

# Handbook for Laryngectomy Patients

## National Association of Laryngectomee Clubs

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### Introduction

This book has been designed for use by laryngectomy patients, both pre- and post-operatively, their families and friends. It will also be of interest to student nurses and speech therapists.

It gives useful information on all aspects of laryngectomy from the initial diagnosis onward and can be used both prior to surgery and at any time following the operation as a reference document and for resource material.

NALC would like to thank all those who contributed to this publication.

Compiled and issued by:

The National Association of Laryngectomee Clubs  
Ground Floor  
6 Rickett Street  
Fulham  
London  
SW6 1RU

## 1. Diagnosis

### Symptoms

The main symptom of laryngeal cancer is hoarseness. Unlike the hoarseness associated with a cold and laryngitis, this is not temporary but persists way beyond what would be expected, and it gradually worsens with time. This may be associated with a feeling of irritation and discomfort in the throat. As the cancer enlarges, there may be pain in the throat, earache, and difficulty with swallowing and breathing, which may become noisy (so called stridor).

Very occasionally the cancer in the larynx itself may not give rise to symptoms, and the only abnormality noticed might be a lump in the neck due to the spread to a neighbouring gland.

### Signs

The diagnosis of cancer is always made on the basis of an examination of the voice box. This is most often done with a mirror held in the back of the throat, enabling the surgeon to get a view behind the tongue. More

recently, flexible telescopes have been introduced (fibre-optic endoscopes), which have a very small diameter and can be slid painlessly along the floor of the nose and down the back of the throat, giving an excellent view into the voice box. In some cases, enlarged glands may be felt in the neck but the examination of a patient with laryngeal cancer is usually, in all other aspects, normal.

### **X-rays and special tests**

The special tests which doctors arrange are usually directed both to assess a patient's general state of health and also to give more detailed information about the site and extent of the growth in the voice box itself. Blood tests are usually arranged.

The urine is usually tested, and a chest X-ray is always done, since most people with laryngeal cancer have been smokers at one time or another and have been heavy smokers at that.

Special X-rays may be ordered of the voice box, and these can be taken in progressive views showing the voice box in detail from front to back. In some cases a highly detailed X-ray scan may be required.

### **Examination under anaesthetic and biopsy**

The preliminary examination and tests are usually carried out on an out-patient basis, and it is normally a straightforward matter for the surgeon to decide whether or not admission to hospital for a more detailed examination of the voice box is necessary. Most surgeons explain that an abnormality in the voice box has been identified as a cause of the hoarseness, and, because of the underlying worry that what has been seen might be cancerous, the patient may be advised to come into hospital for examination under anaesthetic, and to have samples taken (biopsy).

The breaking of this news usually causes considerable anxiety and many questions will come to mind. It may be impossible to answer these at this early stage in the diagnosis, but it is as well to voice them all so that those that can be answered can be dealt with, and those that must wait for answer can be jotted down on a piece of paper and answered later on. Patients with suspected cancer are always given priority when it comes to admission to hospital, and arrangements will be made for admission within days or weeks at the latest. As far as laryngeal cancer is concerned, providing that there are no complications, the examination and biopsy of the larynx is a relatively straightforward procedure, although a general anaesthetic is required.

When you are admitted to hospital you will usually be seen again by the surgeon just prior to the procedure, and there may be an opportunity for further questions. You will also be seen by the anaesthetist, who will explain the anaesthetic procedure and any pre-medication, which may be given.

The procedure for examining the larynx and taking samples (laryngoscope and biopsy) involves inserting a pipe-like instrument through the mouth and into the voice box. The surgeon can look down this directly, and samples can be taken and sent to the laboratory.

The laryngoscopy procedure itself is usually painless, and it is often possible for you to go home and to return to the hospital a few days later for the results of the biopsy.

This is obviously a period of anxiety for all concerned, which cannot be adequately relieved until the report has been received from the laboratory. These days, most doctors will be very frank with their patients about the diagnosis, the likely treatment, and the chances of a lifetime cure. In the case of laryngeal cancer, this is made somewhat easier, because overall the results of treatment are excellent and, for some cancers, cure rates may be as high as 90% or more.

## **Radiotherapy**

Most patients with cancer of the larynx are treated with radiotherapy in the first instance. A few cancers may be treated initially by surgery, and this may sometimes be followed by a course of radiotherapy.

Following a course of radiotherapy treatment, all patients are kept under close observation by their surgeon, and a laryngectomy will usually only be necessary if the disease recurs at some future date. In some cases, the cancer will never go away although it may shrink substantially, following radiotherapy, and it will be apparent within a matter of months that surgery is necessary. In others, there may be quite a long time interval of months or even a year or two of apparent freedom from the disease, before the symptom of hoarseness recurs, and it is clear to the surgeon that the growth has come back.

If, following a course of radiotherapy, a surgeon suspects that the disease has recurred; the procedure of re-admission to hospital, laryngoscopy and biopsy will be repeated. If cancer is confirmed, most patients will require total removal of the voice box (laryngectomy) and the fashioning of a permanent breathing opening in the neck (tracheostomy). Most people in this position will already have been in hospital once or twice, and they may have seen other patients on the ward who have undergone similar surgery. They will, as a result, have a vague idea of what the outcome is likely to be. Nevertheless many fears and worries will pass through your mind, and these can all be dealt with by discussion with the surgeons, the nurses and the speech therapist in the days or weeks preceding surgery.

Once a decision has been made that laryngectomy is necessary, it is usual to make arrangements for this to go ahead within a few weeks. A provisional date may be given, and this will usually be confirmed either by telephone or in writing, by the hospital Admissions Office. Clear instructions will be given about where to go and when, what should be brought into hospital, and the arrangements for visiting, etc.

Most patients are admitted into hospital a day or two prior to surgery, so that all the preliminary blood tests and X-rays may be carried out. You will be visited by members of the team who will be responsible for your care.

On the morning of your operation, a nurse will be assigned to look after you and escort you to the operating theatre.

## **2. The Operation**

### **The Larynx**

The larynx or voice box lies behind your Adams apple and the removal of the larynx results in there being no connection between the patients mouth and nose and the stoma which is surgically formed at the base of the neck during a laryngectomy operation.

It does mean that a permanent hole remains in the neck, which is easy to breathe through. If this breathing hole has a tendency to narrow, it may be necessary to wear a tube through the opening for a while.

Sometimes it may be necessary for more extensive surgery to be done since the most important thing is that the surgeon makes every effort to remove all traces of tumour.

## **3. After the Operation**

Following your operation you will be transferred to your own bed in the recovery area. When you have recovered from your anaesthetic, the nurse who will be looking after you will collect you from theatre and return you to your room or the intensive care unit. You will have a nurse with you at all times for the first 24 hours. You will be aware of various tubes, bandages and drains attached to you. Neither you nor your relatives

should be frightened by these or all the equipment that may be in your room. It is perfectly normal after a laryngectomy operation and everything is there for a purpose.

### **Intravenous infusion (drip)**

This is a needle inserted into a vein, usually in one of your arms, and attached to a tube and bag of saline or blood. This will keep you hydrated and also enable any drugs you may need to be given to you in the first few days after your surgery. It will be removed a few days after the operation, once you start being fed by the feeding tube.

### **Feeding tube**

Until the stitchline inside your throat has healed, you cannot eat or drink in the normal way, so you will be fed through a tube that has been passed either through your nose and down into your stomach or through a small hole at the back of your stoma into your food passage (oesophagus). The nurse will feed you through this tube with a liquid diet until the tissues inside the throat are healed and there are no signs of leakage through the wound. This normally takes about ten days. The tube can then be removed and you should be able to eat and drink as before.

### **Neck dressings**

You may have a bulky bandage around your neck, and from the neck wound two drainage tubes running into bottles attached to your bed. These help to prevent bleeding and will be removed after 2–5 days. The stitches in your neck will be removed about 7–10 days after your operation.

### **Your stoma**

Immediately after the operation, you may have a tracheostomy tube in the stoma. The tube may be plastic or metal and will be held in place by tapes tied at each side of the neck. This may be removed completely or changed to another type of tube after a few days. Many patients will not need to wear a tube or button in their stoma by the time they leave the hospital or need only to wear one at night. Every patient is different and your surgeon will decide if you need to wear a tube or stoma button and for how long.

You will have an oxygen mask over the stoma when you first wake up. This will help warm and moisten the air passing into your lungs for the first few days after surgery.

### **Suction**

For the first few days after the operation, your lungs will be producing more mucus than usual. Eventually you will learn to cough the mucus up and wipe it away from your stoma with a handkerchief. Until you can do this, a nurse will remove the mucus with suction equipment. A small tube will be put into your stoma and you will hear a hissing sound as the mucus is sucked out. The physiotherapist will also help you to learn to cough up your secretions and keep your chest clear.

### **Communication**

Immediately after your surgery nurses will see that you have a call bell and pen and paper at all times. The speech therapist will start teaching you to speak again once the tissues in the throat are healed and your feeding tube has been removed.

### **Mobility**

The nurses will assist you with all your daily activities and you will usually sit out of bed on the first day after your operation. As you progress, and the drip drainage bottles and oxygen mask are removed, you will then be

able to care more for yourself and wander around the ward.

## **Visiting**

Your family and friends will want to visit you, but you may be very tired at first so it is sensible to keep visitors to very close family/friends for the first few days after your surgery.

The nurses will give you regular painkillers by tube or injection after your operation. Do not be afraid to let the nurses or doctors know if you have any pain, sickness or worries. Everyone wants you to be as comfortable as possible so you recover quickly.

Your family should feel free to discuss any worries that they may have about your operation with your doctors or nurses who are looking after you. As you gradually recover you will be shown about caring for your stoma in preparation for your discharge home.

## **4. Speech Therapy**

Communication is a very basic need and activity it is what keeps us in contact with the people around us. Without it we may become isolated, frustrated, depressed and unhappy.

One of the most important things for both the laryngectomee and his family, and for the team looking after him, is to re-establish a communication system as soon and as easily as possible. We use the term communication rather than speech as there are many ways of communicating speech is just one of them. In the early days, writing, gesture, etc., may be the most appropriate but soon we need something more.

Usually you will have met your speech therapist before your operation. It is easier then for you to get to know each other. As well as simply introducing herself, she will be able to explain the various ways in which you will be able to communicate during the next few months, and her plans for helping you to develop your new voice. She will also answer any other questions you may have. If you wish, it may also be possible for her to arrange to introduce you to a person who has had the same operation. Many people find this an encouraging and reassuring experience, but some would prefer this meeting to be after their operation or not at all. The decision is up to you. Your family may have questions they want to ask the speech therapist or another family, and it is important that these are answered.

Let us look at the normal way of producing voice. We need a source of air, a vibrating source, lips, tongue and palate (articulators) to shape the sound into words.

### **Before a laryngectomy**

- The source of air is the lungs
- The vibrating source is the vocal cords

After a laryngectomy, for oesophageal speech

- The source of air is the oesophagus
- The vibrating source is muscle fibres in the wall of the upper oesophagus/pharynx (PE segment)

In both instances, the articulators are the same that is why the accent, dialect and the mannerisms of your speech do not change. You will see that after the operation there is no connection between the lungs and the mouth. It is obviously an advantage to have the lungs as the source of air, rather than the small amount which can be held in the oesophagus. This gives the possibility of greater power (volume) and length of sentence. It is this which is the principle behind S.V.R, surgical voice restoration in which a connection is made between the windpipe and the oesophagus and a small device is fitted to shunt the air. This prosthesis does not make sound it simply re-routes the air

There are various communication options open to us:

## **Oesophageal voice**

Since it is the mouth lips, tongue, palate that shapes the sound into the words, we must find another resource of air which can pass to the mouth. This must be the oesophagus (gullet).

Learning oesophageal speech means learning to take air into the upper part of the oesophagus then bringing it back, causing a small segment of muscle fibres to vibrate as it returns, to produce a sound. To develop such a new skill takes time, although to some it comes quite quickly and easily.

## **Surgical voice restoration**

(T.E Puncture Speech. E.g. Blom–Singer)

Increasingly, nowadays patients are being offered Blom–Singer or similar prostheses. The decision as to whether appropriate must be made by the surgeon; it is not suitable for everyone. The procedure may be done at the time of laryngectomy or may be done later.

There are various types of prosthesis but the one most commonly known is the Blom–Singer. The principle behind this method is that air is shunted from the windpipe to the oesophagus, as previously explained.

Since you are using air from the lungs it is possible to maintain a longer flow of voice and obtain greater volume. The prosthesis does not produce sound, it only re–routes the air.

## **Artificial larynges (larynxes)**

This covers the various types of electronic devices, etc. which can be used to produce sound. There are two main types:

1. Intra–oral. These feed the sound directly into the mouth by a small tube.
2. Neck placed. These are held against the neck and transmit sound through the tissues. They are not appropriate immediately post–operatively or if the tissues are hard as a result of radiotherapy.

With both types the user articulates in the normal way.

This is a rapidly developing field so types and models are constantly changing. Never buy an artificial larynx without advice and a chance to try various models. (See Resource Section.)

Many people use an artificial larynx in combination with other methods. For example:

In noisy surroundings  
On the telephone  
With a hard of hearing partner or friend  
When feeling very tired

For some people the artificial larynx is the preferred method of communicating.

Regaining voice after a laryngectomy is a joint effort between you and your speech therapist.

It is for your speech therapist to explain and instruct you in the various ways to communicate again, but then it is up to you to work at it with determination and commitment.

The choice of whether to use an artificial larynx or to work at oesophageal speech, or to use a combination of both, is up to you and your family.

At different times you may use several methods. The choice depends on several factors, including the type and extent of the surgery you have undergone and how recently, the circumstances of your way of life, e.g. living alone or getting back to work, your own personality and the support of family and friends, your determination to persist and overcome the difficulties, and the availability of speech therapy near to you. The most important thing is that you use the method you feel most comfortable with and is most suitable for your lifestyle.

## **5. Stoma Care**

It is important to keep your stoma clean and free from crusts or the skin will become sore. Initially you may need to clean your stoma several times a day, but eventually once a day may be enough.

You will have been taught how to clean your stoma in hospital by the nurse, but these guidelines may be helpful:

1. Always remember to wash your hands before and after cleaning.
2. Warm water can be used with gauze to wipe gently around stoma. A mirror will make inspection of the stoma easier at first.
3. Never use any lotions or creams around the stoma without discussing it with your doctor or nurse first.
4. Always store your stoma items such as tubes, button, gauze in a clean, dry place, e.g. a special sponge bag, or plastic tub.

### **Changing your tube**

You can change your stoma button or tube (if you wear one) at the same time as cleaning your stoma. The nurses in the hospital will have taught you how to do this and you should follow their instructions. The following principles should be applied:

1. Assemble all equipment before you begin, such as spare tube and introducer, tapes for holding tube in place, keyhole dressing, tissues, mirror, container for soaking dirty tube in, sodium bicarbonate solution or water, and gauze.
2. Clean around your stoma once you have removed the dirty tube, but before replacing the clean tube in the stoma.
3. Clean dirty tube thoroughly as instructed by your nurses using pipe cleaners, bottle brush or gauze. A very crusty tube may be soaked in sodium bicarbonate solution prior to cleaning.
4. Remember the importance of washing your hands and working in a clean area.

### **Tying the tapes on your tube**

An example of how tapes can be tied is given below:

Equipment Required: Tracheostomy tube, Tape  $\frac{3}{4}$  wide, 36 long x2

1. Fold one piece of the tape in two with folded end uppermost.
2. Push folded end of tape through the gap in the flange of the tracheostomy tube from the back pulling the tape toward you about 4.
3. Pull free ends of tape through the loop.
4. Pull free end of tape tight.
5. Repeat steps 1–4 on the other side of the tube.

Insert tracheostomy tube into the stoma and tie tapes by:

1. Passing one end of tape on the right around the neck to the left, pick up one piece of tape from the left and tie a secure flat knot on the side of the neck.
2. Pass one end of piece of tape on the left around the neck to the right and pick up one piece of tape from the right and tie in a secure flat knot on the other side of the neck.

Alternatively, you may use a commercial tube fastener such as Velcro to hold your tube in place.

## **Applying a stoma dressing**

You may find it comfortable to wear a small keyhole dressing around your tube. A variety of commercial dressings are available. Alternatively, a keyhole dressing can be made from gauze. An example of how to do this is given below:

## **Making a stoma gauze dressing**

Equipment required:

Gauze Scissors Tape

Method

Fold a piece of gauze to 4 square, so that all raw edges are on the inside.

Halfway along one of the edges of gauze cut a straight line into the middle.

Then cut a small hole as a continuation of the line to fit around the tracheostomy tube.

Turn dressing with cut side uppermost and fit into position, with the cut hole around the tracheostomy. Secure, if required with a little strapping.

## **Humidification of your stoma**

Before the operation, the air that reached your lungs passed through your nose and mouth, where the air is moistened and filtered. After your operation, the air that enters the stoma is dry. It is therefore important to humidify the air that you breath to prevent your chest secretions becoming dry. This is especially important if you live in a centrally heated home where the atmosphere can be very dry. There are simple ways of doing this:

Always wear a cover over your stoma. This will stop secretions soiling your clothes as well as acting as a filter to prevent anything entering your stoma, it also warms air you breath in.

There are several types available:

- A piece of gauze worn over a piece of ribbon.
- Laryngofoam which is a small foam square with a self-adhesive strip at the top.
- Buchanan Covers are larger and can be washed out.

The three covers mentioned above are all available on prescription and as you have a permanent stoma, you will not have to pay prescription charges.

- Romet Collars which looks like the top of a sweater and comes in a variety of colours.
- Alternatively, you can make your own stoma cover or wear a scarf or cravat.

2. You may have been given a glass (Rogers) or plastic spray bottle by the hospital to take home with you.
3. If you are having problems with crusting of secretions, the steam from a hot bath may help. Alternatively, in centrally heated houses, a room humidifier may be useful.

Some people worry about bathing after a laryngectomy. There is no reason why you cannot bath or shower, but you must be careful that no water enters your stoma. You can adjust the shower head on your shower unit so that the stream of water hits your body below the level of your stoma. Alternatively there are shower shields available from Kapitex.

If you have any worries about caring for your stoma, do not be frightened of getting a friend or relative to telephone the hospital ward for advice or reassurance.

## **6. Returning to Normal Life**

### **Psychological Adjustment**

Any major surgery is a shock to the system and for many people the psychological adjustment following a laryngectomy operation is more difficult than the physical. When you are in hospital it is the physical aspects that are uppermost in your mind, both before and after the operation itself. Nursing staff are very adept at helping you to cope with the practicalities of life and can be called upon at a moments notice.

Hospital life is very busy and it is often the case that you do not have time to feel sorry for yourself.

You may experience a different range of different feelings anger, despair, grief for the loss of your voice, frustration, sorrow and even revulsion. These feelings are very common and it is a mistake to try to ignore them. Of course, on the positive side, without the operation, you may well not be around to tell the tale. As you learn to come to terms with cleaning your stoma and the change in your speech, these negative feelings will lessen and, after a few months, you will adjust completely.

It is often the case that a small worry or irritation can play on your mind and if these are allowed to build up, it is easy to become depressed. When you are worried by what you feel is a trivial problem, deal with it then dont try to push it to the back of your mind. After you have been discharged from hospital, the staff are only at the end of a telephone and if you do not feel confident enough to telephone them, go back to the ward and ask their advice; apart from being able to answer your queries, they will be pleased to see you.

### **Eating**

After your operation you may notice that your sense of taste and smell are affected to some degree. Taste usually recovers quite quickly but the impairment of the sense of smell may persist for some time. You may also find you make some modifications to your eating pattern. You may eat more slowly, or you may need to cut your food smaller or avoid certain foods. If you eat slowly and particularly if your sense of smell has diminished, your appetite suffers, so smaller meals taken more frequently may be a good idea. Do look after yourself though, dont miss meals. It is important to stay well nourished.

### **Family support**

Your family and friends are just as important, if not more so, after your operation as they were before. The help and understanding of close friends is essential to a speedy recovery. But you must remember that they are only human and are not only having to deal with their fears and anxieties but also have to deal with yours. The old song which says You always hurt the one you love is very apt. It is easy to take out your frustrations on those closest to you this is another danger of letting feelings build up. Try to be honest with those close to you, talk about your feelings openly. Old habits die hard and it will take time for your partner to realise that a question shouted from another room, like would you like a cup of tea?, will not receive a shouted answer.

Patience is needed on both sides.

Unfortunately some people mistakenly think that if someone has a communication problem, they are also mentally deficient. There have been cases where people speak about you as though you were not there. A good example of this is asking someone else in the room if you take sugar in your tea!

It is easy to become angry with situations like this but bear in mind that it is not your problem, it is the other person who needs educating. Most people have never met a laryngectomee before and are unsure of how to react. Most of the things that cause most irritation are often the result of the stranger trying to spare you from what they feel is the effort and discomfort of trying to talk, or to spare themselves the embarrassment of not being able to understand you. It is usually best to be open about this tell them that it doesn't hurt you to talk, that you still want to be involved in the way you were before. Use gesture to support your speech, and remember that the most useful assets are patience and a sense of humour.

One of the most frequent comments from new laryngectomees is about the reactions of members of the public, and how little they are aware of the difficulties you face. Each one of us has the opportunity to help the people around us to be aware of what laryngectomy is, that it can happen to anyone, and how best to respond and react. People are only too prepared to help and support when they understand, and it might not only be you, but any laryngectomees they may meet in the future who would gain.

### **Improving communication skills**

Remember your partner is having to learn a new skill too lip reading. As we grow older our hearing becomes less acute anyway, which may make it even harder for your partner to hear your quiet, developing new voice. Lip reading doesn't come easily to everyone so it often happens that as one of you struggles to learn a new way of speaking the other has to learn a new way of understanding. It is important to give full attention to speaking situations don't try to be doing something else at the same time. Face each other and watch the speaker's lips. If you are the laryngectomee, try to make yourself easy to lip read speak a little more slowly, make all the sounds as clearly as you can but keep to the normal phrasing and manner of speaking. If you feel it would help to write down something that is causing difficulty, just a clue one word or short phrase might be enough to put your listener on the right track.

### **Social activities and hobbies**

There is no reason why you cannot, within reason, carry on with any hobbies you had before your operation. If your hobby was a very physical one jogging, etc., begin gently, see how it feels and build up slowly.

A drink down the pub with friends is one of the situations which is easiest to deal with. Pubs are usually fairly noisy places and therefore bar staff rely to a great extent on lip reading rather than listening to orders given. It can be a great confidence builder to go into a pub and order a round of drinks for your friends.

Although you will have been told by your doctors never to allow water to enter your stoma, many laryngectomees can now enjoy swimming. Special swimming aids have been designed and there are many patients in this country who swim regularly. If you would like further information about swimming contact NALC (see resources section for address).

Many people travel abroad, either for holidays or visiting friends and relatives. There is no reason why a laryngectomee should not travel, although it is advisable to check with your surgeon first, especially if it is soon after your surgery. Most airlines include laryngectomy in their first aid training and are therefore able to deal with emergencies should they arise. It is a good idea to take supplies of stoma covers, etc., with you rather than try to obtain them whilst you are away Britain is one of the few countries where stoma covers are available free of charge on the National Health Service.

Some people find that, during long-haul flights, their stoma may bleed a little because of the alteration in air pressure this is quite normal and nothing to worry about but if you are worried go to a doctor on your arrival.

NALC has a list of contacts in Laryngectomee Associations overseas if you would like to visit them while you are away.

## **Back to work**

It is usually possible for people to return to their former employment after a laryngectomy operation, although if your job included lifting heavy weights or working in a very dusty atmosphere you may encounter problems.

Before your operation you had a valve mechanism in your larynx to close off a column of air in your chest. Your back muscles used this air to press against and in this way you were able to lift heavy weights. Now that you no longer have a larynx you will not be able to use this method to lift heavy objects. If you work in a dusty atmosphere, you may find that it is advisable to wear a thicker type of stoma cover and change it more frequently.

One of the main worries of a laryngectomee preparing to return to work is whether your colleagues will be able to understand you and, if you deal with the general public in your job, either face to face or on the telephone, whether they will understand what you say. It is surprising how much the general public relies on lip reading rather than actually hearing what is being said to them, it is therefore worth trying communicating without any aids but if you do have difficulty in being heard, there are speech amplifiers available small hand held (for one to one conversation); large types with their own microphone (for speaking to groups of people); and some specifically for use with a telephone.

Artificial larynxes are often very useful they give more volume and are clear on the telephone and can conserve your voice. It often seems that if you are unwell or just generally feeling low the first thing to go is your voice. It is therefore quite useful to have learned to use an artificial larynx of one sort or other, as it is then easy to switch to it when needed. Your speech therapist will be able to give you more information about various kinds of speech aids and to advise you as to which one would be most suited to your needs.

If you decide to take early retirement or it is not possible for you to return to your former employment do not view this as a failure there are many people who would be only too pleased to give up work!

## **Sexual relationships**

It is very common for people about to have a laryngectomy operation and for those who have recently undergone surgery to be unsure of their sexual attractiveness to their partners. Following any major surgery there must be a period of adjustment. Some laryngectomees are afraid that, because of the loss of their larynx, they will be unattractive and unlovable. It is a mistake to place so much importance on such a small part of you. People are loved for their total worth not for the appearance of their neck. If you were considered attractive and lovable by your partner prior to your operation, the chances are that you still are! Remember that you are, with a very small exception, the same as you were before you went into the hospital. There are however some practical tips that may be of help to you.

Sometimes your partner may find that stoma odours and noisy breathing can be distracting. Try using aftershave or perfume to mask any odours, wear a stoma cover in bed this will reduce any noise from your stoma and, as it can sometimes be a somewhat disconcerting experience to be breathed on through a stoma rather than a mouth, turn your head away from your partner.

It is very important that you share your feelings and worries with your partner; remember that they are anxious about you and although being open about your feelings may at first be difficult, as the old saying goes it takes two to tango. Many counsellors agree that people often take sex too seriously. It should be enjoyable

and fun and what you did prior to your operation, you still can.

If you find that sexual problems persist, do not suffer in silence, seek help from a counsellor at the hospital or contact an organisation such as Relate (see Resources section for address).

## **7. The National Association of Laryngectomee Clubs**

The National Association was inaugurated in 1976 with the sole objective of promoting the welfare, in any way possible, of laryngectomy patients and their families living throughout the British Isles and Eire. To this end NALC has concerned itself with various aspects of laryngectomy and thereby has grown from a very small organisation to the National charity it is today.

It is due to the help and dedication of both patients and the members of the professional team actively working in the field of laryngectomy that NALC continues to flourish and expand.

NALC is always delighted to hear from patients and professionals, both in this country and overseas, who feel that we may be able to assist them and we do our utmost to be of constructive help to anyone who contacts us.

The services offered by any national charity must, of course, cover many different topics relating to the group of people they endeavour to help, and, to this end, NALC has expanded dramatically in order to cater, not only for patients and their relatives and friends, but also to provide appropriate services which would be of benefit to those professionals working with such patients. The following is a summary of our activities to date and also our plans for the coming years.

### **Seminars**

Since 1976 a large part of the work of the Association has been concerned with seminars both for patients and their families and for professionals working in the field of laryngectomy.

NALC staged two three-day residential seminars at Poole (Dorset) in 1978 and Abingdon (Oxfordshire) in 1980. Both of these were very successful and attracted audiences from all professions concerned with laryngectomy. We were able to gather a tremendous amount of invaluable help and guidance as to what services NALC should provide as well as making personal contacts with many people who still support us today.

Following these two seminars we began staging an on-going series of one-day seminars around the country. To date we have organised many such events some have been multidisciplinary (for professionals) some for patients, their relatives and friends several have been for specifically for nurses and others for district speech therapists. NALC also staged a two-day residential seminar for lecturers at speech therapy training establishments during 1989.

### **Laryngectomee clubs**

At the formation of the Association in September 1976, there were 6 laryngectomee clubs affiliated to NALC.

Now we have clubs in all parts of the British Isles, with several more to join us in the near future. For many years groups of laryngectomy patients have met from time to time around the country and, in many cases, these groups have become fully-fledged clubs.

The object of these clubs is to provide a relaxed social atmosphere where patients, in the company of their relatives and friends and interested professionals, can meet regularly to give and receive encouragement.

Although NALC is prepared to advise on the setting up and running of such clubs, it does not interfere with their day-to-day activities. The composition of a club is for its members to decide upon as is the venue but

most clubs find that hospitals will provide facilities for the club meetings and it is open to a club to seek affiliation of NALC at any time.

Most of the clubs hold monthly meetings and organise a variety of social events, including visits to other clubs for social evenings, day trips to the coast and an assortment of fund-raising activities.

One of the main tasks undertaken by NALC clubs around the country is publicity, both of the clubs and Associations activities as well as laryngectomy in general. We are also fortunate that many club members lecture to Schools of Nursing, the Emergency Services, St John Ambulance Service, etc., about laryngectomy and the need, in the case of an emergency, for mouth-to-neck resuscitation.

### **General services**

Apart from its work in helping clubs and groups of patients around the country, NALC plays a large part in the education of student nurses, speech therapists, etc.

Many of our members regularly lecture to schools of nursing about laryngectomy and, although we must realise that some of these students may never treat, or, in some cases, encounter a laryngectomy patient during their professional life, NALC feels that it is helpful to give as much support to these training establishments as possible. Such lectures cover both what it is like to be on the receiving end of a laryngectomy operation and the adjustments which must be made in order to carry on with a normal life and for the patient to be able to return to society as soon as possible.

The Association also has a library of speech aids and other related supplies which are demonstrated at such lectures.

It is, in the case of an emergency, essential that mouth-to-neck resuscitation is performed and NALC is always prepared to visit St John Ambulance and British Red Cross groups to help in the instruction of first aid personnel. This type of lecture includes the screening of a film (or video) clearly showing emergency resuscitation being performed on a laryngectomy patient.

The Association produces a range of literature, covering many topics, for both patients and professionals and also publishes a quarterly newsletter, CLAN, which, apart from a large circulation in Britain, is currently sent to 44 countries throughout the world.

Another very important service offered by NALC is to visit patients and their families both pre- and post-operatively. The Association has a number of experienced and selected visitors who are always happy to visit patients in co-operation with and following invitation from professionals.

Experience has shown that many patients and their relatives benefit from such a visit as it enables them to speak to someone who is coping well after surgery.

NALC Head Office offers a problems solving and help service and it is open to any patient, relative or friend of a patient or professional to contact NALC by either post or telephone on any matter relating to laryngectomy. Needless to say, we will do our utmost to help with any query.

You will appreciate that the role of the Association is very wide and it is a case of: if in doubt, contact NALC. Our Head Office staff are very experienced in dealing with enquiries on any subject relating to laryngectomy and we are only too pleased to be of assistance to anyone.

### **8. Resources**

There are various resources available to laryngectomees and their families. This chapter endeavours to list those commonly used and available in the United Kingdom.

The aim is to list that which is available and not to make particular recommendations. Trial of materials is advised, wherever possible, before a purchase is made.

Addresses are correct at the time of publication.

It should be noted that artificial and speech amplifiers are available on National Health Service prescription. Health Authorities (and NHS Trusts) in England and Wales should purchase medical and surgical aids and appliances (including laryngeal vibrators) in accordance with Booklet MHM 50. Information about the safety requirements for mains-driven chargers or transformers (supplied for the purpose of recharging suitable batteries for laryngeal vibrators) and related technical enquiries should be made to: Mr J. A. Marshall, Medical Devices Agency, Device Technology & Safety, Hannibal House, Elephant and Castle, London SE1 6TQ (Tel: 020-7972 8166 or Fax: 020-7971 8106). Any safety related incidents concerning laryngeal vibrator devices should be reported to the Adverse Incident Centre at the address above (AIC Hotline: 020-7972 8080 or Fax: 020-7972 8109).

## **Aids for the Laryngectomee**

### **Artificial larynges**

There are three main types of artificial larynx and the type chosen will depend upon the individual needs of the laryngectomee at that particular time. Of course needs change: one aid may not be the correct one for the individual all of the time. An opportunity to borrow communication aids for trial is recommended so that the most appropriate choice can be made. The first type of artificial larynx to be described is:

#### **1. Electronic mouth-type artificial larynx The Cooper Rand**

Two different types of no hands models are available for those unable to activate the switch with their hands.

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W. Yorkshire LS22 4GH. Tel: (01937) 580211

#### **2. Electronic neck-type artificial larynx**

There are various types of neck-type artificial larynx but they generally consist of a cylindrical hand-held box, which contains a rechargeable battery. The head of the box contains a vibrating electronic sound source, activated by a push-button control. When pressed firmly against the neck (or sometimes the cheek) it transmits sound into the oral cavity. This sound can be moulded into speech as the person mouths words.

### **The Servox and the Servox In-Tone**

This is a small light artificial larynx. It has the additional feature of having two tone buttons, which allows for the possibility of some intonation during speech.

The Servox has a compact battery charger which allows the complete Servox to be inserted for easy charging, whilst charging a spare battery at the same time.

An oral adaptor is also available which allows immediate use post-operatively.

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W. Yorkshire LS22 4GH. Tel: (01937) 580211

## **Vocaltech**

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W.Yorkshire LS22 4GH. Tel: (01937) 580211

## **Rexton Laryngophone**

Available from: A&M Hearing Aids Ltd., Faraday Road, Crawley, Sussex, RH10 2LS

## **Speech amplifiers**

Amplifiers are of value to those who have either clear oesophageal voice or artificial larynx speech which requires a little more volume.

Those commonly used are:

### **The Amplicord Amplifier**

There are two models:

a)Hand held; b) Headset.

### **Vocaltech Amplifier**

There are two models:

a)Hand held; b) Headset.

### **Medela Amplifier**

There are two models:

a)Hand held; b) Headset.

### **Voicette Amplifier**

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W.Yorkshire LS22 4GH. Tel: (01937) 580211

## **Telephone amplifiers**

There are varying types of telephone amplifiers contact British Telecom Sales locally for information.

## **Stoma covers**

It is advisable to wear a cover over the stoma. This will help to warm and humidify the air as it is breathed in. There are commercial covers which will be listed but some people prefer to make their own (see details in chapter 3).

Commercial Designs

### **Buchan Laryngectomy Protector, Laryngofoam Filter**

Available from: Chemists on Prescription or

Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W.Yorkshire LS22 4GH. Tel: (01937)

580211

Both these stoma covers are available on the National Health Service. They are usually available from hospitals. Sometimes arrangements can be made with the laryngectomees local chemist.

### **Hirst Bib**

Available from Chemists on Prescription or  
James Hamer Ltd., 10A Bolton Street, Bury PL9 0LQ  
Tel/Fax: (0161 761 5833)

### **Romet Laryngectomy Collar**

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W.Yorkshire LS22 4GH. Tel: (01937) 580211

### **Tracheostomy Dressings**

Available from: Downs Surgical, 41 New Cavendish Street, London W1M 8EB. Tel: (020) 7486 3611

## **Stoma Sprays**

### **Rogers Crystal Sprays**

Available from: Langham Pharmacy, 3 Marylebone High Street, London W1.  
Tel: (020) 7937 8365/2588

### **Atomizer (Glass Bottle)**

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W.Yorkshire LS22 4GH. Tel: (01937) 580211

Note: Many people use small plastic sprays available from chemists.

## **Emergency identification**

These give information about the patient and his medical condition. They advise that breathing is through an opening in the neck and that, in case of need, mouth to neck resuscitation should be applied.

### **Emergency Pocket Card**

### **Emergency Car Sticker**

Available from: The National Association of Laryngectomee Clubs, 6 Rickett Street, Fulham, London, SW6 1RU. Telephone: (020) 7381 9993.

### **Med Alert Bracelets and Necklaces**

Available from: Local Chemists and:  
Talman Ltd., 21 Grays Corner, Ley Street, Ilford, Essex, IG2 7RQ. Tel: (020) 8554 5579 Fax: (020) 8554 1090

## **General Publications**

### **Reading material for the laryngectomee**

The following may be of value to the laryngectomee and family pre-operatively and shortly after surgery. They may also be of use to students and all members of the rehabilitation team.

#### **After Your Laryngectomy: A Guide for Patient and Family**

A booklet covering most aspects of both physical and psychological adjustments after laryngectomy.

Available from: Kapitex Healthcare Ltd. Kapitex House, 1 Sandbeck Way, Wetherby, W. Yorkshire LS22 4GH. Tel: (01937) 580211

#### **The National Association of Laryngectomee Clubs Pamphlet**

A small pamphlet which briefly describes the surgery and the result of the operation. It includes a brief description of the role and aims of the Association.

#### **CLAN Newsletter**

A quarterly newsletter issued by NALC. Distributed through the clubs and to individuals on request.

Available from: The National Association of Laryngectomee Clubs, 6 Rickett Street, Fulham, London, SW6 1RU. Telephone: (020) 7381 9993.

## **Useful Addresses**

**The National Association of Laryngectomee Clubs**  
**6 Rickett Street, Fulham, London, SW6 1RU. Telephone: (020) 7381 9993.**

**MacMillan Cancer Relief**  
**89 Albert Embankment, London, SE1 7UQ**  
**Tel: (020) 7840 7840 Fax: (020) 7840 7841**

This organisation is concerned with the needs of people suffering from cancer. It provides financial assistance to individuals and relevant agencies. All applications for assistance must be made through social workers or community nurses. It publishes a quarterly newspaper Cancer Relief News.

**Relate Formerly The Marriage Guidance Council**  
**Local addresses and telephone numbers can be found in local telephone directories or from Directory Enquiries.**

**The College of Speech Therapists**  
**2 White Hart Yard, London, SE1 1NX**  
**Tel: (020) 7378 1200**

This is a professional body for speech therapists trained or working in the British Isles. It can advise on speech therapy services and provide other information of use to laryngectomees.

## **Communication Aids Centres**

Communication aids Centres hold demonstration models of all speech aids relevant to laryngectomees. Your speech therapist can make an appointment for you to try the various aids.

### **Scottish Centre for Technology for the Communication Impaired**

**Westmark, Southern General Hospital, 1345 Govan Road, Glasgow, G51 4TF Tel: 0141 201 2619**