BOARD & COMMITTEES _____

DELEGATES TO IAL ANNUAL MEETING _____

ANNUAL MEETING (LOCAL) _____

In addition to the club information, your audience will like to know just what the club does. Therefore, listed are a number of services that clubs provide and you can just go down the list and check off the items in which your club participates. Be sure to insert any activities not included in which your club engages.

- Cooperation with ACS
- Cooperation with doctors
- Speakers to clubs, etc.
- Consult families
- Help laryngectomees find employment
- Speak to patient's present employer
- Provide transportation to meetings
- Distribute literature at public meetings
- Visit patients pre-op in hospital
- Visit patients post-op in hospital
- Give speech instructions to individuals
- Conduct group speech classes
- Give first aid demonstrations
- Help new patients with tips and hints
- Have special parties
- Provide transportation to speech clinics
- Act as ACS Crusade Helpers

HAND-OUT LITERATURE

It is wise to distribute some kind of literature to the audience after your speech. Do not hand it out before or during the speech, for invariably people will look at it instead of listening to what you say. IAL and ACS literature is available for any type of audience. It may be obtained through your local Unit or state Division of the American Cancer Society, and they will usually be glad to furnish it without charge.